

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

Venue- Zoom Conference call

Date & Time- Thursday 21<sup>st</sup> January 2021– 9:00 to 13:00

<p><b>Present</b></p>	<p>Simon van Eeden (SvE) Chair Victoria Beale (VB)</p> <p>Lorraine Britton (LB)</p> <p>Alex Cash (AC) Ali Cobb (ACo) Claire Cunniffe (CC) Sinead Davis (SD) David Drake (DD) Yvette Edwards (YE) Helen Extence (HE)</p> <p>Toby Gillgrass (TG) Norman Hay (NH) Vanessa Hammond (VH) Peter Hodgkinson (PH)</p> <p>Nichola Hudson (NH) Sarah Kilcoyne (SK)</p> <p>Jason Neil-Dwyer (JND)</p> <p>Ginette Phippen (GP) Sandip Popat (SP) Craig Russell (CR) Jules Scott (JS) Jackie Smallridge (JSm)</p> <p>Alistair Smyth (AS)</p> <p>Guy Thorburn (GT) Imogen Underwood (IU) Rachael Willis (RW) Yvonne Wren (YW)</p> <p><b><u>In Attendance:</u></b> Catherine Foster</p>	<p>Cleft Development Group Chair Clinical Director, North West, IoM&amp; North Wales Cleft Network</p> <p>Lead Speech and Language Therapist, Trent Regional Cleft Lip &amp; Palate Service</p> <p>Clinical Lead, South Thames Cleft Service Clinical Director South West Cleft Service CLAPA Chief Executive Cleft ENT and Audiology SIG Lead, Lead Clinician for Cleft Care Scotland Managers CEN Lead Clinical Director, The Welsh Centre for Cleft Lip and Palate</p> <p>Clinical Lead for Scottish Cleft Surgical Service Clinical Director North Thames Cleft Service, Clinical Psychologist CEN Lead Clinical Lead, Newcastle Site, Northern and Yorkshire Cleft Service</p> <p>Deputising for Lead Nurse Helen Robson Chair of NIHR Clinical Studies Group of Cleft and Craniofacial Anomalies</p> <p>Clinical Director, Trent Regional Cleft Lip &amp; Palate Network</p> <p>Clinical Director, Spires Cleft Lip &amp; Palate Network Restorative Dentistry CEN Lead CRANE Clinical Project Lead Orthodontic CEN Lead Consultant Paediatric Dentist, CleftNetEast, representing Paediatric Dental CEN</p> <p>Clinical Lead, Leeds Site, Northern and Yorkshire Cleft Service Surgical CEN Lead Clinical Director, West Midlands Cleft Service Clinical Lead, Cleft Net East Lead, Cleft Collective</p> <p>Clinical Effectiveness Unit Research Coordinator, RCS</p>
<p><b>Apologies, absence and welcome to new members</b></p>	<p><b><u>Apologies:</u></b> Mechelle Collard</p> <p>Chris Hill David Landes Helen Robson</p> <p>Norma Timoney</p>	<p>President, Craniofacial Society of Great Britain and Ireland</p> <p>Clinical Lead, North ern Ireland Cleft Service Public Health Consultant Lead Nurse, North West &amp; North Wales Cleft Lip and Palate Network Cleft TIG Committee Chair</p>

	Ian Sharp Marc Swan	Deputy Chair, CDG 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 videoconference. The chair welcomed Ali Cobb and Sarah Kilcoyne to their first meeting of the CDG.	

