

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

Venue- Zoom Conference call

Date & Time- Wednesday 30th October 2020 – 9am to 1pm

<b>Present</b>	Simon van Eeden (Sve)	Cleft Development Group Chair
	Victoria Beale (VB)	Clinical Director, North West, IoM & North Wales Cleft Network
	Lorraine Britton (LB)	Lead Speech and Language Therapist, Trent Regional Cleft Lip & Palate Service
	Alex Cash (AC)	Clinical Lead, South Thames Cleft Service
	Claire Cunniffe (CC)	CLAPA Chief Executive
	Sinead Davis (SD)	Chair, CEN for Cleft ENT and Audiology Consultant ENT Surgeon
	Scott Deacon (SDc)	Clinical Director South West Cleft Service
	David Drake (DD)	Clinical Lead Cleft Care Scotland
	Helen Extence (HE)	Clinical Director, The Welsh Centre for Cleft Lip and Palate
	Vanessa Hammond (VH)	Clinical Psychologist CEN Lead
	Jason Neil-Dwyer (JND)	Clinical Director, Trent Regional Cleft Lip & Palate Network
	Ginette Phippen (GP)	Clinical Director, Spires Cleft Lip & Palate Network
	Marie Pinkstone (MP)	Lead Speech and Language Therapist, North Thames Cleft Service, deputising for Norman Hay
	Helen Robson (HR)	Lead Nurse, North West & North Wales Cleft Lip and Palate Network
	Craig Russell (CR)	CRANE Clinical Project Lead / Clinical Lead, Scotland
	David Sainsbury (DS)	Consultant Plastic Surgeon, Newcastle, deputising for Peter Hodgkinson
	Jules Scott (JS)	Orthodontic CEN Lead
	Jackie Smallridge (JSm)	Consultant Paediatric Dentist, CleftNetEast, representing Paediatric Dental CEN
	Alistair Smyth (AS)	Clinical Lead, Leeds Site, Northern and Yorkshire
	Guy Thorburn (GT)	Surgical CEN Lead
Norma Timoney (NT)	Cleft Surgery Training Interface Group	
Imogen Underwood (IU)	Clinical Director, West Midlands Cleft Service	
Rachael Willis (RW)	Clinical Lead, Cleft Net East	
Yvonne Wren (YW)	Lead, Cleft Collective	
<b>In Attendance</b>	Catherine Foster	Clinical Effectiveness Unit Research Coordinator, RCS

<b>1.Apologies for absence and welcome to new members</b>	<b>Apologies:</b>	
	Mechelle Collard	President, Craniofacial Society of Great Britain and Ireland
	Norman Hay	Clinical Lead, North Thames Cleft Service
	Peter Hodgkinson	Clinical Lead, Newcastle Site, Northern and Yorkshire Cleft Service
	David Landes	Public Health Consultant
	Sandip Popat	Restorative Dentistry CEN
	Ian Sharp	Deputy Chair, CDG

	Marc Swan	Representative, The British Association of Plastic, Reconstructive and Aesthetic Surgeons
	The chair welcomed the Cleft Development Group to the meeting. The group joined the meeting via Zoom teleconference.	

