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 – Friday 13th May 2016, 11.00am – 1.30pm

1. Present	Stephen Robinson (SR)	Chair, CDG
	Lorraine Britton (LB)	Lead Speech and Language Therapist, Trent Regional Cleft Lip & Palate Service
	Alec Cash (AC)	Clinical Lead, South Thames Cleft Service
	Scott Deacon (SD)	CRANE Clinical Project Leader
	Toby Gillgrass (TG)	Lead Clinician of Cleft Care Scotland
	Norman Hay (NHa)	Clinical Lead, North Thames Cleft Service
	Peter Hodgkinson (PHo)	Clinical Lead, Newcastle Site, Northern and Yorkshire Cleft Service & Chair Cleft Centres
	Nichola Hudson (NH)	Lead Clinical Nurse Specialist
	Jacquie Kemp (JK)	National Programme of Care Senior Manager – Trauma, NHS England
	David Landes (DL)	Public Health Consultant
	Kate le Marechal (KLM)	Clinical Psychologists SIG
	Norma Patterson (NP)	CDs and Managers Group
	Marie Pinkstone (MP)	Lead Speech & Language Therapists
	Sandip Popat (SP)	Restorative Dentistry CEN
	Jonathan Sandy (JS)	Lead, Cleft Collective Birth Cohort and Gene Bank Study
	Ian Sharp (IS)	Clinical Director, West Midlands Cleft Centre
	David Steel (DS)	Chair Programme Director, National Services Division, NHS Scotland
	Adrian Sugar (AWS)	CRG / Wales Clinicians
	Simon van Eeden (SvE)	Clinical Lead, North West, IoM & North Wales Cleft Network
	Jennifer Williams (JW)	Deputy for Per Hall and Lead Clinical Nurse Specialist, CleftNetEast
	In Attendance	
	Jackie Horrocks (Minutes)	Minutes / Administrator, Clinical Effectiveness Unit
Apologies	Victoria Beale (VB)	Consultant Cleft & Maxillofacial Surgeon
	Sinead Davis (SDa)	Chair, SIG for Cleft ENT and Hearing and Consultant ENT Surgeon
	David Drake (DD)	Cleft Surgery Training Interface Group
	Per Hall (PH)	Cleft Surgeon (BAPRAS) and Cleft Surgeon, CleftNetEast
	Chris Hill (CH)	Northern Ireland Clinicians
	Karine Latter (KL)	President, Craniofacial Society and Nursing deputy for NH
	Sian Lewis (SL)	Acting Medical Director - Welsh Health Specialised Services Committee
	Jason Neil-Dwyer (JN-D)	Clinical Director, Trent Cleft Service
	David Orr (DO)	Cleft Services in the Republic of Ireland
	Susan Parekh (Spa)	Paediatric Dentistry CEN
	Bill Shaw (BS)	Lead at Manchester Clinical Trials Centre
	Jackie Smallridge (JSma)	Consultant Paediatric Dentist, CleftNetEast
	Alistair Smyth (ASm)	Cleft Surgeon (BAOMS)
	David Stokes	CLAPA Chief Executive
	Jan van der Meulen (JvdM)	Senior Epidemiologist, Clinical Effectiveness Unit
	Mike Winter (MW)	Medical Director, National Services Division,, Scotland