Item	Notes	Actions
<b>2. Minutes of the Cleft Development Group Meeting, 30<sup>th</sup> September 2020</b>	Amendments to the draft minutes from 30.09.20 were suggested by the committee.	
<b>3. Matters arising</b>	<ul style="list-style-type: none"> <li>• CR noted that the Delphi will be going ahead, but with some delay</li> <li>• 30/09/20: 3.1 – CC has circulated draft CDG lay person representation Job Description. ‘Lay person’ has been changed to ‘Patient/parent representative’, to correspond with CLAPA terminology. The Clinical Studies Group have recently appointed a Patient/Parent representative; SK gave an overview of the process and offered to share the CSG ranking system with CC. It was suggested that it would take approximately 1 month to appoint a Patient/Parent representative for the CDG. CC suggested that it would be helpful to form a sub-group within the CDG for appointing Patient/Parent representation. CC welcomed CDG members to contact her should they wish to contribute to the sub-group.</li> <li>• 30/09/20: 7.1 – 7.1 – SvE is yet to receive feedback from NT regarding vacancies, but several Clinical Directors stated that contact has been made.</li> <li>• 30/09/20: 8.1 – Clinical Directors met twice in December 2020. Although little movement had been made so far, the meetings have proved to be positive. SvE has been in contact with NHS commissioners and will feedback on this later in the meeting.</li> </ul>	<ul style="list-style-type: none"> <li>• 21/01/21: 3.1 – CDG members to contact CC regarding potential input to Patient/Parent representative sub-group.</li> </ul>
<b>4. Covid 19 – Updates and impacts of current lockdown</b>	<ul style="list-style-type: none"> <li>• <b><u>Feedback from Cleft Centres (UK)</u></b></li> </ul> <p><b><u>Scotland (TG)</u></b>  Scotland’s mid-term report (up to Sept 20) suggests 84% compliance with Cleft care Scotland Primary surgery guidelines. At present, Scotland have only one child breaching the guidelines for primary surgery, but this is due to cancellation as a result of ill health. Lyndsay Kirk has been appointed as a substantive Coordinator. Funding has been secured for weekend nursing cover for the Cleft Specialist nurses, which is hoped to start in April 2021. All MDT appointments have been moved to remote consultations whilst Scotland sit within level 4 restrictions. Acute/essential clinic reviews continue as face-to-face. Currently no adult operating is taking place.</p> <p><b><u>Leeds Site, Northern and Yorkshire Cleft Service (AS)</u></b>  Largely Primary surgery targets have been met without any delay from protocol timing. Some progress has been made with secondary surgery, partially in regards to alveolar bone grafts. However, a new surge plan has recently been introduced causing significant impact on the planning of lists for cleft surgery by reducing lists down to 15%. Leeds now have only 2 full day cleft lists over the coming 10</p>	

weeks. The centre are experiencing staffing issues within theatres as a result of staff redeployment to adult critical care and sickness/shielding levels. Furthermore, cancellations have been made due to parents testing positive for Covid-19.

A single Orthognathic case was completed in October/November, but adult surgery has now closed with no imminent plans to restart. Nurses continue to see new babies at home, and continue to carry out the early pre-operative visits. Weekly MDT clinical meetings continue in addition to telephone and video consultations. In the first instance, the centre is looking to recommence face-to-face MDT clinics in Leeds only.

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

New cleft baby numbers were relatively low in 2020 with 118 (84 at Alder Hey and 54 at Royal Manchester Children's Hospital) across the network, as opposed to the usual average of approximately 154. Alder Hey operative lists had returned to pre-Covid levels but has recently reduced to 50% due to the impact of anaesthetic and theatre staff redeployment to look after adults in paediatric critical care. One surgeon is currently shielding and the government advice is to remain non-patient facing during lockdown, even after both vaccine doses.

Royal Manchester Children's Hospital operative lists had returned to 2/3 of pre-Covid levels, but elective operating is expected to stop next week due to redeployment of theatre staff and anaesthetists to adult critical care. One surgeon is due to retire in the spring. A Cleft Fellow is due to complete specialist and fellowship training in April. Paediatric surgical backlog had been largely caught up with at both sites. 16 RMCH patients had surgery at Alder Hey between July and November which prevented inequalities due to different levels of theatre list access across the Network.

Currently no adult cleft operating is taking place at either site. There was one list/operation in Manchester over the past 12 months in November; the other patient on the list was cancelled due to bed shortages.

Orthodontics have reduced capacity at Alder Hey due to Trust limitations. There are problems with North West access to orthodontic treatment due to long waiting lists and an unfilled DGH post. Some patients are travelling to Alder Hey, but this isn't an option for many and is now impacting on capacity for Liverpool patients. One orthodontist at RMCH has recently started maternity leave, the other has increased hours to provide extra cover. Both sites have waiting lists for routine orthodontic treatment. The Trust are prioritising patients already in treatment and those for ABG orthodontics.

