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

Venue- Microsoft Teams Conference call

Date & Time- Tuesday 1 February 2022– 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
	Julia Cadogan (JC)	Deputising for Ali Cobb, Clinical Director, South West Cleft Service
	Alex Cash (AC)	Clinical Lead, Evelina London Cleft Service
	Christine Couhig (CC)	Lead Clinical Nurse Specialist, Newcastle
	Claire Cunniffe (CCu)	CLAPA Chief Executive
	David Drake (DD)	Lead Clinician for Cleft Care Scotland
	Martin Evans (ME)	Clinical Director, West Midlands Cleft Service
	Helen Extence (HE)	Clinical Director, The Welsh Centre for Cleft Lip and Palate
	Louisa Fergurson (LF)	Chair of the Cleft Training Interface Group
	Toby Gillgrass (TG)	Clinical Lead for Scottish Cleft Surgical Service
	Vanessa Hammond (VH)	Clinical Psychologist CEN Lead
	Sarah Kilcoyne (SK)	Chair, NIHR Clinical Studies Group of Cleft and Craniofacial Anomalies
	David Landes (DL)	Public Health Consultant
	Joanna May (JM)	Paediatric Dentistry CEN 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, Lead SLT CEN Lead
	Sandip Popat (SP)	Restorative Dentistry CEN Lead
	Anne Roberts (AR)	Deputising for Ali Cobb, Clinical Director, South West Cleft Service
	Helen Robson (HR)	Lead Nurse, North West & North Wales Cleft Lip and Palate Network
	Craig Russell (CR)	CRANE Clinical Project Lead
	Heather Sahunta (HS)	Lead Nurse CEN Lead
	David Sainsbury (DS)	Deputising for Peter Hodgkinson, Clinical Lead, Newcastle Site, Northern and Yorkshire Cleft Service and Cleft Multidisciplinary Collaborative
	Julia Scott (JS)	Orthodontic CEN Lead
	Lucy Southby (LS)	Interim Clinical Lead for Cleft.NET.East
	Guy Thorburn (GT)	Surgical CEN Lead
	Yvonne Wren (YW)	Chief Investigator, Cleft Collective
In Attendance	Catherine Foster	Research Coordinator, Clinical Effectiveness Unit, Royal College of Surgeons of England
Apologies	Ali Cobb	Clinical Director South West Cleft Service
	Norman Hay	Clinical Director North Thames Cleft Service
	Peter Hodgkinson	Clinical Lead, Newcastle Site, Northern and Yorkshire Cleft Service
	Alistair Smyth	Clinical Lead, Leeds Site, Northern and Yorkshire Cleft Service
	Marc Swan	Representative, The British Association of Plastic, Reconstructive and Aesthetic Surgeons

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, 4 October 2021	The committee suggested amendments to the draft minutes from 4 October 2021. Minutes confirmed but for the suggested amendments.
3. Matters arising	**Action 04/10/21: 3.1** – CDs to explore potential CDG Managers Group representation within their centres for representation on CDG and the Quality monitoring and improvement committee and report back to SvE: • CDG Managers Group representative is yet to be established. SvE requested that CDs contact him regarding this. **Action 04/10/21: 4.1 –** GP and HR are to begin preparations for CDG Patients and Parent involvement, following the Cleft Care Scotland model: • GP and HR provided an update. The advertisement for application for the National Cleft Development Group Patient Engagement Group has been uploaded to the CLAPA website (as shared by CC). GP and HR have met to discuss the patient and parent involvement model, which is based on that of Cleft Care Scotland. Member of the PPI group will be provided with CDG minutes and agenda in advance and will be given the opportunity to attend CDG meetings if they should so wish. The process and representation will be flexible, will evolve over time and support will be provided throughout the process. **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: • The CDs met on 29 October 2021 to discuss the backlog in the South West • SvE wrote to the Chief Executive in Bristol. SvE shared a summary of the response: Two additional all day lists per fortnight have been secured at Derriford Hospital (University Hospitals Plymouth NHS Trust – UHP) from November 2021 until the end of March 2022 for paediatric patients. ABGs have been prioritised for these lists, with two ABG patients able to be done per list (4 per fortnight). Five full days lists have been carried out so far, with nine patients treated so far. They are looking to extend the arrangement from April 2022, which is currently under discussion with UHP. They have so far had offers of help from the Welsh Centre for Cleft Lip and Palate, which has offered two full day operating lists in Swansea with capacity for 6 Primary Cleft Palate Repair patients. In addition, West Midlands Cleft Service and Northern & Yorkshire Cleft Service have also offered support, and discussions are underway with both services to work through the details of that support. It is looking likely, based on discussions so far, that the best cohort of patients to send would be those requiring Cleft Palate repairs, which will allow the SWCS team to focus on capacity in BRHC on those individual patients medically unfit to transfer or other cohorts, such as speech surgery patients, who would be best operated on in Bristol. Cleft Net East have also been in touch but, although they thought they could help, due to the emerging Omicron situation, they have had to pause that offer and will review in January. Waiting List Initiative lists are also offered at weekends at the BRHC where there is surgeon availability. A full capacity and demand analysis of the service is being undertaken to quantify the recurrent and non-recurrent capacity required to sustain the run rate and clear the backlog, which will then help determine a trajectory for recovery back to within target dates. BRHC is working to establish additional recurrent capacity where possible. One additional list per month on a Wednesday morning has been provided from January 2022 and they are actively exploring whether any simple day case lists can be moved to the independent sector to free up more theatre lists at BRHC for Paediatric Cleft and other high priority cases. They are in the very early stages of working with BRHC to look at the feasibility of an additional Cleft surgeons and the associated additional capacity to support them. A harm assessment and mitigation plan for children who experienced delays in their treatment within the Cleft Service has been instigated with the aim to clearly quantify the

	currently projected delays within the Trust and assess the levels of harm which a child, adult or family may come to due to delays in surgery or treatment within the cleft service. Harm assessments will be undertaken using agreed criteria with patients reviewed holistically by the MDT. Once harm is assessed, the findings will be used to support several processes including, as part of a wider framework of information, to support prioritisation of delayed patients; to inform an individual and service level mitigation plan to counteract the harm and to combine and cost the mitigation plans to be fed into the Trust's Operational Plan. • Anthony Prudhoe has confirmed that funding for any patients moving from one unit to another would be the responsibility of the local commissioners. The commissioner for the South West has confirmed that although no funding is available for Bristol, an Elective Recovery Fund provided by BRHC is available if needed. • SvE raised the option of cleft surgeons from other units in the UK (Peter Hodgkinson has previously suggested this as an option and offered his potential support) using fallow lists in BRHC and SvE discussed this with Karen Maxfield (operational manager at BRHC) at a meeting recent meeting and she assured SvE that honorary contracts would be easy to sort out if this option became viable. **Action 04/10/21: 5.2 –** AP is to circulate RSV data update and refugee referral letter to the group: • AP shared the RSC data update and refugee letter with the group **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: • The CDG ToR was finalised and uploaded to the CRANE website. **Action 02/01/22: 3.1** – CDs have to explore CDG Managers Group representation within their centres and report back to SvE.
4. Feedback From Cleft Centres (UK)	**The Welsh Centre for Cleft Lip and Palate (HE)** Paediatric surgery is now back to normal protocol for the babies. Speech cases have 4-6 month wait for operation but can be moved to P2. We offered to do 6 babies for Bristol but were only able to do 4 due to covid and illness. Cardiff had hoped to look at some cases but have some issues with anaesthetic cover. The Health Board management and commissioners have offered support to Bristol with their backlog (see matters arising) and Tom O'Neill continues to be happy to support these lists. Should any further support be needed from Bristol, HE felt that it would be looked upon favourably. HE is waiting to hear back from Bristol regarding this. SvE thanked the HE and her service for offering to help Bristol with their backlog. In terms of adult patients Wales have been looking at some private contracts for rhinoplasty and lip revisions. This is yet to be secured and only have one date in February, further need to be secured and there is one ad hoc list at the Singleton site. Adult speech cases are a problem as they can only be done at Morriston Hospital and there are issues with bed capacity and theatre lists here and despite the health board and commissioners giving assurances only 2 adult speech cases have been done since covid; this is being flagged up continually. All paediatric outpatients are being seen in outpatients. Adult 20 year old reviews are taking place via telephone, with those patients being signposted to individual specialities rather than MDTs. Orthodontic outpatients have the longest wait to been seen due to reduction in orthodontic staff and covid. A restorative dentist, Karl Bishop, retired in October 2021 and a replacement is yet to be appointed; more dental nurses and surgery space needs to be established for the post to be advertised. A vacancy for a Band 7 FT SLT appointment is about to go to advert, and an 8A 0.5 Clinical Psychology post will be going to advert in March. The Respiratory team have worked to create a clearer pathway for children with PRS. **Scotland (TG and DD)**