ACTION

2. Leavers and Joiners. Membership of the CDG	SR introduced Sandip Popat representing the Restorative Dentistry CEN and Jacquie Kemp, the National Programme of Care Senior Manager – Trauma, NHS England	
3. Dates for meetings	Future meeting schedule agreed: Wednesday, 12th October 2016 - **venue - Blond Seminar Rooms, 4th Floor main Royal College of Surgeons Building, London.** **The meeting in January 2017 has been changed from Tuesday 31st to 24st January 2017** - venue - Research Boardroom, Nuffield Building, Royal College of Surgeons	
4. Minutes of previous meeting	Amendments to the draft minutes from 28.01.15 were accepted by the committee.	
5. Terms of Reference CDG	SR asked for any comments on the Terms of Reference (ToR). DL noted that they mention 'Health Authorities' and these are now dissolved. He suggested that 'Health and Social Care Bodies' might be better for England at least. NH said that Special Interest Groups (SIGs) had now been largely replaced by Clinical Excellence Networks (CENs) which needed to be reflected in the ToR. IS felt that CDG members needed to reflect before commenting further and SR that they needed redrafting to reflect the NHS Structure. It was agreed that they should be discussed as a draft at the October meeting and then revisited in January 2017.	**ToR to be redrafted and discussed at Oct CDG meeting**
6. Future of CDG/Election of new Chair	SR had received two nominations for chair of the CDG – SvE and IS. The CDG voted and SvE was elected. It was suggested that a role of Deputy Chair could be set up and it was agreed that this should be discussed further at the next meeting.	**New CDG Chair Elected - SvE**
7. Changes to NHS England CRG	AWS noted that the Cleft Clinical Reference Group (CRG) does not exist anymore but that there will be two seats available on the amalgamated Paediatric CRG. He recommended that CDG members apply. It was mentioned that IS had applied already and suggested that SvE apply as well. AWS said that there needed to be a commissioner from NHS England on the CDG. He noted there were commissioners from Scotland and that Sian Lewis and Claire Nelson will now be representing Wales.	
8.Reports from Cleft Centres	**South Thames** AC reported that South Thames was still in derogation on the clinical dashboard due to the shortfalls in the clinical psychology service but a business case has been prepared for this. He said the centre was about to lose a surgeon who is relocating to Cleft Net East and AC would like a maxillofacial surgeon to be appointed. He noted that maxillofacial registrars in London do not generally rotate between centres but said the South Thames TIG Fellow has been encouraged to move around centres. AC said that South Thames only gets 50% of the Registrar fee and a placement fee for the TIG Fellow. PHo said there was a £13,000 finders fee. SvE said that centres receive	

	the full basic registrar fee but that was a lot less than needed. AC said that the trust has to find extra money so it is a disincentive to take them on and also for the TIG Fellow themselves as the South Thames Fellow is on the bottom of the pay scale. SvE said that this issue was raised at the TIG meeting and the discouraging effect flagged as a problem. SvE had to get more money from Health Education England to bump up the salary of the Fellow in Bristol. AWS said that when a surgeon becomes a TIG Fellow they do not give up the registrar number. The problem with the TIG Fellow in Wales was that even though he had an English registration number, the authorities said he was not registered as he did not have a Welsh registration number. AC said that the non TIG Fellow at South Thames will be able to use his non TIG year at South Thames as part of his specialty training. SvE said there are precedents for this and that TIG cannot comment on non TIG training. AWS said he was surprised that non TIG training is granted retrospective validity. AC said he was worried whether surgeons would have the skill mix needed for the job if this is allowed. **South West** SD reported that Bristol was in derogation due to Speech and Language Therapy provision but that there is a proposal to sort this out waiting with the hospital finance department. He said there are concerns about the Children Hospital. South Wales are helping with speech and language as the equipment in the South West was not fit for purpose and new equipment is needed. Bristol has agreed that more provision is needed but none is arranged yet. SD said two surgeons are retiring within the next 18 months. The posts are split between primary and secondary surgery which creates issues in recruiting. SD said there is no official path to replace these posts. **Newcastle** PHo thinks Newcastle might be in derogation over its clinical psychology service but is not sure. He said that Newcastle had been asked to provide support to Edinburgh but Lothian owe Newcastle a great deal of money and the trust now wants to be paid. This is impacting on PHo capacity to do primary and secondary surgery due to financial constraints from the trust's finance department. **West Midlands** IS reported that performance delivery in Birmingham is fine but the clinical psychology service is underfunded and there are issues in speech and language therapy provision. He said the Fellowship training is going well. Work is ongoing to recruit a part time replacement for a retiring senior surgeon. **North Thames** NHa said the service is still down to two surgeons. Primary surgery is up to speed as everyone is pulling together but that secondary surgery is taking a back seat and North Thames is trying to recruit to cover this. They are reviewing whether to get a locum to clear the backlog. There are two good maxillofacial surgeons for bone grafts. An investigation is taking place into whether there is enough speech and language provision. An	

