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

Venue – Blond Seminar Rooms A/B at the Royal College of Surgeons of England
Date & Time – Wednesday, 12th October 2016, 11.00 – 15.00

1. Present	Stephen Robinson (SR)	Chair, CDG
	Alec Cash (AC)	Clinical Lead, South Thames Cleft Service
	Scott Deacon (SD)	CRANE Clinical Project Leader
	David Drake (DD)	Cleft Surgery Training Interface Group
	Yvette Edwards (YE)	CDs and Managers Group
	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
	Marie Pinkstone (MP)	Lead Speech & Language Therapists
	Jonathan Sandy (JS)	Lead, Cleft Collective Birth Cohort and Gene Bank Study
	Ian Sharp (IS)	Clinical Director, West Midlands Cleft Centre
	Alistair Smyth (ASm)	Cleft Surgeon (BAOMS)
	David Steel (DS)	Chair Programme Director, National Services Division, NHS Scotland
	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
	<u>In Attendance</u>	
	Jackie Horrocks (Minutes)	Minutes / Administrator, Clinical Effectiveness Unit
Apologies	Victoria Beale (VB)	Consultant Cleft & Maxillofacial Surgeon
	Lorraine Britton (LB)	Lead Speech and Language Therapist, Trent Regional Cleft Lip & Palate Service
	Sinead Davis (Sadh)	Chair, CEN for Cleft ENT and Hearing and Consultant ENT Surgeon
	Per Hall (PH)	Cleft Surgeon (BAPRAS) and Cleft Surgeon, CleftNetEast
	Toby Gillgrass (TG)	Lead Clinician of Cleft Care Scotland
	Chris Hill (CH)	Northern Ireland Clinicians
	David Landes (DL)	Public Health Consultant
	Karine Latter (KL)	President, Craniofacial Society and Nursing deputy for NH
	Kate le Marechal (KLM)	Clinical Psychologists CEN
	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
	Sandip Popat (SP)	Restorative Dentistry CEN
	Bill Shaw (BS)	Lead at Manchester Clinical Trials Centre
	Jackie Smallridge (JSma)	Consultant Paediatric Dentist, CleftNetEast
	David Stokes	CLAPA Chief Executive
	Adrian Sugar (AWS)	CRG / Wales Clinicians
	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	Yvette Edwards has joined the CDG and, jointly with Elizabeth Adamson, will be representing the Clinical Directors and Managers Group.	
3. Dates for meetings	Future meeting schedule agreed: Next meeting will be on **Tuesday 24st January 2017** - venue - Research Boardroom, Nuffield Building, Royal College of Surgeons The meeting after that will be on **Thursday, 18th May 2017** in the same venue.	
4. Minutes of previous meeting	Amendments to the draft minutes from 13.05.15 were accepted by the committee.	
5. Matters arising from previous meeting	IS has joined the new joint Clinical Reference Group (CRG) representing the Midlands and North West and is the only member of the CDG in the Group. He agreed to circulate a list of the 16 members to the CDG.	**IS to circulate names of joint CRG to CDG**
6. Terms of Reference CDG and plans for election of CDG Vice Chair	SR suggested the Terms of Reference (ToR) needed updating on an annual basis. He asked for comments on the current ToR which was last updated in 2014. The changes will be incorporated into a draft version and circulated to CDG members before the January meeting. PHo felt that a new arrangement should be set up to define the relationships between the bodies involved in CRANE as the current Tripartite Agreement was drawn up in 2007. SD suggested that it would be useful to have commissioner input on this. SR agreed to write to PHo as the current Craniofacial Society (CFS) President to formally request that this be discussed at a CFS Council meeting. ASm suggested that the commissioners should be informed that changes are taking place to the CDG Terms of Reference. SR agreed to investigate who would be the most appropriate people to contact. PHo is currently a Trustee of CLAPA and will raise the issue of to a lay representative for the CDG. It was agreed that CDG will vote for a Vice Chair at the January meeting. Nomination forms will be sent out to CDG members beforehand.	**SR and JH ToR redrafted and circulated to CDG** **SR to ask CFS to discuss ToR at CFS Council meeting** **Commissioners to be informed of ToR changes** **CLAPA to appoint lay representative** **Nomination forms sent for Vice Chair Vote January CDG**
7. Feedback from CENs	**Speech and Language Therapy update report** MP reported that part of the Speech and Language Therapy update report had been submitted to Jacquie Kemp at NHS England. She suggested it could be helped by being designated a CQUIN. The Lead Speech and Language Therapist group have asked for the CDG to provide a supporting statement to the executive summary of the report. It had been suggested that the findings be published as part of a general scoping exercise for all cleft specialties and that CLAPA will support it. MP asked if they should hold off publication until other specialties complete their scoping exercises. DD noted that CDG members would need to see the report first before providing support and MP agreed to	**MP to send SLT report to JH for circulation to CDG for discussion at January CDG**

