Promoting excellence in cleft care

Cleft Registry and Audit NEtwork Database

Organisational Audit Report

An Organisational Audit of services providing care to children born with a cleft lip and/or palate in England, Wales, Northern Ireland and Scotland

Published 18 July 2025
On behalf of NHS England and the Cleft Development Group

At the request of NHS England and the UK NHS Cleft Development Group, this report was prepared by:

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Acknowledgements

We would like to acknowledge all cleft services for participating in the Organisational Audit (OA). We are grateful for the time taken to consider and respond to each question. It is a rare outcome to achieve a 100% response rate to an OA. Cleft services are commended for this. We recognise the extra time and effort it has taken for clinical colleagues to engage and respond so constructively.

The CRANE website provides detail on the project team, and the project's governance and funding arrangements CDG Membership and Terms of Reference.

Contents

Document related to this product, for reference, published separately	**Published**
2025 Organisational Audit Questionnaire (PDF)	18 July 2025

Executive Summary

The Cleft Registry and Audit NEtwork (CRANE) Database team conducted an Organisational Audit (OA) of cleft services across England, Wales, Northern Ireland, and Scotland at the request of NHS England (NHSE) Specialist Commissioning. It is the first comprehensive OA of cleft services to be performed since centralisation following the Clinical Standards Advisory Group (CSAG) report into the quality of UK cleft care in the late 1990s[1].

This OA aimed to provide a focused comparison of cleft service structures across the UK to inform the developing NHSE Cleft lip and palate and non-cleft velopharyngeal dysfunction Service Specification for England through 2025 and beyond. It will also serve as a resource that may inform future service developments in the rest of the UK.

Methods

Design: A questionnaire was created to gather information on the organisation of cleft services at individual hospital trusts and Health Boards.

The OA was developed with input from the Cleft Development Group (CDG), including representatives from commissioning, services, and each cleft specialty Clinical Excellence Network (CEN), as well as other key stakeholders such as NHSE and the CRANE team.

Data collection: The OA focused on the 2024 calendar year and requested a single response from each cleft service in the UK via Clinical Leads, or other nominated persons, requiring a multi-professional effort within each service.

Analyses: Quantitative data were analysed and reported as frequencies or percentages, while qualitative data were assessed for themes.

Key findings

- 100% of cleft services responded.
- The majority (60%) of services are led by surgeons and most operate across multiple sites (average: five sites).
- There was considerable variation in commissioned services, staffing levels, and access to diagnostic and operative facilities.
- Many services deliver unfunded elements of care, raising concerns about sustainability.
- Workforce shortages and recruitment challenges are widespread, especially in psychology, orthodontics and paediatric dentistry.
- Equitability of access remains a challenge across geography and specialties, especially for paediatric dentistry and speech and language therapy.
- 80% of services reported having concerns about delayed detection or delayed referral of clefts, but only 40% said they were adequately funded to engage in training professionals outside of their service.
- The majority of services aimed to repair the lip by 3 or 4 months and the palate by 9 months; however, 33% reported delays to these timings during 2024.
- services are highly engaged with the CRANE Database and value its role in benchmarking and quality improvement.

Conclusion

The OA responses reflect the context of cleft care in the UK in 2024. The findings demonstrate that cleft services are complex and diverse, and they reinforce the need for a clear, well-resourced, and consistent model of cleft care delivery across the UK.

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[1] Clinical Standards Advisory Group. Clinical Standards Advisory Group: Report of a CSAG Committee on Cleft lip and/or palate. London: The Stationery Office; 1998

1. Introduction

1.1. Background

The CRANE Database team conducted an Organisational Audit (OA) of cleft services across England, Wales, Northern Ireland (NI), and Scotland at the request of NHSE Specialist Commissioning. The survey is part of the process towards developing a new national service specification for cleft services in England. Previous national service specifications for England have been used in Scotland, Wales, and NI to inform development of service within these devolved nations.

1.2. Objectives

- To provide an up-to-date overview of current clinical cleft service delivery to support the development of NHS England's 'Cleft Service Specification'.
- To inform clinical services in their ongoing work to improve cleft care within the UK.

1.3. Scope

- Focus: Current cleft service structure
- Time period considered: **2024**.
- Respondents: One response required from each cleft service, with completion requiring a multi-professional effort within the service.

2. Methods

2.1. Design

The OA survey was drafted in consultation with the CRANE Database team, NHSE England (NHSE) Commissioning, and the CDG, including Clinical Excellence Network (CEN) leads.

The final version was transformed into an online survey in January 2025. Resource constraints (temporal and staffing) meant there was no opportunity to pilot the survey.

2.2. Sample and data collection process

All 14 NHS organisations providing cleft care in England, Wales, Northern Ireland and Scotland were invited to respond to the online survey via email.

The survey utilised the Clinical Effectiveness Unit's (CEU) Survey Monkey account (Copyright © 1999-2025 SurveyMonkey) and included 116 questions, across 15 sections (resulting in 626 data points).

1. Introduction and respondent information
2. Care structures: Networks, facilities and staffing
3. Public and Patient Involvement (PPI)
4. Pathway specific
5. Review clinics / Preventative care
6. Outcomes and specialty specific: Surgery
7. Outcomes and specialty specific: Nursing
8. Outcomes and specialty specific: Paediatric Dentistry
9. Outcomes and specialty specific: Orthodontics
10. Outcomes and specialty specific: Speech and language therapy (SLT)
11. Outcomes and specialty specific: Hearing / ENT
12. Outcomes and specialty specific: Psychology
13. Resilience and recovery
14. Audit and engagement with CRANE Database
15. Closing comments

To support the OA completion process, a PDF of the online OA survey was provided to each service Clinical Lead to allow services to review the questions and response options prior to completion. This was done to help ensure all the necessary information was to hand at the time of survey completion. Only one OA survey was completed for each cleft service, and the service Clinical Lead was advised that completion of the OA required a multi-professional effort within the service.

Respondents were asked to reflect on the most recent full last calendar year, **2024**. Respondents were also requested to complete all questions in the OA to the best of their understanding.

Responses were collected during February-March 2025, and each survey took an average of 84 minutes to complete.

All data collected via the OA was treated in accordance with data management and security policies at the Clinical Effectiveness Unit of The Royal College of Surgeons of England, where the audit data are held.

2.3. Analyses

The OA was designed for mainly categorical data collection. Nevertheless, both interval/ratio data and qualitative data in the form of comments were also collected.

Raw data was reviewed, organised, and recoded to ensure accuracy and consistency within Microsoft Office Excel (Microsoft 365).

Quantitative data analysis and synthesis were conducted using Excel. Calculations were performed to determine the distribution and percentage of key variables, providing a clear understanding of data trends. Utilising:

- PivotTables created to summarize and analyse the data, allowing for the identification of patterns and relationships.
- Excel embedded statistical functions and formulas. These were employed to manipulate data efficiently, ensuring the analysis was both appropriate and sufficient.

Qualitative analysis of survey comments was also conducted and involved examining responses to uncover themes and patterns and provide context for the numerical / quantitative data.

These techniques collectively enabled the generation of a detailed report that will provide greater insight into the current structure of, and challenges faced by, clinical teams involved with cleft care. In so doing, this report will inform decision-making in relation to the updating of the cleft service specification for England, and its future utilisation in any review of cleft services in the devolved nations.

2.4. OA questions and responses

A PDF version of the OA survey questions is published separately. In addition, the question summarised in each section of this report is referenced in square brackets, for example **[Q1]**.

Overall, results across all services are synthesised and reported in Section 3 to 17. Some respondents shared additional notes / comments they wished the OA to consider in the context of this audit, which are shared in Section 11.

3. Respondent information

3.1. Cleft service location

15 survey responses were received, representing all Regional Cleft Networks/services in England, Wales, Northern Ireland and Scotland (**Table 1** below) **[Q1]**.

Table 1. OA respondents: Service (Region)

Belfast (Northern Ireland)
Birmingham (West Midlands)
Bristol (South West)
Cambridge (Cleft Net East)
Evelina London (South Thames)
Great Ormond Street Hospital (Broomfield (North Thames)
Leeds (Northern and Yorkshire)
Liverpool (North West North Wales)
Manchester (North West North Wales)
Newcastle (Northern and Yorkshire)
Nottingham (Trent)
Oxford (The Spires)
Salisbury (The Spires)
Glasgow (Scotland)
Swansea (South Wales)

3.2. Clinical leads and their specialty

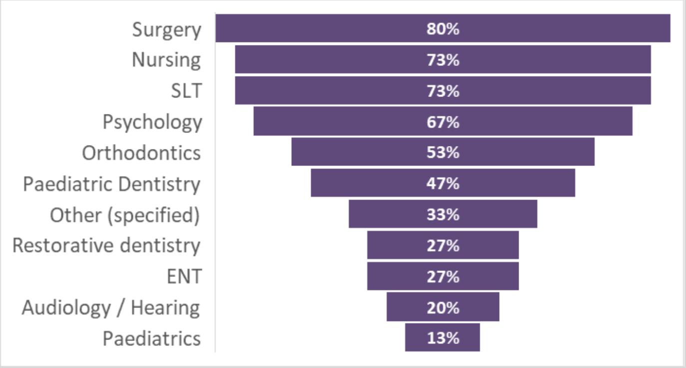
93% of respondents were the Clinical Lead/Director for their cleft service. Where this was not the case, a speech and language therapist (SLT) had been nominated to complete the OA on behalf of their service **[Q3]**.

