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- Tuesday, 9th January 2018, 11-3pm

1. **Present**	Simon van Eeden (SvE)	Chair, CDG & Clinical Lead, North West, IoM & North Wales Cleft Network
	Victoria Beale (VB)	Clinical Director NW, IOM and NW Cleft Network
	Lorraine Britton (LB)	Lead Speech and Language Therapist, Trent
	Alex Cash (AC)	Clinical Lead, South Thames Cleft Service
	Scott Deacon (SD)	CRANE Clinical Project Leader and Clinical Lead Bristol.
	Norman Hay (NHa)	Clinical Lead, North Thames Cleft Service
	Nicola Hudson (NH)	Lead Clinical Nurse Specialist
	David Landes (DL)	Public Health Consultant, PHE
	Kate le Marechal (KLM)	Clinical Psychologists CEN
	Kanwalraj Moar (KM)	Consultant Cleft Surgeon, Addenbrookes, Deputising for CD Cleft Net East
	Sandip Popat (SPo)	Restorative Dentistry CEN
	David Steel (DS)	Chair Programme Director, National Services Division, NHS Scotland
	David Stokes (DSt)	CLAPA Chief Executive
	Imogen Underwood (IU)	President, Craniofacial Society, Principal Speech and Language Therapist, Birmingham
	David Sainsbury (DS)	Consultant Cleft Surgeon, Deputising for Peter Hodgkinson, Clinical Lead, Newcastle Site, Northern and Yorkshire
	Marc Swan(MS)	BAPRAS representative and Consultant Cleft Surgeon, Oxford,
	<u>In Attendance</u> Catherine Foster (Minutes)	CEU Research Coordinator
2. Apologies for absence and welcome to new members	Ian Sharp (IS)	Vice Chair, CDG, Clinical Director, West Midlands Cleft Centre & CRG Representative for CDG
	Sinead Davis (SD)	Chair, CEN for Cleft ENT and Hearing and Consultant ENT Surgeon
	Mark Devlin (MD)	Lead Clinician of Cleft Care Scotland
	Chris Hill (CH)	Northern Ireland Clinicians
	Peter Hodgkinson (PH)	Clinical Lead, Newcastle Site, Northern and Yorkshire
	Jackie Smallridge	Consultant Paediatric Dentist, CleftNetEast
	Susan Parekh (SP)	Paediatric Dentistry CEN
	Jonathan Sandy (JS)	Lead Cleft Collective Birth Cohort and Gene Bank Study
	Jenny Williams (JW)	Deputy for Per Hall and Lead Clinical Nurse Specialist, CleftNetEast
	Jason Neil-Dwyer	Clinical Director, Trent Cleft Service
	Ginette Phippen	Clinical Director & Lead Speech and Language Therapist
	David Drake	Clinical Lead, South Wales and Cleft Surgery Training Interface Group Chair

Item	Notes	Actions
3. Minutes of the Cleft Development Group Meeting, October 2017	Accepted as a true and accurate record of the meeting	
4. Matters Arising	1. CRANE and data group progress- (SD): Crane have met with the responsible commissioner (Ceri Townley) to further discuss establishing a contract but still no action has been taken. This leaves CRANE in a strange situation but we have received some sympathy. We are trying to resolve the situation but obtaining the contract presents as difficult to achieve. We are waiting to hear back from the CRG and data group. 2. Young Researchers Group- Clarification of finances were discussed at CFSGBI and funding has now been agreed. 3. BASCOD Representative has been requested. DL has spoken to the chair of the BASCOD consultants group but is yet to hear back. 4. ToRs- SvE has emailed Steve Robinson concerning the last meeting. MS has confirmed that he will be the BAPRAS representative. 5. Surgeons have balloted for a maxillofacial representative. SvE has contacted BAOMS and the president said it will discussed at an upcoming association meeting. SvE is yet to hear feedback. 6. SLT audit- IS has spoken to CRG but has had no response. 7. Clarify consistent approach within SLT- LB has spoken to SLT at the Leeds Speech Therapy meeting in regards to producing a summarising exclusions paragraph for the dashboard. A speech therapist has now completed said paragraph and action is now being taken for inclusion on the dashboard. 8. Dashboards have been sent to relevant units, of which Nina has now analysed. The dashboard has been circulated and all exclusions have been included. N.B. Few services have entered exclusions in any detail.	**4.3 DL to chase.** **5.4 MS to feedback to BAPRAS.** **4.5 SvE to chase. CF to feedback to Alistair Smyth.**
5. Terms of Reference	Changes to ToR: 1. (DL): 'Health bodies' to be changed to 'health authorities'. Addition of CDG is responsible for training guidance. 2. 2. (SC): Tripartite Agreement is historical as there is no tripartite agreement as of present. It is noted with importance, when meeting NHS England, it would be beneficial to consider the potential replication of TA or, deciding on a different path. Statement is to be left in ToR as it is of present.	

