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

Venue- Research Boardroom at the Royal College of Surgeons of England

Date & Time- Monday 11th November 2019, 11am-3pm

Present	Simon van Eeden (SvE) Chair Kenny Ardoiun (KA) Lorraine Britton (LB) Mechelle Collard (MC) Sinead Davis (SD) Scott Deacon (SDC) Helen Extence (HE) Sarah Good (SG) Norman Hay (NHa) Peter Hodgkinson (PH) Nicola Hudson (NH) Toni Kitchingman (TK) Jason Neil-Dwyer (JND) Helen Robson (HR) Craig Russell (CR) Jonathan Sandy (JSan) Julia Scott (JSc) Jackie Smallridge (JSm) Guy Thorburn (GY) Rachael Willis (RW) **In Attendance** Catherine Foster	
Apologies, absence and welcome to new members	Victoria Beale Yvette Edwards Ginette Phippen Sandip Popat Ian Sharp Alistair Smyth Marc Swan	

Item	Notes	Actions
2. Minutes of the Cleft Development Group Meeting, May 2019	Amendments to the draft minutes from 17.05.19 were suggested by the committee.	
3. Matters arising	• In the last meeting of the CDG, CLAPA had identified some individuals for lay representation for South Wales. CLAPA are to draft a CDG lay representation Job Description document to give some guidance to the potential candidates. • The Speech and Language Therapy CEN have looked into finding a representative to sit in the quality monitoring and evaluating committee, but felt that more work needs to be done on the committee prior to representation allocation.	3.1 TK to draft CDG lay representation Job Description and circulate to the group for feedback.
4. CDG Chair	In accordance with the Cleft Development Group Terms of Reference, the CDG chair must be elected by the group, and should remain in office for three years. SvE has now come to the end of his three year term as chair, and it was put to the group as to whether SvE should be re-elected as chair, or if an alternative candidate should be chosen. SvE left the room whilst the group discussed the chairmanship. The group agreed that SvE should remain as CDG chair for an additional three year period. SvE was notified, and thanked the group.	
5. Audit	SvE congratulated CR on his newly appointed positon as Clinical Lead for CRANE. CG thanked SDC for his time spent on the CRANE team. **<u>CRANE</u>** *Reporting-annual report/regional audit* SDC presented the draft 2019 CRANE Annual Report to the CRG. The CRANE 2019 Annual Report to due to publish in December 2019. Key points for the 2019 CRANE annual report: • The team have been working in collaboration with CLAPA to produce a larger infographic for the report. SDC thanks CLAPA for their time spent on this. • The report contains an extended list of recommendations • The CRANE data chapter has been renamed 'Registrations and Early Care' • The beginning of each chapter now starts with a table of summaries. This will make it easier for the reader to extract information. • Diagnosis chapter – the team have looked at the last 10 years of data on the proportions of cases detected late. They have found there to be a marginal improvement, which falls in line with the work done by the Royal College of Paediatrics and Child Health (RCPCH) on the identification of	

	cleft palate in new-borns. As a result, CRANE are now negotiating with the RCPCH to have a stand at the RCPCH Conference and exhibition in 2020. • For the first time, weight, health and dental health will report DMFT at 10 years • For the first time, Speech at 5 years will include a data completeness funnel plot. Data completeness is a common topic seen throughout the 2019 Annual Report, and CR is keen to address data completeness going forward in the next audit term. Also for the first time, this chapter included Pierre Robin sequence. • The report conclusion will be more focused on the projects reflection and the plans moving forwards, and less on concluding results. SDC invited the CDG to send their thoughts and comments to the CRANE project team within the next coming weeks. SvE thanked SDC for his time spent as Clinical Lead of the CRANE project **<u>Data, Publication and Outliers</u>** CR presented issues with data, publication and outliers, in relation to the CRANE database. CR took on the role of CRANE clinical lead on 1st September 2019. Moving forward into the next CRANE Annual Report, CG proposed that the report will consist of two parts: Registry and Audit (Governance), and Research and new developments. CG proposed that when regarding registry and audit data, CRANE will publish year by year national level data for agreed clinical areas. This will allow the tracking of national performance in process and outcomes over time, and enable the team to feedback positive outcomes to commissioners. CRANE will also produce annual regional reporting of agreed process and outcome data. CR suggested that there should be a minimal level of data completeness for unit inclusion in the analyses. The reports will aim to move to use risk stratified data in funnel plots, and also include funnel plots for all outcomes regarding data completeness. All aspects of the MDT will be treated similarly in the report. CR discussed why there is a concern regarding data completeness. CR highlighted that missing data has the potential to introduce error; elevating outcomes means and narrowing confidence interval. High returning units are therefore potentially at greater risk of being an 'outlier'. Missing data also has the potential to introduce inaccuracy in risk stratification models. CR noted that CRANE are themselves an outlier amongst most National Clinical Audits, in that they do not have an outlier policy. In the new audit term, CRANE intend to trial an Outlier Identification Policy, with aimed adoption for 2021. CR presented the 7 Stage	**4.1** – CDG members to send feedback to the on the draft 2019 CRANE annual report to the project team.