TG(lead for surgical service): 50% of primary surgery lists had been cut between October 2021 and January 2022 resulting in a backlog in primary and speech cases. The centre are now starting to breach surgical protocol. No adult operating has taken place since mid-2021. The adult waiting list remains the same and phone consults have taken place with the patients on the waiting list with some choosing not to continue with surgery. SvE asked which patients have declined surgery? TG reported that a large proportion of orthognathic patients that were in braces have had their braces taken off and do not want to proceed to surgery anymore. Outpatient clinics continue, with some areas more backlogged than others as 7 MDTs are covered around Scotland.
DD(Network Lead): Across the Network there is concern regarding the access to dentistry. The Network clinics are running and functioning well. The network are continuing to try to get into CRANE but there are still issues with data sharing. DD is awaiting confirmation from National Services Scotland. There is agreement to host the administration of CRANE data in Glasgow and a bid has been submitted for CRANE technical support in Glasgow.

Newcastle Site, Northern and Yorkshire Cleft Service (DS)
From a team perspective staffing remains stable. Clinics are running via a combination of face-to-face and telephone/video. Outreach clinics are yet to resume. Clinics are being triaged a couple of months in advance as an MDT to streamline patients. Face-to-face children's clinics are becoming busy due to social distancing and lack of outreach clinics; the centre are considering running additional children's clinics. The orthognathic pathway is being reviewed so that patients see psychology and speechbefore coming in for a detailed assessment in the orthognathic clinic. Surgery timings are on target; lip repairs have been moved to 6 months so that they move from P3 to P2 as they were being cancelled when they were being listed earlier as P3s. There is the occasional cancellation due to the lack of beds or occasional child with covid. Plastics previously coordinated the waiting list, but due to shortage of staff the centre are considering moving it back to the cleft team's control.

Leeds Site, Northern and Yorkshire Cleft Service
No report from Leeds site, Northern and Yorkshire Cleft Service.

Trent Regional Cleft Network (JND)
Lip repairs are at 4-5 months, with a target of 3 months. Cleft palate repairs have dropped below 10 months, with a target of 6 months. Secondary speech is at 3-4 months after listing. ABGs are at 6 months after listing. Osteotomies at 8 months after listing. The main backlog consists of lip revision and nose surgery of all ages and sits at approximately 18 months. The list capacity is governed centrally by the children's hospital and some capacity has been given to more urgent paediatric cases meaning that Trent cannot help others units. On the current capacity, normal performance will resume within 12 months.
Clinics are up and running on a hybrid model face to face and video, with triage a month before and most clinics have video slots at the beginning or end of the clinic. The Network are looking to develop the pathway for children over 10.
Staffing in paediatric dentistry remains an issue; meeting have taken place with Charles Clifford Hospital and commissioners on a monthly basis to discuss potential solutions. A full time psychology appointment is in process for application.
The Network are starting to see a strain on community SLT, with less provision for therapy available meaning that after 4 sessions of therapy a new application has to be made for a further block of therapy-Trent are talking to commissioners about this. SvE asked about return of adult /orthognathic operating and JND replied saying that as of this week all adult operating and ITU capacity has been returned to surgery as capacity hasn't been as affected by omicron as was predicted. Rhinoplasties also starting to return meaning that Trent has been able to do more than they thought they would be able to do.

North West, North Wales & Isle of Man Cleft Network (VB)
Manchester have reduced access to the theatre; averaging 3 sessions per week with approximately 50% cases cancelled due to bed / staff shortages. This has been mitigated by

	cross cover by surgeons. Primary surgery is at the upper limit of Quality Dashboard timings. Some palate repairs are beyond 13 months due to cancellations by hospital / patients illness, combined with later than standard protocol timings. Speech surgery wait is approximately 4-5 months. ABGs have been appropriately prioritised but several patients cancelled 3-4 times before their operation goes ahead. Manchester have been offered some adult ad hoc lists but they have been cancelled. Surgeons have been asked to join parent speciality consultant of the week 1 in 10, with all cleft activity cancelled. There has not been any significant adult operating for 2 years and VB has not done an osteotomy for 2 years. In Manchester all maxillofacial surgeons have been asked to join a consultant of the week trauma 1:10 rota and this will impact on cleft service 1 in 5 weeks, dependant on agreement of recharge to cover adaptations required in cleft service. Liverpool have had some reduction in capacity over the Christmas period but otherwise are as pre Covid in terms of list and surgery timing. Adult surgery has restarted but at a reduced capacity. Surgery was provided for a child from Northern Ireland who was having difficulties accessing care locally, although this was not entirely straightforward. A vacant lead nurse post is soon to be advertised. The centre are hoping to appoint a fixed term specialist dentist to support backlog of patients in Manchester. There is reduced Speech Therapy staffing in Liverpool and Manchester due to maternity leave and long term sickness respectively; the teams are coping well regardless. Orthodontics are fully staffed with one orthodontist back from maternity leave in January. A new Network manager has been in post for just over 6 months. This was a good appointment and has had positive impact on the Network and she might be interested in getting involved in some of the national cleft initiatives. Local orthodontic access remains an issue in North Wales due to long term vacant posts at DGH's, but they now have applicants for posts so are more optimistic. The Network are running a mix of virtual and face-to-face clinics. They are happy with this balance and are likely to continue seeing some patients virtually in the long term. There has been a significant reduction in cleft births in 2021. The numbers are being verified to ensure none are missing from CRANE. They anticipate up to 50 less cleft births across the Network in 2021 compared to the 10-year average. Births are also down in 2020 and it will be interesting to see if this rebounds after Covid or whether the lower cleft birth rate is sustained. **<u>West Midlands Cleft Service (ME)</u>** The centre met with Bristol in December 2021. The West Midlands would like to assist with the backlog in Bristol but are currently unable to do so due to management and staffing issues; the situation is however being monitored. Bristol have sent through details of cases recently, but no offers of treatment can be made at the moment. SvE thanked the West Midlands service for offering to help Bristol with their backlog. Covid has reduced operative capacity, but overall, they are operating to protocol. There are staffing issues in theatre but cleft and craniofacial remains stable. An admin position has been appointed. Two part time locum orthodontists have been appointed-1 has started and the other is due to start in April-to replace a retirement and a resignation. SLT are overdue by 40 patients but are keen to get through the backlog by spending a week providing intensive treatment. **<u>Cleft Net East (LS)</u>** Theatre allocations are at 90% of pre-covid level. Primary surgeries are back to protocol. Speech surgery has a 10 week wait. Adult surgery have a long wait (70 weeks). Orthognathic surgery is not being done. Quite a long wait for ABGs with approximately 2 ABGs are taking place a month. Outreach clinics have resumed. Virtual consultations are being used particularly for older patients and we will monitor this to see if we continue to use this in the longer term. A Psychologist and a nurse have been recruited. The recruitment of a full time SLT is underway. Neil Briley, locum consultant, is covering Kana Miyagi whilst on maternity leave. Cleft Net East will be looking to recruit an orthodontist soon. The admin team have been struggling to recruit but have recently managed to do so. Provision for community SLT intervention is strained and the SLTs are looking at ways of using SLT centre resources to help with this.