Item	Notes	Actions
<b>2. Minutes of the Cleft Development Group Meeting, 2<sup>nd</sup> June 2020</b>	Amendments to the draft minutes from 02.06.20 were accepted by the committee.	
<b>3. Matters arising</b>	<ul style="list-style-type: none"> <li>02/06/20: 3.1 TK to draft CDG lay representation Job Description and circulate to the group for feedback. – CC is to follow this up before the next meeting.</li> <li>02/06/20: 5.1 MS to email SvE Ethical Framework for circulation. – The Ethical Framework circulated and discussed later in the meeting.</li> <li>02/06/20: 5.2 CR to circulate CRANE Outlier Policy for discussion at the next meeting – CRANE Outlier Policy circulated. CR to present later in meeting.</li> <li>02/06/20: 5.3 CR to circulate email to CENS regarding what CRANE require from them regarding the delphi and timings. – CRANE have requested that when the CENs have a discussion about what is appropriate for child and adolescent outcome reporting. The deadline is the end of 2020. CRANE will report to CDG in January 2021.</li> <li>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. – Nigel Mercer was contacted immediately after the meeting in June and the changes agreed at CDG had already been incorporated. The most recent document has no changes to cleft prioritisation.</li> </ul>	30/09/20: 3.1 CC to draft CDG lay representation Job Description prior to next meeting.
<b>4. Covid 19 – Updates and Resumption of services</b>	<ul style="list-style-type: none"> <li><b><u>Feedback from Cleft Centres (UK)</u></b> <b><u>South Wales (HE)</u></b> Wales have had 4 lists since March, so have only seen 9 babies. They have recently been allocated 2 lists for October, with 3 patients on the list. This has been escalated to the Health Board and Commissioners. As a result, the Morriston Hospital is now taking Paediatric Surgery more seriously. They are now looking at outsourcing to private providers and hope to get more lists. The Centre have received some complaints from parents who are</li> </ul>	

concerned about waiting times. Pre-Covid adult long-waiters have been addressed. Outpatient sessions have resumed, with an added session per week. MDTs have resumed, however some clinicians are joining remotely. Some staff have been deployed, with Psychology Services supporting the Wellbeing Service. Most staff have been working from home; only coming onto site when needed. SLT clinics are being run virtually, with some face to face therapy and assessments taking place when required. Paediatric dentistry are now catching up, seeing patients regularly in clinics. Orthodontic services have resumed, however they are working from a long backlog. An SLT assistance has been appointed, as has a Medical Secretary.

#### **Bristol (SDc)**

Bristol are running some children's lists on a regular basis, but at 50% of their previous capacity. As a result, they are prioritising patients to be treated and expect this to continue up until Christmas. Regarding Adult work, Bristol are starting to do some Orthognathic work within the private sector, but at the moment have no capacity to do any lip revision or rhinoplasty work with adults. Outpatient clinics are taking place via Attend Anywhere. Face to face clinics resumed last week in a bespoke clinic in Plymouth and they are started to increase face to face components in Bristol.

#### **South Thames (AC)**

The Centre have appointed a new Lead Cleft Nurse Specialist, who is due to start next week, and surgeon David Grimes, who started in July. The team have been working remotely but have started to come back together physically. Theatres access has been a significant problem, having 99 primary cases waiting for operation in June. They had some access to private theatres at the Portland Hospital, whoever offsite activities became difficult. They now have roughly 55 babies waiting for primary surgery. Adult services have been complex. The centre were in the process of moving Adults Services to another site within the Trust, and have just started Adults surgeries within the new space. Outpatients clinics at St Thomas' have been massively restricted by infection control measures, although they are slowly getting back to face to face working. They have significant VPI backlog, but have secured some additional space to address this. The Centre are looking at redesigning their outpatients services, and hope for a new timetable in 2021.

#### **North Thames (MP)**

MP represented North Thames in Norman Hay's absence. At GOSH, the centre is beginning to have more access to theatres. They have been appraised for how they have approached clinical prioritisations and are now beginning to see more lists opening up. VPI surgery backlog is beginning to move forward. Broomfield Hospital in Chelmsford have been an adult Covid site and as a result have had difficulties with bed access and theatres. Outpatient clinics have been running virtually via Attend Anywhere and Zoom. They are started to open up face to face MDTs focusing on new babies and complex patients. VPI assessment backlog has been completed, via

triaging via zoom and site visits for follow-up x-rays.