The majority (60%) of Clinical Leads were surgeons, 20% were SLTs, 13% were Orthodontists, and 7% were psychologists **[Q6]**.

3.3. Specialties contributing to the completion of the OA on behalf of cleft services

Multiple specialties contributed to the completion of the OA on behalf of their cleft service. As shown in **Figure 1**, the specialties of surgery, nursing, SLT and psychology were involved in completing the OA in at least two-thirds (67%) of the participating services. 33% of services included 'other' specialties, specified as clinical directors/service management and cleft coordinators**.** Anaesthetics and genetics specialities did not directly contribute to the OA **[Q7].**

Figure 1. Specialties contributing to OA



4. Care structures: networks, facilities, and staffing

4.1. General structure

40% of respondents stated that the structure of their funded cleft service in 2024 was a Managed Clinical network (MCN), 33% were Hub and spoke, 13% were centralised, and 13% reported being a Regional Specialist Centre **[Q8]**.

4.2. Diagnostic and operative facilities / services

Respondents provided information on diagnostic and operative facilities/services available on-site within the trust/MDT in 2024. On-site meant present at any site within the trust/MDT. If patients are referred to a different hospital within the same trust/MDT to undergo care, this still counted as on-site. If patients are referred to a different trust/MDT to undergo this service, then this was considered off-site.

In additional, respondents indicated whether these were cleft service funded or non-cleft service funded **[Q9]**. As per **Figure 2** on the next page:

- **Cleft service funded diagnostic and operative facilities/services - available on-site** in at least 90% of services: **Surgeons** (incl. Cleft Surgeons and Orthognathic Surgeons), Administrative support, **Clinical Nurse Specialists**, and **Speech and Language Therapy** incl. With dysphagia spec.
- **Cleft service funded diagnostic and operative facilities/services - available off-site** in at least 50% of services: **Speech and Language Therapy** incl. With dysphagia spec. One service had cleft funded SLT off site but no dysphagia SLT off site.
- **Non-cleft service funded diagnostic and operative facilities/services - available on-site** for at least 80% of services: **Paediatric airway support** incl. patient ENT surgery & paediatric sleep medicine, and **Specialised Paediatric Anaesthesia**.
- **Non-cleft service funded diagnostic and operative facilities/services - available off-site** for at least 80% of services were Health visitors / School nurses.
- **Non-cleft service funded diagnostic and operative facilities/services – not applicable** for at least 80% of services: Patient transport services

Figure 2. Diagnostic and operative facilities/services available to services (cleft service funded/non-cleft service funded)

Cleft service-funded - available **on-site**

Cleft service-funded - available **off-site**

Non-cleft service-funded - available **on-site**

Non-cleft service-funded - available **off-site**

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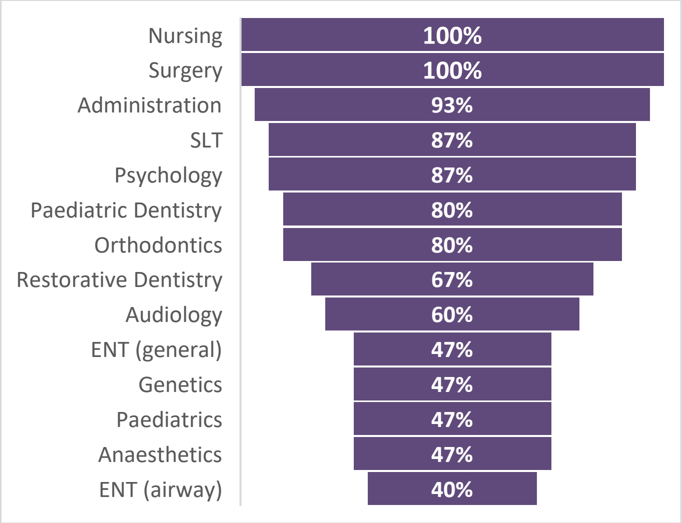
4.3. Commissioned services

At least 80% of respondents stated their service was commissioned to provide the following services to all being treated for a cleft in **2024**: Nursing, Surgery, Administration and Psychology. **Figure 3** illustrates the distribution across all selected response options **[Q10]**.

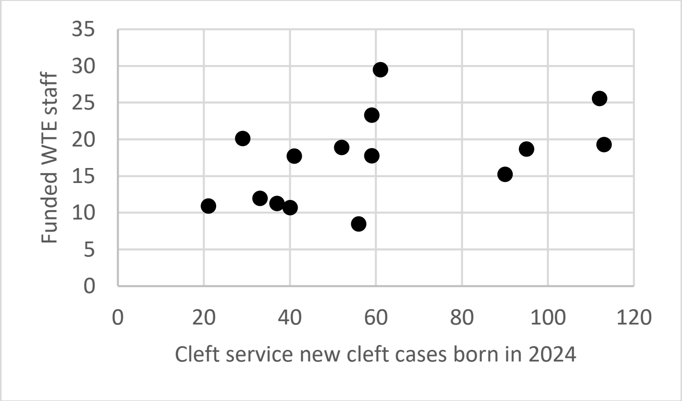
Figure 3. Commissioned services



4.4. Staffing levels

Respondents provided information on whole-time equivalent (WTE) staffing for specialties (excluding trainees /assistants) dedicated to support their service. This included vacant roles.

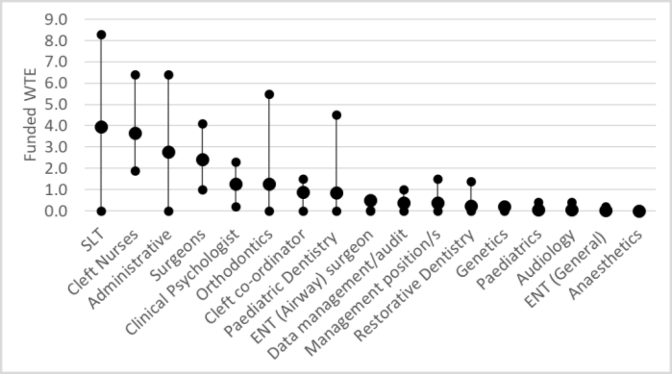
Figure 4. Service-level WTE funded staff according to new cleft cases born in 2024 (CRANE registrations). Each marker represents a responding cleft service



Funded staff members: In total, 260 WTE funded staff members were reported for cleft services across the UK in 2024. The number of total funded WTE staff members per cleft service ranged between 8.5 and 29.5, with a mean of 17.3. The total funded WTE members per service did not correlate with the service-level number of new cleft cases born during that year (**Figure 4**).

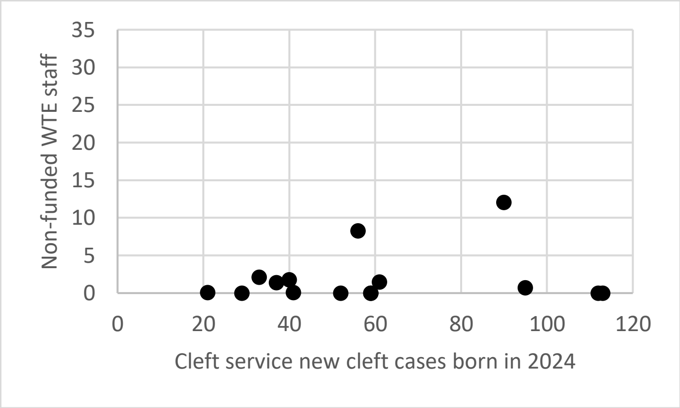
For example, a mid-size service (based on new cleft cases) reported the most funded members and one of the largest services reported under 20 WTE members. Overall, 23% of WTE funded roles were SLTs, 20% were Cleft Nurses, 14% were Surgeons and another 14% were Administrative or Secretarial roles. **Figure 5** illustrates the cleft service average WTE and range for each specialty **[Q11]**.

Figure 5. Funded staff members (WTE)



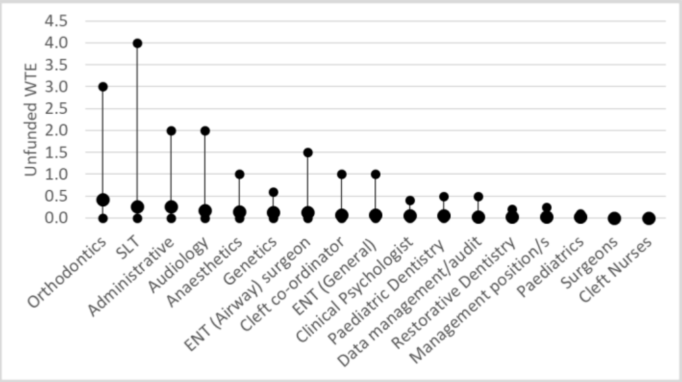
Non-funded staff members: Half of respondents reported having non-funded staff supporting their service. In total, 28 WTE non-funded staff members supported cleft services across the UK. Non-funded WTE members ranged between 0 and 12.1 between services, with a mean of 1.9 (**Figure 6**).