	external review of North Thames's psychology service has resulted in a reorganisation with only two dedicated psychologists available and any referrals going to general clinical psychology but the Centre is trying to manage with this provision. He said the new database was still a problem at North Thames. **South Wales** AWS said there was a chronic problem with adult revisions which have people waiting years. Speech and language therapy provision has been discussed with Bristol and AWs is trying to get an extra list. They have 2 out of 14 sessions. He said it was difficult to recruit nurses so the centre is having to wait nine months to get a nurse from the Philippines. The only pressure to get things done is from patients. The lead nurse has been off sick for four and half months which is a real problem, even with the other nurses covering, as she is allocated most of the cleft sessions. The management is supportive but the problem remains. AWs said that the whole Cleft service will be moving into the new office block soon, next to Children's services. **Cambridge** JW reported that there were financial issues at Cambridge as the Trust is still in special measures. But a new locum has been appointed which gives some stability to the service. PH and Tariq Ahmad are reducing their own workload to adjust to the new provision. JW noted that the lead Speech and Language therapist can only work a limited amount of hours. There is a new clinical psychology lead starting in September and the current psychologist is contributing for the time being. There are problems with administrative support as there is no network manager and reduced co-ordinator hours. But there is an internal service review driven by the clinical provision of care. A research nurse was appointed to start at the end of May but there are still delays in inputting. JW raised the issue of mixed private/NHS care. The parents of one patient went private for one part of their care but it is not clear how this sits, administratively, with their NHS care. SR said that they would have to transfer back officially to the NHS cleft service and pick up CRANE input. NH said a baby from Bristol is being treated at Worthing. JW said it is a complex issue. LB said that her centre only serves the local area so would not be able to do home visits to such patients but can treat them in clinic. PHo said it was a matter of whether the parents were willing to travel. **Scotland** TG said the public consultation on the Surgical Service has finished their report which will be sent on to the Health Secretary if approved. Scotland is developing its adult cleft service. He reported that the Norcleft Conference will be on 16th June in Glasgow. **North West** SvE reported that there were two staff shortages. One dentist has resigned and the Service is now in derogation due to this. They are trying to find another. The clinical psychologist has started and there is an advertisement for another nurse. The speech and language therapy has been affected by maternity	

