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

Venue- Microsoft Teams Conference call

Date & Time- Monday 4th October 2021– 9:00 to 13:00

Present	Simon van Eeden (SvE) Chair	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, Evelina London Cleft Service
	Ali Cobb (ACo)	Clinical Director South West Cleft Service
	Claire Cunniffe (CC)	CLAPA Chief Executive
	Sinead Davis (SD)	Cleft ENT and Audiology SIG Lead,
	David Drake (DD)	Lead Clinician for Cleft Care Scotland
	Kezia Echlin (KE)	Deputising for Imogen Underwood, Clinical Director, West Midlands Cleft Service
	Helen Extence (HE)	Clinical Director, The Welsh Centre for Cleft Lip and Palate
	Louisa Ferguson (LF)	Chair of the Cleft Training Interface Group
	Vanessa Hammond (VH)	Clinical Psychologist CEN Lead
	Norman Hay (NH)	Clinical Director North Thames Cleft Service
	Peter Hodgkinson (PH)	Clinical Lead, Newcastle Site, Northern and Yorkshire Cleft Service
	David Landes (DL)	Public Health Consultant
	Joanna May (JM)	Paediatric Dentistry CEN Lead
	Gillian McCarthy (GM)	CLAPA External Engagement Coordinator & Scotland Lead
	Felicity Mehendale (FM)	President Craniofacial Society of Great Britain and Ireland
	Jason Neil-Dwyer (JND)	Clinical Director, Trent Regional Cleft Lip & Palate Network
	Ginette Phippen (GP)	Clinical Director, Spires Cleft Lip & Palate Network
	Sandip Popat (SP)	Restorative Dentistry CEN Lead
	Anthony Prudhoe (AP)	NHS England Women and Children's Programme of Care National Programme of Care Lead
	Helen Robson (HR)	Lead Nurse, North West & North Wales Cleft Lip and Palate Network
	Craig Russell (CR)	CRANE Clinical Project Lead
	Lucy Southby (LS)	Interim Clinical Lead for Cleft.NET.East
	Marc Swan (MS)	Representative, The British Association of Plastic, Reconstructive and Aesthetic Surgeons
	Yvonne Wren (YW)	Chief Investigator, Cleft Collective
	In Attendance:	
	Catherine Foster	Clinical Effectiveness Unit Research Coordinator, RCS
	Stuart Worthington	Trainee, North East and Yorkshire Region
	Apologies:	
	Toby Gillgrass	Clinical Lead for Scottish Cleft Surgical Service
	Sarah Kilcoyne	Chair of NIHR Clinical Studies Group of Cleft and Craniofacial Anomalies
	Jules Scott	Orthodontic CEN Lead

	Alistair Smyth Guy Thorburn Imogen Underwood	Clinical Lead, Leeds Site, Northern and Yorkshire Cleft Service Surgical CEN Lead Clinical Director, West Midlands Cleft Service

Item	Notes
1. Apologies, absence and welcome to new members and invitees	The chair (SvE) welcomed the Cleft Development Group to the meeting. The group joined the meeting via Microsoft Teams teleconference. Apologies were given for those unable to attend (see above).
2. Minutes of the Cleft Development Group meeting, 28th May 2021	The minutes of the last Cleft Development Group meeting on 28th May 2021 were reviewed, and approved as a true and accurate record of the meeting.
3. Matters arising	**Action 28/0/05/21: 3.1** – CDG are to consider CDG Deputy Chair nominees, for discussion during the next meeting. • To be discussed later in the agenda. **Action 28/0/05/21: 8.1** - CLAPA, CFSGBI, Surgical CEN, Psychology CEN, Orthodontic CEN, Restorative Dentistry CEN, the CD group lead and the Managers group are to contact SvE regarding representatives for the Quality Improvement and monitoring committee. • It was agreed that JND would provide CD group lead representation for the Quality Improvement and Monitoring Committee. A Managers Group representative is yet to be established as a Manager currently does not sit on CDG. SVE requested feedback on CDG Managers Group representation from CDs. All over representatives were agreed prior to the meeting. **Action 28/0/05/21: 8.2 –** CDG are to prepare any feedback on the adjusted CDG ToR for discussion at the next meeting. • To be discussed later in the agenda. **Action 04/10/21: 3.1** – CDs have to explore potential CDG Managers Group representation within their centres and report back to SvE
4. CLAPA	**CDG Patient and parent involvement, CLAPA External Engagement Coordinator and Scotland Lead, Gillian McCarthy** GM gave a presentation on CDG Patient and Parent involvement. GM, GP and HE had previously met to discuss patient and parent involvement within the CDG. GM discussed the patient and parent involvement model used by Cleft Care Scotland. Cleft Care Scotland have determined that parent representative is not beneficial within steering group meetings. The patient and parent engagement group do however meet prior to the steering group meetings to discuss the steering group agenda, papers and any queries. GM then feeds this back during the steering group meeting. Following the steering group meetings, the programme manager distributes the meeting minutes to the engagement group for review and feedback. The engagement group also provide feedback on patient pathway and patient/parent focused events. GP and HE felt that this model could be applied to CDG; patients/parents could meet prior to and after CDG meetings to provide input and feedback. JND shared his concerns regarding the transposing of patient/parent views, and instead suggested that an individual attended the CDG meeting for a brief period to discuss their concerns. GM noted that CLAPA could provide patient feedback. GP commented that the patient/parent group should decide how they would like to represent themselves. It was agreed that the CDG, as led by GP and HE, would begin work on CDG Patient and Parent involvement, following the model proposed by GM. **Action 04/10/21: 4.1 –** GP and HE are to begin preparations for CDG Patients and Parent involvement, following the Cleft Care Scotland model.

