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 – Thursday, 16th October 2017, 11.00 – 16.00

1. Present	Simon van Eeden (SvE)	Chair, CDG & Clinical Lead, North West, IoM & North Wales Cleft Network
	Ian Sharp	Vice-Chair and Clinical Director, West Midlands Cleft Service
	Lorraine Britton(LB)	Speech and Language Therapist
	David Drake	Cleft Surgery Training Interface Group
	Scott Deacon (SD)	CRANE Clinical Project Leader
	Norman Hay (NHa)	Clinical Lead, North Thames Cleft Service
	Peter Hodgkinson (PHo)	Clinical Lead, Newcastle Site, Northern and Yorkshire
	Nichola 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
	Ginette Phippen (GP)	Clinical Director, Spires Cleft Service
	Marie Pinkstone (MP)	Lead Speech and Language Therapist
	Jonathan Sandy (JS)	Lead, Cleft Collective Birth Cohort and Gene Bank Study
	Jackie Smallridge (JSma)	Consultant Paediatric Dentist, CleftNetEast
	Imogen Underwood(IU)	President, Craniofacial Society, Principal Speech and Language Therapist,
	Invited Guests	
	Jonathan Lewney	DPH NorthEast
Apologies for absence and welcome to new members	Victoria Beale (VB)	Clinical Director NW,IOM and NW Cleft Network
	Alec Cash (AC)	Clinical Lead, South Thames Cleft Service
	Mark Devlin (MD)	Lead Clinician of Cleft Care Scotland
	Yvette Edwards (YE)	Joint Representative of CDs and Managers Group
	Per Hall (PH)	Cleft Surgeon (BAPRAS) and Clinical Director, CleftNetEast
	Chris Hill (CH)	Northern Ireland Clinicians
	Jason Neil-Dwyer (JN-D)	Clinical Director, Trent Cleft Service
	Ailbhe McMullin (AM)	Orthodontic CEN Chair
	Susan Parekh (SP)	Paediatric Dentistry CEN
	David Steele (DS)	Chair Programme Director, National Services Division, NHS Scotland
	David Stokes (DSt)	CLAPA Chief Executive
	Jan van der Meulen (JvdM)	Senior Epidemiologist, Clinical Effectiveness Unit
	Mike Winter (MW)	Medical Director, National Services Division, Scotland

Item	Notes	ACTIONS
2. Minutes of the Cleft Development Group meeting, May 2017	Page 3 item on SLT to be corrected should read “support from” Accepted as a true and accurate record of the meeting	
3. Matters arising	1. To await contact from excellicare 2. No feedback from AWS about psychology – action closed 3. ToRs are complete but yet to be submitted 4. No feedback yet from David Stokes about the lay member 5. Imogen Underwood has been invited and is present 6. LAHSHAL form – see Crane report 7. PREM – covered in CRANE report. Has been submitted to council, awaiting feedback. Council meeting is on Nov 9th. (IU) 8. Linkage between Cleft collective and CRANE – response to chair from Jan van Der Muelen. No change in position on cost of the linkage development. Cost will remain at £9600. (email attached). JS expressed view that cost for linkage was too high and at that price the Cleft Collective would not be able to afford the link to CRANE. Discussion of future contracting arrangement for CRANE (SD): Responsible commissioner (Ceri Townley) has been contacted and the database position is uncertain. East Midlands currently hold the money for it, (central money) and they have it in a budget and they will pay it but there actually isn’t an active contract in place for the provision of it. She is also trying to organise a national review of all clinical databases, to see which ones are worth are pursuing in the long-term. And while that is undergoing, there is no conversation about budgets but the review was supposed to have started about six months ago, and hasn’t happened yet. There is no update from her about what the timescale for that is. So, it leaves CRANE in a rather odd position, where we don’t have a contract in place, we don’t have confirmation of our funding from them in writing, which we do need. This is important when making an application to, say, NHS Digital, or other people for linkage, one of the things they ask for is confirmation of the funding stream to see that you’re a sustainable project and CRANE doesn’t have that, which is a problem. The College Clinical Effectiveness Unit (CEU) are getting irritated by the whole thing, because they’re underwriting the cost of the staff. JS This is where a commissioner would be useful on this. 9. Young researchers group – No real progress. Terms and conditions have come from Scar free society and from CFSGBI. Needs clarification of finances for this project. (PHo /IU). Agreement that a record needs to be reached with regard to funding envelope and use of resources. 10. Letter to DPH drafted and sent. No reply received.	**3.7 GP to contact Steve Robinson** **3.8 IS to feed back to CRG and data group with regard to progress on this point. SVE SD and IS to discuss and progress** **3.9. To be discussed at CFSGBI** **3.10. 1. DL to chase**

