

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 22nd November 2018, 11am-3pm

Present	Simon van Eeden (SvE) Chair Lorraine Britton (LB) Claire Cunniffe (CC) Scott Deacon (SD) Yvette Edwards (YE) Norman Hay (NHa) Nicola Hudson (NH) David Landes (DL) Kate le Marechal (KM) Kanwal Moar (KMo) Jason Neil-Dwyer (JND) Jinette Pippen (JP) Sandip Popat (SP) William Prior (WP) Craig Russell (CR) Jonathan Sandy (JS) Ian Sharp (IS) Jackie Smallridge (JS) Marc Swan (MS) <u>In Attendance</u> Catherine Foster	
Apologies, absence and welcome to new members	Alex Cash Susan Parikh Victoria Beale Yvonne Dailey Chris Hill Ailbhe McMullin Helen Robson David Steel	

Item	Notes	Actions
2. Minutes of the Cleft Development Group Meeting, May 2018	Amendments to the draft minutes from 16.05.18 were accepted by the committee.	
3. Matters arising	<ul style="list-style-type: none"> SvE has written to David Landes regarding BASCD representation. Yvonne Dailey has agreed to join CDG but was unable to attend the present meeting. SvE has written to Norman Hay in his capacity as President of the Craniofacial Society. The Society have now agreed to fund lay representation. SvE has written to Julia Cadogan regarding potential CDG members from South Wales, but is yet to hear back. CC offered for CLAPA to that the lead in contacting South Wales representation. YE raised the issue of a mandatory postcode field with the CEN, receiving no resistance. CDG are free to make changes. BAOMS representation to be confirmed PREM report has been published, in conjunction with the Annual Report, on the CRANE website. Data collection is slightly delayed due to maternity leave but SD is to follow up on progress. 	<p>3.1 CC to contact Julia Cadogan regarding CDG lay representation for South Wales.</p> <p>3.2 Mandatory postcode field to be added.</p> <p>3.3 SvE to follow up</p> <p>3.4 SD is to follow up on data analysis progress</p>
4. Terms of Reference	<p><u>Quality Indicators</u></p> <p>SvE has made changes to the ToR and will circulate once suggestion have been made regarding quality indicators.</p> <p><u>Patient representation and funding</u></p> <p>Patient representation and funding is to be added to the ToR</p> <p><u>Irish representation</u></p> <p>SvE has received an email from David Ord regarding Irish representation. David is invited to all CDG meetings but feels he would be better served by attending on an adhoc basis. The group agreed to add this to be added to ToR.</p> <p><u>CDG role in monitoring audit data (CRANE / Dashboard) and investigating outliers</u></p> <p>LB raised the challenges involved when contacting outliers and highlighted that, particularly in S&L therapy, individuals are becoming irritated by a lack of improvement, despite spending lengthy time collecting data. LB felt that the CDG needs to do more proactive work in monitoring audit data. JD felt that there needs to be a support network for outliers and that the CDG should be more</p>	<p>4.1 SvE to circulate amended ToR</p> <p>4.2. Irish representative attendance to CDG to be added to ToR (SvE)</p> <p>4.3 LB and JND to present discussion paper regarding outlier support at next CDG meeting</p>

	<p>involved with this. JD suggested presenting a paper with LB regarding the matter at the next meeting.</p> <p>Discussion followed about Trust reporting (LB and JD) and the role of patient participation groups. IS raised the issue of information dissemination at local, regional and national levels. CR referred to the process the cardiac society had gone through starting with a national investigation and report. PHo discussed the cardiac societies national benchmarking and good practice compendium noting that this required a full time person to do this. IS felt that there was no appetite to discuss this at CRG and offered to raise these issues with Sir Bruce Keogh as chair of his local hospital. JD felt the focus should be on good performers so they can be learnt from.</p>	4.4 IS to discuss with Sir Bruce Keogh and feedback to CDG
5. Feedback from CENs	<p><u>Lead Nurses</u></p> <ul style="list-style-type: none"> • Dates for the Cleft Course in Manchester are yet to be established, which may cause some issues when allocating staff with leave time. The course will cost £850 and there is a meeting in December where dates will hopefully be finalised. • SLUMBERS study will hopefully continue and a meeting with Ian Bruce has been arranged. • Lead nurses are continuing to meet 4 times a year, but are trying to explore alternative ways of conducting these meetings as cost and timing in these frequency can be problematic. • The whole CEN met in Oxford, receiving good feedback and plans are being made for the next meeting in April. • The present CDG meeting will be Nicola's last and Helen Robson will be taking over as Lead nurse representative. The chair thanked NH for her time and input. <p><u>Speech and Language Therapy</u></p> <ul style="list-style-type: none"> • S&L therapy met two weeks ago at the GOSH boardroom. LB highlighted that this had excellent teleconferencing facility and recommended using the room for future CDG meetings. During this meeting, the team requested LB to bring the issue of adult patients accessing S&L therapy to the CDG. Most adult speech and language therapy only tackle adult acquired neurological communication disorders. • CAPS-A training is still in discussion and is to be handed over to a new group of trainers. There has been some discussion with the Craniofacial Society regarding the funding of this, but conversation is still ongoing. • There was some discussion around the benefits versus the work load of 5 year audit, which will be further discussed at the next speech and language therapist meeting - with the aim of creating a discussion paper to be presented at the next CDG meeting. • VPI competencies are close to sign off, receiving great support from Marie Pinkstone from GOSH. • CEN had a recent study day in which Ann Harding-Bell presented on phonetics. 	