	<u>CLAPA Feedback</u> CC provided an update on CLAPA. CLAPA are now delivering a digital only online strategy (April 2021-April 2022), and are currently in the process of reviewing this. The next 3 year strategy is currently being planned, and will run from April 2022 to April 2025. The current strategy has worked successfully and the CLAPA website is being developed. Staff, children and young people, and community website and social media consultations have taken place. The summer survey has been distributed. CLAPA have recruited a community engagement coordinator, who is running a programme of online events. Coffee clubs for parents continue, and a successful coffee club for grandparents has recently taken place. A series of employment seminars for adults are due to begin alongside other adult social events. The adults' leaver pack has now been circulated to all cleft teams. GM has been working to provide packages of support for research projects (e.g. SLUMBRS). Siobhan Handley (Professional fundraiser) has been appointed to the Board of Trustees. CC thanked those who took part in virtual bar at the CFSGBI conference. The Christmas Campaign is due to launch in October. CC suggested that Cleft Teams establish a CLAPA champion that can feedback to CLAPA, and welcomed any feedback on this. HR feedback that the new online form has been hugely useful, and praised the ongoing feeding service.
5. **Feedback From Cleft Centres (UK)**	Prior to the meeting, SvE requested that the CDs provide feedback on surgical waiting lists and stated that any yet to get back to him provide an update on this. SvE and AP have met to discuss waiting times. With regard to COVID and historical waiting lists, some units are starting to develop waiting list issues and are struggling to meet protocols. As a result, a freedom of information request has been generated from parents of patients who are concerned that their children are to be operated outside of normal protocol with a detrimental effect to outcomes. **<u>North Thames Cleft Service (NH)</u>** COVID infection rates in the hospital have now dropped to negligible levels and as a result staff absence has returned to normal levels. All staff within the team have now been offered a booster vaccination. There is a reduced complement of CNS nurses (lead having left in July but we have appointed to this position and the plan is to start in November) which has been made up in some part with bank cover. There is a full complement of surgeons. This has allowed the centre to keep up to date with the primary cleft surgery, but they have an inevitable backlog of patients requiring secondary surgery including cleft revision surgery, alveolar bone grafts and orthognathic surgery. This continues to affect the adult service for surgery which is limited in both secondary surgery centres. The Paediatric inpatient facility at Broomfield Hospital has been severely compromised/completely absent over a period of 9 months. This is due to the closure of the paediatric surgical ward One of advantages of being a twin site has been the ability to operate on time dependent patients from Broomfield at GOSH meaning that the service has been able to keep up to date with primary surgery. Downside of this is that here has been a knock on effect on secondary speech surgery. New ward due to be completed and opened on the 13-12-21. The SLT department have continued to provide a service virtually and are now also providing a service within the trust with the necessary measures in place. Psychology are continuing to provide a virtual service over Zoom, but unfortunately, unlike at Broomfield, Great Ormond Street are only providing a referral service. Limitations have meant they are no longer routinely attend cleft MDT clinics, which is inadequate for our patients and this has been highlighted to the lead for the psychology service; are now being provided with one hour of a psychologist for each MDT clinic, which makes it difficult on deciding which hour is the most suitable. ENT and

	audiology service continues to run will with much of the audiology service now provided at local rather than centralised level. Restorative service is back up and running, but with increased necessity for AGP's, there are longer waiting times between patients. Orthodontic service is fine. The paediatric dental service is currently down 1 full time consultant paediatric dentist with the result that capacity is reduced. Currently, inpatient work has been prioritised but there is a long wait for outpatient appointments. Again, priority is given to those most in need. The post for a specific 10 session Paediatric dental consultant post has been approved and will be advertised imminently. The department has been largely running as normal since June of 2020. However, because of the need for social distancing in the waiting area and the need for additional cross infection measures between patients, appointment times are usually 30 minutes. This has reduced capacity for outpatient reviews. In addition, as alluded to earlier, there are delays in the delivery of alveolar bone grafting (6 months) and with orthognathic surgery (12 months). The maxillofacial surgery department have been working hard to reduce this in recent months. They currently have no service manager in place at GOSH (New person interviewed and due to start in end Oct), and have lost their current cleft data supervisor to maternity leave and this position will hopefully be filled soon but this has made keeping up to date with CRANE and the dashboard more difficult. GOSH General Manager and divisional director are due to leave in Jan 2022. Specific problems significantly affecting the service currently: 1. The absence of a calibrated paediatric dentist at the cleft audit clinics has completely compromised past admissions to the crane database. This is despite several attempts, with the support of the trust, to try to appoint a clinician to this role. 2. The Paediatric inpatient facility at Broomfield Hospital has been severely compromised/completely absent over a period of 9 months. This is due to the closure of the paediatric surgical ward. As result of this, they have a common waiting list for the whole North Thames network, with the highest priority cases being transferred to Great Ormond street for surgery. More recently there has been some additional inpatient activity at Broomfield with the service prioritised as one weeks operating per month. New ward due to be completed on the 13-12-21! 3. Recent report from CRANE about 3 of the measures on the CRANE database being outside 3 standard deviations of data completeness. Report due in 28 days from the arrival of the letter. NH is to provide an update on surgical backlog to SvE after the meeting. VH stressed that the psychology CEN is concerned about the psychology situation and that the psychology service should not be a referral based service and needs to be an embedded part of the MDT; especially concerning because there was previously such a good psychology service in NT but the lead psychologist is having to work according to the managers' dictate. VH offered the CENs support and encouraged NH to use the cleft service specification to point out that a referral service does not meet the cleft service specification. NH replied saying that he has met with the lead at GOSH to no avail; this is not happening at Broomfield and the inequity of the service across both sites has also been highlighted. NH re-iterated the importance of psychology within the MDT and stressed that any help from a national perspective would be greatly appreciated. SvE pointed out that the outlier report for CRANE needs to go to the MD and the executive team and that it might be an idea to send a copy of the cleft service specification with the report to help change the perception about psychology input? AP suggested that NH contact local commissioners and regional teams about psychology as he is aware that

GOSH is challenged on a number of fronts as far as psychology is concerned eg. The epilepsy team is having similar problems. AH re-iterated getting in contact with regional teams if problems were not being addressed at trust level.

CR mentioned that there are 5 cleft units who are either outliers or on negative alerts for psychology and there are 5 units that are positive outliers meaning that there are some services providing an excellent psychology service and for others it is a real challenge.

The Welsh Centre for Cleft Lip and Palate (HE)

Surgical lists continue to be reduced, but the centre are now able to serve speech surgery and ABG cases. Babies are being treated at 7-8 months, and alveolar bone grafts and speech surgeries at 3-4 months after being placed on the list. Adult surgery is more challenging - A list for adult speech surgery had been secured but was cancelled due to lack of beds hospital wide. The centre are aiming to conduct P4s-rhinoplasties and lip revisions- within the private sector and are now waiting for a facility only contract to be finalised for Saturday sessions. There are approx. 42 adult patients waiting for surgery. Clinics are back to normal, with all specialities in attendance. There have been some issues with securing rooms for Psychology and baby clinics. There is a 0.5 8a Psychology post and a band 7 SLT post currently available. Karl Bishop, a restorative dentist in Cardiff, has retired and this post is due to be advertised shortly. Due to Covid, there is currently a 2 year waiting list for Orthodontic Treatment. Lots of changes in the health board with lots of key players used to working with the cleft service are either retiring or moving on so we are now working with new managers and finance partners, which will be an ongoing challenge for the cleft team. SvE asked about orthognathic patients –HE replied that they had been prioritised and are therefore up to date.

