

# Specialist Paediatric Dental Services

## Patient and Carer Engagement Findings



Lancashire and  
South Cumbria  
Integrated Care Board

Commissioned by:  
NHS Lancashire and South  
Cumbria Integrated Care Board



# Contents

- 03** Executive summary
- 04** Introduction and purpose
- 05** Methodology
- 06** Overview of findings
- 08** What families value about the service
- 10** Accessing specialistpaediatric dental services
- 11** Observations and anecdotal feedback
- 13** Travel, cost and hidden barriers
- 14** Differences and common patterns across sites
- 15** What this engagement tells us
- 16** Implications for service delivery and commissioning

# Executive summary

**This report brings together feedback from children, parents, and carers who have used specialist paediatric dental services across Lancashire and South Cumbria, including services in Blackburn with Darwen, Blackpool, Burnley, Kendal, Preston, Chorley and Morecambe.**

The work was commissioned by NHS Lancashire and South Cumbria Integrated Care Board to support the development of a Paediatric Oral Health Needs Assessment, following the delegation of dental commissioning responsibilities from NHS England to integrated care boards in July 2023. Specialist paediatric dental services offer care for children and young people aged 0-18 who cannot access routine dental services. This includes children with severe dental disease, complex medical conditions, disabilities, or high levels of dental anxiety. For many families, these services are not optional but the only way their child can safely receive dental care.

The engagement concentrated on understanding how families perceive these services overall. This included experiences of referral and triage, waiting times, booking appointments, travelling, attending appointments, and interactions with staff, as well as the broader impact on family life.

Across all sites, families consistently expressed positive views about the care their children received. Parents and carers described staff as kind, patient, and skilled at supporting children with complex needs. Many families mentioned that staff took time, explained procedures clearly, and adapted their approach to each child. Feeling listened to, reassured and not judged was a central theme in positive experiences. Families also reported difficulties in accessing services. Referral pathways were often perceived as slow or unclear, appointment availability was limited, and booking systems were not always user-friendly. These issues were most prominent in Blackburn with Darwen and Blackpool, but they were also evident in Burnley and Morecambe. Feedback from Kendal showed fewer access concerns, although fewer responses were received from this area.

Low awareness of the NHS Healthcare Travel Costs Scheme was a recurring theme. Many families did not realise that they could receive financial support, even if they travelled long distances or were willing to do so. This raises concerns about hidden financial pressures and potential inequalities in access.

Overall, the findings emphasise services provided by dedicated and compassionate staff, often within strained systems. Families value the care their children receive but often need to allocate considerable time, effort, and emotional energy to access the service. The findings offer insights into unmet needs and systemic pressures that are directly relevant to the Paediatric Oral Health Needs Assessment and future commissioning decisions.

# Introduction and purpose

**This engagement was commissioned to support NHS Lancashire and South Cumbria Integrated Care Board in developing a Paediatric Oral Health Needs Assessment focused on specialist paediatric dental services.**

The aim of the work was to go beyond activity data and waiting-list figures to understand how families experience the services they rely on. This includes not only clinical care but also the systems and processes supporting it, recognising that access, communication, and predictability are vital for children with complex needs and their families.

# Methodology

## Engagement was carried out with parents and carers of children attending specialised paediatric dental services across all service locations in Lancashire and South Cumbria, excluding West Lancashire.

Feedback was collected through surveys completed in clinical settings. At all locations, an iPad was provided to parents and carers to complete the survey while attending appointments. A small number of children and young people also gave direct feedback where appropriate.

(Engagement did not take place in West Lancashire as access to the Skelmersdale service location could not be secured during the engagement period.)

Participation was voluntary, and the Spring North team clearly explained this before engagement. Families were informed about the purpose of the activity, how their feedback would be used, and that all responses would be anonymised. To encourage participation, parents and carers who completed the survey had the opportunity to enter a prize draw as a small incentive (46 chose to participate). Entry into the prize draw was optional and not linked to the care or treatment provided, but it did help to improve engagement.

As the Spring North team supported parents and carers in working through the survey questions, this created opportunities for discussion and clarification. These conversations enabled families to share additional feedback and contextual information that might not have been captured through the structured survey responses alone.