Management

- YE- Nothing to report as CEN did not meet in October

Psychology (KLM)

- A new rep from CEN has been agreed to work with CLAPA. The adult CLAPA conference took place last week, with two Clinical Psychologists presenting. The CEN are hoping to continue their good links with CLAPA.
- Psychology have been working closely with CRANE as this will be the first report to include Psychology 5 year outcomes. They are working on year by year improvements and have been looking at regional variations.
- A new ToR has been developed
- There have been some developments in Psychology services for adults returning to cleft services for the first time after a prolonged period. South Thames have developed a new adult pathway, whereby patients are offered a Psychology appointment prior to a clinic appointment. The Psychologist will then be present during the clinic appointment and debrief after.
- YE asked about the referral pathway into cleft teams and CC mentioned the work CLAPA was doing at CLAPA to disseminate surveys etc.
- The current CDG meeting will be Kate's last and Vanessa Hammond taking over as Psychology representative.

ENT & Audiology (SD)

- The CEN have not officially met for a short while but several members managed to meet at the last Craniofacial society meeting.
- The group currently has approximately 8 members and are aiming to meet on the same day as Craniofacial society, or use conference calling on other occasions.
- SD requested the CDG to share her email with any Audiologists or ENT specialised who may be interested in joining the group.

Paediatric Dentistry (JS)

- The next meeting is due to take place on 13th February 2019, with half the day spent on calibration and the other half national projects.
- A project has been set up looking at photos versus clinical findings in 5 year olds. They have looked at this with the Cleftcare UK 5 year olds data and have found that 32% of the photographs are unusable for scoring. Consequently, PD feel that photographs are not a reasonable substitute for scoring 5 year olds.
- PD are pleased with the new method of reporting PD in the CRANE report, but have feedback that there is no comparison of data and national data. SD stated that these points have been acknowledged and will be rectified.
- PB are looking to find a new CDG representative as SP no longer deals with cleft patients.

	<ul style="list-style-type: none"> • Calibration – The speaker talked through the process of calibration training, as discussed in the previous meeting. The current system of calibration has been developed to keep down costs; previously BASCD training costs were large (approx. £20,000) with little willingness for funding. The current system largely relies on volunteer time with no payment for calibration. SD highlighted that it is difficult to compare calibration data to national average as it differs from BASCD data. PB felt that changing the data for submission to CRANE would be difficult as they do not have access to the original data sheets. It was suggested to alter BASCD data to resemble PD data to see if there is any difference. SD asked for PD to consider this and get back to CRANE. • CDG requested PD to set up a calibration day. SD offered to potentially fund this, but will need a price confirmation. PB to set up Cleft data stream and BASCD data stream. • Discussion followed about funding out of the service budget for each unit (PHo) and the need for re-calibration every 2 years and the expense thereof (NHa). MS asked who can be calibrated as in the past orthodontists and dental therapists were able to be calibrated-it is now limited to specialists and consultants in paediatric dentistry. <p><u>Orthodontics</u></p> <ul style="list-style-type: none"> • Orthodontic chair was unable to attend, but SEN are to meet in a few weeks' time. This meeting will be hosted by Craniofacial Society. <p><u>Restorative Dentistry (SP)</u></p> <ul style="list-style-type: none"> • The group are looking to create a second meeting as once a year is not sufficient. • RD are looking into why adults come back to the service. They will be looking at the last 5 years of referral letters. • Presented at 2nd adult CLAPA conference, to great success. • GOSH will be hosting a restorative Cleft study day on 1st March 2019. 	5.1 Pediatric dentistry to contact SD regarding funding for calibration day
6. Audit	<p><u>CRANE (SD)</u></p> <p><u>Funding</u></p> <p>The new Cleft Clinical Lead, Joanna Reid, will be starting in the summer. JR is sympathetic to CRANE's contract issues and had planned to have discussion with other people regarding the matter. SD is yet to hear back but is continuing to pursue her. This is to be added to the agenda for the CRG meeting on 10th December.</p> <p><u>Annual Report</u></p>	6.1 Funding to be discussed at CRG meeting in December