	Cleft Net East are hoping to be able to help Bristol and are currently in the process of exploring their options. SvE thanked the Cleft Net East service for offering to help Bristol with their backlog. **North Thames Cleft Service (HR)** Large backlog of patients requiring cleft MDT appointments; the list has been validated but needs clinicians input to access urgency-approximately 400 patients waiting. Due to construction at Broomfield hospital, there has been an increased transfer of primary surgery cases to GOSH, adding pressure to GOSH surgical services-The Broomfield ward has now opened on the 31.1.2022. Previous cancellations of P3 and P4 cases has resulted in a backlog of ABGs and orthognathic surgery. Delays in secondary surgery, orthognathic, and lip and nose revision in adult hospitals Broomfield and the Royal London, with access on an ad hoc basis. Orthodontic clinics, MDT, bone graft, and audit clinics are running as normal with face-to-face, however large gaps between orthodontics appointments, due to backlog, are contributing to increased treatment times. The service are in the process of recruiting a paediatric dentist consultant, which has a significant impact on the submission of NHS England and CRANE data. A new substantive consultant paediatrician has been recruited to the cleft team and is due to start in April. Long standing consultant geneticist, Melissa Lees is retiring after 20 years, and a plan has been agreed with the genetic department for recruiting to the cleft team. Long standing CNS, Jill Loxford at Broomfield, is also due to retire. HR is currently in the process to reappointing to this roll and one of the other cleft CNSs is due to take a year's sabbatical to travel so cleft is looking for a secondment from the surgical ward to backfill this position. The general manager of the cleft service has left but the position has been re-appointed to and is due to start in April. The director for surgical services is due to retire in March and her successor, the deputy director of the service, has been appointed. SvE made the observation that it seems as though the service is short of CNSs? HR replied in the affirmative and noted that North Thames has a high ratio of patients to nurses compared to the North West, North Wales & Isle of Man Cleft Network where she previously worked. **Evelina London Cleft Service (AC)** Omicron has had a significant impact on the service, resulting in significant backlogs. All operating, bar 2/3 lists, was cancelled during January. All adult surgery and outpatient dental treatment appointments were cancelled due to dental nurse redeployment to the wards, vaccine centres and to support community services. The nurses are being assessed today to determine if they are okay to return to their "day jobs" in the service which, includes a psychological assessment. Outpatients MDTs have continued in outreach and within the centre. It is predicted that adult pressures will continue well into the future. Some adult capacity has been offered but at 50% pre- Omicron levels and this is something the cleft service will continue to lobby for but it is difficult to influence adult services when one is a predominantly paediatric based service with management structures based in the paediatric hospital. Four members of staff are currently on maternity leave, mostly with cover in place-mixture of locum and fixed term positions. SLT team are under significant pressure across the Trust, so the service are managing a planned retraction of speech input to the team. The Trust are supportive of this and plan to look at over-recruitment to potentially overcome this in the future but the issue is whether there is a big enough pool of SLTs to recruit from? Some junior surgical fellows are coming to the end of their appointments and the service are struggling to reappoint to these posts. The service have had to repurpose monies that were aimed at Trust fellow level appointments to employ FY doctors instead. The service continue to work on their CRANE outlier issues. Access to dental services across the Network not attached to Trusts i.e. in the community are strained. AC will be standing down as Clinical Lead for Evelina London Cleft Service and will be succeeded by Kate le Marechel. AC thanked the SvE CDG for their support to the service.

Spires Cleft Lip & Palate Network (GP)

GP fedback on behalf of Marc Swan, who took over as clinical director in January 2022.
The deep dive visit from NHS England commissioners and the surgical ODN has been moved twice but is now confirmed for 9th March. Data needs to be returned at the end of next week and will look at the service in relation to the national service specification. The service welcomes this and will hopefully be helpful.
Theatre, bed and critical care availability are still the rate limiting steps on both sites. The service are going to robustly respond to the challenges and access of treatment, especially in terms of primary surgery elsewhere. They are trying to utilise the availability across both sites but it is not simple to look for treatment elsewhere across the country.
Recovery from Covid is being hampered by consultant sickness in Salisbury (2 Months). They are prioritizing and Adam Sawyer will be returning to do some locum work on long waits from March, not for primary work but to help with some of the other long waiters. Other staff absence relating to maternity and Covid related absences are putting pressure on nurses and psychology, but the team are pulling together to manage that. Serena Martin from Northern Ireland is joining as a non-TIG fellow from March for a year. The TIG application has stalled due to financial constraints from a Trust perspective.
SvE asked GP to expand on why the service was looking for help from elsewhere and what the pressures are on primary surgery? GP doesn't have the latest data and deferred to GT;
GT confirmed that they are breaching primary surgery protocol frequently especially for cleft palate repairs in Salisbury (more than 13 months). SvE asked if there were lists not being filled because of the current vacancy and GP confirmed this was the case-SvE then suggested that the centre explore getting some help with this. GP noted that Marc Swan(MS) has already started some of these conversations and added that it would be useful for SvE to discuss this with him. SvE asked GP to ask MS to contact him.

South West Cleft Service (JC and AR)

JC: The service has started a harm review of all cases undertaken by the cleft team since the Frenchay transfer in 2014, in conjunction with Trust HQ. The Southwest regional and National NHSe commissioners are aware of this and the team meet with them regularly. The service are mapping the description of harm and potential harm NHSe harm guidelines to paediatric and adult cleft care, and to each speciality within the team – surgery, specialist nursing, psychology, cleft speech therapy, paediatric dentistry and orthodontics. This description has been sent to all current clinically active cleft surgeons in the UK to achieve agreement nationally, and via the CENs for the other specialities. The harm review will look at over 1000 cases and grade harm / potential harm from each cleft speciality's perspective. A duty of candour process will then follow.
The service have held discussions with Cleft services in South Wales (Cardiff and Swansea), Birmingham, Newcastle, and Cambridge about transferring cases (mutual aid). Cases have been done at Swansea and Newcastle already for which the team are extremely grateful. Private cleft surgery for some patients is being undertaken by colleagues in London. The team are grading priority according to FSSA guidelines but upgrading when other individual circumstances require it. Alternate weeks 4 session operating has started at Derriford (Plymouth) for ABGS and this contract has been extended by another year. This means that in addition to lists at the Bristol Children's Hospital, they are averaging 4-5 cases for paediatric cleft surgery every week.
Primary cleft palate repair is currently undertaken by 13 months, and lip repair before palate repair is by 10 months. Adult operating has not really restarted yet. They have undertaken some day case work and are working with a local private hospital to undertake rhinoplasty there – however the contract has stalled and is yet to start.
Meanwhile restarting audit and MDT clinics in spoke centres is particularly difficult and they are working with the Southwest ODN regarding this.
There are currently 2 vacant clinical psychologist posts in the service, which is a picture that is occurring nationally across psychology and not only in cleft services. There is a dental nurse vacancy as well. They are still trying to finalise a speech therapy post for Devon, which has been vacant for 3.5 years.

