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- Wednesday 16th May 2018, 11-3pm

Present	Victoria Beale (VB) Lorraine Britton (LB) Rosemary Bryan (RB) Scott Deacon (SD) Yvette Edwards (YE) Norman Hay (NHa) Nichola Hudson (NH) Ailbhe McMullin (AM) Kate le Marechal (KM) Jason Neil-Dwyer (JND) Susan Parekh (SPar) Ginette Phippen (GP) Sandip Popat (SP) David Sainsbury (DS) Jonathan Sandy (JS) David Stokes (DST) Marc Swan (MS) Imogen Underwood (IU) Simon van Eeden (SvE) <u>In Attendance</u> Catherine Foster	
Apologies, absence and welcome to new members	Ian Sharp Jackie Smallridge David Landes Alex Cash Craig Russell David Drake Kanwal Moar	

Item	Notes	Actions
2. Minutes of the Cleft Development Group Meeting, January 2018	• Page 2, 4.3- 'BASCOD' to be changed to 'BASCD'. • Page 3 – Feedback from CENS – 'LST' to be changed to 'RCLST'. • Page 4 – Action 'DS to forward details for DMFT national calibration to SD' to be changed to 'DL to forward details from DMFT national calibration to SD' • Page 5 – 'SD to change TRENT input and incorporate into the delivery of the annual report' to be changed to SD to change speech and language therapy input and incorporate into the delivery of the annual report'. • Page 5 – 'SD to inform JB of TRENT data comparison changes' to be removed. • Page 7 – Spires – 'Succession planning for first time' to be changed to 'Nurses succession planning for first time'. • Page 8 – '(NH)' to be changed to (NHa)' • Page 9 – Action – 'IM to contact chairs of each speciality' to be changed to 'IU to contact chairs of each speciality' • Page 10 – 'SEN' to be changed to 'CEN'	
3. Matters arising	1. SvE yet to hear back from DL regarding the public health representatives. 2. MS has fedback to BAPRAS 3. SvE has been contacted by the BAOMS chair, Patrick McGuiness. They have confirmed that they are happy for Kanwal to be their representative. 4. CF yet to collate membership data. CDG members to add join date to the attendance sheet. 5. DS has received some interest from parents regarding potential CDGM attendance but with no development as yet. (KIM) mentioned that Tina Owen has been in contact with a parent who is keen to join the CDG. 6. SD has been provided with contact details for PHE.	3.1 SvE to chase DL regarding representatives 3.2 CF to collate membership data for next meeting.
4. Terms of Reference	SvE has incorporated the suggested changes from the last meeting into the ToR. This was circulated to the group. Once agreed, the CDG ToR will be added to the CDG section of the CRANE database website. <u>Review of Draft:</u> • Addition of date (Footer/header) • 10. 'A Specialist Cleft nurse' to be changed to 'A Lead Specialist Cleft Nurse'.	

	• 11. 'A Psychologist (1) *(to be nominated by the Cleft Psychologist **CEN**)*' to be changed to 'A Clinical Psychologist (1) *(to be nominated by the Cleft Clinical Psychology **CEN**).* • JND suggested an addition regarding ongoing improvement in roles. It is suggested embellishing (1) in 'The Roles of the CDG' with a statement to promise supporting involved units in the improvement of quality of care. <u>Patient Representation (PR)</u> • SvE has had correspondence with South Wales regarding a patient interested in joining the CDG as a representative. There has been some trepidation around how to navigate this and Ian Sharp has spoken to Linda Doherty about the matter. It was concluded that as the CDG is not an official body, the recruitment of a PR is completely flexible. SvE asked the group of any suggestions about how the CDG may go about doing this, and how the group could support a PR. • The group discussed providing travel expenses for a CDG patient representative, of which has previously been an issue. IM suggested that the craniofacial society would be able to fund a PR.	4.1 JND to consider wording for addition and get back to SvE 4.2 SvE to write to Craniofacial society regarding the possibility of funding for a CDG PR. 4.3 SvE to write t0 Julia Cadogan in South Wales to say that the PR has been discussed.

