

Facilitators and barriers to delivering an optimal specialist service in the United Kingdom: An example from cleft lip and palate care

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Abstract

Aim: Despite published standards of care, inequities and variations in specialist care delivery in the United Kingdom have been identified. Using cleft lip and palate (CL/P) care as an example, this study aimed to identify common barriers to delivering an optimal specialist service, as well as potential facilitators.

Methods: Individual interviews were conducted with 50 specialist CL/P practitioners, representing all sixteen UK centres.

Results: Thematic analysis identified a range of barriers, including working within a restrictive medical model, declining resources, and an insufficient evidence base. To facilitate optimal care delivery, participants described a need to share best practice, partnering with academics to demonstrate service effectiveness, the utilisation of technology in clinic, and the authentic integration of patient-centred care.

Conclusions: Specialist teams need to work more closely with commissioners to ensure allocation of resources based on need and the optimisation of service delivery and patient outcomes.

Key words: Specialisation; Commissioning, Optimisation; Multidisciplinary; Patient-Centred Care

Key points:

- 1.** Variations and inequities in specialist healthcare in the United Kingdom have been identified. To understand why, this article explores key barriers and facilitators to providing an optimal specialist service from the perspective of (non-surgical) specialist health professionals, using cleft lip and palate care as an example.
- 2.** Barriers identified included working within a restrictive medical model, declining resources, and an insufficient evidence base.
- 3.** Specialist clinicians are encouraged to partner with academics, share best practice with non-specialists, and work more closely with commissioners to ensure fair allocation of resources and to optimise outcomes for patients and families.

Introduction

A cleft in the lip and/or the palate (CL/P) is one of the most common congenital conditions in the world, affecting approximately 1 in every 600 live births in the United Kingdom (UK; CRANE, 2020). Although surgery to repair the cleft is normally performed during the child's first year of life, infants born with CL/P and their families are expected to engage in a multidisciplinary treatment pathway throughout childhood and often into adulthood (Berkowitz, 2013). In addition to surgery and orthodontics, this includes support from Clinical Nurse Specialists (Nurses), specialist Clinical Psychologists, and specialist Speech and Language Therapists (SLTs), who are involved in the entire pathway from prenatal consultation to maturity.

In countries with high resource levels, specialist health professionals work collaboratively to deliver holistic care according to published standards (e.g. NHS England, 2013). In the UK, CL/P care is delivered via 12 centralised specialist networks consisting of 16 regional teams. These services are commissioned by the National Health Service and managed locally by clinical commissioning groups.

Commissioners are responsible for the allocation of resources and are guided by the Cleft Development Group, a national independent body of clinicians, researchers, charitable organisations, and patient/parent representatives. CL/P services are funded via a national budget, alongside contributions from local NHS Trusts, and are free at the point of delivery. The UK CL/P service was designed on a “Hub and Spoke” model, with all cleft surgery and key assessments taking place at the specialist centres, and with all other core services being delivered in the centre or by outreach in collaboration with community services.

Despite these National standards being in place and largely positive reports of care according to health professionals and patients (Scott et al., 2015; Searle et al., 2015; Stock et al., 2018), significant variations in care delivery across teams are still common (Scott et al., 2015; Stock et al., 2020), as are inequities in the way services are funded (Searle et al., 2015; Lead SLT group, 2016). Ongoing evaluation of service configuration and performance is crucial for the continued development of CL/P teams, and for achieving optimal outcomes for patients and families (Fox & Stone, 2013). Specialist health professionals are ideally placed to assess the ongoing state of care provision, yet data offering their perspective remains relatively scarce (Stock et al., 2020). Further, the views of the non-surgical specialities (such as nurses, psychologists, and speech and language therapists) are rarely heard in research (Scott et al., 2015), despite the multidisciplinary nature of care. While available quantitative data are useful for evaluating service delivery, qualitative investigation can offer a richer insight into the realities of delivering a highly complex and specialist service.

The aim of the present study was to better understand variations in specialist care from a qualitative perspective, using CL/P services as an example. The study set out to identify common barriers to the delivery of an optimal CL/P service, as well as potential facilitators from a (non-surgical) multidisciplinary perspective.

Method

Design

The core non-surgical disciplines in CL/P care include specialist Nurses, Clinical Psychologists, and Speech and Language Therapists (SLTs). Individual, semi-structured telephone interviews were conducted with all three groups. Participants were either currently working in one of the 16 UK specialist CL/P centres, or who had recently retired (<2 years) from CL/P services.

Ethical Considerations

Institutional ethical approval was obtained from the Faculty Research Ethics Committee at (*University*). Participants were informed that their contribution to the study was voluntary, their data would be stored confidentially, they would not be identified during dissemination of the findings, and they could withdraw their data from the study at any time prior to the completion of the analysis.