	Management of Potential Outlier to the group. The seven stages are as follows: 1. Potential Outlier identified – 2nd research independently analysed 2. CRANE inform Provider Lead Clinical of potential outlier status – request identification of data error / justifiable explanation (phone call followed by formal letter) 3. Provider Lead Clinician to provide written response to CRANE 4. CRANE Review of Provider response- a. No Case to answer – Data error corrected / providers response logged and formal letter informing of change of status to within 3SD to Provider Lead Clinician b. Case to answer – confirmed that either data inaccuracies do not change 3SD status or original data accurate – proceed to stage 5. 5. Contact Provider Clinical Lead by telephone / follow with formal written confirmation of Outlier status (copy letter to Provider Clinical Governance lead / Medical Director / CEO. Outlier given opportunity to provide narrative to status (unedited) for inclusion in CRANE report. 6. Acknowledgement of receipt of letter 7. Public disclosure for comparative information that identifies Providers (e.g. CRANE report)	
	The use of an Outlier Identification Policy will need to be discussed and accepted before trial, and will also require CRANE to have defined timelines for data submission, data extract, data analysis, outlier stages and publication. CR presented a CRANE analysis timeline 2020 for the pilot of the outlier process, and a CRANE analysis timeline for 2021.	**4.2 –** CR is to circulate CRANE timeline and CR presentation slides to CDG.
	The following topics were raised in discussion: • PH highlighted that excluding entire units due to data completeness could potentially mask bad results. He further noted that outliers in funnel plots within a single year could occur by chance of statistics. He felt that noting the consistency of outliers would be more impactful. CR responded that the outlier identification process will enable the team to determine whether outlier status is by statistical chance or not, with input from the improvement committee. • GT noted that the skewing of data can come from other centres, pulling the mean across. CR commented that for this to happen, data would have to be highly skewed to pull the mean across, and that the root cause of this would be data completeness. CR added that any unit that does not submit the threshold for data completeness (95%), would not be included in the analysis. This action would stop units with poor data completeness appearing better in the analysis.	**4.3 –** CR is to produce a formal document for the CRANE Outlier Policy and circulate to the CDG prior to the next meeting.

	• SvE noted that the team will need an epidemiologist to look at the data completeness threshold percentage each year. SDC added that it would be hard to determine a solid percentage year on year, and so 95% is more of an aspirational target. PH suggested that funnel plots could be used to set the standard for data completeness, rather than a percentage. SDC and CR agreed that this would be a good solution. • LB requested that training be provided on entering data onto the CRANE database, as she felt it would take significant work to attain a 95% level of data completeness. LB suggested that exception reporting from CRANE would be helping, including names of data not reported. CR noted that, if required, the project team have a 'how to' document for CRANE data input. CRANE will also have a stand at the Craniofacial Society Conference in April, where they will be able to aid with inputting data. CR felt that exception reporting for each unit would be too large of a work load for the project team. • HE suggested that an instruction DVD on CRANE data input would be more useful that a document. SDC noted that CRANE are moving web design platforms from CROWN to a UK based platform, with whom they are in discussions with regarding video guides. • CR suggested that CRANE aim to make single year data available rather than waiting for three year rolling data, so that outliers can be caught earlier and outlier units can be alerted. SvE felt that one year and three year data would be useful. **ICHOM** SDC has had a teleconference with ICHOM, who had sent their Memorandum of Understanding. However there have been issues with this document, and ICHOM were in the process of rewriting it. Since this teleconference, SDC is yet to hear from ICHOM. Until the new Memorandum of Understanding is received, there is little to report. CR will now take over this matter. **Minimum Data Set** The minimum data set is currently running on the Delphi. SDC and CR have agreed that SDC will continue to run and complete the Delphi after he has left his post as CRANE Clinical Lead.	
5. Terms of Reference	**Quality monitoring and evaluating committee** LB presented the quality monitoring and improvement committee paper to the CDG. Since the last meeting, LB has amended the CDG Terms of Reference to include items regarding the Quality monitoring and improvement committee. Furthermore, LB has produced a Terms of Reference for the quality monitoring and improvement committee. LB noted that CRANE's proposed 7 Stage Management of Potential	