5. Feedback from CENs	• Clinical Psychology (KM) – Last meeting took place at the conference. CP are in collaboration with the early careers research group. They have a Clinical Psychologist attending the group and feeding back, which is boosting research processes. They are currently collaborating on a systematic review (in particular Clinical Psychology literature) of multi-disciplinary outcomes for children born with BCLP. They are currently working closely with the CLEFT collective, of whom are allowing access to the data. They are working together to determine what to do with the data that has been collected so far, of which will be useful from a psychology perspective. Psychology made several presentations at the conference and are trying to maintain a strong presence in terms of audit research and demonstrating Psychology work. Clinical psychology have started entering data into CRANE in a formal way (dates when children are first seen by CP, parental reports of emotional wellbeing at the age of 5). Clinical Psychology staffing within cleft teams is variable around the country • Speech and Language Therapy (LB) - Marie Pinkstone and LB were asked to present their commissioning experiences to the Royal College of Speech and Language Therapies last week. SCPLT, with the Hearing Impaired Specialism, have developed some commissioning guidance for S&LT services. These have the potential to be modified and be a guide that could be given to local S&LT services to help them in their commissioning discussions with CCGs. SD attended the last S&LT meeting to discuss the overlapping issues with CRANE. This has helped the team understand how CRANE integrates collaboratively with speech outcome reporting. A plan has been agreed for reporting 5 year speech outcomes using a 3 year rolling structure, and other projects that might use the CRANE data have been discussed (e.g. educational outcomes, common syndromes). The issue of how the 5 year speech outcome and dashboard is being monitored was raised, particular the lack of monitoring of the dashboard data. In relating to investigating outliers, there is still no governing system in place, despite this matter being raised in CDG meetings and at the craniofacial society. There has been questioned raised about how the 5 year data is being used (or not used) which had led S&LT to is considered how worthwhile the labour intense	

	process of collecting this data is if it is not being monitored or impacting on patient care. Two CAPS-A training courses were organised; an introductory in March and a re-calibration in June. Unfortunately the course in March was under attended due to the lack of funding for attendance from local NHS trusts. They are relying on CAPS-A trained listeners and the local trusts cannot tackle this lack of funding alone. The basic course costs £800 per person and the re-calibration £400. CEN have held two study days (Nov 17 and April 18). The meeting in November focussed on genetics and the meeting in April on parent led care by Triona Sweeney and Debbie Sell. There has been discussion about having a pool of CAPS-A listeners to use for projects outside of audit collection. • Lead Nurses (NH) – Lead nurses met in Birmingham. There was a high number of delegates and new clinical lead nurses (37), which was very positive. Many of the nurses are excited about research and more people have been thinking about attending the early research group. Ian Bruce is moving forward on the NIHR SLUMBR Project. NH will get in contact with Simon and David and they are needing some supporting evidence for the NIHR Project. There will be a second arm to the project, which Salisbury will be involved with. A previously discussed Cleft Course will be going ahead, with the aim of occurring at the end of this financial year and the next. The autumn meeting will focus on International nursing roles and responsibility. • Paediatric Dentistry (SPaR) – Also had their meeting in Birmingham which was positive. Have discussed a pack with CLAPA that has been put together and will hopefully be going out soon. DS is looking for sponsors. KLM gave a talk on Psychology which was very helpful and raised the issue of how to develop some PROMs for outcomes. How to support centres that cannot provide data was discussed. Lots of presentations were made during the conference. The trainees in paediatric dentistry survey revealed that they would like some access to Cleft clinics or teaching and different training days across the country were highlighted.	

	• Restorative Dentistry (SP) – Also met in Birmingham which was positive and are now looking to develop A PROM for restorative dentistry. They are developing a survey, which they will then present to the Psychology CEN to potentially become a collaborative piece of work. A pilot has taken place. Succession planning has been discussed and have been planning annual event where restorative dentists can present what takes place with RD. Have been in discussion with the ECRG about lateral incisor replacement. • Surgery (MS) – Debates occurred around how UCLP are classified and how data is collected for the Cleft consensus; no conclusions were made. There was a good discussion about on-call for cleft patients a better way on coming to a conclusion on issues needs to be made. Submissions to the Cleft Collective were good with the first primary operation but tailed off significantly with the second operation, which will cause difficulties when collecting data. There was some surprise within the CEN as to the difference in Research Coordinators, with come centres not knowing who their Research Coordinator was. They had an excellent final talk from Nigel Mercer from Bristol and about his career in cleft. • Orthodontics (AM) - Have had two meeting in the last year; one in Birmingham and one at the conference. They are continuing to do the 5 year old UCLP and BCLP 5 and 10 year old scoring. This year is the first year that input has been received from all the teams, but there are still some on-going issues with missing records. They have noticed a trend of less study models and more photographs coming through, and there have been some issues with scoring photographs. They have done some local study pilots and introduced case discussions. Due to new consultants, they have identified a need for a new recalibration exercise and are working with Mike Mars to present this at the next conference by doing a workshop in the morning. There are on-going issues with recruitment and some more locum posts are coming up. There are also some issues for succession planning for the future.	