South West Cleft Service (ACo)

ACo thanked SvE and AP for their help and time given to the centre. There are backlogs in both operating and clinics at University Hospital Bristol and Weston. Regarding operations, there are approximately 300 children's operations required-waiting lists and those waiting to come into clinics that will need surgery- and 90 adults' procedures. Reduced operating facility can be seen throughout the trust in both adults and children, but cleft is now seen as a priority. The service are looking at starting adult work in the private sector, although the enhanced tariff negotiated by the Trust was nowhere near the increase expected. Clinics are delayed, especially the South West Peninsula, including the audit clinics, as they rely on other South West trusts partners and they are not a priority and Covid is prevalent-5000 confirmed cases from a music festival recently. The centre have been notified by CRANE that they are an outlier on child growth data and dental health data ito returns, which the South West are responding to. The centre now have a waiting list for speech therapy. Three cleft orthodontists have left, one returned as a locum. A name Cleft Restorative dentist has been appointed but is not due to start for some time. All areas of the service need to expand and is not just a surgical issue. The centre are working with the South West Operational Delivery Network. They now meet with the ODN, South West specialist commissioners, University Hospital Plymouth trust and UHBW Director of Surgery weekly in Cleft Recovery meetings. Operating in Plymouth will start shortly and for safety reasons will be looking at ABGs only for now-short term option. PH and ACo have talked through options in Newcastle. Cardiff has offered weekend operating but the centre are unsure if they can accommodate this yet. The service are committed to keeping patients treated within the South West Cleft team at the moment for continuity of care. The South West Commissioner for NHS England meets regularly with the UHBW Director of Surgery and Medical Director although the medical director has just left. This is for updates on progress but also the ongoing root cause

	analysis of their position, which predates Covid. Primarily the plan is recovery to prevent harm to people awaiting surgery. The centre then plans for redevelopment of the commissioned provision for the South West – along the lines of the Scottish managed clinical network, probably with the SLA and funding being held by the South West Cleft Service. TG and ACo met a few weeks ago to help to understand this. A Freedom of Information request has been made by a parent of the service. These parents are very supportive of the service and the delivery of their child has been brought forward. The parent's first report has been sent to Sajiv Javed in the Ministry of Health, which focusses more attention on the trust. SvE asked about running to protocol - ACo replied that they had dropped to 14 months but now back to 15-16 months for palate. SvE asked if speech surgery and ABGs were being done instead of primary surgery or was the issue operating lists? ACo reported that they were getting hardly any lists – the main focus is getting primary palates treated and those patients with cleft lips and palates. The problem is that there is not enough operating capacity in the hospital. Currently the operating that is being done is P2 and urgent. SvE asked HE about the Cardiff offer of support – HE replied that the offer was for speech and ABG patients and that discussions/emails were ongoing between the commissioners and providers – South Wales were unable to do any of their babies in Cardiff but through commissioners and in particular Sian Lewis they secured lists for speech and ABG surgery. In May when South Wales resource in Swansea improved and lists in Cardiff were no longer necessary HE contacted ACo to suggest using the resource in Cardiff but that the only way to do this is to go through the commissioners. The Cardiff theatre team have a SOP for ABGs and speech surgery and would want to work to this and offer Saturday theatre lists and would want HE and the South Wales surgeon Tom O'Neill to deliver this rather than bringing in surgeons and having to go through new governance processes. Tom O'Neill has offered to provide this service and has done so on a number of occasions. This offer by providing surgery for speech and ABG would hopefully free up resource in Bristol for primary patients. The group discussed the possibility for mutual aid for Bristol regarding their waiting list. PH commented that 300 patients waiting translates into at least 200 operating sessions and asked ACo if there was a plan in place to address this as Pho stated that he could not see how Bristol could manage this on their own and wondered if as a community we should see what we could do to help? Pho offered to come and help in Bristol if the hospital was able to free up theatre space and beds? PHo feels that a plan is needed and asked what the plan was? SvE replied saying that he is currently working with ACo and English and Welsh commissioners to try and come up with a more local plan but that a national plan is indicated to deal inequitable care. AC had similar problems previously but said they were able to build their way out of a situation using tariffs and PBR but with block contracts now he asked how to get out of this situation with block contracts? AP agreed but felt that funding should not be a barrier and if it is funding it needs to be raised with commissioners. Pho, JND and KE all stated that they had received contact from patients in the South West requesting referral. The centres approached have stated that they will not take on patients unless specifically requested by the CD of said unit. JND asked what is the NHS position on patients moving to other centres? AP replied that NHS England's stance is that parents do have a choice of where they are treated but it then becomes an issue of capacity. AP then asked is there scope for mutual aid and is this part of Bristols plan. SvE felt that conversation should be continued in a separate CD meeting. KE felt that a connected decision needed to be made about what CDs are to say to these patients. KE added that the West Midlands have taken on patients from the border and that some patients had moved house in order to get treatment in Birmingham. CC added that the parents from the South West who initiated the freedom

	of information request had had their baby and the father has set up an independent parents group that he has now put on Facebook with CLAPA have given him permission to advertise this group on the CLAPA website and CC feels that families contacting teams other than the South West is going to get worse because the parents (mentioned above) are going very public but while they have been supportive of ACO and the South West team they want the best for their child and other families in the South West and are now playing an advocate role. CC reported that there are already 10 other members of the Facebook group and felt that while this sort of pressure could be beneficial in expediting change it may increase the contact with other teams. ACo noted that the background to this issue is that Bristol is too small and is not fit for purpose and the hierarchy within which they work-ACo stated that he has still not met the medical director but goes instead through the chain of command; after he had met the local commissioner about this issue on the advice of AP and the CDG he was unpleasantly "hauled up" in a telephone conversation and feels that the system is very hierarchical; he stated that Bristol would like to treat their own patients but they are acutely aware of a red line of delays and harm and that once this line is crossed then the South West needs to be declared as a failed service in order to gain aid from commissioners. ACo felt that this should probably occur now. AP suggested he contact his commissioner and ODN colleagues directly regarding this. AP suggested that he liaise with the ODN regarding what CDs should do in the case of patient referrals. AP to contact CC about parents discussed previously. DD reported his involvement as they are both dentists and was put into contact with DD by a mutual maxillofacial colleague and he provided evidence to them of harm caused by delayed surgery. JND stated that it is useful to get the issue onto the trust boards risk register and the specialised commissioners risk register and the CQC then expect this risk to be discussed at every board meeting- which then helps to get resolution and has helped Trent to get movement on longstanding issues. SvE suggested a meeting of the CDs, following AP conversations with the ODN and South West commissioners, to discuss the matter in more detail. **Action 04/10/21: 5.1 –** AP is to liaise with the ODC regarding CD action in the case of patient referrals. Following this, CDs are to meet to discuss the matter in more detail. **Spires Cleft Lip & Palate Network (GP)** Spires have similar issues but not to the same degree as the South West. The centre are having regular surgical lists. There are some differences between Oxford and Salisbury which is proving problematic as it is inequitable. The centre have met with NHS England, through the ODN, and were challenged as to whether Spires were working as a Network, the centres views on the continuity of care, and were asked why Salisbury patients couldn't just be treated in Oxford without understanding patient and patient support complexities. The team was also challenged on the high number of P2 cases in Salisbury compared to Oxford and the rest of region. They also queried the team's designation of P2 patients and the team were able to defend this position. The solutions were then pushed back to the Network to establish, although they are receiving some support from the ODN and by working closely with the trust to bring the waiting list down. The network are managing primary cases well, but have a lot of school age children waiting for speech surgery particularly on the Salisbury site and are struggling with ABG more on the Oxford site. We are looking to accommodate these patients where theatre space arises across both surgical sites. No adult surgery is taking place apart from Orthognathic surgery which has recently restarted for urgent cases. The network have been asked to create a plan for P2 cases and a longer term stability plan going forward as they have more theatre time and surgical resource in Oxford.