### **Cambridge (RW)**

Since July, Cambridge have treated 50 inpatients cases but still have a significant backlog, predominantly in Paediatrics. They will be returned to their normal theatre allocations from November. Private capacity has been utilised for some adult cases, but are yet to begin Orthognathic. The overall utilisation of case lists are still low. Outpatient clinics are running both virtually and face-to-face. MDTs are running via attend anywhere, with key members of team attending in person. Psychology and SLT are predominantly being run virtually, with some face-to-face capacity. Dental are at 35% pre-Covid capacity. They have a new surgeon in post and they have just finishing recruitment for a Lead CNS and Lead Psychologist.

### **Spires, Oxford and Salisbury (GP)**

Primary surgery restarted in Salisbury in September, with 2 lists. More lists were available in Oxford but there is now a theatre refurbishment taking place. They are now working on ongoing prioritisation within both trusts, with support from the Ethic Committees. MDTs and SMDTs have been taking place virtually. Face-to-face appointments are taking place where considered to be essential. There are some concerns around how to support category 4 patients, who have been waiting for 18 months for revisional surgery.

### **West Midlands (IU)**

IW has been appointed as Clinical Lead, replacing Ian Sharp who stepped down in July. The full-time Consultant Cleft post is yet to be filled, so the case load is being managed amongst the team. Due to ongoing pressures, there are currently no plans to fill the post. There has been some long-term sickness within the admin team, which has impacted on the capacity to manage the clinics. Inpatient lists have been available since July, which have been gradually increasing over the subsequent months. List allocation is now up the Pre-Covid level for Paediatrics. They have had one list for adults but have no plans for anymore due to other services taking priority. MDT clinics started in July at a limited level. This is now increasing and the team are working on how to see more patients. Protocol patients are being seen virtually. Adult clinics are up and running but Orthodontics has moved to Good Hope Hospital, which has been a difficult time for the team. VPI clinics have restarted and are working through the backlog. SLT waiting lists are causing some issues as it is difficult to access any therapy locally.

### **Trent Regional Cleft Network (JND)**

Nottingham are in the middle of second wave planning. Nursing visiting continues and Dashboard Measures are still being fulfilled. Surgery has been through a process of Paediatric prioritisation since May. As a result, all Paediatric surgery, across the trust, has been operating at normal level since September. The trust has now agreed that Paediatric surgery will be given the same prioritisation as cancer surgery. MDT clinics are running partly virtual and face-to-face. VPI clinics have restarted, with some face-to-face capacity.

Some limited face-to-face SLT has been approved. Orthodontics are working through emergency cases but have no capacity for new cases.

#### **North West, North Wales & Isle of Man (VB)**

MDT clinics have been taking place via Attend Anywhere but some face-to-face clinics have started to resume. Outreach clinics are currently taking place virtually. Most patients in the region are currently in lockdown, but essential nurse visits are still taking place. SLT and Clinical Psychology have started up some face-to-face clinics, but the majority are still taking place virtually. Orthodontics has been operating largely face-to-face since late June. Paediatric dentistry has operating virtually with some face-to-face triage where appropriate. Surgery resumed in June, with Liverpool back to pre-Covid lists and Manchester back to 2/3 of pre-Covid lists. There was a nurse retirement in the summer, which they are now looking to recruit for.

#### **Leeds (AS)**

Primary Cleft surgery recommenced at the end of May, with regular operating at reduced capacity. There is currently no backlog for children awaiting Primary Cleft surgery. There is still no adult cleft surgery being provided and there are no imminent plans for recommencement. Weekly virtual MDT meetings are taking place, where they continue to review patients who would have attended clinics locally. Face-to-face surgery consultations are recommenced. A Cleft fellow is working on rotation at the moment, but training is prolonged due to Covid. The 3<sup>rd</sup> CNS has been recruited and replaced and 3 senior Speech and Language therapists have left within the last 6 weeks and a 4<sup>th</sup> has left within the last 6 months, so some major changes are expected within SLT. Orthodontics and Paediatrics dentistry has recommenced but at reduced capacity.

