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

Venue: Microsoft Teams conference call

Date & Time: Monday 27th November 2023 – 9:00 to 14:00

Present	Simon van Eeden (SvE) Chair	Cleft Development Group Chair
	Melanie Bowden	President of CFSGBI
	Sophie Butterworth(SB)	Chair of the early career researchers group
	Alistair Cobb	Clinical Director, South West Cleft Service
	Peri Codling (PC)	Clinical Lead, Cleft Net East
	Rebecca Crawford (RC)	Clinical Psychology CEN Lead
	Chris Couhig (CCo)	Chair of the lead nurse group.
	Claire Cunniffe (CCu)	CLAPA Chief Executive
	Helen Extence (HE)	Clinical Director, The Welsh Cleft Lip and Palate Unit
	Peter Hodgkinson (PH)	Clinical Lead, Newcastle Site, Northern & Yorkshire Cleft Service
	Kate Le Marechal (KLM)	Clinical Director, Evelina London Cleft Service
	Joanna May (JM)	Paediatric Dentistry CEN Chair
	Gillian McCarthy(GM)	from CLAPA, representing the Patient engagement group.
	Eilish OConnor (EO)	Representing the Northern Ireland Cleft Service
	Ginette Phippen (GP)	Representing the PEG Group
	Sandip Popat (SP)	Restorative CEN Chair
	Anthony Prudhoe (AP)	National Senior Programme of Care Manager, Specialised Services: Women and Children's Programme of Care
	Helen Robson (HR)	SLUMBRS representative
	Patricia Rorrison (PR)	Clinical Director, North Thames Cleft Service
	Craig Russell (CR)	CRANE Clinical Project Lead and Scottish Cleft Service
	Heather Sahunta (HS)	Cleft Nursing CEN Chair
	Julia Scott (JS)	Orthodontic CEN Lead
	Jill Scotson(JS)	Representing the Management CEN
	Marc Swan(MS)	Clinical Director, The Spire Cleft Service
	Chris Sweet (CS)	Clinical Director, North West, IoM & North Wales Cleft Network
	Guy Thorburn(GT)	Representing the Surgical CEN
	Imogen Underwood (IU)	SLT CEN and Lead Groups and West Midlands Cleft Service
	Yvonne Wren (YW)	Chief Investigator, Cleft Collective
	Antonia Yiakumetti (AY)	Patient Engagement Group Representative
In Attendance	No-one in attendence from…	Clinical Effectiveness Unit, Royal College of Surgeons of England
Apologies	David Drake	Lead Clinician for Cleft Care Scotland
	Chris Hill	Clinical Director, Northern Ireland Cleft Service
	David Orr	Plastic surgeon and cleft surgeon, Dublin Cleft Centre
	Alistair Smyth	Clinical Lead, Leeds Site, Northern and Yorkshire Cleft Service
	David Sainsbury (DS)	Representative for The British Association of Plastic, Reconstructive and Aesthetic Surgeons
	Sarah Kilcoyne (SK)	Chair, NIHR Clinical Studies Group of Cleft and Craniofacial Anomalies
	Khurram Khan (KK)	Clinical Director, West Midlands Cleft Service
	Toby Gillgrass(TG)	Lead Clinician, Scotland
	Louisa Ferguson (LF)	Chair of the Cleft Training Interface Group
	Sinead Davis (SD)	ENT & Audiology CEN Chair

<table>
<tr><th colspan="2">Item</th><th>Notes</th></tr>
<tr><td>1.</td><td>Apologies, absence and welcome to new members and invitees</td><td>The chair (SvE) welcomed the Cleft Development Group (CDG) to the meeting. The group joined the meeting via Microsoft Teams teleconference. Apologies were given for those unable to attend (see above). All attendees introduced themselves.</td></tr>
<tr><td>2.</td><td>Minutes of the Cleft Development Group meeting, 12 May 2023</td><td>The minutes of the CDG meeting on 12th May 2023 were screen shared and SvE asked for approval as the minutes had been circulated prior to the meeting-approval was confirmed by CDG.</td></tr>
<tr><td>3.</td><td>Matters arising</td><td>
<table>
<tr><th>Actions from Cleft Development Group meeting: 12th May 2023</th><th>Owner</th><th>Due Date</th></tr>
<tr><td><u>Action 12/05/23:3.1:</u> AP will talk to Harry Lewis after the meeting and provide CC with information on how people affected with cleft across the UK can access information and be supported by nationwide organisations when cleft service is managed locally?</td><td>AP</td><td>27/11/2023</td></tr>
<tr><td><u>Action 12/05/23:3.2:</u> There seems to be a disconnect between the proposal, the current actions, and the involvement of patient and public voice. AP is going to speak to the engagement team and NHS England about the signalled impression of disconnect between the proposal, the current actions and the involvement of patient and public voice, and update CC and AS.</td><td>AP</td><td>27/11/2023</td></tr>
<tr><td><u>Action 12/05/23:8.1:</u> The CEN leads and the CDs will go back to their groups and teams to see if there were any willing volunteers to sit on the steering group and that this could be finalised at the next meeting-To be discussed under the steering group agenda item.</td><td>CEN leads/CDs</td><td>27/11/2023</td></tr>
<tr><td><u>Action 12/05/23:9.1:</u> Reasons of variability of outcomes in speech and dental outcomes across the country will be discussed at the next QMIC meeting-To be discussed under the QMIC agenda item..</td><td>SvE/CR</td><td>27/11/2023</td></tr>
<tr><td><u>Action 12/05/23:15.1:</u> CDG members to send nominations for the new CDG chair to SvE before the next CDG meeting-To be discussed under the CDG chair agenda item..</td><td>CDG Members</td><td>27/11/2023</td></tr>
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<tr><td>4.</td><td>CDG Patient Engagement Group (PEG)</td><td>GM fed back from the PEG:
PEG meets monthly now;
First topic GM fedback on was about self-referrals, which has been an ongoing discussion; the ideal scenario for adults, to improve access to treatment, is to have a self-referral form, which some teams offer but the majority of teams don't. GM felt that the Cleft Net East model, which is a compromise but has gone down really well with the patients might be a model that other cleft teams could adopt? She explained that they have modified their previous referral form and have made it easily accessible on their cleft team website with an email address on it for it to be returned too. GM said that a patient could fill in or at least know the questions before they contact their GP or dentist to at least have the answers ready and then have it signed by the GP and/or the dentist. Patients</td></tr>
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	have to add some information, and this addresses some of the concerns that some cleft teams have about self-referrals. Patients reported that after looking at the Cleft Net East form that it was easy to fill in and it also means that patients won't necessarily need to have an appointment with the GP to get this filled in. It might be something that could be done over a telephone appointment or possibly via email correspondence depending on the GP or the dentist. All on the PEG felt that that was a good alternative to having a self-referral form. GM asked if CDs could look at the Cleft Net East website to see if this could be a possible alternative to self-referral. The PEG quoted examples of adult returners having real difficulty getting timely referral to the correct cleft team wasting both patient and NHS time. GM also asked if cleft teams would consider having a PPI link person that she could link in with in order to have conversations about the issues raised by the PEG so that the delays between decisions at CDG meetings could be improved and to make it easier for GM to contact cleft teams directly. She suggested that it could possibly be the cleft team co-ordinator in each team but could also be any of the cleft professionals. GM also asked whether there was anything that as a group CDG would like the the patient engagement group to be considering thinking about or responding to for the CDG? SvE thanked GM for her feedback and agreed that GMs suggestions sounded like good ideas; he then asked if the CDs had any comments on GMs suggestions and invited PC from Cleft NetEast to comment on the form developed by Cleft NetEast? PC: The form is available on our website.and can be downloaded by the GP or the patient. The form needs to be discussed with the GP, so that they can fill it out or alternatively the patient can fill the form out themselves, download it and just ask the GP to sanction it. This means that there is a paper trail which clearly shows what the patients issues are with GP oversight; this has been used for three months and is working really well. This was also discussed at the recent TRICENTRE meeting and the idea was positively embraced. SvE thanked PC for her summary and asked for comment. MS: He reported that after a lot of discussion at Spires the network are now distinguishing between adult returners from their own service and new referrals to their network. The former are able to self-refer either via the Spire website or via their GDP or GP. The latter group who are new to their service, would need to be referred by their GP or GDP and this has been made clear on their website. This distinction has been made as they feel it is necessary to have background information for new patients that the GP or GDP provide. MS did go onto say that he does like the idea of a referral form that the patient can use and take to their GP to facilitate the referral as he does appreciate that it can be quite a painful process getting a referral to a cleft team. AY felt that the form was a good idea and went onto give a recent example that came up on the CLAPA Facebook group for patients, of an adult patient who had difficulty getting referral to a cleft team and as a result ended up seeking help in the private sector-she felt that a referral form could avoid these difficulties. SvE asked PC if she could share the Cleft NetEast form so that CDs could discuss this with their teams and make any changes they thought appropriate to their service. PC agreed to share the form. When SvE then asked the CDs to liaise with GM about a PPI representative the CDs marked their affirmation with "nodding heads". HE asked GM if they were the only service offering referral to patients via a telephone call to the unit? GM thought that NI and Scotland did the same and went onto say that the PEG felt that this was the ideal scenario meaning that the patient is able to contact the cleft team directly and self-refer whether it's via a form, email or a phone call - whatever is best for those individuals. GM felt that if teams weren't able to adopt this approach then the Cleft Net East form is a good alternative.

	KLM posted the Cleft Net East form in the meeting chat room for all CDs to access. SvE then moved onto GMs third point about feedback from the CDG by asking if there was anything that members of the CDG would like specifically to have discussed by the PEG and fed back to CDG? As there was no immediate discussion SvE suggested that members of the CDG contact either GM or HR if there was anything that they would like discussed in the patient engagement group.
5. Matters arising specific to AP and discussion about the ICBs and the national cleft specification.	SvE welcomed AP to the meeting and returned to the matters arising as AP was not present at the start of the meeting and he screenshared the matters arising pertinent to AP: Action 12/05/23:3.1: AP will talk to Harry Lewis after the meeting and provide CC with information on how people affected with cleft across the UK can access information and be supported by nationwide organisations when cleft service is managed locally? Action 12/05/23:3.2: There seems to be a disconnect between the proposal, the current actions, and the involvement of patient and public voice. AP is going to speak to the engagement team and NHS England about the signalled impression of disconnect between the proposal, the current actions and the involvement of patient and public voice, and update CC and AS. SvE asked AP if these actions had been addressed? AP replied saying that in terms of the development of integrated care boards, that the work is still happening and that patient and public voice representation is place but that this is not necessarily specific to any particular patient group. At the moment, AP thinks there's still work that needs to be done on this in terms of the relationship between this group and the patient and public representatives within this group and the clinical reference group. AP says that if we are to influence integrated care systems, then there will need to be closer relationship between this group i.e CDG and the clinical reference group. By doing this then the views of this clinical group and the patient and public voice representation within it then has a formal link to the NHS. AP asked if Sally Cavanagh (NHS Commissioner) had asked SvE as Chair of the CDG to be a member CRG? SvE replied in the affirmative but went on to say that he had explained to her that as this was his last meeting as chair the invitation would need to be extended to the incoming chair to be decided on later in today's meeting. AP re-iterated the importance of the next CDG chair joining the CRG as they would need to be involved in formation of the cleft service specification working group. AP went onto say that cleft services will be delegated to ICBs but that there are still opportunities to talk to ICBs about the standards for cleft services. He feels that this is an opportunity to refresh the service specification and at the same time have a broader discussion about its rollout once it is finished. The other important issue is about the patient and public voice input into of the service specification review and AP acknowledged that the PPI involvement within the CDG could be part of that service specification review. AP informed the CDG that he is having very high level discussions with integrated care systems but is not having detailed conversations with the integrated care systems at the moment in relation to cleft and a number of other services. He explained that the integrated care systems across England have self-assessed themselves with regards to their readiness to actually receive and to manage delegated services and the output of that self-assessment will be presented to the NHS England board in December of this year meaning that at this point in time we actually don't know what the landscape is going to look like in terms of integrated care systems and their readiness for delegation. What they do however know is that a number of integrated care systems will probably not be ready for delegation by April 2024 and that there will be another period of time

	to enable those integrated care systems that are not ready to get ready by April 2025. There are therefore still quite a lot of unknowns which will hopefully become clearer after the board meeting in December. SvE thanked AP for his explanation. CR felt that the invitation of the CDG chair to join the CRG is a big step forward from CRANE perspective especially from a funding point of view as it is as it is the CDG that is ultimately responsible for the funding of CRANE and this has been a been struggle for many years. SvE agreed and informed the CDG that as the Chair of CDG he had previously applied for membership of the CRG but his application had been unsuccessful. CC asked how it would work with regard to the service specification if some of the ICBs moved to delegation earlier than others meaning that some would be then working under local specifications and others still under national specifications? AP explained that regardless of who is commissioning the service, whether it's NHS England or integrated care boards, all of the cleft services will be subject to the national service specification meaning that the specification is there to be delivered regardless of who's commissioning the service. There will always be a single service specification for the service and NHS England remains responsible for the service specification and the update of its standards. He went onto explain that ICBs will eventually be responsible for the commissioning of cleft services but that in the current system it is the regional teams that commission cleft services and it is not the national team that commissions these services. AP did admit that he nor others knew what it would mean in practice if some ICBs are ready and others are not. He informed the CDG that this information would come through as part of the road map linked to delegation. PH asked AP if there was a disconnect between local needs and interpretation of the specification to suit these by ICBs which means deciding on and following a local specification rather than a national one? AP replied saying that national service specifications for all specialised services will remain national, and that they're not up for tinkering with and those service specifications will still be inside NHS Trust contracts and are not open to negotiation; but how local services go about delivering the service specifications and the configuration of community services, hospital services, specialised services working together will be down to integrated care systems and integrated care boards -the actual standards that we expect from the service will remain fixed. PH felt however that this may mean, as has happened in the past that some services will be disadvantaged depending on the priorities within the local integrated service; he went on to say that this new system had been brought in by NHS England without local consultation and without determining whether this can be run locally-discussions that he has had locally is that many have yet to understand this new system; he went onto say that as a cleft community we found out about these changes accidentally and he suspects that many other services still do not know about the changes and wondered whether these services are being brought on board or whether they are going to find out in 2025 when the new framework is about to start. AP explained that the ICBs and integrated care systems will be responsible for the bulk of commissioning including hospital based services, tertiary based services and community based services and these systems will be responsible for gluing all of that together. AP went onto say that he does know that the staff within the integrated care systems and integrated care boards are working with hospital systems and community based systems as part of integration and that this will take time to roll out and consolidate. AP admitted that this is a move away from specialised commissioning brought in in 2013 (which was not popular at the time) back to local integration, which he feels gives rise to tremendous opportunities.