The network have a band 8A part time Clinical Psychology vacancy, which has been extended twice. The network have been identified as a CRANE negative outlier for psychology, so GP will be contacting the trust to try and establish other options for their psychology service. The network have also been identified as a positive CRANE outlier for dental outcome, despite not having a paediatric dentist. The network will consider this and other factors when responding to CRANE. GP will be stepping down as CD at the end of 2021, with a new CD starting in the beginning on January 2022. GP requested that she complete her work setting up the CDG Patient and Parent involvement group despite stepping down as CD. SvE and the group were happy for GP to complete this.
JMa asked who was collecting the dental data and are they calibrated. GP replied that this was being done by calibrated orthodontist. AP asked if the ODN has set a particular time frame. GP replied that they are working to a 2 month deadline until the next meeting.
SvE thanked GP for her input during her time on CDG.

Evelina London Cleft Service (AC)

Paediatric surgery is back to pre-pandemic level with minimal pressures on primary operating. Private venues and paid for weekend lists had previously been used to generate additional capacity. For the first time, the centre have had an operating list cancelled due to RSV and staff shortages since pre-covid and warnings have been issued that routine operating will be impacted through winter. The Adult service is impacted but is working and coping with adult pressures. Clinics are running well in all specialities, although they are stretched with maternity and sickness within the team. Maternity locums have been appointed where possible and teams are stepping up to fill the gaps. There are no significant vacancies within the team and all have been offered Covid boosters. Still have hospital outpatient covid protocols, which is proving to be challenging for those patients that despite being informed, are not adhering to these protocols. The network have been identified as 4 CRANE outliers, which they are currently working through. CC asked about adult treatments and how CLAPA reports back to and supports adult patients in view of the significant backlogs. CLAPA is planning an adult conference and would like to know how the waiting issues should be addressed? AC replied that there is difficulty advocating for and progressing adult issues for adult patients seen within paediatric hospitals but would support adult patients coming back to cleft services rather than having treatment in units without cleft experience.

Cleft Net East (LS)

The network is doing well in relation to primary surgery largely due to sharing and accommodating P2 lists across paediatrics. There are some long waits for others, including adults, ABGs and speech surgery. There are long standing vacancies in the nursing and psychology team with real difficulties recruiting to the psychology team been out to advert 3-4 times and the most recent advert is about to close and a large turn over in the admin team and a new co-ordinator is about to start. A surgeon is due to begin maternity leave at the end of the year and the team are in the process of planning how to manage/cover this. Orthodontic capacity is stretched across the region and although Rachel Willis' maternity leave is being covered by Ahmed Din there is a lot of pressure on the Addenbrookes orthodontic team. A new consultant restorative dentist and a speciality dentist to support Jackie Smallridge in the paediatric dentistry, have started. SLT still struggle with PPE and have added this to their risk register. The network are hoping that clear masks will have approval soon. There are ongoing concerns about the postcode lottery for SLT access across the regions. The network have engaged with the

ODN regarding this. The network continue to struggle recording listening for CRANE. CAPSA training is now planned for this year, so progress is being made.
Audiology capacity is challenged and Cleft NetEast still has room capacity challenges for outpatients' clinics including MDTs. This includes current outpatient covid rules and a longstanding lack of outpatient facilities.

Trent Regional Cleft Network (JND)

Surgical capacity normalised over the summer with 3 patients per list and 3 lists per week to get back on protocol but over the last 4 weeks, due to reduced paediatric nurses and increased acute respiratory viral conditions, capacity has reduced. There were no lists for 3 weeks and this week are hoping to do 5 cases and have now gone back to using an individual case by case prioritisation system, with only 25% of bed base open in Nottingham Children's Hospital. Primary surgery protocol is not yet being breached, and ABGs and speech surgery continue to happen on a prioritised basis. No adult work has taken place since the start of Covid, bar some orthognathic work. The cleft team have, together with other paediatric surgical services and community services managed to convince the trust that paediatric P4 cases are different to adult P4 cases in that age based changes do still occur in these patients and this has altered the way in which these patients are prioritised within the trust and has worked well. Cleft will continue operating within the NUH capacity, but are looking at outsourcing some of the more routine ENT procedures or getting more funds in. Clinics are running well, with many running on a hybrid model of virtual and face to face clinics.
A new orthodontist has started in Sheffield and another is due to start in Lincoln. The network were identified as a CRANE outlier for both data completeness for Clinical Psychology,(Trent do not have a psychologist but plans for a psychologist are on the back burner due to covid but there had been a recognition that this was a trust wide problem with no psychology embedded in any of the services and the trust will start addressing this) and Paediatric Dentistry- Paediatric dental offer is to be expanded across the region and this will hopefully result in a paediatric dental service for the cleft team.. The Family Network day is due to take place at the end of October with 120 participants booked in AP asked about the network day and how covid has made things better? JND replied saying that this more to do with the development of hybrid clinics resulting in improvement in long waiters. Network day was copied from SvE in Liverpool/Manchester. VH commented on the positive moves regarding psychology and re-iterated the importance of the psychologist being embedded in the team so that they can't be pulled away to other teams. WRT to shortages in psychology numbers on the doctoral courses have been increased to address this nationally.

West Midlands Cleft Service(KE)

Paediatric operating is to back to full capacity. Lips are coming in at 6 months and palates 9-10 months. Speech surgery and ABGs are also running. The trust are short of theatre nurses, in particular ODPs, due to lack of those qualifying during the pandemic to replace those leaving. Some senior staff are due to retire next year, which may lead to some difficulties. Adult services are struggling as the adult operating is on another site, which is currently struggling because of covid and lists can only be used for day cases. They are currently putting an SOP together for day case rhinoplasty. The service is currently short of a Clinical Lead and are hoping that Imogen Underwood will be reinstated to the role and if they don't it might be a problem as many of the other leads in the cleft team have other leadership roles within the trust and this would mean they would have to drop this to take the cleft lead role.. The service are a CRANE positive outlier for dentistry and a negative outlier for Psychology-there is long term sickness in psychology and the team

changed the way in which psychology worked during covid meaning that data wasn't collected and the team is underfunded from a psychology point of view compared to some of the other teams so West Midlands is hoping to use this as leverage within the trust to increase the amount of psychology support that they have within the cleft team but psychology is struggling across the trust presently. The Lead Orthodontist has retired and advert should be going out shortly-have one part time orthodontist within the team but there will be a knock on effect on the orthodontic waiting lists. Clinics are up and running as were pre-Covid, with some video but predominantly face-to-face. There is plan for some super Saturday clinics to deal with protocol backlog identified by Imogen Underwood. DD and PHo commented that they have done most of their rhinoplasties as day cases and offered their support should it be needed.