The Trust had been asked to take on a trainee orthodontic therapist. This was discussed at the Network meeting and was advised to be inappropriate because the service specification states that cleft patients must be treated either by a consultant or senior orthodontic trainees. The topic potentially needs further discussion at Orthodontic CEN.

Nursing have had two retirements in the past 6 months and one nurse has recently started maternity leave. One band 7 post has been filled. The appointee has previous cleft CNS experience and is expected to start in April 2021. Other candidates were interviewed but were deemed not appointable. The Network is now advertising a band 6 training post with a view to later appoint to band 7 cleft CNS post when advertised.

Dental are having issues with access to theatres at RMCH. There is reduced theatre capacity at Alder Hey.

Clinical Psychology are fully staffed and continuing virtual appointments with some face-to-face.

Both sites are largely running MDT clinics virtually, with selected patients being seen face-to-face e.g. ABG assessments and adult returners.

There has been a recent neonatal death of a child born with a unilateral cleft lip and palate. A non-accidental injury is suspected.

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

Nottingham University Hospital have been in surge since the end of October and are now down to a third of normal capacity. The Trust is committed to maintaining the current capacity through the redeployment of staff. The Network is roughly meeting the criteria for under 13 months for Primary surgery, but no secondary cleft speech surgery is currently taking place.

Within all areas, cases are being reviewed on a case-by-case basis to determine what is most clinically effective (virtual/telephone/face-to-face).

Trent had utilised some private sector space towards the end of September but due to the current covid wave, that capacity has now been taken over by cancer.

Staffing is stable, but a senior cleft nurse is currently on long-term sick leave awaiting elective surgery.

An ongoing investigation is taking place in relation to a misdiagnosed cleft palate during a virtual consultation earlier in the year.

#### **West Midlands Cleft Service (IU)**

The West Midlands lead Orthodontist is retiring at the beginning of March, but will be returning to the service whilst the team look to reappointing his role. A full-time Consultant Cleft post is still to be filled, so the case load continues to be managed by the other two surgeons.

Surgery was getting back on track, with under 13 months for Primary surgery and some speech surgery being carried out. However, as of next week there will be a reduced schedule due to redeployment to adult critical care in Birmingham. The Network has lost one day's list and can only operate on p2 patients. The Network are currently discussing this with the trust, with the aim of getting primary surgery patients onto the remaining lists.

Outpatient services are continuing as normal; activity is to remain as was pre-covid. Virtual clinics are taking place where clinically viable, with some face-to-face when deemed necessary.

**Spires Cleft Lip & Palate Network (SP)**

Despite the increase in admissions, the network is managing to continue with Primary priority patients on both the Oxford and Salisbury sites. There is particular pressure on alveolar bone graft and speech surgery capacity. Currently no adult surgery is taking place.

Outpatient clinics are taking place virtually, with some face-to-face where essential.

There will be three retirements within the CNS team. A lead nurse is due to leave after 17 years in the service.

**Cleft Net East (RW)**

Cambridge have lost all operating capacity due to surge planning. Currently cases can only be appealed on a case-by-case basis. This is expected to continue until the end of March. Prior to this, primary cases were being treated as per protocol, but little secondary and adult surgery had taken place. The current backlog consists of 21 dental cases (p2 & p3), 17 primary waiting, a further 16 which should be completed by the end of May, and significant impact to secondary surgery and alveolar bone grafts.

All face-to-face outpatients clinics are been cancelled until the end of February, although high-priority patients can be brought in on a case-by-case basis. MDTs continue to be run virtually. All Spoke activities have stopped. All dental and orthodontic activity has stopped, bar emergency cases.

A new Lead CNS has been appointment and began in January. A CNS has been redeployed to critical care. A Lead Clinical Psychologist has been appointed and is due to start at the end of January.

Dentistry are hoping to put out a post for a Specialist Paediatric dentist to support Jackie Smallridge.

New cleft baby numbers are relatively low, with currently half of what would be expected normally.

Staff MDT meetings are running virtually.