Procedure

Potential participants were initially approached through the relevant specialist UK Clinical Excellence Networks (CENs). A CEN is composed of all specialist clinicians working within a particular discipline and field; in this case the Cleft and Craniofacial Nursing, Psychology, and SLT CENs were approached. Health professionals were informed about the aims of the study and what participation would entail and were encouraged to contact the researchers if they were interested in participating. A mutually convenient time to conduct a telephone interview was then agreed. Participants gave verbal informed consent for their interview data to be used for research purposes before the interview began. The interview schedule was designed by the first and second authors and was based on a review of the current literature (Stock & Feragen, 2016) and consultation with clinicians. Interview topics included: participant information (e.g. year of qualification, main responsibilities); observations from working with patients and families (e.g. common challenges encountered by patients/families, characteristics of those who cope well/struggle); current approaches to intervention (e.g. typical approaches used, format, comparison with other UK/international colleagues); barriers and facilitators to intervention (e.g. factors influencing intervention success,

training needs); multidisciplinary team working (e.g. benefits and challenges of multidisciplinary approach, perceived need for service improvement); and audit and research (e.g. current audit procedure, opportunities for research activity). Interviews took place between September 2016 and March 2017 and were conducted by the second author.

The interviews yielded a large amount of data and therefore the findings were divided across two papers. The first paper presented the key challenges encountered by patients and families affected by CL/P and the types of non-surgical interventions used to address these challenges (*redacted for anonymity*). The current paper is the second paper to utilise the interview data and focuses on perceived facilitators and barriers to delivering an optimal specialist service.

Participants

Seventeen Nurses, nineteen Clinical Psychologists, and fourteen SLTs participated in this study, totalling 50 participants. All sixteen specialist UK CL/P centres were represented. Disciplines were represented across all sites, with the exception of the SLT group (two teams unrepresented) and one team who did not have a Clinical Psychologist in post during the interview period. In some cases, more than one representative from each site participated.

All participants were female other than two male Clinical Psychologists. Nurses reported an average of 15.5 years working in specialist CL/P services (range 4 years – 31 years). Clinical Psychologists reported an average of 7.4 years (range <1 year – 20 years), and SLTs reported an average of 11.8 years (range <1 year – 28 years). On average, interviews were 58 minutes in length.

Analysis

Interviews were transcribed verbatim and subjected to inductive thematic analysis (Braun & Clarke, 2006) as follows: (1) becoming familiar with the data; (2) identifying interesting features of the data; (3) searching for themes; (4) reviewing themes; (5) defining and naming themes; and (6) producing the report. Analysis was treated as a recursive process, and themes were subsequently chosen for their prevalence and/or importance (or ‘‘keyness’’) in relation to the research question. Analysis was

performed independently by the first and second authors, who are trained in qualitative methods. Findings were compared and any discrepancies were discussed until full agreement was reached. Anonymised preliminary findings were presented to all members of the three CENs at the annual meeting of the Craniofacial Society of Great Britain and Ireland in April 2017. A focus group discussion with each CEN was subsequently facilitated by the first and second authors to ensure the accuracy of the interpretative process and to discuss the implications of the findings.

Results

Study findings are summarised below and presented in Tables 1 and 2 using exemplar quotes.

Barriers to the Delivery of Optimal Care

Thematic analysis identified several barriers to the delivery of optimal CL/P care (Table 1). Nurses and Clinical Psychologists discussed the negative impact of a poorly delivered diagnosis, the variable quality of online information, and an increase in the uptake of private antenatal screening scans on new and expectant parents. Clinical Psychologists and SLTs highlighted how patients' and families' preconceptions of therapy and level of therapeutic engagement could be barriers to meeting service specifications and achieving optimal outcomes. Working within services dominated by a medical model was identified by all three disciplines as a significant challenge, particularly in relation to an imbalance in the priorities of care, due to a focus on surgical outcomes. This resulted in a mismatch in the optimal ages to undertake records for audit/quality control purposes, a desire to simplify complex issues, and a misunderstanding by other clinicians of the contribution that the three disciplines offer. Clinicians from all three disciplines discussed the challenges of delivering best practice in the context of declining resources, describing how ongoing disputes with their regional hospital managers surrounding cost-effectiveness, the importance of specialisation, and general understaffing was a source of national inequity of care. Participants from all disciplines also described a weak evidence base for therapeutic interventions in CL/P, and the potential for this to

impact on their confidence as clinicians and their ability to demonstrate their value to others. However, participants also highlighted the challenges of collecting traditional ‘higher level’ evidence (e.g. clinical trials) within their particular disciplines. While Nurses often supported other clinicians’ research (such as surgical trials), they acknowledged that they rarely carried out research within their own discipline. Finally, participants from all disciplines suggested they could be engaging more in interdisciplinary research and doing more to support the integration of preventative work.

