DRAFT - Minutes of a meeting of the National UK NHS Cleft Development Group

(Joint meeting with the NHS England Clinical Reference Group for Cleft Lip and/or Palate)

Venue - Research Boardroom at the Royal College of Surgeons of England
Date & Time – Wednesday 13th October 2015, 11.00am – 1.30pm

1. Present	Stephen Robinson (SR)	Chair, CDG
	Victoria Beale (VB)	Consultant Maxillofacial Surgeon
	Alec Cash (AC)	Clinical Lead, South Thames Cleft Service
	Sinead Davis (SDa)	Chair, SIG for Cleft ENT and Hearing and Consultant ENT Surgeon
	Scott Deacon (SD)	CRANE Clinical Project Leader
	David Drake (DD)	Cleft Surgery Training Interface Group
	Toby Gillgrass (TG)	Lead Clinician of Cleft Care Scotland
	Per Hall (PH)	Cleft Surgeon (BAPRAS)
	Norman Hay (NHa)	Clinical Lead, North Thames Cleft Service
	Peter Hodgkinson (PHo)	Clinical Lead, Newcastle Site, Northern and Yorkshire Cleft Service & Chair Cleft Centres
	David Landes (DL)	Public Health Consultant
	Karine Latter (KL)	President, Craniofacial Society and Nursing deputy for NH
	Kate le Marechal (KLM)	Clinical Psychologists SIG
	Jason Neil-Dwyer (JN-D)	Clinical Director, Trent Cleft Service
	Norma Patterson (NP)	CDs and Managers Group
	Marie Pinkstone (MP)	Lead Speech & Language Therapists
	Rosanna Preston (RP)	CLAPA Chief Executive
	Jonathan Sandy (JS)	Lead, Cleft Collective Birth Cohort and Gene Bank Study
	Rona Slator (RS)	Clinical Director, West Midlands Cleft Centre
	Jackie Smallridge (JSma)	Consultant Paediatric Dentist, East of England Cleft Network
	Adrian Sugar (AWS)	CRG / Wales Clinicians
	Simon van Eeden (SvE)	Clinical Lead, North West, IoM & North Wales Cleft Network
	In Attendance	
	Jackie Horrocks (Minutes)	Minutes / Administrator, Clinical Effectiveness Unit
	Jibby Medina	CRANE Database Research Fellow
Apologies	Geoffrey Carroll (GC)	Medical Director, Welsh Health Specialised Services
	Michele Davis (MD)	Regional Programme of Care Manager London
	Mark Devlin (MDe)	Clinical Lead for the Cleft Surgery Programme Board, Scotland
	Chris Hill (CH)	Northern Ireland Clinicians
	Nichola Hudson (NH)	Lead Clinical Nurse Specialist
	Thayalan Kandiah (TK)	Paediatric Dentistry SIG
	Natalie Kirk (NK)	Network Business Manager for Cleft Net East
	David Orr (DO)	Cleft Services in the Republic of Ireland
	Bill Shaw (BS)	Manchester Lead, Cleft Collective Birth Cohort and Gene Bank Study
		Cleft Surgeon (BAOMS)
	Alistair Smyth (ASm)	Chair Programme Director, National Services Division,
	David Steel (DS)	NHS Scotland,
	Jan van der Meulen (JvdM)	Senior Epidemiologist, Clinical Effectiveness Unit
	Mike Winter (MW)	Medical Director, National Services Division,, Scotland

ACTION

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<tr><td>2. Leavers and Joiners. Membership of the CDG</td><td>RS announced that she would be stepping down as Clinical Director of the West Midlands Cleft Centre and that Ian Sharp, Consultant Oral and Maxillofacial Surgeon, would be taking over. SR thanked RS on behalf of the CDG for all her valuable work over the years. AWS mentioned that commissioners were now spread more thinly and the CDG lacked input from the commissioners who actually fund the CRANE Database.

SR welcomed Karine Latter, the current President of the Craniofacial Society and Sinead Davis, Chair of the SIG for Cleft ENT and Hearing.