	<p>The Annual Report has been circulated, receiving good feedback regarding progress. The feedback is currently being addressed. The deadline for CDG feedback is 30th November. SD asked the group if they have any input to make at the current time. LB would like a table supporting the funnel plots to be added to the report. CRANE intend to add this table to the appendices. LB further highlighted that there is missing speech data for all centres in the UK, despite their greatest efforts. She questioned as to whether centres could be given notice of this prior to the publication of the report. SD is to discuss this with Jibby Medina and get back to LB.</p> <p><u>CROWN</u></p> <p>CROWN IT support and interface finished 3 year contract but this has been extended by a year Leonardis-Lithuanian group has been sub-contracted by CROWN and no changes to CRANE are therefore possible at this time.</p> <p><u>Leadership</u></p> <p>SD will be stepping down as CRANE project lead in April 2020. The CDG now need to think about how to find his replacement and update the job description. The group needs to consider whether the lead will come from an academic or clinical background. SD felt that his replacement will need a good understanding of Cleft service delivery, as this is lacking in the rest of the team. SvE is to edit the job description with SD and then share with CDG to look at in more detail. SD intends to have a crossover period in which he can mentor his replacement. If a replacement can be found by springtime 2019, then this allows a 12 month period where SD will still be present. This could either be funded by SD taking a pay cut, or the RCS putting forward some extra money. After the job description has been adjusted, SD and SvE are to meet with David Cromwell and Jan van der Meulen to discuss the recruitment process. This leaves a tight timeline so SvE requested the CDG to look at the job description, and get back to him by the end of January 2019.</p> <p><u>GDPR</u></p> <p>The GDPR has caused some issues with linkage work; something the project heavily relies on. Data that CRANE previously had usage approval for, now needs new approval in accordance to GDPR. PHE have given approval for hearing data, of which they are subcontracting to Northgate. CRANE will now have to pay extra to Northgate for linkage. The CRANE Consent Policy has been updated - as has the Privacy Policy on the website. GDPR checklists have also been completed. The data retention policy has been clarified – CRANE will be keeping data for up to 30 years and the database has a cut-off point of 16</p>	<p>6.2 CDG to send CRANE annual report feedback by 30th November</p> <p>6.3 CRANE to include funnel plot supporting table to report appendices</p> <p>6.4 SD to discuss center notification with JM and report back to LB</p> <p>6.5 SvE to edit CRANE project lead job description with SD</p> <p>6.6 SvE and SD to meet with David Cromwell to discuss recruitment process for SD's replacement.</p> <p>6.7 CDG to give job description feedback to SvE by the 31/1/19</p>
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	<p>years of age. If adult data is desired then a separate consent will have to be collected.</p> <p><u>Scotland</u></p> <p>A letter of confirmation has been received from Scotland regarding joining CRANE on 1st April 2019. The logistics of this is yet to be determined, but SD has asked David Steel to consult on this. SD is yet to hear back from DS. CR to prompt DS for response.</p> <p><u>ICHOM</u></p> <p>ICHOM have sent SD a memorandum of understanding requesting CRANE data, in order to produce benchmarking standards papers. CRANE will be given authorship if they contribute towards these papers. SD wants to arrange a teleconference with individuals running this project before making any recommendations to the group. SD to resend memorandum of understanding to SvE. SD is to speak with ICHOM and then discuss at the next CDG meeting.</p>	<p>6.8 CR to prompt DS for response regarding Scotland CRANE involvement</p> <p>6.9 SD to resend ICHOL memorandum of understand to SvE</p>
7. Quality Dashboard	<p><u>Proposed changes by Methods</u></p> <p>SvE provided the group, prior to the meeting, with the proposed changes by methods and items for discussion. SvE received several emails regarding this and added these concerns to the document. SvE asked the group for any further proposals. SD highlighted that, within the notes section, the 'include patients only with LASHAL code' meaning needs to be clarified.</p> <p>CDG are to look at proposed changes and get back to SvE. These changes are to be collated into a document for review at the next meeting.</p> <p><u>Clarification of data set for CLP00 (% chn diagnosed with CLP-denominator) CLP05 (hearing)</u></p> <p>Leeds current and previous coordinators have expressed concerns in the description of CLP00 and exactly which children are applicable to this (new-born / diagnosed antenatally / late diagnosis). As centres are providing some part of the data and CRANE the other, there is likely to be consistency in this confusion, leading to potential inconsistency in data. LB feels that there needs to be some guidance as to who is included when submitting data.</p> <p><u>Failure to meeting nursing standards of first contact due to language difficulties</u></p> <p>SP highlighted that first contact calls are being ignored as they are not coming from a foreign number. SvE questioned if this needed to be something taken back to methods. SD felt that this could be seen as an issue with the service, and would not be in favour of excluding this data. LB suggested that an 'attempt of appointment' section</p>	<p>7.1 CDG to send all guidance notes suggestion to SvE by 1st April 2019.</p>

