

National UK NHS Cleft Development Group Meeting Notes

The Cleft Development Group met virtually from 14:00 pm to 17:00 pm on Thursday 15th May 2025 using Microsoft Teams.

Agenda item

1. Apologies

Craig Russell, Ali Cobb, Nicola Stock, Wendy Jones, Khurram Khan, Imogen Underwood
Welcome to new members: Joanne Waldron (Chair of SaLT CEN)

2. Record of CDG meeting 20/11/24 – apologies that there are no minutes available. Updates and slide presentations have been circulated.

3. CRANE update presented by Kate Fitzsimons (circulated)

Priority continues to be seeking secure contract, to allow CRANE work to continue without ongoing uncertainty (ideally 3 + 2 year contract).

The team is reduced but have completed database enhancements and an organisational audit, with responses from all cleft services.

Thanks to Jibby Medina who left at the end of March, for all her contribution.

The formal outlier policy will be implemented this year.

4. CDG Patient Engagement Group feedback

PEG is grateful to CDG members for responses to the question about implementing adult self-referral and for proposing questions for PEG to consider.

- 4.1 Adult self-referral implemented – 6 service/unit YES,
3 service/unit PARTIAL
4 service/unit NO
1 service/unit No response

Helen Extence shared data from South Wales on volume of adult self-referrals received and focus primarily on dental care. However, it was noted that a focused referral may lead to additional requests to the wider team and resources being required for this.

- 4.2 CEN/PEG engagement – Several CEN members have attended PEG meetings (Genetics & Clinical Coordinators/Managers). It was noted that there may have been changes to chair contacts for each CEN. The PEG would like to extend an open invitation to all cleft CENs, either to attend a PEG meeting or for PEG members to attend a CEN meeting.

5. CLAPA update presented by Claire Cunliffe, CEO – 2025-30 Strategy

Adult conference planned for 14th June in Manchester, but low numbers registered.

6. Quality Monitoring and Improvement Committee update provided by David Sainsbury who has taken on role of CDG vice-chair, including oversight of QMIC. The next **Cleft QMIC Policy Meeting is to be held on Wednesday, 17 September 2025 10:30am - 12:00 noon.**

7. UK Cleft Centre/Unit updates

7.1 Cleft Services Deep Dive – Katie Jones, (Senior Programme of Care Manager, Women & Children, Specialised Commissioning, NHS England), shared an update relating to NHSE delegation, and information gathered in a deep dive meeting (11th March) with clinical leads/directors and regional colleagues from ICBs, ODNs and CLAPA (slides circulated)

Key points:

- NHSE legal accountability for services remains.
- Work on revised service specification to re-start July 2025
- A series of actions to be led by the Specialised Surgery in Children CRG, within input from Elective Recovery, ODNs, ICBs and Regional teams
- A Gateway 0 paper initiating the work has been developed and will be shared with ICB colleagues via the Integrated Delivery Group this June

7.2 Escalation and Mutual Aid – Stacey Marriott (Transformation Lead – Elective Care and Health Inequalities, Specialised Commissioning, Service Transformation Team, NHS England) highlighted key recovery actions around RTT/planned waits, mutual aid and cleft surgery data. Data sub-group to review the Cleft data and coding with Cleft Clinicians and Network leads, ensure we have the most accurate picture of recovery.

Stacey invited CGD members to contact with any further queries relating to specialised elective recovery:

england.speccom-electiverecovery@nhs.net

Mutual aid flowchart circulated in NHSE slides

7.3 Cleft Units – updates circulated, thanks to CDs/Clinical Leads

8. Discussion/Questions from item 7. Please send any post-meeting feedback.

9. CRG update – covered in item 7.1

10. CEN/Lead Specialty Group updates – circulated, thanks to CEN chairs/leads

11. Research

- Cleft Collective - update circulated. Yvonne Wren highlighted value of the long surgical forms and also grateful for units sharing 5 year outcome data – further submissions awaited.
- Cleft @18-23 – update circulated
- Clinical Studies Group - Yvonne is interim Chair, seeking permanent replacement
- Cleft Multidisciplinary Collaborative
- Early Career Researchers Group – update circulated, thanks to Sophie Butterworth
- Centre for Appearance Research – apologies from Nicola Stock

12. CFSGBI Update – Congratulations to Rye Mattick on a successful conference in Newcastle. She will now hand over to Rebecca Crawford, Clinical Psychologist to begin preparations for the 2026 Glasgow conference (22-24 April).
CFSGBI AGM is scheduled for 03/06/25

13. Training – update provided by Jonathan Syme-Grant by email post meeting:

Points discussed in the meeting in March:

The last remaining TIG fellow has started in a locum consultant role and the next fellow has just started. We haven't discussed the number of posts to interview but will do so in the next meeting. In the current financial climate lots of Trusts are questioning the financial burden of having a fellow. There is work ongoing on the paperwork and meeting facilities on ISCP to accommodate the shift to post-CCT.

Louisa Ferguson is to demit, and Kanwal Moar will take over as the chair.

14. Any other business: Ginette (chair) advised the meeting that she is partially retiring and would like to hand over the role of chair of CDG to someone more actively involved in cleft care. Ginette invited anyone who is interested to contact her gphippen@nhs.net

15. Date of next meeting 18th November 2025 9.00-12.00

ATTENDEES	
Anne Duarte	Patient Engagement Group representative
Antonia Yiakoumetti	Patient Engagement Group representative
Calladine, Samantha	Acting Lead Clinician Northern and Yorkshire Regional Cleft Service (Leeds)
Chris Sweet	Clinical Director, North West, North Wales & Isle of Man Cleft Network
Claire Cuncliffe	Chief Executive, CLAPA
Crawford, Rebecca	Chair of Clinical psychology CEN & CFSGBI President
DE, Su	Chair & National Specialty Adviser (NSA) for Specialised Surgery in Children CRG
Emma Blair	Clinical Nurse Specialist (Leeds)
Gillian McCarthy	CLAPA External Engagement Coordinator
Helen Extence	Clinical Director (Welsh)
Joanna Waldron	Chair of SaLT cleft & Craniofacial CEN
JONES, Katie (NHS ENGLAND)	Senior Programme of Care Manager, Women & Children, Specialised Commissioning
Kana Miyagi	Lead Clinician (CleftNetEast)
Kate Fitzsimons	CRANE
Kirk, Lyndsay	Chair of Clinical Coordinator/Manager CEN
Le Marechal Kate	Head of Service for Evelina London Cleft Service
MARRIOTT, Stacey (NHS ENGLAND)	Transformation Lead – Elective Care and Health Inequalities, Specialised Commissioning
MATTICK, Rye	CFSGBI outgoing President
MAY, Joanna	Chair of Paediatric Dentistry CEN
OConnor, Eilish	Lead SaLT, NI Cleft Service
Patricia Rorison	Lead Clinician (North Thames)
PHIPPEN, Ginette	Chair of CDG
Popat, Sandip	Chair of Restorative Dentistry CEN
Rachel Green	Lead CNS, Southwest Cleft Service
SAHUNTA, Heather	Chair of Cleft Nursing CEN
SAINSBURY, David	Vice-chair CDG/QMIC Lead
Sophie Butterworth	CRANE Clinical Fellow
SYME-GRANT, Jonathan	Lead Clinician (Trent)
Toby Gillgrass	Clinical Lead for The Cleft Surgical Service for Scotland
WILLIS, Rachael	Chair of Orthodontic CEN
Yvonne Wren	Chief Investigator, Cleft Collective