	SVE added that he hoped this would mean that funding of our community services, especially speech and language therapy and paediatric dentistry, would be taken forward with this. PR introduced herself as the new CD of the North Thames service and agreed with PH, by way of an example about funding for EPG, that she has been told by the ICB representative that EPG is not part of core funding for the cleft service; she feels that a small speciality like cleft will be overlooked for funding compared to large services such as cancer. AP replied saying that the cleft specification is national policy-it is Department of Health and social care policy, enshrined in law and the legal system. He went on to say that while he could listen to the concerns raised by PH and PR for example, he was not in a position to do anything with these comments. What he suggested instead was if there were concerns, to talk to trust managers and other colleagues who can take those concerns forward with integrated care representatives in the meetings that they're actually attending. JM informed CDG that the paediatric dentists were aware of this and have set up a working group to work through some of the Integrated Care board issues. JND asked about changes to the service specification and SvE informed him that this was the next item on the agenda and he asked AP to comment on this: AP offered to send the methodology to the CDG that underpins the development and review of service specifications and the template that goes with this. He went onto explain that there is an expectation that the service specifications of the future are outcome focused and there is a whole section on this. He went onto say that the service specification is still about the standards that are required from the services, the teams that the NHS wants to see in place and the patient pathways that have to be delivered. Refreshing the service specification is an opportunity to review how the NHS wants things to look and how it wants services to be delivered. The last service specification was written in 2013, so it is now out of date. He told the CDG that the service specification review will be clinically and patient and public voice led. He explained that whilst commissioners facilitate the development and the review of service specifications, the review will be clinically led and it is therefore important to have the right team in place to develop a revised draft service specification, which will then be subject to wider stakeholder testing. He noted that all within the CDG would be formal stakeholders and that all would have a chance to comment on that redraft. AP emphasised that with the revised service specifications it is important to consider the whole patient pathway and not just the specialised elements thinking about the patient journey from beginning to end and all the different other organisations that will be involved. AP said that a service specification working group will have to be more than the specialised services clinical input and will also need cross clinical input from community colleagues. SvE agreed saying that it has been difficult to get provision of paediatric dental services and speech and language services for cleft patients in the community and that this is now becoming an issue for orthodontics too now. AP feels that there is now an opportunity to move away from silo commissioning that has gone on for years in relation to specialised services and that there is now an opportunity to influence the integrated context throughout the patient pathway. While CDG focuses on the specialised standards side, it is important to take into account the wider network of services and be very clear about how they interface with one another.
6. Feedback from CLAPA	CC gave the CLAPA feedback speaking to the powerpoint presentation shared with CDG prior to the meeting-**see appendix B**
7. Vote for next CDG Chair	SVE moved onto the vote for the next chair and informed CDG that he had received one nomination Ginette Phippen; she was nominated by YW and

	seconded by MS. Sve asked if there were any other nominations? As none were forthcoming he recommended GP to CDG as the next Chair and he asked if there were any obvious issues anyone would like to raise or if there was any opposition to GP's nomination? None were forthcoming and SvE congratulated GP on her election to the post and he informed CDG that he will give GP a full hand over after the meeting and that she will then contact all to arrange the next CDG meeting and take all the issues that are raised forward into the future. AP congratulated GP and confirmed that she would be chairing the service specification working group. AP also informed CDG that he had emailed the methodology document for service specification revision/update and the existing service specification and that he looked forward to starting this work with GP and representatives from the CDG.
8. Feedback from Cleft Centres (UK)	SvE asked the CDs present to highlight any issues that need to be raised other than that received in the updates received by CDG from the CDs prior to the meeting-**see Appendix C for all Centre updates.** HE spoke to the written update from the **Welsh Cleft Lip and Palate Unit**. SvE thanked HE for her update and there were no questions from CDG. MS spoke to the written update from the **Spire Cleft Service**. MS highlighted the fact that Spires are looking at succession planning for maxillofacial provision, particular for the secondary work across the service. Spires is working with the maxillofacial departments at both ends of the service and there will be an opportunity for at least one appointment. SvE thanked MS for his update and there were no questions from CDG. AC spoke to the written update from the **South West Cleft Service**. SvE thanked AC for his update and following ACs presentation there was an active discussion and there were a number of queries: PR asked AC about the private cases referred to GOSH saying that as CD she knew nothing about this and she thought that Norman Hay, the previous CD was also not aware of this. She wanted to know if this had been discussed at NHS level because GOSH(NHS) could have helped in that MS and PH have been helping. She went on to say that she thought it entirely odd for the NHS to be paying for private care when there's a possibility to do this within the NHS. AC replied saying that mutual aid is a national process that they have to go through. Initially, after lockdown, arrangements could be made by approaching individual units, but thereafter they were informed by NHS England colleagues and local commissioners that they had to go through the national process-they are now not to approach individual units and have to wait for the office to come back to them about the list of their requests. He went on to say that these arrangements are made not with GOSH private patients or with the GOSH cleft service but that it's with a proven pathway with a private provider who sits within an NHS cleft service. AC encouraged the CDG to approach him if there were any questions about this and he would explain the logic coming from those above him. His role has been to clinically assess the proposals. He re-iterated that there hadn't been any more offers than those he spoke about in his report although he has been in liaison with colleagues in Birmingham but capacity has decreased and he noted that in the past GOSH hadn't been able to help with any NHS cases before. PR refuted this saying that she had been saying to Norman Hay that GOSH could help and that she wasn't aware of any approaches to the unit and she felt that the process seemed very opaque. SvE informed PR that mutual aid had been raised in CDG on more than one occasion and mutual aid from GOSH had never been offered. He also informed PR that at extraordinary meetings with all clinical

	directors with AP present about mutual aid for the SW GOSH did not inform the meeting that they were able to accommodate mutual aid patients on an NHS level. SvE went onto say that it was very positive news that GOSH does in fact have capacity for mutual aid and suggested that this is taken forward. AC agreed and PR offered to speak to the relevant people and the unit would try to accommodate some of these patients. AP agreed that it is not possible for hospitals to contact other hospitals to try to sort out mutual aid through themselves informally and that it has to be linked to working with commissioners to facilitate this. It was important that the SW commissioners were sighted on the issues that Bristol had with cleft. As part of that process then there should have been Commissioner to Commissioner discussions between London and SW and trust to trust discussions as part of that framework. AP asked AC if the plan he had reported on in his feedback had been agreed with commissioners and signed off by them AC confirmed that he currently meets with SW commissioners, namely Greg Martin, every 2 weeks but that this will be moving to a monthly meeting soon. AC was under the impression that Greg Martin reported back to AP. AP clarified that the national team isn't responsible for day-to-day operations or mutual aid or restoration and recovery. He stressed that it's really important that local Commissioners are leading this process and he noted that when he did get involved in trying to support things locally he was told off by SW commissioners simply because this is very much their job and they're in charge of this. AC confirmed that he was meeting regularly with SW commissioners and Surgery and Children's Operational delivery Network leads as well as having regular "in-house" meetings. SvE asked AC why the SW service hadn't been able to utilise the offer of theatre lists from Swansea. AC replied citing case-mix, medically suitable cases, and maintaining continuity of care for patients needing more than one procedure wanting want the UCLPs and BCLPs to be going through one surgeon, if possible. AC went onto say that the SW currently has a locum and that there were 7 cases that could have gone to Swansea but these cases are already assigned to operating lists for the locum and by sending these to Swansea it would have removed the opportunity for him; alveolar bone grafts are locked down by agreement with Southwest specialised commissioners until reasons for their failures at Derriford have become clearer. PHO asked AC if in terms of continuity of care he was trying to maintain patients with the same surgeon? AC replied in the affirmative. PHO then opined that as we work in teams, we're supposed to have been mutually respectful of our similar skills and as the patient belongs to the team patients will sometimes go from one surgeon to the other because there is mutual respect; Pho went on to say that as we work as a cleft team, we're all supposed to be as good as each other and patients belong to the team, not to an individual consultant surgeon and PHo is of the opinion that AC is making a rod for his own back by trying to insist on continuity of care and in so doing is making it harder than it could be. AC felt that with all the changes and compromises that have taken place in the SW team by maintaining surgeon continuity they would maintain quality of care in this area at least. PHo disagreed as he feels that by insisting on surgeon continuity of care that might introduce delays with subsequent compromise in care. AC agreed to reconsider this decision. JND asked AP how to get the same level of commissioner involvement that the SW has been able to attain? AP offered to make an introductory email. SvE felt that this would be great greatly received by CDs as many have real issues contacting their Commissioners. AP offered to take responsibility for making the individual links between clinical colleagues on CDG and regional Commissioners and AP agreed to let SvE have these contacts by email. AP informed CDG that from a regional commissioning point of view, there are medical directors of

	commissioning who are all clinicians and commissioner colleagues responsible for day-to-day commissioning. AC agreed that his contact with regional commissioners has been mutually beneficial. HE informed CDG that the Welsh commissioners and Helen Fardy in particular, have been very supportive over mutual aid and they have been liaising with the Commissioners in England. The Health Board managers have also been in liaison and there is a contract in place which was put in place in April /May. HE is concerned however that as a provider, plans from the SW haven't been shared with her meaning that it has been difficult to populate lists and as a result lists are then re-purposed despite asking commissioners and AC what the SW plans for Wales are for mutual aid. AP suggested that HE contact commissioners again to raise her concerns and to copy AP into the email; AP also offered to update Su De, chair of the CRG about her concerns and although she does not have any direct influence over commissioning it's useful to get senior clinician sighted on these issues. KLM spoke to the written update from the **Evelina London Cleft Service**. SvE thanked KLM for her update and there were no questions from CDG. JND spoke to the written update from the **East Midlands and Nottingham Cleft Service** and also informed CDG that Lorraine Britton, the lead SLT, will be retiring and returning. SvE thanked JND for his update and there were no questions from CDG. PR spoke to the written update from the **North Thames Cleft Service**. On the issue that PR raised about the trust not agreeing to top up funding for NT to host a cleft TIG fellow SvE suggested that she contact the Dean of Health Education England about this as there is often extra funding available from unfilled TIG fellow posts. SvE thanked PR for her update and there were no questions from CDG. IU reported on **West Midlands Cleft Service** – the written update received prior to the meeting couldn't be opened but was sent by KK post-meeting and is added to the appendices. SvE thanked IU for her update and there were several questions from CDG: CC enquired, on behalf of CLAPA, about the official stance of the West Midlands Team on the acceptance of adult patients into the service as patients had reported to CLAPA that The West Midlands was closed to adults at the moment. IU prefaced her reply advising CC to contact KK, the CD, directly to get all the details but went on to say that because of a lack of cleft clinical psychology cover, as funding for cleft psychology has been withdrawn, the West Midlands team was not accepting new adult patients into the service; old established patients were still being treated. IU reported that adult services were under pressure across all adult hospitals in Birmingham. CC agreed to follow this up with KK. AP asked IU if local commissioners knew about the issue. She replied saying that KK has met with regional commissioners but was not sure of the finer details and lamented the fact that previously the West Midlands had been known for an excellent service. She promised to add more detail about the adult service in the written report to CDG. PC reported on the **Cleft Net East Cleft Service**-a written report was not received prior to the meeting but was received thereafter and appended to this document.

	In addition to the written report PC finished on a positive note to say that Cleft Net East, with Anglia Ruskin University, has taken over the running of the cleft nurse course and eventually all students passed the 30 credits at master's level. They have started recruiting for the next course, which will run from 5th February 2024. PC went on to say that the evaluation from the students for those on the call who played a part was really good and she went on to thank all that contributed and looks forward to their contribution in 2024. SvE thanked PC for her update and there were no questions for PC. CS spoke to the written update from the **North West, IoM & North Wales Cleft Network**. In addition to the risks highlighted in his report to CDG CS included the fact that there is no cleft operating microscope at Royal Manchester Children Hospital and the surgeons are having to use the ENT microscope. Although this is on the risk register and has been highlighted several times and attempts have been made to get funding for this CS feels that APs offer to link up with regional commissioners would be very much welcomed. He also reported that patients are reporting problems with access to dental care and speech and language community provision. SvE thanked CS for his update and there were no questions for PC. SvE spoke to the **Leeds Site, Northern & Yorkshire Cleft** report provided by AS prior to the meeting. There were no questions following this report. PHo spoke to the written update from the **Newcastle Site, Northern & Yorkshire Cleft** Service. In addition to his written report Pho reported on the following: The hospitals CQC rating which was outstanding has been suspended, which he thinks is quite unusual-The threats to the service are related to this. He gave an example of the waiting list office being in disarray and the cleft service having to keep a separate list to make sure they were aware of how long patients had been waiting; there has also been a nurse shortage for over 3 years and a ward has had to be closed because of this. Pho feels that this is a failing of senior management. As far as the cleft service is concerned the cleft coordinator has been allowed to go down to three days a week when it's clearly a 5 day a week job and the cleft service has not been able to backfill her position largely, he thinks, because it's not been well managed. From a nursing point of view they have done well in relation to succession planning and 2 nurses have joined the team. Pho reported that he is not allowed by his organisation to speak to the Commissioners-he was told this some time ago and as a result he has not tried to for many years SvE explained that with regard to the recent surgical appointment he had written to Pho and DS as chair of the CDG as the original advert that went out was only for plastic surgeons, making it not possible for any other speciality to apply; he went on to say that he had been asked to do this on a number of occasions and the reason for his intervention is that the ethos within the cleft community is that cleft jobs should be open to the specialities that are amenable to a Cleft TIG fellowship. He had therefore contacted the cleft team directly and had not excluded them. Pho did not want to personalise the issue and he said that the original advert had been a mistake by their head of department and that this was rectified immediately; he went onto re-iterate that the process had caused distress within the cleft team. AP confirmed that the comments Pho had made about not being allowed to talk to Commissioners is correct as NHS England don't encourage that kind of direct contact but instead encourage divisional managers and their clinicians to contact

	Commissioners. He went on to say that it is important that these conversations happen within a formal framework to enable joined up conversations rather than random conversations. Pho replied to say that he didn't think that the divisional manager responsible for cleft surgery is speaking to the Commissioners; he added that he used to have really good relationships with the Commissioners and that he met with them quarterly and it was mostly helpful, and it was a great shame when that was discontinued -he looks forward to that contact being resumed in the future. CR spoke to the written update from the **Cleft Surgical Service for Scotland.** In addition to the written report, he added the following: The reasons for remaining on protocol for primary surgery is because of the reduction in cleft birth rate consistent with the rest of the UK; the way in which they are nationally funded with the hospital and Health board has also offered some protection. They aren't however able to offer mutual aid because across all other surgical specialties, there are still significant long waiters post COVID. He reported that there is a wider risk to the service due to a lack of paediatric anaesthetists and paediatric theatre staff. They are watching this closely but as a small user of theatres they can't influence this significantly and will have to respond to any changes that are made. He went on to say that the wider cleft network is currently under review, and it is uncertain as to whether it's going to become part of a larger network because cleft is quite small within Scotland or whether the functions of the wider network will be transferred to the cleft surgical service? SvE thanked CR for his update and there were no questions from CDG. EO spoke to the written update from the **Northern Irish Cleft Service**. SvE thanked EO for her update and there were no questions from CDG.
9. Feedback from CENs	SvE asked for the Lead groups and CEN feedback. **See Appendix D for CEN and Lead updates** . **Nursing Lead Group**-As CCo had to leave the meeting SvE spoke to the report received prior to the meeting. HS then spoke to the written update from the **Nursing CEN**. SvE thanked her for her update and there were no questions from CDG. **Cleft Clinical Psychology CEN**-RC spoke to the written update from the Cleft Clinical Psychology CEN. SvE thanked her for her update and there were no questions from CDG. **Ortodontic CEN(OCEN)**-JS spoke to the written update from OCEN. JS highlighted concerns about patients accessing general dental care in the community and voiced support for the work the paediatric dental CEN were doing on dental deserts. JS made a plea for all units to get back to OCEN with their updated ABG and orthognathic waiting lists. PC fedback that she was unaware of this request and asked JS to send out the email with this request again. JS agreed to do so and added that adding narrative to the returned waiting list would also be very useful. **Paediatric dental CEN**-JM spoke to the written report from the Paediatric dental CEN. During her feedback on dental deserts CC offered to share the answers to the dental questions as part of the CLAPA community survey with the paediatric dental CEN? JM replied in the affirmative. SvE thanked JM for her update and there were no further questions from CDG.