**South West Cleft Service (ACo)**

Prior to the pandemic, Bristol were struggling to hit targets and had had broken speech investigation equipment for 14 months. There is currently a waiting list of 200+ patients per week. Palates are currently being listed at roughly 16 months.

Team staff have been redeployed to other services to support covid care/immunisation, and children's theatre staff/space have been redeployed to adult acute care.

There are currently 60+ adult patients on the waiting list. Bristol are reliant on the private sector to help work through this.

There are a few surgical lists coming up, but these could be taken by cancer cases.

Outpatient clinics are being run virtually via Attend Anywhere, with some face-to-face where essential. All peripheral unit clinics have been closed. Nurses continue to see babies at home where appropriate.

A speech therapist has been appointed to the team in Bristol and has previous cleft experience. Orthodontic clinics are being run for adjustments but not for new appliances. Psychology continue to operate virtually via Attend Anywhere, with some face-to-face where necessary. A new Clinical Psychology trainee has recently started training with the team. Some Psychologists have been redeployed to clinical settings.

#### **The Welsh Centre for Cleft Lip and Palate (HE)**

Following pressure from the Welsh government and commissioners, UHW have allocated the centre some theatre space at the weekends. The aim is to use these lists to address the backlog of alveolar bone grafts and speech surgery patients. Lip and palate cases will continue to be untaken in Swansea. No adult surgery is taking place. HE thanked Newcastle for the support that they have offered over past weeks.

Non-essential outpatients appointments in January/February have been postponed. Cleft MDTs and review clinics are continuing face-to-face, with some specialities operating remotely. Many patients are continuing to be seen via Attend Anywhere, namely SLT and Psychology. Dental and Orthodontics are beginning to catch up with face-to-face appointments.

There have been some staff changes in SLT and Psychology. A new Chief Executive, Chief Operating Officer, General Manager, and Paediatric Manager have been appointed in the Hospital, so changes are to be expected.

The team continue to show excellent resilience, operating on a mixture of home and on-site working.

#### **North Thames Cleft Service (NH)**

Within the North Thames region, the recent surge in Covid infections has limited elective and outpatient activity. GOSH has again become the referral centre for general paediatric referrals in the North Thames region. This is with the aim of increasing capacity for patients in these hospitals. Despite this, North Thames are still able to provide primary surgery for patients within the therapeutic envelope.

Secondary speech surgery had been provided for some older patients, but this has reduced with the increasing Covid incidence. In general, all activity that can be provided off trust for staff members at both trusts is carried out virtually over Zoom or Attend Anywhere. The only patients attending the trust for MDTs currently are the new babies in preparation for/to have their Primary surgery.

The situation at Broomfield Hospital is more critical as elective operating has been cancelled until at least 1<sup>st</sup> April. There is currently no paediatric surgical inpatient ward at Broomfield Hospital, which is due to open on 1<sup>st</sup> April.

Patients from both centres are being constantly prioritised onto a common list, with most urgent Primary surgery taking place at GOSH.

Dr Amir Sadri, the new cleft surgeon, was appointed in December.

Dental and Orthodontic outpatient clinics are carrying on as normal, provided patients are happy to attend. Some limited SLT therapy is taking place with the necessary precautions in place.

All staff have been offered the opportunity for the Covid vaccine.

The Trust are adhering to the policy with the 2<sup>nd</sup> dose to be given 3 months later.

CNS are down to one nurse following the resignation of a senior nurse to head up another team. This post has been recruited but the candidate is not due to start until June.

Psychologists have been removed from the MDT and are only available by referral.

Paediatric Dentistry remains a big problem with currently no calibrated clinician available to attend audit clinics. North Thames have attempted to address this problem but unfortunately the consultant appointed has resigned her post in favour of an academic position. Training for Orthodontists has been affected by limited opportunities.

NH expressed full admiration for the team for showing resilience whilst still providing a service for their patients.

#### **South Thames Cleft Service (AC)**

AS a result of the most recent wave of Covid-19, the Paediatric hospital has been taken over by ventilated adults. Surgery is only proceeding on the CEPOD model, where cleft care is not featured. Currently minimal elective surgery is taking place but South Thames do have access to the Portland Hospital, which they are utilising as much as possible.

