

The Cleft Development Group met virtually from 09:00am to 12:00pm on Tuesday 18 November 2025 using Microsoft Teams.

Agenda items

1. Apologies & welcome to new attendees

Apologies were received from:

- Gillian McCarthy, Hannah John, Khurram Khan, Eilish O'Connor, Su De, Chris Sweet

Stand-ins were present for several services, and attendance was confirmed during the meeting.

2. Record of CDG meeting – 15/05/25

The meeting notes from 15 May 2025 were circulated in advance.

Decision:

The notes were agreed as an accurate record with no amendments.

3. Chair of CDG / Terms of Reference

Ginette Phippen advised that no expressions of interest had been received to take on the role of CDG Chair. She reiterated her intention to step down but expressed concern about continuing in the role while no longer closely embedded in frontline cleft service leadership.

It was noted that:

- The CDG Terms of Reference are overdue for review (last dated 2021).
- The mandate and governance role of CDG require clarification and reaffirmation, particularly in the context of wider NHS England changes.
- Jonathan Syme-Grant has taken on the chairing of the Service Specification Working Group, supported by Matt Fell.
- David Sainsbury has assumed the role of Chair of the Quality Monitoring and Improvement Committee (QMIC).

Discussion highlights:

- CDG is perceived externally as a key national forum coordinating cleft services across the UK.
- Members highlighted the importance of reaffirming CDG's mandate with NHS England.

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- Patient representatives emphasised the significance of CDG's work for patients and families.
- There was consensus that this is a timely opportunity to review CDG's purpose, remit, and governance.

Actions:

- CDG members to review the Terms of Reference and submit comments to Ginette by **early January 2026**.
 - Ginette to continue as Chair for a **further 6 months**, to allow time for review of CDG remit and identification of a successor, with a planned handover.
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4. Patient Engagement Group (PEG) feedback

Anne Duarte provided an update on behalf of PEG.

Key points:

- Ongoing recruitment to PEG, with challenges around diversity of applicants.
- Continued concerns about adult self-referral pathways, which vary significantly by region and individual needs poorly understood by some GPs and GDPs.
- Evidence that adults are frequently blocked from re-entering cleft care pathways.
- PEG members contributed to the development of CRANE's revised patient information leaflet.

Discussion:

- Suggestions included development of a national template letter for adults to present to GDPs/GPs.
- ENT colleagues highlighted that not all adult presentations require cleft service re-entry and suggested guidance to support appropriate signposting.
- CLAPA confirmed existing "Returning to Treatment" resources but acknowledged ongoing gaps.
- Proposal to lobby the GDC and BDA regarding duty of care and access to dental care.

Actions:

- Explore joint CDG/CLAPA lobbying to GDC and BDA on dental access issues.
 - Consider development of nationally consistent guidance/resources to support adult re-entry to care.
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5. CLAPA update

Claire Cuniffe (CEO, CLAPA) presented an update.

Key updates included:

- New staff appointments (Head of Comms & Marketing; fundraising roles).
- Launch of the **Cleft Dental Crisis** campaign, calling for lifelong NHS dental care for people born with a cleft.
- Active MP engagement across all four nations.
- Increasing demand for advocacy and support services.
- Expansion of counselling and youth mentoring services.
- Development of a new CLAPA website and full rebrand, launching January 2026.
- Concerns regarding the NHS cleft webpages, which do not reflect cleft as a lifelong condition.

Actions:

- CDG members to express interest in contributing to revision of NHS cleft webpages.
 - Members encouraged to support and share CLAPA's dental campaign and petition.
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6. CRANE update

Craig Russell and Kate Fitzsimons provided a comprehensive update.

Key points:

- **CRANE Annual Report 2025** scheduled for publication on **8 December 2025**.
- Introduction of full Outlier Policy implementation, including:
 - Risk-adjusted analysis for dental and speech outcomes.
 - Simultaneous notification to services, senior management, and commissioners.
- Recognition of anxiety generated by outlier status and commitment to supportive, contextualised communication.
- Organisational audit data sharing discussed with NHS England, with assurances regarding appropriate use (NHSE is joint data controller).
- Concerns raised regarding speech outcome reporting and interpretation.

Speech outcomes:

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- North Thames raised concerns regarding speech outlier status.
- A stakeholder meeting was held and agreed wording added to the report advising caution in interpretation.
- Proposal for a **Short Life Working Group** to review speech assessment, standards, and translation into outlier reporting.

Actions:

- Establish a working group (linked to but distinct from QMIC) to review speech outcome reporting, with balanced multidisciplinary and patient representation.
- CDG/QMIC Chairs and CRANE to agree membership and remit.