	Speech and Language Leads group and CEN-IU spoke to the written report from the SLT Leads group and CEN. IU raised the registration of submucous cleft palates on CRANE and SvE suggested that this be deferred for discussion under the CRANE agenda item. IU referred back to the work being carried out by the PDEN CEN on dental deserts and access to dental care and noted that when collecting data about patient access to speech and language therapy it is important to differentiate between treatment provided by cleft centres with that provided in the community. IU reported that the SLT CEN had conferred honorary membership on Marie Pinkstone and Caroline Shipster. SvE thanked IU for her update and there were no further questions from CDG. **Audiology CEN:** SvE reported that SD wasn't able to attend the meeting today and that he had not received a report from the Audiology CEN. **Restorative Dental CEN**-a written report was not received by CDG. SP reported back: a recent CEN meeting had focussed on trying to get restorative consultants and dental technicians together to attend a clinic together to look at speech prostheses. A date for this has been arranged for Friday the 3rd of May, 2024 and a consultant from each of the 12 centres will attend with a dental technician. It is planned as a clinical day with 4 or 5 patients and they have therefore had to limit the numbers to 24; the meeting will be hosted by Oxford and the plan is to discuss the different treatment options so that hopefully there will be consensus at the end of the meeting. A follow up meeting is then planned where all the speech and language therapists and surgeons to try to establish a streamlined pathway that can be followed by cleft teams. The CEN is also working towards getting observership contracts which is taking some time. He finished by reporting that The Spires Cleft Centre was trying to set up a 5PA restorative consultant post in the Salisbury hub as it was difficult for patients from this part of the network to travel to see him in Oxford. This would initially be advertised as a locum position. SvE asked SP and JM if Nabina Bhujel had contacted them to arrange a meeting together with CR about access to dental care and data variability following discussion about this issue at the September 2023 QMIC meeting? They replied that they had not had any contact and SvE suggested that they arranged a meeting to discuss this-they agreed to do so. MB added to what SP said about the speech prosthetics by informing CDG that she chairs the national Speech prosthetics group, which meets virtually and they hope that following SP's course on intra-oral speech Caroline Reed and Ali Birch from Evelina will be able to offer something similar about the nasal obturators and then all can perhaps come together to have a consensus meeting about both types of prosthesis. SvE thanked SP for his report and there were no further questions from CDG. **Cleft Managers CEN group:** SvE asked JS to feedback about the Cleft Managers CEN group. JS reported that a meeting has been called by Lynn Kirk based up in Scotland, which as far as JS is aware is the second meeting. JS hadn't been included in the first circulation of the group. The next meeting will be a national meeting planned for the 5th of December. JS will be able to feedback on this at the next CDG and she is hoping to generate interest in the April Manchester conference, and she is hoping to have a session there for the managers and the coordinators. SvE thanked JS and re-iterated the importance of this CEN group as many units face the same operational and funding issues and sharing these problems will be useful.

	AC asked how his manager/co-ordinator could get involved and suggested JS use his email address to contact the South West manager. JS thanked AC and offered her email address placed on the thread (jill.scotson@mft.nhs.uk) as a contact point for those on CDG who wanted to get their co-ordinators/managers involved in the group. **Surgical CEN** GT spoke to the written report received after the meeting and is appended to these minutes. He was able to join CDG after the craniofacial report. SvE informed him about the service specification template provided by AP and GT noted that the wording of the service specification would have to be changed to comply with the new GMC guidelines. SvE thanked GT for his report and there were no questions for GT.
10. Feedback from CRANE	CR provided an update on CRANE and spoke to the slide presentation appended below-**APPENDIX E** CR was keen to discuss the formation of a separate steering group to oversee CRANE direction and activity as a sub-committee of CDG so that more time could be spent on this. SvE summarised the discussions form the last CDG meeting namely that CR felt that a group of 5-6 members would be adequate and a discussion had followed as to whether members should be drawn from the CEN groups or whether there was a need for representation geographically and from specialist groups meaning that the group would then be larger than 5-6 members but if meetings were virtual this wouldn't be a big issue. An agreement was reached that the CEN leads and the CDs would go back to their groups and teams to see if there were any willing volunteers to sit on this group and that this could be finalised today. SvE had not been informed of any discussions about this and wondered if these discussions had taken place? None of CDG was forthcoming on this and CR suggested using the QMIC to extend its role and its meeting duration to do this. SvE agreed that this could be a good alternative and GP suggested co-opting deputies to the QMIC in case of absence or sickness. GP as the new chair of CDG agreed to take this forward. AP returned to CR's presentation, and the concerns raised by CR about CRANE funding. He explained that all national audits are overseen by a separate commissioner group (business intelligence group) that is separate to national and regional NHS commissioners. He explained that this group is having discussions with almost all database providers at the moment linked to future contracts and funding. CR explained that he was aware of this and said that he was having to have separate conversations about what national commissioners want from CRANE and how CRANE is funded. AP asked where the conversations on funding have got to and CR replied saying that after a lot of negotiation with help from Sally Cavanagh a new contract had suddenly been provided with a new clause added into it. This clause appears to be driven by the aspiration for all registries to come under one national entity so that a record can be kept of implant use (breast implants, pelvic meshes) and CR felt that there is very little understanding from the commissioners of registries focussed on outcomes. This new clause was not highlighted and was discovered by CRANE and CR feels that this has caused much uncertainty and that the communication from the NHS England Transformation Directorate about this has been very poor and has caused such a reaction that the registries and the audits involved have come together to form their own federation. AP told CDG that he was unable to help with this issue although he could have informal discussions with the national team about this. CR reported that he had never been invited to a meeting with Scott Pride and his clinical counterpart Tim Briggs but the chair of the abovementioned federation was due to meet to discuss this. CR went onto say that this was one of the issues that CRANE was dealing with and the other

	was about the funding for CRANE. He conceded that with AP and Sally Cavanagh's help CRANE had a funding increase to reflect what CRANE's current costs are but that current funding restricts what CRANE can do; he reported that part of CRANE's funding has come from the CEU in ways that CR hasn't been able to understand and this is due to come to an end. So although he is grateful that in, April, last year CRANE had an uplift to cover their existing budget this was probably about 1/3 of what a recently commissioned National Audit would have been funded to. He explained that there is some variance from audit to audit, as to the number of people required to robustly run these audits but it is more than the 1.7 whole funding equivalent that CRANE is currently managing on. This means that CRANE is limited to what it can do until it gets an uplift; he suggested that CRANE's budget is now probably somewhere between 55% to 65% of what the other HQUIP funded audits are getting. This means that CRANE is still underfunded in terms of having their ability to do everything they want to do and to do what would normally be required by both commissioners and stakeholders. The feeling in the CEU is that CRANE takes up too much time and effort compared to how it is currently funded and compared to the other well-funded audits in the CEU ; furthermore CR is spending most of his time focussing on funding and staff retention issues rather than focusing on the clinical issues he should be focussing on as the clinical lead for CRANE. CR feels therefore that CRANE is currently at risk of being released from the CEU of the Royal College of Surgeons in England which will mean looking for another host with the need to satisfy their funding criteria. AP offered to meet with CR and Sally Cavanagh to discuss these issues outwith CDG and raise them through the women and children's programme of care to enable a formal conversation with the team managing this. AP added that at the same time they could have a conversation about what commissioners would want from CRANE such as the metrics they want to see within the service specification using CRANE as the data source for those metrics. SvE and CR agreed that a meeting was necessary, and AP and CR agreed to arrange a meeting early in 2024 to discuss these issues and to discuss the way in which CRANE can extend its activity to get full coverage across all aspects of cleft care. CR moved onto the annual CRANE report: the annual report has been sent to all members of the CDG with the final draft of the registry and outcome section of the report which is for comment. He asked CDG to email Jibby Medina if there were any issues in the draft that members wanted addressing. The plan is for the report to be finalised and published by mid-December. He hoped that CDG likes the revised appearance which has been streamlined in response to past feedback. The information tables are all supported by the information in the associated Excel worksheet raw data available to look at in more detail. He went on to the challenges with data completeness and re-iterated that data entry is part of the service specification and encouraged all teams to improve their data completeness to enable full utilization and full benefit from what Crane has to offer. He emphasised the importance of having dedicated personnel to do data collection in each team and how this has become apparent in the feedback sessions from the CDs of those units doing well with their data collection. He went on to talk about the role of the team and particularly the nurses in the CRANE consent process and that CRANE would continue to work with the cleft nurse specialists to focus on new registrations but that any missed registration was the responsibility of the team. SvE thanked CR for his CRANE feedback and for all his hard work at CRANE; there were no further questions for CR.

11. Quality Monitoring and Improvement Committee (QMIC)	SvE gave feedback on the quality monitoring and improvement committee meeting in September 2023: the focus of the meeting was on variability in speech and dental outcomes and although a lot of services are falling within the two standard deviations, there is variability that occurs on a year by year basis between and within units. There was a long discussion about access to paediatric dental care in the community and that those that come from poorer socioeconomic groups struggle even more. There was a brief discussion about the risk adjustment of dental outcomes to include things like fluoridation but to be able to do this CRANE needs to be properly funded. Variability within speech was also discussed with discussion about how patients access speech and language therapy and whether services were a centralised service or whether services were more reliant on the delivery of speech and language therapy in the community; it seems as if the speech and language therapists feel that community speech provision has become even worse than that reported and presented to the Royal College of speech and language therapists in 2014 and think that this might have an adverse effect on speech outcomes? A decision was made to invite the units with the best speech and language therapy results to the March QMIC meeting so that best practice can be shared. The next QMIC meeting date is to be decided by GP and QMIC and SvE shared that he had usually done this with doodle poll. CR added that although there was initial improvement in outcomes following CSAG, improvement has plateaued and variability is now the norm; he urged CDG to be aware of our recent past and cautioned against the appointment of too many cleft surgeons as this would dilute the volume of primary cases per surgeon with the risk that numbers per surgeon would return to pre-CSAG numbers with an associated drop in standards. SvE agreed with CRs concerns.
12. Research	a. Bristol-Cleft Collective b. NIHR Clinical Studies Group of Cleft and Craniofacial Anomalies c. Early Career Researchers Group (ECRG) d. Cleft Multidisciplinary Collaborative e. Early Career Researchers Group f. Clinical Studies Group update g. The Side Lying and Upper airways Maintenance in Babies Requiring Surgery (SLUMBRS) study **PLEASE SEE WRITTEN REPORTS APPENDED UNDER APPENDIX F** **Bristol Cleft collective(CC):** YW: Spoke to the report sent to CDG prior to the meeting. YW then spent some time focussing on the cleft@18 to 20 study: she reported that she had visited 12 cleft sites and thanked all teams for the time taken to accommodate her; there are four more sites that she needs to visit and dates for 3 of these have been arranged and the fourth still to be confirmed. YW then spoke to a slide she had prepared about the main points that had arisen following her visits namely: -dental measures: these still need to be finalised and she is hoping to arrange a meeting early in the New Year with the dental CEN leads and anyone else who feels the need to be present at this meeting, to address this. -age of 18-20-this was chosen so that it would be possible to capture the original Cleft Care UK children and comparisons could then be made with the five year data from Cleft Care UK and early CRANE data. Some sites have raised the issue that for some patients treatment wouldn't have finished by the age of 18-20 and it would therefore be better to see these young adults when they're older. YW

	said that it would be possible to do this but that CC have constraints imposed from the funders and CC would need to go back the patient community to talk to them about this change. The problem with changing the age though is that CC wouldn't then be able to compare the outcomes with any five year data meaning that it wouldn't be possible to see if the CRANE five year data is a good proxy for outcomes at the end of treatment? YW asked CDG to think about this while moving onto the to the second question which had been asked about collecting as much data as possible remotely: the one reason for this is that it is a real challenge to get this population back into cleft units for clinical appointments let alone for research appointments even with CC incentives in place. The problem that she raised with a remote approach is how then would some of the data such as images, dental measures and speech samples be collected? She added that the other big thing to consider is that one of the reasons for inviting them in, given that as there are a lot of self-reported measures to collect, is to give them access to a psychologist in clinic if need be? She added that this has been costed into the project. She conceded that teams had alluded to the fact that this is a generation that does everything online and that if access to a clinical psychologist was available after completing made the self-report questionnaires, then perhaps this could be done remotely. YW stopped sharing and asked for views from CDG? SvE confirmed that there was time for a brief discussion about the points raised by YW but that if the discussion was taking up too much time he asked if it could be continued outwith the CDG meeting with YW personally? CR reported that teams had asked him about sharing CRANE data with CC. He explained that the data from teams on CRANE belonged to the individual teams and as such it was up to the individual teams to share that data with CC if consent was in place to do so. JND raised the point that it was important at the outset of the trial to make sure that the study was collecting outcomes after treatment was complete and not to collect outcomes while treatment was ongoing; he felt therefore collecting outcomes for UCLP patients at 18 to 20 would mean that many would still not have completed their treatment as most in his unit only finished their journey by the age of 25. He cautioned therefore that the study would then be at risk coming to incorrect conclusions, with dissatisfaction and poor outcomes, but the data will be meaningless because it's not at a point where the intervention has been completed. This would be similar to the outcomes reported in the recent TOPS trial. SvE concurred and cited the delay in revisional and orthognathic treatment for this cohort of patients as a result of the Covid pandemic meaning that for many of them their treatment would have been delayed further. JM commented on the difficulty of the remote collection of dental outcomes and the use of photographs for this and she cited a previous project that showed that using clinical photographs for scoring was difficult as it was difficult to see all tooth surfaces this way. YW promised to pick this up with JM when she met up with the dental CEN leads. GP asked YW if the outcomes had to be collected at the end of treatment or whether it was about outcomes up to this point in time? YW replied saying that the study was trying to look at unmet needs in this cohort and that if there was treatment still planned there would obviously be unmet needs; if they however are using unmet needs as a proxy for long-term outcomes then that might be a different issue. YW said that she wanted to get a feel of the opinion from cleft teams so that a final decision could be made. KLM supported the research project but raised her teams concerns about having to put on additional clinics with staff time to run these clinics in the face of backlogs and clinical pressures so wanted to know how much time this project