There has been significant redeployment cross the team. Where possible, they are continuing to try and run a service. Where possible clinics are being run virtually, with some essential face-to-face. Outreach centres and MDTs are being run virtually via Attend Anywhere clinics.

Two CNSs have been appointed, with one already started and the other due to start soon.

#### **Northern Ireland**

No update from Chris Hill

#### **Newcastle Site, Northern and Yorkshire Cleft Service (PH)**

Cleft operating resumed in July. All lists were up-to-date until the microscope was broken on Christmas day. This is due to be fixed shortly, but at a cost of many thousands of pounds. As a result, two children have missed palate repair surgery. Half of all lists were lost within the last week. Adult lists have been converted into older children and alveolar bone graft lists, therefore the adult waiting list has dramatically increased.

One face-to-face clinic is taking place every week, triage clinics are taking place virtually, and SLT is being delivered virtually.

- **Feedback from Lead Groups and CENs**

**Speech and Language Therapy (LB)**

The Lead SLT group have been meeting every two months, with the groups last meeting taking place last week. Most SLT services in Children's Hospitals are being told to continue activity as normal, but many SLT services are still working predominantly via teletherapy. No services are running 5 year audit clinics. The Lead SLT group have started discussing end of care, which was something that featured on the CRANE Delphi.

**Orthodontic CEN (JS)**

The Orthodontics CEN are yet to meet, but the Leads are due to meet on 5<sup>th</sup> February 2021, where they will be discussing the Delphi.

**Nursing CEN(NH)**

The CEN is yet to meet but will hopefully have an AGM in the Spring. The next Lead Nurse meeting is in March, of which NH will be stepping down as Chair. The SLUMBRs study continues to be in the background.

**Psychology CEN(VH)**

All Psychologist are doing a mixture of face-to-face and video appointments. There has been a good variety of initiatives within Psychology in terms of group working etc. There is some concern from Psychologists regarding a reduced number of referrals. Psychology are wondering whether this is due to Psychological needs not being picked up as easily through Attend Anywhere appointments. There is increased anxiety regarding the downturn in surgery and the impact this may have on individuals' mental health, particularly for adolescents waiting for surgery. One of the leading Child Psychologists in Wales, Liz Gregory has written recently release a blog focusing on surviving lockdown with a new baby. VH agreed to circulate this to the rest of the CDG.

21/01/21: 4.1 – VH is to circulate Child Psychologist Liz Gregory's new baby in lockdown blog with the CDG.

**Paediatric Dentistry CEN(JSm)**

The CEN met in November and plan to meet again on 24<sup>th</sup> February. A full virtual Calibration day is due to take place virtually on 29<sup>th</sup> January and 19 people have registered for this. JSm asked for Clinical Directors to check if anyone within their units would wish to join for calibration and if so, to contact her. Audit is currently not happening as this needs to be face-to-face, but most 5 year old patients are still being contacted in one form or another to check in.

**ENT & Audiology SIG (SD)**

The SIG met in November and plan to meet again on 10<sup>th</sup> February, however a number of audiology colleagues are being redeployed which may impact on the meeting going ahead. The SIG are hoping that CR can join the virtual meeting in February.

**Surgical CEN (GT)**

The Surgical CEN had been planning to meet virtually but the date has been pushed back due to the latest covid surge. Once the

workload has evened out across the country, the CEN hope to meet in early Spring. Around the country waiting times for all types of cleft surgery are still hugely impacted. Surgery will need a coherent plan across the centres for managing the increased case load in the future.

**Restorative Dentistry CEN (SP)**

The CEN are yet to meet but are aiming to meet virtually in March.

**Managers Group CEN(YE)**

The Managers and Coordinators met in December to discuss how the services have been coping. CRANE and the dashboard were discussed and it was felt that there were some gaps in CRANE awareness and dashboard training. The Managers Group were hoping to meet the CR and Jibby Medina (CRANE Programme Manager) in April to discuss the issues. CR added that CRANE are aware of the challenges faced by Admin teams and are working on some CRANE webpages that will give detailed information on the dashboard elements that CRANE contribute to.