	leave and there is a VPR list. One anaesthetist is on leave. SvE said there had been no contact with the North West commissioner. Funds are going to be re-organised in Manchester so SvE is concerned about the impact of funding to Liverpool. **Nottingham** A second surgeon with maxillofacial skills is to be appointed to cover for the imminent retirement of Mark Hanley and John Rowson. AWS said the official advice is to advertise for a cleft post, covering the range of cleft surgery. PHo said the smallest volume of surgery is for orthognathic surgery, only around five so they need to do maxillofacial work as well. It was agreed that orthognathic surgery is problematic and AWS noted that there no reviews of relapse rates. PHo said one surgeon was stopped from doing this surgery. SvE said that cleft orthognathic surgery is difficult to do and surgeons have to be properly trained. IS noted that some surgeons refuse to do it. The case for clinical psychology provision has been written but not taken any further yet. The patient group is very strong in Nottingham. **The Spires** SR said there were the usual staffing problems as several surgeons are approaching retirement. One surgeon has been replaced but more need to be appointed. There are two or three sites for Oxford and Salisbury and this setup is successful but is reliant on surgeons being willing to travel. SR resigned as Clinical Director at Salisbury in December 2015 and is now employed full-time by Portsmouth. But the Spires did not replace him and are relying on SR doing extra sessions at Salisbury. SR asked if centre's quality dashboards reflect their practice. JW said Addenbrooke's was using it to ensure that nursing hours are replaced in order to meet the requirements of the dashboard. LB asked how the quality dashboards were policed and SR said that it is hoped that the new CRG should be doing this.	
9. Changes to NHS England CRG	Jacquie Kemp from NHS England joined the meeting. AWS said that to reduce the number of CRGs, Cleft was now going to be part of Paediatric Services. SvE will apply to join which AWS felt would be valuable for the CDG. JK said there would also be affiliated members in the CRG. She said there was a summit booked for June but this may be cancelled. AWS said that the constant restructuring was difficult to deal with for clinicians. He asked how issues like speech and language provision should be addressed and where Cleft would fit in with Paediatrics. JK said she has met with Anthony Prideaux to discuss this issue. She said that Linda Docherty, the Paediatric surgeon, would be happy to attend the CDG meetings and give other support. JK has also stressed that the CDG should continue. The CRG would be an advisory group who can help the CDG and also CDG members can present work at CRG meetings. Regional proposals will be referred to the new CRG. AWS said the five year plan was still applicable and this included speech and language. JK reported that the 2016/17 Service Review would be recruiting project managers soon and	

	the CDG can be included in this. PHo asked if centres can opt out of this as they have been reviewed a lot. AWS said there was nothing to fear from this and JK said centres would be able to ask relevant questions. AWS said it was good to keep cleft in people's minds and thanked JK for coming to the meeting. JK said that focus groups are developing a website to publish quality measures and dashboards online but that this was in progress. PHo said he asked to enrol but was unable to do so as the system is not operational yet. JK asked him to send the details to her so that she can investigate. She said the Clinical Dashboard will continue and a Service Specification Review will be done. LB said it had been for modification. AWS said these issues can be discussed at CDG and referred to the CRG. JK said she will make sure they are mentioned. She said there was a sign off at a clinical panel and that a commissioner is to be appointed. LB said there was a meeting with lead speech and language therapists and LB made a draft report taking variability and inequality in speech and language provision across the centres into account. She said there was an erosion of provision. She said changes should be made to the service and all local centres should have a local link. She will be sending a revised version by the end of next week to JK. AWS said that extra information can be put in appendices and that there should be an Executive Summary and Recommendations. LB said she had been asked to do this work in the light of inequities between regions in speech and language provision. SvE said it was the same for all cleft services and this was just the start. NH said she was intending to look into nursing provision also. JK said that a report can be signed off by NHS England and sent out to the regions or, alternatively, circulated more informally amongst the centres. AWs said that a sign off by NHS would make the initiative more robust. JK said that JK and NHS England have a meeting with the regional commissioners every two months and that she can mention it then. LB said she was willing to do a presentation if required. SD asked about the review of NHS funded databases. JK said that Kerri Townley (KT), Head of Informatics was going to review the databases two years ago. JK has asked her to look into this and she and JK will look at what is needed. She said Pete Davis, in the Midlands is in charge of finances and has asked for a review. JK and SD agreed to discuss this after JK meets KT. JK will ask if KT supports the CRANE case for a finding uplift.	**PHo to send details to JK so can investigate dashboard/outcome measures website problems** **JK and SD to discuss databases review after JK and KT meeting**
10. Research	**Cleft Collective Birth Cohort – written report by J Sandy** The written report was circulated before the meeting and JS said all the news was contained in it. He said that the programme of work on anaesthesia in the first year of life was aiming to explore a link to cognitive development. He noted that the Healing Foundation's new strategy was to concentrate on 'scar-free' research only. He said that antenatal recruitment was the golden egg for the geneticists but the problem with this was the shared care arrangement and they are trying to sort this out. Within the no-cost extension, JS had to go to ethics for a tariff to give incentives to the team. He said the worse	