	3. CDG group membership item is to be added to the agenda for future meetings. CF is requested to collate membership data to be reviewed at the beginning of each meeting. SvE questioned if commissioners from Specialist Commissioners Groups in England need to be nominated by a specialist commissioning group in England (As started in ToR). It is decided that the group will elect a Vice Chair and remove said part from the ToR. Commissioners of Cleft care' to be rewritten as 'Commissioners from the Specialist Commissioning Group of England will be invited and it is hoped that at least one will attend'. 4. 'Representative from restorative dentistry' to be added. AC queried the possibility for a cleft patient parent to attend the group. DS will try to encourage a parent to attend but felt there may be some difficulties with travel expenses. ENT representative to be added. Specialist cleft nurse, Orthodontist and Psychology to be changed from CIG to CEN 5. The group is to meet in May and November, rather than the previous three times a year.	**5.3 CF to collate membership data for next meeting.** **5.4 DS to approach cleft parent regarding potential CDGM attendance.**
6. Feedback from CENS	**Speech and Language Therapy (LB)** – Local speech therapy provision has got much worse, in particular within Bristol and Leeds since the SLT survey. NHS contracts are being commissioned very tightly in terms of local ST provisions. In Bristol, preschool children are permitted strictly four SLT sessions whereas Leeds are contracted for two. This is making the provision of effective SLT impossible. LB has briefly spoken to DS about CLAPA's involvement in relation to mobilising some parents; little progress has been made. ST has produced a report in the LST bulletin and CLAPA published survey but have received disappointing feedback. A paragraph has also been developed for the comment section of the dashboard. Plans are ongoing regarding CAPSA training for new therapists. VPI competencies is also ongoing. **Orthodontists** – CEN chair not present – no report. **Clinical Psychology (KLM)** – CLAPA have published a paper regarding the role of Clinical Psychologists. Various CEN projects are ongoing and several Psychologists presented at last year's conference. A number of Psychologists attended the Scar Free Symposium and have been trying to provide some feedback on the incorporation of the Psychosocial aspects of Scarring. CP are also trying to provide feedback on CBT effectiveness for cleft related stress.	

	CP are having continuing issues around Psychology staffing but are currently using the dashboard to suggest additional Psychology. This has had positive responses but Psychology remains fragile amongst the majority of services throughout the country. **Surgeons** (**MS)** – Have recently visited Phillip Chen in Taiwan and are now planning to make regular overseas trips. **Nursing (NH)** – Have met with Ian Bruce in Manchester and are now circulating notes of interest for people to join the NRHI study on sleep positioning, however have experienced some delay in LNs filling out the form. Have gained two new lead nurses and have recently started a buddy system to support staff taking up new responsibilities. Lead Nurses have been experiencing some difficulties for nurses' release from duties in order to attend LN meetings. Hopefully another Cleft course will run in 2019 but support from the local trust is vital so that time will not be taken as annual leave. **CRANE (SD)** – (See CEN report). **Paediatric Dentistry** – (SD): Consultant calibrated Paediatric Dentists (CCPDs) collecting DMFT scoring was raised after some concerns from SPIRE. CRANE is also in a difficult position as they are passing on these scores to the dashboard. The current guidance from the Paediatric Dental CEN seems to be leading to the exclusion of interested clinicians who are not Specialist PD's wanting to attend DMFT calibration courses. CRANE feels as though they need some guidance from CDG. SD has met with the paediatric group with regard to the collection of data and the Paediatric Dental CEN has raised this issue of calibration after recent CRANE reports. DL confirmed that non CCPDs are welcome to join PHE courses and offered to provide contact details for the person responsible in Public Health England for dmft calibration. Questions were asked as to why it had to be consultant pediatric dentists rather than calibrated dentists within the context of national data being collected by community dentists.The expenses for utilising Specialist PD's for dmft collection was also discussed. The use of dmft and audit data to support posts was highlighted as was the need in the population. SvE highlighted that it is not necessarily the need for PD for calibration but rather to encourage their involvement in Cleft teams. KM suggested calibration training to CLEFT team. SvE suggested putting this discussion to one side until the paediatric CEN had a representative present. DL will forward details for PHE national calibration to SD	**DL to provide SD with contact details for Public Health England.** **DS to forward details for DMFT national calibration to SD.**