RP had announced by email that she had resigned from CLAPA and will be leaving next April. She said that CLAPA were in the process of appointing her successor. SR thanked RP for her valuable contribution to the committee over the last 10 years.</td><td></td></tr>
<tr><td>3. Dates for meetings</td><td>Future meeting schedule agreed:

Thursday, 28th January 2016
Friday, 20th May 2016
Wednesday 12th October

Venue - Research Boardroom, Royal College of Surgeons, London</td><td></td></tr>
<tr><td>4. Minutes of previous meeting</td><td>Amendments to the draft minutes from 13.05.15 were accepted by the committee.</td><td></td></tr>
<tr><td>5. Future of CDG/Election of new Chair</td><td>SR noted that he had still received no applications for the Chair of the CDG. Both SR and AWS stressed that the CDG was a very important body for cleft care and that the CDG needed to focus on a replacement for SR.</td><td></td></tr>
<tr><td>6. Reports from Cleft Centres and CLAPA</td><td>North West
SvE had circulated a report from the North West region.

With regard to activity, he provided the table below:
<table>
<tr><td>2014</td><td>2015</td></tr>
<tr><td>Babies>1 year 137</td><td>Babies>1 year 126, 111 Clefts</td></tr>
<tr><td>Adult>21 years 36 (new patients)</td><td>Adult>21 years 27 (M-20; L-7)</td></tr>
<tr><td>Other 153 Non Cleft VPI</td><td>Other 144 (M-66; L-80)</td></tr>
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He reported that, financially, there was no additional resource since the last CDG meeting and that the network is likely to have a percentage reduction in its overall budget. In line with SLR, all services are being asked to find and realise efficiencies where possible although no ‘official’ CIP has been asked for yet.

He noted that two vacant Nurse Specialist posts have been appointed and commenced. Leanne McDowall (North Manchester) and Katy Stephenson (Lancashire). There are on-going pressures on SLT capacity due to maternity leave. Sessions have been covered but not all of them. Also the secretary in Manchester is on sick/maternity leave and the department is waiting to recruit and an audit administrative support post is currently being advertised in Manchester. But no</td><td></td></tr>
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	posts have been lost since the last meeting. Susana Dominguez Gonzalez and Haydn Bellardie's tenure as Centre Leads ended in September 2015. Vicky Beale (Consultant Cleft/Maxillofacial Surgeon) and Dr Zoe Edwards (Clinical Psychologist) have now taken over the role. The pressures on the Network include: - Paediatric Dentistry (Liverpool, Manchester & North Wales); Restorative Dentistry (Wales, Preston) and Audiology service (Liverpool). Also there is reduced availability of community SLT to carry out local speech therapy due to service reviews and cost saving measures. **South Thames** AC said that two of the most senior nurses at South Thames had left but had been replaced. A new paediatric dentist will be appointed soon. Administrative support had improved recently after the past problems in provision but that there were many problems with the Excel database at the hospital as it was unwieldy to use, lost patient records and was unable to run useful reports. In education South Thames had been working in conjunction with Spires on training for higher orthodontic trainees. He suggested training opportunities were not the same for maxillofacial surgery but the team looking to set this up. This was followed by a discussion on out of hour's cover and the potential impact of any proposed new junior contract. He suggested cleft surgeons were currently covering the on call work. RS said that the new junior doctors' contract was already affecting Birmingham and it was difficult to provide training but felt this was just one step on a long process affecting provision. DD said that the TIG would be discussing this. JS said that many trainees were now aiming to go abroad when their training was completed. JN-D said that others were thinking of changing career. **Scotland** TG reported on the situation in Scotland. The centrally funded surgical service review implementation continues and there is a meeting at the end of October to progress this. There are difficulties developing the work of the non-commissioned Cleft Care Scotland Network while the uncertainty over the surgical service continues. Rebecca Crawford, the Consultant Clinical Psychologist has started and there will be further appointments once the fate of the surgical service is decided. Following discussion with the help of CLAPA and an adult group TG is looking to develop the adult service. To this end they have formed a restorative dentistry group within Scotland and TG hopes their nominated lead will attend the next executive group in December. Again concerns have been raised with management about the loss of two key secretarial staff within the service and it is presumed they may be subsumed into a coordinator role, although this will not happen until the design of the surgical service is decided. SD said he was to visit Scotland in November to encourage the cleft service to participate in the CRANE Database.	

