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

Venue- Zoom Conference call

Date & Time- Friday 28th May 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
	Nabina Bhujel (NB)	Deputising for Jackie Smallridge, Paediatric Dentistry CEN Lead
	Alex Cash (AC)	Clinical Lead, South Thames 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
	Helen Extence (HE)	Clinical Director, The Welsh Centre for Cleft Lip and Palate
	Toby Gillgrass (TG)	Clinical Lead for Scottish Cleft Surgical Service
	Vanessa Hammond (VH)	Clinical Psychologist CEN Lead
	Loshan Kangesu (LK)	Deputising for Norman Hay, Clinical Director North Thames Cleft Service
	Sarah Kilcoyne (SK)	Chair of NIHR Clinical Studies Group of Cleft and Craniofacial Anomalies
	Felicity Mehendale (FM)	President Craniofacial Society of Great Britain and Ireland
	Jason Neil-Dwyer (JND)	Clinical Director, Trent Regional Cleft Lip & Palate Network
	Eilish O'Connor (EOc)	Deputising for Chris Hill, Clinical Lead Northern Ireland Cleft Service
	Ginette Phippen (GP)	Clinical Director, Spires Cleft Lip & Palate Network
	Sandip Popat (SP)	Restorative Dentistry CEN Lead
	Helen Robson (HR)	Lead Nurse, North West & North Wales Cleft Lip and Palate Network
	Craig Russell (CR)	CRANE Clinical Project Lead
	David Sainsbury (DSa)	Deputising for Peter Hodgkinson, Clinical Lead, Newcastle Site, Northern and Yorkshire Cleft Service and Cleft Multidisciplinary Collaborative
	Jules Scott (JS)	Orthodontic CEN Lead
	Alistair Smyth (AS)	Clinical Lead, Leeds Site, Northern and Yorkshire Cleft Service
	Guy Thorburn (GT)	Surgical CEN Lead
	Imogen Underwood (IU)	Clinical Director, West Midlands Cleft Service
	Yvonne Wren (YW)	Chief Investigator, Cleft Collective
	In Attendance:	
	Catherine Foster	Clinical Effectiveness Unit Research Coordinator, RCS
	Apologies:	
	Lorraine Britton	Lead Speech and Language Therapist, Trent Regional Cleft Lip & Palate Service
	Norman Hay	Clinical Director North Thames Cleft Service
	David Orr	Clinical Director, Irish Cleft Service
	Jacqueline Williams	Paediatric Dentistry, CEN Lead
	Rachael Willis	Clinical Lead, Cleft Net East

	Chris Hill	Clinical Lead, Northern Ireland Cleft Service

Item	Notes
1. Apologies, absence and welcome to new members	The chair (SvE) welcomed the Cleft Development Group to the meeting. The group joined the meeting via Zoom teleconference. Apologies were given for those unable to attend (see above).
2. Feedback from CRANE	**<u>CRANE Preliminary Report</u>** CR presented the CRANE Cleft Development Group Update. The presentation included: • COVID Challenges-issues with child care and issues regarding mental health and isolation; also issues with connectivity. Have got good at using teams; everything has been slowed down as face to face meetings haven't been possible particularly on linkage areas; contract negotiations around CRANE have also been slowed but have been progressed through teams. Scotland participation hasn't progressed because of Covid challenges as decision makers have been focussed on cancer screening services. • Staffing – A member of the project team is due to start maternity leave from end of July, bring the current 1.4 WTE down to 1.0 WTE, which does present its challenges; will affect ability to respond to queries and the ability to carry out analyses. • Funding – CRANE funding has previously been very uncertain and funding has been on an annual basis and this lurches from letter of intent to letter of intent and confirmation of funding usually arrives after the beginning of the financial year and the college therefore takes a risk on this and is also disconcerting for staff and has an effect on data linkage eg with HES. CRANE have now however through SvE's introduction to Anthony Prudoe, NHS England Women and Children's Programme of Care, National Programme of Care Lead, managed to get face to face meetings on Teams with commissioners and now have active engagement and meetings with Commissioners. Discussion is ongoing but there are suggestions that they may be able to provide a 2 year contract with an option for a third year. This will hopefully be confirmed in the next 4-5 months. This would make CRANE more stable and allow longer term planning and entry into contract relationships on a less risky basis and will reduce the cost of linkage projects (HES/NPD etc.). Still ongoing discussions to ensure full CRANE budget is covered as the current funding only covers two thirds of current costs and the college and Clinical Effectiveness Unit picks up the rest of the costs, which is not sustainable in the long term. • Comment on Leeds review-significant workload for CRANE looking at data, revising data and providing analyses for the review team and the local team. This has lead to many positives that will be taken forward nationally with CDG's agreement. This has principally been about understanding risk modulators to speech outcomes. We have been able to provide a report to the reviewers and the Leeds team that has adjusted the funnel plots for speech outcomes for cleft type, extent of palate involvement, patient sex, and presence or absence of Pierre Robin Sequence all of which have been shown to be independent modulators of cleft outcomes. Kate Fitzsimons has put together a risk adjustment model that has changed the outcomes for Leeds and CR hopes that this is helpful to them. Work has also been done with HES linkage which has shown that the timing of palatal repair and the number of operations to achieve palatal repair in Leeds are well within national norms, which again should be reassuring for local service managers. • 2020 Report and Local Action Plan – the 2020 Local Action Plan document is now available on the CRANE website-way to crystallise thoughts around the

recommendations made at the end of each CRANE report around ways to improve things either at a local or national level; CRANE have put suggestions in but CR would be looking for in the future is engagement from CDG and then later the QMIC once it is set up to run a national level discussion about what the priorities should be and how the recommendations can be taken forward. Each local cleft team could also use this to crystallise their own thoughts and stimulate discussions within their own teams on how to use the CRANE report to drive services forward locally. There is a whole section on the CRANE website about quality and links to other websites with tools that could be of use to all.