	The service are very concerned for the adult waiters, some of whom are waiting for ABGs in addition to rhinoplasty, and orthognathic patients. Adult ABGs cannot be done at Derriford. The team are considering how they can support these patients and are looking to access some funding through the accelerator covid fund to provide some psychological support for these waiters, for some of whom mental health has become so critical that there have been issues around suicidal ideation and related concerns. Audit clinics are starting to resume for 5 year olds and 10 year olds. AR's department have recently undertaken some training for community SLT. AR: Speech surgery wait is currently at just over 12 months. SvE questioned if the lateral video fluoroscopy was up and running. AR confirmed that they have a fortnightly lateral video fluoroscopy list at the Children's Hospital but unfortunately, they cannot do endoscopy there. These lateral video fluoroscopy lists are adding to the waiting list burden as they are adding patients for speech surgery at a rate of approximately 70% of patients on the list ie 3 patients per clinic after these investigations. Some patients have waited for 18 months for the lateral videofluoroscopy and are then going to wait another year for their speech surgery reflecting the seriousness of the situation. SvE questioned if there had been any discussions within the Trust about the medium-long term provision of resources e.g. increasing number of theatre lists, access to theatres in both adult and paediatric services? AR noted that no decisions have yet been made regarding this but that Alsitair Cobb (AC) is involved in lots of meetings about this-they have been given 1 additional list a month but nothing more than that at the moment. AR added that the cleft service is not the only service struggling; many services across the Trust are also suffering and cleft is competing with other delayed services for theatre-eg. orthopaedics have more than 400 patients waiting for surgery. Staffing the theatres and productivity are a huge issue-they are only able to get 2 cleft cases done on each all-day cleft theatre session. SvE queried whether the hospital that they have moved to has the capacity to support all services. AR said that AC had always argued that since the move from Frenchay Hospital there has not been enough cleft theatre capacity in the new hospital and that covid has only exacerbated the problem. Bristol argued that due to projected efficiencies cleft wouldn't need as much theatre time as they had at Frenchay but this has not been shown to be true. SvE asked about the previous Frenchay capacity and AR thinks that these have now gone to maxillofacial surgery. JC also added that when cleft moved to the paediatric hospital they were then in competition with all the other paediatric surgical specialities which hadn't been the case at Frenchay as it is mainly an adult hospital. SvE noted that with over 200 paediatric cases on the waiting list that this would take at least 2 years to work through on its own without considering the new patients that are being added onto the list so without extra resource and a long term strategy this issue will not be solved. JN-D noted that no Trust has any spare capacity at the moment and that most Trusts are trying to offer support but are running into the same barriers. He wondered whether we should use the knowledge about performing high volume operating abroad on cleft missions that exists within the UK cleft community and use this to possibly do the same within the UK by firstly identifying facilities and use these for say a week and staff it with trained cleft personnel from within the UK ? He further added that they need to look outside the normal process to find extra capacity to deal with backlog. SvE agreed saying that this idea had been suggested before by Peter Hodgkinson and the snag would be to find facilities that would most probably be within existing cleft units that could be used and that CDs would need to look within their own services in the first instance to see if this was a possibility? CR noted that without doing something like JND suggested the situation will get worse as for every child that has a cleft palate repair after 13 months, the chance of needing secondary speech surgery increases significantly-so for every 100 children having their surgery after 13 months 40 more will need speech surgery. ME queried whether the South West need to be thinking about a more direct campaign to bring the issue to government to say that these children are really suffering and perhaps think about approaching the media. DD noted that Bristol have been prioritising local waiting list pressures in orthopaedics over nationally commissioned services, which is not acceptable. He further added that there has been a flow in paediatric work from the Peninsular into Bristol due to a lack of delivery resource further out. DD commented that to operate on 100 children in a week, 4 operating theatres and 40 bedded

	ward with HDU facilities would be required, which is unlikely to be available in the UK. SvE queried as to whether the private sector may be an option so that there is no competition with NHS cleft centres. DD felt that there might be an issue with licencing to operate on babies within private hospitals. JC added that the team are encouraging and supporting patients to vocalise their concerns across the lifespan and media. CCu added that CLAPA have been and can support and signpost any parents wishing to contact the media. ME commented that OXFAM campaign and CCu explained that a charity can do this if it is stated in their objectives which it is not In CLAPA's current objectives and to change this requires firstly a desire to change the objectives and then a lot of work with the charitable commission. GT suggested setting up a separate campaign lobbying group that sits apart from CLAPA with lobbying expertise. AR added that Bristol want to express their thanks for all the support they have received so far and that the team in Bristol is working hard to resolve this themselves. SvE queried if there are any big business in Bristol e.g. Dyson that the service could approach for funding. AR commented that she will take this back to the team to explore. JS suggested approaching one of her contacts that has set up multiple IVF clinics across the Southwest and is successful in establishing funding; JS will explore this in the first instance. CR added that funding of this scale needs to come from government level, rather than just individuals.
5. Feedback from CENs	**<u>Audiology and ENT</u>** No report from Audiology and ENT due to sick leave. **<u>Nursing CEN (HR)</u>** There are several nursing vacancies across the country. Jane Sibley has recently joined the lead nurses from Spires. Most of the lead nurses work at the moment is about the cleft course and they have done some work with Anglia Ruskin University in Cambridge who are happy to facilitate the Cleft Course – so thanks must go to Heather, Chris, Jenny Williams and Perry Codling. The course is due to launch on 19th September and will involve one face-to-face week in September, and a virtual week in December. They will be looking at assessment and OSCEs, and will be inviting the specialities to present. HR said that there is a lot of interest in this course and the hope is to run this over the next few years with 15 students for the first course. HR requested that the Side Lying and Upper airways Maintenance in Babies Requiring Surgery (SLUMBRS) study be added as a recurring item (under Research) to the CDG agenda going forwards. North Thames and Newcastle are in a position to start recruiting soon and there is a bottle of champagne for the first team to recruit a participant to the study. The study is due to be extended. HE queried the cost of the Cleft Course. HR stated that it should cost approximately £800. **<u>Action 01/02/21: 5.1</u>** The Side Lying and Upper airways Maintenance in Babies Requiring Surgery (SLUMBRS) study is to be added as a recurring Research item on the CDG agenda. **<u>Orthodontic CEN (JS)</u>** The leads are meeting on a quarterly basis, with good engagement. Orthodontics is beginning to return to normal protocol, although there are concerns in some areas regarding ABGs and orthognathic waits. Compared to non-cleft orthognathic patients, the wait is significantly longer despite being more complex and sitting within a much longer pathway, which is having a significant psychological effect for patients. The CEN are unsure of what to do with their cleft orthognathic cases. JS has contacted Helen Travess, Chair of Consultant Orthodontic Group of the British Orthodontics Society, to discuss the cleft orthognathic cases. This is on the agenda for the March meeting of this group. The CEN intend to get some data together to look at the number of patients waiting, with the possible inclusion of psychology etc. The whole CEN met virtually in December and have a half day prior to Cleft 2022. The CEN have submitted 5 abstracts for Cleft 2022. Important to try and engender interest in cleft and JS has circulated information to all orthodontic trainees inviting them to the CEN meetings and also to advertise Cleft 2022 to encourage their attendance. SvE asked why the cleft orthognathic patients are waiting longer than cleft orthognathic patients-in the South West it is predominantly due to the

fact that the cleft patients need to be operated on centrally in Bristol and have been caught up in the long waiting lists here.