North East
PHo said there were 20 new adults being treated and there was an advertisement for a new cleft surgeon. He said there was a general squeeze on 'therapies' including psychology and funding is being reviewed. He felt there was little money to fund the Cleft Collective participation. He noted that the two North West centres were sharing a TIG cleft fellow but he would like another one.

Nottingham
JN-D said that there was now another primary surgeon and when two other surgeons retire, their posts will be amalgamated into one cleft surgeon post. He said the service is very much consultant and nurse specialist led with trainees always supervised. He said the centre had not had a plastic surgery trainee for 10 months and that he had objected to this but with no result yet. He said that all community services were now under tender including speech and language therapy. He said that a cleft specific orthodontist had been appointed

Fiona Gilchrist as the lead Paediatric Dentist is to do some scoping work on what is needed. He said there was also a review in Nottingham of administrative support, which will be centralised across specialties. He noted that parent support for care is good in the Nottingham area with £10,000 raised from a recent Ball.

North Thames
NHa said that the main problem recently had been that between October 2014 and March 2015 there had only been one surgeon covering for three surgeons' work. He said the situation had improved now with the help of locums but another surgeon was injured in June who will only be coming back on a phased return. There had also been shortfalls in administration in that one secretary had been on sick leave for around 10 weeks. There had been temporary staff but this provision was not reliable. He said clinical psychology had been affected by a reorganisation. There was now no specific cleft clinical psychologist but they were allocated from a central pool of clinical psychologists. NHa said he had complained about this. Speech and language therapists had been on maternity leave and although, this had been covered internally, it had left less time for therapy. There was now adult provision at Broomfield and the numbers were increasing of adult patients. He noted that MP is working closely with CLAPA.

South West
SD said the South West service was in a fragile state. There is a restructure of administration and other services and all expenditure has to be justified. Two surgeons are talking about retiring. There is a primary and secondary service model but if surgeons retire, there will only be funding for one position combining plastic and maxillofacial surgery.

Cleft Net East
PH reported that the idea of a pool of psychologists as at North Thames had been suggested and cleft nurses had been requested to work on other wards, although they had declined to do so. The psychology service is seen as top heavy and if

	people leave they will either not be replaced or replaced by someone in a lower band. Due to the financial problems, the Trust was in special measures. One million pounds on the tariff has not gone to the cleft service. But PH said he was feeling more positive about the electronic patient system. He said the cleft patient information group was currently rewriting the hospital patient information booklet and designing a logo. NHa said that electronic case notes were introduced at North Thames and paper notes were being destroyed after six months. He would advise PH to ask for them to be kept in a vault at Addenbrookes. PH said he had suggested this but it was ignored. He felt it was very worrying and even worse for North Thames as they have many referrals from other cleft services. AWS said he had argued for the paper notes to be retained in South Wales by saying the commissioners would like an archive. But the Trust said it was too expensive to scan the notes for a digital record. **Birmingham** RS said she was feeling quite positive about the service at the moment with many patients being treated successfully. They were trying to get orthodontic treatment sessions located in the Children's hospital. There are two speech and language members of staff on maternity leave. Like North Thames, there is now a pool of clinical psychologists with just one part time cleft clinical psychologist. She said more nursing staff was needed. There were more administrative staff but as the finances were very tight, the service was unable to appoint a replacement of the same calibre as Alex Levine, the Cleft Co-ordinator, who has now left. There was also no IT support but RS is looking into this. RS noted that the regional CLAPA co-ordinator had been very helpful in setting up a small feedback group of patients and parents. **South Wales** AWS reported that the staffing at the centre was stable. He noted that the junior doctors' contract would not apply in Wales, which was a bonus. He said colleagues were talking about recruiting from England. He said the second attempt at obtaining more funding from the Welsh Government had failed. He said the specialised commissioners rank requests and cleft was always outranked by services such as cardiac treatment. He felt it was just as well the organisation had been different in the past to enable cleft to get some funding. He noted that the cleft service had moved into a new centralised cleft centre, which was part of the new outpatient centre. This meant the service was much more integrated with the Paediatric, ENT, Maxillofacial and X-ray services nearby, which was great. He said that photography were nearer than before although not as near as the other services and the photographers were able to store equipment in the cleft centre which was useful. He felt the new computer system, although it had some limitations, gave the clinicians more control and has had an impact on the delivery of services. He noted however, that as £40million had been cut out of the budget for the whole of the Outpatient Department. there were, at present, no offices. But a new office block was being built next door which should be ready early next year. Also the long waits were still the biggest problem for cleft treatment and around 100 patients had waited several years for non-urgent surgery.	