- 2021 Interim report – The 2021 Interim Report was shared with CDG in April 2021. The report was produced in accordance with the Outlier Policy. The report details: consent verification rates 2012-14 and 2020, variation in Cleft Types between units, variation in PRS reporting, variation in Syndrome reporting, and variation in data completeness for all the clinical outcomes. There are variations in clinical outcome but one of the concerns that has been raised is that it is felt that the outlier policy cannot be trialled when there is a limited dataset due to Covid. What needs to be discussed however is what funnel plots can and not do and the relationship we have with funnel plots and the outlier policy. The trial of the outlier policy is not whether funnels work or not as funnels are a well established statistical tool used widely in international audits but the outlier trial is rather a trial of process to see if CRANE can step up and do what is said in the timeline in terms of getting data out, getting letters to the relevant people, checking the data locally if a unit is an outlier; then informing services that they are potential outliers; then we need to see if services can do the local checking within the timeline that has been agreed to date to be able to say yes we think the data is correct and that is how we sit. Once this has been done then are we able to notify the relevant medical and clinical managers in each organisation.
  CR went on to stress that unit position on funnel plots are not a league table but tell a story: they tell a story about data completeness, specific outcomes, and how that relates to national means. It is not about one unit being above another and we cannot say statistically that there is any difference between any of the units that sit within the 2 standard deviation funnel. It is therefore not a league table and what we are trying to do is give information that can drive care forward. There is quite a lot of variation in data completeness across all the speciality groups and all the different outcomes that are measured. The variation in data completeness has potential to show significant insight into different units pre- and peri-COVID including (but not exclusively): consent processes, service structure, administration resource, clinical resource allocation, audit process, physical infrastructure, and relative stress resistance/local protection of service. By producing a report that shows that a unit is unable to produce the data then it makes that unit stand out from the others and provides the unit with an argument that can be taken to local operational managers and commissioners about the resource allocation currently in place to deliver the service. If there is obvious inequality this serves as a powerful lever as the NHS is meant to be an equitable service for all members of society in the UK and politicians don't like inequality and they might apply the necessary pressure to get the inequality addressed. Being a negative outlier is therefore not necessarily a bad thing and we need to understand why they might be a negative outlier and then help local services to understand this and put things in place to help improve this.
  As far as individual outcomes are concerned:

- Physical growth-there are 6 positive outliers and 5 negative outliers meaning that we are widely spread and calls into question whether units can measure physical growth i.e height and weight.
- Similarly for psychology there are both positive and negative outliers in terms of data completeness and 2 negative outliers in terms of outcome-this raises the question of why this is occurring and how we can improve this.
- The same can be said for dental where we have data completeness and outcome differences
- For speech there are data completeness differences and one alert for outcome 2a regarded as the surgical outcome
- For facial growth there are data completeness differences and 2 positive alerts meaning that there is the potential of learning from these units

The story therefore is one of inequality of access, inequality of resource, inequality of prioritisation of care by units, and inequality of unit resilience to deal with the stress of covid. It should also be remembered that Covid has not been the same across the UK and some areas have suffered significantly greater than others.
I want to reassure everyone that CRANE is listening and that we know there are stresses across the UK and we will, through dialogue and discussion modulate what we put in the annual report. We will find a consensus path.

- 2021 Annual Report plans – In discussion with the Speech and language therapists (discussion is still to be had with the other speciality groups) it has been agreed that the 2021 report will include speech reporting and trialling of the outlier policy for Birth Cohort 2011-13, and data completeness reporting for 2012-2014 by year (probably presented in a tabular form, rather than funnel plots). We will do it by years to see what was happening before Covid and since Covid to see how Covid has impacted on unit's ability to collect data. CRANE will also listen to hear what other clinical groups / clinical directors / commissioners want to do. All parties need to be involved in the discussions. CRANE intend to use the data completeness results from 2012-2014 as a springboard for a service survey, to understand physical as well as clinical service structures and to look at how this has impacted on the ability to collect audit data. The intention would be to establish recommendations for how services can be structured to be more robust when withstanding stresses such as COVID or any other stresses that may arise.
- Database development:
    - CRANE is currently building and putting in the defects of dental enamel that the dental CEN have asked for and is being worked on by the IT provider and will go live hopefully later in the year.
    - working on converting LAHSAL to LAHSHAL and that will hopefully start by the last quarter of the year to the early part of next year to make it available to next year's cohort of patients.
    - CRANE is in discussion with the ENT and audiology SIG about what data can be included and what data can be collected nationally about hearing experience particularly in the first 5 years of life
    - Is ongoing dialogue with the Orthodontic CEN to develop a measure that looks at their activity and their outcomes that can be used in the future
- Ongoing academic collaborations:
    - Continue to work with the Cleft Collective(CC) on phenotype as a first step to look at concordance of data; hopefully this is the start of future collaborations with the CC.
    - Have been helping 2 PhD students with their applications, which are about to be submitted to look at outcome modulators in speech, dental and

psychology outcomes to build on the work already done on risk adjustment tools.
    - Mike Mars and Mary Calvert have been working with a Swedish group, with the support of CRANE for analysis, to look at the predictability of the 5 year index and GOSLON index for facial growth and we are in discussion with the orthodontic CEN and Mike Mars and Mary Calvert to see how we can take a UK based study forward. I hope to be able to report back at the next CDG meeting about how that might be planned.
    - CRANE has had an approach from an Australian colleague to look at the potential influence of laterality in clefting; CRANE has started looking at this and this may potentially feed into risk adjustment as initial findings are that right sided clefts seem to have better speech outcomes than left sided clefts in UCLPs.

CR welcomed comments regarding the 2021 Interim Report.
SvE thanked CR for his thorough presentation and for all the hard work being carried out by CRANE.

- The CDG received the following report from the Lead Speech and Language Therapy Group regarding the auditing of children born in 2014/2015:

"Over the last year Lorraine, as chair of the Lead SLT team, has consistently explained to CRANE and CDG that we would be unable to comprehensively audit children born in 2014/15 due to covid 19.
We would now like this to be translated into a discussion regarding how this data is used in:

- CRANE Reporting
- Piloting of outlier policy
- There are several reasons that 2014 / 2015 audit records are not available:
- Not prioritising collecting audit recordings due to COVID restrictions on face to face contacts over the last 18 months.
- Inability to analyse audit recordings due to COVID restrictions
- Lack of CAPSA trained listeners in some centres – and inability to provide further CAPSA training due to COVID restrictions on face-to-face training.
- Backlog of clinical work coming out of COVID restrictions.

As the CRANE Interim report has demonstrated, this has led to a very incomplete data set for 2014 births. There is likely to be even less data next year for 2015 births.
Given the incomplete data set, the Lead SLT team have grave concerns about the use of 2014/2015 birth data in CRANE speech outcome reporting.
The Lead SLT team therefore wish to recommend that **2014 and 2015 speech 5 year old speech outcomes are NOT reported nationally by CRANE with comparison between centres (i.e. funnel plots) because the data sets will be incomplete due to COVID19.**
In terms of the following:
1. Trialling the outlier policy : We would argue that trialling the outlier policy is not realistic without a complete data set and will be very unfair / unsettling for centres if done using incomplete data from 2014/15 births. Full comparison across centres could be done for the 2012/13 data sets.
2. Feeding back on individual units data– This can still be done without comparative data being shared. National outcomes could be calculated for 2014/15 using pooled