Paediatric Dentistry CEN (JM)

The CEN met virtually in November 2021. The CEN discussed CRANE outlier status, the validity of the data collected, and calibration. Many units are finding that workload is high and that paediatric dentist specialists could not always attend audit clinics meaning that data, as was previously agreed by the CEN could then not be entered onto CRANE. Therefore, the CEN are hoping to expand the scope of individuals able to upload data to CRANE. The CEN have some ideas about this but need to be tight on the definition of who should be able to do this - for example there are colleagues in Scotland not on the specialist list but with a lot of experience who could do this.

The CEN has discussed the calibration course, which is available online on the CFSGBI website, and how they might be gatekeepers for access to that login so that they can monitor who is calibrated and can therefore input data onto CRANE. Fiona Gilchrist has been nominated to be the council rep for the Others Group and for paediatric dentistry for the CFSGBI council. There was discussion about the content that is on the CFSGBI website for paediatric dentistry, the role of paediatric dentists and the links that the CEN want to be on there. A few paediatric dental trainees are involved in the trainee part of the website.

Access to local dental care is an issue across the UK resulting in an increased workload for cleft paediatric dentists. A local dental audit took place across all the centres and have data from 6 centres, which has been submitted as an abstract for Cleft 2022. The CEN also plan to look at how Covid has affected data collection for audit.

A few centres have mentioned that paediatric dentists are now involved with AGB clinics, which has been useful for treatment planning and this might also be submitted as an abstract for Cleft 2022.

JND-asked about the fact that when commissioners have looked at commissioning of paediatric dentistry there seems to be a split between specialist and direct commissioning and units that are outliers and does the CEN think there is a systemic problem with direct versus specialised commissioning of paediatric dentistry. JM replied saying that as far as direct commissioning is concerned there is a known shortage of specialist paediatric dentists across the country and specific areas have severe shortages; this is constantly under discussion within the consultant paediatric dental group and the British Society of Paediatric dentistry-this has partly to do with location and also to do with specific job roles and on top of this there is access to primary care for paediatric patients-a lot of these patients could be managed in primary care but are not because of a lack of experience and competence and this is amplified in cleft patients meaning that a lot are referred into cleft centres for treatment planning, which is not always appropriate as they have long distances to travel increasing the burden of care. SvE asked if there was any scope for the paediatric dental CEN to get involved with dental schools to improve the education of dental students about cleft? JM replied that cleft is covered in dental schools but perhaps not specifically under the auspices of paediatric dentistry; she went onto say that the audit the CEN has been involved with is looking at communication with local GDPs and explaining what is required of them and what specialist treatment the centre would be providing; there was also a presentation at the last cleft conference that reported that paediatric dental trainees also feel less competent dealing with cleft patients and that this is something that also needs targeting and perhaps by calibrating the paediatric dental trainees to collect cleft audit data they will become more involved in the cleft clinics and in so doing develop the confidence to manage these patients. SvE also commented that this kind of involvement might also help with succession planning.

CR raised issue of who can and collect data CRANE does not determine this as it is determined by the speciality. He made the point that if one is calibrated then one is calibrated to collect the data and that cleft data is often compared with non-cleft data and that non-cleft data is collected by dental therapists, so we are comparing data collected by specialists compared to data collected by dental therapists. JS confirmed that the latest dental survey data was collected by dental therapists. JS went on to say that the Dean of the Peninsula Dental School, Chris Tredwin, is chair of Dental Deans group and they are busy putting together virtual training

	package on cleft for undergraduates across the UK and there is scope for all the CENs to get involved and JS is happy to contact Chris and perhaps this resource could be made available on-line on the CFSGBI websites for GDPs and interested parties. SP informed CDG that Chris Tredwin has asked him to do a seminar on cleft for the Peninsula dental school undergraduates and he has been impressed with their engagement in cleft. SP is in favour of getting involved in undergraduate training so that GDPs learn how to manage the dental health in cleft. SP agreed with CR that if a person has been calibrated they should be able to submit the data regardless of the speciality. SvE suggested that we should separate data collection from treatment planning and that it is important to get the data submitted. JM happy to take this back to the CEN to discuss. SP commented on DMFT collection versus all the other cleft dental issues and that we should be able to submit DMFT if calibrated. JM remarked that having agreed that data inut onto CRANE is by specialist paediatric dentists some units, as a result of maternity leave, have not submitted data and are now flagging as outliers and other units not adhering to this agreement are continuing to submit data despite the lack of a paediatric dentist. SvE noted that if data is not entered then it is not possible to evaluate the service nor highlight any issues, manpower or otherwise. JND raised the point though that if data is collected by non-specialist paediatric dentists it might not highlight the lack of specialist dental resource. SvE felt that poor DMFT scores might show poor paediatric dental input. The discussion was concluded with mention of the treatment index and care index collected by CRANE but not reflected on the quality dashboard. **<u>Psychology CEN (VH)</u>** There is a lot of concern about the psychological impact of delays to adult surgery. The CEN had written a paper on the risks associated to delays in lip revision, rhinoplasty, and orthognathic surgery, which could be used to argue any cases locally. A lot of the anxiety amongst cleft is related to appearance issues and therefore delivery of orthognathic surgery is an important part of alleviating this and delays to this has resulted in a substantial increase in anxiety. Changes to the treatment pathway, which patients have been informed of from a young age, have removed some of the psychological containment for families. The CEN have seen an increase in anxiety, difficulties with feeling let down, gender issues with boys more likely to be adults before getting rhinoplasty surgery compared to girls, and that the lack of replacement plans has caused an increase in patient and parent anxiety. Adolescents have also been more severely impacted by delays during the pandemic and a year delay for an adolescent is more significant than at other times along the pathway. VH also mentioned the effect on the over 25s as well with worsening psychological outcomes when surgery is delayed. The psychologist are more than happy to support those with unforeseen temporary delays to surgery, but are much less comfortable in supporting those with delays and no plan for surgery. VH highlighted the psychological impact of surgical cancellations on both child and parent with increase in anxiety and poorer pain management etc. A 10 year audit of Psychology in Wales has seen a huge increase in referrals in 2020. VH flagged the impact of isolated working on staff wellbeing and underestimating the advantages of working together and sharing clinical skills. VH will share the paper on this once published. A number of teams were outliers on CRANE, which has been useful for highlighting lack of psychology resource. The CEN are reporting positive experiences of being able to run online groups. The CEN have submitted several papers nationally to Cleft 2022 so the CEN should be well represented. VH echoed and supported JS' stance of exposing junior trainees to cleft to engender interest going forward and encouraged teams to expose assistant psychologists and doctorate students to the cleft MDT. **<u>Speech and Language Therapy CEN (GP)</u>** GP acknowledged Lorraine Britton's hard work and tenacity especially with regard to outcomes and she continues as a member of the LSLT group. The LSLT Group met at the beginning of January 2022, where GP took over from Lorraine. The focus of the meeting was to discuss