Facilitators of Optimal Care Delivery

A number of facilitators of optimal care delivery were identified (Table 2). Participants from all three disciplines believed that the sharing of best practice was a key facilitator in creating an optimal service. Participants expressed this could be achieved through the provision of CL/P training for non-specialists (such as midwives) and joint working, by engaging local services, and by adopting a genuinely collaborative working approach with colleagues. Participants from all disciplines outlined the possibility of using alternative research methods to evidence their contribution to the service. These included the use of qualitative methods, case studies, and the implementation of Goal-Based Outcomes. Clinicians from all three disciplines discussed opportunities to partner with academics, and emphasised the difference that additional support staff, including dedicated Link SLTs in the community, Assistant Psychologists, students, and Research Nurses can make to community service delivery, and to audit and research productivity. Similarly, participants from all disciplines discussed the utilisation of technology for cost-effective communication and record-keeping, efficient data collection, and the delivery of interventions. Finally, Nurses and Clinical Psychologists discussed the importance of normalising psychological support to reduce stigma and increase uptake, and the value of building an MDT that genuinely values and carries out patient-centred care.

Discussion

The aim of this qualitative study was to better understand variations in specialist care using CL/P services as an example. The study set out to identify common barriers to the delivery of an optimal service, as well as potential facilitators. Due to a previous reliance on the views of the core surgical specialities, this study drew upon the perspectives and experiences of non-surgical CL/P specialists. The findings provide an understanding of the key challenges of specialist care, in addition to ways in which improvements could be facilitated.

Appropriate Allocation of Resources

Effectively Resourced Teams and Community Services

Participants from all disciplines expressed significant concerns regarding a steady decline in healthcare resources over the previous ten years. At a regional level, this had reportedly led to the understaffing of CL/P units, a downgrading of posts, and a delay in or failure to replace key staff members. Despite being categorised as a commissioned specialist service, participants reported being instructed to cover other clinical services, which reduced their capacity to support those affected by CL/P at crucial times in the treatment pathway. Authoritative reports on the optimal delivery of child and adolescent mental health services and speech and language therapy have recommended a minimum number of full-time equivalent staff relative to the population in need, including an appropriate balance of gradings from consultant level to newly qualified (BPS, 2017; I CAN, 2018). Yet, erosion of both services was reported across the UK, including a systematic dilution of specialist and community-based services and enormous variations in reported spending between geographical areas (Lead SLT group, 2016; BPS, 2017; I CAN, 2018; Longfield, 2019). Clinical Directors have previously reported a lack of clarity about how commissioning and funding of services is handled, that funding decisions are often made without a full understanding of the needs of patients, and that inconsistencies in funding models between specialist teams impact significantly on equitable service delivery (Searle et al., 2015). Parents of children with CL/P have also expressed concern and dissatisfaction at the availability of community support, citing long waiting times, a lack of continuity of staff, and conflicting advice depending upon the therapists' level of expertise (Lead SLT group,

2016). Without an appropriately resourced workforce inclusive of applied scientists and specialist therapists, vulnerable patients are unlikely to be offered appropriate interventions, leading to a lack of support and/or the use of ineffective and/or unnecessarily prolonged treatments (BPS, 2017; I CAN, 2018; Longfield, 2019). Taken together, these findings suggest discrepancies in resource allocation are impacting specialist teams' ability to meet the UK's National Service Specification (Searle et al., 2015; Lead SLT group, 2016) and which could ultimately jeopardise patients' and families' long-term outcomes. The need for specialist teams and commissioners to work more closely is crucial, as is ongoing implementation of feedback from key stakeholder groups. The substantial benefits of dedicated "Link" community SLTs in improving the quantity and quality of local SLT provision have also been demonstrated (Lead SLT group, 2016), suggesting that funding for these posts should be protected.

Delivering Cost-Effective Practice

Participants reported an ongoing battle to justify the costs of home visits to their respective regional hospital managers, despite a report by the British Psychological Society (2017) stating that home visits are a proven way of reaching vulnerable and/or marginalised groups and should be prioritised (BPS, 2017). Another proposed way of engaging families included the utilisation of technology. For example, Nurses reported that digital health records and mobile phones enabled easier communication, which in turn saved mileage and nursing hours. Others felt technology, such as iPads, could improve efficiencies in the clinical setting, thereby saving the hospital money over time. Finally, participants felt technology had the potential to be used in therapy, including the opportunity to deliver interventions remotely (Sweeney et al., 2020), to save travel costs, and to better meet the needs of families for whom English is an additional language. Leading reports and systematic reviews have also stated that digital tools are user-friendly, have the potential to foster and maintain clinical change, and may successfully augment traditional treatments (Speyer et al., 2018). Utilising support from Assistant Psychologists/SLTs, students, and Research Nurses may also be a cost-effective way to improve audit and research productivity without compromising clinical time.

Ultimately, the integration of health economics to demonstrate longitudinal cost savings may be necessary.

Evidencing the Contributions of Specialist Health Professionals

Challenges of Documenting Therapeutic Interventions

Despite the evidence base to support broad therapeutic approaches (such as Cognitive Behavioural Therapy), guidance for delivering these interventions to address condition-specific issues is scarce (Bessell et al., 2013; Norman et al., 2015). This created uncertainty for some clinicians and impacted their level of confidence, particularly if they were relatively new to the field. Participants also described how a lack of ‘higher level empirical evidence’ (e.g. clinical trials) made it more difficult to demonstrate the value of their role, particularly when working within the surgically-focused context of a medical model. However, there are challenges associated with collecting empirical evidence when patients present with complex needs. In order to offer integrative and flexible care based on the needs of the individual, alternative methods of collecting evidence should be considered (BPS, 2017). Such an approach could also provide information about how to appropriately target interventions at an early stage, to prevent initial difficulties gaining complexity and becoming more entrenched over time.