7. Audit	**CRANE Update Report(SD)** • The report was tabled. • The current funding does not enable the execution of desired tasks and is hampering the benefits of using a longitudinal database to supply data to other groups. The team are currently overspent and are having to pay others to access data. SD has met with Ian and Simon to discuss the strategy and as a result has decided to go through the CRG structure, as recognised by the NHS, when raising funding issues. IS has formally raised funding and contract issues with Linda Doherty but has received minimal feedback. The costs of databases review is yet to start. • CRANE have distributed the annual report and have received good feedback. Feedback has mainly addressed typos, DMFT data (as discussed above) and SLT (TRENT report not illustrating the new changes to service). (LB): TRENT is not involved in the feedback and instead is concerned with the national reporting of outcome data. SLT data is now reported cumulatively in CRANE. A previous agreement had been made with Jibby Medina that a 3 year report of cohort data would be used. LB wishes to start using a new cohort of three years to create a new national standard (2010-2012) and to disregard the cumulative data. SD happy to change and incorporate into the delivery of the annual report. Currently 2007-2011 data has been added to the appendices of the most current CRANE report. • The PREM pilot has been completed and recommendations have been received, jointly with Psychology SEN and the CF council. CRANE have made recommendations of a minimum response rate from centres (30 cases from a small team, 60 cases from a larger team). It is aimed for data to be collected both electronically and on paper until most centres are able to submit electronically. CRANE is to operate data analysis. • In the last meeting it was raised if the CDG would be happy for CRANE to share data with the National Congenital Anomaly of Rare Disease. This has been discussed with NCARDD and it has been established that in principle, they could share data but with cost implications. NCARDD have stated that they do not pay for data and therefore CRANE data sharing has been postponed.	**SD to change TRENT input and incorporate into the delivery of the annual report.** **SD to inform JB of TRENT data comparison changes.**

	• (LB): Request to use 09-11 ST data and compare it to the existing standard of 04-06. SD agreed and will inform Jibby Medina. • The group agreed for SD to remain in position as CRANE Lead following his 10 year anniversary. • No report from ICHOM since the last meeting.	

8. Quality Dashboard	• The group provided positive feedback on the current layout for the Quality Dashboard.
	• **Data from Methods**
	  o (SD): Methods are becoming increasingly rigid in terms of data delivery deadlines. CRANE have received complaints from the dashboard but are not to blame. It is suggested that methods should be approached regarding the reduction of time between data and methods deadlines. Currently all dashboard deadlines are the same but methods are refusing to create an individual deadline for CRANE which would correlate with the publication deadline.
	• **Cumulative data Discussion**
	  o It is agreed that this discussion was completed during the CRANE agenda.	

9. Research	• **Report from Bristol (J Sandy)** – (See report) • **Manchester, CTG & Young Researchers Group** o (DS): Paper on methodology and logistics of running a cleft training collaborative is close to publication. A systematic review of unconventional factors influencing cleft repair also ready to commence. Currently ideas for future collaborative projects for trainees and teams are being requested but little response has been received thus far. Ideally a project that is relatively quick and easy, involving trainees, is preferred but the project is hoped to make a meaningful difference regardless. (SvE): It could be beneficial to ask the CENS or lead groups for ideas that would lend themselves to junior members of the group. The group suggests providing more specific details for the kind of project they are seeking when approaching CENs.	
10. Feedback from Cleft Centres (UK & Ireland)	• **South Thames Cleft Service** – (AC): Staffing is the main challenge and has consequently increased waiting times for surgery. An interview date has been established for the end of February and there is interest in the post. Two TIGS are currently being hosted and an overseas fellow was recently appointed. GMC still need to confirm said fellow's start date. The	

	cleft and paediatric service manager is due to leave after 11 months. The Cleft baby boom continues, resulting in the need for expansion both generally and in outreach clinics. Investment into IT improvements at the outreach team has been received. • **Spires** – (NH): Orthodontists interviews are due to take place at the end of the month. There have been some changes to admin but the biggest pressure at present is bed spaces; HDU beds are unpredictable. Two training days are coming up and there has been some discussion around succession planning for the first time. The current IT support system is no longer fit for purpose and so will need commission for a new system very soon. • **Cleft Net East** – (KM): A new orthodontist has been appointed and several changes have been made to the ST and Psychology team. New Paediatric dentist has been appointed. Births are stable. • **North West** – (VB): NW network manager is due to return from adoption leave in March. In December they had a short notice Orthodontic retirement. Currently still waiting on the trust to approve the vacancy advertisement but it should be activated by the end of the month. There is currently a halftime band 7 ST vacancy at Alderhey which should be advertised soon and interviews for a dental therapist are due to take place shortly. • **Newcastle -** (DS)**:** A new chairman of the trust has been appointed, which will hopefully allow the appointment of a new chief executive. Some reconfiguration in the way that the SL therapist work in terms of ease of travel. Hospitals are experiencing winter pressures. • **Birmingham**-(IU): Primary Cleft surgeon handed in their notice before Christmas, causing disruption to the team. Rona Slater is currently out of action due to injury. An experienced admin staff has also handed in their notice due to bandings. Team morale is low. SLT team is maintained and a new database has been launched. • **Trent** - (LB): A new coordinator has been appointed and is due to start shortly. A lead	