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	11. Oral Surgeons delivering alveolar bone grafts – DD raised the point that this is not part of the training of oral surgery and so should not be supported	
4. Terms of Reference	Changes to ToRs reviewed. Tabled version is not updated. Health authorities needs to be amended, contract for CRANE needs to be updated. Composition to include commissioners, who should remain on the circulation list, CLAPA member to be included, amend psychologist to cleft clinical psychologist, Cleft surgeon nominations.	4. **BAOMS and BAPRAS to be contacted** ENT also to be included. **Await changes from Steve Robinson and then to be recirculated.**
5. Feedback from CENs	**Paediatric Dentistry (JS)** – session about cleft was delivered at BSPD conference by JS, Victoria Clark, Michelle Connells, and Joanna May with good feedback. Current work ongoing to update patient information leaflets for cleft patients / parents. Calibration day in January is booked and is already full. Tri-Centre work is being reviewed and some changes are suggested. Cleft Care UK findings were presented to Oral Health England board. (JS updated that the message on caries rate was presented nationally) **Clinical Psychology(KLM)** – Continued activity towards projects across multiple centres. South Thames are leading on orthognathic, other projects on psychosocial aspects, some goal based outcomes and patient reported outcomes projects. Ongoing work with CLAPA utilising social media to improve access. Close work with Centre for Appearance Research. Data sharing is being discussed with regard to implications of publication and consent. **Surgeons** – No update **Clinical Directors(Pho)**– Outstanding action for the need to meet to discuss datasets for ten year olds. SD has a plan to arrange a conference about this in the middle of 2018. **Nursing(NH)** – Some changes in leadership of the CEN and Leads group. NH is chair of the Leads Group and Helen Robson is the chair of the CEN group. Meetings have had good feedback. Looking at extending feasibility study of positioning of babies project (SLUMB R) with Ian Bruce. **ENT** – No face to face meeting due to difficulties with people getting study leave, time off and expenses but updates via	

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	emails have occurred. Are hoping to meet before the end of the year or early in the New Year. Not all networks are represented in the SIG and needs to be encouraged**.** **SLT(MP)** – CEN meeting is in November, focus on transcription For the Leads, we are looking at CAPSA training because there's a dire need for both validation of those who did the original training but also for new staff. There has also been discussion with Debbie Sell and Anne Harding-Bell, with plans to move this forward in 2018. Christine Haden and MP looked at some VPI competencies which will be discussed at the next LEAD meeting in November -particularly looking at establishing a benchmark for all staff who are within the VPI service. Also looking into Sheffield course and continuity of specialist training for this group of staff. There is also ongoing discussion of audit. **Orthodontics** – Chair of CEN unable to attend at short notice. No report. Due to meet in Birmingham in November. Just in relation to the SEN there are three ongoing projects looking at: orthodontic outcome for patients; impacted canines in orthognathic cases and the British Association of Oral Maxillofacial Surgeons minimum dataset to see how well we're adhering to this in the management of cleft orthognathic patients. Audit was also discussed and there is an ongoing discussion about ten vs five year audit datasets.	
6. Audit	**CRANE (SD)** – Report tabled. Informed that live information is available both to users and also a limited dataset is publically available. Discussion of making information public is ongoing with Crown Informatics. Proposed work which requires some guidance from CDG – Usually buys 12 days per year of Crown Informatics time – expecting change with LAHSHAL, developing a surgical section, paediatric developments of DDE at 5 and 10, real time update of late diagnosis. Priorities for time requested – DD suggest focus on direct patient related activities – delayed diagnosis and dental anomalies; KM suggested that LAHSHAL work underpins other work and should be prioritised. PHo raised the question of bracketing the S in LAHSHAL for submucous clefts? SD said it was likely to be difficult and the function already exists in CRANE with a tickbox. Annual report is being drafted currently and will be due at year end. More focussed and less repetitive of information available via website. Will be circulated to CDG prior to publication. CRANE is seeking permission to access dental data, which is a difficult process and takes time due to legislative framework. Looking at mapping birth vs first surgery to determine if there is movement between centres. PREM work is ongoing.	