	The Spires SR said the Spires had run a cleft specific database for the last 12 yrs. designed and built by Axsys Technology from Scotland. He suggested they paid nearly £15,000/yr. in maintenance and upgrades and are currently reviewing the contract. He wondered if the North West system should be looked as an alternative. There had been a recent Care Quality Commission visit to the Oxford site specifically to review the SLT Service, which was currently managed outwith of the acute Trust. He suggested a review of current service structure was underway as part of an on-going process of succession planning. **CLAPA** RP said preparations were underway for the CLAPA Conference on 21st November and new employees had reinvigorated CLAPA. She said the new website will allocate each branch their own page and a new member of staff is to be appointed for Wales. Also a draft of the reviewed information materials will be ready by the end of November.	
7. Audit: CRANE Database and ICHOM	The CRANE team had circulated relevant papers to the CDG committee beforehand including the draft Annual Report. SD noted that October was a busy time and asked that feedback on the Annual Report could be submitted to the CRANE team by the end of the month with the aim of publishing the final report by the end of November. SD noted that tables in the report make reference to Regions/MCNs and Administrative Units, which are really hospital names. He asked if CRANE should consider changing Administrative Units /Hospitals to NHS Trust names to report at the organization level. SD asked if the CDG could confirm that all Special Interest Groups (SIGs) are now referred to as Clinical Excellence Networks (CENs) as the team has assumed this in the Annual Report. KIM said that all groups were now referred to as CENs except for Audiology but that she will investigate and confirm to CRANE. PH has asked that centres who are reported as having underperformed in the Annual Report could have a section within the report to explain why. JN-D said that the marked variation in completeness of data between centres meant that the funnel plots need processes to avoid selection bias. JM said that the methodologists have suggestions to combat this, including perhaps, removing outliers. DD said there were huge variations in completness so the graphs need consistency and a minimum standard to make it fair. He said that incomplete data was not equal to complete data for analysis purposes. JN-D agreed but SD felt funnel plots were fairer than the percentages league table used before and he said that he needed to move the process along. JN-D felt there had been a unilateral process of decision on this and was worried that the centres would receive no support when the report comes out and patients question poor results which were due to selection bias. RS said there was robust governance on how to improve and NHa said that he felt clinicians could use poor results to pressure the Trust for more help. JN-D felt the results would be used to 'blame and shame'	**CDG members to submit comments on CRANE report by 30th October** **KIM to check if CENs or SIGs** **CRANE and JN-**