	Outliers, would encompass what the committee had intended to do. LB questioned how the responsibility for these stages would be delegated between CRANE and the committee. This was discussed and it was concluded that CRANE would be responsible for: • The review of the CRANE Annual Report and NHS England Dashboard reports on agreed outcome measures and key performance indicators. • Identifying any outliers who fall outside the 99.8% confidence limits (3 standard deviations) from the agreed National Outcomes. The outliers may be positive or negative. The quality monitoring and improvement committee would be responsible for: • Facilitating outlying units/centres to review their data to look for explanations for the difference in their performance. • Offering services the opportunity to discuss their quality improvement plans or share lessons in excellence. LB suggested that a committee of 2 or 3 people would be more suitable than the previously suggestion 10/11 people. SDC noted that the chair of CRANE should not be involved in the committee. The CDG agreed that the committee should go ahead and should include representation from each CEN. LB added that committee meetings should fit around CRANE's schedule. SDC noted that the ToR should include and item on funding. SDC noted that clinical directors need to be able to financially support the time and travel involved. LB is to adapt the terms of reference for the committee to reflect the CDG's input. LB invited the CDG to contact her regarding any further feedback.	**5.1** – LB is to amend the committee Terms to Reference to reflect input from the CDG.
6. Feedback from CENs	**<u>Orthodontics</u>** • The Orthodontics CEN met in November 2019 in Liverpool. JSc has been appointed as chair of the group, and Monica Bedelia is the new honorary secretary. • The framework for the next three years has been agreed. The group have identified 10 current projects, and are working towards regional and national projects to present at Edinburgh; with a view to progress into publications after the conference. • The group have agreed on their 5 years plus outcomes for the minimal data set, which will be circulated shortly. **<u>Speech and Language Therapy</u>** • The speech and language therapy CEN met in early November 2019. The group discussed the National PRS Project. Jane Meraka and Stephanie Van Eeden answered question surrounding the project, and as a result, they have written a more formal protocol, which will be sent to all units going forward with the project. **<u>ENT & Audiology</u>**	

	• The ENT and Audiology CEN have not met since the last CDG meeting in May. SD has not received any correspondence from the CEN since July, and so has nothing to report. SD asked the CDG for any suggestions as to how to take things forward. SD asked to forward her email to all the clinical directors, asking them to confirm email addresses. **Paediatric Dentistry** • The Paediatric Dentistry CEN have not met since the last CDG meeting in May. • The next calibration will take place on 28th January 2020, in a venue yet to be confirmed. • Staffing across all the units has changed; Cambridge is down and several units have had maternity leave and other issues. • The CEN has several projects taking place. They are looking at photos v clinical results in units, which is progressing well. They are interested in looking at the difference between cleft calibration and BASCARD calibration. • They have had some issues with the data collected by the CEN during clinical visits, in that it is different from the consensus. JSm has discussed this with the CRANE project manager, Jibby Medina, who has provided them with screen shots of how to look at the consensus level. **Surgical** • Round two of the 2008 National Bilateral Cleft Palate Audit has begun. • The CEN are collecting information from around the county regarding surgical consent, with the aim of achieving some standardisation across the UK. **Lead Nurses** • Cleft Collective hosted the morning of the last meeting in Bristol. They looked at writing some nursing proposals, as they are currently quite weak in that area. Cathy Marsh presented the late detection rates, which are going down. • HR and Cathy Marsh attended an event in Rotterdam in early October, exploring an alternative online cleft course for nurses. • Lead nurses are working with NCARD, and have discovered that they are underreporting. • A new secretary was appointed during the April meeting, but then promptly left cleft leaving the committee without a secretary. **Psychology** • The CEN continue to work on national research projects, often in collaboration with research colleagues, with the aim to ensure that clinical perspective of psychology is represented widely in research literatures. • Psychology continue to support CLAPA with the psychology elements of the adult leavers pack.	