#### **Newcastle (DS)**

Newcastle were fortunate that operating resumed at the end of June. Paediatric plastic surgery lists have been given over to the cleft teams, giving them the chance to catch up with primary surgery. Speech surgery has recommenced with some adult surgery starting at the end of October. Newcastle intend to modify their clinic format. Face-to-face children's clinics are taking place with roughly ten children. Adult clinics have recently resumed. No outreach is taking place with no plans to resume in the near future. A Senior nurse has recently retired and two CNS have been appointed.

#### **Scotland (DD)**

Scotland's operating resumed in June as 2/3 normal capacity. They have caught up with the backlog waiting babies and are making progress with speech surgery and alveolar bone grafts. Clinics are taking place via Attend Anywhere, with some face-to-face appointments for urgent cases and new babies. Face-to-face clinics are running at reduced capacity due to protocol within the Hospitals. They are starting to be offered ad-hoc lists for adults and adults clinics will be resuming in Glasgow.

- **Feedback from CENS**

### **Lead Nurses (HR)**

Surgery has been reinstated across the network, increasing pressure on the Nurses workload. Nurse recruitment has started across the network. Within the North West, a nurse has been released from the Nightingale Hospital. The nurses have been working with multiple projects including CLAPA. HR thanked CLAPA for the Summer Survey and their continued support with supplying bottles. Nursing have linked with Cleft Collective and the University of West England COVID-19 study, which is gaining momentum. Lead Nurses have having meetings and answering questions from NIHR regarding the SLUMBRS study, and have been given a potential start date of April 2021.

### **Speech and Language Therapy (LB)**

The Lead SLTs met on 29<sup>th</sup> October 2020. There was great concern within the meeting around the postcode lottery with regards the surgery and the massive difference in list provisions between centres. SLT are having difficulties with the interpretation of infection control across different hospitals as it is impacted on the delivery of therapy.

Due to Covid-19 restrictions, SLT are having to provide their service in a completely different way (virtual, teletherapy etc), which is made more complicated due to different hospital systems i.e. different platforms and how files are shared. Most centres are now doing some face-to-face diagnosis assessments and diagnostic speech assessments. All services are looking at how to deliver speech therapy in different ways such as running workshops and creating videos to share with patients, but this requires a lot of time and creativity. Most services are not providing face-to-face therapy or outreach SLT liaison clinics. It was concluded in the Lead SLTs meeting that SLT cannot prioritise providing face-to-face audit collection data for 2014/2015 births as clinics have limited face-to-face appointments which need to be prioritised clinically. SLT want to assure that virtual 5 year reviews will be taking place and data will be collated and feedback locally.

### **Orthodontics (JS)**

Due to pressures, the Orthodontics CEN meeting has been deferred until Spring 2021. Currently there is prioritisation for existing patients and prioritising up for alveolar bone grafting. JS welcomed any suggestions for increasing engagement from CEN members. LB commented that the Lead SLTs have been meeting every two months virtually, and that it may be worthwhile setting up a Lead meeting as less time consuming.

### **Paediatric Dentistry (JSm)**

Over the past months most PD have been delivering acute care in dental hospitals, so most routine work has not been taking place. Units have been coming back in different degrees with most catching up. Phone and video have been used for examinations, although this is difficult when examining small children's teeth. A CEN meeting is planned for November, with a few informal group meetings in between. An online calibration session is being planned

for the new year.

### **Psychology (VH)**

The Psychology CEN is due to meet next week (WC 5<sup>th</sup> November). Moving forward, Psychology will be looking at how they can use video on combination with face-to-face appointments, although there are some difficulties in using both e.g. using the room in video appointments, face-to-face whilst wearing a mask, building the therapeutic relationship. There are some concerns about people being left behind in terms of surgery and long term impacts of Covid. There are also concerns about the impact on staff from not being able to offer the service that they had previously been able to offer. The CEN are reviewing their input to CRANE and are going through a calibration process for their tiers of involvement measure. Psychology continue to work with a number of notational projects which are due for presentation at Cardiff and Edinburgh.