Utilising Alternative Methods to Collect Evidence

Participants identified three alternative methods that could help to better document their contribution to the service: qualitative approaches, case studies, and goal-based outcomes. Qualitative approaches include many diverse sources of information, and can shed light on families’ experiences and the factors contributing to successful interventions, yet they remain underused in healthcare (Nelson, 2009). As a research strategy, case studies have traditionally been viewed as lacking rigour when compared to more traditional methods (Rowley, 2002). However, they can offer valuable insights into the ‘how’ and ‘why’ of a phenomenon not achieved using other approaches, particularly when existing evidence of a given topic is insufficient and when the variables are difficult to control

(Rowley, 2002). Especially when applied in a systematic way, analysis of case studies can provide important additions to knowledge. Also gaining traction is the use of single case experimental design studies, in which detailed analysis of a change in the dependent variable over time is conducted. Such studies have been shown to integrate well into routine clinical practice (Perdices & Tate, 2009). Finally, Goal-Based Outcome tools are designed to capture changes to the unique goals that a patient or family member wants to alter through intervention. Such tools are driven by the patient and can be used with any intervention and therapeutic modality (Law & Jacob, 2013). Goal-Based Outcomes can also be combined with clinician's ratings of outcomes to give an overall assessment of the progress of an intervention (BPS, 2017). Unlike costly clinical trials, these types of evidence could be relatively easily integrated into routine care and over time could demonstrate the need for additional resource.

Upskilling Clinicians in Research

Despite participants' desire for a stronger evidence-base, several clinicians described being anxious about research and did not feel they had the skills required. Another recent CL/P study found that interventions are in fact being trialled by teams, yet these studies rarely appear in the literature due to inadequate research design and/or a lack of research time (Stock et al., 2020). One potential solution to these challenges is to partner with academics. Such partnerships would combine the extensive knowledge of both parties and maximise the implementation potential of research findings and is therefore strongly advocated (Haynes & Haines, 1998). Given the relative size of specialist fields, international partnerships could also increase research activity globally. Participants in the current study also felt they could be engaging in more interdisciplinary research within their MDTs, as well as partnering with colleagues from broader perspectives, such as sociology, social policy, and nursing and health services (Nelson et al., 2012). Clinicians keen to pursue academic development could also explore opportunities to undertake clinical academic training.

Collaborative Working

Integrating Patient-Centred Care

One of the key barriers to implementing an optimal service identified by participants was working within a restrictive medical model, whereby surgery often takes precedence in treatment planning. Psychological research has consistently demonstrated that ‘objective’ treatment outcomes are superseded by the patient’s own perceptions of the impact of the condition on everyday life, emphasising the importance of multidisciplinary holistic care (Clarke et al., 2013). According to participants in the current study, the integration of non-surgical specialties into the service is an important first step, but all disciplines need to be heard and feel valued for the collaboration to be meaningful. Recognising the unique contribution of all specialists to team care and working collaboratively rather than simply side by side can help to ensure an optimally functioning team (Fox & Stone, 2013). Educating all specialties on the importance of patient-centred care and how to provide it may help to reduce this gap (Stock et al., 2020).

Sharing Best Practice with External Colleagues

In previous research, parents of children with CL/P have reported a lack of knowledge of the condition among non-specialists, such as diagnostic sonographers, midwives, and health visitors (Costa et al., 2019; Stock et al., 2019). This is despite CL/P being one of the most common congenital conditions in the world, and despite the key role that these non-specialists play in the families’ healthcare journey. In order to address these challenges, Nurses and Clinical Psychologists suggested creating more teaching opportunities for non-specialists, and carrying out joint family visits, to ensure non-specialists had access to accurate, up-to-date information and that all clinicians involved were providing consistent advice. This may also increase the frequency with which those affected by complex conditions are directed to reliable sources of online information. Finally, participants identified engagement with other local services, including nurseries, schools, and representatives of charitable organisations to be a key facilitator of best practice.

Methodological Considerations

This study involved a large number of interviews from all 16 UK CL/P sites to elicit the combined expertise of three non-surgical disciplines. A key strength is the presentation of the clinician perspective, which is crucial in understanding the current state of clinical practice yet is not often explored. Specifically, the views of non-surgical specialists are seldom heard, and this study has brought those voices to the fore. Nonetheless, several methodological issues should be considered. First, all Nurses, Clinical Psychologists, and SLTs working in specialist UK CL/P services were invited to participate, yet not all were able to commit within the study's timescale. This opens the possibility that not all views are represented. However, to combat this, members of all three CENs also participated in focus groups to discuss the findings. Second, this study focused specifically on three key (non-surgical) disciplines central to CL/P care. Future research could also expand on what is already known from the perspectives of other core disciplines, such as surgeons, orthodontists, and other dental specialties, and other specialist services. Finally, further understanding of the extent to which these findings apply to clinicians based in other countries would be extremely beneficial, as would highlighting key differences across global healthcare provision.