	<p>should be added into the guidance with the same notes for all centres.</p> <p>SvE asked for guidance notes suggestions from the relevant specialities by 1st April. SvE will then relay these to Methods to explore if guidance notes can be added to the dashboard.</p>	
8. Research	<p><u>Report from Bristol (JS)</u></p> <p>The following report was provided by Jonathan Sandy and discussed at the meeting: “Cleft Development Group 22nd November 2018 The Cleft Collective birth and 5-year-old cohort studies and gene bank Summary of key milestones since the May Cleft Development Group meeting</p> <ul style="list-style-type: none"> • All seventeen cleft teams have now joined the study and are in various stages of development in the recruitment process. We have now received all approvals from Belfast and they will start recruitment in the near future. Sixteen teams have recruited to the study and to date: 7129 (previously 09/04/2018: 6289) individuals from 2536 (previously 2237) families have been recruited (as of 04/10/2018). Number of antenatal participants = 262 (previously 09/04/2018: 166) Number of antenatal families = 108 (70) Number of postnatal participants = 4599 (4188) Number of postnatal families = 1603 (1435) Number of 5-year participants = 2268 (2005) Number of 5-year families = 825 (732) • Guys and St Thomas’ Hospital, London and Glasgow’s Royal Hospital for Sick Children suspended recruitment from July 2018 due to research nurse shortages. The project manager is working with both Trusts to ensure that recruitment starts again as soon as possible. Salisbury suspended antenatal recruitment from August 2018 due to a specialist cleft nurse shortage. This specialist nursing is essential for this strand of recruitment. Because of these difficulties our recruitment has been reduced by approximately 20 participants per month, largely because Guys and St Thomas’ Hospital are one of our biggest recruiters. We anticipate recruitment rates returning to normal once these sites recommence recruitment. • We recently gained ethical approval to send 10-year questionnaires to the Five-Year Cohort participants and Five-Year questionnaires to the Birth Cohort participants. • We are currently developing a mechanism to enable participants to complete the follow up questionnaires online. • We are very pleased with completion rates for the surgical forms and recognise the enormous amount of work that many of the teams have also undertaken in retrospectively addressing this issue. This has increased our surgical form return rate for first surgery to 94% (1123/1195). • Our application to NHS Digital for mortality, cancer and tracking 	