6. Paediatric Dentistry	• SvE – Paediatric dentistry was cut short during the last meeting as no PD were present, but a lot of work has taken place during the interim. • SPar – Raised that there has been some discussion about calibration and entering data onto the dashboard for DMFT for 5 year olds. There were some concerns about the robustness of the calibration and why PDs are needed to be involved. • SPar presented the work of Paediatric Dentistry and Specialist PD calibration to the group. SPar highlighted the importance of a PD for calibration; not only can data be calibrated, PD care can be given. • NHa questioned PDs calibration process. He explained that during previous calibration training, participants did not complete both days. He is experiencing difficulty and their only calibrated consultant does not attend on the days where audit reviews take place, causing difficulties in the collection of calibrated data. NHa questioned SPar as to the costs of calibration, SPar responded that training is self-funded. NHa further questioned how long it takes until a trainee is notified as to whether they can attend the second day of training. SPar explained that during the first day, a clear explanation is given of how each tooth is measured etc, from there a CD of images is distributed, which the individual scores in their own time. If the individual has a high enough reproducibility for scoring, then they are then classified as calibrated. • GP questioned whether an alternative model would be possible for those without a SPD. GP discussed other specialists in her team being calibrated in order for data to be submitted. VB highlighted that without a SPD, data cannot be submitted, but without data, it cannot be proven that the unit needs a SPD. SD explained that enforcing SPD for calibration leaves little scope for the development of a cheaper model, allowing other roles to be calibrated. He is meeting with PHE soon to discuss calibration and why specialist are needed to do it. SPar stated that they are happy to discuss this with PHE but wanted to present this to the CDG first. • NHa suggested condensing calibration training into one day rather than two. SPar will relay this to the CEN. NHa further	6 .1. SPar to relay suggestion calibration condensing to the CEN.

	questioned whether scoring could be taken from photographs (if high quality enough) rather than face to face. SPar felt that marking from photographs would tick the boxes for calibration but would not provide the SPD care for the patient. • MS raised that the CDG needs to support SPar when communicating with PHE regarding SPD calibration. He also supported NHa suggestion of marking from photographs rather than a live process. SvE raised that calibrating from photographs could help audit clinics without SPD, highlighting that they need a SPD. • GP raised that caution needs to be taken around making the assumption that children receive poorer care without PD. She then questioned why an orthodontist cannot be calibrated in the absence of PD. SPar explained that some units feel that they do not need a PD, and so needing a SPD for calibration encourages units to utilise PD to improve care. • JS noted that the rate of dental caries has not changed since the CSAG report • LB informed the CDG that any SLT can attend CAPS-A training.	6.2 SD to discuss PHE meeting with SPar 6.3 SPar to raise discussed calibration issues with PHE and relay back to CDG
7. Audit	A. <u>CRANE (SD)</u> • The update report has been circulated and a letter has been received concerning funding for this financial year, although they would prefer to receive funding for a longer period of time. The IT contract with CROWN is coming up for renewal in September and so negotiations are being made about the length of the contract; as CRANE are only receiving a year of funding, it is hard to determine length of contracts with other suppliers. • They have been working with CLAPA to produce the patient and public report; being provided support with the use of language and infographics. • IT developments – Postcode is currently not a mandatory field in the database but it is useful when linking information to the MPD. The team are therefore aiming to make postcode a mandatory field at registration. The developers have suggested doing a validation of postcode, potentially with 5 year data. SD checked with the group as to whether this would cause any issues with for the CDG before going ahead. YE to check and report back to SD.	7.1 YE to check with CEN regarding mandatory postcode field and report back to SD