Figure 6. Service-level non-funded WTE staff according to new cleft cases born in 2024 (CRANE registrations). Each marker represents a responding cleft service



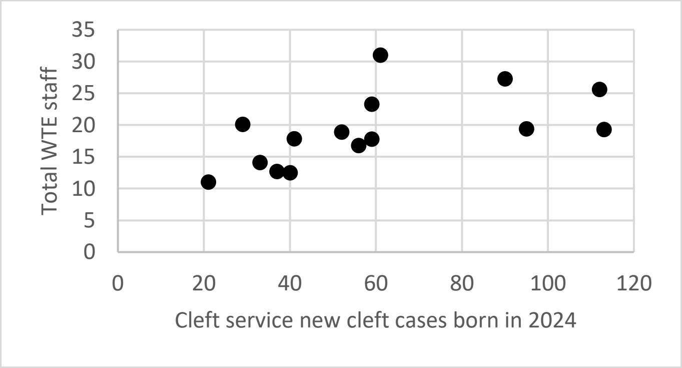
One service reported having four non-funded WTE SLTs and three non-funded WTE Orthodontists. This was unusual compared to other cleft services. **Figure 7** illustrates the average non-funded WTE and range for each specialty **[Q12]**.

Figure 7. Non-funded staff members (WTE)



Reported **total WTE staff members** (funded + non-funded) ranged from 12.5 to 31 between services, with a mean of 19.2. **Figure 8** illustrates inequity between services when plotting WTE staff against new cleft cases born in 2024.

Figure 8. Service-level total WTE staff according to new cleft cases born in 2024 (CRANE registrations). Each marker represents a responding cleft service



4.5. Recruitment challenges

Vacancies by staff group: In 2024, there was a reported total of 18 WTE vacancies across UK cleft services. Of these, six were for SLTs, three for Clinical Psychologists and three for Cleft Nurses. Other vacancies were reported for Surgeons, Paediatric dentists, Orthodontists, and data managers/audit clerks **[Q13]**.

Specialties/roles with recruitment challenges: 80% of services reported having at least one vacancy lasting greater than six months in 2024. One respondent reported having four different roles that were difficult to recruit to, and at least 20% stated they struggled to recruit Clinical Psychologists, Orthodontists and Paediatric Dentists.

4.6. Clinics

Core MDT clinics: Core MDT clinics were reported to occur weekly, and these typically included Surgeons, SLTs, Nurses, Psychologists and Orthodontists. For the majority of services (67%), these clinics also included Paediatric Dentists. **Figure 9** shows that for other specialties, the frequency of their attendance at MDT clinics varied.

Specialties involved in joint clinic working: Most services (87%) reported Joint clinic working, but the frequency varied according to cleft service and specialty (**Figure 10) [Q15]**.

4.7. Team meetings and site information

Frequency of MDT meetings outside of clinics (annual): These were held, on average, six times a year (cleft service range: 1-24) **[Q16]**.

Number of sites worked across: Funded services most worked across five sites (cleft service range: 2-15) **[Q17]**.

4.8. Service coverage

Non-cleft cases: Respondents reported that non-cleft cases accounted for an average of 21% (cleft service range: 1%-60%) of their caseload **[Q18]**.

Referred for suspected non-cleft Velopharyngeal Dysfunction (VPD): In 2024, over 500 patients were referred to cleft services across the UK for suspected non-cleft VPD, which included submucous cleft palate cases (cleft service range: 7-90). Most services reported that up to 50% of these cases go on to have surgery **[Q19]**.

Clefts covered: As well as covering oro-nasal clefting (cleft lip and palate), 60% of services also covered Tessier/facial clefts, while 27% covered either only the soft or soft and hard tissue of Tessier/facial clefts. 13% of respondents stated they covered different combinations**,** including ‘all clefts and non-cleft VPD as per our service spec, as well as Tessier clefts’ **[Q20]**.