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	National Congenital Disease registry is requesting link to CRANE. GP – national dataset for Congenital Disease registry has been requested via centres, but should now be done via CRANE. Scotland have suggested that they would like to join CRANE and the dialogue is ongoing with regard to permissions and privacy impact. LB – request for data in relation to NorCleft group. Agreed to proceed with delayed palate diagnosis work as priority for CRANE **Speech and Language Audit (MP and LB) –** Two updates. National survey – still no response from commissioners with regard to the survey. It is now available via the CEN in full form and anonymous. Published in SLT bulletin. CLAPA have also published the information with a proforma to fill in and send to their MP's, which may precipitate requests for information. Still to be delivered are the changes to NSS. Exclusions- submission of data to dashboard has been done for some time, but is not published currently in the QSSD dashboard. Suggestion that reporting to centre on exclusions should cease. Discussion about value of this information. PHo, IU, LB, IS contributed to discussion. **ICHOM** – SD has been asked to speak at the Dutch cleft meeting with regard to data. Erasmus centre are using the software package to collect data. No other updates. NH commented that package may not be applicable to other centres as easily as was thought.	**4.1 To be taken back to CRG – IS to action request for authority to proceed.** **4.2 To clarify with CEN to ensure consistent approach across the country**
7. Publication of Local Outcomes (MP)	Request for local publication of outcome data via the GOSHWeb. Question as to the possibility of publishing CRANE outcomes locally. No evidence in previous minutes with regard to this. DD – publish data against national standards rather than as a direct comparator to other units. This was agreed on after discussion about who the audience was, the importance of the local narrative and exclusions and the context of the local service.	
8. LAHSHAL Codes and the Quality Dashboard	See other discussion above in relation to LAHSHAL. Update on funnel plots below **SvE presentation:** SVE presented data on dashboards. All the data has been submitted to SVE and examples were presented. Cumulative data for all units reviewed, presented as centre specific data for each area of the dashboard. Suggestion that all data for the units should be reviewed and narrative added by CDG to show that there is governance of services and the issues within the dashboard. The feeling was previously, that if the unit is within the grey area, the unit is doing okay. If not, then there's probably a reasonably good reason why.	

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	On evaluation of the quality indicators it was felt that in general most units were doing well. For those that were falling outwith the grey area it was felt that there would be a reason for his and this is not necessarily reflected in individual QD's. Discussion from all followed, which included the QD data finding it's way into the public domain (either via Freedom of information requests or the media) without the appropriate narrative then patient care and possibly units reputation could be compromised. It was felt that the individual units would like to review their own QD's and to add their own narrative to the red areas. A request was also made to Nina of Methods to put annual data together rather than individual quarter information.	**4.3 SvE to send QD's to individual units** **4.4 SvE to write to Nina to ask her to do this**
9. Research Report from Bristol (JS)	Report previously tabled. CC now running for 5 years. All the 17 teams in the study, and 16 actively recruiting. Return rate of the questionnaires has been increased. Yvonne Wrens separate cleft palate speech and language study has now got 12 sites, which is two more than last year. Antenatal recruitment is gathering momentum. with 31 people recruited to it, and 29 core bloods. • Data dictionary is available for members of the group to access. CLAPA engagement has happened and was positive. Scar free foundation is aiming to achieve scar free healing within a generation and hope to raise £ 24 million for this. Cleft Collective, has now moved into a phase where we are starting to look for additional funding. Funding runs until 2019 and it can be eeked out until September 2019. There will be very respectable numbers by then but there needs to be another five years of funding. MRC and Wellcome have been approached, CC may well fit within a co-funding model across the large funding organisations. Needs to maintain cross-unit nature of research going forward. University of Bristol has committed two posts to this grant. • John Thompson in New Zealand, who's been linked in with the CC right from the start has just got a grant from the New Zealand MRC to run a case-control recruitment study, using a similar design to the CC. For every child born with a cleft (in New Zealand there's only a hundred of these children a year) two controls will be recruited from the same maternity unit, in the same week. • Cleft trainee collaborative have worked hard to deliver on data requirements and have been successful in publication. • CleftCare UK has just published another supplement on the effects of centralisation. This reports will give each centre its own data, and then compare it to a national mean, and each centre will be able to see where they are within those plots- other centres information will not be available.	