	will take and how do teams justify doing these clinics instead of doing clinics addressing clinical need? MB wondered whether clinics on Saturdays for example, that wouldn't compromise normal clinics with additional payments, as was done for the TOPS trial, would address KLMs concerns? YW also added that perhaps remote data collection could also address KLMs concerns? SvE thanked YW for her update and encouraged CDG to contact YW outwith the meeting if they had any suggestions or concerns. **Early Career Researchers Group (ECRG)** SB the new chair spoke to the written report she provided to CDG prior to the meeting (see appendix). SvE thanked SB for her report and there were no questions for SB. **NIHR Clinical Studies Group of Cleft and Craniofacial Anomalies:** SK had given her apologies prior to the meeting and she asked SvE to give her presentation. This presentation together with the updated studies list and completed studies list was provided to CDG prior to the meeting and can be found in appendix. SvE presented the slides and encouraged CDG to contact SK directly if there were any queries arising from the presentation. **The Side Lying and Upper airways Maintenance in Babies Requiring Surgery SLUMBRS study..** SvE noted that HR had to leave the meeting and therefore read out the report HR had provided to CDG prior to the meeting (see appendix). Following this report both HS and PC noted that the cleft nurses nationally were devastated that the trial had been withdrawn and that they were trying to find a way to look at the data that had already been collected. **Discussion about Feedback to CDG from Centre for Appearance research** SvE reported that he had been approached by Nicola Stock from the Centre for Appearance Research to ask CDG to consider whether the Centre for Appearance Research could sit as a part of the research representation on the CDG? He asked CDG to give this consideration and to feedback to GP about this.
13. Quality Dashboard	QD there was nothing to discuss. The QD remains as a standing item on the agenda.
14. CFSGBI Feedback	MB spoke to the report she provided to CDG prior to the meeting (**SEE APPENDIX G**). She expanded further to say that there are now 10 CEN groups with a new genetics CEN started by Emily Anderson from Liverpool working with Marian Jones from Great Ormond Street. They have sent out flyers to genetic colleagues and MB asked CDG members to mention this to their genetics colleagues and to inform them that there will be a genetics CEN meeting on the 17th April 2024. MB shared that there will be webinars open to all leading up to the conference in the evenings for a couple of hours and these will be announced forthwith. She reported that finances for the conference are tight and encouraged as many as possible to attend and asked CDs to facilitate and encourage attendance from their teams. She confirmed that there are 7 keynote speakers, the usual drinks reception on the Wednesday evening and the Gala dinner on the Thursday with a live 5 piece band for the dinner. SvE thanked MB for her report and there were no questions for MB
15. Training	LF was planning to feedback to CDG but had unfortunately left the meeting by the time this agenda item was discussed. JSG, as a member of the TIG committee however was able to feedback on her behalf. He reported that there had been a lot of discussion about whether TIG

Commented [Sv1]: Please append ECRG report to the minutes

Commented [Sv2]: Please append CSG report to the minutes

Commented [JM3]: JM: From my review it appears this agenda item was mainly skipped – could also apply to items 13 and 14

	should advertise for another fellow as workforce planning suggests there may be a wait until a consultant post is advertised; but because this was an uncertainty, and it was felt important to keep inertia going TIG has advertised for one fellow post and interviews are planned for January 18th, 2024. The fellows remain very positive about their training and the new curriculum which has now started and is much clearer in terms of their requirements. It also stresses the importance of interacting to a high level with the wider MDT involved in their training and getting feedback from them. There are no significant training issues that TIG are aware of. The shift to post CCT fellowships has not resulted in much of a change with no real difference in those applying. He went on to say that the standards of those applying for TIG fellowships is very high which augurs well for the future of cleft surgery. JSG confirmed the date for TIG interviews was the 18th January 2024, the day after the upcoming TIG cadaver course. He went onto thank all of those who participated in the TIG cadaver course and all who will participate in the future. SvE thanked JSG for his feedback and there were no questions from CDG.
16. AOB	SB asked if commissioning for sub-mucous clefts and non-cleft VPI and how these are added to CRANE could be added to the agenda as this is an issue often raised with CRANE by speech therapists and one in which there is a lot of variability and this can change numbers quite considerably. SvE agreed that this was a live issue and had previously been discussed at CDG and it had been agreed that the topic was going to go back to the speech CEN/leads group regarding thinking about resource management for this. SvE asked the incoming CDG chair to add this to the agenda for the next meeting. PC finished on a positive note by thanking CC and the team from CLAPA and one of the adult patients for attending their first face to face tri-centre meeting a couple of weeks ago, which was very successful. The meeting focussed on adult returners and the adult patient that attended gave all a lot of food for thought; the day was really well evaluated and really positive. CC thanked PC for her compliments. MB asked the CDs if they wanted a separate CEN meeting at the CFSGBI conference on the Wednesday; she mentioned that while a separate room hasn't been booked for this perhaps arrangements could be made for a meeting at lunchtime or later in the day? SvE replied that there hadn't been one at the last conference and couldn't remember when there had last been one. There was no comment from the CDs present and MB asked them to get back to her if they did want to have a CEN meeting. AC thanked SvE for his time as CDG chair and for leading the committee with such professional standards and for all the support offered. SvE thanked AC for his compliments and he thanked the CDG membership for all their support over the years. SvE asked GP to arrange the next CDG in her role as the new chair of CDG

The next meeting of the Cleft Development Group will take place virtually on Monday 27 November 2023 (9am-2pm).

Actions from Cleft Development Group meeting: 27th November 2023	**Owner**	**Due Date**
Action 27/11/23:4.1: Members of the CDG to contact either GM or HR if there was anything that they would like discussed in the patient engagement group.	Surgical CEN Chair	TBC

Commented [JM4]: Said would extend to 5hr meeting – possibly incl. lunch break in response to NH feedback (time squeezed and people unable to speak)

Commented [MB5]: To be updated

Commented [MB6]: Simon - please update

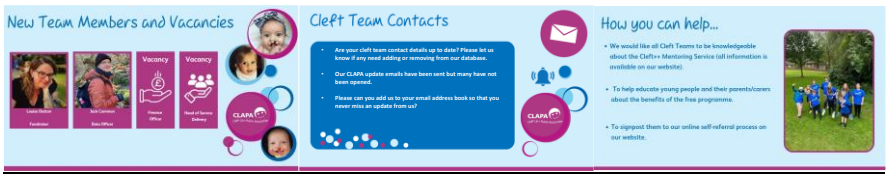
Commented [Sv7R6]: Please see my comments in the text above and add these as action points

Action 27/11/23:8.1: AP to take responsibility for making the individual links between clinical colleagues on CDG and regional Commissioners and AP agreed to let SvE have these contacts by email.	SvE	TBC
Action 27/11/23:9.1: SP, JM and CR to arrange a meeting with Nabina Bhujel to discuss access to dental care and data variability following discussion about this issue at the September 2023 QMIC meeting	JM, SP and CR	Next CDG meeting
Action 27/11/23:10.1: GP as the new chair of CDG to extend role of QMIC to include acting as the CRANE steering group	GP	Next CDG meeting
Action 27/11/23:10.1: AP and CR to arrange a meeting early in 2024 to discuss CRANE funding issues and the way in which CRANE can extend its activity to get full coverage across all aspects of cleft care.	CR, AP	Next CDG meeting
Action 27/11/23:11.1: GP as chair of QMIC to invite the units with the best speech and language therapy results to the March QMIC meeting so that best practice can be shared.	GP	Next QMIC meeting
Action 27/11/23:12.1: CDG to consider whether the Centre for Appearance Research could sit as a part of the research representation on the CDG		Next CDG meeting
Action 27/11/23:16.1: commissioning for sub-mucous clefts and non-cleft VPI and how these are added to CRANE to be added to next meeting agenda	GP	Next CDG meeting
Action 27/11/23:16.2:S GP to arrange the next CDG in her role as the new chair of CDG	GP	Next CDG meeting

APPENDICES
APPENDIX A: PATIENT ENGAGEMENT UPDATE-GILLIAN MCCARTHY:

The professional group last met 1/11/23.
Same issues discussed.
Returning adult and the process for networks accepting referrals as self referral can not be accepted as will need a GDP /GP to continue treatment.
CLEFT East have developed a protocol with their coordinator and was discussed at the tricentre on the 2/11/23.
A proposed audit of network websites is planned
Develop a PPI link for each cleft centre.

APPENDIX B: CLAPA PRESENTATION - CLAIRE CUNLIFFE



APPENDIX C CLEFT CENTRE UPDATES

C1: THE WELSH CENTRE FOR CLEFT LIP AND PALATE- HELEN EXTENCE

1. **Staffing updates**

Surgeon

Tomas O'Neill has resigned for personal reasons; he will return to Ireland. His last working day in the unit will be the 15th Jan 2024. A 10 session cleft post will be advertised asap.

Locum surgeon, Serryth Colbert finished with us in Oct 2023 and has taken a local maxillofacial locum post. The purpose of taking on a second locum surgeon was to pilot how a 2 surgeon model could work for the unit. Due to the lower birth year, we could not support a second surgeon as the numbers did not warrant this. We continue to explore with our Welsh commissioners the possibility of sharing a second surgeon with Bristol. Our commissioners are keen to work with English commissioners to discuss this further as this could also support Bristol in their issues addressing their waiting lists. Such an arrangement could be of mutual benefit to both sites.

Band 6 Clinical Nurse specialist- 26 hours (post derived from Michaela Rowe, lead nurse reduction in hours) start date 8th Jan 2024- Emma Gregory

Band 7 SLT- 22.5 hours Laura Williams start date 4th Dec 2023

Band 6 SLT – maternity cover 26.25 hours- Catriona Taylor start day 8th Jan 2024

Psychology assistant – 33.75 hours Band 5- Jade Evans start date 27th November 2023

- MDT clinic delivery/status

Resumed all MDT clinics, caught up with our backlog of 15 year old patients and adult clinics.

Orthodontic waiting lists for treatment and delays for those in treatment in Swansea Bay but not in the other health boards throughout the region. The issue is with the lack of dental nurse support to run the clinics as well as room availability as orthodontics are only back up to 80% of their pre covid capacity. This has been escalated to senior management and to the commissioners. Discussions are ongoing and it is hoped we will have a solution in Jan 2024.

- Currently on top of our waiting lists, able to treat 3 paed cases per list. Tomas O'Neill has taken a couple of extra lists to undertake surgery prior to his departure. So both paed and adult lists are looking healthy.

Primary Surgery Status- back to our usual surgical protocols

a. Primary lip surgery currently operating around 3 months
b. Primary palatal surgery currently operating around 6 months
c. Alveolar bone grafts after listing waiting 2-3 months for surgery

- **Secondary Surgery Status**

a. Speech surgery Paed cases are treated 2-3 months from being listed.

Adult speech cases are now being treated in Singleton hospital with the support of the Enhanced recover unit. Currently these are ad hoc lists but we are hoping to consolidate this and share the list with Maxfac. Adult surgery requiring to be undertaken in Morriston for anaesthetic/respiratory reasons continues to be challenging. Only one list has been undertaken this year on the Morriston site. We have another list for 6th December 2023 but we are unsure whether this will go ahead. Discussions are ongoing.

b. Orthognathic surgery- now being listed on maxillofacial lists when ready for surgery and undertaken in Singleton Hospital.
c. Lip/Rhinoplasty surgery- Appointment of second surgeon allowed the service to prioritise these patients at Singleton Hospital, list now into single figures.

Mutual aid to Bristol patients

To date we have undertaken surgery for 19 Bristol cases at Morriston Hospital. (5 lip repairs, 7 palates, 7 pharyngoplasties). A contract has been put in place for 12 months with Bristol but the up take has been slow. Patients have been treated on an ad hoc basis, more lists could have been sought with planning. Since the last CDG, we have provided 2 list in July, 1 list in August, 1 in November. The list on the 1st Dec could not be filled as Bristol did not have patients to send. We continue to be committed to providing mutual aid and I thank the whole team and the management of the Health Board in Swansea for supporting this extra workload.

- **Current Risks/Threats to Service Delivery**
- Period of time without a surgeon- an interim plan has been put in place with Locum on Duty contracts and the substantive post (10 sessions) will be out to advert prior to Christmas.

We have identified how many lists are required in this interim period to treat our lips and palates, speech surgeries and ABGs. MDT clinics will continue and those requiring review by the surgeon will come back just to see the surgeon, once a surgeon is appointment.

If any surgeon feel they would be able to support any ad hoc lists, then please make contact with me. Thank you. helen.extence@wales.nhs.uk

C2: SPIRES UPDATE-MARC SWAN

- Staffing updates
    - Juergen Schlabe (Locum Max-Fax Surgeon, Oxford) has resigned to commence a Cleft Fellowship at the Evelina Hospital.
    - Helen Travess (Consultant Orthodontist, Stoke Mandeville) has joined the Spires Cleft MDT as Mr Giles Kidner has dropped sessions in his approach to retirement.
    - Maternity leave in Clinical Psychology and Nursing have placed significant pressures on the team; we have been unable to appoint a locum Clinical Psychologist in Salsibury.
    - Matt Fell (TIG Cleft Fellow) has settled in well and is making the most of his Fellowship.
- MDT clinic delivery/status
    a. No significant concerns.
    b. The service is looking at how to optimally run our 5/10/15/20 year clinical review clinics and integrating PIFU for the adult patients.
    c. Adult returners can self-refer (e.g. via the Spires website) if they are ex-Spires patients. If they are not previously known to our service then we would request a referral (e.g. from their GP or GDP).
    d. Minimal PIC waiting list; although the Oxford fluoroscopy machine is being upgraded in spring 2024 which will inevitably have an impact.
- Primary Surgery Status
    a. Primary lip surgery Total: 23 (OUH: 13 SFT: 10)
    b. Primary palatal surgery Total: 34 (OUH: 18 SFT: 16)
    c. Alveolar bone grafts Total: 25 (OUH: 17 SFT: 8)

- Secondary Surgery Status

a.	Speech surgery	Total:	25	(OUH: 14		SFT: 11)
b.	Orthognathic surgery		Total:	6	(OUH: 4	SFT: 2)
c.	Lip/Rhinoplasty surgery	Total:	35	(OUH: L 13; R 12		SFT: L 1; R 9)

- Current Risks/Threats to Service Delivery
    - Impact of winter bed pressures and future Industrial Action on elective surgical capacity.
    - Impact of dwindling community service support (e.g. dieticians, dentists & CAMHS) on cleft service.