Figure 9. Specialties involved in Core MDT clinics

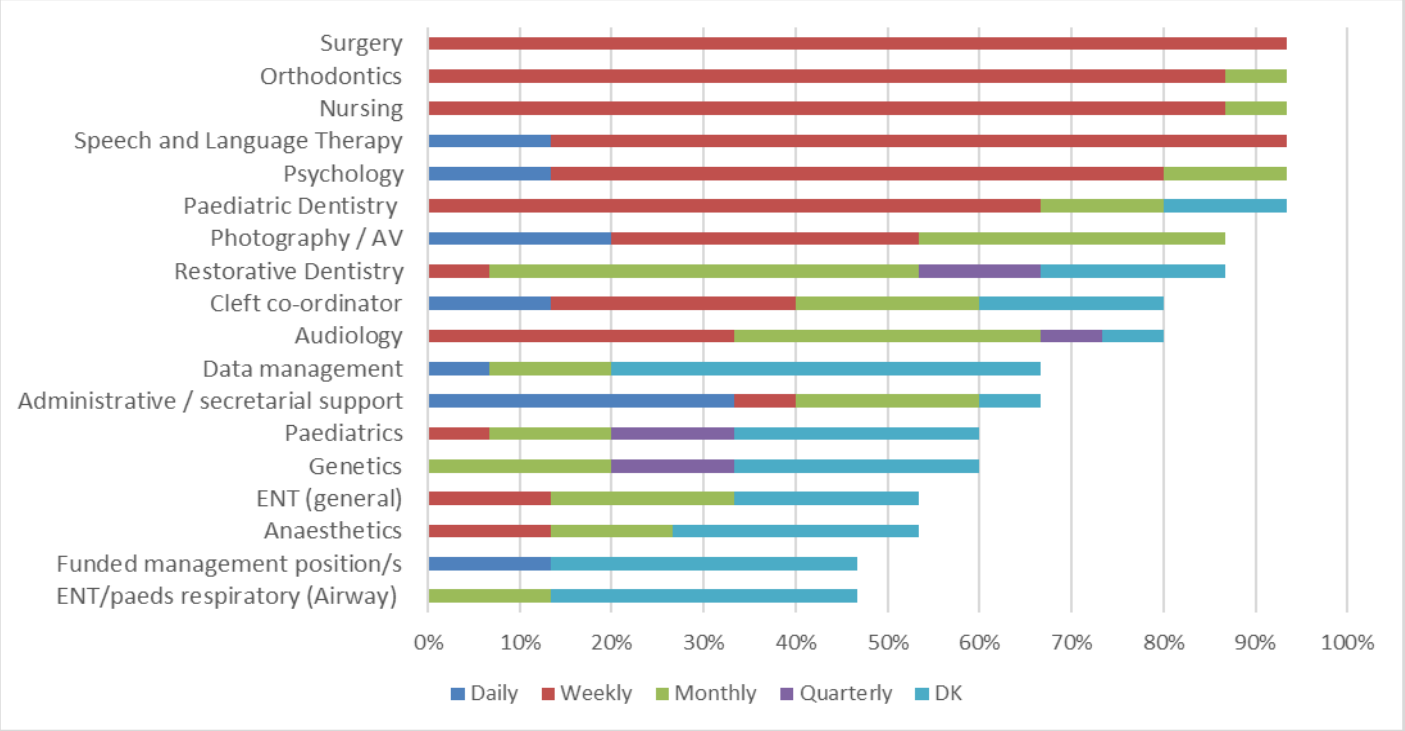


Figure 10. Specialties involved in joint clinic work

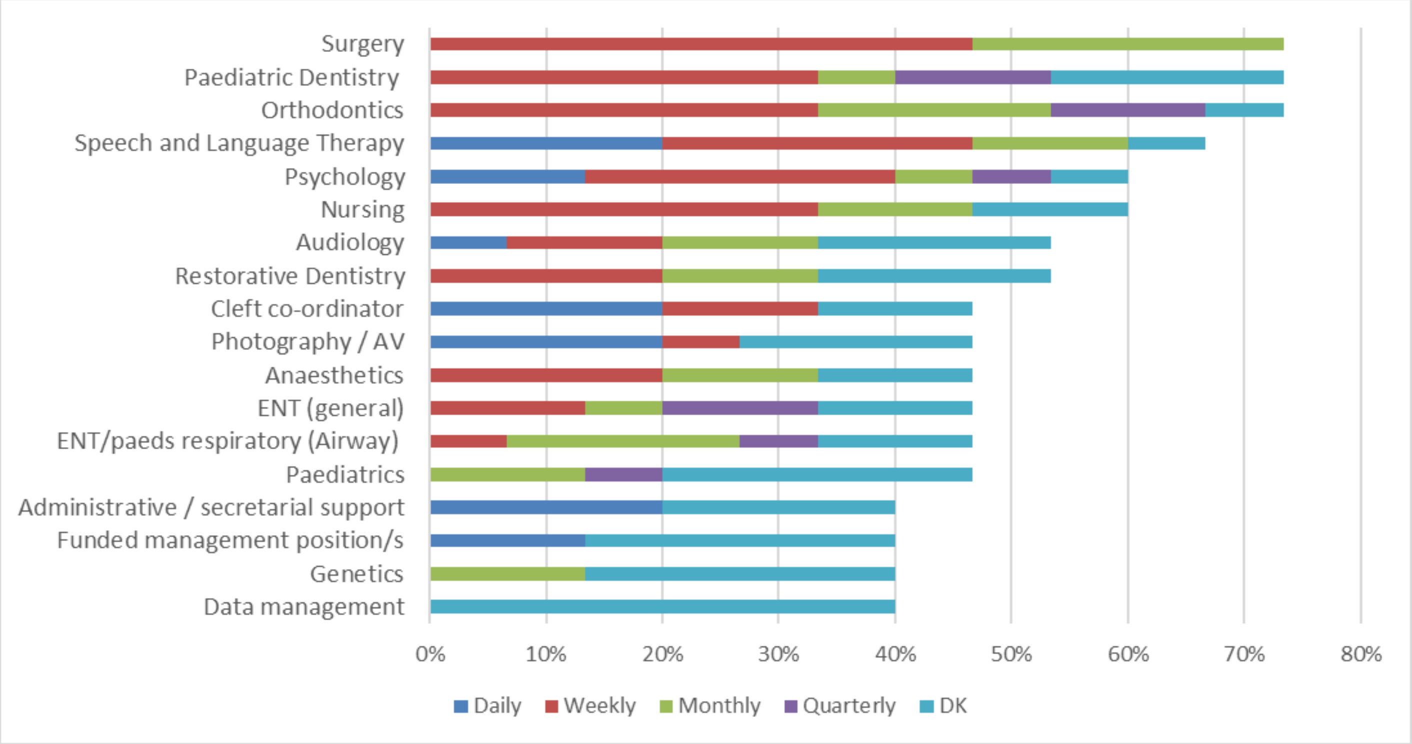
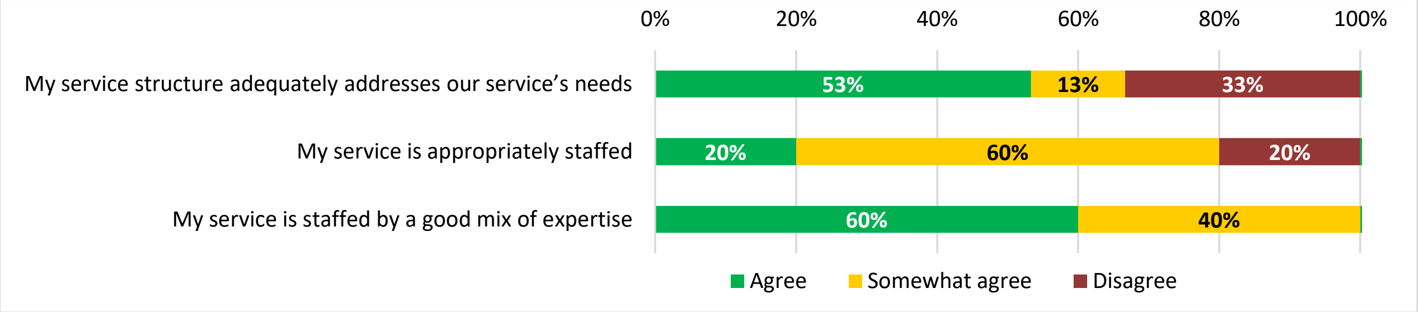


Figure 11. Service structure and staffing adequacy



4.9. On-call services

93% of services provide on-call service for Bank Holidays and weekends **[Q21]**. Where services did, 43% reported this included surgery and nursing, 36% stated this was nursing alone, while 14% stated surgery alone contributed. One service's 'other' arrangements involved the hospital on call team (incl. the plastic surgery team) providing this cover rather than the cleft service directly **[Q22]**.

4.10. Service structure and staffing adequacy

All services (100%) rated three statements on adequacy of service structure and staffing. As **Figure 11** shows, over half (53%) of services 'agreed' that their service structure adequately addresses their service's needs and is being staffed by a good mix of expertise (60%). Most respondents rated their services as 'somewhat' appropriately staffed (60%) **[Q23]**. Services were invited to share reflections that put the above in context. These are summarised below.

Specific service shortages:

- ❖ 'Lack of paediatric dentists and restorative dentistry.'
- ❖ 'Shortage of paediatric dentistry and secondary OMFS consultant surgeons in the service.'
- ❖ 'Insufficient sessions for paediatric dentistry and ENT.'
- ❖ 'Reliance on a single clinician for certain services, posing a risk.'
- ❖ 'Theatre capacity issues for orthognathic procedures.'
- ❖ 'Need for extra funding to build resilience in these areas.'

Geographical challenges:

- ❖ 'Challenges faced working across two countries and a wide geographical area, particularly in SLT, dentistry, and orthodontics.'

Primary care issues impacting service delivery:

- ❖ 'Long waits for community services like SLT, dentistry, audiology, and orthodontics.'

5. Public and Patient Involvement (PPI)

5.1. PPI undertaken by service

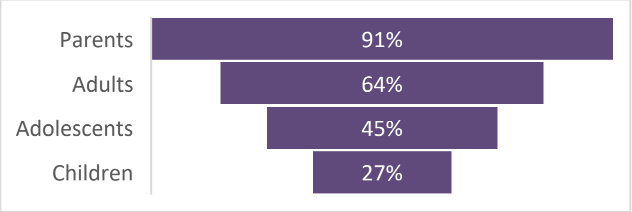
74% of services stated they had undertaken PPI, 20% had not, and 7% reported this as 'unknown' **[Q24]**.

Where services had undertaken PPI, 46% had done so sporadically, 18% had done so twice a year and 9% annually **[Q25]**. 27% described alternative approaches including:

- More frequent PPI i.e. Monthly PPI undertaken.
- PREM (Patient Reported Experience Measures) provided weekly at MDT meetings.
- Efforts underway to establish a PPI Forum.

Figure 12 shows the percentage of respondents indicating who was included in their PPI membership /forum **[Q26]**. Parents were most likely to be members and children least likely. 27% of services included only parents, and 9% only adults. The remaining services included a combination.

Figure 12. PPI Forum/Group membership



PPI engagement was managed by a combination of various specialties for 55% of respondents. Including surgeons, cleft nurses, SLTs, psychologists, management, cleft coordinators, and administrative/secretarial support **[Q27]**.

For the remaining 45% of respondents, PPI engagement was managed solely by the following specialties:

- Clinical psychologist.
- Management positions.
- Cleft coordinator.
- Administrative / secretarial support.
- Other, specified as ‘ad hoc’.

5.2. Changes made as a result of PPI consultation

Services described changes implemented because of PPI consultation, as summarised below **[Q28]**.

Changes to clinics:

- Clinic streamlining: ‘Reduction in number of MDT clinicians in clinics and streamlining clinics to reduce required attendances.’
- Clinical pathways: ‘Some changes made based on PPI consultation.’
- Day case admissions: ‘Switched to day case admissions.’
- Audiology checks: ‘Requirement for audiology checked prior to clinic to avoid unnecessary repeat testing.’
- Visual timetable: ‘Implementation of visual timetables for all 5-year clinics and children with additional needs.’

Changes to resources and approach:

- Leaflet development: ‘Redesign of patient leaflets based on feedback.’
- Adult self-referral: ‘Development of an adult self-referral form in collaboration with Patient Engagement Group.’
- Young persons information: ‘Development of additional young person-directed patient information and transition pathways.’
- Emotional support:' ‘Identification and support of children's emotional development around cleft.’

6. Cleft detection

6.1. Referral information

Requesting information on how the cleft was detected: 80% of services reported always requesting information on how the cleft was detected when accepting a referral, 13% did so sometimes, and 7% reported they never requested this information **[Q29]**.

Delayed detection and/or delayed referral of clefts: 80% of cleft services had concerns in 2024 about the delayed detection and/or delayed referral of clefts in their referring maternity services **[Q30]**.

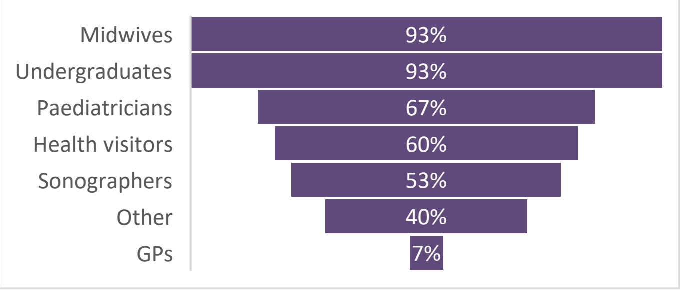
Referring maternity services’ cleft detection training: 93% of cleft services had liaised with referring maternity services to ensure their cleft detection training was up-to-date **[Q31]**.

6.2. Training of services’ clinical professionals

Only 40% of respondents felt their service was adequately funded to engage in training of clinical professionals outside the cleft service **[Q32]**.

Despite this, most services did engage in training. **Figure 13** shows the percentage of respondents reporting training given to each professional group **[Q33]**.