	in Nottingham. He felt CDG/CRANE needed to offer support on improvement as well as collecting data. AWS said that Nottingham may not be as bad as JN-D fears and that South Wales and the South West were in the same position. He noted that in the past he had met John Rowson and written to the CEO at Nottingham to give support to the Nottingham service on behalf of the CDG. He felt the people to deal with the situation were the commissioners. SD suggested that CRANE and JN-D could add something to the report to explain varying results but he said that it was not in CRANE's remit to offer support. RP suggested that an explanation can also be put on the CRANE website. With relation to 'transfer of care' from centre to centre when patients move, SD said that CRANE was working on showing better where patients are being treated. SD highlighted that the target date for the launch of the new version of the CRANE website was 1 February 2016 but that this would be confirmed closer to the time. SD asked that the CDG start to think about how surgical episodes should be recorded on CRANE. He also asked that the CDG submit any suggestions on the proposed information leaflets for the CRANE Database and for Data Linkage, and the consent form covering consent for each type of data collection/linkage. He noted that the consent form was designed for the parents to opt out rather than opt in and that there would be no re-consent forms for adult patients. SD said that the Patient (and Parent) Reported Experience Measure (PREM) that CRANE and the Cleft Psychology CEN are collaborating on, will be discussed at the Clinical Psychology CEN on 22nd October and there will be a report at the end of the month. The mid-year report will be discontinued in 2016 with the innovation of CRANE news and website improvements. **ICHOM** Nothing new to report at present but the site costs are reported to be £20,000-25,000 but would reduce if multiple centres were involved.	**D to discuss adding explanation to CRANE report** **CDG to start thinking about surgical episode reporting** **CDG to comment on information leaflets and consent form**
8. Training	DD reported that there will be two new cleft fellows in post soon at Birmingham and South Thames. Two previous post holders would be eligible for consultant posts on completion of training. He said that no more posts will be advertised in the next six months. DD reported that higher surgical training was undergoing a review and there were two options for the future. The first was that the TIGs continue as they are, which is DD's preferred choice. The second option is that TIGs will be subsumed into one super-specialty group. No report has appeared yet so DD does not know what will happen. A cleft fellow was to be employed at Cambridge but there was a problem in agreeing starting increments. There is a move to part-time cleft jobs which are	

	open to all but DD felt these were not good for cleft surgeons and thus not attractive to applicants. PHo said he and ASm as centres with TIG fellows would like to be sent ongoing reports, diaries and minutes of meetings and other relevant documents. RS agreed that this would be useful for centres with TIG fellows. DD agreed to look into this but said that JCHT does not do this routinely.	**DD to look into disseminating TIG information to hosting centres**
9.Research	**The Cleft Collective Cohort and the Gene Bank Study - Bristol. Progress Report (attached)** JS had circulated a progress report on the Cleft Collective Cohort and the Gene Bank Study at Bristol (attached). With regard to the graph, RS noted that Birmingham had set the target bar very low to avoid being penalised. She noted that if there are to be increasing amounts of research studies, separate direct funding to cleft teams will be necessary. JS said he was very pleased with the recruitment rates of patients into the study. He said that they were aiming to have a cohort of 9,000 patients and are now re-configuring the budget to include direct payments. He said this was not finished yet but he stressed that he was as keen as RS to enable this to happen. He noted that a data dictionary was being devised. He said the Cleft Care UK paper had been accepted for open access in the online Orthodontic and Craniofacial research journal. SvE said that he had been approached by two very concerned orthodontists after JS's presentation. But JS said that the data in the presentation had been very preliminary. It was noted that the Healing Foundation had withdrawn funding from the Manchester Clinical Studies Centre which had led to staff layoffs. JS said this was a decision made by its research committee. He said there was a Craniofacial Society group meeting on the following Friday. Manchester will now not be able to help develop several projects. KL said that the CFS was struggling with funding at the the moment and this would be discussed at the CFS Conference in 20-22nd April 2016. She noted that the improved website would be available in January 2016.	
10. SIG/Clinical Excellence Networks	ENT/Audiology - SR welcomed SDa to the group. She reported that the ENT and Hearing SIG had held three meetings since the beginning of July 2014 and were now working on the National Minimum Dataset. There was a current concern about the data centres were putting on the Quality Dashboard and a lack of consistency. The SIG are developing a minimum acceptable practice. She said they were grateful to have a voice on the CDG. Paediatric Dentistry - JSm said a calibration day was coming up for paediatric dentistry. Restorative Dentistry – SR reported there would be a restorative dentistry study day this week in Birmingham attended by 36 people.	
11. Any Other Business	It was noted that NICE have a scoping exercise in process on 'Transition from children's to adults' services'. At present it is in consultation with stakeholders and should be published in	

	February 2016. KL said there would be a keynote speaker on this at the CFS Conference in April.	
11. Date of the next meeting	The next meeting will be on Thursday, 28th January 2016 and will be held in the Research Boardroom on the 7th floor of The Royal College of Surgeons of England as usual.	