### **ENT & Audiology (SD)**

SD apologised for ENT's lack of engagement with CRANE and the Delphi study. The ENT CEN are yet to meet but the group have finally agreed to a proposed virtual meeting. There are some concerns regarding grommets. As grommets are category 4, children are currently not receiving them and any child waiting for grommets are not being seen. Similarly, fitting hearing aids are difficult without face-to-face consultations. Some face-to-face hearing tests are taking place in Swansea. ENT clinics are still going ahead, but practice seems to vary across the board.

### **Managers Group (YE)**

The Managers Group is yet to meet and YE had not heard from the group. The CEN is trying to support teams with virtual clinics and new ways of working but feels that it would be good to have some uniformity across all centres.

### **Surgical**

No report from Surgeons.

#### **• CRANE Response**

CR presented the CRANE Cleft Development Group Update. The presentation included:

- Covid Challenges
- Data Completeness / Outlier Policy
- 2020 report preview / Future reports
- Dashboard
- New CRANE website
- Adolescent / Adult Delphi Study

CRANE hope to circulate a full draft of the Annual Report to the CDG by November, giving allowance for feedback and comments to be received before the Christmas period.

SSQ Dashboard - Methods have contacted CRANE requesting the last quarter of 2020/2021 data. CRANE requested that all Cleft teams contact CRANE with regards to what they wish to do with the second