Conclusions

Although multidisciplinary care for those born with CL/P and their families is a commissioned service in high-resource countries such as the UK, wide variations in regional and local resources were reported. Consideration of services based on need should be promoted, alongside assessment of the utility and cost-effectiveness of various forms of technology and support staff. In order to further demonstrate the essential contributions of specialist health professionals and to improve the evidence base for intervention, clinicians are encouraged to consider alternative methods of data collection and to seek out partnerships with academics and other interdisciplinary colleagues. Finally, it is crucial to work collaboratively, both within multidisciplinary teams and with community-based colleagues, to share best practice and to fully integrate patient-centred care.

References

American Cleft Palate-Craniofacial Association (2017). Parameters for evaluation and treatment of patients with cleft lip and/or palate or other craniofacial differences. *Cleft Palate Craniofac J* **55**(1): 137-156. doi: 10.1177/1055665617739564.

Berkowitz S (2013). *Cleft Lip and Palate: Diagnosis and Management (3rd edition)*. Springer-Verlag Berlin Heidelberg.

Bessell A, Sell D, Whiting P, et al. (2013). Speech and language therapy interventions for children with cleft palate: A systematic review. *Cleft Palate Craniofac J* **50**(1):e1-e17. doi: 10.1597/11-202.

Braun V and Clarke V. (2006). Using thematic analysis in psychology. *Qual Res Psychol* **3**(2):77-101. doi: 10.1191/1478088706qp063oa.

British Psychological Society (2015). *What good looks like in psychological services for children, young people and their families: The Child and Family Clinical Psychology Review*. Available at: <https://www.bps.org.uk/news-and-policy/care-quality-commission-review-finds-child-mental-health-services-are-fragmented>. Accessed on: 18 January 2017.

Clarke A, Thompson A, Rumsey N, et al (2013). *CBT for appearance anxiety: Psychosocial interventions for anxiety due to visible difference*. John Wiley & Sons; West Sussex.

Cleft Registry and Audit Network (CRANE; 2020). *2020 Annual Report*. Royal College of Surgeons: December 2020.

Costa B, Williams JR, Martindale A, Stock NM & the VTCT Foundation Research Team at the Centre for Appearance Research (2019). Parents' experiences of diagnosis and care following the birth of a child with cleft lip and/or palate. *Br J Midwifery* **27**(3):151-160. doi: 10.12968/bjom.2019.27.3.151.

Fox LM and Stone PA (2013). Examining the team process: Developing and sustaining effective craniofacial team care. In: S. Berkowitz; *Cleft Lip and Palate: Diagnosis and Management (3rd edition)*. Springer-Verlag Berlin Heidelberg: pp.885-906.

Haynes B and Haines A (1998). Barriers and bridges to evidence-based clinical practice. *BMJ* **317**:273. doi: 10.1136/bmj.317.7153.273.

I CAN, Royal College of Speech and Language Therapists (2018). *Bercow: Ten Years On*. Available at: www.bercow10yearson.com. Accessed on: 5 May 2018.

Law D and Jacob J (2013). *Goals and Goal Based Outcomes (GBOs): Some useful information (3rd edition)*. CAMHS Press; London.

Lead SLT group for the Craniofacial Society of Great Britain and Ireland (2016). *Variation in speech and language therapy provision for children born with a cleft lip and palate in England and Wales*. Available at: <http://www.cleftsig.co.uk/wp-content/uploads/2012/02/Report-to-NHS-England-on-SLT-Provision-in-Cleft-Care-V13-Final-Anonymised-1-3-17-june.pdf>. Accessed on: 15 October 2017.

Longfield A (2019). *We need to talk: Access to speech and language therapy*. Children's Commissioner for England, London. Available at: <https://www.childrenscommissioner.gov.uk/wp-content/uploads/2019/06/cco-we-need-to-talk-june-2019.pdf>. Accessed on: 23 August 2019.

Nelson PA (2009). Qualitative approaches in craniofacial research. *Cleft Palate Craniofac J* **46**(3):245-251. doi: 10.1597/08-121.1#.

Nelson PA, Glenny AM, Kirk S, Caress AL (2012). Parents' experiences of caring for a child with a cleft lip and/or palate: A review of the literature. *Child: Care, Health & Dev* **38**(1):6-20. doi: 10.1111/j.1365-2214.2011.01244.x.

NHS England (2013). *NHS standard contract for cleft lip and/or palate services including non-cleft velopharyngeal dysfunction (all ages)*. Available at: <https://www.england.nhs.uk/wp-content/uploads/2013/06/d07-cleft-lip.pdf>. Accessed: 2 June 2016.

Norman A, Persson M, Stock NM, et al (2015). The effectiveness of psychosocial intervention for individuals with cleft lip and/or palate. *Cleft Palate Craniofac J* **52**:301-310. doi: 10.1597/13-276.