	data and individual centres could be told their outcomes relative to the national outcomes. 3. **Giving a picture of what has been able to be achieved for all services through the COVID period –** CRANE could report back on data completeness due to COVID19 without the outcome data. This requires much more narrative than given in the CRANE interim report. COVID19 has impacted centres in different ways and for different reasons. Data returns to CRANE are just one aspect of a much more complex picture. We understand that these recommendations will need to be approved by CDG today in time for writing the CRANE Annual Report over the summer and so we would be grateful if this could be discussed today." • IU commented that SLT believed it had been agreed that speech audit data would not be collected for children born in 2014/2015 because of Covid. UI felt that due to this, the data that had been collected would not be valid and would not show a variation in service provisions because it had been an active decision not to collect. • HE added that if data had been collected then it should be submitted; SLT would like for the 2014/2015 data to not be identifiable per centre in the annual report. She added that, although the comparisons are not seen as a league table by most, this is not necessarily the case for all in the room, for cleft parents and for commissioners. HE went onto say that the data from 2014/15 should be anonymised and accompanied by a clear narrative of why we are not reporting by centre because of the variation around the country in collecting the data and in the consensus listening. CR commented that the interim report is not a public report and that this report reflects what has happened and that the final report and analysis will be done in collaboration with the CENs. He added that CRANE will report 2011, 2012 and 2013 data per centre as the 2013 data hasn't been looked at in this way and the 2014 data would only include data completeness. • JND reported that Trent run a distributed network and they were a little surprised with the amount of data that has been returned; they left it up to the network to collect the data or not. • AS felt that 2014 data should be included wherever possible. He felt it would be detrimental to not include important data, and that the more data included the more reliable it would be and he felt that the data should not be anonymised as there should be sufficient data to make inter-centre comparisons. He added that if this data was not included, this would impact upon accurate determination of resource allocation going forward. Last point important to AS in the light of the current Leeds review is that he would like Leeds to submit 2014 data on the background of the external review. HE commented that data that has been collected should be submitted, but the issue is in the way that it is reported. HE felt that information should be fedback to individual units for service planning, but that this should be anonymised within the report. • LK felt that reporting bad results is not a bad thing; LK is for transparency, and he felt that the effect of Covid on units should be reported as it is and not anonymised • JND supported LK's transparency and feels that it raises the question of what we do when differences are highlighted. We need to navigate the findings and maintain focus on quality improvement. • CR explained the difference between not getting the data or taking an active ethical decision not to bring patients in for data collection during a pandemic and this difference would not be picked up in the raw data and would need an accompanying narrative. IU replied that this is not about reporting poor outcomes but that it was decided as a speech and language group that it was not ethically

	right to bring children in for data collection during a pandemic. It is important to remember where we were a year ago in the middle of the Covid storm. • SvE commented that his understanding from CDG is that this data should be reported in tabular form for 2014 to highlight what Covid has done for reporting, but that it would be difficult to apply an outlier policy for those years in terms of outcomes. CR will be in dialogue with all the CEN's and suggested that once the report is in its final draft form, it comes back to CDG for review. • SvE asked CR about Quality Dashboard: CRANE returns 2/3 of the data fields and return them as they are. SvE asked if there are any issues anyone wanted to raise with CR re the QD; SD has raised issues with the denominator and their SIG feels that this is not accurate and SD asked if she could get a list of the denominators; CR replied that these can be found on the website and CR explained that CRANE can only report on the data it receives from individual units. SD will be contacting CR to discuss the denominator and numerator for the audiological data. • SvE thanked CR for his input while on leave
3. CLAPA	CC provided an updated from CLAPA. CC shared the CLAPA Strategy for April 2021 – April 2022, which is now on the website. CLAPA now taking a different approach, and this has been influenced by Covid moving from a face-to-face organisation to a digital one. Going forward, CLAPA will be providing their services completely digitally via a UK wide model without any face-to-face contact at least until the end of this financial year. The CLAPA website will be redeveloped, and the information service will be rebuilt with a digital focus. CLAPA will be building on their social media presence and will create a programme of inclusive, engaging and varied online events that proactively meet the community's existing and emerging needs. The one-to-one support services will be developed to help those in need of guidance and support, and CLAPA will formalise and develop their collaborative approach to community involvement in research. The staff team have been restructured as it became obvious that having a member of staff in each region is not sustainable financially nor did it provide an equitable service, so a decision was made to move from a regional model to a UK wide model. While no redundancies were made a couple of part-time staff decided not to continue with CLAPA and have recruited 2 new employees. Now have a team of people that focus on themes and the team leader is Cherry Leroy; Daniel Richards is now the advocacy co-ordinator working 2 days per week; Claire Evans is children and young people's co-ordinator working 28 hours per week; have just appointed a new communications engagement co-ordinator, Joy, and Laura who is the adult services co-ordinator who will be replacing Kenny's role. Gillian McCarthy is retaining her role in Scotland and has taken on the role of external engagement co-ordinator interacting with research organisations, getting PPI. CLAPA have reduced their office space and are now moving towards a hybrid working model (home/office working). Aims are to inform, connect, reassure and empower will be applied to all everything that CLAPA does to make sure that at least 2 of the aims are met before going forward with an opportunity so that quality is maintained, and resources aren't spread too thinly. Inform-develop website; refresh information service with digital offer Connect – creating on-line events and activities; and social events Reassure – helping navigation of treatment pathway, journey, put people in contact with each other Empower - patient voice and working with the CC and the SLUMBRs project and others to ensure that patients/parents have a voice in research and in CLAPA. CLAPA have recruited 2 new trustees-an adult with a cleft and parent of a child with a cleft both with a legal background making it now 12 trustees.