	speech therapy provision in speech centres and community. They are planning on updating their 2016 publication and continue their work lobbying for speech therapy provision. The group are also looking at centre roles and how they can deliver more intervention where appropriate. An additional audit meeting took place in October 2021, where they regrouped around audit and the impact of the pandemic. The group discussed issues surrounding data completeness, inclusions and exclusions. All of the centres expressed their commitment to continue audit work, but there was a large amount of variability in centres actually able to do so. The CEN had a virtual study day in autumn 2021, which was extremely successful. There were presentations on obturators from Evalina, digital stories from Wales, speech at home and telemedicine and Stephanie van Eeden and Lisa Crampin presented on TOM VPD outcome measures. CAPSA training has resumed and a virtual refresher took place in November 2021, which was well run and successful. A full course, for 12 participants, is being run in Oxford in March, 2022, which will focus on those centres who have a lack of CAPS-A trained calibrated therapists. Over the last 9 years over9000 speech recordings have been successfully audited resulting in a massive amount of data. FM questioned whether CAPSA funding is still a challenge for SLTs. GP noted that it can be, but the challenge now is access to external training by some Trusts. HE explained that CAPSA training is currently £200 for a two-day course -the 2 therapists HE and LS deliver this free of charge. FM suggested that HE write to the CFSGBI regarding partial funding for CAPSA training and offered to support where CFSGBI can. HE promised to right to CFSGBI in this regard. **<u>Surgical CEN (GT)</u>** The Surgical CEN met virtually in November 2021 with good discussion and feedback. The next meeting is due to take place on 20th May 2022. GT requested that any trainees that may want to give a presentation at the next CEN to contact him. GT raised the harm classification system circulated to the surgeons by Alistair Cobb saying that this is set out in statute meaning that it is designed for the NHS as a whole and is designed very much for short term injuries or reviewing accidents so the assumptions for that is that an individual can know how much harm they have caused immediately, which is not the case for cleft care. GT has been in discussion with the governance team in Oxford to discuss this the difficulty being that the amount of harm can only be quantified after growth is complete. GT suggested linking up with the other paediatric long-term conditions groups, particularly the surgical ones, to explore alternative models for quantifying or assessing harm in cleft care. **<u>Restorative Dentistry CEN (SP)</u>** The CEN met in December 2021 discussed the issue of access to general dentistry, which impacts on our patients but hopefully this is gradually improving. The CEN also focused on nasal obturators and speech prosthetics and are engaging with the national group to look at this. They are hoping that their training day this year will incorporate some education for CEN members. Also hoping to increase the profile for cleft restorative dentistry at CLEFT 2022 as at the last international cleft conference in Chenai there was only 1 consultant in restorative dentistry at the conference from the UK but 5 abstracts have been submitted for Cleft 2022. SvE requested that the new consultant restorative dentist at Alderhey be included in the CEN.
6. Feedback from CRANE	CR provided an power point update from CRANE: Team: The CRANE team remains unchanged, with 8 members to the team (currently 1.5 WTE's), however Kate Fitsimmons is currently on maternity leave and returns in August meaning that we will hopefully be able to complete the work on risk adjustment in speech outcomes. Covid-tham have continued to work remotely and CR recognises how challenging this has been. Contract: CRANE has not had a contract in place or increase in funding since 2008. CRANE hope that within the next month they will be signing a contract for the 2021/22 financial year and this should provide a basis for funding in the future. CRANE are currently working with NHS England to secure improved funding arrangements. Website has been updated and it has improved utility.

	Database enhancements: In the last 12-18 months, added Ethnicity, updated Syndromes / Congenital malformations, and DDE have been added / updated to the database. Commissioners have shown increased interest in regional differences. LAHSHAL enhancements have been put on hold until inter- and intra-relator reliability is better understood. Surgery data is on hold to remove data burden to teams and CR is hoping that with linkage to HES surgical information could be accessed without having to burden cleft teams. Further additions to Psychology, Orthodontics and Hearing will be added in the future. Linkage: Linkage is not as easy as before as legal contracts have to be agreed by both sides and linkage is often associated with extra cost. CRANE have a HES extract that goes up to the 2012 birth cohort and the team are in the process of updating to 2015. This a the current time, because of CRANES current funding contract, will cost in excess of £20000; if CRANE had a more permanent funding contract the cost would be an initial cost of £20000 and then a cost of £4000 thereafter. Therefore, without better funding, this will be the last update CRANE will be able to do. The National Pupil Database is in developmental stage although the third of 3 papers from this linkage in the past is due out soon-deficit in cleft children has been shown to be related in a dose-response way to school absence and the longitudinal study has shown that on the whole the deficit in cleft children is maintained through their schooling. NHSP linkage completion is expected in early 2023 and we will be looking at congenital deafness in the cleft population. Outlier Policy: CR thanked all the team and CDs for their involvement and response to the outlier process notifications. There were no clinical outcome outliers in this cohort but there were a few process outliers. There were a few clinical outcome alerts and SvE will be raising this at the next QMIC meeting as if this status is repeated then these units will move from alert to outlier status. The Outlier Policy is to be discussed during the next Quality Monitoring and Improvement Committee meeting. Outlier issues: The SLT group have raised concern regarding the reporting methodology. With the outlier policy as agreed by CDG we benchmark against current data from all units rather than benchmarking against historical data, which was what was previously agreed for speech outcomes will be including a chart of annual proportion meeting standards to watch for year-to-year changes. Reporting developments: The CRANE 2021 Annual Report was published in December 2021. Going forward, CRANE will report on the 2012 – 2014 cohort for the process and outcome funnel plots, and the 2015 data in tabula form. This will hopefully provide a national overview and help to identify resource shortfalls and support arguments for more resource. Research and Development: CRANE have supported a number of papers this year including collaborating with the cleft collective on Maxillary Growth and Speech Outcomes, Passive Smoking and Incidence, and range and frequency of Congenital malformations. CRANE are working on papers on Longitudinal Educational Attainments and Risk Determinants in Cleft Speech Outcomes. Going to do this for dental outcomes as well. Governance and QMIC: QMIC is up and running and will hopefully be instrumental in improving outcomes for all cleft patients nationally. For those looking for guidance on changes/improvements that can be made locally please see The CRANE Local Action Plan 2021 which, is available to download on the CRANE website. 2022 CRANE Timeline: CR talked the CDG through the 2022 CRANE Timeline. CRANE will be hosting a Quality assurance meeting in May 2022 where cleft teams can review their outcome data via the PR, and ensure CRANE records are accurate. 2022 and beyond: CRANE hope to improve their funding position that reflects activity and ambition. With this, they would like to secure a longer-term HES linkage, which will reduce the