	• The consultation for older children was discussed at the conference. The team have begun consultations and they aim to look at outcomes and create a scoring system. SD will be looking for volunteers to score the outcomes in the future. • SD to resend PREM report to Craniofacial Society. • SD to invite Marie Right to the next CDG meeting to discuss PRS. • SD meeting with PHE to discuss DMFT. • They are meeting with the Chief Dental Officer IT Department as they are looking to introduce a new coding system to the whole of dentistry (SNOMED system). B. ICHOM • There was discussion about the use of the Cleft Q and KLM informed CDG that this has been discussed at the CEN. • There was discussion about as to whether changes should be made to audit in the UK to incorporate ICHOM? • Anne Klaasen is currently narrowing Cleft Q questionnaires down C. Syndromics • Discussion about syndromic diagnoses and audit tabled by NHa – Nha felt that for Sticklers, VDW, PRS, etc. audit is usually OK. Questioned whether audit was appropriate for all syndromic patients • Agreement that syndromic patients with global difficulties not to be audited	7.2. SD to resend PREM report to Craniofacial Society 7.3 SD to invite Marie Right to the next CDG meeting to discuss PRS
8. Quality Dashboard	• SvE highlighted to the group the changes that have been made to the quality dashboard. • SvE to circulate highlighted version of dashboard to the group for discussion in the next CDG meeting. (Via CF)	
9. Research	• <u>Report from Bristol (JS) (Circulated prior to the meeting)</u> • They have been given a long term no cost extension meaning that work can carry on until money runs out. • They have a preliminary application to the Wellcome Trust for a collaborative award but are waiting to hear back if they can put in a full application. If successful, they will be sending out requests for confirmation of collaboration. Within the Wellcome Trust bid, there will be money for training so they are hoping that Cleft Clinicians will begin to consider clinical PHD programmes.	

	• Funding for the next five years from the Scarfree Foundation has been confirmed. Bristol university will received £300,000 per year to fit with the Scarfree mission. • Antenatal recruitment is successful and they have had many maternity units signing up. • They are now in a position to start sharing data. They also have £200,000 to start genotyping their collection of genetic data. This collective will be unique as it contains environmental information collected from questionnaires. • Rerun of the Team Working study – Charlotte Molyneux has approached several of the PIs and CDs about discussing the project. This project will be entirely questionnaire based. • <u>Manchester, CTG & Young Researchers Group</u> • DS – The Early Career Researchers Group met in March with roughly 30 attendees across the full spectrum of MDT. They plan to do a systematic review of outcomes in Bilateral Cleft palette. They met at the conference to work out the search criteria for the project. • The Multidisciplinary team has just had a paper accepted in the Cleft Palette and Craniofacial Journal. • The group have been asked to help in a survey of children within unrepaired cleft palate in each unit. SD offered for CRANE to assist with this and will liaise with Sophie regarding the matter.	
10. Feedback from Cleft Centres (UK & Ireland)	• <u>Bristol</u> Heavily involved in recruitment due to multiple retirements. They have just employed a new part-time Clinical Psychologist to the outreach hub but are waiting for surgeon positions to be approved. It is hoped that by the end of the month the admin team will be complete. Bristol will be hosting the Tricentre Audit meeting in June. There has been some disquiet around the function of the quality improvement arena. SD has done some consultation with the team around improvement and the transformation team have become involved. They are also planning a workshop style morning focusing on how the Tricentre Audit works and how it can be improved. The Tricentre day this year will focus on Quality improvement rather than the presentation of data. • <u>South Thames (KiM -Update from Alex Cash)</u> A new service manager has been recruited and have expanded their clinical admin team with a shared coordinator post with plastics. The 4th and final	