The engagement activity took place during November and December 2025, and January 2026. The survey combined structured questions with open-ended comment boxes. Structured questions explored experiences of access, referral processes, waiting times, appointment scheduling, travel, and communication. Open-ended responses allowed families to describe their experiences in their own words and to explain how the services affected their child and family.

Demographic information was gathered alongside experience data, including service location and whether children had additional needs or disabilities. This facilitated the analysis of variations in experiences and helped identify potential inequalities. The focus of the analysis was on recognising patterns in lived experiences rather than assessing service performance. All collected data has been anonymised.

# Overview of findings

Across all sites involved in this engagement, survey responses indicate high satisfaction with the care children received and the staff who provided it. A clear majority of respondents rated their overall experience positively, with particularly strong feedback about staff kindness, communication, and understanding of children's needs. This pattern was consistent across all locations, although the strength of responses varied slightly by site.



## 1. Blackburn with Darwen: Barbara Castle Way

28 | 24%

## 2. Blackburn with Darwen: Darwen Health Centre

1 | 1%

## 3. Blackpool: Blackpool Victoria Hospital

8 | 7%

## 5. Blackpool: Whitegate Drive

23 | 20%

## 6. Burnley: St Peter's Health Centre

21 | 18%

## 7. Central Lancashire: Bamber Bridge Health Centre

1 | 1%

## 9. Kendal: Westmorland General Hospital

7 | 6%

## 10. Morecambe Bay: Morecambe Health Centre

11 | 9%

## 11. Morecambe Bay: Royal Lancaster Hospital

4 | 3%

## 12. Preston: Ashton Health Centre

5 | 4%

## 13. Preston: Royal Preston Hospital

8 | 7%

This quantifiable overview was backed by qualitative feedback. Parents and carers often reported feeling reassured once their child was attended to, and many emphasised how staff interacted with their child rather than focusing on the technical aspects of treatment. These themes consistently emerged across different sites and were particularly noticeable with children who had additional needs or anxiety.

**“Always been so wonderful with my special needs”** Parent



- Satisfied 67.2% (78)
- Dissatisfied 31.9% (37)
- Very Dissatisfied 0.9% (1)

**“They are amazing. So patient and made the appointment so much fun for my child.”** Parent

Alongside this, the conversations captured a clear difference between experiences of care and access. While questions about care received high scores, responses regarding referral pathways, booking, waiting times, and appointment arrangements showed greater variation. This contrast was one of the most consistent patterns throughout the engagement. Parents’ comments help highlight this contrast. Many expressed gratitude for the care their child received, while also describing the process of accessing that care as stressful or exhausting.

**“It is under-resourced and, therefore, difficult to get appointments as often as we need. All staff are fantastic.”** Parent

**“I feel like the referral process can be really hard and overwhelming at times, and it often feels like I’m just stuck at the beginning again. But I do want to say that the dentists have been really helpful.”** Parent