Mr Marc C. Swan
21st November 2023

C3: SOUTH WEST CLEFT SERVICE- ALISTAIR COBB

Recent focus has been on

i. More surgical opportunity for operating
ii. Following recommendations made from SWCS Harm review, additional recurrent funding has been awarded to support SWCS work force.
iii. Looking more closely at our large geographic area and needs for peripheral clinics in Gloucester, Devon and Cornwall.

- **Staffing updates**
    a. Surgery
        i. Richard Thomson started 12 month locum consultant post in June. He has a regular weekly operating list plus others. We sought advice from colleagues at other units about nurturing into role new starting locum consultants and are booking his lists focussing on CLO, CPO and pharyngoplasty, with the aim of improving our age-related surgery targets (which are improving).
        ii. We aim for 3 full time cleft surgery consultant posts but are waiting on recurrent theatre allocation to accommodate new consultant before permanent appointment advertised and made.
        iii. Nitisha Narayan has completed a very successful 12 months fellowship post with us. The post is now vacant.
    b. Psychology
        i. Dr Vanessa Garrett, Consultant Clinical Psychologist has been appointed and started as new lead following Dr Julia Cadogan's retirement.
        ii. 0.2 new session psychologist post for North Devon has been funded and advertised.
        iii. Dr Jess Black returning from one year maternity leave – uncovered.
    c. Nursing
        i. Rachel Green has taken over Lead CNS role following retirement of Cathy Marsh.
        ii. Helen Bouillet has started as new CNS to fill vacant post.
        iii. Cornwall SLA link post is under review with increase from 0.1 to 0.2 wte funding.
    d. Speech and language therapy
        i. Increased time for band 6 and band 7 current team members.
        ii. Following work force review, we are in discussions with regional colleagues to standardise contracts across south west region and increase funding of SALT posts in all areas. This funding will be held by SWCS and delivered through local Service Level Agreements.
        iii. This is particularly beneficial where we do not have cover in place – eg Plymouth link SLT not covered for 5 years and Bristol based SLTs travelling down regularly.
    e. Orthodontics
        i. Dr Jules Scott is now Lead for Devon and Cornwall. Scott Deacon (SAD) is lead for

Somerset, Bristol and Gloucestershire.
ii. Dr Nik Gogna is working alongside SAD providing treatments one day/ week.

f. Paediatric dentistry
   i. 2.25 extra sessional funding has been allocated between paediatric dentistry and dental consultant care. However, recruitment is difficult.
g. Administration
   i. Hannah Pickup has taken over as SWCS Performance and Ops manager full time (increased from predecessor).
   ii. 0.4 wte SWCS coordinator is being recruited to work alongside current 0.6 wte. This is currently covered by bank.
   iii. SWCS POMS and Coordinator roles are thus now funded full time.
h. Funding has been agreed for 1 session dedicated Paediatric medicine consultant for SWCS.

a) Primary Surgery Status:

a. Primary lip surgery (4-5 months)
b. Primary palatal surgery (6 – 12 months)
c. Alveolar bone grafts (< 3months from ideal)

- **Secondary Surgery Status**
  a. Adult waits slowly reducing approx. 10- 15 months
     a. Awaiting purchase of new operating microscope in adult theatre.
     b. Working toward RTT 65 week wait by March 2024.
  b. Orthognathic surgery - longest wait 56 weeks

  c. Paediatric secondary speech surgery – longest wait 54 weeks (family choice). All other cases under 35 weeks

- **Current Risks/Threats to Service Delivery and developments**
  a. Alveolar bone grafts were undertaken at Plymouth last year. This was a unique opportunity and a collaborative process between many NHS partners.

However, we have found that over 50% of cases have failed. There is a mixed pattern of failure. We had already ceased operating there because of sick leave by the surgeon (AC). We discussed this finding immediately with Cleft Surgical colleagues and Specialist Commissioning and SIC ODN. We have been reviewing all possible variables and aim to have an outcome and plan for recovery to restart early next year. Until then it was agreed that transfer out of region would not occur.
Meanwhile where appropriate, some more urgent cases have been undertaken by Peter Revington at local private hospital where no previous problems had occurred. Outcomes are not yet known.

b. "GLANSO" lists (preferentially paid WLI lists at weekend and evenings run by in house anaesthetic led private company) are happening for cleft and other specialties. Medically and surgically straight forward cases are undertaken on these lists.
c. Regular lists are most Mondays all day (increased from alternate weeks), alternate Wednesdays and Friday mornings.
d. We have accepted all offered unused lists from other specialties in BCH.
e. We have therefore listed 50 children for surgery at Bristol Children's hospital in October and November.
f. Many surgeons have offered to come to Bristol to operate for us. We are extremely grateful for these offers. However, the limitations are with staffing of theatres not surgeons. Regularly 4 or 5 lists per week at BCH theatres are cancelled because of staffing issues. New recruits from overseas have started but it is a slow process. Cleft has largely been exempt from these cancellations.
g. CRANE negative outlier status in 7 areas for data completeness – child growth, dental health, facial growth, speech, psychological wellbeing TIM & SDQ.
   i. Work force planning for a data input role is being looked at.
   ii. Process for addressing backlogs in clinics throughout the South west region has been started.

iii. Uncovered parental and sick leave in the service has contributed to this and workforce planning for more robust in-built cover for such eventualities is part of our recovery process.

h. Audit clinics – currently only focussing on 5 and 10 years old. 15 and 20 year old reviews by MDT are replacing audits in those ages.
i. Mutual aid - Swansea
    i. Successful mutual aid cases undertaken by South Wales colleagues in Swansea for which we are extremely grateful. We are very sad to see Tom O'Neill leaving. We have not been able to take advantage of this latest offer of help.
        1. wanted to preserve continuity of care so UCLPs and BCLPs were not appropriate
        2. Richard Thomson has taken on the same caseload of cases at BCH
        3. We have been able to send only medically appropriate cases.
j. Mutual aid – Newcastle
        1. We have not been able to send any more cases since last CDG, as local Newcastle surgical need has closed this opportunity. We are very grateful for Peter Hodgkinson and team for their help while they were able.
k. Mutual aid – Spires.
        1. We have not been able to take advantage of the offer of three speech surgery operations to be undertaken at Salisbury. We had treated the patients in question by the time we had confirmed the opportunity, and we now have Richard Thomson in post to undertake the same case load.
l. GOSH private wings transfer of NHS cases.

Conversations between Directorate leads and SW Spec Comm led to the possibility of utilising NHS policy about providing private treatment where unable to deliver NHS treatment in commissioned manner. The focus has been on continuity of care cases mostly UCLP; GOSH private wing is also able to accept patients with complex medical, which Swansea is able to accommodate.
Previous South West patients who had chosen private treatment at GOSH had gone with Paul Morris. Good working relationship with him administratively and clinically had been developed over a long period. Paul had capacity to undertake cases for us in the right timeframe at weekends not compromising NHS care. Our specialist commissioners were able to support us in this and the cases are transferred under NHS conditions. 15 operations were agreed upon – which has not started yet.

m. Peripheral clinic backlogs – over 1000 appointments are required in our outpatient clinics in Exeter, Plymouth, Cornwall, and Gloucestershire. As explained at previous CDG, our focus is looking south as a service to our extensive geographical region covered and working with colleagues in these counties to recover and improve our systems.
n. Increased numbers of regional clinics have been mapped out for 2024, including virtual clinics.
o. Continued regular meetings with Spec Comm and SW commissioners and SIC ODN.

C4: EVELINA LONDON CLEFT SERVICE -KATE LE Maréchal

- Staffing updates

We have almost a full complement of staff in all areas.

Our orthodontic team is going through some changes with 2 members of the team based at St Thomas' dropping PAs. We have a Locum Consultant (who is one of our regional orthodontists) covering one day a week and this is working well but we need to make some more robust plans for the future.

We have a new cleft lead CNS but her job has been set up differently from previously. She does not have a clinical role but manages the CNS team in cleft and a number of other specialties. We are currently recruiting for a band 7 cleft CNS (0.8 wte).

- Primary Surgery Status This info refers to our unplanned or 'RTT' waiters.

a. Primary lip surgery
b. Primary palatal surgery
c. Alveolar bone grafts

We are completing all primary lips and palates within the national protocols of first lip repair lip repair at 3-6 months (by 6 months) and palate repair 6- 12 months (by 13 months). ABGs are a little more variable depending on the individual surgeon – one surgeon has limited access to paediatric lists and so his waits are longer but all ABGs are being done before 52 weeks and most within 6 months. The need for extractions before listing for ABG (versus extractions at the time of surgery) can complicate the picture and we are currently discussing what variation there is on this within our own service but also nationally – hopefully we will run an audit to look at extractions pre ABG.

- Secondary Surgery Status This info refers to our unplanned or 'RTT' waiters.

a. Speech surgery
b. Orthognathic surgery
c. Lip/Rhinoplasty surgery

It is difficult to report entirely accurately on our secondary and adult surgeries at this time because, in the move to the Epic IT system, there has been a 'glitch' where our RTT has been merged with the paediatric plastics surgery and patients have to be manually checked rather than sorted in a database. We haven't 'lost' patients but the task of reporting on wait lists is a much longer process at present.

Secondary surgery is hardest to quantify as it varies from surgeon to surgeon. We have fewer adult lists post-covid and two of our surgeons don't have their 'own' adult lists and are reliant on dropped or given over lists from colleagues – hence there are longer-waiters for these surgeons. But we have a plan to deal with this issue and make sure these adults get their surgeries.

For adult **speech surgery** we have just 3 waiting over 18 weeks and none over 52 weeks. There are 6 children waiting for **speech surgery** over 18 weeks but none longer than 32 weeks and all have a plan.

We are on track with our orthognathic surgery – we have one patient waiting over 52 weeks but this is due to issues with finding dates that the patient can accept rather than a service backlog.

For adults - we have 7 patients waiting over 18 weeks for **lip revisions** and 2 of these are over 52 weeks (1 has a date). 4 of these patients are waiting for surgeons who do not have adult lists. We have been given permission to operate on the youngest patients (17 and 18 years old) in the children's hospital

We have 10 patients waiting over 18 weeks for **nose revisions** and 3 of these are over 52 weeks (2 have dates).

- Current Risks/Threats to Service Delivery

The move to the ABCD theatre timetable (repeating 4-week pattern rather than having 5th days of the month anymore) at the end of April 2023 has been achieved but it has impacted particularly on staff members who work in other roles or trusts which have remained on a 12-month year. This has affected our orthodontic team in particular and has led to clinicians dropping days where they cannot make their external timetables match with the ABCD pattern.

The switch over to the EPIC database in early October 2023 has also had a significant impact on all Evelina services. It has been challenging to get to grips with the new system – the training was not fit for purpose and there are lots of problems. We are in the 'optimisation' phase now and slowly resolving issues one at a time – problems have included not being able to specify the appropriate clinical procedure when booking surgery, not having letter templates set up, clinicians having to make 'orders' for patient appointments as admin are unable to action anything without an 'order' etc.

C5: TRENT REGIONAL CLEFT NETWORK-JASON NEIL-DWYER

- **Staffing updates**
    - Unable to appoint to 0.6 wte Band 7 Psychology post – currently rebanding
    - Lead orthodontist retire and return – appointing new lead 1/1/25

- **Primary Surgery Status:**
    a. Primary lip surgery (3-5 months)
    b. Primary palatal surgery (6-10 months)
    c. Alveolar bone grafts (12 months from listing – extracontractual consultant surgeon providing additional lists and clinics monthly from January 2023)

- **Secondary Surgery Status**
    d. Adult waits slowly reducing approx. 6-9 months
    e. Speech surgery (2-3 months)
    f. Orthognathic surgery (on 72 weeks)
    g. Lip/Rhinoplasty surgery (less than 6 months)

- **Current Risks/Threats to Service Delivery**
    - University Hospitals Leicester and Leicester Partnership Trust challenging legacy funding of Leicestershire Specialist Speech therapist. Awaiting meeting with previous Specialised Commissioner as representative of East Midlands Specialised Commissioning ICB forum.

C6: NORTH THAMES CLEFT UNIT-PATRICIA RORRISON

- Staffing updates

We have appointed a 0.6 WTE paediatric dentist.This is a step forward, but we need to recruit another paediatric dentist and have a significant backlog for treatment
Otherwise a full complement of staff, with a maternity locum in place for one of our CNSs
We may have a problem with sickness absence in SLT, this may cause difficulty with staffing VPI clinics.

- MDT clinic delivery/status

No problems, but potential for difficulty in staffing VPI clinics with the added complication of a planned refurbishment of the fluoroscopy suite.
Plans in place to start an holistic MDT at Royal London Hospital to streamline adult care. Extra SLT support will have to created for this.

- Primary Surgery Status
    a. Primary lip surgery – timely repairs 3-6 months unless any medical issues cause delay
    b. Primary palatal surgery – timely repairs 6 - 13 months unless any medical issues cause delay
    c. Alveolar bone grafts – no problems

- Secondary Surgery Status
    a. Speech surgery – 3-6 month waiting list
    b. Orthognathic surgery – delays mainly caused by difficulty in streamlining transition to adult clinics at both Chelmsford (plastic surgery and SLT) and Royal London Hospital (maxillo-facial only)
    c. Lip/Rhinoplasty surgery – 6-9 month waiting list

- Current Risks/Threats to Service Delivery

Problems with funding EPG plates as changes in management have resulted in a loss of continuity of understanding of basic service specifications. Frustrating to be arguing to have normal cleft care provided.
Disappointing decision by management that they will not provide the top up funding to allow North Thames to host a TIG Cleft Fellow.

C7: WEST MIDLANDS CLEFT SERVICE – KHURRAM KAHN

1. **Staffing Update**

- Neil Brierley has started as substantive Cleft Surgeon Jan 2023
- Hannah John commenced as Locum Cleft Surgeon March 2023 for maternity leave cover 12 months
- Maternity leave in Orthodontics from Oct 2023 has caused significant disruption. Planned interim cover from Jan 2024.
- Sickness in paediatric cleft psychology has caused significant disruption for several months, cover in place from Nov 2023.
- Loss of funding for Adult cleft psychology has caused significant disruption since March 2023.
- New SLT appointments (x2). Mat leave Beth Fitzpatrick for 12 months.

2. **MDT Clinic delivery/status**

- Addressing significant delays in protocol appointments due to on-going effects of pandemic and staff shortages. A number of extra clinics have been run/put in place along with re-organisation of protocols.
- Dental OPD refurbishment resulted in a reduced service for several months. Upgrade has increased clinic room capacity.

3. **Surgery Status**

- The team has worked very hard over the last year to reduce significant wait times, in particular for speech surgery.

- Lip: 4-6 months (including 1st stage for UCLP/BCLP)

Palate: 6-9 months, 9-10 months for PRS (preferred age)

- ABG: 9-10 years

- Speech Surgery: 6 – 12 month wait time

- Adult service: still significant delays in surgical wait times across the board. Hoping for increased capacity and access from April 2024.