	circulation to CDG members and to Jacquie Kemp. It will then be discussed at the January CDG meeting. **Nursing CEN** NH reported that the CEN had begun to work on a scoping document with input from all lead nurses. She noted that many lead nurses are planning to retire over the next few years and succession planning was an important current issue. There had been a recent CEN meeting with a busy programme involving nine presentations. NH stated those clinical nurse specialists were often seen as part of the wider hospital workforce with local pressures to participate in routine work on the wards. This is being monitored nationally but they support to protect their cleft work. DD noted that staff need to honest about when they are retiring so that succession planning can be put in place. SR raised the issue of succession planning across all cleft specialities and described how designation of some existing cleft services had provided a bank of skilled and enthusiastic staff. We need to identify and nurture the next generation with appropriate training programmes that attract the best candidates. The different CEN groups will need to identify their training needs as part of the process and perhaps the scoping exercise was a good starting point. DD said that cleft care was well defined and funded in comparison with other specialties. He felt there were trends in how popular specialties were in attracting applicants. He noted that head and neck oncology was popular 15-20 years ago but now non-oncology specialties were more popular such as paediatric surgery which trainees find interesting. SD suggested that cleft needed to be actively promoted to trainee surgeons. NH suggested that cleft roles were popular in nursing but many nurses were reluctant to take on leadership roles. DD said that trainees need exposure to cleft in their general training which is an issue often ignored. He noted in Wales, funding was provided to train nurses even if no immediate job was available. MP described how some nurses have already been trained but find the travelling involved in the role hard and leave wasting good training resources. NH noted that the travelling can also make it a lonely job. SvE said that there had been six or seven applications for a nursing job in the North West. MP said that greatest difficulty in the recruitment of nurses is to leadership posts. NH noted that there are still some very strong candidates applying for jobs. JW felt the problems in recruitment were also geographic as there were difficulties in the East notably in Norfolk and Suffolk. SD said there were plenty of applicants in clinical psychology and PHo said the problem with psychology posts was securing the funding to set them up. AC also noted that the trend is away from full time jobs.	
8. Audit	**CRANE Database** SD had circulated an update report on the CRANE Database (enclosed). He noted that the publication of the CRANE annual report has been delayed until January 2017, largely due to staffing issues. He thanked the CDG for contributing ideas on	**Crown to work on functionality issues**

	content and format. He reported there had been very little problem with the new website except for some minor functionally issues which Crown Informatics will be working on as part of their work quota for this year. The developmental defects of enamel (DDE) collection and further report tables for download by users will require further funding as they are outside the current budget. This is being discussed within the CEU with NHS England. SD said he had met with Marie Wright who is managing the BPSU Pierre Robin Sequence Surveillance project and that she would be happy to report her initial findings to the CDG. CRANE is also exploring options for validating her data collection in a joint project. SvE agreed to invite her to the next CDG meeting in January. SD noted that it was becoming very time-consuming and difficult to set up projects involving linkage to other data sources as they tend to involve more documentation than in the past. The National Newborn Hearing Screening Programme now requires a detailed proposal involving methodology which was not part of the original proposal. Work on a link to NHS dental care data through NHS Primary Dental Services has been put on hold until December 2016. SD had been invited to Scotland to a Network Day in September but this was cancelled due to ongoing issues with the surgical review. SD has been contacted by Scottish managers for advice on how services are structured in England. **Excelicare and Infoflex** SD said that Excelicare have visited him in Bristol but noted that they are interested in putting forward a UK wide proposal to all cleft centres. He described how they had a new chief executive officer (ex Apple) who was keen to present what Excelicare can do. SD asked the CDG if they wanted to invite them to a CDG meeting to do this. MP felt that using their system depended on how well it tied in with the current patient management systems already in place in hospitals. SD felt that if they can offer a nationwide system this may be more efficient avoiding double data entry and reduce costs of data collection. SR said that the CDG will need a detailed breakdown of costs. SvE felt that Excelicare and Infoflex should be asked to present at CDG. He noted that some aspects of Infoflex needed adjustment. AC said that Excelicare came to South Thames to give a quote six or seven months ago. He felt the system can be adapted but stressed that the setup should be standardised. SvE added that a database which uploads directly to CRANE would be desirable. SR described how the Spires have used the system for over 12 years and although limited in places it had proved useful to running the network. He would welcome the concept of a UK wide system. SvE noted that the new systems can be quite flexible using various identifiers to access information and can link to images, ECGs and other bolt-ons. AC said that all centres use their data systems in different ways. He said South Thames has outreach services so they are dependent on other bodies to provide information to the system. To this end, he said that Infoflex can use Cetrix to access systems in outreach clinics. It was noted that it was possible to follow a child's pathway from	**Further funding to be raised for other CRANE projects** **SvE to invite Marie Wright to speak on Pierre Robin project at January CDG**