Perdices M and Tate RL (2009). Single-subject designs as a tool for evidence-based clinical practice: Are they unrecognised and undervalued? *Neuropsychol Rehab* **19**(6):904-927. doi: 10.1080/09602010903040691.

Rowley J (2002). Using case studies in research. *Manage Res News* **25**(1):16-27. doi: 10.1108/01409170210782990.

Scott JK, Leary SD, Ness AR, et al (2015). Perceptions of team members working in cleft services in the United Kingdom: A pilot study. *Cleft Palate Craniofac J* **52**(1):e1-7. doi: 10.1597/13.111.

Searle A, Scott JK, Sandy J, et al (2015). Clinical directors' views of centralisation and commissioning of cleft services in the UK. *BMC Oral Health* **15**:12. doi: 10.1186/1472-6831-15-12.

Speyer R, Denman D, Wilkes-Gillan S et al (2018). Effects of telehealth by allied health professionals and nurses in rural and remote areas: A systematic review and meta-analysis. *J Rehabil Med* **50**(3):225-235. doi: 10.2340/16501977-2297.

Stock NM, Anwar H, Sandy JR, et al (2018). Centralisation of cleft lip and palate services in the United Kingdom: The views of adult "returners". *Cleft Palate Craniofac J* **55**(5):676-681. doi: 10.1177/1055665617744064.

Stock NM, Costa B, Williams JR, et al (2019). Breaking the news: Parents' experiences of receiving an antenatal diagnosis of cleft lip. *Cleft Palate Craniofac J* **56**(9):1149-1156. doi: 10.1177/1055665619830884.

Stock NM, Feragen KB (2016). Psychological adjustment to cleft lip and/or palate: A narrative review of the literature. *Psychol Health*. **31**(7):777-813. doi: 10.1080/08870446.2016.1143944.

Stock NM, Marik P, Magee L et al (2020). Facilitating positive psychosocial outcomes in craniofacial team care: Strategies for medical providers. *Cleft Palate Craniofac J* **57**(3):333-343. doi: 10.1177/1055665619868052.

Stock NM, Zucchelli F, Hudson N, et al (2020). Promoting psychosocial adjustment in individuals born with cleft lip and/or palate and their families: Current clinical practice in the United Kingdom. *Cleft Palate Craniofac J* **57**;186-197. doi: 10.1177/1055665619868331.

Sweeney T, Hegarty F, Powell K et al (2020). A Randomised Controlled Trial Comparing Parent Led Therapist Supervised Articulation Therapy (PLAT) with Routine Intervention for Children with speech disorders associated with cleft palate. *Int J Lang Comm Disorder* **55**(5):639-660. doi: 10.1111/1460-6984.12542.

Table 1: Barriers to the delivery of optimal care as identified by CL/P specialist health professionals

Theme	Barriers
<p data-bbox="175 607 395 674">Managing Misinformation</p> <p data-bbox="175 736 395 792">(Nurse Specialists and Clinical Psychologists)</p>	<p data-bbox="557 376 1225 409">Mixed level of knowledge among non-specialists:</p> <p data-bbox="467 436 1321 546"><i>“The psychologists and the nurses, we spend a lot of time trying to undo the damage of a poorly delivered diagnosis” – Clinical Psychologist #7</i></p>
	<p data-bbox="564 577 1217 611">Variability in the quality of online information:</p> <p data-bbox="448 638 1348 786"><i>“There is a lot of misinformation online so if families...aren’t directed to a trusted source...the messages and the language aren’t helpful... Antenatal visits can take anything from 1 hour to 3 hours depending on what the family’s been reading” – Nurse Specialist #5</i></p>
	<p data-bbox="620 815 1161 848">Increase in the uptake of private scans:</p> <p data-bbox="435 875 1348 1023"><i>“The other thing we have to think about are the private companies. More and more people are going for gender scans at 16 weeks and it’s just not handled properly and...families aren’t referred” – Nurse Specialist #13</i></p>
<p data-bbox="197 1164 373 1232">Patient Engagement</p> <p data-bbox="175 1294 395 1350">(Clinical Psychologists and SLTs)</p>	<p data-bbox="624 1055 1158 1088">Patients’ and families’ preconceptions:</p> <p data-bbox="448 1115 1337 1225"><i>“There is definitely a stigma around mental health still... Sometimes just a mention of the psychologist...they’re put off straight away and we don’t hear from them again” – Clinical Psychologist #13</i></p>
	<p data-bbox="687 1256 1094 1290">Therapeutic non-compliance:</p> <p data-bbox="435 1317 1348 1464"><i>“When patients aren’t attending appointments, that can be frustrating, and you feel like...clinical time is wasted... Or if you’ve asked a school to carry out a programme of work and...you find out later that they haven’t done it” – SLT #5</i></p>
<p data-bbox="169 1637 400 1704">Working within a Medical Model</p> <p data-bbox="175 1767 395 1852">(Nurse Specialists, Clinical Psychologists and SLTs)</p>	<p data-bbox="762 1489 1019 1523">Priorities for care:</p> <p data-bbox="448 1550 1342 1697"><i>“Often in a surgical team, appearance and function take high priority with regard to treatment planning... [A patient] can have good physical outcomes...but if they aren’t psychosocially adjusted, has it all been worth it?” – Clinical Psychologist #12</i></p>
	<p data-bbox="639 1729 1142 1762">Multidisciplinary team audit points:</p> <p data-bbox="448 1789 1337 1937"><i>“The audit points that suit the rest of the MDT [e.g. surgeons] aren’t necessarily the...best measurement points for other disciplines like SLT and psychology... We could probably do with reassessing what the key assessment points are for us” – SLT #9</i></p>
	<p data-bbox="667 1966 1115 2000">Simplification of complex issues:</p>