	<p>data was reviewed by the Independent Group Advising on the Release of Data (IGARD) on the 11th of October. We are still awaiting a response. Applications to the National Pupil Database (NPD) were suspended in April nationwide whilst they overhauled their application process. Applications for NPD data are now dealt with through the Office for National Statistics (ONS). The ONS have proposed that all NPD data will be accessed through an online portal within an approved secure site. The portal does not have the capability to house genetics data and lacks governance to add linked data from other sources. For this reason, we are currently in talks with the ONS to determine a different method for accessing these data. We are using a range of approaches to determine phenotype data, including linking to medical records held by cleft teams, obtaining extracts from cleft databases or visiting the cleft teams and collecting the data from the medical records. To date we have successfully set up processes with six of the cleft teams and will continue to work with the others to establish linkage to their cleft records. Although extremely time consuming, it has been necessary for us to obtain phenotype data via these mechanisms because of continuing slow progress in linking to the CRANE database.</p> <ul style="list-style-type: none"> • The Cleft Collective Speech and Language Study (CC-SL) is nested within the Birth Cohort study. Ten sites are currently recruiting, a further three have approval to recruit but are unable to at the moment due to limited research nurse capacity. Another two sites are keen to start the approvals process soon. The research and development team for one site have declined to be involved. The study was developed with the SLTs and all were involved in agreeing what data would be collected and when. The study has been designed around existing clinical care pathways to reduce patient burden and to maximise the opportunities for data collection. Recruited to date: 633 (559) individuals from 316 (279) families. Two hundred recordings have been captured with the LENA recordings of children's vocalisations and interactions with parents at age 13months. One hundred and sixty-eight assessments have been returned for children aged 18 or 24m and forty-eight have been returned for children aged 36m. Recruitment and data collection are going well, and attrition is minimal so far. • Antenatal recruitment is surpassing our expectations. We are able to collect cord blood from the mother at time of delivery and this provides the opportunity to measure the exposures of the mother and infant with cleft during pregnancy. We have now received 83 (previously 58) samples of cord blood. We currently have 80+ maternity units approved for this across the UK. These are all ready to collect cord blood and there are more to follow. • Data are continually being cleaned and prepared ready for analysis to enable researchers to use the resource. A detailed dictionary explaining the data that is currently available is online and updated monthly (http://www.bristol.ac.uk/dental/cleftcollective/professionals/access/). The Cleft Collective Project Management Group have received and approved two proposals to use Cleft 	
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	<p>Collective data in the last 6 months.</p> <p>All approved research proposals are now logged on the website: http://www.bristol.ac.uk/cleft-collective/professionals/access/projects/ See appendix for research proposals received to date.</p> <ul style="list-style-type: none"> • Team members are continuing to engage in ongoing PPI and public engagement activities (e.g. in relation to the development of questionnaires, the content of the website, through conferences, social media, participant feedback and newsletters). We have agreed a Public Involvement Strategy with our PPI partners, CLAPA, and will hold meetings three times a year with the CLAPA Cleft Collective Patient Consultation Group. Two of these will be held remotely using video-conferencing software and one will be held in person in Bristol. The last meeting took place on October 15th with eight members of the Public Consultation group. In addition, we are seeking novel ways to engage the public in our research findings and are planning a series of YouTube videos to achieve this. • We have now started to send birthday cards to the study children and have received very positive feedback from parents regarding this. Please see our newsletter in the Appendices. • There are ongoing collaborations with the various cleft Clinical Excellence Networks (CEN), including surgeons, psychologists, nurses, speech and language therapists. Members of the team meet with clinicians on a regular basis for the purpose of ensuring that data collection is capturing all clinically important variables and is feasible within clinical practice. • Team members continue to progress the research funding strategy and to develop initial funding applications. In addition to small pump-priming bids which have been awarded to carry out discrete pieces of work within the studies, we are preparing a submission to the MRC Partnership Grant scheme. • We were delighted to receive £293,760 in funding from the Scar Free Foundation to generate genotype data for all the non-syndromic cases and their families within our cohort. This will be an immensely important resource for future work exploring the genetic and non-genetic causes of cleft and cleft-related outcomes. Gemma Sharp has just received notification of success with a MRC New Investigator Award (£350,000). • The New Zealand case control study (led by Dr John Thompson) has been funded (\$NZ 1 million) and is using questionnaires, ethics, PIS and SOPs developed by the Cleft Collective. The data collection and recruitment has started and will run over four years. This collaboration is key and seems to recognise much of the work that has been carried out by the UK Cleft Teams working for the Cleft Collective. This study has also had an effect on clinical care in that some surgeons (there were 13 from a variety of parent specialties, plastics ENT, maxillo-facial, operating on only 100 babies a year) have volunteered to cease operating in order to increase surgical volume for the remaining surgeons. • We have had contact and a teleconference with Associate 	
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Professor Dr Elizabeth Leslie who worked previously in Pittsburgh and Iowa, collaborating with Professors Mary Marazita and Jeff Murray. Her relevant interests are in Van der Woude syndrome and the correlation of genetic factors with phenotypic heterogeneity within the syndrome. Her interest is in developing a cleft cohort study in Atlanta. Professor Sir Mike Owen (Cardiff) is seeking closer links with the Cleft Collective, his interest in the 22q11 deletion syndrome is particularly relevant. We have met with him twice and he is keen to collaborate by providing data from siblings of a 22q11 cohort as controls for our genetic and epidemiological analyses. We have also established a collaboration with the Norway Facial Clefts Study who are very keen to support and contribute to our work. Dr Gemma Sharp and Dr Evie Stergiakouli met Dr Anil Jugessur and Dr Hakon Gjessing from the study at a meeting in Bristol. Gemma also met these researchers again in Oslo, along with the founder of the study, Prof Allen Wilcox. We have arranged a meeting at the study site in Bergen next year to discuss how to analyse our trio genotype data using open source software they have developed.