4. **Current Risks/Threats to Service Delivery**

- Orthodontic cover for next 12 months will have significant impact for the paediatric and adult population
- Adult Psychology in particular has been challenging to address. We have put any new patients referred to the adult service on hold until adequate cover is put back in place.

- Theatre capacity has been reduced by 4 sessions per month. Job plans have been re-organised, and commissioners informed. Due to review in 6 months time, but according to current capacity and demand models this will yet again disrupt waiting times for surgery.

C8: CLEFT NET EAST-PERI CODLING

- Staffing updates

Network Manager – We welcomed Nathan King who has been seconded for a year to replace Mary Bance who is undertaking a new role in women and children's service, unfortunately Nathan was offered a substantive post as a deputy Operational Manager and left in the summer – He is still supporting the service in his new

capacity but we have yet to replace his.
Psychology We have re Banded the 1.4 WTE band 7 posts which we have been unable to fill into 1 WTE bank 8a. We are optimistic that we will be able to recruit shortly but in the meantime, the impact of this is no Psychology support in any clinics and a lengthy triage process with longer waits for patients to be seen following referral and issues not being picked up face to face in clinics.
SLT – Hannah Chandler has replaced Lucy Southby as the Lead for the SLT service in a development role. George returned in June but on a reduced contract. Staff is limited in SLT but we are looking to recruit a further Band 6/7 full time. Again poor staffing in this service has resulted in clinics not being covered by a full MDT
Clinical Nurse Specialists – We are currently at full capacity having recently recruited a new Nurse to the team and welcome Tracey Taylor to the team
Dentistry – Jackie Smallridge left at the end of August and we have successfully been able to increase the number of PA's for our dentistry service to 8 and have recruited 2 new Paeds Dentists one @ 6 PA's another hopefully @ 2 PA's – hoping to welcome them in the new year.
Orthodontics – We are currently attempting to recruit a second Orthodontic consultant after losing Sally Zahran in October – this has also impacted on clinic activity and waiting lists.
Audiology – Some issues with getting children seen locally in some spoke hospitals due to capacity which adds pressure to the one day a week we are currently funded for.
Surgeons – 3 full time Surgeons with 1 part time surgeons in post – Sadly Per Hall retired at the end of November it is unclear if we will be able to recruit into his part time post. Strike action, BH and other factors has hugely impacted on access to regular lists for some of our other surgeons ,but we are not quite back to pre-Covid numbers, despite an increase in our birth numbers over the previous 12 months (2022 – 88 babies). We are struggling to meet the expected ages for both primary lip and palate repairs and we have a number of ABG's still waiting for surgery.
Admin - The admin team are struggling with the loss of an SLT assistant, a secretary and the waiting list co-ordinator over the past 3 months and our spoke secretary is currently on Parent leave. We welcome the return of Jenny Bailey 3 days a week (reduced from FT), another secretary who has recently returned from parent leave this month. Our Admin team have also completed GCP to support collection of Crane consent for those children missed (2015-2017. Although this is currently on hold due to capacity.

Risk factors and concerns

Ongoing issues with Dentistry and long waiting lists – reported and added to the risk register. We anticipate that this will improve once the new dentists are in post

Numbers of cancellations almost weekly of children having primary and secondary surgery, due to poor health/URTI, on our surgical lists – difficulties with repeated cancellations for some children and a higher number of complex babies results in children being much older and falling outside of the expected age range for lip and palate surgery.
Identified poor support from Local teams to monitor the well-being of children- paediatric and anaesthetic reviews- Inability to review children face to face by anaesthetic team due to capacity/not part of Job plan/inadequate numbers of paediatric anaesthetic consultants for reviews/No additional clinic space and time etc.

Reintroduction of a Face to face Pre-assessment by CNS to assess and create a pool of children, who can be added into lists at short notice rather than lose slots on theatre lists is working well. Also developing a model of care to identify a patient who can attend at short notice to fill vacant slots when there are short notice cancellations

We have worked hard to improve our crane data completeness and although some areas have improved we still have a little way to go.

Staffing has had a big impact on our service and on moral, with staff struggling to attend clinics and meet expected standards.

I will be stepping down as the clinical lead and Lead CNS and retiring from the NHS after 42 years as of the 2nd February 2024.

C9: NORTH WEST, ISLE OF MAN and NORTH WALES NETWORK - CHRIS SWEET

- Staffing update

Nursing
Appointed 1 band 7 CNS F/T post in Oct. Starting post in Jan 24
Did not appoint to 12 fixed term post
1 CNS on sick leave

Paediatric dentistry
RMCH: Fixed term specialty paediatric dentist post has been approved. Will be going out to advert asap. Hope this will allow team to address back log of pts.

Orthodontics
Continued pressure on Lancashire out reach service due to P/T Locum at Royal Preston Hospital.

Admin
Have appointed to SLT admin post at RMCH. Vacant secretarial post in RMCH. Considering conversion to data clerk role for the network.

Clinical director
Miss Beale stepped down from role after 6 years as Network CD. New CD appointed after interviews in June. Started role Sept 24 (Mr Chris Sweet, Cleft/OMFS surgeon, Alder Hey) 3 year tenure.

Psychology
Alder hey: 1 cleft psychologist (Band 7) has left the team leaving a vacancy. Hopefully new psychologist will join the team early 24 (limited previous cleft experience)

Surgery
Alder Hey. Resignation of senior cleft surgeon due to retirement. Leaving service end of March 24. Recruitment process to appoint replacement surgeon is in progress.

- MDT clinic delivery/status

No psychology attendance to regular MDT clinics

- Primary Surgery Status
    a. Primary lip surgery
    b. Primary palatal surgery
    c. Alveolar bone grafts

Achieving national specification for surgery across the network at present. Reduced capacity across both hospitals may challenge this position.
On going pressures at RMCH with reduced theatre capacity. Vacancies for Approx. 40 members of theatre staff.
Alder Hey had previously been offering mutual aid to RMCH. There has now been a reduction of 15 theatre sessions (multispecialty) per week in Alder Hey theatres. This equates to a loss of 2 full day cleft lists per month.

- Secondary Surgery Status
    a. Speech surgery
    b. Orthognathic surgery
    c. Lip/Rhinoplasty surgery

Surgery
Currently managing case load across network and ensuring patients are treated to national specification, resulting in increased waiting times for revisional and non cleft VPI surgery patients.

Adult surgery Manchester: 15-18 months wait.

Alder Hey: Improved due to improve, regular adult theatre access.

- Current Risks/Threats to Service Delivery

The risks are as described above. Reduced access to theatres across the network and staffing vacancies.

C10: LEEDS CLEFT UNIT-ALISTAIR SMYTH

1. Staffing updates
Full complement of staff. Commencement of second cleft surgeon (current locum appointment) in September 2023 however still awaiting provision of additional regular theatre capacity.
2. MDT Clinic Delivery – full resumption of patient-attending full day MDT clinics throughout the clinical network
3. Primary Surgery
a. Primary lip surgery – continue to offer optimum timing of surgery according to national and local protocol in appropriate cases (3-5 months of age)
b. Primary palatal surgery - continue to offer optimum timing of surgery according to national and local protocol in appropriate cases
c. Alveolar bone grafts – some impact on reducing waiting times over last 6 months however delayed waiting time to surgery remains (presently around 12 months). Trust have entered negotiations with twin-site service in Newcastle regarding possible assistance. Cleft Orthodontic provision in Hull remains a challenge due to resignation of previous consultant orthodontist and part-time contract of present incumbent.
4. Secondary Surgery
a. Speech surgery – continuing delay in timely provision of secondary speech surgery (6-12 months). Anticipated reduction in waiting times prevented by delayed provision of additional theatre sessional capacity following appointment of second surgeon.
b. Orthognathic surgery – no delay in provision. Timely provision of surgery following pre-surgical orthodontic preparation.
c. Lip/Rhinoplasty surgery – no significant delay.
5. Current Risks/Threats to Service Delivery
Need for additional regular theatre sessions to manage bone grafts and secondary speech surgery requirements.
A.Smyth Lead Clinician

C11: NEWCASTLE CLEFT UNIT-PETER HODGKINSON

1. **Staffing updates**
Full complement of staff. Change to Lead SLT from with the unit.
The senior surgeon has reduced their hours, and an excellent new cleft surgeon has been appointed, starting 30 October 2023. The appointment process was marred by significant external influence that caused a lot of stress and upset throughout the cleft unit and beyond. These external pressures resulted in the Clinical Lead and, all but one other member of the cleft team, being excluded from the selection process. It appeared that external support for a particular surgical specialty was being prioritised above the appointment of the best candidate.
2. **MDT Clinic Delivery** – we continue to deliver most clinics in Newcastle but have recently resumed clinics in Middlesbrough, our second largest spoke.
3. **Primary Surgery**
Our surgical planning has been upset by inefficiencies in the waiting list office, but this is being resolved. We currently maintain parallel waiting lists within the team.
a. Primary lip surgery – continue to offer optimum timing of surgery according to national and local protocol in appropriate cases (3-5 months of age)
b. Primary palatal surgery - continue to offer optimum timing of surgery according to national and local protocol in appropriate cases
c. Alveolar bone grafts(abg) – currently a 3-4 month wait but keeping up and very well supported by our abg clinic. We hope to be able to support Leeds but will be hampered in this by the continued shortage of beds in the GNCH. We are looking to modify surgical protocols to mitigate this.

4. **Secondary Surgery**
a. Speech surgery – currently a 3-4 month wait
b. Orthognathic clinics/surgery – no delay in provision. Timely provision of surgery following pre-surgical orthodontic preparation.
c. Lip/Rhinoplasty surgery – currently probably nearly a 12 month wait, partly due to prioritising abg and speech surgery.
5. **Current Risks/Threats to Service Delivery**
The on-going children's bed shortage and the waiting list inefficiencies are our biggest concerns. Having what is essentially an additional 0.4 senior cleft surgeon who can work flexibly for the next year may mitigate this.
6. **External support**
The Newcastle Cleft Service has in the last 12 months supported Cleft Services in Nepal and the Philippines and hopes to continue this work.
We remain happy to share with anyone good practice across the team but particularly in surgery.
Peter Hodgkinson, Clinical Lead Newcastle Cleft Service

C12: CLEFT SURGICAL SERVICE FOR SCOTLAND-TOBY GILGRASS

- **Staffing updates**
    - 0.5 CNS down advert soon Plus Clinical assistant for CNS.
    - Issue relating to consent (retrospective to add 2016/2017 data)

- **Primary Surgery Status:**

Challenges gaining all lists. Slow increase in age of procedures. Presently just within CCS guidance (As dashboard).

a. Primary lip surgery (4-5 months)
b. Primary palatal surgery (10month)
c. Alveolar bone grafts (< 3months from ideal)

- **Secondary Surgery Status**

h. Adult waits slowly reducing approx. 6-9 months
i. Speech surgery (9 months)
j. Orthognathic surgery (a.a)
k. Lip/Rhinoplasty surgery (a.a.)

- **Current Risks/Threats to Service Delivery**
    - Lists have become more regular, and threat reduced.

C13: NORTHERN IRELAND UPDATE-CHRIS HILL

- **Staffing updates**

2nd surgeon due to start in NI in near future which will relieve pressures on waiting lists for MDT clinics in both paediatric and adult sectors however difficulty is staffing pressures in Dental. Following resignation of Speciality Dentist earlier this year we have a Consultant Dentist with 2 sessions in Cleft Unit, and she is due to leave post in January 2024. The updated ad for specialty dentist with cleft sessions is due to released imminently. No plan as yet for replacement of Consultant dentist with Cleft sessions.

The NHSCT recently re-advertised a part-time Orthodontic Consultant post with a regional role in orthodontic treatment of cleft patients. The closing date was the 3rd November but once again there were no applicants. Darren Johnston therefore remains the NHSCT's only orthodontic consultant and the regional cleft orthodontist. This was originally agreed as a temporary role and is not sustainable.

Continued efforts to secure post in Restorative Dentistry which includes Cleft sessions for our older teens and adults. Latest update from RD; post is awaiting approval from Royal College.

Have had no Psychologist for several months due to vacant post, new Psychologist due to start next month (0.6WTE).

Down to one Cleft Coordinator due to retirement (Pamela Larmour has retired) with no admin support.

- **MDT clinic delivery/status**

Due to long w/l particularly at 10/15/20 year age groups we are offering palate only patients clinics without Surgeon in order to address this.

2nd opinion referrals are waiting 12 months for initial assessment – in order to attempt to deal with this, we are adding 1 patient from this w/l to a Cleft MDT clinic when surgeon is present.

- Primary Surgery Status
    a. Primary lip surgery/ primary palate repair

2022 births
Cleft Lip only: 5 births
Number Waiting: 1
Average age at time of surgery: 3.25months

Isolated Cleft Palate: 14 births
Number waiting: 4
Average age at time of surgery: 13 months

Cleft lip/palate: 5 births (x1 RIP)

BCLP's: 2
Average ages for Lip Adhesion: 3month
Average age for Definitive Lip and Palate Repair: 7-8 months
Average age for Residual Palate Repair: >13 months see below

15 months awaiting residual soft palate repair
Was booked for 10/11/23 age 15m but RBHSC cancelled due to no over night bed
Second waiter is 12 months listed for Dec but ??over night bed availability

UCLP: 2
Age of longest waiter and reason: 0 at present
Average age for Definitive Lip and Palate Repair 5 months
Average age for Residual Palate Repair x1 12m, x 1 13.5 months

Lip/hard palate repairs waiters: 0

Others:
X2 Cleft Lip and Cleft of Soft Palate - repaired
X1 Cleft Lip and SMCP – repaired
Query SMCP Referrals – 5 that are being kept on case load – others have been d/c , x1 had surgical repair

    b. Alveolar bone grafts

In 2022 21 patients had ABGs (25 actual grafts placed)
In 2023 (to date) 38 patients have had ABGs (47 grafts placed)
With visiting Cleft surgeon Tom O'Neill, there have been 59 patients grafted (a total of 72 actual grafts placed)
When Tom started in July/August 2022 there were 42 patients ready and waiting for ABG (some were on the UHDs surgery waiting list others were not) so we have provided ABGs for all of these patients as required.
Currently 35 waiting for ABG.