- **Feedback from CD meetings**

Clinical Directors from across the country have met twice to discuss the postcode lottery and how the Covid-19 pandemic has affected surgical waiting lists. CR created a spreadsheet collating the Covid waiting lists, which were circulated to the CDG. The meetings highlighted that Secondary surgery has been negatively impacted across all centres, and that Primary surgery was particularly suffering in Bristol and Spires, Oxford and Salisbury.

In both meetings, an English commissioner (Anthony Prudhoe) and two Welsh commissioners were present. This has led to the South Wales team receiving much needed access to theatres during the weekends. Although there has been little movement elsewhere, the CDs felt that this was a useful exercise to determine waiting lists, resulting in some interest from English and Welsh commissioners. GP asked to clarify whether the spreadsheet should be split into weekly or monthly sessions. SvE offered to share the spreadsheet with CDs so that it can be updated to the end of January.

SvE shared an email he received from Anthony Prudhoe regarding cleft surgical waiting lists. Anthony stated that he had raised the Bristol and Leeds waiting list issue with the ODN managers on 22<sup>nd</sup> December 2020, but has had no response and will follow up. He asked that CDs clarify the issues that they face and questioned how to manage these cases going forward. Anthony stated that an operational note has gone to Regional Directors of Commissioning and Trusts reinforcing the need for NHS systems to protect capacity for P1 and P2 patients and combine waiting lists across systems. He added that P3 and P4 treatments can continue if there is no unmet demand within the region or support being asked from another

21/01/21: 4.2 – SvE is to circulate the waiting times spreadsheet with the CDG so that it can be updated to the end of January

region that could benefit from release of these assets. He continued to state that he would like to have cleft as a theme for the Surgery in Children Operational Delivery Networks to focus in on as a priority area, but felt that they will need to be clearer about what the challenges are in relation to outcomes, and whether there is a time critical factor beyond any of the areas first discussed. He concluded by requesting that the CDG discuss this and invited the CDs to meet with him to help describe how to manage these issues at a Trust and Regional level.

The group discussed the FSSA guidelines for surgical prioritisation. GT shared the FSSA Recovery Prioritisation Matrix with the group. CR added that cleft, more so than other specialities, have robust data indicating the negative impact of delaying surgery. He suggested putting together an evidence document that could be used to support the argument for the prioritisation of cleft surgery. SvE added that this is something that the CDs working group could look at. SvE further added that it would be useful tfor VH to join these meetings in order to give her input from a Psychological point of view.

- **Surgical prioritisation**

- **Secondary cleft and non-cleft speech surgery – to avoid breaching 5 yrs of age**

The FSSA guidelines state that secondary cleft and non-cleft speech surgery must be done to avoid breaching 5 years of age. LB expressed concern that these guidelines could be limiting to some services who would need to prioritise under 5 year olds, rather than those over 5 who require speech surgery for their intelligibility.

- **CRANE response**

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

- Covid-19 impact – the team continues to work from home, limiting productivity.
- The new CRANE website
- CRANE Annual Report 2020 – the CRANE 2020 Annual Report was published on 19<sup>th</sup> December, despite Covid challenges. The Patient/Carer’s version is currently being worked on and will be shared with CLAPA before publication
- CRANE Outlier Policy- the CRANE Outlier Policy has been in development over the last 12 months. There will be a Planned Trial in 2021 utilizing 2013/2014 data.
- Current Challenges – CRANE continue to struggle with their 1 year rolling contract. CRANE are significantly underfunded. The team are currently challenged by the increasing workload.
- Plans for 2021-
  - Seek more robust contracting process / outcome
  - Maintain regular work streams
  - Develop/secure data linkage with HES/NPD/NHSP and similar for developed national services

21/01/21: 4.3 - CR and CDs working group are to explore producing a document of evidence indicating the negative impact on delaying surgery. VH is to contribute to this in her capacity as Clinical Psychology CEN Lead

- Develop collaborations with Cleft Collective
- Further develop / test risk stratification for speech and dental outcomes
- Investigate potential risk modulators for other current outcomes
- Complete Delphi exercise for adolescent / adult outcomes
- Engage with Clinical groups not represented in current outcome measures.