- Longitudinal data relating to the three themes of genetics, speech and language and psychology continue to be collected for the study. Dr Yvonne Wren and Dr Sarah Lewis continue as Speech and Language Theme and Genetics Theme leads respectively. Changes in funding decisions at UWE has meant that Dr Nicola Stock and Dr James Kiff are now based at UWE rather than UoB. We continue to liaise with them and they have plans to continue to use the data.
- We have discussed the Research Tissue Bank with the University's research governance team and Dr Sue Ring (Head of Laboratories and Executive Director of ALSPAC). A Research Tissue Bank ethics application will be submitted when we have further funding in place. Please see related document in Appendices (See end of document*).

RND Departments

The Salisbury RND department have recently turned down two studies as they were not NIHR portfolio standard studies. Their rationale is to only support NIHR funded studies. Salisbury have suggested that anyone wanting to come forward with a cleft study speaks to them first so that they can find a route around this. SP has had a similar problem with Audit, in that RND have stated that data sharing cannot take place off site. To combat this issue, a data sharing agreement had to be created which and other service must agree with.

Manchester, CTG & Young Researchers Group

The following report was sent from David Salisbury prior to the meeting:

	<p>“The two current clinical projects we are work on are 1. Identification of the number of children with unrepaired cleft palates and 2. Outcomes in Children with Robin Sequence.</p> <p>These are both multi centre studies involving collaborators from UK cleft teams. We are hopeful we will have sufficient data to submit abstracts to next year’s CFSGBI Annual Conference.</p> <p>The systematic review we have been conducting on non-interventional factors influencing outcomes following cleft palate repair is progressing well. The literature searches are complete and we are awaiting funding to allow purchase of the software to enable the data extraction for the relevant studies. The protocol has been submitted to the journal “Systematic Reviews”.”</p>	
<p>9. Feedback from Cleft Centres (UK)</p>	<p><u>Bristol (SD)</u></p> <p>SD has recently recruited a new primary surgeon to replace Nigel Murcer. Peter Revington is due to retire, leaving Bristol with an overflow of alveolar bone graft and orthognathic cases. Bristol have been asked to set up a Craniofacial service by NHS England, which is further taking up time and filling the work load. A service operations manager has recently been recruited. Retirements of senior team members will be taking place in the next 3 years and there are only 4 nurses at the moment-SD is splitting managerial time to create more money for the nursing rota.</p> <p><u>Cambridge</u></p> <p>There have been several changes in staff including a new lead Psychologist. There is still a lacking in research assistants, but they are trying to slowly increase this.</p> <p><u>Trent (JND)</u></p> <p>There has been little success in creating more funding. A business case for the Psychology service has been submitted. They are still in the process of building a bottom up funding model. They were unable to recruit to the band 8 nurse position but have a band 7 nurse to cover. Due to retirement, they are hoping to recruit towards the end of the 2019. John Rosen is slowly phasing out and Ian Ormiston has recently announced his retirement. Over the last year there has been a drop in activity, and so lists have been dropped. Cleft palate births have been gone down by 15 cases.</p> <p><u>West Midlands (IS)</u></p> <p>Delivering on all targets. A recent financial report has shown that the centre have brought in £690,000 more than the previous year. A cleft coordinator has recently left, and they will be looking to recruit</p>	

in the new year. A new surgeon has been recruited and is due to start in April. A newly trained specialist nurse has been converted into a full time post, and they are now trying to continue a succession programme.