	Principles on this document integral are sustainable, safeguarding, community led and accessible and diverse. The CLAPA feeding service will continue to be delivered and developed. CC presented CLAPA social media stats following the 2021 Cleft Lip and Palate Awareness Week. It was a phenomenal success. Following input from their Patron Carol Vorderman, CLAPA received significant social media engagement. FB post shared 2200 times reaching over 180000 people; on twitter videos and infographics seen 250000 times – 500% more than usual; on Instagram post was seen 120000 times by 6600 people; 75 people took part in the step-up campaign; raised over K22 on FB during the week. Thanks to all who helped during the week. Office space has been reduced and are moving to a hybrid working system with hot desking. SvE asked about progress on patient/parent representation on CDG due to be discussed under matters arising: 21/01/21: 3.1 – CLAPA are yet to establish their patient/parent representative subgroup. CC felt that a parent representative attending every CDG meeting would not be feasible/beneficial but that it would be better to set up a sub-group to work on what the aims would be regarding a patient representative. CC didn't think it would be appropriate for a parent/patient representative to attend all the CDG meetings. GP happy to be on the subgroup and SvE suggested that DD could sit within the subgroup as he is already experienced in working with CLAPA and in Scotland. DD happy to be part of this. CC happy to have GP, DD and Gillian McCarthy. HR also volunteered to sit within the subgroup.
4. Minutes of the Cleft Development Group Meeting, 30th September 2020	Amendments to the draft minutes from 21.01.21 were suggested by the committee. Page 5 under West Midlands Primary care patients onto remaining lists" should be "primary surgical patients". Page 12 should be Astor and not Aster Minutes confirmed but for the changes above.
5. Matters arising	• 21/01/21: 3.1 – discussed under CLAPA feedback and to go forward in a subgroup. • VH did send link around wrt to Liz Gregory's lockdown blog • Restorative dentistry has been added to the QMIC ToR membership. • SvE has written to the medical directors sharing QMIC and the outlier policy documents using the addresses provided by the clinical directors. • 21/01/21: 6.1 – Ian Sharp is no longer able to continue his role as Deputy Chair of the CDG, therefore a new deputy chair needs to be nominated. SvE asked the CDG to consider nominees for discussion during the next meeting. • 21/01/21: 4.2 – SvE met with Anthony Prudhoe on 9th February 2021. CDG are to feedback to Anthony regarding resource issues across centres. IU noted that banding for Lead SLT (8a) indicated inequality nationally and that SLT need support from CDG and commissioners to address the general inequality of banding within SLT. SvE emphasised the importance of service equity and highlighting inequality nationally through CR's proposed survey and taking this forward to commissioners when we have all the information to improve resource. • SvE thanked VH for her work with the psychology CEN on the negative effects on delays to lip surgery; and JS and the OCEN on their work on delays to ABG's and GT with VH and JS on delays to adult surgery, which is ongoing. • **Action 28/0/05/21: 3.1** – CDG are to consider CDG Deputy Chair nominees, for discussion during the next meeting.
6. Feedback From Cleft Centres (UK)	**Newcastle Site, Northern and Yorkshire Cleft Service (DSa)**

Staffing remains stable. Paediatric surgery is operating per protocol. The Adult waiting list mainly consists of rhinoplasty, although this is under control. Triaging has been taking place months in advance. Currently there are no outreach clinics, with no plans for recommencement in the coming future.

Leeds Site, Northern and Yorkshire Cleft Service (AS)

Primary cleft surgery is not yet back to full capacity (80% of previous capacity), and it is hoped that this will improve from July onwards. Currently concentrating on primary surgery meaning that there is currently a waiting list for alveolar bone grafts and secondary speech surgery. Adult operating and Orthognathic surgery has resumed, with adult orthognathic surgery taking priority over rhinoplasty principally because the orthognathic patients re currently in appliances. It is hoped to move alveolar bone grafts onto the adult list in discussion with managers and this is something that has been done before.

Face to face MDT clinics have resumed but only in Leeds. It is likely that MDTs will be provided within all the spoke networks, provided that adequate facilities and adjustments are in place, including access to electronic records. MDT clinical meeting continues.

The lead SLT therapist is due to start maternity leave at the end of June and there have been internal changes and a new starter is joining shortly.

2014 speech data has not yet been submitted as they only have 1 CAPSA trained therapist within the service but are trying to validate data with external SLTs by the CRANE deadline in June. The Leeds external review is in process and some members of the team have been interviewed and others including AS are due to be interviewed in the coming weeks. The supplementary report that CR mentioned before has not yet been shared with the Leeds team yet.

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

The Network Manager, Yvette Edwards, has moved onto a new post and a new Manager will be starting in July. Alder Hey is at pre-covid operating levels, with no restrictions on cleft cases. Manchester is at 2/3 pre-covid lists, with priority 2 cases only. One surgeon in the network is retiring in September, with interviews for replacement taking place on 8th June. Regular adult operating is not taking place at either site, but there was one adult list last week. One orthodontist in the network is on maternity leave, but this is being covered. There are waiting lists at both sites, but they continue to prioritise patients that are already in treatment. SLT appointments are still virtual. Manchester is running a face to face speech investigation clinic, and Age 5 MDTs should be face to face by July. One nurse is on maternity leave, but a new CNS started in April and a band 6 support nurse has also been recruited. Issues with access to dental theatres are ongoing. A Psychologist at Alder Hey is on maternity leave, and one has recently handed in notice. Both sites continue with virtual MDTs, but face to face are gradually increasing.

Scotland (DD+TG)

DD - verbal

Paediatric surgery is up to date and has been helped by a lower birth number for 2020. Adult lists resumed 3 months ago (Rhinoplasty, speech, lip revisions). Orthognathic is yet to resume. One psychologist is leaving the centre due to relocation, and interviews are due to take place for a band 4 admin member which will bring the admin team up to full complement.

TG-written

Scotland's mid-term report (up to Sept 20) suggests 84% compliance with Cleft Care Scotland Primary surgery guidelines. At present, Scotland have only one child breaching the guidelines for primary surgery, but this is due to cancellation as a result of ill health. Lyndsay Kirk has been appointed as a substantive Coordinator.
Funding has been secured for weekend cover for the Cleft Specialist nurses, which is hoped to start in April 2021.
All MDT appointments have been moved to remote consultations whilst Scotland sit within level 4 restrictions. Acute/essential clinic reviews continue as face-to-face.

West Midlands Cleft Service(IU)
West Midlands have one vacant consultant cleft surgeon post and are about to advertise for an orthodontist position following a retirement in April. Surgery is back to full capacity. Primary surgery has some delay. Adult surgery lists have recommenced for category 2 & 3, and no Orthognathic surgery taking place. All MDT clinics have been running throughout the pandemic, and paediatric face to face clinics resumed in August 2020. SLT are running on a hybrid model depending on the needs of the patients. The network has validated the patient lists. Community services are impacting on SLT waiting lists. Pathway protocols have been updated.

Trent Regional Cleft Network (JND)
Surgical capacity returned on 10th May. Nottingham are part of a collective sharing capacity for children. Clinics are running on a hybrid model (face to face/virtually). The network are developing software that attaches to video clinic system for some patients to do a triage Cleft-Q probably in the 15-20 year old group over the next 6 months or so. The cleft coordinator has recently been changed, with a two week overlap. The admin team are hybrid working. Ages for surgery are at 5 months for lips and 10 months for palates. ABG's and osteotomies are progressing. Adults secondary surgery has been put on hold with an agreement that this will not recommence until all primary surgery is down to an acceptable level and orthognathic surgery has been carried out for patients in appliances.

Cleft Net East (SvE on behalf of Rachael Willis)
Outpatient services continue a reduced template with the majority of clinics run as hybrid face to face and virtual consultations. Attend Anywhere is being used to enable MDT input for F2F and virtual due to ongoing social distancing and room number restrictions. The network resumed some F2F Age 5 Audit clinics also on a reduced template. Palate investigation clinics have also resumed. Orthodontic and Dental outpatient services remain affected by social distancing with no plans to implement changes to increase activity levels. The network continue to work with the outpatient services to try to resolve this. As such they are not starting any new treatments unless time sensitive e.g. ABG preparation. ABG clinics are slowly catching up based on age and priority. Spoke clinics are all set to resume in the next couple of months F2F however some will be unable to offer the same allocation of rooms and services.
Theatre allocations continue to improve with no delays in primary surgeries. Secondary speech surgery has recommenced on a priority basis. ABG backlog is reducing, no breaches of ideal timing to date. Adult surgery is still noticeably affected - particularly secondary surgeries (e.g. Rhinoplasties), private sector is being re-explored for these cases.
No recent appointments. Interviews for an 8a Clinical Psychologist post scheduled. Paediatric dentistry recruitment continues to be challenging.