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

Following a gap of 4 months, a Network Manager is now in post; currently off following a family bereavement. David Whitby retired in September 2021 and Marnie Fullarton our previous cleft fellow started as a cleft surgeon the following week, which is a success of the TIG fellowship programme. Alder Hey operating lists are at pre-covid levels and timings are at pre-covid protocol. Manchester are at 2/3 of pre-covid operating lists, with lots of cancellations due to bed issues. The Manchester surgeons have picked up some lists at Alder Hey when Alder Hey consultants have been on leave. Manchester palate repairs are taking place at 11 months, lips by age 5 months, and speech surgery and ABGs are being appropriately prioritised. Births have been low across the Network, with 2/3 of the typical number (76 births) meaning about 100 births for the year compared to a usual birth rate of 150. Have also had queries to take patients from other units but we don't currently have capacity to do this. Ad hoc adult operating sessions are taking place at Liverpool but at short notice and there has been 2 lists offered in Manchester resulting in long waits for adults. Access to orthodontics in North Wales remains problematic and will be exacerbated due to a further retirement at the end of the year-there is longstanding difficulty recruiting to orthodontic posts in North Wales generally. One of the network orthodontists is on maternity leave but one of the part-time orthodontists picked up these sessions. SLT is operating on a mix of face-to-face and virtual appointments-both sites coping well and fully staffed. The lead nurse is transferring to North Thames from 1st November, so the network will be looking for a new Lead Nurse. A band 6 support nurse was appointed earlier in the year and this has worked well. One of the nurses is on long-term sick leave and another has just returned from maternity leave meaning that the nurses are under pressure but despite this they are managing to cope. There are issues with access to dental theatres in Manchester and a backlog of dental patients waiting for outpatient review and treatment. One Clinical Psychologist at Alder Hey is on maternity leave and one Psychologist has given notice in Manchester. Cover for both of these posts has been established. MDTs are going back to face to face but will continue with virtual clinics for older patients.

Leeds Site, Northern and Yorkshire Cleft Service (SvE on behalf of AS)

Cleft operating in Leeds remains reduced and still approx. 55-60% pre-Covid levels. Whilst primary surgery has been prioritised this is beginning to impact on the timing of surgery but current timing of primary surgery is still within quality dashboard limits for routine cases. The waiting times for ABGs and secondary speech surgery is more of a concern. As a team, the service have also recommenced regular MDT clinics throughout the network, taking place within the spoke hospitals, as per pre-covid.

Newcastle Site, Northern and Yorkshire Cleft Service (PH)

With the support of the Bristol Team, the service have operated on two cleft and lip palate patients from Bristol. The service carried out new patient consultations by video, and have been supported subsequently via remote appointments and by Newcastle nurses. Have 2 new nurses but they were "oven ready" as they worked on the cleft ward. The service have good data which has enabled them to plan in accordance to the RSV problem. Due to this the Orthopaedic ward has closed and moved in with the Paediatric plastic surgery ward. In theory, the service have the correct number of lists, but patients are frequently cancelled the day prior. Last week, PHo and David Salisbury decided to change the lip protocol to 6 months. Palates and some secondary speech surgery and ABGs are taking place. Some adult rhinoplasty have taken place, but this has now stopped due to inpatient covid patients and lack of a plastics ward. Outreach clinics are yet to resume and clinics are only taking place in Newcastle meaning that they have reduced from 60-80 patients a week down to 15. This has been managed in various ways: clinics are only in Newcastle; clinics are triaged 2 months in advance; clinics usually run with 4 rooms and clinicians move from room to room; DNA rates are improved for face-to-face clinics. SLT is running successfully virtually meaning that they do less travelling and the SLT team have won green prizes as they have reduced their footprint. Tongue tie and lip tie issues have returned. Psychology issues might be on the horizon as PHo was informed that psychology will be moving to a centralised referral pathway for all psychology patients - PHo informed the psychology lead that this would not be happening within the cleft service. HR concurred that she has been bombarded with tongue and lip ties. PHo trainee doing an article on this in the BMj to inform GPs. Pho to share this when it is published. DD thinks that health visitors should be targeted with regard to this. NH asked whether there was a funding stream available for psychology previously prior to his role as a CD. PHo in his work on year of age tariff previously might be able to share historical GOSH data with NH. VH agrees with PHo that psychology should remain embedded in the cleft team.

Scotland (DD)

Throughout the summer the centre were operating to national protocol at almost pre-Covid levels, but lists are now starting to be cancelled due to medical admissions and lack of staff. Surgical timings are okay, but are starting to push the boundaries but he thinks this will get worse. No adult elective surgery is taking place across the country. There are some staffing gaps due to maternity leave in SLT and nursing. There is a vacancy due to open up in Psychology. Back to doing peripheral clinics but clinics are running on a hybrid model. Scotland continue to try to get into CRANE but data sharing issues need to be ironed out.

National Children's Perspective – Anthony Prudoe

AP if there are specific codes for cleft and tongue ties? CR from CRANE can feed into this for AP. DD added that there is a code for an upper labial fraenectomy but this should be age based. AP is to circulate the RSV data update with the group.

SvE asked AP for a national overview and he informed the CDG that RSV numbers were plateauing but that the susceptible population is still present meaning that RSV is still a threat and will continue to put pressure on NHS service and he would circulate the latest PHE data to the CDG. ED were under increasing pressure and the August data of this year compared to August 2019 has shown an increase in 0-1 year old attendances by 30%. Elective surgical admissions for August have shown a 16% reduction, which is concerning. Non-elective admissions have increased in August by 13% meaning pressure on the system including primary, secondary and tertiary care. The big issue for PICU is a shortage