Figure 13. Training of clinical professionals

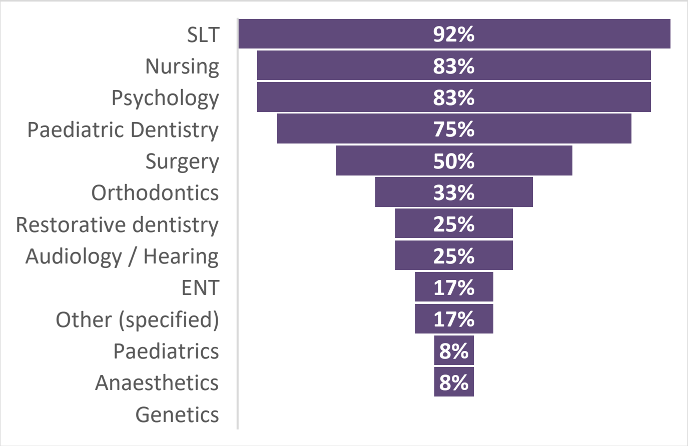


7. Review clinics and preventative care

Most services (87%) reported that they provided review / preventative care clinics **[Q34]**. Among services reporting these clinics:

- Both face-to-face and virtual clinics were offered by the majority of services (58%), and solely face-to-face clinics offered by 42% **[Q40]**.
- 100% reported this happening in a coordinated way, on the same day for all specialties **[Q36]**.
- 75% felt this equitable across the geography their service was responsible for **[Q39]**. Of those who felt it was not equitable, they reported
  - ‘Different health boards have different input’.
  - ‘Differing community access to SLT and dental care’.
  - ‘Clinics vary in composition and frequency’.
- SLTs, Nurses, Psychologists, and Paediatric Dentists were most likely to attend clinics. **Figure 14** shows the percentage of services reporting the contribution of each specialty **[Q35]**.

Figure 14. Specialties contributing to review / preventative care clinics



Other arrangements by services (17%) included:

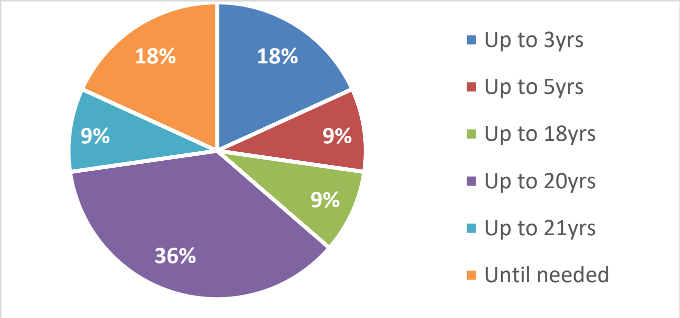
- All specialties offering **review clinics** to review patient progress.
- Only certain clinics providing specific **preventative** advice. E.g. 18-month paediatric Dental Clinics focus on preventing future dental issues in children.

Frequency of review clinics: This varied considerably **[Q37]**. Arrangements for review clinics included:

- **Active treatment reviews**: ‘Frequency dictated by ongoing treatment (Orthodontics, SLT, Surgical) and age-related reviews.’
- **Regular cleft care pathway reviews:** ‘Occurring at specific intervals within the pathway, e.g. national service specification ages (2.5y, 5y, 7.5y, 10y, 12.5y, 15y and adult.’
- **As-needed reviews**: ‘Held until no longer needed, always after surgery or if there are concerns.’
- **Special clinics**: ‘Including SLT "babble group" and "SNAP" (speech, nurse, and psychology).’

Duration of review clinics: The reported duration of review/preventative care clinic provision varied considerably between the 11 services reporting this information **[Q38, Figure 15]**. The majority (73%) provided these until at least 18 years, but three services (36%) reported a relatively short duration of 3 or 5 years.

Figure 15. Duration of review/preventative care clinic provision



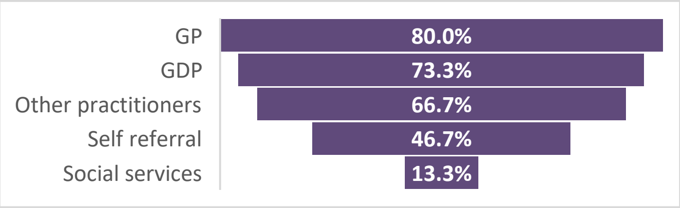
Care in adulthood [Q101]:

- 93% of services provided lifespan services
- 40% provided separate paediatric and adult services, requiring transition.
- 47% provided mixed age clinics (paediatric and adult), depending on geography.

Patients transitioned to adult services between the ages of 15 and 20 years. The most common age for transition was 16 years **[Q102]**.

Adult referrals: Referrals were accepted from multiple sources by most services **(Figure 16)**. These typically included General Practitioners (GP) and General Dental Practitioners (GDP). Three services (20%) accepted only self-referrals, and two services only accepted self-referrals for ex patients of their service **[Q42]**.

Figure 16. Accepted source of adult referrals

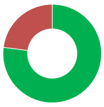


8. Specialties and outcomes

8.1. Surgery

8.1.1. Equitability of surgical services

Two thirds (67%) of respondents felt the service that surgery provided was equitable across the geography of the area their service was responsible for **[Q43]**.

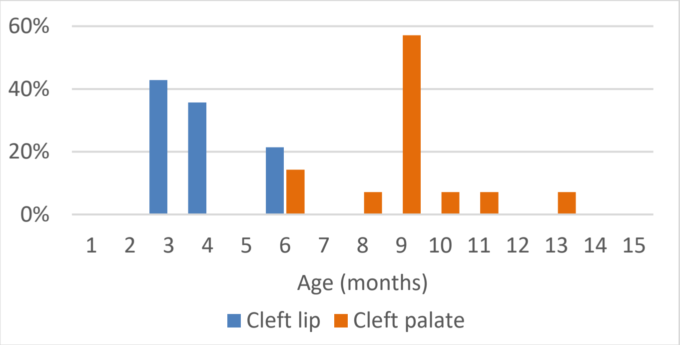


8.1.2. Surgical care provision

Age of primary repair: 93% of services reported ages (in months) by which they typically aim to repair the cleft **[Q44, see Figure 17]**:

- Cleft lip: An average of four months (cleft service range: 3-6 months) was reported.
- Cleft palate: An average of nine months (cleft service range: 6-13 months) was reported.

Figure 17. Timing of primary repair



Surgical timing challenges: One third (33%) of services reported experiencing challenges with achieving desirable timing of repair during 2024 **[Q45]**. For these services, the following delays were reported **[Q46]**:

- Cleft lip: 1-3 months, resulting in some cleft lip repairs taking place at seven months.
- Cleft palate: 1-4 months, resulting in some cleft palate repairs taking place at 13 months.

Challenges cited include:

- ‘No surgeon in post’.
- ‘On the day cancellation rate of 25%’.
- ‘Delays for clinic reasoning’.

Day-case cleft repairs: 80% of services reported offering cleft lip repairs as day-case admissions **[Q47]**. On average, 22% of lip repairs were offered as day-case surgeries (cleft service range: 2%-99%).

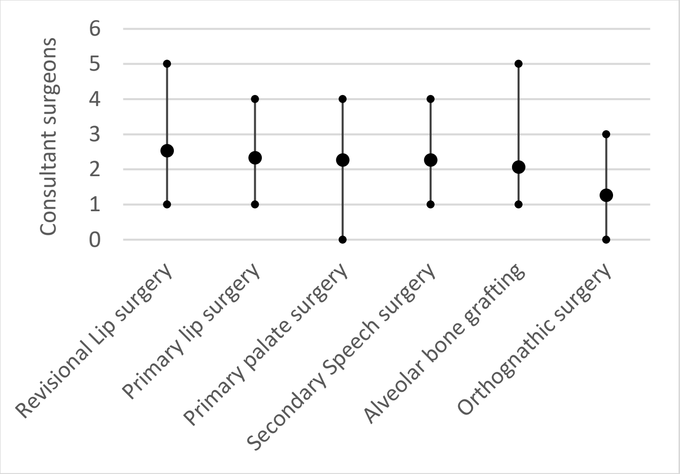
Only one service (7%) reported offering cleft palate repairs as day case admissions, and this was done for 5% of their palate repairs.

8.1.3. Number of consultant surgeons and theatre sessions

Figure 18 shows the mean (and min and max) reported number of **Consultant Surgeons** operating on children in each service, according to type of procedure. The highest average was for revisional lip surgery (2.5 Consultant Surgeons, cleft service range: 1-5), and the lowest was for Orthognathic surgery (1.3, cleft service range: 1-3) **[Q49]**.

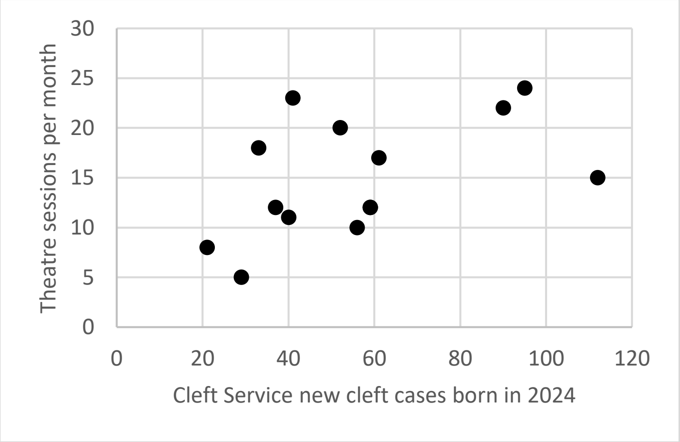
Services reported a total of 35 consultant surgeons who performed primary repairs. Approximately 850 children were born with a cleft in 2024. Based on numbers of new (service-level) cleft cases, each individual surgeon treated an average of 27 new cases in 2024 (range: 14-45). This is less than the number recommended in the original CSAG report (40-50 per surgeon). Furthermore, only five of the 15 reporting services treated enough new babies to ensure that their surgeons operated on the minimum number of 30 new babies with cleft, as set out in the previous 2013 service specification (D07/S/a).