RW is due to start maternity leave at the end of May and hopes to announce the interim service lead soon.

North Thames Cleft Service (LK)

LK written report: 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 received their 2nd vaccination. We have a reduced complement of CNS nurses which has been made up in some part with bank cover. We have a full complement of surgeons. This has allowed us to keep up-to-date with the primary cleft surgery but we have an inevitable backlog of patients requiring secondary surgery including cleft revision surgery, alveolar bone grafts and orthognathic surgery. This is particularly affected the adult service which is currently extremely limited in both of our secondary centres. Our SLT department have continued to provide a service virtually and now also providing a service within the trust with the necessary measures in place. Our psychologists 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 that they no longer routinely attend cleft MDT clinics. Our ENT and audiology service continue to run well with much of the audiology service now provided at a local rather than centralise level.

Problems:

1. The absence of a calibrated paediatric dentist at our 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, we 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.

Dental:

Our Restorative service is back up and running, but with increased necessity for AGP's, there are longer wait times between patients.

The paediatric dental service is currently down 1 full time consultant paediatric dentist. 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 orthodontic 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.

LK verbal report: Mixed picture-GOSH close to normal; Broomfield heavily affected by COVID and continues to struggle; primary surgery is up to date but 18 children have been

transferred to GOSH for surgery, which is a big hit as Broomfield only does about 40 primaries per year; ABG's are on target and just starting speech surgery. Adult surgery is yet to recommence at Broomfield or the Royal London Hospital. One CNS has left. At GOSH psychology has been affected as unable to have a psychologist sitting in the clinic and have to refer patients for psychology and this is due to funding cuts. The paediatric dentist at Broomfield has left, which is severely impacting on CRANE submissions. Furthermore Broomfield are down one administrator who is responsible for submitting CRANE data, so they will struggle to meet the CRANE data submission deadline and we are asking the Trust to help us out.

VH - It is a concern for the CEN that psychology at GOSH has been reduced to the current situation and she feels that this will mean that GOSH will not be able to meet the national service specification or the minimum audit standards or what is about to be the clinical psychologists requirements for CRANE by just accepting referrals. VH feels that this is a huge loss and such a shame as GOSH a few years ago had a large psychology department so this is a big change. LK replied that they communicate regularly with Jo Shearer (Cleft clinical psychologist) about this and at the moment there is no end in sight but Norman Hay is constantly working to improve this. SvE pointed out that this issue would ideally be flagged up as a lack of audit data and failure to meet the quality dashboard standards and this could be possibly used to pressurise commissioners to raise additional resource. LK requested that SvE and VH write a letter to assist Norman Hay restore funding for the psychology service at GOSH. SvE re-iterated the fact that the lack of data reflected on the quality dashboard is a powerful tool that should be used as a lever to get more resource; this also goes for the issues GOSH has with paediatric dentistry and the lack of data submission. SvE emphasised that this is what CDG should be helping with. LK will draft an email to connect SvE with NH regarding this. IU commented that this is a common issue where the trusts are split over different departments and not under a cleft umbrella; there is the same problem in Birmingham with psychology and speech where you are split over different departments and funding isn't very clear. SvE said that these are the sorts of issues that should be highlighted to Anthony Prudoe and although we have been focussing on the delivery of surgery these issues have a major effect on the delivery of care for cleft patients. IU volunteered her involvement with that of the West Midlands cleft psychologist to LK and felt that working together might present a stronger case as this is something West midlands is constantly struggling with. SD Mentioned that Broomfield does have a representative collecting the audiological data but as there is no-one currently at Broomfield to submit this data to there will be a knock on effect on the QD submissions. This is the first that LK has heard about this. SvE encouraged LK to use this to advantage when it is flagged up on the QD.

Spires Cleft Lip & Palate Network (GP)

Following the loss of three nurse positions, Spires have recruited a lead nurse, and a band 7 nurse in Salisbury, so back up to establishment. We have also been successful in job matching the nursing posts to band 7, which is a step forward in recognising the role that the CNSs have in the speciality team. There are regular theatre lists in both Oxford and Salisbury working on similar priorities to others, with more capacity in Oxford than in Salisbury. Currently Spires is at the upper end of the age brackets for primary surgery and there is a backlog for alveolar bone grafts, and are just beginning to look at Orthognathic surgery for this summer and looking at these in appliances. There is no other adult surgery happening now.

Surgeons have recently met with the Operational Delivery Network representatives in Children's' surgery for Thames Valley and Wessex, which is hoped to help with backlog and pre-covid capacity issues.

Face to face clinics are increasing, but virtual is retained where valuable and to reduce the burden on families as much as possible. Community services vary, particularly in SLT depending on local recovery plans.
The surgical fellow application is currently being finalised.

South Thames Cleft Service (NB)

Paediatric lists are doing well, but adult lists continue to be sparse. Alveolar bone grafts recommenced this week and prioritising long waiters. Dental (orthodontics and paediatric dentistry) have started back on a face-to-face basis. `For PD length of appointments and fallow time for AGP's is a problem. STCS is aware of issues with CRANE consent and is currently trying to address this. MDT clinics are working on a hybrid model. Audit clinics are yet to reopen. Outreach clinics are now face-to-face. There are 3 maternity leaves due to start shortly, one being a surgeon and a maternity locum was appointed last week.

South West Cleft Service (ACo)