Northwest, Isle of Man and North Wales (YE)

An orthodontic consultant post has been filled in Manchester. A part time staff grade has been appointed. There are Psychology vacancies on both sites due to maternity leave. A paediatric dentist is due to have a baby in spring, and so they will be looking for a locum to cover the service. A date has been set for the NorCleft agenda and some information will be released about it in the new year. The Network day will take place on 29th November. This will cover all specialities, but will focus on adult themes. The audit and research group has been reformed and is gathering momentum. The Speech event and Nursing event has taken place.

Spires (GP)

A new service manager has been recruited and is due to start in January. The website is being redeveloped and is making good progress. They are currently working with the Oxford University Trust and Oxford Health Community Trust to build a business case for Paediatric dentistry. Spires are supporting Cleftcare with some of their phenotype collection. Winter pressures are already building, with capacity and financial issues becoming problematic.

Newcastle

Struggling with trust management to address funding and banding following the Lead SLT's move to a part-time PhD.

Scotland

Scotland currently have a full active component of surgeons, however they lost 75% of administration staff within the previous month. They currently have no appointed clinical leads but have recently appointed an operational manager. Scotland are aspiring to submit data to CRANE by April, but this is looking to be difficult due to lack of staffing.

South Thames

Staffing remains a key challenge. CNS and Psychology team are all in post and through induction. There has been some increase to administration. A 4th surgeon was appointed in the summer, expanding relations with ENT. They have recently started an ONFS specialist training rotation from KSS and London. They are continuing to struggle to recruit quality service fellows but are due to interview shortly. A new service manager has recently been

	<p>appointed. They are business casing for an expansion of other cleft services due to the volume of patients, including business casing for a 5th cleft surgeon and other accompanying services. There is a continuing struggle to accessing local S&L therapy services. RTT performance is significantly challenged.</p> <p><u>North Thames</u></p> <p>A new cleft Orthodontist was appointed in August. She is now on maternity leave and so a locum Orthodontist has been subsequently appointed. The existing cleft locum surgeon has now been appointed to a full time position. A lead CNS has been appointed. There is a continuing problem with the calibration of Paediatric dentists. Patients are still being seen by a PD, regardless of calibration, this however mean that the centre is into the red by 3 standard deviations in reporting. There is reduced support in Psychology but this has been reviewed. Cases are being made for re-establishing some of the Psychologists. A new computer system is to be installed in April 2019, this will results in the reduction of clinics to allow time for adjustment.</p>	
10. Data Sharing (KMo)	It was suggested that the CDG formulate a data sharing protocol to send back to the trust. KMo to circulate the pre-existing protocol.	10.1 KMo to circulate data sharing protocol
11. Training	Interviews for two Cleft fellows are due to take place on 7 th December. This will aim to target shortages seen across the county.	
12. Any other business – CDG and dates of next meeting	<ul style="list-style-type: none"> SD asked about lead CNS recruitment and asked if the CEN were doing anything in this regard and wondered if there was a lead CNS job description. JD wrote the JD for the Nottingham team. CC reiterated that CLAPA are still in a challenging financial position and so asked the CDG for any potential contacts for sponsorship or funding. CLAPA are also in the process of recruiting for clinician trustees. Peter is soon to step down and so a vacancy for the board has become available. CC invited contact from any CDG members who may be interested in taking the position. 	

The next meeting of the Cleft Development Group will take place on 17th May 2019 at the Royal College of Surgeons of England