- **Training**

AC provided an update on training on behalf of NT. Interviews are due to be held online on 18<sup>th</sup> February 2021. There is a standardised process for all TIGs. The interviewers have already been invited by the Severn Deanery. Two jobs have been advertised for one year in the first instance, with start dates in August in line with all TIGs. The intention is to keep all future start dates from October. There will be a TIG group meeting on 29<sup>th</sup> January 2021. Two LTFT TIG fellows are in post whose training has been impacted by Covid-19, resulting in their time being extended after the first wave.

- **CLAPA (CC)**

CC thanked the teams for the work that they are doing during this difficult time and offered CLAPA support via letters of support, updates on the CLAPA website etc.

The CLAPA offices remain closed with all staff working from home. They are in the process of formalising this as a long term approach as they will be terminating the lease for one of the CLAPA offices in March. The feeding service continues to operate from the office, and will continue to do so from the same office space in the future.

Currently CLAPA are offering an answerphone service which is checked once a week, and an email service. Once staff are able to return to the office, the phone line will open again. All staff have returned from furlough and are working full-time.

CLAPA continue to work towards their organisational strategy and operational place which will result in significant changes to service delivery. CC highlighted that there may currently be some delay in response from the team as an internal restructuring is taking place. They are hoping to retain their staff and redeploy individuals to different roles, focusing on a National approach. Services will be primarily delivered online for at least the next 12 months.

Children and young people will be a bigger part of CLAPAs new approach, and they look forward to working with the Psychology CEN when developing this work.

Rona Slater has stepped down as Chair of Trustees and has been replaced by Nick Astor, a communications professional. Kath Allen, North East engagement officer, has left her position and CLAPA do not intend on replacing her post.

CLAPA would like to start attending the CEN meetings where possible to discuss CLAPA's plans for the future and how they can offer their support.

	<p>ACo noted that parents can be misled by expectations set out on the CLAPA website i.e. positive outcomes, children getting surgery, during the current climate. CC agreed and said that this will be discussed with their Communications Manager.</p> <p><b>I. <u>Discussion on CDG lay person</u></b></p> <p>CC has circulated draft CDG lay person representation Job Description. ‘Lay person’ has been changed to ‘Patient/parent representative’, to correspond with CLAPA terminology. The Clinical Studies Group have recently appointed a Patient/Parent representative; SK gave an overview of the process and offered to share the CSG ranking system with CC. It was suggested that it would take approximately 1 month to appoint a Patient/Parent representative for the CDG. CC suggested that it would be helpful to form a sub-group within the CDG for appointing Patient/Parent representation. CC welcomed CDG members to contact her should they wish to be part of the sub-group.</p>	
<p><b>5. Research</b></p>	<ul style="list-style-type: none"> <li>• <b><u>Bristol Cleft Collective</u></b></li> </ul> <p>Recruitment has restarted and, while numbers are understandably reduced, we have received consent forms and biological samples from sites over the last three months. Total numbers for recruitment are 9145 individuals from 3263 families across both the birth and 5-year-old cohorts.</p> <p>Genotyping is ongoing and 5785 individuals have been genotyped to date. A post-doc research associate has been employed with funding awarded to Professor Sarah Lewis from the MRC to carry out preliminary analyses using the genotyped data.</p> <p>Proposals to access and use the data continue to increase with 14 received in the last 12 months and 33 in total (three received since the last meeting in September). Recent proposals cover a range of areas including speech, aetiology and impact of Covid-19.</p> <p>Promoting the resource will be assisted by the six papers which have been accepted for the American Cleft Palate and Craniofacial Association annual conference.</p> <p>Clinicians have been successful in obtaining funding to work with the Cleft Collective for a year. Specifically, two trainee cleft surgeons and one lead speech and language therapist have joined the team to use the dataset to address clinically relevant research questions.</p> <p>Funding for these roles has been provided by VTCT Foundation, Craniofacial Australia and The Underwood Trust (via Bristol Speech &amp; Language Therapy Research Unit).</p> <p>Data Sharing with CRANE is in process as described in the CRANE Annual Report 2020. This work will validate cleft type for both datasets.</p> <p>Key findings from research using the data in 2020 have provided information on the impact of the pandemic on children born with clefts and their families; informed clinical practice regarding the impact of Covid-19 on cleft care; and provided reference data for</p>	