The network are currently carrying out one Adult Rhinoplasty / lip revision over the last 4 weeks and 2 paediatric cases per week over the last few months. Age at treatment currently remains the same. 3 patients have chosen to go to Newcastle and we have suggested that they do that as a transferring care package and then SWCS will take back into the service as if they have moved into the region, but with support from South West nursing and other members of the team appropriately.
AC said that Covid has exposed SWCT's structure – they don't have robust systems and these are failing now. This has been partly due to the move from Frenchay hospital to the children's hospital, which has caused issues (other services such as neurosurgery have also had problems with the move) and partly due to the end of what he called "gentalperson agreements" because of retirements -there speech therapists and psychologists throughout the region who continued in the role they had in the unit at Frenchay but now that they are retiring those roles are not being reappointed by local partner trusts; this is particularly problematic with private contract holders such as Virgin who didn't include the SWCT in their contracts.. County boundaries are also causing issues in that a patient from one county cannot be seen by a team from an adjacent county. There has been a decrease in community SLT provision, which is worsening. This means that SWCS cannot rely on them to deliver speech and language therapy locally meaning that this will have to be delivered in Bristol where there is already a limit on the number of therapy sessions allowed per child. The trust is listening now as a result of the e-mail sent to the medical director by SvE and this was discussed at trust board level; AC thanked SvE for this. The evidence that has been collected through the CD group and outcomes through CRANE has been crucial and has come as a shock to the board.
Anthony Prudoe has put AC in touch with commissioners and AC will continue to try to address the issues with what is a failing service; were first put in touch with the regional ODN, Angela Clawson, and have had several meetings regarding SLT contracts and service provision. Her line manager is however focussed on RTT pathways and has difficulty understanding timed surgical protocols meaning that there is a constant need for re-education. All private operating opportunities have evaporated as a result of the cleft block contract and the surgical fee structure, which differs for example to that of maxilla-facial where the fee charged for a particular procedure is a lot less for cleft than it is for maxillofacial for the same procedure. This is very frustrating and has resulted in missed opportunity for doing orthognathic surgery and rhinoplasties in the private sector.
Clinics are operating on a hybrid model, with the plan to continue with virtual where possible. Face to fae clinics have resumed in Bristol and will be resuming in Derriford

soon. The geography of the region is difficult and audit clinics undertaken in 6 different centres is causing issues for resuming the service. The network is about to be down two orthodontists and we are looking ways of potentially managing this in discussion with Jules Scott. Possible options are to run a hybrid model using facilities at another centre to provide the necessary services and older children operating (eg ABG's) as an interim solution. Also currently looking at the non-cleft VPD referrals and PRS CNS involvement as this does not specifically form part of the original service specification and whether another surgeon is needed?

The Welsh Centre for Cleft Lip and Palate (HE)

The network is now able to secure weekly surgical lists-have 4 lists per month down from 6. Commissioners have supported the network in obtaining surgical sessions-commissioners escalated the issue to the Welsh government and the government told HW that they had to provide surgical sessions. There are 4 Saturday lists in Cardiff (Speech and alveolar bone graft). Within own health board have secured extra Saturday lists to do isolated lip surgery and have one list for ABGs and speech surgery. Most of the patients have been populated up until July, with only a few patients on the waiting list; are hopeful that these will now be seen within tusual protocols. Orthognathic adult work has recommenced via maxillofacial lists. The network has begun discussion regarding the outsourcing of rhinoplasties and lip revision work, and more discussion is needed for outsourcing speech surgery that need to be undertaken at Morriston Hospital.
Regular MDTs for all specialties have recommenced. There are some difficulties with room space for psychology in Cardiff but can see 5 patients on the MDT. Audit has now started again and dental and orthodontics are catching up and they are regularly seeing patients face-to-face. Virtual appointments are continuing in SLT and Psychology but face-to-face appointments are taking place when required.
Staffing has been stable. Have additions in SLT having appointed a band 6 SLT (O.6) therapist, and a band 4 SLT (0.5) assistant. In psychology we replaced an existing post and have had a 0.8 band 5 assistant and a 0.5 band 5 assistant join the team and have a 0.5 band 8 psychology post vacant and are looking to recruit to this. Staff continue with hybrid working but a few are looking forward to returning to the office.
In summary Wales are in a better position but still need to fight for adult surgery.
HR asked whether the Saturday lip only cases were day stay; HE answered that they were overnight stays.

Northern Ireland (EOc)

Northern Ireland have had a very low birth rate so far which has helped with catching up on surgery. Chris Hill is currently working 50% capacity as he has lost Monday pm surgery slot. Currently at upper age limit for primary palate repairs and lips.
ABG has resumed in NI following a break due to training of a new surgeon– have currently 38 waiting. NI now have regional ABG clinics that has been set up in the last year coordinated by 2 Consultant Orthodontists and a Maxillofacial surgeon. They have received positive feedback from all service users involved. Unfortunately they have insufficient funding to employ a regional cleft orthodontist, but are looking into requesting funds from a variety of sources. Surgeon Chris Hill has been off work following an accident but is thankfully now back.
A new dentist, Catherine McCann has joined from Glasgow Cleft service. Now able to run clinics as required, which was not possible in the recent past because of staffing shortages. The network has obtained funding for a Cleft Psychologist, however due to a lack of accommodation, the post cannot be advertised.

	FTF MDT clinics have been running since July 2020 on a carousel model and all in OPD to reduce footfall through the hospital. Early intervention clinics are due to start in July/August 2021.
7. Feedback from CEN's	**<u>Nursing CEN (HR)</u>** There have been some changes in lead nurses within networks, which has led to some reluctance to change roles within the CEN. HR is taking on both the lead of the Nurses CEN and of the Nurses lead group, which is putting her under pressure. In terms of research, Ian Bruce met with the Lead nurses to discuss the SLUMBRS 2 project, which is ready to roll out in June- all the networks are participating and the North West will be the first to take on the project because they were involved in the feasibility study 2 years ago. **<u>ENT & Audiology SIG (SD)</u>** The CEN have met twice on 10th February and the 23rd of April. The network has a project operating across all the centres collecting 5 year data to produce a paper assessing if 5 year data is of any use. The CEN now has representatives from all but one centre across Great Britain, but are still missing representation from NI and the Republic of Ireland. There are concerns regarding the data collected for the Quality Dashboard, including that it may not be 'clean' data that is being submitted. There are concerns about the ENT and audiology data collected on CRANE mainly in terms of the support that will be required as in order to be able to enter the data correctly a detailed understanding is needed of all the different kinds of audiology tests that can be undertaken and the different clinical findings when examining an ear; this will require extensive admin support and training as the CEN members will not have the time to enter the data onto CRANE themselves. This Admin training and support will have to be undertaken and agreed before data can be entered and CDs will have to be on board in terms of supporting that, which will of course require extra time and funding. **<u>Surgical CEN (GT)</u>** Dates and topics are being finalised for the Surgical CEN meeting, with the aim to meet either side of the CFSGBI meeting in September. The meeting that was meant to take place in the Spring had to be postponed because of covid pressures. **<u>Psychology CEN (VH)</u>** The CEN are midway through their calibration for TIMs score, which is the involvement measure recorded at MDTs and this links to the audit data. There is a lot of activity around school change as all the teams address this a little differently and there is now a national pack of resources that is available to send out to all children in Year 6 coming up to secondary school. There has been a lot of concern raised by children and adults about integrating back as we move out of Covid and the removal of facemasks post Covid. For those with anxiety about appearance there is relief of this when wearing a face mask and going back to not wearing masks will be difficult for a lot of people. This is particularly relevant for year 7s who have moved up to secondary school during the pandemic and have most probably been wearing face masks since starting – this is then a big issue for these children. This issue has also been flagged up by adults. **<u>Speech and Language Therapy CEN</u>** SLT CEN feedback was provided via the report from Lorraine Britton.