	antenatal appointments onwards with links to the dashboard. It was decided that both companies should be invited to present at the January CDG meeting to explain what they can offer and what centres would need to go through to facilitate the set up. They are to be allocated half an hour each and one will present at 11.30am and the other at 1.30pm. DD felt it should be an information gathering exercise not competing bidding. NHa felt it might be useful to have IT experts in attendance who will know if the systems are compatible with in house systems already in place in the hospitals. DD felt this should come later and SD said they would have to provide a proposal to be shown to the RCS IT department anyway and this could be shown to the hospital IT departments. **ICHOM** SvE said there was no update on ICHOM.	**Excelicare and Infoflex to be invited to present at May CDG**
9.Research	**Cleft Collective Birth Cohort and Gene Bank Study (Bristol) (enclosed)** JS had circulated a written report before the meeting. He said that ethical approval had been given to measures to increase participation. He said the University of Bristol has committed three posts to the study so it was well supported. He noted that Nicola Stock had been prolific in producing papers and that the project had generated much grant funding. **Early Career Researcher** JS noted that the Early Career Research Award received by Nicola Stock was funded by the European Research Council (ERC) not by the Cleft Trainee Collaborative chaired by Rona Slator. **Manchester Clinical Trials Centre** JS has spoken to BS who said that the TOPS trial has stopped collecting data now. BS has recruited a Scandinavian researcher who will take over the projects when BS scales back on his work.	
10. Training	**Training Interface Group** DD said that the restructuring of RCS Training Interface Groups had begun including cleft. He said a chair of the new joint council with the power to sign off trainees had been appointed but not named yet. Once this part of the process had been completed cleft should fit well into the new model. He thought the timeframe will slip as the process is reconfigured. He suggested there were three potential Cleft Fellow vacancies and one suitable applicant has recently been appointed with an ENT background. He said there had been some problems in recruitment, as two possible applicants were not able to be appointed at the end of the process. One had failed their exam and the other finished their general training before the required time and so could not be interviewed. An advert will be put out again soon. Also there are two current Fellows still in post, one who has finished their training and one who is near finishing. DD said that all training posts were funded on a tariff system and averaged out throughout the country. This was adjusted for on-call elements. He said there was no solution at the moment to	