	burden of data collection for cleft teams. The team hope to improve the reliability / relevant of reporting and demonstrate the value of CRANE. CR does not think that patients from Crown dependencies should be registered on CRANE as CRANE is funded by NHS (England, Wales and Northern Ireland) and this does not cover the crown dependencies – CR wanted CDs opinion/approval on this? Dashboard/CRANE report mismatch: This has to do with data extract timing differences and the misuse of the tab patient not attending service-this tab will be removed shortly and support will be offered to those teams where this is an issue-this will also be discussed at a session: Making it Better which, CRANE will be hosting a session of learning from excellence on 7th Feb 2022 from 10.30-12:00. There is a plan for a 2nd session in May to support data issues (after interim report delivery). In the longer term, dependent on resource, CRANE plan to host quarterly new user introduction sessions. The CDG discussed the challenges of registering patients from crown dependencies on CRANE. CDs are to discuss this with their teams and report during the next CDG meetings SvE queried whether non-cleft VPDs should be reported on. CR suggested that a small working group should be set up and recommendations be reported back to CDG, which can then be presented to commissioners. This is to be discussed during the next SLT Leads meeting. CR felt that any working group should include surgeons, psychologists and managers. **Action 01/02/22: 6.1** CDs and teams are to discuss whether patients from crown dependencies should be registered on CRANE, and report back during the next CDG meeting. **Action 01/02/22: 6.2** The reporting of non-cleft VPDs are to be discussed during the next SLT CEN meeting
7. CDG Terms of Reference	The CDG Terms of Reference was agreed during the last meeting and have been uploaded to the CRANE website.
8. Quality Monitoring and Improvement Committee (QMIC)	**November 2021 meeting** The Quality Improvement and Monitoring Committee met for the first time in November 2021. The meetings will be held twice a year, for one hour each. Meeting times will be determined via doodle poll. The next meeting is on 21st March 2022. During the first meeting, the following was discussed: • Terms of Reference • CRANE outlier process. CR shared the positive and negative outliers and alerts. The group decided to begin with focusing on positive alerts for clinical outcomes only. It was agreed that the CDs from each positive alert unit would be invited to join the meeting on 21st March to discuss how others may improve their outcomes. This will then be shared with the CDG and the wider cleft teams. • The Leeds report. It was decided that the Leeds reviewers would be invited to speak to the committee to feedback on the process and feedback on what could be improved. **Action 01/02/22: 8.1** QIMC feedback from positive alert units will be shared with the CDG once available
9. CLAPA	The following CLAPA update was provided by CCu after the meeting: • "We are still developing CLAPA's Organisational Strategy for 2022-25 along with an 18 month budget forecast and underlying Communications, Fundraising and Finance Strategies. We will launch the new strategy in March. • Cherry LeRoy, currently Engagement and Services Manager, is retiring at the end of April after 7 years working for CLAPA, initially as Regional Coordinator for the South East of England.. Our Communications Officer, Kate Flanagan is also leaving us this month to take

	on a more senior role with another charity. We are currently recruiting for their replacements - https://www.clapa.com/sitetag/vacancies/ • I was hoping to use the meeting to promote our Consultancy service https://www.clapa.com/about-us/what-we-do/consulting-with-clapa/ and to ask members of the CDG to consider utilising our service when embarking on a research project and to promote it to colleagues who are about to apply for funding for research to potentially include costs for patient engagement. • A huge thank you to those Cleft Teams that have put forward members of their team to be a CLAPA link person / champion. Cherry LeRoy is leading on this until she leaves at the end of April and is currently developing the role and would welcome any input from Cleft Teams regarding what the role involves and to feed in what would be helpful for the teams. Of the Cleft Teams, 5 have put forward a representative so far and we would be very grateful if the remaining teams could also discuss this with their staff team to see if anyone would like to take on the role. • We are currently recruiting for members of our Children and Young People's Council and have space for up to 6 young people as more of our existing members are reaching 18 years of age. I would be grateful if members of the CDG could promote this opportunity to patients and parents - https://www.clapa.com/support/young-people/ • We continue to deliver a series of online events for all sections of the cleft community including Employment Webinars for adults, our very popular Baby Sign course, our regular Coffee Clubs and Creative CLAPA sessions for children, young people and their families - https://www.clapa.com/events/."
10. Research	**Bristol-Cleft Collective** YW provided a written update to CDG from the Cleft Collective. **Overview** • Recruitment to the birth cohort is up and running at 14 of the 16 recruitment sites, with a 15th due to start soon. Total numbers for recruitment are 9723 (September: 9507) individuals from 3482 (September:3399) families across both the birth and 5-year-old cohorts. • Recruitment to the speech sub-study is improving but still behind pre Covid levels. As previously mentioned, we are now recruiting children up to age 36 months. Total numbers for recruitment are 914 (September:881) individuals from 455 (September:442) families. • Genotyping is ongoing and over 7000 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. Genome wide association study analysis (GWAS) meta-analysis investigating the contribution of maternal genetics to the development of cleft in their offspring is now proceeding with our collaborators at the University of Bonn. Additional projects using the genotyped data are in preparation. • Proposals to access and use the data continue to increase with 44 in total (see below for those submitted since last meeting). • Data sharing with CRANE has commenced and two linked datasets have been received from CRANE detailing child's cleft type and syndromic status. These data have been 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. A new dataset containing cases where cleft classifications differ between sources has been sent to CRANE from the Cleft Collective. • Eight peer reviewed papers have been published/accepted for publication since September. Two more are in submission. See details below for those published. • Impact from the papers includes a description of the range of surgical repair techniques used commonly in the UK and the median and range of timing of surgery, information which can be used prospectively in future analysis of the effectiveness of utilised protocols; and increased

understanding of the association between three different perioperative antibiotic regimens in cleft palate repair and the rate of postoperative fistula. Little evidence was found to suggest a difference in fistula rate between the three regimens ($\chi 2=4.34$, $P=0.114$). To be able to provide a substantive conclusion a randomised control trial will need to be conducted to be able to control for other factors which may influence fistula rate. We are currently in the initial stages of seeking funding to undertake this trial nationally.

• A panel presentation has been accepted at the American Cleft Palate and Craniofacial Association Conference as part of the 'Guest Nation' Invitation. This will consist of a question-and-answer session with key members of the Cleft Collective team and partners (participants, site PI, data user).

• A funding application to the MRC to use Cleft Collective data to identify children most at risk of mental health needs was successful and will provide a small amount of core funding for the study as well as address an important question in cleft care.

• Focus groups to determine content for an adolescent research clinic linked to Cleft Care UK have taken place and this work is now being written up while grant funding to run the clinics is sought.

Data collection

Data collection is ongoing and has continued throughout the pandemic.

• We are still monitoring the number of saliva samples returned as some teams need to send the kits home with parents rather than take the sample on site. This has an impact as parents sometimes forget to take the sample or saliva kits are lost. We are working with the recruitment nurses to ensure return rates are kept at their pre-covid rate.

• Our return rates for questionnaires remains consistent at 50% for our baseline questionnaires and a 39% return rate for our follow-up questionnaires.

• Surgical form return rate for first surgery is 93%. 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 a couple of sites which have a very low return rate. We welcome discussion with these sites 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 o LENA recordings - 85% (315 of 368 returned)

o 18/24 month assessment form - 91% (397 of 437 returned)

o 36-month assessment form - 67% (274 of 406 returned)

• The online survey of speech and language therapy intervention is still paused while we prepare and submit an amendment to ethics to alter the process for requesting input from community teams.