	of nursing staff affecting capacity across the country. Pressures set to continue throughout winter to March/April time. **<u>Accommodation of refugee referrals</u>** SvE asked about refugee referrals to cleft teams and for guidance from NHS England about these? AP noted that guidance had been sent to NHS Hospitals and directors two weeks ago. AP is to circulate this letter to the CDG. **<u>Action 04/10/21: 5.2 –</u>** AP is to circulate RSV data update and refugee referral letter to the group.
6. Feedback from CRANE	CR provided an updated on CRANE at the CFSGBI conference in September, and intended providing an updated presentation today but due to a new computer was unable to do so-he will be doing so in due course. He did provide an update on the CRANE 2021 Outlier/Alert Summary during the meeting with a slide showing a list of the outlier status of all the centres-this shows that performance across centres is variable and there are process and outcome alerts that will feed into the outlier policy next year if alerts occur again. CR encouraged all CDs to look at the annual report in detail and look to improve outcomes where alert status has been identified to avoid becoming an outlier the following year. CR hopes that the report will help units negotiate with managers and commissioners for improved resource in the areas where centres are designated as outliers. As a group CR would like all to try and improve the variability from a bimodal distribution to a normal distribution so that being an outlier is a rare event rather than the pattern that is currently being seen. CR highlighted potential issues with reporting next year as data collection for the 2014 and 2015 cohorts has been severely impacted on by the coronavirus pandemic. CR highlighted that CRANE staffing is currently stretched and response times may be delayed. CR thanked AP for his input and support over the previous 12 months helping with getting a contract in place for next year.
7. Feedback from CENs	**<u>Nursing CEN (HR)</u>** There are several nursing vacancies across the country and so Lead Nurse recruitment needs to be addressed. HR is moving to North Thames, and the North Thames nurse has moved to Spires. There was no Spires Lead Nurse representation at the last Lead Nurse meeting. A virtual CEN day is due to take place on 5th October, which will be the first in two years. CLAPA, SLUMBRS and Cleft Collective are due to provide an update on the day. PHd mentioned that their Lead Nurse was concerned about the move to telephone contact for diagnosis of babies with cleft at time of antenatal diagnosis. There is evidence about the value of face-to-face contact at this point and PH strongly supports continuation of face to face contact in these circumstances. HR voiced her support of this and noted that this will discussed during the CEN day. **<u>Surgical CEN (MS)</u>** The Surgical CEN are due to meet on 19th November 2021. GT is finalising the agenda, which will be circulated shortly. **<u>Speech and Language Therapy CEN (LB)</u>** The Lead Speech Therapist group continue to meet on a two monthly basis and have met twice since the last CDG meeting. The group have been working with YW around the protocols for the CCUK Intervention Study, and have been looking at the Speech at Home programme package that has been put together by Debbie Sell and Triona

	Sweeney. The group have been trying to work with Clearer Talk regarding bespoke obturators, but unfortunately the company does not currently have the investment needed to take the obturators into production. There is still huge discrepancy in the provision of SLT around the UK due to discrepancies in Covid rules across hospitals. Most centres are using a hybrid approach for SLT. Many centres have not been able to secure rooms for audit clinics, which will effect data collection for the 2016 birth cohort. The CEN are working with the CRANE team on the wording for the 2021 CRANE report regarding centre discrepancies and a paragraph will be inserted into the 2021 CRANE report to explain this. There is an audit specific meeting taking place shortly. HE and other CAPSA trainers will be running a CAPSA training course next year. LB will be stepping down as chair of the SLT CEN in December 2021. SvE thanked LB for her input, enthusiasm and passion during her time on the CDG. **Psychology CEN (VH)** The CEN continue to work on the calibration process for TIMs score. The CEN are due to meet next week and will be finalising their national projects, which will be put forward to the Edinburgh Congress. CEN welcomes the process with CRANE highlighting the disparity in the resourcing of psychology services across the country. A tricentre in the West of England have been working on ABG child and parent experience and the support needed with ABG, which will hopefully be feedback nationally. The CEN have supported CLAPA with the development of the leaver's packs for those transitioning to adult services-CEN had a vey good presentation from Danielle McWilliams who works for the Centre of for Appearance Research on her qualitative research on adolescents transitioning to adult services. **Paediatric Dentistry CEN (JM)** JM took over at Paediatric Dentistry CEN chair in March 2021 from Lucy Burbridge. The CEN met virtually in June and have another meeting planned for November. An online calibration course was organised for August but had to be postponed until 20th October. The CEN need to do some calibration future planning for when Jackie retires. They are hoping to have the course hosted on the CFSBGI website. Most units are now returning to face-to-face appoints for children. It has been noted that many children have not been able to access their local dentist and primary care providers during the Covid pandemic, which has led to a lack of preventative care. A multicentre audit of questionnaires regarding this has been circulated to all parents attending MDTs. Paediatric dentists around the country are now attending ABG clinics and are finding this incredibly useful for treatment planning and the identification of dental decay. The Delphi survey has been discussed and was concluded that the DMFT data needs to be established prior to putting any other outcome measures onto the database. CR has concerns about calibration and outliers and the validity of data presented-CRANE represents data from units and worries about legal challenge in the future so when talking about calibration it would be useful to engage with CRANE to establish user reliability and he asked if this could be placed as a separate agenda item at the next CDG meeting. SvE noted the request. GP highlighted that because there isn't a paediatric dentist on the Spires team they are sometimes missed when it comes to paediatric dental audits so she asked if she could be contacted directly when these audits arise so that Spires could contribute? JM acknowledged this and offered to place GP on the paediatric dental CENs distribution list. **Orthodontic CEN** No updates received or from orthodontists in the meeting.

	<u>Restorative Dentistry CEN (SP)</u> The CEN has appointed a new secretary Khalid Malik in Birmingham. The CEN are due to meet in mid-October and the focus will be on setting up an education and training day for STRs. The meeting will also focus on nasal obturator services across the country and speech appliances. The CEN also have issues with access to NHS dentistry across the country as a consequence of the covid pandemic. **<u>ENT & Audiology SIG (SvE on behalf of SD)</u>** The CEN haven't met since the last CDG meeting but have a meeting arranged for 6th October where they will meet with CR and Jibby Medina to discuss their concerns regarding the denominator of the QD. SD noted that ENT and Audiology data collection for CRANE seems to be complex, and many centres do not have the capacity to support data entry. **<u>Manager CEN</u>** SvE noted that there didn't appear to be a managers CEN currently nor is there a managers representative on CDG so he asked all the CDs to ask their managers if anyone would be interested in both representing the managers on CDG and restarting the manager CEN as the problems being faced by centres across the country are similar and often it is the managers that have to deal with these issues?
8. CDG Terms of Reference	The CDG ToR was circulated prior to the meeting. No issues were raised in regards to the ToR. The CDG ToR were accepted to the group. SvE is to circulate the ToR to CRANE to be uploaded to the CRANE website. **<u>Action 04/10/21: 8.1 –</u>** SvE is to finalise CDG Terms of Reference and circulate to CRANE. CF will then upload the CDG ToR to the CRANE website.
9. Quality Improvement and Monitoring Committee	**<u>Member update</u>** SvE read the membership of the group – all members now in place. Invites for the first meeting will be circulated in the coming months and SvE noted that the committee will in the first instance try and establish a way of working and feeding back to CDG. **<u>Leeds update (AS email)</u>** CRANE have reviewed the data and established that Leeds were an alert rather than an outlier. SvE thanked the review committee (Melanie Bowden, Lead Specialist Speech and Language Therapist, Northwest England, Isle of Man and North Wales Cleft Service, Lisa Crampin, Specialist Speech and Language Therapist, Clinical Lead Cleft and Craniofacial Anomalies, Royal Hospital for Children, Glasgow (Scottish Cleft Network), Mark Devlin, Consultant Cleft and Maxillofacial Surgeon, Royal Hospital for Children, Glasgow (Scottish Cleft Network) and David Whitby, Consultant Cleft and Plastic Surgeon North West England, Isle of Man and North Wales Cleft Service) for their time on this, which involved a lot of work and commitment.. The review feedback and recommendations have been sent to Leeds. AS (via email to SvE) thanked the committee for their time and feedback. Leeds are currently working through the recommendations. SvE is due to meet with the review committee this week to discuss the process and how to make it easier should another review be needed in the future. One of the issues was that all the meetings were held virtually as a result of covid and they found this quite difficult in some respects as they had wanted to meet the team