	<u>Paediatric Dentistry CEN (NB)</u> Calibration took place in January and the next is due provisionally on 25th August 2021. The CEN is due to meet on 16th June. The CEN are trying to do national audits where viable. The new Paediatric Dentistry CEN lead is Joanna May and was unable to attend this meeting as she was on leave and NB was asked to step in. **<u>Orthodontic CEN (JS)</u>** Thanks to SvEs suggestions the CEN have had two leads meetings. Most services are returning to some semblance of normal but with some issues with capacity particularly around social distancing, down time between surgeries, issues of patients not wanting to attend as they are fearful of coming into a hospital setting and theatre space for ABGs and osteotomies. There has been separate work done on the delay to cleft osteotomies and at the Leads meeting it was felt that this is a wider issue and relates not only to cleft patients but to osteotomies in general; this needs thinking about and JS feels that data collection on numbers, waiting times and impact would be useful-this can then be taken to BAOMS and BOS highlighting our concerns and perhaps this could then be taken to a bigger forum. A virtual CEN meeting is due to take place on 25th June. The meeting will include Audit updates, presentations for Cleft 2022, and also to get members to respond to the Delphi, which has been dragging on. **<u>Restorative Dentistry CEN (SP)</u>** The CEN are due to meet in June 2021. They had a successful National Conference, which had a morning session dedicated to cleft, with over 500 delegates. The CEN have lost their secretary and are now looking to recruit. **<u>Managers Group and CD Group(SvE)</u>** The CDs have met with Anthony Prudhoe to discuss surgical prioritisation. SvE felt that it would be beneficial for the group to continue meeting on a regular basis to discuss centre differences and resourcing issues; SvE suggested discussing this with Peter Hodgkinson, the CD lead. SvE requested that the CDG reach out to their CDs to establish a lead for the Managers Group as Yvette Edwards who had previously represented this group has left cleft. **<u>Action 28/0/05/21: 5.1</u>** – CDG members are to contact their CDs to establish a Lead for the Cleft Centres Managers Group and feedback to SvE.
8. COVID 19 update	**<u>Surgical Backlog</u>** Centres have reported on current status so SvE felt that there was no need to revisit this. SvE received an email from Alex Cash, via the Royal College of Surgeons of England, regarding the paediatric surgical backlog. The email suggested that the lay public should be involved with lobbying different NHS Trusts to prioritise childrens' operating. SvE reported that he resisted this at the time as after meetings with Anthony Prudoe access to theatres for cleft was improving and what we didn't want was to do anything that would raise anxiety across the country by the highlighting differences that might exist between Trusts and in so doing possibly encourage patients to choose one unit over another. I therefore held off until this meeting to get CDGs opinion rather than making a unilateral decision.

	YW feedback on a query that she has had: Aside from cleft YW has been involved in interviews and writing articles about the impact of lockdown on Speech and Language Development via several media outlets. As a follow on from this YW was asked if there were any other areas of interest and she raised cleft in a general sense. The media then asked about the impact covid has had on delays to surgery and in discussion with SvE we decided that this wasn't a good route to go at that point in time. It has since gone quite but if there are any messages we would want to get out, there is a potential route we can use to do this. YW highlighted that this could be an opportunity to use these media outlets as a platform for highlighting cleft issues (e.g. anxiety around the removal of face masks post covid). YW also highlighted the way in which an article that she wrote that provided a balanced view was changed to reflect the medias agenda and cautioned that this is always the danger. YW's agenda for doing this is to raise awareness about cleft generally to emphasise that there are issues beyond the first operation. SvE concurred saying that one of the considerations and concerns at the time was the lack of editorial control on anything submitted to the media for publication. YW said that it was better to do a live interview as it was easier to shape the answer. SvE asked for any comments or queries about these issues: GP shared concerns about raising anxiety levels but also wondered whether CLAPA is a better route of engagement for highlighting these issues and provides a safety net. SvE did share that CC was copied into the correspondence between YW and SvE about this, and CC concurred with our opinion as highlighted previously. VH agrees it is important to share that there are reasons why children and adults with clefts might be more at risk of anxiety but would be concerned that this might be emphasised out of context and that the real issue of getting services back up and running might be missed. SvE read out the email from the RCSEng. AC replied that it is difficult to ensure that the public understands who the gatekeepers are about access to services and that media articles in relation to Bristol are often prefaced with the previous Bristol heart issues. FM agrees with point about anxiety and destabilising the situation by moving patients around the country but wondered if there was any value in presenting national data and saying these are the maths; this is our backlog, this is our capacity and something needs to be done to address it without going to granular and this might then raise the issue but at a more distant level? AC agreed that this would be ideal but wondered if there was a risk that Trusts would prevent local data from entering the national domain? SvE agreed that getting national data was important and that this was something that CR and CRANE were going to work on to find out where the issues were and suggested that once this data was available that it should be brought back to CDG for discussion. These issues could then possibly be highlighted more generally through the media without specific mention of local units? FM emphasised that cleft needs to be careful of being left behind other specialities who were highlighting their issues and if cleft were not it might give the impression that cleft was fine. **<u>Surgical Prioritisation</u>** SvE highlighted the work that VH and the Psychology CEN have done on the risks associated from the delay of lip repair surgery, and the Orthodontic CEN Report (especially TG and JS) on the risks associated with delayed alveolar bone graft surgery in the mixed dentition, and the ongoing work being done on delays to orthognathic surgery by JS, GT and VH.

	VH fedback to say that as the orthodontic CEN feel that orthognathics is a wider issue, the Psychological CEN paper is going to be a combined paper on concerns about delayed secondary surgery, namely rhinoplasty and osteotomies, from a psychological perspective and this can be added to the previous paper about delayed primary surgery. SvE felt that this was an important perspective but added that the orthodontic perspective about ongoing damage to teeth in those waiting prolonged time for surgery in appliances, and the loss of patients from treatment that have had to be debonded because of the delay to surgery should be heard. JS replied saying that here were reports at the Leads meeting that there are patients that have decided to discontinue orthognathic treatment because of the delays. JS also said that debonding these patients once decompensated puts them in much worse position in terms of appearance and function than they were before treatment, which is also anxiety provoking-it would therefore be useful to get data on this looking at patients that have changed their minds or who have transferred to a different unit and the length of time the treatment has taken.
9. Quality Improvement and monitoring committee	**<u>Member Update</u>** SvE has heard back from the ENT and audilogy group and they have nominated 2 members who will take turns to attend meetings; SLT have nominated Siobhan McMahon and HR will be representing nursing. SvE is awaiting representative nominations from CLAPA, CFSGBI, Surgical CEN, Psychology CEN, Orthodontic CEN, Restorative Dentistry CEN, the CD group and the Managers group. SvE requested that those still to provide a representative are to contact him. **<u>Leeds Update</u>** The Leeds review team was established soon after the last CDG meeting and comprises 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. SvE has had some oversight and CDG thanked the review team from the Leeds Review, which has been time consuming. CR has also been very helpful and active and has supplied the mitigating data to the review. It has been agreed that the new CRANE data should be shared with Leeds and SvE reassured that the data would be available to the Leeds team. SvE requested the CDG to prepare feedback on the adjusted CDG ToR for discussion during the next meeting as there is not enough time today. SvE re-iterated that this is an important public document that needs to be ratified. **<u>Action 28/0/05/21: 8.1</u>** - CLAPA, CFSGBI, Surgical CEN, Psychology CEN, Orthodontic CEN, Restorative Dentistry CEN, and the Managers group are to contact SvE regarding representatives for the Quality Improvement and monitoring committee **<u>Action 28/0/05/21: 8.2</u> –** CDG are to prepare any feedback on the adjusted CDG ToR for discussion at the next meeting
10. Research	**<u>Bristol-Cleft Collective</u>** An update report was circulated prior to the meeting. YW thanked all for helping with this research.