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	Manchester, CTG & Young Researchers Group - Report tabled by chair from David Sainsbury. Name of the group is changing to the Cleft MDT collaborative. 48 trainees are involved from a wide range of specialty areas(plastic surgery, 16, maxillofacial surgery, 15, restorative dentists, 7. paediatric dentistry, 4, orthodontics, 3, research nurse, 1, speech and language therapy, 1, medical student, 1). Encouraged further engagement. Have provided data for 900 missing phenotypes, which involved 21 trainees, 11 of which were maxfax trainees, 9 plastic surgery, 1 restorative dentist, 1 research nurse, and 1 orthodontist. A paper about this is being produced. Further projects are being planned and they are looking at cross centre activities and audits. JS commented on how great a success this has been.	
10. Feedback from Cleft Centres (UK &Ireland)	**North Thames:** NH – staffing is an issue. Lost one surgeon to another centre, one has just returned on a phased return, managing on one and one third wte. Pressure in the system in terms of revisional surgery and secondary surgery. Recently have also lost one OMFS surgeon which has had a double impact on delivery. Paediatric dentist also on long term absence, which also has an impact on delivery. One orthodontist has also moved. Psychologist about to go on maternity leave. Experienced CNS is also due to retire soon. Difficulty recruiting to secretarial posts in central London. Audiology and ENT protocols are currently being reviewed. Despite staffing issues across most specialities there is a good MDT dynamic and team spirit is holding the service together and keeping primary activity on track. **Birmingham:** IS -staffing issues through the year which are now settling. A&C staff have been under pressure, but hopefully will be improving soon. Speech issues remain in regard to banding. In the pot for a TIG trainee. Delivering expected standards. Currently working on a database to improve continuity of care. **Wales:** DD -AWS has retired and DD is now CD. Staffing okay apart from secretarial support staff. No problems in delivery for paediatric service, but bed availability is a constant challenge. Delivery of secondary care remains a challenge. **Cambridge:** KM - Full complement of surgeons. Two part time and 2 full time. Out to advert for a new orthoodontist and paediatric dental sessions. TIG fellowship is funded if an applicant takes up the post. Financially the Trust is recovering and are starting to see the benefits of Epic EPR. Fine with regard to admin staff. We have a midgrade service manager, which has had significant improvement in the way we're running and meeting targets. Difficult areas are theatres and beds but this is not really impacting on the children, but on the adults. Orthodontic provision regionally is also proving to be a challenge.	