	face to face but despite this they have provided a very good review. SvE will feedback to CDG regarding this.
10. Research	**<u>Clinical Studies Group</u>** No updates **<u>Early Careers Research Group (ERCG) Cleft Multi-disciplinary collaborative group</u>** No updates **<u>Bristol-Cleft Collective</u>** YW provided a written update to CDG from the Cleft Collective. **Overview** Since May 2021: • *Recruitment* to the birth cohort is up and running at 13 of the 16 recruitment sites. One of the three should be starting in the very near future as approvals are now in place, one is waiting for new research staff to start and the third is in the process of employing new research nurses. Total numbers for recruitment are 9507 (May: 9337) individuals from 3399 (May:3334) families across both the birth and 5-year-old cohorts. • *Recruitment* to the speech sub-study is still low. We are working with sites to explore the reasons for this and ways we can help. An amendment to the study means that children can now be recruited at any age up to 36 months. As this will mean we will not obtain LENA data for those families recruited after 12 months and we will not obtain 18/24m data for those recruited when older, it will still enable us to consider speech and language performance at age 3 in relation to many other exposure and later outcome variables to determine which children are most at risk and which do well. Total numbers for recruitment are 881 (May:865) individuals from 442 (May:431) families. • *Genotyping* is ongoing and 7242 (May:6244) individuals have been genotyped to date. A post-doc research associate, Garan Jones, has been employed with funding awarded to Professor Sarah Lewis from the MRC to carry out preliminary analyses using the genotyped data. The focus has been on performing quality control analyses of the genotyped data and imputing the data using Haplotype Reference Consortium (HRC) and TopMed imputation platforms. The data are now ready for genome wide association study analysis (GWAS). • *Proposals* to access and use the data continue to increase with 38 in total (see below for those submitted since last meeting). A future focus of our work will be maximising awareness of the resource for people to access and use to address questions which can impact on clinical care and patient experience and outcome. On this note CC has been asked to give a webinar by the Circle of Cleft Professionals in November and CC have submitted for a panel at the next ACPA conference as part of the guest nation work with FM also hoping to have a panel at the world cleft meeting next year in Edinburgh. We welcome our partnership with the CDG to help achieve that. • *Data sharing with CRANE* has commenced dto look at phenotypes and two linked datasets have been received from CRANE detailing child's cleft type and syndromic status. This data is being used to help validate cleft type for both the Cleft Collective and CRANE datasets. At least two sources of cleft classification data are available for 2633 children. We have determined a validated classification for 73.6% of

this sample. This work was presented at the CFSGBI conference in September, and we plan to publish a paper detailing this work in 2022.

- *Six peer reviewed papers* have been published/accepted for publication since March. Two more are in submission. See details below for those published.
- *Impact* from the papers includes an increase in our understanding of the nature of early communication development in children with cleft palate with and without PRS and of the role of smoking as a causal factor. We have also identified some of the issues for parents and carers in the provision of SLT services during the pandemic which services can use to amend future care. Research by Baker et al has also highlighted the need for routine hearing screening in audit clinics which will assist those services in making a case for this where this is not already provided.
- *Five oral* presentations, five posters and one update session were given at the CFSGBI Virtual Conference in September 2021
- *Funding* bids to maintain and extend the study have been successful with the Underwood Trust and the VTCT Foundation committing support alongside the Scar Free Foundation. With this funding, we will be able to continue to recruit and collect data until March 2023. Further bids are currently in process. Our aim is to continue recruitment to facilitate future analyses which can be carried out on cleft subtypes as well as to facilitate longitudinal data collection. Funding is a continual challenge and takes a lot of time and CC needs substantial funding to be able to achieve the goal of continuing for another 5 years. A funding bid has been submitted to the European Research Council but it is important to note that only 9% of these are successful and the documents, which are 60-70 pages long take months to put together. If they get through the outline phase then the success increases to 39% so CC is always looking for other funding streams. Still have an underspend from the Scar Free Foundation
- *New research* – aside from the main work in the Cleft Collective, we have been awarded additional funds to work with clinicians from each of the sites to develop plans for a clinic for participants from the CCUK study as they reach adolescence. The data collected from this work will be unique in being able to consider the trajectory of treatment and outcomes for children born with cleft from age 5 to when they approach adulthood. Tring to reach these patients before they turn 18. Plan is to work with the CENs to decide on the data that needs to be collected? Need to do a number of focus groups to determine this.

Data collection

Data collection is ongoing and has continued throughout the pandemic.

- We are expecting to see a reduction in the number of saliva samples returned as some teams need to send the kits home with parents rather than take the sample on site. This has an impact as parents sometimes forget to take the sample and more parents need to be reminded of lose the kit. This is being monitored.
- Our return rates for questionnaires remains consistent at 50% for our baseline questionnaires and a 38% return rate for our follow-up questionnaires.
- Surgical form return rate for first surgery is 93%. These data are vital for many research questions and the data are increasingly being requested in proposals submitted to access the resource. Return rates for most sites is much higher than 93% - and in fact is at 100% for first surgeries for many sites. The overall

rate is brought down by one site which has a very low return rate. We understand from this site that the surgeons are unable to complete the forms. We welcome discussion with this site and are happy to talk with any teams where completion of the surgical forms is challenging. We have been informed by many surgeons that the forms take no more than 2 minutes to complete.

- Some forms are also being returned for subsequent operations though we do not yet know how complete those data are.
- Return rate for speech sub-study
    - LENA recordings - 85% (309 of 364 returned)
    - 18/24 month assessment form - 90% (389 of 430 returned);
    - 36 month assessment form - 64% (250 of 390 returned)-low on data here so YW asked if there was anything CC could do to help improve this to let her know.
- The online survey of speech and language therapy intervention which was launched in December 2019 is ongoing. Reminders and new requests for the online intervention survey have been paused until we are through the worst of the pandemic though we are hoping to restart this again soon.