	Cleft Multidisciplinary Collaborative / Early Career Researchers Group Met in March across the MDT-had radiology reporting for example looking at 3D MRI foetal scanning. An update report was circulated prior to the meeting **Clinical Studies Group (SK)** The group have recently reviewed their ongoing studies (as circulated prior to the meeting). 6 of these studies have come to fruition with results published and disseminated; there are 30 studies that are still ongoing. The group have welcomed 2 new clinical members and 3 new dynamic PPI members. The group have received 4 new submissions for studies, 2 of which were covid related. It is important for CDG to know that previously the Scar Free Foundation and the CFSBGI provided matched funding to the Clinical Studies Group to provide admin support and facilitate meetings. This funding has now expired without the option to renew. This is not a reflection on the CSG but is because the CSG sits under The NIHR, which is administrated by the University of Liverpool and they have not been accountable for the grant funding and are yet to feedback to the funders. Rhona Slator and now SK have been working tirelessly to try and sort out the funding issues and the CSG have met with the Scar Free Foundation and CFSGBI to discuss creative ways forward because it is important that Cleft research has NIHR recognition. FM added that the CFSGBI are looking at ways to try to support the CSG and establish if there are alternatives to the current structure within NIHR and she recognised the hard work that Rhona Slator previously and SK presently have done to try and sort out the funding and get NIHR transparency. SK thanked FM for her support. HR asked for the SLUMBRS study to be added to the standing research agenda?
11. Quality Dashboard	See under CRANE report above.
12. CFSGBI Feedback	Mechelle Collard has handed over to FM; she stayed on for an extended period because of the pandemic and clearly the pandemic has changed plans for both the Cardiff conference and the Edinburgh conference. FM provided an update on CFSGBI. FM thanked Mechelle Collard for her time as President of the CFSGBI. The Cardiff 2021 conference will take place virtually on 9th & 10th September; Michelle did a good job on reclaiming much of the deposits, but a financial hit has been taken for both conferences as CFSGBI has had to change the bookings. The AGM will be held virtually on 9th September. The Edinburgh 2022 conference will take place on 11-15th July 2022. On the run up to the conference there will be free webinars on a bi-monthly basis. The new CFSBGI website will hopefully be launched in September, with the aim to make it better value to members. There is a survey of the members asking them what they would want from the website and FM is keen to hear feedback from the CEN chairs on what they would like to see more of from the society. FM requested the CEN chairs to contact the CFSGBI administrator Grant Davies-Ratcliff regarding any changes to CEN chairs. FM asked CDG members to feedback to her if there was anything that they would like the CFSGBI to be doing and she provided her email address on the meeting chat. **Action 28/0/05/21: 11.1** – Current CEN chairs are to contact Grant Davies-Ratcliff regarding any changed to CEN chairs.
13. Training	SvE noted that NT was not present and that he hadn't received an apology from her. SvE asked VB if she could feedback from TIG as she is currently on TIG. VB provided on update on the TIG fellowships. The next training meeting is due to take place in July. There were two trainees appointed during the last round of appointments (3 shortlisted): one appointed to South Thames and the other to Scotland and they will be

	staring in August. One TIG trainee is due to finish in the coming months subject to appointment to a consultant post. Going forward there will be a move to a post-CCT fellowship; currently in an interim period at the moment while the change over from pre-CCT fellowships to post-CCT fellowships takes place. Louise Ferguson will be taking over the chair of the Cleft TIG and this will be effective from the next meeting; this might be delayed as she may have some time off soon. SvE explained that the TIG chair rotates amongst the specialities and that the TIG chair was due to come from ENT, which Louisa Ferguson is. SvE added that Health Education England will provide funding for the post-CCT fellowships and added that the post-CCT might enable more to apply as in the past some have missed out on TIG application as their CCTs became due before interviews occurred. VB added that the expectation was however that applications would come from those having recently achieved CCT and not necessarily from long-standing consultants.
14. Any other business – CDG & dates of next meeting	VB raised an issue related to a patient's father refusing to comply with Covid rules while their child is in hospital for surgery and asked if anyone on CDG had similar experiences. GT described similar issues and described ways in which they were trying to mitigate for this and still look after the child. VB said she was going to take advice from her defence organisation as she is unsure how she is going to be able to provide care for this patient under the circumstances. YW: The Cleft Collective have been successful in obtaining research funding to explore the potential for an adolescent clinic for the CCUK children as they approach the end of their care pathway. This is currently exploratory and the CC wants to hear back from the CENs and Leads to find out what should be done. They will be looking to recruit for this shortly (band 7, two days a week for 9 months or something similar) and will be seeking an individual with cleft experience. YW asked the CDG to share this within their teams. SvE asked CDG about the number of meetings they would like per year as previously agreed to have bi-annual meetings, but this was changed to 3 during Covid. CDG would like to continue with 3 per year. The next meeting of the Cleft Development Group will take place virtually on Monday 4th October 2021 (9am-1pm).

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Actions from Cleft Development Group meeting: 28th June 2021	Owner	Due Date
Action 28/0/05/21: 3.1 – CDG are to consider CDG Deputy Chair nominees, for discussion during the next meeting.	CDG	4th October 2021
Action 28/0/05/21: 5.1 – CDG members are to contact CDs to establish a Lead for the Cleft Centres Managers Group and feedback to SvE.	CDG	Summer 2021
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	CDG	Summer 2021
Action 28/0/05/21: 8.2 – CDG are to prepare any feedback on the adjusted CDG ToR for discussion at the next meeting	CDG	4th October 2021

Action 28/0/05/21: 11.1 – Current CEN chairs are to contact Grant Davies-Ratcliff regarding any changes to CEN chairs.	CDG	Summer 2021