Figure 18. Number of Consultant Surgeons operating on children at service (minimum/average/maximum)



Theatre sessions per month averaged 14.3 (cleft service range: 5-24) **[Q50]**. **Figure 19** shows Theatre sessions and size of service, according to number of new cleft cases born in 2024.

Figure 19. Service-level theatre sessions per month plotted against new cleft cases born in 2024 (CRANE registrations). Each marker represents a cleft service



8.1.4. Junior medical support and their involvement

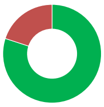
All services reported having registrars, as **junior medical support**. At any one time, 53% had Core Trainees, 40% had Foundation Doctors, 27% had TIG Fellows, and 13% reported 'Other', which included Dental trainees and Junior Cleft Fellows **[Q51]**.

Junior medical support care was present in clinic, wards and theatre in 47% of services, in theatre alone in 27%, in ward and theatre in 20%, and clinic alone in 7% of services **[Q52]**.

8.2. Nursing

8.2.1. Equitability of nursing services

80% of respondents felt the service that nursing provided was equitable across the geography of the area their service was responsible for **[Q53]**.



8.2.2. CNS care provision

On-call care: 57% of Clinical Nurse Specialists (CNS) provided on-call care for new diagnoses, airway problems, and feeding problems. 36% did solely for new diagnoses and 7% solely for feeding problems **[Q54]**.

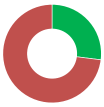
Delivery of care: 80% of services delivered CNS care during home visits, hospital outpatients, and virtual appointments (telephone/video). 13% provided care solely by virtual appointments (telephone/video) and 7% provided both home visits and virtual appointments, but not in outpatients. **[Q55]**.

Training/support provision relating to nasopharyngeal airway: 73% of services' CNS teams reported providing this. Other services stated this was provided by the respiratory team or ENT **[Q56]**.

8.3. Paediatric dentistry

8.3.1. Equitability of paediatric dentistry services

Almost three quarters (73%) of respondents felt the service that paediatric dentistry provided was <u>**not**</u> equitable across the geography of the area their service was responsible for **[Q57]**. Services reported various reasons for this, including:



- 'Paediatric dentistry is not available across all sites.'
- 'Lack of paediatric dentistry appointments.'
- 'Access available but must travel to central hub for consultant care.'
- 'Not currently recruited in our service.'

- ‘Limited access to specialists in some areas, access to NHS dental care especially limited in some areas.’
- ‘Community access is variable.‘

8.3.2. Dental care provision

Calibrated dentists: 100% of services stated they had a calibrated dentist as part of their MDT **[Q58]**. 73% of services reported having consultant paediatric dentists as calibrated dentists / part of their MDT. Two services (13%) without a consultant paediatric dentist reported having a calibrated orthodontist **[Q59]**.

Access to dental care under general anaesthesia: This was accessible to 80% of cleft services **[Q60]**. Of these, one service had access to extractions only and all others had access to comprehensive dental care. However, it should be noted that one service with access to care reported a two-year wait list **[Q61]**.

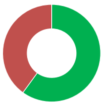
Theatre sessions per month: Services reported an average of 4.8 sessions per month (cleft service range: 0-28) **[Q62]**. Some reported this was only arranged on an ad hoc basis.

Referring to other paediatric dentist specialists in the region: 87% of services had the ability to do this **[Q63]**.

8.4. Orthodontics

8.4.1. Equitability of orthodontic services

60% of respondents felt the service that orthodontics provided was equitable across the geography of the area their service was responsible for **[Q64]**.
Among those that felt it was not equitable, reasons for this included:



- ‘Provision across spoke sites has dramatically reduced over 5-10 years due to Units closing, unfilled posts and loss of expertise.’
- ‘Significantly reduced availability outside of metropolitan areas.’
- ‘Access to consultant orthodontics in some areas is problematic.’
- ‘Some district generals have suspended services.’

8.4.2. Orthodontic care provision

Care: 60% of services manage all orthodontic care, while 13% have a shared-care model, and a further 13% manage only patients with clefts with alveolus involvement **[Q65]**.

Dental models: To plan orthodontic treatment, 53% of services used models made from impressions only, 33% used both impressions and modern digital scanning techniques, and 13% used digital scanning techniques only **[Q66]**.

Adequate storage for dental models: 87% of services reported having adequate physical storage and 47% reported adequate digital storage. All services reported having either adequate physical or digital storage **[Q67]**.

Orthodontic planning: 47% of services reported undertaking two-dimensional (2D) treatment planning, 33% use both 2D and three-dimensional (3D) planning, while 20% use only 3D planning **[Q68]**.

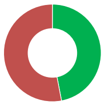
Adequate technician support: 80% of services reported having this **[Q69]**.

Delays: 27% of services reported having a delay for definitive orthodontic management **[Q70]**, while 47% reported delays for orthognathic treatment **[Q71]**.

8.5. Speech and Language Therapy (SLT)

8.5.1. Equitability of SLT services

53% of respondents felt the service that Speech and Language Therapy (SLT) provided was <u>**not**</u> equitable across the geography of the area their service was responsible for **[Q72]**. services reported various reasons for this, including:



- ‘All children under the cleft service have equal access to our specialist SLT team at the main hospital site, but local [community] SLT provision is much more patchy.’
- ‘[One of our sites] can offer more therapy sessions than the other as more WTE per case.’
- ‘Community SLT is not equitable across the region.’
- ‘Therapy is provided by primary care within different ICBs’

- ‘Challenges due to funding arrangements.’

8.5.2. SLT care provision

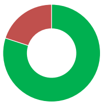
Care: The majority of services (87%) reported that funded specialist cleft SLT posts were embedded with the central service. One service (7%) reported these were mixed between central service and community, and another service (7%) reported “funded separately by each health board”. **[Q73]**.

Non-service funded link SLT posts: 73% of services reported that their region benefited from these posts **[Q74]**.

8.6. Audiology/Ear Nose and Throat (ENT)

8.6.1. Equitability of audiology/ENT services

80% of respondents felt the service that audiology/ENT provided was equitable across the geography of the area their service was responsible for **[Q75]**.



8.6.2. Audiology/ENT care provision

Audiological surveillance in keeping with national protocol: 93% of respondents reported that their service offered this **[Q76]**. Out of six services stating who led this, one reported it varied across the region and all others said it was led by audiology.

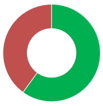
Otitis media with effusion and conductive hearing loss (CHL) [Q77]: The majority (87%) of services reported that treatment for these cases was provided by the local ENT service, either alone (47%) or in combination with the centralised cleft-funded ENT service (20%), the centralised non-cleft funded ENT service (7%), local audiology (7%), or as a combination (7%). 13% of respondents stated that the Centralised non-cleft funded ENT service alone would provide treatment.

Additional audiological or ENT surveillance: 87% of services did **not** seek to deliver these appointments outside of national protocol **[Q78]**. One service could offer appointments, depending on clinical need.

8.7. Psychology

8.7.1. Equitability of psychology services

60% of respondents felt the service that psychology provided was equitable across the geography of the area their service was responsible for **[Q79]**. Among those that felt it was not equitable, reasons for this included:



- ‘Only provided at the central site.’
- ‘Some inequitable access to follow up care in spoke settings due to room constraints.’
- ‘CAHMS support and access is variable.’

8.7.2. Psychology care provision

93% of services reported their cleft psychologist posts were funded to provide postnatal support for parents, support for children with cleft, and support in relation to future surgery or treatment decisions **[Q80]**. 87% reported they were funded to provide antenatal support for expectant mothers, support to young people and/or parents re the psychological impact of having a cleft, and support for adult returners.

Furthermore, at 100% of services psychology provided the following by phone or face-to-face:

- One-off discussions with families/children/young people/adult returners,
- individual/family psychology appointments, and
- signposting to other services.

60% of services reported provided themed ‘groups’ to talk about common issues **[Q81]**.

9. Resilience and recovery

9.1. Primary surgery

Services reflected on whether they were adequately resourced to meet UK guidance on timings of primary surgery **[Q82]**:

- 80% felt they were with respect to lip and palate surgeries.
- 60% felt so with respect to alveolar bone grafting.

Where services did **not** feel they were adequately resourced to meet UK guidance on timings of primary surgery, average age for repairs were at the upper limit of guidance and further interruption or difficulty in accessing theatre would result in breaching national guidance **[Q83]**.

9.2. Secondary interventions

60% of services stated that they were able to meet treatment time guidance on secondary interventions (e.g. Lip revision and secondary speech surgery) **[Q84].**

Where services did **not** feel they were able to meet treatment time guidance on secondary interventions, average age for repairs were as follows **[Q85]**:

- 25 months with respect to lip revision surgery (range 8-68).
- 19 months with respect to secondary speech surgery (range 8-36).
- 13 months with respect to alveolar bone grafting (range 7-24).