	• Psychology are reviewing calibration amongst the CEN, including tiers of involvement.	
7. Quality Dashboard	**Update** Met in the Summer. The quality dashboard document drawn up in the last meeting has been adopted. Reporting and submission times were discussed. The submission times for both CRANE and unit submissions are now on the same date. It is hoped that the same date will help avoid discrepancies. SDC is to forward document from Nina regarding this to CF for circulation to the CDG.	**7.1** SDC to forward quality improvement document to CF for circulation to CDG.
8. Research	**Bristol** See appendices **Cleft Collective** JSan presented an update from Cleft Collective. CC are starting to see some issues regarding funding. CC have roughly 18 months of funding left. CC have put in a grant to the MRC through their partnership scheme, which requires the application to project for 5 years what they intend to do if they collect. CC provided 5 areas that they intend to explore. MRC also asked how this will be sustainably funded over the 5 years, which is where the CC start to struggle. The MCR declined the CC grant application, but have not been discouraged from reapplying. The Health Foundation grant, of which SDC was a co-applicant, has also failed. This application would look at better linkage, not only with CRANE, but also with other databases across the country. The CC will not be able to reapply for another two years. The CC also has the option of approaching the Wellcome Trust for a collaborative award. CC are meeting the Scarfree Advisory Panel. JSan noted the Scarfree have lost their interest in cleft, and are instead focusing on conflict wounds. CC are trying to refocus them.	
9. Feedback from Cleft Centres (UK)	**North Thames** North Thames are trying to recruit to paediatric dentistry, which is in turn impacting on calibrated outcomes from paediatric dentistry. Their only calibrated paediatric dentist is not available on audit days. 6 months ago, the centre started some 3D planning, and obtained some 3D printers for printing splints. This is still at development stage. The centre has a new electronic database system, which is called EPIC. Although they had a big drop in numbers whilst this system was being introduced, numbers are now coming back up to normal on clinics. Whilst the clinics will have better access to data, inputting into the system has been time consuming. **Wales** The centre has received some the money from their government bid. They have used some of this money to work on their RTT and adults waiting list. A number of these patients have been on waiting lists for several years, but now some of them are being seen and	

	outsourced to other centres. The centre now need to look at a sustainable plan going forward. The centre are having problems with anaesthetic cover on their adults list. They are working on a plan to deal with this issue. The centre are managing their paediatric list well, although there are some issues with ward staffing. Wales have received their MDT funding, and so have recently appointed a band 8a Psychologist and a part-time 0.4 Psychology Assistant. They have interviews for a band 8a (upgrade from band 7) and band 7 speech therapist in November. Wales have increased 1 session for Orthodontists, 1 session for ENT and 1 session for Paediatric Dentistry. The team are looking forward to hosting the 2020 Craniofacial Society Conference in Cardiff. **Spires** The team are advertising for a cleft surgeon, which closes on 21st November. They are also advertising for a Network Service Manager, following a departure earlier in the year. The team have managed to cover a maternity leave in Orthodontics and Clinical Psychology. SG has been appointed as president of the Craniofacial Society for 2022. Surgical capacity on for both sites is stretched. Staffing in aesthetic and nursing in wards have impacted on surgical beds. There is also some delays in service with the new database. Spires are about to launch their new website. **Newcastle** Staffing has been fairly stable, bar a few maternity leaves which have been covered. Plastic surgery, where the cleft team sits, has moved into a bigger directorate, which has caused some issues in relation to management. PH is using this opportunity to try and move their speech and language therapists into the plastic surgical directorate. The team are about to have a change in ENT surgeons. They are currently contributing a 5th into their ENT surgeon, but this does not always reflect in their availability for the cleft team. Newcastle are not currently experiencing any waiting list issues. Patient records will be soon be made electronic. Newcastle has the biggest number of late diagnosed cleft palates in the CRANE Annual Report. PH reported that this was due to one of their retired paediatric surgeons performing tongue tie divides for issues with feeding, rather than spotting cleft palates. PH noted that the NHS have identified cleft lip and palate are a rare disease, and that every child with a rare disease must carry a rare disease information card. JS asked the group if anyone has experience in producing these. It was suggested that the card should state: I am a patient of …. Team. If I have any problems please contact…, I may need time off of school, I may have problems feeding, I may have hearing problems.	