<p>quarter data.</p> <ul style="list-style-type: none"> <li> <p><b><u>Impact on Audit</u></b></p> <p>SD questioned how Orthodontics felt about how they may cope with collecting audit data for 5 year appointments, and which years they may think may suffer as a result of the COVID crisis. JS commented that 5 year data is being collected where possible, although collection is sporadic. Orthodontics have agreed that full datasets for 2013/14 are not a priority, but will try their best to collect data where possible. JS suggested that she will contact the individuals collecting the data and feedback any information to CRANE.</p> </li> <li> <p><b><u>Quality Dashboard</u></b></p> <p>The group discussed adding hearing outcome date to CRANE. The group felt that it would be useful to add hearing outcome data to CRANE but SD felt that ENT would struggle to collect this data. CR suggested that if there was an appetite for adding hearing data, he would be happy to meet with ENT to discuss next steps.</p> <p>The Quality Dashboard has been suspended by NHS England until further notice. In the previous meeting it was agreed that all teams should stop inputting to the dashboard to give consistency across the board. The group revisited this and discussed participation in inputting data onto the Quality Dashboard on a local level. LB felt that recording data quarterly was a good way of measuring and documenting the problems of resuming surgery. It was added that it would also highlight the impact of COVID on CNSs.</p> <p>A poll was taken and it was agreed that all units are to contribute towards second quarter data on the quality dashboard.</p> </li> <li> <p><b><u>CLAPA (CC)</u></b></p> <p>CC returned from maternity leave at the beginning of September. CC thanked Toni Kitchingman for time as acting CLAPA CEO in her absence. The CLAPA office remains closed for the vast majority of staff. All staff have been working from home since the beginning of lockdown. A number of staff were furloughed; some staff are now back on flexible furlough and two members of staff are still on furlough but due to return shortly. Flexible furlough staff are due to return to their posts after the current furlough scheme ends. CLAPA are reviewing their office situation as currently the office is only open for staff managing the feeding service, which is still operating as normal. The phone service is currently not in operation so people are contacting via email. Many of CLAPA's services are unable to operate due to lack of face-to-face capacity. CLAPA are currently undertaking an organisational review looking at an 18 month strategy for delivering services appropriately during the current situation. Some of the services have started to move online such as live Q&amp;A sessions with parents, virtual coffee clubs and virtual workshops. CLAPA's financial position is starting to improve having secured grants from the Big Lottery Fund and the VTCT foundation. However, funding is still a challenge for CLAPA as many of their fundraising outlets are not available due to Covid i.e. marathons, community events etc. CC invited the group to contact CLAPA to provide any help on a national level i.e. messaging, online poles, and</p> </li> </ul>	<p>30/09/20: 4.1 – It was agreed that all units are to contribute to second quarter data on the Quality Dashboard.</p>
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	communication with the community.	
<b>5. Terms of Reference</b>	<ul style="list-style-type: none"> <li>• <b><u>Quality monitoring and evaluating committee</u></b> SvE and LB were concerned that the Quality monitoring and evaluating committee had not been mentioned within the CRANE Outlier Policy. They felt that some work needed to be done to streamline the two documents together. LB and CR are to work on this and circulate prior to the next meeting. Once finalised, the document can be uploaded to the CRANE website. CR felt that he should not chair the Quality monitoring committee in his capacity as CRANE Clinical Lead, and that the vice chair of CDG should chair the Quality monitoring committee.</li> </ul>	30/09/20: 5.1 – LB and CR to streamline the Quality monitoring committee document and CRANE outlier policy to be circulated prior to the next meeting.
<b>6. Research</b>	<ul style="list-style-type: none"> <li>• <b><u>Bristol-Cleft Collective (YW)</u></b> SvE welcomed Yvonne Wren to her first meeting of the CRG. YW has replaced Jonathan Sandy at Chief Investigator at the Cleft Collective. An update report from Cleft Collective was circulated prior to the meeting.</li> <li>• <b><u>Cleft Multidisciplinary Collaborative and Early Career Researchers Group(DS)</u></b> Stephanie Van Eeden has been running a review on bilateral cleft palate, which they hope to present at the International Cleft meeting. Sophie Butterworth has conducted a survey on the number of children who had unrepaired cleft palates. SB now wants conduct interviews of parental experience with a thematic analysis. Interviews have now commenced. Data extraction has commenced on a Systematic Review on factors influencing speech outcomes. A national study has taken place looking at Pierre Robin Sequence, which was presented by Stephanie at the cleft lip and palate meeting. In Edinburgh, there is a study looking at the impact of Covid on cleft surgery, with several centres showing interest in signing up. Sophie Butterworth is looking at starting a project investigating the learning curve for intravelar veloplasty.</li> </ul>	
<b>7. Training (NT)</b>	<p>Covid has interrupted training for a few months. One trainee was appointed pre-Covid so was finishing training, another trainee has been uninterrupted. Two trainees are less than full time, so training has been extended. Within the unit they are back to normal training. NT has received messaging requesting non-TIG fellowships because of the delay. All TIGs are changing and they will still be recruiting next year. The same benchmarking will apply for post CCT TIGs. A new non-face-to-face interview mode for TIGs is being established. CR questioned what expected vacancies there are and how many fellows they are intending to advertise for early next year. There will be one vacancy in Birmingham, although this is currently dependant on finances. GOSH are yet to advertise their vacancy, but NT predicts that they will need two. Swansea is keen for one and Bristol may need more. Leeds, Yorkshire and Manchester each have a fellow and are working towards a vacancy in the next year or two. SvE urged Clinical directors to contact Norma regarding planned training vacancies.</p>	30/09/20: 7.1 – Clinical Directors are to contact NT regarding planned training vacancies.
<b>8. Any other</b>	The group discussed how to prevent the development of a postcode	30/09/20: 8.1 – CR to

<b>business</b>	lottery in regards to the resumption of surgery. SVE suggested that a working group of Clinical Directors could be put together to support centres with managing local workloads and waiting lists. CR is to put together a spreadsheet for centres to complete regarding capacity. All CDs agreed to the proposed working group and a meeting will be organised after the spreadsheet is finalised.	create and circulate spreadsheet regarding postcode lottery.
<b>The next meeting of the Cleft Development Group will take place virtually on Thursday 21<sup>st</sup> January 2021.</b>		