	problem was data transfer. SD said that the Bristol University system is in meltdown. JS said there are various models toward work on scarring and healing. He said that a cohort study with Manchester was possible.	
11. Audit	**CRANE Database** SD and JM had circulated an update report to the CDG, together with a parental consent form, data information booklet, parental data linkage booklet and a Patient (and Parent) Reported Experience Measures (PREMs) feasibility study review. SD said CRANE was doing more linkage involving parents. He said the paperwork to settle governance issues was very labour intensive. Also many of these institutions were increasingly claiming fees to access their data. Thus there was a greater cost and more complexity in doing these measures. SD said that the new system is able to create more reports which is useful. SD noted that the CRANE project team recently received approvals for linkage to the following two additional outcomes data and were negotiating the data transfer: 1. National Newborn Hearing Screening Programme data – to examine the relationship between clefts and Permanent Childhood Hearing Impairment; and their effect on children's outcomes: 2. Primary care dental data – to examine the quality of this data for children with clefts of the lip and palate: He noted that there is a negotiating fee for this and CRANE is expecting a quote for this linkage service from Chris Gooday (Information Governance Manager) and Graham Mitchell (Information Services Manager) at NHS Dental Business Authority. SD had been asked to attend the International Consortium for Health Outcomes Measurement (ICHOM) on 16 / 17th May where he will look into any problems and the possible relationship with CRANE. SD asked what should be done regarding pre-2000 data. One idea was just to have this available locally for the cleft teams and not part of CRANE. DL said that really robust long term data is useful so he felt it should be stored somewhere. SD said he likes the locally kept only option to avoid consent issues but also felt the data should be stored as it is still being added to. Another possibility is to have it stored on CRANE without being accessible. SvE suggested that both options could be implemented simultaneously but SD felt this would not work. He said for the second option the data could be available to just a few at the RCS to avoid governance issues. LB asked if CRANE knew who uses this data. SD said that they did and the users were very keen to maintain access to it. JW felt the consent and information booklets were huge and would be expensive to print out (especially in colour – as noted by LB). She asked if they needed to be as long. SD said this was necessary because of governance. AWS said the centres could probably keep the printing costs down but that if they were printed centrally, it might be a big expense for CRANE. However, SD agreed to look into having these centrally printed. JW asked if separate consent was need for data linkage but SD said it was not.	**CRANE working on linkage projects** **SD to attend ICHOM Conference and report back in Oct**

	ICHOM SR asked SvE who owned ICHOM and if it was profit making. SvE said it was not profit making and was run by Michael Porter and Boston whose stated aims were 'value based healthcare'. SvE said the only way to determine this is by outcomes. He said there was a cleft specific meeting on the Sunday before the main Consortium meeting where there would be a report back from cleft centres involved. He highlighted the difference between the Erasmus Rotterdam Center which was fully funded and the North West England/North Wales teams which had none. SvE said the background to the project was that a dataset was agreed by a working group in December 2014 which led to a feasibility study, working on a 'Cleft Q'. How to collect the data will be discussed and a 'gap analysis' of shortfalls in data is to be prepared by July and then benchmarked by October. NHa said that non state-funded outcomes measures were better designed for this. He said a number of centres are doing outcomes already so they are not keen to collect more extra information. He said it was too much work for them and KIM added that it might be a burden for patients too. SvE agreed and said that centres were being asked to do more work without extra funding. AWS asked what extra information they were being asked for. SvE said it included PROMs AWS said CRANE was moving towards this. SD noted that CRANE was aiming to carry out PREMs rather than PROMs. KIM said that it was the way questions were asked that made a difference in the way they impacted on the patients. SvE said the 'Cleft Q' was the one used as it was the only one available. SvE said it was necessary to look into the feasibility of collecting all this data. KIM said that ICHOM failed to talk to UK national bodies such as the clinical psychology organisations before it was set up. AWS added that it also did not approach the CDG beforehand either. JS said that the UK had been collecting data for 20 years and should have been driving this initiative. NHa noted that ICHOM is not operational yet. SvE said he had felt a lone voice in participating in ICHOMs and that there was an engagement issue with other centres. NHa did note that ICHOM would provide comparisons with a greater population as it was international. AC asked if Sweden was involved and SvE said they were very involved. The original project arose from the collection of prostate data which drove up standards in this specialty. **Minimum Dataset** LB said that Rona Slator has circulated the minutes of the last meeting on the minimum dataset and feels that it needs to be renewed in two years' time. LB said that the Craniofacial Society website is being redone.	
12. Training	**TIG** SR reported that there are changes in the RCS Fellowship. Also DD is continuing as chair of TIG for another year. SvE said the timing for the next round of interviews will be decided in June at the TIG meeting. AWS noted that the latest proposal suggested that possibly only one cleft person will be on the	