	the funding situation. The average tariff is 50% of the top placement fee so there is always a potential shortfall. A budget is held in hospitals for an average amount of trainees. He said that if a job looks like a service appointment rather than a training post, it is more likely to receive full funding. DD advised that centres should contact TIG directly if there are any problems, and then they can speak to the local Dean responsible in that area. He said the training time can vary and is affected by retirement plans. PHo said that one fellow was refused training in cleft because by a strict interpretation of application rules and potentially a good candidate had been lost. DD said that the rules had been set up by JCST and were very rigid. DD said that trainees have to know how to use the system effectively. He said the lack of interest in cleft fellowships would be discussed at the next TIG meeting. SD asked DD if there was a way of finding out who is retiring. DD said that Michael Cadier had created an informal database with potential retirement dates or the only other way was by word of mouth. PHo said that trainees need to be competent to level 4 in general orthognathic surgery to be trained in cleft orthognathics. AC said he was looking to make use of his cleft trainee's ENT training. **Nursing** JW said that at least 10 trainees were needed for the cleft nursing course. Some were already in nursing posts. The course costs £800.	
11.Feedback from Cleft Centres	**North Thames** NHa reported that they were still one surgeon down out of a full complement of three but with some local cover. He said the remaining cleft surgeons were currently taking on extra lists. The centre is up to date with primary repairs with everyone pulling together. He said the clinical psychology review had led to reduced psychology input and it was now less bespoke without psychologists having a varied level of experience in cleft care. DD said that cleft psychological training was generally funded by cleft money so the centres should be able to choose psychologists with experience of cleft. NHa said this was a Trust wide issue locally but has not affected the service very much at present. He said provision of endoscopy equipment was more of a problem as there was no budget set up for it. SR said that the parents had raised money to buy the endoscopy equipment at the Spires. SD suggested that all equipment should have an end of life date and written into the annul budget for replacement when due. **North East** PHo reported that a second cleft surgeon had started in Newcastle and shares the existing waiting list with PHo to ensure no-one misses their surgery if a specific surgeon is not available. PHo said that the lead clinical psychologist had been seconded to the care of children with congenital heart disease and another clinical psychologist had been seconded to cleft from another department. He noted that cleft nurses were not put on general wards. He said the centre was recruiting for the Cleft Collective now as they have a fraction of a research nurse's time. He said a clinical nurse specialist had been appointed but it had been a difficult process.	

North West, North Wales and IOM
SVe said that the retirement of one surgeon was imminent and there was an extra cleft list using a locum. He said Infoflex was now live and in use in the centre but required some minor troubleshooting. He noted that he still had not met the NHS commissioners despite requests being made. He predicted some short term budgetary issues when the health funding will be controlled by the new Manchester mayor when elected in 2017. They continue to be in derogation on paediatric dentistry but two sessions at Manchester and two at Liverpool have been arranged.

Wales
DD reported that the new NHS commissioner was a positive influence and also that the new outpatients' department was working well. He said the main problem was a backlog in adult revisions but this was helped by dome operating at another centre. He said that all three of the senior cleft nurses are retiring over the next three years but that the Trust was allowing the centre to appoint replacements in a succession planning exercise.

Leeds
ASm reported that there were changes in the network surgical provision. One orthodontist is to retire in December. The centre is hoping to appoint a new one at Bradford and at Hull. He said there is an existing vacancy in speech and language therapy and an advert has gone out for a band 7 appointment. The deputy lead SLT has stepped down and consequently there is some delay in provision but this should be sorted out. The centre was asked recently to compare the service with the national service specification and was found to be compliant. They are continuing to audit at 5 and 10 years. Surgery is up to date with the protocol in primary surgery and there are no waiting lists for secondary surgery.

South Thames
AC reported that they are one surgeon short at South Thames and a waiting list is developing. He feels they may need to prioritise paediatric surgery. An advert is to go out for a new surgeon. A new TIG fellow has been appointed but there is no start day yet. He said that one of the South London clinical nurse specialists is leaving and the centre will be recruiting another. The Trust is to appoint another clinical psychologist at last and then the service will be out of derogation. The centre was not able to contribute to PREMs.

Bristol
SD reported that there are staffing issues with clinical nurse specialists at Bristol and the service was in derogation. The Trust was restricting clinical psychology and the whole service to free up money to pay for more nursing. SD he was also in the middle of administrative restructuring involving redundancies. He said two or three surgeons were talking about retirement and SD is almost certain that one will retire in March 2017 and he thinks the other will retire soon after that. They have indicated that they are willing to come back just for surgery.