9.3. Paediatric surgery resources

Services averaged 3.6 paediatric theatre sessions per week (cleft service range: 2-7) **[Q86]**.

Figure 20. Challenges to paediatric surgery taking place

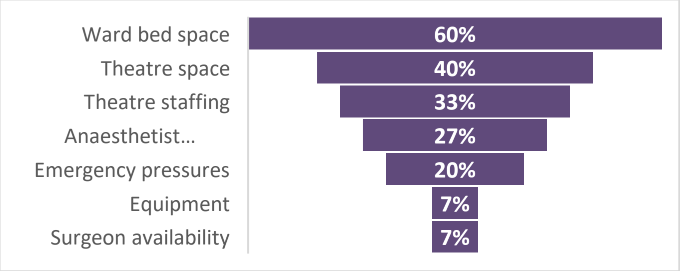


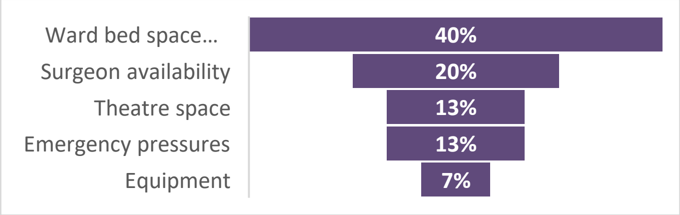
Figure 20 shows the key reported challenges to paediatric surgery taking place **[Q87]**. Ward bed space shortages were the biggest challenge, cited by 60% of services.

9.4. Adult surgery resources

Services averaged one adult theatre session per week (cleft service range: 0-2) **[Q88]**.

Figure 21 shows the key reported challenges to adult surgery taking place **[Q89]**. Ward bed space shortages were the biggest challenge – for 40% of services.

Figure 21. Challenges to adult surgery taking place



Services reflected on whether they were adequately resourced to deliver adult surgery within treatment time guidance **[Q90]**:

- 60% felt so with respect to speech surgery and lip surgery.
- 53% felt so with respect to orthognathic surgery and nasal surgery.

Reflections included services stating that there is a significant backlog for adult surgery, with the waiting list extending over more than one year.

Where services did **not** feel they were adequately resourced to deliver adult surgery within treatment time guidance, average wait times were **[Q91]**:

- 19 months with respect to orthognathic surgery (range 12-24).
- 20 months with respect to speech surgery (range 12-24).
- 20 months with respect to lip surgery and nasal surgery (range 12-36).

9.5. Mutual aid agreements

20% of services stated that they had **local mutual aid agreements** in place **[Q92].**

27% stated that they would **work in association with neighbouring providers and have a shared waiting list [Q93]**. Further to this, 40% of services reflected on caveats and considerations in advance of working in association with neighbouring providers and sharing a waiting list, including:

- ‘A need for clarity as to who would be responsible’
- ‘A need to ensure safety and harmonisation’
- ‘Surgeons need to meet patients before operating on those listed by another surgeon’.

In terms of facilitating work in association with neighbouring providers, 67% of services were able to securely share files between providers **[Q95]**. Secure emails, the Picture Archiving and Communication System (PACS), and the Epic healthcare software system were quoted as facilitators.

9.6. Workforce challenges

93% of services anticipate workforce challenges in the next five years **[Q94]**. These included staffing challenges such as:

- Recruitment – recruitment to funded posts / Struggles with completing business cases / recruitment freezes.
- Workforce shortages – persistent shortages despite potential funding. Cleft Orthodontists, Paediatric Dentists and Psychologists were specifically mentioned by several services.
- Retention – staff moving to independent practice / retiring.
- Need for succession planning.

10. Audit and engagement with CRANE

10.1. CRANE consent and data collection

Effective systems: The average rating by services of how effective their system is for identifying children who should be followed up for CRANE consent was 89%, on a scale of 0 ‘not at all’ to 100% ‘very’. Ratings ranged from 59-100% **[Q103]**.

Obtaining consent: All services (100%) reported seeking CRANE consent either postnatally or between birth and first surgery. Some services (13%) reported using multiple opportunities up to the five-year audit clinic **[Q104]**.

60% of services reported that nurses took sole responsibility for obtaining consent for CRANE data collection **[Q105]**. For the remaining 40% of services, the following arrangements were in place:

- **Primarily managed by the Clinical Nurse Specialist (CNS) team:** With multidisciplinary team (MDT) support as needed, to maximize consent, especially to support retrospective data completion.
- **A combination of CNS and data management / audit coordinator**: Central roles in managing data and coordinating audit activities.
- **A combination of various specialties**: Involving nursing, paediatric dentistry, speech and language therapy (SLT), and research. Administrative staff alert clinicians if consent is outstanding.

93% of cleft service used **data collection in clinics** to record data required for CRANE **[Q106]**.

10.2. Identifying eligible cases for audit

The average rating by services of how effective their system is for identifying children eligible **for the 5-year audit** was 93% on a scale of 0 ‘not at all’ to 100% ‘very’. Ratings ranged from 50-100% **[Q96]**.

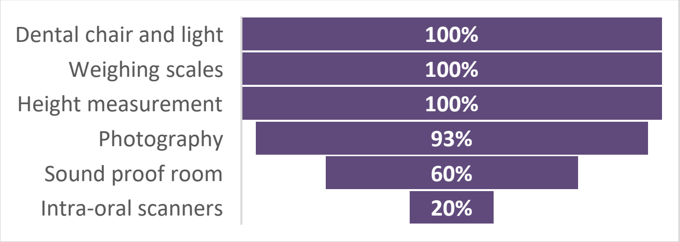
10.3. Audit clinics

If children did not attend their 5-year-old audit appointment(s), 100% of services typically invited families to attend again before the child turned six **[Q97]**.

Just over half of services (53%) reported running clinics beyond the age of five **[Q98]**. All of these offered 10-year audit clinics, and half extended their audit clinics to 15 and 20 years **[Q99]**.

Figure 22 shows the percentage of services with access to equipment for 5-year clinics **[Q100]**. Dental chair and light, weighing scales, and height measurement were available for 100% of services.

Figure 22. Equipment access for 5-year clinics

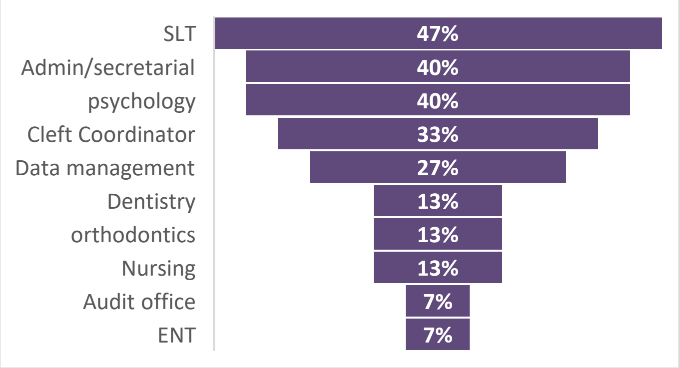


10.4. CRANE data entry and outputs

73% of cleft services used the **CRANE data collection forms** to record data required **[Q107]**.

80% of services reported having a dedicated single/ lead person responsible for CRANE data entry in 2024 **[Q110]**. Despite this, 66% reported multiple team members (cleft service range: 1-6) who enter data onto CRANE **[Q108]**. **Figure 23** shows the percentage of services reporting each specialty involved in submitting CRANE data **[109]**.

Figure 23. Specialties involved in CRANE data entry



CRANE products/outputs: 87% of services discussed the CRANE Annual Report results, as well as the CRANE Preliminary reports (produced up to and including 2024). 'Live tables' behind the CRANE Database log-in were only discussed by 47% of services **[Q111]**.

Discussion of CRANE results took place mainly at services' MDTs and at meetings held for that specific purpose (across 73% of services, for both) **[Q112]**. 40% of services said CRANE results were also discussed at local Morbidity and Mortality (M&M) meetings, and 27% reported discussions at various meetings, including:

- 4-weekly Leads' Meetings
- Performance Review Meetings (PRM)
- Directorate meetings
- Meetings with the Trust executives
- Whole / local service meetings
- Clinical Operations Group (COG) meetings

10.5. CRANE workshops and outputs

CRANE workshops were attended by an average of 13% of members per team (cleft service range: 5-50%) **[Q113]**.