New proposals since September 2021

CC044 M Padashi-Fard - The cost of cleft care for the parent and child
CC043 H Chandler - Early language indicators and their relationship with Speech and Language Therapists ability to judge velopharyngeal function in children born with cleft palate at age 18-24 months.
CC042 M AL Hassini - Left vs right sided clefts – is there a difference in outcomes?
CC041 A Gormley - Caries in Cleft 3
CC040 N Stock - Longitudinal assessment of parental psychological wellbeing and its influence on child outcomes in cleft lip/palate
CC039 M Langford - Do stress levels in parents of children with a cleft differ between parents who also have a cleft and those who have not?

New papers since September 2021

	1. Davies, A., Davies, A., Wren, Y., Deacon, S., Cobb, A.R. and Chummun, S., (2021). Exploring the Relationship Between Palatal Cleft Type and Width with the Use of Relieving Incisions in Primary Repair. The Cleft Palate-Craniofacial Journal, p.10556656211019616. 2. Southby, L., Harding, S., Phillips, V., Wren, Y. and Joinson, C., (2021). Speech input processing in children born with cleft palate: A systematic literature review with narrative synthesis. International Journal of Language & Communication Disorders. 3. Fell, M., Russell, C., Medina, J., Gillgrass, T., Chummun, S., Cobb, A., Sandy, J., Wren, Y., Wills, A.& Lewis, S. (in press) The impact of changing cigarette smoking habits and smoke-free legislation on orofacial cleft incidence in the United Kingdom: evidence from two time-series studies. Plos One. 4. Lane, H., Harding, S. & Wren, Y. (in press) A Systematic Review of Early Speech and Language Therapy Interventions for Children with Cleft Palate. International Journal of Language and Communication Disorders. 5. Southby, L., Harding, S., Davies, A., Lane, H., Chandler, H. & Wren, Y. (in press) Parent/caregiver views of the effectiveness of Speech-Language Pathology for children born with cleft palate delivered via telemedicine during COVID-19. Language, Speech and Hearing Services in Schools. 6. 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. 7. Fell M, Goldwasser M, Jayanth BS, et al. (2022). Adapting Elements of Cleft Care Protocols in Low- and Middle-income Countries During and After COVID-19: A Process-driven Review with Recommendations. The Cleft Palate-Craniofacial Journal. doi:10.1177/10556656211069827 8. Fell, M., Davies, A., Davies, A., Chummun, S., Cobb, A., Moar, K. & Wren, Y. (In press) Current surgical practice for children born with a cleft lip and/or palate in the United Kingdom. The Cleft Palate-Craniofacial Journal **<u>Early Careers Research Group (ECRG) Cleft Multi-disciplinary collaborative group</u>** DS provided an updated from the ERCG. The ECRG membership survey 2021 - 30 members on the distribution list from SLT, surgery, nursing, dentistry and orthodontics. 11 members completed the survey (17 in 2020). Surgeons and SLT's were most active. Activities in 2020-2021: • Data collection: PRS national study; smoking study with CC; PhD studies • Data analysis: thematic analysis in interview study; early communication and gestural behaviors • BCLP scoping review • Other systematic/scoping reviews x 4 • Over 15 oral/poster presentations at conferences (up from 7 in 2020) • 17 publications (5 in 2020) • Additional media activity on websites; podcasts, blogs Other achievements from members: • PhD awarded to one member, now on post-doctoral pathway • RA and Senior RA posts with Cleft Collective • RA post with CRANE • RA post with Bristol Speech and Language Research Unit (BSLTRU) • Clinical Academic mentor for 3 successful NIHR funded pre-doctoral and internship awards Funding: Over 60% were carrying out their own funded research. There have been 4 NIHR fellowship (up from 2 last year), and other funding from RCS, VTCT and HEE.

	Publications: 14 papers reported to be published in peer reviewed journals. Activity is increasing and all involved value the group. The ERCG would like more members from different groups e.g. nursing, dentistry etc. The group will be having a hybrid meeting in March 2022. **<u>Clinical Studies Group (CSG)</u>** SK provided an update. The group have received some great submissions and are getting good PPI input and feedback. SK will provide a written report on current studies. The group are starting to map out which age groups are currently being studied to ensure there is not an oversaturation; the CSG have happy to share with the CDG as it progresses. SvE confirmed that a written report for CDG would be very useful.
11. Quality Dashboard	Nothing to report.
12. CFSGBI Feedback	FM provided an update from the CFSCBI. The conference is a merged conference between our annual conference and the National conference. The CFSCGBI have received approximately 1200 abstracts for the conference. Amongst the delegates, there is enthusiasm to attend the conference in person, though the conference will be run both virtually and face-to-face. Successful abstracts will be notified by 4th March. The first series of international cleft webinars have been completed and were successful; these were all surgical but the hope is that there will be further webinars of a non-surgical nature. The CFSBGI website will go live in late February/early March. The society will be advertising for two social media and website officers at the end of February. The Society are in discussions with the ACPA, who have invited the CFSBGI to be guest nation for their conference this year, to look at potential discount for access to the CPCF for CFSBGI members through the website. FM asked for suggestions how CFSGBI could work more closely with ACPA and other organisations.
13. Training	LF provided an update on training. A round of successful interviews took place last week and 1 further TIG fellow has been appointed although the unit has still to be decided. The HAF forms will be going digital this year; LF encouraged all units to fill out the form this year. LF will email CDs once form has gone live. LF confirmed that the educational supervisor within the TIG cleft unit, along with the TIG chairperson, would be the fellow's TPD post-CCT. SvE raised primary cleft network births and number of surgeons in each unit - SvE showed a spreadsheet of number of primaries per surgeon per cleft centre. SvE asked CDG to consider this in view of the cleft specification. DD replied that the position is more complex as the feeling is that for example stand alone surgeons are not recommended and this would immediately dilute the number of cases per surgeon. CR spoke about unit specific data rather than surgeon specific data and that the number of 40-50 was driven originally by having enough UCLPs to do statistical analysis for surgeon specific analysis. AC remarked that with a lack of access to theatres appointment of more surgeons wont solve any problems. DD also raised the issue that the numbers of non-cleft VPI are not being added into the mix and this should be added into any calculation going forward. JND spoke to low volume and high volume operators and that high volume doesn't necessarily mean good outcomes but low volume operating isn't the answer either and that there is probably a sweet spot of numbers and outcomes. SvE reported that he had been approached by 2 ODNs looking at the cleft specification in detail and SvE suggested that it was perhaps time to form a working group to relook at the cleft specification?
14. Any other business – CDG & dates of next meeting	No other business. The next meeting of the Cleft Development Group will take place virtually on Wednesday 8 June 2022 from 9am-1pm.

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Actions from Cleft Development Group meeting: 1st February 2022	Owner	Due Date

Action 02/01/22: 3.1 – CDs have to explore CDG Managers Group representation within their centres and report back to SvE.	Clinical Directors	8th June 2022
Action 01/02/21: 5.1 The Side Lying and Upper airways Maintenance in Babies Requiring Surgery (SLUMBRS) study is to be added as a recurring Research item on the CDG agenda.	CF / SvE	8th June 2022
Action 01/02/22: 6.1 CDs and teams are to discuss whether patients from crown dependencies should be registered on CRANE, and report back during the next CDG meeting.	Clinical Directors	8th June 2022
Action 01/02/22: 6.2 The reporting of non-cleft VPDs are to be discussed during the next SLT Lead meeting	VH	8th June 2022
Action 01/02/22: 8.1 QIMC feedback from positive alert units will be shared with the CDG once available	SvE	8th June 2022