	West Midlands IS reported a pooling of psychology provision amongst all specialties in Birmingham and they were likely to miss targets on the dashboard. There is a waiting list of patients needing psychology support. Within the nursing service succession planning was an important issue with one senior nurse dropping to half time. Rona Slator cleft surgeon had recently 'retired and returned' and there is a plan to appoint another surgeon in 2017. A new electronic patient record system is in use with a bespoke cleft tracking database. He reported there was now orthodontic provision in both main hub hospitals. They have an advert out for a cleft co-ordinator at band 7. **Cleft Net East** JW reported on the appointment of a new lead clinical psychologist, an increase in hours for the lead speech and language therapist and a new cleft surgeon started in September. She described a new website and the use of cleft pages on the hospital EPR. Bed avail There is increased capacity in paediatric beds but a lack in adult care. They are currently reviewing outreach services in both Bedford and Ipswich and are considering transferring the appointments to Cambridge based clinics. PHo noted that there had been a complaint from a healthcare professional to CLAPA about the withdrawal of the clinic at Bedford. This had been managed by the clinical lead but PHo was concerned that health professionals rather than patients were using a patient body as a weapon. CDG noted that there seemed to be valid reasons for these service changes with benefits to staffing and quality of care through better coordination of MDT care and access to appropriate specialists. **The Spires** SR described how there are continuing battles in both main Trusts to protect cleft monies. When staff leave posts are often frozen and the job plans closely reviewed with significant delays in appointing successors. This saves individual Trusts significant amounts of money over a 6-9month period whilst having a negative impact on patient services. He described ongoing problems with regular access to paediatric anaesthesia. The surgical service is facing restructuring with Michael Cadier and Tim Goodacre retiring within the next 6 months. They are hoping to recruit two surgeons and a new orthodontist advert over the next 6 months. Clinical review/audit clinics have recently been set up for 18 to 20 year olds. It should be considered a 'pilot project' and will update the CDG on its progress. PHo felt it was hard to arrange end of pathway clinics and they were currently only able to offer 5 year clinics and not 10 year ones. SR reported the TriCentre meeting (South West, West Midlands, Spires and Swansea) in the summer was very successful and he felt it would be useful for the minutes of these meetings to be shared with other groups.	**SR to keep CDG informed on 18 – 20 year old clinics**
12. Any other business	**National Service Specifications query and Clinical Dashboard** AC said he had been sent a questionnaire about the National Service Specifications with three questions which did not appear	

	to directly relate to the NSS or the dashboard. He was unable to complete the form as the questions were not relevant to the service and he asked for advice from the CDG. IS said that any questions related to the dashboard varied according to the local area of commissioning and were not standardised. SR felt it was the individual Trust's responsibility to complete the NSS questionnaires and ask the relevant questions of the cleft centre where appropriate. JW reported their service co-ordinator was a band 4 which restricted the job role and perhaps a band 6 would be more appropriate. NHa said that North Thames had changed the job role of the co-ordinator to include management status and felt it was difficult to retain staff without incentives. IS highlighted ongoing problems with dashboard data and the failure of the process to catch up SD said the dashboard time frame needed to in sync with the procedure times. NHa agreed said that he had noticed discrepancies. It was agreed that the dashboard should be discussed at the next CDG meeting in January 2017. PHo said he wanted to know who the dashboard is for and who is analysing it. SR agreed that these issues needed clarification and suggested inviting those in NHS England responsible for providing the dashboards to the January CDG meeting. IS felt there should be a commissioner at the CDG meeting in January. **Exit Passports** JW asked about 'exit passports' and DD said they were a record at the end of the treatment pathway of what care a patient had received. **Orthodontic issues** NHa suggested the need to collect 10 year dental data for CRANE was an additional burden and was affecting efficient collection of 5yr data. SD suggested the response had been varied from different centres and shared NHa's reservations. He noted that CRANE is not using DMFT data for analysis at the moment. **22Q Patients and cleft care** The role of cleft teams in 22Q management was raised. It was suggested there were arguments for cleft teams to support 22Q clinics by seeing them for the first treatment and then referring them locally. DD said his centre offered signposting to speech and language therapy and clinical psychology but was not equipped or funded to continue further with their treatment pathway. He said that the Max Appeal had raised the profile of the condition. Pho said they had a virtual 22Q clinic that meets quarterly in the North East and probably were seen in cleft clinics more than in other parts of the country. He noted that they have no other access to clinical psychology than through cleft units. DD said that Wales will not give out a list of 22Q diagnosed patients because of data protection rules. **Thanks to Outgoing Chair of CDG** SvE the incoming Chair of the CDG, thanked Steve Robinson very much for his leadership of the CDG and for taking on an extra year as Chair. SR said he felt the CDG was a very valuable	**Dashboard to be discussed at January CDG**

	body and had played a large part in stopping the fragmentation of cleft care in an increasingly difficult NHS environment. Its role will be vital in the future to protect what has been a most successful and exciting time in the development of a national specialist service. He wished SvE well in his time as chair of the group.	
15. Date of the next meeting	Future meetings: **Tuesday 24st January 2017** **Thursday 18th May 2017** Venue - Research Boardroom, Nuffield Building, Royal College of Surgeons	