- Secondary Surgery Status
    a. Speech surgery

26 children waiting for secondary surgery, longest waiting 2 years for pharyngoplasty (lack of overnight beds resulting in long waiting times)

6 adults waiting for speech surgery – longest waiting 3 years (lack of theatre space in Ulster Hospital for adult cleft patients).

b. Orthognathic surgery

Currently no Regional Cleft Maxillofacial surgeon, unable to access figures of those waiting as SEHSCT who hold this w/l have moved to Encompass – currently following this up.

c. Lip/Rhinoplasty surgery

60 adults waiting on lip/rhinoplasty in Ulster hospital
16 children waiting for rhinoplasty; 15 children waiting for lip revision; 1 repair uvula

- **Current Risks/Threats to Service Delivery**

Staffing pressures
Lack of beds available in hospital to allow overnight stays following surgery
Waiting lists for surgery and OP clinics

APPENDIX D: CEN AND LEAD REPORTS

D1: CLEFT NURSING CEN AND NURSING LEAD GROUP

CLEFT NURSING CEN-HEATHER SAHUNTA

The cleft nursing CEN continues to build with enthusiasm as we continue with the utilisation of MS Teams for peer communication and support.
Following on from the excellent and varied meeting held during conference in Cardiff the group have recently held their Annual Autumn meeting online, where nurses' were able to share experience and practices of cleft nursing. On this occasion the themes were varied and less UK based as we were able to invite nurses from Australia, The Netherlands' and Sweden to share their experience of cleft pathways of care, an experience of supporting oversea cleft care in India and project work around cleft palate diagnosis particularly in relation to the late/missed opportunities. This project work is the result of a proposal at the Cardiff meeting to develop a subgroup within the main CEN around development and the evidence, since then the 'Innovation, Development and Evidence Based Practice' group has been formed and with undying enthusiasm is pounding along. The group is made up of a representative from each network, meetings are online approximately every 6-8 weeks. Their initial project has been continuation of some fabulous work commenced by Jane Sibley (Spires) regarding cleft palate and tongue ties, where Jane has developed links with the Tongue Tie Practitioners Association who are receptive to working with and learning from cleft specialist nurse's. Its watch and wait at the moment as there's some fabulous ideas and resources in the pipeline as well as rumblings for a next project. The group have nominated themselves a committee with Jane Sibley as Chair who will feed into the main CEN committee.
The Cleft Course hosted through Anglia Ruskin University had great success with its first cohort of students building friendships, professional networking support and best of all they have all 'passed' the module. There was lots to share and learn from variations in practice across the networks as well as asking the 'why's and how's'. We look forward to welcoming the next cohort in February 2024, and thank those from across the networks with continued support of sharing knowledge and practice particularly in delivering lectures as part of the timetable.
Moving on it feels like we will continue to go from strength to strength as a CEN, with members having been encouraged to consider joining the Craniofacial Society of Great Britain and Ireland.

Heather Sahunta
Lead Nurse and Chair for Nursing CEN
Trent Regional Cleft Network
Nottingham Children's Hospital

CLEFT NURSING LEAD GROUP:
Recent meetings

Lead Nurse meeting 21/09/2023 Virtual Chris Couhig (Chair) Heather Sahunta (Deputy Chair)
Ongoing programmes of work

- National service specification
- Cleft Collective Intervention Study. Continue to support this study with consenting parents Antenatal and Postnatal.

Planned programmes of work

- Supporting and teaching on forthcoming cleft course February 2024
- Innovation, Development and Evidence Based Practice group (see CEN report)

Issues to be discussed/raised at CDG

- Despite great efforts to recruit we have only managed to recruit 55 patients out of the predicted 244 infants. Following the end of the 6 month extension period CI Professor Iain Bruce has made the decision to close the SLUMBRS 2 study.

Forthcoming meetings
5th December 2023 Virtual

D2 CLEFT CLINICAL PSYCHOLOGY CEN-REBECCA CRAWFORD

- Recent meetings

a. Ongoing programmes of work

- Working on considering possible alternative audit outcome measures to SDQ & alternative audit ages
- Sub group met in October 2023 to discuss outcome measures
- Continuing to collaborate with CRANE to discuss new data to be included
- Started to look at Adult Cleft Care Pathways and equity across services

b. Planned programmes of work

- Sub group to meet again in January/February 2024 to discuss outcome measures
- Submissions for Manchester conference 2024
- A range of other topics, CPD, case discussion & programmes of work will be covered at CEN meetings throughout 2024

c. Issues to be discussed/raised at CDG

- Adult Cleft Care Pathways

- Planned meetings

- Next meeting 07/02/24
- The Cleft Clinical Psychology CEN will meet 4 times a year in 2024 as usual.

D3 CLEFT ORTHODONTIC CEN – JULES SCOTT

1. Recent meetings

a. Ongoing programmes of work

- Recollecting waiting list data as of 1st November for ABG and Orthognathic cases to share with Liz Jones (GIRFT) and to inform the current position.
- Quarterly cleft leads meetings
- OCEN subgroup working to provide feedback for cleft collective 15y questionnaire

b. Planned programmes of work

- Developing gold standard photoset for UCLP/BCLP scoring
- Toby Gilgrass leading pilot study looking at PAR in cleft patients using SMs – will be assessed in Manchester ?provide outcome for CRANE? Also allows us to look at growth.

c. Issues to be discussed/raised at CDG

- Ongoing concerns about lack of provision of routine dental care for patients - raising at all appropriate forums – JS to contact LDC chair nationally
- Concerns with patients dropping out/ prolonged treatment due to delays (capacity issues)

2. Planned meetings

Leads meetings: 26 Jan 2024, 26 April 2024, 19 July 2024, 25 Oct 2024 (all 08:00- 09:00 virtually)
CEN meeting at CFSGBI meeting in Manchester April 2024

D4: CLEFT PAEDIATRIC DENTAL CEN -JO MAY

- Recent meetings 15th November 2023 – virtual

a. Ongoing programmes of work
   i. Dental deserts project, final questionnaire data to be submitted to Amy Hollis by 30th Nov to be presented at Manchester 2024
   ii. Enamel hypoplasia in primary molars – Data collected from 5 units to be presented at Manchester 2024
   iii. Burden of dental care in cleft children –continuing to collect national data on number of appointments and travel times
   iv. Outcomes for children with PRS – using cleft collective data
   v. Case series for SATB2 children – dental presentation and management
   vi. PROMS for cleft patients
   vii. Online access to calibration through CFSGBI website – British Society of Paediatric Dentistry unable to fund this but updated business case to council

b. Planned programmes of work
   i. Utilisation and publication of 20 + years of dmft data and trends within the data
   ii. Further discussion and analysis of the Developmental Defects of Enamel data collected by the CEN for the last few years
   iii. Collation of leaflets to publish a national leaflet on dental care for children born with clefts and/or a video to go on the website with oral health advice
   iv. Discussion with surgical CEN about timing of dental extractions and ABG

c. Issues to be discussed/raised at CDG
   i. Calibration and maintenance of this long term
   ii. Discussed service specification and we are happy with the current standards and timeframes for paediatric dentistry

- Planned meetings

Face to face meeting April 2024

D5: CLEFT SPEECH AND LANGUAGE THERAPY CEN AND LEAD GROUP-IMOGEN UNDERWOOD

CEN study day (virtual) 17/11/2023	
Speech outcomes for children post-tonsillectomy	**Lucy McAndrew** *Spires Cleft Centre*
CLAPA UPDATE	**Claire Cuniffe** *CLAPA*
Additional Congenital differences and speech **Newborn Hearing experience and speech**	**Dr Sophie Butterworth** *CRANE*
Consider the Chiari - The impact of a Chiari 1 malformation on velopharyngeal function: two case studies.	**Sarah Kilcoyne** *Oxford Craniofacial Unit*
Nasal Obturators - an update	**Alison Birch** *Evelina London Cleft Service* **Jo Waldon** *South West Cleft Service*

Installation of Honourary Members Cleft and Craniofacial CEN Caroleen Shipster Marie Pinkstone	
SPOT - Sensory considerations in Therapy	**Caroleen Hattee** CleftNet East **Sophie Steele** *Occupational Therapist*

Lead SLT group 14/11/2023, Imogen Underwood has taken over from Ginette Phippen as Chair
Matt Fell, Surgical Fellow recorded presentation on recent TOPS paper (NEJM)

Ongoing programmes of work

- National service specification (specialty specific updates proposed)
- Cleft Collective Intervention Study. Some centres expressed concern about the amount of work involved. Lead SLTs are committed to principle of this study and collecting this data but teams will have to monitor demands and proceed at their own pace with data collection.
- Work with CRANE on static speech outcomes and variation between units

Planned programmes of work

- Planning for Cleft@20 research involvement, liaison with Yvonne Wren
- Review of use of nasometry
- Review of SLT led nasendoscopy and use of procedure generally**Issues to be discussed/raised at CDG**
- Updated CRANE guidance for registration individuals with SMCP

D6: CLEFT SURGICAL CEN-GUY THORBURN

- Recent meetings

Face to Face meeting 19/4/23 Cardiff

We also combined with the orthodontic CEN for 1 hour (standing room only) for discussion of growth measures and views on publishing identified outcomes.
Clinical discussions on ABG, cleft nasal surgery, and approached to extremely wide palates.
Updates from multiple other groups eg Headlines, CLAPA, Cleft Collective.
Initial discussions about cleft service spec updates – presented by Simon.

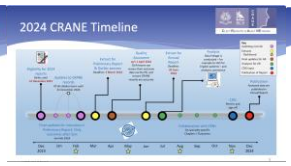
a. Ongoing programmes of work – Service Specification wording – pulling together feedback from the CEN about future updates and wording. Parts of the current document apply obligations on individual surgical consultants rather than on the Trusts, when it is the Trust that enters the agreement with commissioners. Other aspects would benefit from update to reflect that challenges with delivering services have changed over time, and reflect more recent progress such as GIRFT.
b. Planned programmes of work
c. Issues to be discussed/raised at CDG - nil

- Planned meetings

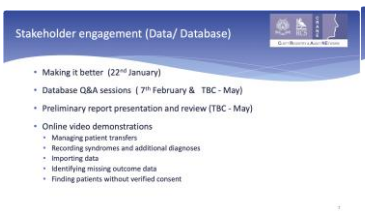
Next Virtual Surgical CEN Meeting Thursday 11/1/24 1300-1700 – pressure on everyone's clinics and operating lists making it increasingly hard to find an agreeable date…
Plan is to continue one F2F and one virtual meeting per year.

APPENDIX E: CRANE REPORT – CRAIG RUSSELL

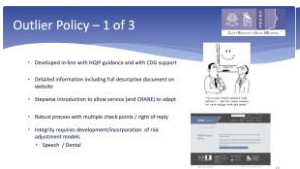

CRANE Team
Currently 1.75 WTE's
Programme Manager - Jibby Medina (0.2 wte)
Historically significantly more
Research Fellow - Kate Fitzsimons (0.8 wte)
Maternity Cover for KF extended to March 2024
Clinical Research Fellow - Sophie Butterworth (0.4 wte)
Clinical Project lead - Craig Russell (0.2 wte)
Clinical epidemiologist - Jan van der Meulen (0.05 wte)
Data Manager - No person in post
CEU Admin. Support Officer – Recently appointed (0.1 wte)


2024 CRANE Timeline


Alert
Please remember when contacting CRANE about a patient
Only use CRANE ID
Never send patient identifiable information:
NAME
DOB
HOSPITAL NUMBER
STOP


Stakeholder engagement (Data/ Database)
Making it better (22nd January)
Database Q&A sessions (7th February & TBC - May)
Preliminary report presentation and review (TBC - May)
Online video demonstrations
Managing patient transfers
Recording syndromes and additional diagnoses
Importing data
Identifying missing outcome data
Finding patients without verified consent

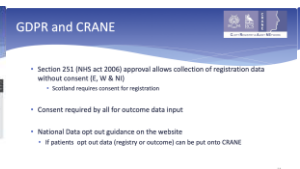

Database Enhancements
Achieved 2023 – Useability
Scotland incorporation
Ethnicity
Syndromes / Congenital malformations
DDE
Developments by year end
Removal of Unconsented Outcome data
Psychology (TMS revisions)
LAHSHAL – on hold until inter and intra relator reliability better understood
Uncoupling of SMCP and LHASAL small 's'
Updating dmft inconsistencies


Outlier Policy – 1 of 3
Developed in-line with HQIP guidance and with CDG support
Detailed information including full descriptive document on website
Stepwise introduction to allow service (and CRANE) to adapt
Robust process with multiple check points / right of reply
Integrity requires development/incorporation of risk adjustment models:
Speech / Dental

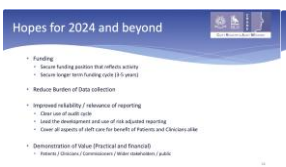

Outlier Policy – 2 of 3
Positive response to the pilot
Helpful particularly in resource discussion
CDG approval for incorporation into reporting cycle
Piloted 2020-21
Introduction / adoption into reporting practice 2022-2025
Notification of alert / outlier status to CO's 2022 onwards
Right of reply inception (unedited responses included in annual report appendix)
2-year alerts will be identified as outliers from 2023 report
Aim introduction of risk adjustment for speech and dental by 2025 report
Full active reporting to begin in the 2025 annual report cycle
Including notification of outlier status to MD's / CEO / CQC or equivalent
Process / outcome


Outlier Policy - 3 Of 3
Risk Adjustment
Speech
Cleft type/Extent of HP involvement /PRS/css
Associated Cardiovascular/ Neurological malformations
Socio-economic status / timing of operation/ number of operations
Dental
Cleft type / Social Deprivation
Risk adjustment will be an iterative process improving over time as more becomes known about determinants of outcome
Identify
Publish
Incorporate with CDG approval


Governance and QMIC
Responsible to Lead Commissioner (NHS England)
CRANE Activity and reporting overseen by CDG
Quality Improvement involves Completing the Audit Loop
Local and National
Local
National
QMIC
CDG / CFSG&L


GDPR and CRANE
Section 251 (NHS act 2006) approval allows collection of registration data without consent (E, W & NI)
Scotland requires consent for registration
Consent required by all for outcome data input
National Data opt out guidance on the website
If patients opt out data (registry or outcome) can be put onto CRANE


Use of CRANE data


Hopes for 2024 and beyond
Funding
Secure funding position that reflects activity
Secure longer term funding cycle (3-5 years)
Reduce Burden of Data collection
Improved reliability / relevance of reporting
Clear use of audit cycle
Lead the development and use of risk adjusted reporting
Cover all aspects of cleft care for benefit of Patients and Clinicians alike
Demonstration of Value (Practical and financial)
Patients / Clinicians / Commissioners / Wider stakeholders / public


Sharing of CRANE Data
Funder Requires Data Sharing Policy to be put in place (cost recovery)
Policy will be developed in line with HQIP/NHS Digital process cost model
CRANE can only put in place once we have secured funding model that allows monitoring of contracts


CRANE Collaborations
Individual with good research ideas can approach CRANE for collaborative research /developmental work
Requires A4 proposal
Intro / literature review
Clear question
Proposed methodology
Dissemination plan
CRA adoption / support
Ability to engage will be very much dependent on current workload / planned work loads at CRANE
CRANE project team will review and advise on viability / timescales
In such instances Data cannot leave CRANE
Either in house analyses and results shared
Or Honorary contract to work at CRANE

APPENDIX F RESEARCH UPDATES
F1: CLEFT COLLECTIVE-YVONNE WREN

Research updates/Cleft Collective_CDG_UpdateRepNov2023_FINAL.pdf

F2: Early Career Researchers Group / Cleft Multi-Disciplinary Collaborative -SOPHIE BUTTERWORTH

Background
The Early Career Researchers Group (ECRG) and Cleft Multidisciplinary Collaborative (CMC) exist to expand and enhance the opportunities for its members to engage with high quality research and quality improvement projects, benefiting NHS Trusts and ultimately our patients. It is open to all disciplines involved in cleft care, regardless of an individual's clinical or research experience.