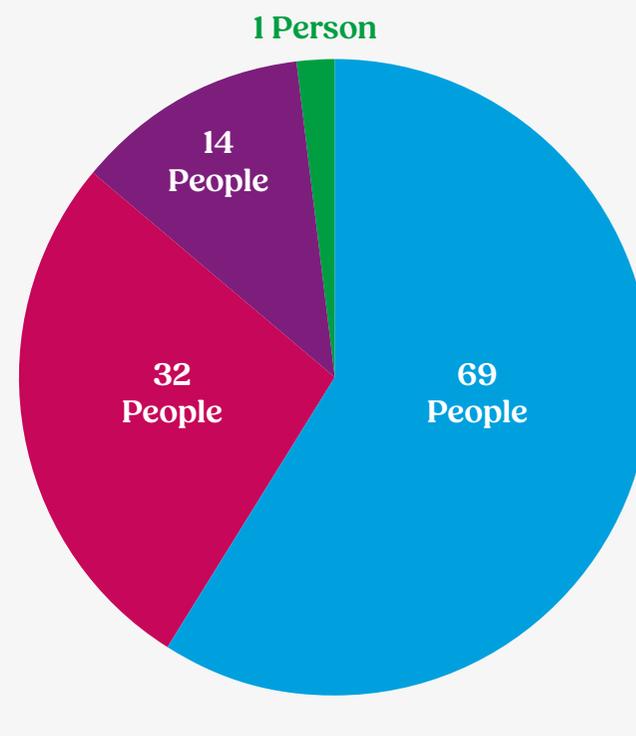
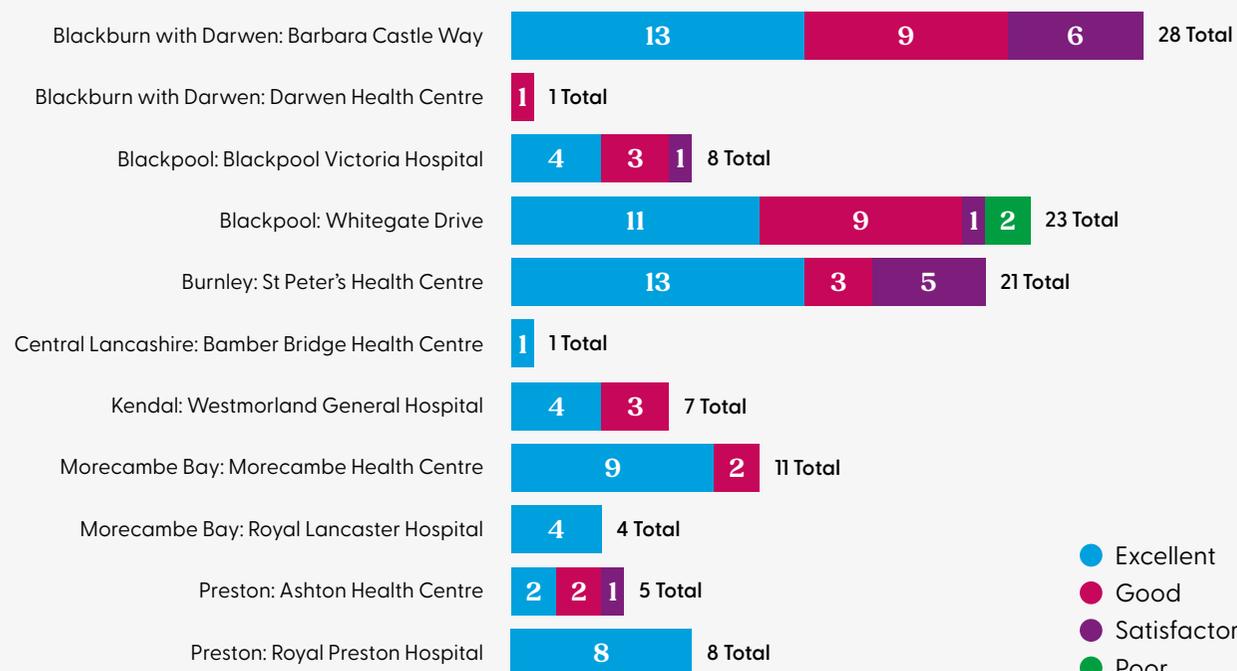


# What families value about the service

When asked about their experiences, families valued the way care was provided most highly. Survey questions about feeling listened to, being treated with respect, and having things explained clearly received the strongest scores across all sites. These aspects of care were consistently rated higher than practical or logistical aspects of the service.

## Where is your appointment today/your most recent appointment?

Please rate your experience - explanation about referral by own dentist



Open-text responses added considerable depth to these findings. Parents often described staff taking time, slowing appointments, and tailoring their approach to meet the needs of individual children. This was especially important for families of children with autism, disabilities, or high levels of dental anxiety, who frequently viewed specialised services as the only place where their child could receive dental care.

**“The dental service we received has always been fantastic. They tailor his treatment to meet his needs and are always happy to explain and go into detail with both myself and my son in a way that he can understand. Nothing is ever too much trouble”** Parent

Many parents described appointments as calm and reassuring, even when the broader process of accessing care was challenging. This contrast between the quality of care and the difficulties of gaining access recurred across sites and helps explain why overall satisfaction remained high despite access issues.

**“Caring friendly dedicated staff. My daughter was nervous and they put her at ease. Can not praise this dentist enough. The reception staff are welcoming and professional.”** Parent



# Accessing specialist paediatric dental services

Access proved to be the most challenging part of the service journey. Survey responses regarding referral processes, waiting times, and appointment arrangements showed greater variation and lower overall satisfaction than those regarding care quality.