	nurse post has been advertised. A meeting with the Specialised Commissioners had been arranged but was cancelled by the commissions due to 'having more important things to do'. The Psychologist business plan has been put forward to the commissioners but to no outcome – the service currently has a psychologist one day a week. • **North Thames** – (NH): Currently down to one of the three surgeons but have appointed a locum to start in March. This will raise them up to 2 1/3 consultants, lightening the load for the two consultants currently doing the surgical workload. One Maxillofacial surgeon left in April so Caroline Mills has been doing the MXF work alone. A MXF locum is to start imminently. Recent retirement of the lead CNS and due to reconstruction, a replacement is yet to be allocated. Have received another resignation from CNS and have shortlisted her replacement for interview. Another CNS is on long-term sick leave. Have appointed a locum to the Cleft Orthodontist post and are hoping to open a substantive post in April/May. Psychology cuts by trust and a paediatric dentist down. New PD due to start in March. • **Bristol** - (SD): SD term of CD ended in September but is continuing in the role for another three years. The service has been conducting a review over the last 3 months but has received very little feedback. The Divisional accountant has blocked all posts regarding the planned reconstruction as they felt it would not be line managed appropriately. Currently having problems with SLT provision in the SW- private providers are slowly degrading what they are willing to support within the community and effectively not providing therapy for cleft children. SD has approached the trust and advised them to speak to the commissioners directly as he is no longer permitted to. One surgeon is leaving at the end of the month and a non-TIG trained surgeon has been appointed to locum, receiving negative feedback. The trust has developed a new IT project locally and have now been employed by NHS England as a digital exemplar; they are now developing their own electronic record. This is currently being trialled at SD service.	

	• **Scotland** – (DSTe): Staff allocations are fully in place with the exception of the surgical team, according to the board of chief executives; only 2 surgeons are currently working. All patients are being seen appropriately. Service is not at full capacity-local services are being revived to strengthen this but they are not currently commissioned centrally. They have also had a large number of Orthodontist Specialist Care retirements but this is local responsibility at present. Psychological services have increased because of the single surgical service. • (SvE): No reports from Northern Ireland, Swansea or Leeds.	
11. Pressures of Cleft Surgery (Theatres/Beds)	• (SD): All CENs having the same issue of annual cancelling of theatre lists. • (VB): Manchester have moved to a short stay ward and have seen great changes; better care, more beds, more chance of an ill child being noticed. A similar move is suggested to other CENS. • Ian to raise issue at SIG meeting	**Ian to raise bed issues at SIG meeting.**
12. Training	• (SvE): has received a letter from David Drake regarding the three new TIG surgeons appointed in October and one coming to the end of training. • There is a new Hospital Application Form (HAF) that needs to be completed for each unit if they wish to be recognised for training. • David Drake chairs his last meeting on 24th January and there will be a JCST appointed replacement. Interviews for this will take place over the next coming months but so far they have only received one applicant. • Orthodontists have a national training day coming up and several others across the country. The lack of Orthodontists applying for training is discussed. The group will aim to enthuse Orthodontists to become involved in Cleft and highlight its benefits • NH suggested to discuss the life as a CO in SEN meetings and future training. • SvE suggested becoming involved in undergraduate programmes to encourage CO. • (AC): Have been experiencing a lack of rotation in MXF rotation in SThames and a lack of consultants wanting to start due to geographic pressures. • TIG Fellows: plastic surgeons are being appointed more frequently than MXF.	
13. Any Other Business- CDG & Dates of Next Meeting	• (IU):With regard to SEN training days at CFSGBI in April – IU will be in contact with the chair of each speciality but for now encourages the group to consider meeting length and estimated	**IM to contact chairs of each speciality**

	attendees in order to arrange room bookings. The group is reminded that 5 fully funded bursaries are open to application but applicants must have been a member at the last conference. • Next CDG meeting – 16th May 2018	**regarding SEN training days.**