YW reminded the CDG that CC has a lot of psychology and dental data on 5 year olds that could be useful to clinical teams in terms of resource allocation and encouraged teams to contact her if they thought this could be of use to them.

New proposals since May 2021

CC038: Vijeta Saxena - Describing the prevalence of other developmental anomalies and family history among children born with a cleft in the UK

New papers since March 2021

van Eeden, S., Wren, Y., McKean, C., & Stringer, H. (2021). Early Communication Behaviors in Infants With Cleft Palate With and Without Robin Sequence: A Preliminary Study. *The Cleft Palate-Craniofacial Journal*. https://doi.org/10.1177/10556656211031877

Baker, S., Wren, Y., Zhao, F., Cooper, F. (2021) Exploring the relationship between conductive hearing loss and cleft speech characteristics in children born with cleft palate. *International Journal of Pediatric Otorhinolaryngology. 148. https*://doi.org/10.1016/j.ijporl.2021.110820

Southby, L., Harding, S., Davies, A., Fell, M. & Wren, Y. (in press) Speech-Language Pathology provision during the COVID-19 pandemic for children born with cleft palate in the United Kingdom - Parent/Caregiver perspectives and experiences. *Perspectives of the ASHA Special Interest Groups.*

Tran, C., Crawford, A. A., Hamilton, A. J., French, C. E., Wren, Y. E., Sandy, J. R., & Sharp, G. C. (2021). Maternal stressful life events during the periconceptional period and orofacial clefts: a systematic review and meta-analysis. *The Cleft Palate-Craniofacial Journal.*

Molyneaux, C., Sherriff, M., Wren, Y., Ireland, A., & Sandy, J. (2021). Changes in the Transverse Dimension of the Maxillary Arch of 5-Year-Olds Born With UCLP Since the Introduction of Nationwide Guidance. *The Cleft Palate-Craniofacial Journal*. https://doi.org/10.1177/10556656211028511

	Fell, M., Dack, K., Chummun, S., Wren, Y., Sandy, J & Lewis, S. (in press). Maternal cigarette smoking and cleft lip and palate: A systematic review and meta-analysis. *The Cleft Palate-Craniofacial Journal*
11. Quality Dashboard	The group discussed the outcomes on the quality dashboard since the Covid-19 pandemic. VB questioned whether there had been an agreement on when more complete audit data collection will resume. LB noted that every centre is currently submitting what they can. CR noted that audit collection depends on the clinical director and the management structures within the centres and not the CEN groups. CR noted that he is happy to discuss the reporting of missing data with the Clinical Leads, Clinical Directors and CENs. CR acknowledged that there will be a lot of missing data and that CRANE are happy to receive paragraphs (to be included in the CRANE report) from the CENs, explaining missing data and variability. CR feels that covid will be present for some time to come and that we now need to develop ways of collecting data/working around covid rather than not collecting data because of covid. VB asked whether units were prioritising audit data collection as they were before the covid pandemic. GP replied to say that they were prioritising clinical reviews at age 5 and then collecting the data at the face to face encounter where possible dependent of facilities and available resources. NH reported that GOSH were doing the same but that there was a period when no data was collected as the hospital was basically shut meaning that a cohort of patients have been missed.
12. CFSGBI Feedback	FM provided an update from the CFSCBI. Abstract submissions for Cleft 2022 and registration are open. Face-to-face registration and the various tiers of registration are open on the CFSGBI website. There is a discounted registration available for CFSBGI members. FM welcomed any email suggestions for Cleft 2022-those on the scientific committee have had a google doc to fill in but FM is keen to hear about ideas from the wider community. The society has received a guest nation invitation from ACPA and are working on what that partnership will look like. The new website is due to go live in December and the society will be advertising for two social media website officers. The society currently have 250 members and are looking to grow this. They are hoping to do this through conferences and CFSGBI is looking for a potential discount for access to the CPCJ. CEN chairs are asked for an update to include in the CFSGBI newsletter.
13. Training	LF has taken over as chair of the TIG committee from Norma Timonee. There are 3 TIGs currently in post; one who will finish in the next 6 months and two who started in August. LF has met with them all and training is going well and thankfully covid has not had too much of an impact on their training. All TIGs will be going post CCT from next year, which will change the process for applications. There are two TIG awareness campaign days taking place on 12th and 16th November 2021-this will be widely advertised on platforms such as BAPRAS and ASIT. This will also mean a change in curriculum and the TIG committee have been working on this over the past months. The main change is a move to a competency based system rather than a number of procedures done kind of system , which will include an end of TIG checklist that all TIGs will need to complete with their trainer. Once finalised by the Cleft TIG committee this will be sent out for circulation. Adverts will go out in November for the new TIG recruitment and interviews will take place on 25th January 2022. LF has emailed all CDs asking for updates about surgical vacancies and potential retirements so that appropriate surgeon workforce planning can be carried out by the TIG-LF encouraged all CDs to get back to her about this even if there aren't any vacancies. SvE mentioned that Health Education England were still going to fund the TIG fellowships and he asked about JCST quality assurance oversight; LF confirmed that the JCST were still going to provide quality assurance oversight for all TIG fellowships.

14. Deputy Chair of CDG	SvE raised the issue of a deputy chair as no nominations had been received. HR asked SvE if he was coping without a Vice Chair and he answered that he was coping fine at the moment. It was agreed that the group would continue without a Vice Chair.
15. Any other business – CDG & dates of next meeting	HR raised that the SLUMBRS trial was about to start. CR asked for comments when the CRANE annual report is sent out in draft form. No further points were raised under AOB. The next meeting of the Cleft Development Group will take place virtually on Tuesday 1st February 2022 (9am-1pm).

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Actions from Cleft Development Group meeting: 4th October 2021	**Owner**	**Due Date**
Action 04/10/21: 3.1 – CDs have to explore potential CDG Managers Group representation within their centres and report back to SvE	Clinical Directors	1st Feb 2022
Action 04/10/21: 4.1 – GP and HE are to begin preparations for CDG Patients and Parent involvement, following the Cleft Care Scotland model.	GP & HE	1st Feb 2022
Action 04/10/21: 5.1 – AP is to liaise with the ODC regarding CD action in the case of patient referrals. Following this, CDs are to meet to discuss the matter in more detail.	AP & Clinical Directors	Winter 2021
Action 04/10/21: 5.2 – AP is to circulate RSV data update and refugee referral letter to the group.	AP	Winter 2021
Action 04/10/21: 8.1 – SvE is to finalise CDG Terms of Reference and circulate to CRANE. CF will then upload the CDG ToR to the CRANE website.	SvE & CF	Winter 2021