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	Trent: LB – Staffing is a challenge. Nursing leadership has been lost and is fragile currently with the added retirement of one of the specialised ward nurses. Three surgeons (2 maxillofacial surgeons and one plastic surgeon) are about to retire and two orthoodontists are also due to retire. No clear plan for replacement of orthodontic service as it is on an SLA. We have a psychologist still on one day a week, and that's still a rolling temporary contract. A&C staff also under pressure. Due to meet with commissioners to look at the whole service after a long period (years) without a meeting. Outcomes for the service are looking better. Have recently had the second annual family day. **Newcastle**: PHo - Recent sacking of chief executive. Full complement of staffing, although likely to be a risk in nursing. Surgical activity working well- work a pooled base and patient's seem to be quite happy with that and this helps with planning. Adult service is subject to IFR and prior approvals. Now getting up to speed with recruitment into CC studies. Visit from Malmo team suggested that they share similar challenges. Had significant input into trying to change the trusts policy on chocolate donations to the trust. **South Thames:** KlM- staffing challenges. One surgeon down, with increased waiting times for secondary surgery and orthognathic surgery. Success in recruitment in psychology so now up to full complement. Business case ongoing for new CNS. Had quite a baby boom in the last 12-18 months, so a lot more babies. We've had our full quota of babies by this far through the year that we normally get the whole year. **Bristol**: SD -staffing is a challenge. Two surgeons are retiring and will need to be replaced. This will require reconfiguration of the service. Currently a review of the whole service due to be undertaken as a result of the surgeon vacancies and only after this will it be possible to advertise for surgeons. A lot of the cleft team are due to retire in the next few years, which will mean replacing a very experienced workforce by a very inexperienced team. **Oxford / Salisbury:** GP -Now have third surgeon in place appointed in September 2017 meaning 3 primary surgeons across the network. . Also looking at consolidating treatments for orthognathic surgery at one site but looking at the impact that would have on patients travelling etc . Likely to be a challenge to nursing recruitment over the next few years. Possibly in a position to recruit an orthodontist soon for Salisbury. Just recruited an experienced psychologist for Salisbury. Also looking at the network communication strategy because there has been	

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	a lot of new staff and changes-looking at the websites and other platforms for possible engagement with patients and colleagues across the network. **Liverpool / Manchester:** SVE – Vicky Beale is now the CD. Chris Sweet has been appointed into a permanent to replace Chris Penfold who will be stepping down from cleft at the end of October. Impending shortfall in orthodontic provision with retirement of full time orthodontist in Manchester. Yvette Edwards has taken adoption leave, for six months leaving the network without a network manager at the moment. There were plans to backfill her post, but this hasn't happened yet. In terms of other staffing issues, there have been admin issues at Alder Hey - When we moved into the new hospital Alder Hey's long-standing cleft coordinator left. She had been replaced by a number of locums with associated continuity problems and this reflects in the 2009 audit data. A lot of patients fell through that net and that just shows the importance of having a good coordinator within the team. Currently have a young but very motivated locum. A senior psychologist has taken a redundancy package and has created difficulty in replacement. As far as research is concerned, we haven't been able to join the speech and language therapy arm of the Cleft Collective, because of lack of research nurse support. Apart from that, the only issue that will raise its head again is bed pressure during Winter. We've been asked to pare back on the number of the number of patients we're able to do on a full day list. So, going from three or four a day, we have been asked to list only two a day. **Scotland:** Report was tabled by Mark Devlin, which has been circulated. Support for nursing in Scotland has been provided from England nursing group SD raised the question with regard to succession planning in other parts of the service. Surgeons are planned nationally. SVE suggested that these issues need to be raised via the CEN groups to develop solutions.	
12. Training	DD reported that training committee met last week. TIG structure has changed significantly in the RCS but this has not affected cleft TIG. Two trainees are in post and three appointments are about to be made following interviews last week meaning that there are 5 trainees in the system. Likely to need another appointment early in the new year. DD due to demit as chair in February, only one applicant has come forward.	
13. Any other business	PHo – CLAPA have raised willingness to work collaboratively on patient information. A recent Smile Train advert, which was felt to be highly iappropriate was brought to the attention of the CDG. CLAPA have responded.	

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	Recent joint meeting in Germany attended by PHo demonstrated the positive aspects of cleft services in the UK. Feedback is that the UK services are significantly ahead of the rest of Europe.	
14. Date of the next meeting	The next meeting will be on: **11H00, Tuesday 9th January 2018** Venue - Research Boardroom, Nuffield Building, Royal College of Surgeons	