Current membership

Sophie Butterworth was appointed as Chair of the ECRG March 2022. Stephanie Van Eeden is Vice Chair.
2022 meetings (Over 30 MDT members)
March hybrid face to face and virtual
June virtual meeting
October virtual meeting + CPD (Analysing large datasets using STATA and R by Penny Birmpili)

2023 meetings (Over 50 MDT members)
April face to face meeting
September virtual meeting + CPD (Thematic analysis by Amy Burton, Associate PI scheme by Holly Speight)
December virtual – hoping to discuss how to write an abstract and how to peer review a paper

Previous Projects

1. **Scoping Review of Outcomes for Children with Bilateral Cleft Lip and Palate**

Current status

- Oral presention at CFSGBI 2023

Data extraction is complete and SLT group will continue to write up as a broad scoping review identifying gaps in the research with regard to BCLP outcomes. Not all specialty groups were able to identify sufficient data to complete a scoping review, particularly nursing group.

2. **Non-Interventional Factors Influencing Outcomes in Velopharyngeal Function in Initial Cleft Palate Repair - A Systematic Review**

Current status

- Protocol published (*Systematic Reviews* 2019 8:261)
- Funding received from CFSGBI to fund 8 licenses for Distiller SR (systematic review software) for 12 months.
- Three levels of screening completed and data extraction of 383 papers completed.
- Poster presentation at CFSGBI 2021
- Presented at International Cleft Meeting 2022
- Published in CPCJ 2023

Background

This systematic review aims to inform the development of a screening tool which pre-operatively predicts which children are likely to develop velopharyngeal insufficiency, one of the causes of poor speech outcomes, following cleft palate repair. This would be highly beneficial as it would inform pre-operative counselling of parents, allow targeted speech and language therapy and enable meaningful comparison of outcomes between surgeons, techniques and institutions. Currently it is unclear which factors influence speech outcomes. A systematic review investigating the non-interventional factors which potentially influence speech outcomes following cleft palate repair is warranted. This may be inherently illuminating or provide foundations for future studies.

Publication available on request.

3. <u>Outcomes for Robin Sequence</u>

Current status

- Presented at ECPCA, Utrecht, June 2019
- 10 centres involved in UK
- Data on 250 patients
- Presented at International Cleft Meeting 2022
- Manuscript in progress – Jane Kerby and Stephanie Van Eeden leading on this

We are looking to describe a group of PRS patients born between 1st January 2005- 31st December 2009. We would like to capture basic demographics, treatment details (for example, airway management, feeding methods, age of cleft repair, requirement for revisional surgery), and then record speech outcomes at 18 months (18-24 months), 3 years, 5 years and 10 years (where available). 5 year speech outcomes has been chosen as the primary outcome measure.

Data from patients across ten sites in the UK has been collected and analysed. This was presented at ECPCA, Utrecht last June. The sites that were included in this initial project were Newcastle, Liverpool, Northern Ireland, Oxford and Salisbury. Five more UK sites have contribute to this dataset. The definition as laid out by the international consensus – micrognathia, glossoptosis, airway difficulties (+ cleft palate in our case).
RS subtype with cleft palate have poorer speech outcomes at 5 years compared to children with cleft palate only but there was no difference by age 10.

4. <u>Impact of the COVID Pandemic on Cleft Surgery</u>

Current status

- Study has been peer reviewed and is supported by the NIHR Cleft and Craniofacial Conditions Clinical Studies Group
- Funding granted from the Edinburgh Clinical Trials Unit for managing the RedCAP database
- Endorsed by the Royal College of Surgeons of England
- Data collection to date:
    - 8 units entering data
    - 651 operations details entered
    - Data entry closed on 7 June 2021
- Oral presentation at CFSGBI 2021 and ACPA 2022
- Presented at International Cleft Meeting 2022

- Manuscript in progress – Alex Plonkowski leading on this

This study aims to determine the impact of COVID on cleft surgery. This the first time in the UK that a large cohort of patients will be undergoing cleft surgery with such large delays in timing of surgery. Additionally, we do not know how the prevalence of COVID in the community and possibly in patients will affect the postoperative course of children undergoing surgery, particularly in the case of babies and procedures that may bring about a temporary reduction in airway volume. Given the relative rarity of COVID in babies and children, it is particularly important that we share data across the UK following the resumption of cleft surgery. This will enable better understanding of perioperative safety and outcomes. Additionally it will provide data to guide practice, in particular the need to suspend/delay elective surgery during further waves of this pandemic. This is also an opportunity to study the impact of delays to planned cleft surgery, in a large cohort and identify any impact on outcomes that may be related to such delays.

This study will also examine cleft surgeons experiences of wearing PPE with loupes, headlights or the operating microscope and will study solutions that may prove useful in similar situations. PPE is particularly relevant for cleft surgery, because the surgeons face is close to the patients mouth and the endotracheal tube (ET) for a considerable duration. Cleft surgery requires a Rae tube, curved to lie flat on a patient's chin. Not all units in the UK had access to cuffed Rae tubes in small sizes and this practice has been changing. Our study will report on these changes.

Primary Objective

- To determine the impact of the COVID pandemic, on elective cleft surgery timings and outcomes.

Secondary Objectives

- Study individual units screening processes, screening outcomes and their impact on clinical decision making regarding timing of surgery
- To determine prevalence of COVID positive tests in infants (and parents where testing is done as part of unit protocols)
- Incidence of post-operative complications
- Impact on patient follow up (remote or in person)
- Duration to return to usual protocol timelines
- Surgeons' reports of challenges of wearing PPE and operating with loupes/headlight/microscope

Primary Endpoint

- Point at which patients are able to have surgery in keeping with UK standards and unit protocols, in terms of timing of surgery.

Study Design

Study type: Observational
Setting: Tertiary cleft centres. All 11 cleft units (16 cleft surgical sites) in the UK will be approached for participation. This will include cleft surgery consultants and trainees. There is an well-established network and history of multicentre collaborative studies across the 11 UK cleft centres.
Study Duration: Until UK Cleft surgery has caught up with the COVID backlog.
Follow up duration: 3-4 months, until patients have had at least one post-op review

5. <u>Delphi Fistula Project</u>

Current Status

- Rounds 1 and 2 of Delphi Survey completed
- 35 members for expert panel
    - 14 cleft consultants
    - 6 SLTs
    - 6 Cleft specialist nurses

    - 3 Paediatric Dentists
    - 6 Orthodontists
- Accepted for presentation at ICCPCA 2022
- Manuscript in progress – Neil Brierly leading on this

The aim of this study is to provide a consensus opinion on how Cleft Teams in the UK report fistulae. An expert panel was invited to complete a short series of surveys, with results anonymised, to demonstrate an unbiased consensus opinion. The questions will not primarily be designed to give all answers to the many questions fistulae pose, but more to provide as close to a robust minimum data set as can be achieved.

New Project ideas presented in 2023

1. Mahaveer Sangha – New surgical member

Interested in completing a study looking at socioeconomic factors in relation to patient outcomes. Discussed ideas within the group and felt using the Cleft Collective data would be beneficial. Alex Gormley agreed to kindly 'Buddy' with Mahaveer to introduce him to the team and help him to start forming a research proposal.

2. Using social media for PPI

Following on from our PPI CPD session in March on 'Seldom heard voices' we discussed the possibility of using social media to discuss research questions relevant to the group. The purpose of this was two-fold, firstly to reach people in the community who may not volunteer to participate in focus groups or research panels ordinarily either due to practical issues (childcare, financial, work arrangements) or other concerns (difficulty with speech and being understood). Secondly, to provide data that could be submitted as part of research proposals before people have been awarded funding for PPI.

We plan to take this idea forward in our next face to face session and will look for some relevant studies such as work by Sam Burr (Bristol) in the meantime.

Updates from members on other existing studies

- Steph Van Eeden – results of CLAS study –PhD work
- Alex Gormley – overview of NIHR doctoral fellowship study
- Hannah Lane – NIHR application for doctoral fellowship study

Completed Projects / Publications

1. **Patient Factors Influencing Speech Outcomes in Velopharyngeal Function Following Initial Cleft Palate Repair: A Systematic Review and Meta-Analysis.**

Sainsbury DCG, Williams CC, Butterworth S, et al. *The Cleft Palate Craniofacial Journal*. 2023;0(0). doi:10.1177/10556656231191384

2. **The Cleft Multi-Disciplinary Team Collaborative: Establishing a multidisciplinary network to support cleft lip and palate research in the United Kingdom**

Sainsbury DCG, Davies A, Wren Y, Southby L, Chadha A, Slator R, Stock NM; Cleft Multidisciplinary Collaborative. *Cleft Palate Craniofac J* 2019;56(4):502-507.

3. **Non-Interventional Factors Influencing Velopharyngeal Function For Speech In Initial Cleft Palate Repair: A Systematic Review Protocol.**

Sainsbury D, Williams C, Blacam C, Mullen J, Chadha A, Wren Y, Hodgkinson P. *Systematic Reviews* 2019 8:261

4. **A Closer Look at the Reasons for Delayed Primary Cleft Surgery and Unrepaired Cleft Lip and /or Palate in Five UK Cleft Centres.**

Sophie Butterworth, Clare Rivers, Marnie Fullarton, Colm Murphy, Victoria Beale, Jason Neil-Dwyer, Simon Van Eeden, Stephanie Van Eeden, Peter D. Hodgkinson, Alistair Smyth, David C. Sainsbury

Cleft Palate Craniofac J 2021 Jun 10:10556656211021700. doi: 10.1177/10556656211021700. Online ahead of print.

F3: CLINICAL STUDIES GROUP-SARAH KILCOYNE
Research updates/CDG Update NIHR Cleft and Craniofacial Anomalies CSG.pptx
Research updates/Completed studies list November 2023.pdf
Research updates/Updated Study Table November 2023.pdf

F4: SLUMBR STUDY-HELEN ROBSON
SLUMBRS UPDATE CDG 27/11/23

The Slumbrs study was closed quite suddenly on the 1st November 2023 by the chief investigator Professor Bruce.
Despite great efforts he felt the recruitment had been too slow at only 55 infants.
He felt the challenges from the various trust had led to deviations from the protocols alongside local problems with recruitment and data transfer.
Slumbrs had an unpaid 6 month extension from research for patient benefit (RfPB) and they were seeking reassurance the recruitment target of 255 would be met and it was decided that it could not be met so the study was closed from immediate effect.

APPENDIX G: CRANIOFACIAL SOCIETY OF GREAT BRITAIN AND IRELAND UPDATE-MELANIE BOWDEN
CFSGBI President Update for CDG – November 2023

I took up office in April 2023 following on from Helen Robson who delivered an excellent Annual Scientific Meeting in Cardiff.
I chaired my first council meeting in November 2023 and formally welcomed Rebecca Crawford who is representing the other section – psychology - and is the future president in 2026.
Council membership: Melanie Bowden, President (Speech & Language Therapy), Rye Mattick, President elect 2025 (Orthodontics), Rebecca Crawford, (other- Psychology), Adele Bronkhorst, Honorary Secretary (Orthodontics), Guy Thorburn (Surgery), Michaela Rowe (Nursing) Honorary Treasurer and Grant Davies-Ratcliff (Secretariat Manager).
Website
The website was launched 18 months ago and continues to expand its content thanks to the work of previous council members and Matt Fell. It is a great repository for historical information on the Society as well as for news and links to forthcoming events. It has pages for health professionals as well as patients and families. There are plans to expand it further, I urge you to access this excellent resource.
Membership
Currently 292 full members, 18 Honorary members and 8 Senior members.
Membership now offers an internal partnership with ACPA (American Cleft Palate Craniofacial Association) as well as access to their journal for full paying members. The plan was to offer Honorary and Senior Members the opportunity of journal access for £10 however, the cost of setting this up by changing the membership section on the website was costly hence, Council has decided that we should contact all Honorary and Senior members to ask if they would kindly consider paying full or part membership costs again to help cover this and to help the Society's finances going forward.
As last year, the annual newsletter will be via email circulation and uploaded to the website.
Scar Free Foundation
Bruce Richards continues to represent the society as the Principal Member Representative for the Scar Free Foundation. Bruce and I attended a workshop at the Royal College of Surgeons on 29 September 2023. This was to understand, revive and reinvigorate the relationship between the Foundation and Principal Member Organisations (such as CFSGBI), explore avenues for knowledge exchange and collaboration and understand how the exchange of information between the various participating organisations could be more effective. There was also opportunity to meet LT General Richard Nugee, the new Chief Executive of the Scar Free Foundation. Mr Brendan Eley retired from this role earlier in the year. I wrote to him on behalf of the Society to thank him for his support to the CFSGBI. A virtual follow-up meeting hosted by the SFF is planned for December 2023.
CLEFT
A CLEFT representative is invited to attend council meetings and Brian Sommerlad as chair attended the

meeting on 2 November 2023. In turn, the Council President is invited to be a CLEFT trustee and I have attended 2 meetings in September and November this year. The rationale of CLEFT is for the funding of research and the development of cleft centres in low and middle income countries. Although in the early stages of planning, it has recently been agreed that CFSGBI and CLEFT will host 3 evening webinars early next year in the lead up to the Scientific Meeting in Manchester in April. It is hoped these will focus on: how to get involved in cleft research, how to get involved in cleft projects overseas and how can we help in supporting patients and parents. Information will be made available on the CFSGBI website.

Annual Scientific Meeting 2024

We are currently planning the Annual Scientific Meeting for 2024 which will be a face to face event (there will be no facility for virtual or hybrid). This will be held on 17th -19th April 2024 at The Midland Hotel in Manchester. Putting this together is taking a real team effort and I already need to thank my colleagues from the NWNW Cleft Network for their help and support, in particular Vicky Beale. With this in mind, it is fitting that the themes for our conference are 'team work' and an area of our practice that is so important – 'intervention.' The CEN day will be held on Wednesday 17th April. There will be 10 CEN groups with a newly formed Genetics CEN for 2024!
Registration and abstract submission are open via the conference website:
https://www.delegate-reg.co.uk/cfsgbi2024 .
The closing date for abstracts is 8 January 2024. We have a new professional conference organiser – KC-Jones, appointed for the next 3 years of conference planning. Rebecca-Cadman Jones and her team are extremely helpful and efficient, and we look forward to working closely with them to deliver a high quality event.
Rye Mattick is well ahead with planning the meeting in Newcastle in 2025.
Melanie Bowden
President of the Craniofacial Society of Great Britain and Ireland
November 2023