	Cambridge The team are one consultant down in paediatric dentistry, which is compounded by the lack of specialists in the region, results in a lack of care for patients. This will have a future impact on their dashboard scoring. They have a TIG fellow who is coming to the end of their post. **South Thames** Demand for cleft services have increased by 40% over the last ten years, over both adult and paediatric services. Due to pressures and the impacts of the 52 weeks waiting list, the centre has received trust investment against all specialities. They have expanded in paediatric consultants and have a new orthodontist one day a week. A new maxillofacial surgeon has just started and they also have new appointments in Psychology and speech and language therapy. They plan for expansion in clinical nurse specialists and junior staff. The trust is also expanding – more than doubling the size of the children's' hospital. A TIG has been appointed at half way through their term. South Thames had a strong presence as the European meeting in Utrecht. There have been some problems with accessing the speech and language services within the local units. The team have had issues with some individuals harassing the service, resulting in the production of behavioural contracts. **Trent** Trent currently have the lowest birth rate every registered in a year (80). On the dashboard, speech results have improved which has impacted on secondary surgery rates, but now 25% surgical lists are being cancelled due to a lack of patients. The centre has ongoing issues around paediatric dentistry. This is an east midlands wide issue, with no PDs across the patch. The Centre are to meet with the Charles Clifford Dental Hospital on the 22nd November, to address setting up a paediatric dentistry service for the trust to utilise. Trent still have no Psychology. They are in negotiation with their commissions, and last year were awarded £300,000. JND is currently blocked from using this, as previously any money went straight into a planned deficit. John Rowson is starting to look at retirement dates, so they are investigating how to replace him. **North West** A new consultant orthodontist has just started, filling a vacancy for two years. The paediatric dentist for the network is on maternity leave, returning in the spring. A CNS has left due to a relocation to Cornwall. Two nurses are returning, with one returning on a part-time basis in the new year. Following interviews last week, the centre have appointed to two posts. They are anticipating that David Whitby will retire in 2020.	

	Electronic patient records are being received well. There is a new Psychologist at Royal Manchester Children's Hospital. **<u>South West</u>** The team have had some success in having an influence over the local tongue tie policy, of which the centre had never been consulted on before. Speech and language therapy have developed an early age pathway, which was acknowledged by the CQC in a recent visit; being labelled as outstanding for two years in a row. Speech and language have issues with staffing and a lack of community support, which has been raised with commissioners locally. SW has a surgeon on long-term sick leave, and have 52 week waiting lists on child and adult services. There are a number of staff looking to retire within the next few years, some of which will be complicated to replace. **<u>Scotland</u>** Scotland currently have three surgeons working, bringing waiting times down to an appropriate level up until August; since then the centre have been struggling with a lack of anaesthetists. After a three year hiatus, the network is due to be relaunched at the end of November. Speech and language therapists are under review. The reviewers believe that this service can be run by generalised speech and language therapists, which the centre is fighting against. They have had short term issues with nursing and have been in administration for a year.	
10. Training	A letter was received in October from the JCST, who received a letter from the GMC. TIG training fellowship is no longer in the remit of CCT. GMC have suggested post CCT training under hospital, or possible GMC credentialing. Issues can be expected with funding these posts. GT raised that this will have a large impact on patient care. GT suggested that parent and patient groups need to get together with a legal challenge to this. This matter is to be raised at the next CDG meeting.	
11. CLAPA Feedback	Kenny Ardoiun, the Adult Services Manager from CLAPA, presented an overview of the Adults Services Project at CLAPA.	
12. Any other business – CDG & dates of the next meeting	SDC discussed the progression with CRANE funding. SDC was contacted by an individual running the NHS England Database Review, realising that they had a large number of databases out on contract. Initially SDC met with this individual, who stated they would be happy to have a contract in place ASAP. Since then, there have been no mechanisms to review funding.	

The next meeting of the Cleft Development Group will take place on Tuesday 2nd June 2020 at the Royal College of Surgeons of England