	<p><i>“Psychological issues are very complex...whereas what the rest of the service want from us is a yes/no or a single score or something concrete...which I doubt we’ll ever be able to do in a meaningful way”</i> – Clinical Psychologist #14</p>
<p>Delivering Best Practice with Declining Resources</p> <p>(Nurse Specialists, Clinical Psychologists and SLTs)</p>	<p style="text-align: center;">(In)visibility of role:</p> <p><i>“People don’t have much understanding of what we do...We can be valued for picking up the pieces when people are upset, for example, which isn’t necessarily our biggest skill or contribution”</i> – Clinical Psychologist #3.</p> <hr/> <p style="text-align: center;">Understaffing:</p> <p><i>“We are definitely understaffed...there’s no way we can cover all of the clinics... If a colleague leaves [the service] for whatever reason...they aren’t being replaced...[or] the post is downgraded...and we are arguably one of the better resourced [cleft] teams”</i> – Clinical Psychologist #10</p> <hr/> <p style="text-align: center;">Justifying costs:</p> <p><i>“Even though we’re a commissioned service...it can be a real battle, constantly trying to prove your worth to the Trust and explain why it’s necessary to do what you do”</i> – Nurse Specialist #3</p> <hr/> <p style="text-align: center;">Defending the need for specialisation:</p> <p><i>“Although I’m officially paid by the cleft service, I’ve also been made responsible for overseeing several different clinical areas... It’s tricky because I have very little time to dedicate to cleft...given the constraints I’m under”</i> – Clinical Psychologist #13</p> <hr/> <p style="text-align: center;">Inequity of care:</p> <p><i>“More and more we are expected to provide a better service to a bigger population with less funding...[and] less training opportunities... That’s what leads to national inequity of care”</i> – SLT #7</p>
<p>An Insufficient Evidence Base</p> <p>(Nurse Specialists, Clinical Psychologists and SLTs)</p>	<p style="text-align: center;">A lack of robust evidence for intervention in CL/P:</p> <p><i>“The lack of evidence for what we do...it creates uncertainty... We’re doing our jobs the best that we can, and we think we’re doing pretty well...but actually I don’t have anything to back that up other than anecdotally”</i> – SLT #2.</p> <hr/> <p style="text-align: center;">Challenges of evidence collection:</p> <p><i>“Anything with an n of under 10 isn’t included in systematic reviews and...we’ve heard so many times about the need to work toward Randomised Controlled Trials...but the fact is that it’s almost impossible and perhaps meaningless to try to document our work in that way”</i> – SLT #1</p>

	<p style="text-align: center;">A lack of nursing-led research:</p> <p style="text-align: center;"><i>“We’re not very good at conducting our own research...I think we’re a bit scared of it... We often take on the responsibility of the [large surgical trials], but...nursing papers are few and far between” –</i> Nurse Specialist #6</p>
	<p style="text-align: center;">A paucity of interdisciplinary research:</p> <p style="text-align: center;"><i>“There’s important overlap and...nurses and the psychologists could be doing a lot more working together, for example” –</i> Clinical Psychologist #13</p>
	<p style="text-align: center;">A lack of evidence for preventative work:</p> <p style="text-align: center;"><i>“I think there’s a lot more that could be done preventatively...understanding more about how to build resilience...and collecting evidence for how to appropriately target interventions at an early stage... We shouldn’t always be firefighting”</i> – Clinical Psychologist #14</p>

SLT: Speech and Language Therapist; MDT: Multidisciplinary Team

Table 2: Facilitators of optimal care delivery as identified by CL/P specialist health professionals