**“The whole process was very challenging in regards to getting appointments and referral processes because we are still at square one. The dentist has been fantastic, caring, and helpful in guiding us through appointments and arranging appointments.”** Parent

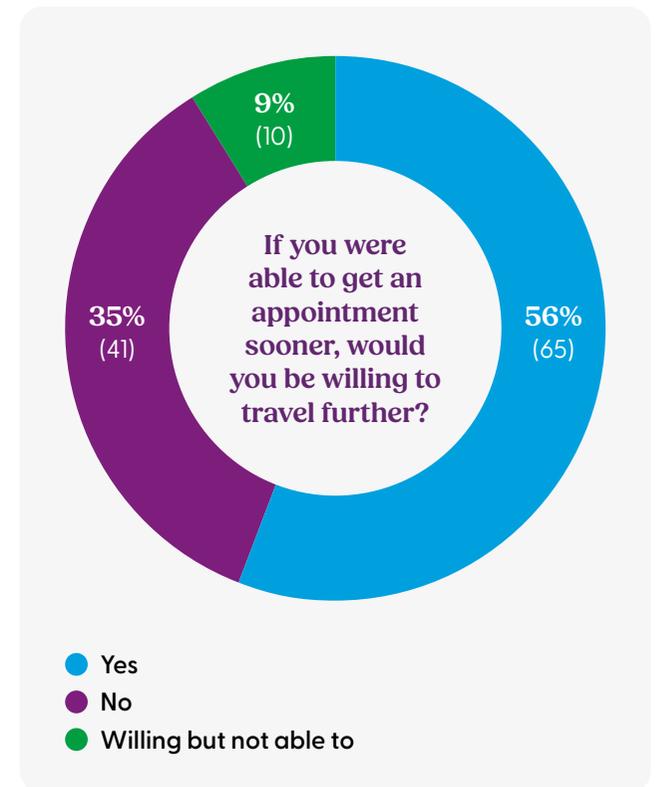
Parents described referral procedures as slow or unclear, with limited information about what would happen next or how long delays might be. This uncertainty was particularly challenging for families supporting children with anxiety or additional needs, where predictability and preparation are crucial.

In some areas, particularly Blackburn with Darwen and Blackpool, a higher proportion of respondents reported difficulties with access.

Parents’ comments highlight the effect of these issues on family life. Some mentioned repeatedly preparing for appointments that were later postponed or rescheduled, while others discussed the challenge of fitting appointments around work, school, and caring commitments.

**“Feels like a waiting game because unable to book appointments. And YP is autistic so we need to preplan and prepare”** Parent

Across all sites, many parents indicated they would be willing to travel further if it meant being seen sooner. This suggests that families are adapting to system pressures rather than disengaging from services.



# Observations and anecdotal feedback

## Informal conversations captured during engagement

Alongside completed questionnaires, informal conversations with parents, carers, and, in some cases, children and young people were recorded during the engagement activity. These discussions occurred while families were filling out surveys or waiting and offered valuable context to the issues highlighted in written responses.

A recurring theme in these discussions was the booking system, especially waiting times and the effect of clinic cancellations, often linked to changes in dentist availability. Families highlighted the difficulty of handling last-minute changes alongside work, school, and caring responsibilities.

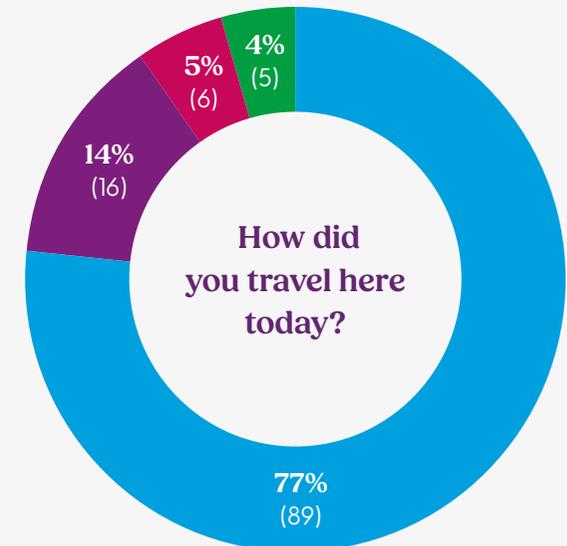
While engagement was conducted across most service locations, the activity was constrained by time, and scheduled sessions did not always provide sufficient time to reach the target number of participants at each clinic. Moreover, several clinic cancellations during the engagement period limited

opportunities to complete face-to-face surveys, thereby impacting overall response rates. It was also recognised that parents and carers often had to complete clinical paperwork before appointments and might not have had the time or capacity to fill in additional surveys afterwards due to other commitments, such as work or caring for other children.