Publications and Conferences since April 2018*

Publications

1. Sainsbury, D.C.G., **Davies, A., Wren, Y., Southby, L.**, Chadha, A., Slator, R., **Stock, N.M.** and the Cleft Multidisciplinary Collaborative (2018). The Cleft Multidisciplinary Collaborative: Establishing a network to support cleft lip and palate research in the United Kingdom. *Cleft Palate-Craniofacial Journal*, [e-pub ahead of print]
<https://doi.org/10.1177/1055665618790174>
2. **Howe, L.J.**, Lee, M.K., **Sharp G.C., Davey Smith G.**, St Pourcain B., Shaffer J.R., Ludwig K.U., Mangold E., Marazita M.L., Feingold E., Zhurov A., **Stergiakouli E., Sandy J.**, Richmond S., Weinberg S.M., Hemani G., Lewis S.J. (2018) Investigating the shared genetics of non-syndromic cleft lip/palate and facial morphology. *PLoS Genet.*;14(8):e1007501
3. **Stock, N.M.** and Feragen, K.J.B. (2018) An illustration of methodological challenges in craniofacial research: An example from the Psychology literature. *Cleft Palate-Craniofacial Journal* [e-pub ahead of print]. doi: 10.1177/1055665618769661.
4. **Stock, N.M., Ridley, M.** and Guest, E. (2018) Teachers' perspectives on the impact of cleft lip and/or palate during the school years. *Cleft Palate-Craniofacial Journal* [e-pub ahead of print]. doi: 10.1177/1055665618770191.
5. **Howe, L.J.**, Richardson, T, Arathimos, R, Alvizi, L, Passos-Bueno, MR, Stanier, P, Nohr, EA, Ludwig, K, Mangold, E, Knapp, M, **Stergiakouli, E**, St Pourcain, B, **Davey Smith, G, Sandy, J, Relton, C, Lewis, S.J.**, Hemani, G & **Sharp, G.C.**, 2018, 'Evidence for DNA methylation mediating genetic liability to non-syndromic cleft lip/palate'. *Epigenomics*. In press.
6. Richmond S, **Howe LJ, Lewis SJ, Stergiakouli E**, Zhurov AI, Facial genetics: A Brief Overview, *Frontiers in Genetics*, section Applied Genetic Epidemiology *In press*

Invited Talks and Keynote Addresses

1. **Wren, Y.E.** (2018) *Predicting speech outcomes in children – Findings from a community population study*. Keynote speech, The Craniofacial Society of Great Britain and Ireland Annual conference. Birmingham, UK.
2. **Wren, Y.E.** (2018) *Writing for Publication*. Workshop, Spires Cleft Speech and Language Therapy Team.
3. **Humphries, K.** and The Cleft Collective team (2018) '*The Cleft Collective Cohort Studies update*', Annual Conference of the Craniofacial Society of Great Britain and Ireland. Nurses CEN. Birmingham, April 2018.
4. **Humphries, K.** (2018) '*The Cleft Collective – Antenatal recruitment*', South West Midwifery Research meeting. Bristol, May 2018.
5. **Sharp, GC.** (2018) '*Molecular Epidemiology in the Cleft Collective*', Great Ormond Street Hospital. London, June 2018.
6. **Sharp, GC.** (2018) '*Prenatal and Childhood Molecular Epidemiology at the University of Bristol*', Norwegian Institute of Public Health, Oslo, September 2018.

Oral conference presentations

1. **Lewis, S.** (2018). Genetic variants for non-syndromic cleft predict philtrum width in the general population. The Annual Scientific Conference of the Craniofacial Society of Great Britain and Ireland. Birmingham, April 2018.
2. **Wren, Y.E., Southby, L.**, Van Eeden, S., Sell, D., Sweeney, T. (2018) *Innovations in research with children born with cleft palate*. Conference of the International Clinical Phonetics and Linguistics Association, Malta, October, 2018.

3. **Stock, N.M., Costa, B., and The Cleft Collective team** (2018) '*Psychological distress and associated risk factors among parents enrolled in the Cleft Collective Birth Cohort*', the Annual Scientific Conference of the Craniofacial Society of Great Britain and Ireland. Birmingham, April 2018.

Conference posters

1. **Humphries, K., Davies, A. and The Cleft Collective team** (2018) '*Using Free Text from Medical Notes to Enrich a Longitudinal Cohort Study studying families affected by cleft*' [poster], International Population Data Linkage Network. Banff, Canada, September 2018.

2. **Sharp GC**, on behalf of **the Cleft Collective Team** (2018) '*The Cleft Collective: A National Cohort of Families Affected by Cleft Lip/Palate in the UK*' [poster], Conference on Epidemiological Birth Cohort and Longitudinal Studies. Oulu, Finland, June 2018.

3. **Lane, H. and Wren, Y.** (2018) '*Patterns of early speech and language therapy delivery for children born with cleft palate in the first year of life*'. Craniofacial Society of Great Britain and Ireland, Birmingham, April 2018.

Grants

1. **Lewis, S., Stergiakouli, E., Sharp G.:** Scar Free Foundation research grant (2018). Genotyping the Cleft Collective £293,760.

2. **Wren, Y., Roberts, A., White, P., Humphries, K., Sandy, J:** University Hospitals NHS Trust Research Capability Fund (2018). What works in speech and language therapy interventions for children born with cleft palate £19,176.

4. **Wren, Y.,** The Underwood Trust (2018). Speech in children born with cleft palate. £20,000."