	Surgeons post has just been filled by an ENT cleft fellow surgeon, who will move into the consultants post in July. S&LT, Psychology and Nursing have successfully business planned and proven the need for additional sessions, which is particularly beneficial for the Nursing team as they have been overwhelmed for some time. There has been a baby boom in the Kent region so this comes as much needed support. IT systems are needing to be strengthened to enable better performance across the network. Connectivity across outreach centres needs to be strengthened, as does the Cleft database. One patient has had some media coverage discussing fundraising for Smile Train. • Leeds (RB) Leeds have recently appointed a new lead orthodontist to take on the Yorkshire half of the service. They will be hosting the Norcleft meeting. RB asked SD for feedback on the SW Tricentre audit meeting. • Trent (JND) Psychology post has been declined by commissioning but they have agreed to do a bottom up costing review of the service, which is currently in process. They are starting to see a turnaround in Speech Audits, in all factors and annual numbers are increasing to a promising level. They have a full complement of admin and have just replaced their coordinator. There have been some changes in nursing, a band 6 nurse and lead nurse have left the service. The lead nurse position is being kept open as currently a nurse is being supported until comfortable enough to take the 8a position. There have been multiple retirements across the region in orthodontics but the FTTA programme has generated lots of people to step into these positions. David Thomas (Paediatrician) is retiring and they have some candidates lined up for his replacement. • North Thames – (NHa) Currently seeking approval for a band 8 lead nurse to replace the one who left. Recently appointed a locum cleft surgeon. Still remaining RTT compliant. Are about to advertise for a substantive 8PA Orthodontic consultant post. The audiology services are still stretched and under resourced. Psychology are being asked to cover more specialities and to broaden their remit. They have just shared their new cartoon video on bone grafting, receiving good feedback. They are in the process of moving to Epic on IT front. Tri-centre audit looked at BCLP's and received good feedback -59/75 delegates. • Spires (GP)	

	There are challenges around accessing sufficient theatre time to deal with the capacity they have. They looking at their Cleft database and there are some longstanding issues with ExcelliCare, which are being reviewed. Speech prosthetics are continuing to be offered and promoted including commercialisation of the nasal obturator. This should be a product that will become available at the end of the year. They are focusing on early dental care and children having alveolar bone graft after a change in staffing. • Birmingham (IU for Ian Sharp) Money is tight but there is some progression with the business case for a new surgeon. Their current surgeons are managing the caseload and being paid retrospectively at present. There is a general clash with Cleft on call and general plastics on call, resulting in one of the consultants having to cancel a whole clinic at an hour's notice. Performance metrics are being hit apart from PAR scoring. Time has recently been consumed with organising the conference. Their patient Dylan, who spoke at the conference, has been invited to present to the Chief Executive, which will hopefully raise Cleft and speech therapy higher up on the agenda within the hospital. • North West, North Wales and Isle of Mann(VB) There have been some admin issues in Liverpool due to staff leaving. A locum cleft coordinator has also left and they're looking into advertising for a full Cleft Coordinator. Problems with peripheral clinics in Wales (rooms and admin staff) & Preston (concerns raised by Preston staff about seeing adult patients in the paediatric clinic-meeting arranged between nursing management and SvE). There is a lack of Orthodontic provision in Manchester and they're receiving little interest in Orthodontic recruitment. They are thinking about whether a Specialist Orthodontist would be able to fill the gap prior to finding a consultant. They have also recently recruited a Dental therapist to Liverpool. • Newcastle(DS) Peter has received positive feedback on his presentation to the annual ACLAPA conference about the organisation of cleft care in the UK. There have been a few changes in Admin staff due to maternity leave. As a trust, IT will be going paperless by June next year. The cleft team have looked into using Infoflex but it has presented as too expensive, particularly the yearly licencing fee of £20,000. A new chief executive was appointed a few weeks ago which has brought a radical change in leadership style (use of social media etc).	

11. Training	• NT – There are currently 4 TIG fellows in training. There are some posts vacant and TIG would like to do another recruitment round in October to recruit 2 more fellows. Hospital application forms are causing some problems in that they are not being properly filled in. The next deadline for these will be in July but forms will only be accepted if all signatures are included. HAF forms will need to be updated every 3 years. VB highlighted that centres can be suitable for training but without the funding, training cannot happen.	
12. Any other business – CDG & dates of next meeting	• CLAPA (DST) – The adult services project has started and road shows with engagement activities are being organised. They are looking for venues an-teams were asked to get in touch if they have any rooms available suitable for 25 adults. The 4 Acre trust will match any donations of £500.00 or more to CLAPA so CLAPA are desperately looking for donations. • VB highlighted that members should contact the Craniofacial society if any funding is needed for training, calibration etc. • LB asked that her issues be raised as agenda items	

Date of the next meeting of the CDG: Thursday 22nd November 2018 at the Royal College of Surgeons of England.