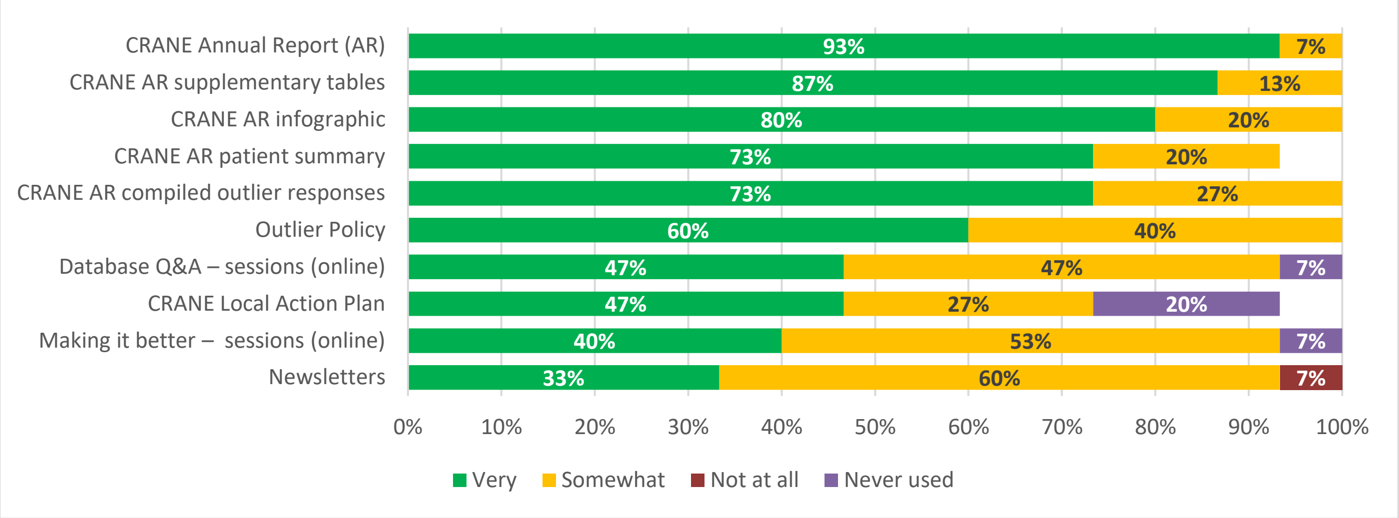
Figure 24 shows that most services (93%) found the CRANE Annual Report (AR) document 'very' useful in 2024. Outputs also found 'very' useful by at least 80% of services were the AR supplementary tables (87%) and AR infographic (80%) **[Q114]**

10.6. Introduction of the Outlier policy

All services (100%) rated statements on the **introduction of the CRANE Outlier Policy [Q115]**.

- **Provides valuable monitoring**: Most services (87%) rated this as 'highly' valuable. The remaining 13% found it 'somewhat' valuable.
- **It is a supportive process:** 47% of services rated the process as 'highly' supportive, while 40% found it 'somewhat' supportive. 13% of services rated it as a 'poorly' supported process.

Figure 24. CRANE outputs found helpful by services in 2024



services shared reflections to put the above in context.

Monitoring:

- ‘This aspect of the CRANE Database is particularly valuable, and CRANE is highly effective in identifying outliers, but its policy requires support from the CDG and commissioners.’
- ‘This is the most valuable part of CRANE.’

Support:

- ‘Funding and Collaboration: CRANE requires adequate funding from NHS England (NHSE) and better coordination between CRANE, NHSE, and host organizations.’
- ‘Challenges with Outliers: Being identified as an outlier can be daunting, especially since some factors, like SLT provision in the community, are beyond the service’s control.’

11. Closing comments from respondents

Services/respondents were invited to share any additional notes or comments to consider in the context of this OA **[Q116]**. These are summarised below.

Completion challenges, arising due to lack of resource to pilot the OA:

- **Restrictions in data entry**: Some questions did not allow multiple choices. Some fields did not allow decimal points, words, or symbols, leading to inaccuracies. Free text boxes were restrictive.
- **System issues**: Glitches in the system prevented accurate responses, affecting the reliability of the data.

Reflections on participation burden:

- **Completion time**: The OA took a long time to complete due to restrictive boxes and unclear questions. Mainly arising from lack of resource to pilot.
- **Requirement to source information beyond that to-hand**: Some respondents had trouble in answering questions / providing accurate answers due to unknown information. Particularly workforce requirements and service commissioning details.

Nevertheless:

- **Participation in this OA was valued**: Despite challenges, respondents felt the OA was useful for comparing how units manage waiting lists and various aspects of cleft care.
- **Respondents expressed support for CRANE**: CRANE was described as “highly valued” and considered “one of the best audit registries in the UK”. Cleft services reported appreciating the role CRANE plays and finding the team responsive.

12. Summary and conclusion

12.1. Summary

This is the first Organisational Audit (OA) of Cleft services across the UK since the centralisation of cleft care following the CSAG report in 1998[2].

All cleft services responded. The findings highlight considerable variation in commissioned services, staffing levels, and access to diagnostic and operative facilities. Resourcing is not equitable across the UK. This was evident in the reported variation in funded and non-cleft funded whole time equivalent staff members and number of theatre sessions assessed against patient population size.

The majority of services aimed to repair the lip by three or four months and the palate by nine months. However, surgical delays in 2024 were reported by one third of services, and these pushed the average time of repair towards the upper limit of national guidance.

Other areas of inequality were identified in review and preventative care clinics, with some services offering these for a relatively short duration (three years), while other services provided these well into adulthood.

The majority of respondents felt that some specialties were not equitable across the geography of their region. Paediatric dentistry and speech and language therapy were considered most problematic, with limited access for users in some areas, particularly in the community.

With the varying geography of the UK, some small differences in service structure and resource should be expected. However, patients, carers, commissioners, government and taxpayers should all expect less inequality than is demonstrated by this audit.

The data contained within this OA and the recent CRANE Annual Reports (2020-2024) suggests that significant inequity in UK cleft care delivery and outcomes exists. More work is required to determine if variation in service structure / staffing and funding directly relate to the variations observed in clinical outcomes.

The delivery of unfunded elements of care raises concerns about sustainability, and this report should provide stimulus for more formal investigation into the inequalities that are present in both service-funded and non-cleft service-funded care delivery. It is clear from this audit that significant within service and between service inequalities exist.

12.2. Strengths and limitations

The 100% response rate from cleft services highlights the dedication that service providers have to cleft care. Multiple stakeholders contributed to the survey's development, ensuring key questions relevant to each specialty or organisation were included.

This OA was constrained by limited resources, specifically in terms of time, staffing, and funding. This impacted its development and implementation. The absence of a piloting phase, and the inability to refine question structure, wording, and response options, contributed to challenges for some respondents.

The results described in this report reflect reported service provision in 2024 and do not necessarily reflect past or current service provision. This limits the ability to explore service provision in relation to clinical outcomes.

12.3. Conclusion

This unique resource, combined with the CRANE Annual Reports from recent years, highlights ongoing significant variation in cleft care delivery and outcomes in the UK. The substantial change in service delivery following the

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[2] Clinical Standards Advisory Group. Clinical Standards Advisory Group: Report of a CSAG Committee on Cleft lip and/or palate. London: The Stationery Office; 1998

CSAG report of the late 1990s led to improvements in national clinical outcomes. However, the early improvements in mean outcomes after the regionalisation of care have since plateaued and have remained relatively static for the past 10-15 years. The magnitude of current variations in outcome suggests that UK cleft care has not yet reached its potential, and much more can be achieved.

The review of the service specification that this report was commissioned to inform, along with the upcoming publication of risk adjusted cleft-related outcomes for the UK, presents an opportunity for the Cleft Community (patients, advocates, clinicians, commissioners and political leaders) to re-examine how services are delivered. The community should draw insights from those achieving the best outcomes and work together to reduce the existing inequalities in care delivery and outcomes of care, ensuring that every child born with a cleft has the opportunity to reach their full potential.

Glossary and abbreviations

Alveolus / alveolar	The part of the jaw (gum) that supports the teeth and contains the tooth sockets.
AR	[CRANE] Annual Report
CEN	Clinical Excellence Network – previously referred to as Special Interest Group (SIG)
CL	Cleft lip only
Cleft	A failure of tissues to join during development.
CDG	Cleft Development Group: NHS national group representing all stakeholders in cleft care that is responsible for the CRANE Database as well as oversight and guidance on all aspects of the delivery of reorganised cleft care.
CFSGBI	Craniofacial Society of Great Britain and Ireland: An inter-specialty group set up to study cleft lip and palate and other craniofacial anomalies. https://craniofacialsociety.co.uk/
Cleft services / regions	These terms are used interchangeably throughout this report and refer to the hospital / multidisciplinary group that provides cleft surgery and care for children with a cleft; as well as submits data to the CRANE Database, sometimes as part of a wider cleft centre or network.
Cleft surgeon	A surgeon undertaking cleft repair surgery in a region / cleft service.
CNS	Clinical Nurse Specialist
CP	Cleft palate only
CRANE	Cleft Registry and Audit NEtwork
Craniofacial anomalies	A diverse group of deformities in the growth of the head and/or face.
CSAG	Clinical Standards Advisory Group
ENT	Ear, nose and throat
GDP	General Dental Practitioner
GP	General Practition(er)
MCN	Managed Clinical Network
MDT	Multi-disciplinary team
NHSE	National Health Service (NHS) England
OA	Organisational Audit
PPI	Public and patient involvement
SLT	Speech and language therapy
SMCP	Submucous cleft palate: The term submucous refers to the fact that the cleft is covered over by the lining (mucous membrane) of the roof of the mouth. This covering of mucosa makes the cleft difficult to see when looking in the mouth.
VPD	Velopharyngeal Dysfunction
WTE	Whole Time Equivalent (Staffing)