Other CRANE updates:

- “Making it Better” session scheduled for **22 January 2026**.
- Proposed refinements to Outlier Policy metrics, including:
 - Removal of child growth as an outlier metric.
 - Inclusion of antenatal and postnatal diagnosis measures.
- Proposal to report on outcomes for transferred patients as a separate group.

Decision:

- Agreement in principle to proceed with analysis of transferred patients.

7. Quality Monitoring and Improvement Committee (QMIC)

David Sainsbury provided an update on QMIC activity since assuming the Chair role.

Key points:

- First meeting held in September 2025.
- Focus on learning from variation, supporting services, and creating a safe space for quality improvement.
- Slides to be circulated with meeting papers.

8. Cleft Unit / Service updates

Updates were provided verbally and via written submissions (to be circulated). Themes included:

- Ongoing workforce shortages across multiple disciplines.

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- Significant pressures on theatre capacity and outpatient pathways.
 - Increasing reliance on mutual aid and independent sector support.
 - Emotional and operational burden of harm reviews.
 - Positive developments in research, infrastructure, and international collaboration.
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9. Training (TIG fellowships)

Katie Jones (NHS England) provided an update on recent discussions.

Key points:

- A paper has been submitted within NHS England proposing reinstatement of funding for **at least one TIG fellowship per year**.
 - Awaiting further decision.
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10. CEN / Specialty Group updates

Written updates were submitted and will be circulated.

Additional requests:

- Paediatric Dentistry CEN requested submission of intra-oral photos for calibration exercises.
 - ENT CEN requested consideration of hybrid meeting formats to improve accessibility.
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11. Research update summary

- **Cleft Collective:** Recruitment ongoing; increased international interest; funding required for long-term follow-up.
 - **Cleft @18–23:** Clinics running across multiple centres with positive engagement.
 - **Clinical Studies Group:** Proposal submitted to Craniofacial Society to relaunch and strategically align research activity.
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12. Craniofacial Society (CFSGBI) update

Rye Mattick reported:

- Successful Newcastle conference with strong attendance and feedback.
- Preparations underway for the **2026 Glasgow conference (22–24 April 2026)**.

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- Encouragement for CDG members to support CLAPA's dental campaign locally.

13. Any other business

No additional items were raised.

14. Date of next meeting

May 2026 – exact date to be confirmed and circulated.

Attendees

Name	Role / Organisation
Blair, Emma	Clinical Nurse Specialist
Brierley, Neil	Representing West Midlands Cleft Service
Bruce, Lachlan	CLAPA Policy and Campaigns Manager
Calladine, Sam	Acting Lead Clinician, Northern and Yorkshire Regional Cleft Service (Leeds)
Cobb, Ali	Clinical Lead, South West Cleft Service
Crawford, Rebecca	Chair of Clinical Psychology CEN & CFSGBI President
Cunniffe, Claire	Chief Executive, CLAPA
Davis, Sinead	ENT & Audiology CEN
Duarte, Anne	Patient Engagement Group representative
Extence, Helen	Clinical Director, South Wales Cleft Service
Fitzsimons, Kate	CRANE, Senior Research Fellow
Gillgrass, Toby	Clinical Lead, The Cleft Surgical Service for Scotland
Jawad, Sarra	Restorative Dentistry CEN
Jones, Katie	Senior Programme of Care Manager, Women & Children, Specialised Commissioning, NHS England
Kirk, Lyndsay	Chair of Clinical Coordinator/Manager CEN
Le Marechal, Kate	Head of Service, Evelina London Cleft Service

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Luscombe, Carrie	Co-Chair, Clinical Studies Group
Macartney, Emma	Representing Northern Ireland Cleft Service
Mattick, Rye	CFSGBI Outgoing President
MAY, Joanna	Chair of Paediatric Dentistry CEN
Miyagi, Kana	Lead Clinician, CleftNetEast
Phippen, Ginette	Chair of CDG
Rorison, Patricia	Lead Clinician, North Thames Cleft Service
Russell, Craig	CRANE Clinical Lead
Sainsbury, David	Vice-Chair CDG / QMIC Lead
Scott, Julia	Orthodontic CEN
Scotson, Jill	Representing North West, North Wales & Isle of Man Cleft Network
Swan, Marc	The Spires Cleft Service, Oxford & Salisbury
Syme-Grant, Jonathan	Lead Clinician, Trent Cleft Service
Underwood, Imogen	Chair of Lead Speech & Language Therapy Group
Waldron, Joanna	Chair of SaLT Cleft & Craniofacial CEN
WILLIS, Rachael	Chair of Orthodontic CEN
Wren, Yvonne	Chief Investigator, Cleft Collective