	main new TIG NH said that there have many retirements in cleft treatment recently and SD added that there will be a shortfall in clinicians soon. SR is to liaise with DD on the TIG fellowships. **Nursing Training** JW said there was one centre for training in Manchester. There were plans to run another one but it has not been decided yet. JW said funding was being allocated to basic training not to retraining. AWS said he had just written a proposal for the recruitment of nurses as all the South Wales nurses will retire at around the same time **Speech and Language Training** MP said that an endoscopy course will be run in June at Great Ormond Street. Also there would be a revision course on Caps A for the original trainees. Anne Hardy Bell is reviewing the Cleft course at Sheffield and will present on this in the autumn meeting.	
13. Feedback: Clinical Excellence Networks (CENs), CFSGBI, CLAPA	**Surgical** SR said there was a good meeting in Nottingham. **Nursing** NH said there was a good nurse meeting and that there had been a workshop with CLAPA on working with social media. JW said any formal strategy has to go through the Nursing Lead Group not the CEN **Restorative Dentistry** SP said that a National Audit Project is greatly needed as there is no data. **Clinical Psychology** KIM said that a national pilot of patient outcome measures is being carried out. These are goal-based outcomes which are established at the beginning and measured at the end. **Orthodontic Surgery** It was reported that two projects are being investigated: 1) a cohort of 15 year olds will be studied to see what happens to alveolar bone grafts. AWS noted that there is no requirement for x-rays at 15 years. NHa said there is a requirement to take an x-ray at 10 years old. SD said this would be collected on CRANE. 2) Orthognathic surgery as there is no requirement for x-rays of this. This is not in the minimum dataset. **CLAPA** There were no representatives from CLAPA at this CDG meeting. **Craniofacial Society of Great Britain and Ireland** PHo said the website is being overhauled at the moment. He said that there is pressure to get the 2021 meeting in Edinburgh	

	better organised.	
14. Any Other Business	NP reported that Yvette Edwards Will be taking on NP's role in CDG. SR said that there will be a new Clinical Director at the Spires in January 2017 so SR will still be involved in the CDG for the October meeting. It was felt that should be some discussion at the CDG about applications for membership of the Paediatric CRG. AWS said SvE may be invited to join as an affiliate member but it depends on the Chair of the CRG. SvE noted that if he was on the CRG he would probably be expected to work on treatment areas unknown to him such as women and children but AWS felt the CRG Chair would do most of the work and SD that there will be project managers to work on these. There will be a vote on a Vice Chair for the CDG in October. JW asked if LB could share the framework of her review with the other specialties. LB agreed to and said she could share what she had learnt about budgeting as well.	**Discussion on CDG reps on CRG at Oct CDG** **Vote on Vice Chair at Oct CDG** **LB to share lessions of review with other specialties**
15. Date of the next meeting	The next meeting will be on Wednesday, 12th October 2016 - venue - **Blond Seminar Rooms, 4th Floor main Royal College of Surgeons Building, London**	**NB Change of venue for next CDG meeting**