	<p>speech intelligibility in 3-year-olds using the outcome measure for speech used in ICHOM.</p> <p>Future funding to sustain the cohort and support continued recruitment and data collection is a challenge. A revised submission to the MRC Partnership Grant scheme was shortlisted and received strong reviews but was not ranked high enough in the panel meeting to be successful. This is a difficult time to secure research funding with much resource being dedicated to issues arising from the pandemic. We are in discussions with possible future funders however and, whilst these are not yet confirmed, we are optimistic about these possibilities.</p> <ul style="list-style-type: none"> <li>• <b><u>Cleft Multidisciplinary Collaborative &amp; Early Career Researchers Group</u></b> An update from Cleft Multidisciplinary Collaborative and Early Career Researchers Group (Stephanie van Eeden) was circulated to the group prior to the meeting</li> <li>• <b><u>Clinical Studies Group update</u></b> SK provided as update on the Clinical Studies Group. SK encouraged centres to submit studies to the CSG.</li> </ul>	
<p><b>6. Terms of Reference</b></p>	<ul style="list-style-type: none"> <li>• <b><u>Quality monitoring and evaluating committee and outlier policy</u></b> The CRANE Outlier Policy and the Quality Monitoring and Improvement Committee Terms of Reference were circulated to the CDG prior to the meeting. SvE thanked CR and LB for all the time they have spent formulating these documents.</li> </ul> <p>SvE presented the Quality Monitoring and Improvement Committee Terms of Reference to the group. SP requested that the Restorative Dentistry CEN be added to the QMIC membership. CR enquired whether the QMIC would consider reviewing the CRANE Annual Report, as part of its work stream, to look at what ways the CRANE report can be used to drive service improvement. SvE felt that this could be something to be discussed once the QMIC is up and running. The group agreed on the QMIC ToR, which will be presented alongside the CDG ToR.</p> <p>CR presented the CRANE Outlier Policy to the group. JND suggested, that given the importance of the Outlier Policy and its impact, it would be beneficial to have a more robust signing off of the document. CR suggested that the CDG write on behalf of CRANE to relevant Medical Directors of hosting units, stating the proposed CRANE outlier policy and requesting their sign off. The group supported this notion. As a result, CDs are to email the names and contact details of relevant MDs to SvE.</p> <ul style="list-style-type: none"> <li>○ Discussion about Leeds speech outcomes</li> </ul>	<p>21/01/21: 6.1 –The Restorative Dentistry Clinical Excellence Network is to be added to the Quality Monitoring and Improvement Committee membership</p> <p>21/01/21:6.2 – CDG are to write to Medical Directors of hosting units on behalf of CRANE, sharing the proposed CRANE outlier policy and QMIC ToR, and requesting sign off. CDG CDs are to email relevant contact details to SvE.</p>

	<p>In the latest three year cycle, Leeds has fallen to the third standard deviation in the un-stratified data for outcome 1, and is between standard deviation 2 and 3 for outcomes 2 and 3. LB and CR have been contacted by Mike Richards, who is in charge of Children’s services at Leeds, asking for a peer review of their service. The QMIC do not currently have members in place to execute said review. SvE requested that the QMIC ToR be shared with the CENs as soon as possible so that representatives can be established and the committee formed. SvE added that in the interim, it may be useful for individuals from speech and surgery to conduct the review and asked CDG’s permission to appoint reviewers for this process; CDG granted said approval. SvE will feedback to group regarding who these individuals will be.</p>	
<p><b>6. Any other business – CDG &amp; dates of next meeting</b></p>	<p>SvE is to contact Ian Sharp regarding his role as deputy chair of CDG. The next meeting will take place virtually on Friday 28<sup>th</sup> May 2021.</p>	<p>21/01/21:6.1 – SvE is to contact Ian Sharp regarding his role as Deputy Chair of the CDG</p>

**The next meeting of the Cleft Development Group will take place virtually on Friday 28<sup>th</sup> May 2021.**