Theme	Facilitators
<p data-bbox="196 712 376 779">Sharing Best Practice</p> <p data-bbox="173 846 399 927">(Nurse Specialists, Clinical Psychologists, and SLTs)</p>	<p data-bbox="603 338 1182 371">Training opportunities for non-specialists:</p> <p data-bbox="448 398 1342 546"><i>“It’s doing more teaching with the midwives...and maybe getting into the antenatal units...to explain our service, show that [cleft] isn’t all doom and gloom...making sure they have up-to-date information” – Nurse Specialist #7</i></p>
	<p data-bbox="651 577 1134 611">Joint working with non-specialists:</p> <p data-bbox="440 638 1353 824"><i>“Joint working [with non-specialist clinicians] can be really beneficial for all involved...joint home visits to see families for example... There’s less likely to be conflicting information given to families, and it’s dropping into the normal pathways that any other family would be on” – Nurse Specialist #14</i></p>
	<p data-bbox="727 853 1058 887">Engaging local services:</p> <p data-bbox="459 913 1326 987"><i>“School involvement, nursery involvement...working with CLAPA’s regional staff...engagement of local services is key” – SLT #14</i></p>
	<p data-bbox="663 1014 1121 1048">Collaborative working approach:</p> <p data-bbox="440 1075 1347 1301"><i>“We have CEN meetings at least four times a year...and we have a whole paediatric psychology department in the hospital that I can link in with... We meet with the other cleft teams in our region... Sometimes there are opportunities to go to conferences...so I feel very well connected...and get lots of input and knowledge from my colleagues” – Clinical Psychologist #10</i></p>
<p data-bbox="196 1473 376 1659">Using Alternative Methods to Evidence Contribution</p> <p data-bbox="173 1727 399 1807">(Nurse Specialists, Clinical Psychologists, and SLTs)</p>	<p data-bbox="727 1328 1058 1361">Qualitative approaches:</p> <p data-bbox="435 1388 1350 1615"><i>“I think qualitatively...interviewing parents who experienced the service before the [Nurse Specialists] were introduced, and comparing that with parents’ experiences now... We need to be finding other ways of demonstrating the contribution we make...because I think people forget what it was like not having [Nurse Specialists] around” - Nurse Specialist #9</i></p>
	<p data-bbox="799 1646 986 1680">Case Studies:</p> <p data-bbox="440 1706 1347 1892"><i>“We know we can change speech – what we need to do now is show how we do that, when is the best time [to intervene], how intensive it needs to be... We’ve got such wonderful material amongst us all for some case study analyses...which would help us describe exactly what we do” – SLT #1</i></p>
	<p data-bbox="735 1921 1050 1955">Goal-Based Outcomes:</p>

	<p><i>“We’re trying to use the Goal-Based Outcomes with the patient... Hopefully if we start to collate those they could ultimately be used for research” – Clinical Psychologist #19</i></p>
<p>Inclusion of Support Staff</p> <p>(Nurse Specialists, Clinical Psychologists, and SLTs)</p>	<p>Dedicated Link SLTs:</p> <p><i>“The role of the Link SLTs ranges from being a name on a piece of paper that we make the referral to...to having fully funded sessions... When you’re better staffed you can do more outreach clinics...and share working practices... Having that dedicated person in the community makes such a difference” – SLT #1</i></p>
	<p>Audit and research support:</p> <p><i>“Having an Assistant Psychologist makes a huge difference...in terms of our audit and research productivity and what we’re able to do... We’ve got a placement student at the moment too...and we’re well supported by the library...who will do literature searches...and send us abstracts” – Clinical Psychologist #3</i></p>
	<p>Research Nurse time:</p> <p><i>“For all teams, we should have Research Nurse time as standard... It helps us manage big projects...and we can collect clinically informative data...without it taking us away from clinical work” – Nurse Specialist #5</i></p>
	<p>Partnering with academics:</p> <p><i>“Being involved with [academics]...it probably encourages us to do research projects...because it feels overwhelming and a big commitment at first...but if you have a team behind you...you’re definitely better supported” – Nurse Specialist #2</i></p>
<p>Utilisation of Technology</p> <p>(Nurse Specialists, Clinical Psychologists, and SLTs)</p>	<p>Efficient data collection:</p> <p><i>“If we could get the patient to fill in the [audit measures] on an iPad in the waiting room...the results could be projected on the screen so we could all see it as a team... It would all be scored automatically...and all our audit data would be held on a multidisciplinary database so we could look across disciplines see how [patients] are doing holistically” – Clinical Psychologist #18</i></p>
	<p>Delivering interventions:</p> <p><i>“We do a lot more Skype therapy now, so remote working... I think we need more iPads so we can use digital games, and...some more resources on DVD...so it’s much more visual... It would better meet the needs of families with English as an additional language as well” – SLT #13</i></p>
	<p>Cost-effective communication and record-keeping:</p> <p><i>“We have laptops so we can work a bit from home...we have digital health records now. We have iPhones for work as well, so we</i></p>

	<p><i>can get emails and texts and be contacted on the go... Technology really enables easier communication...which in turn saves time and money and mileage and nursing hours” – Nurse Specialist #4</i></p>
<p>Authentic Integration of Patient-Centred Care</p> <p>(Nurse Specialists and Clinical Psychologists)</p>	<p>Normalising psychological input:</p> <p><i>“We do a lot of normalising...reassuring parents that their concerns are normal and...shared by other parents... We make it clear that everyone gets...offered time with the psychologist...it’s a standard part of the service” – Nurse Specialist #3</i></p>
	<p>MDT appreciation of psychological issues:</p> <p><i>“The support of the [cleft] team, knowing that they genuinely value psychology...that they are very psychologically-minded...and we’re all working to the same goal” – Clinical Psychologist #10</i></p>

SLT: Speech and Language Therapist; MDT: Multidisciplinary Team; CLAPA: Cleft Lip and Palate Association; CEN: Clinical Excellence Network