Travel and transport were also mentioned informally. Families observed that flexibility regarding travel arrangements differed by location and that relying on family cars was common. In several instances, the person who brought the child to the appointment was not the same person completing the questionnaire, and some families relied on partners or other relatives for transportation. Consequently, the travel and transport section of the questionnaire may not have fully reflected families' actual travel experiences or the practical difficulties they face when attending appointments.

“Engagement often had to take place around clinic flow, and staff were conscious that families needed to prioritise appointments and clinical paperwork over completing surveys, particularly when they were keen to leave promptly after appointments.”

Observation from survey staff



- Family Car
- Taxi
- Public transport (bus/train)
- NHS patient transport service
- Other transport service (eg Dial-a-ride, voluntary, charity, or community service)

Several families discussed their children's neurodiversity-related needs, especially concerning sensory sensitivities. These needs were not always captured in standard paperwork or survey questions. This issue was most frequently mentioned at Blackpool and Central Lancashire sites. Meanwhile, families of children and young people with SEND shared positive feedback, highlighting examples of reception staff and dental teams showing awareness, patience, and consideration for individual needs. However, some families reported inconsistency in understanding, especially those new to the area or unfamiliar with local services.

General observations indicated that while the quality of care was generally seen as high, flexibility and communication were not always applied consistently across locations and individual appointments. In some instances, families reported differing responses to late arrivals or visible anxiety. For example, a family who arrived late was still seen, demonstrating flexibility; however, this caused a knock-on effect on the clinic schedule, resulting in delays for subsequent families and repeated apologies. In other cases, families felt that communication did not always fully address heightened anxiety, especially when discussions occurred in public areas such as reception spaces. Conversely, some families described more flexible and understanding responses in similar situations, including examples from Kendal. Overall, these accounts suggest variation in how flexibility is experienced, depending on the context and individual approach.

Informal conversations also revealed the emotional burden faced by some parents and carers. While clinicians often dedicated time to explore children's histories and needs thoroughly, parents and carers sometimes appeared overwhelmed by the cumulative effect of repeatedly explaining their child's circumstances. In a few cases, parents were seen to be visibly emotional after appointments, reflecting the wider pressures of navigating services, advocating for their child, and managing anxiety alongside clinical discussions.

During the delivery of the engagement activity, informal comments were also overheard in reception areas. These included minor concerns about last-minute changes to the assigned dentist. For families supporting autistic children, such changes were described as particularly challenging, especially when children had been prepared in advance for a specific clinician or routine. Although these concerns were generally expressed as frustrations rather than formal complaints, they highlighted the importance of consistency and clear communication.

It was also clear that reception staff were handling high volumes of queries and concerns from families. Informal conversations indicated that reception teams were under considerable pressure when responding to parental questions, frustrations, and confusion, particularly regarding appointment changes and scheduling. At some sites, including Burnley, reception staff also assisted members of the public unfamiliar with the building and seeking directions to other services, such as GP practices. This added to the overall workload and increased the operational pressures faced at reception.

**“It is under-resourced and therefore difficult to get appointments as often as we need, staff are fantastic.”** Parent

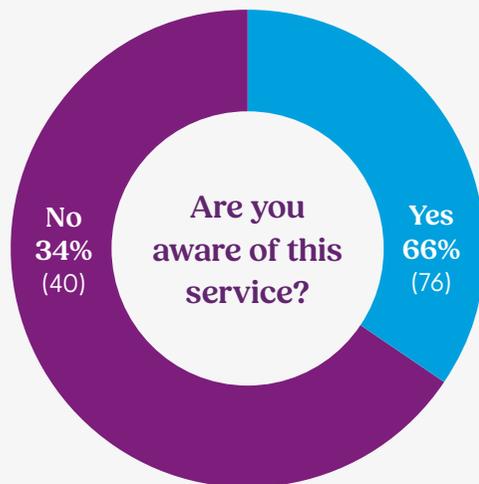
Together, these informal insights offer valuable context to the questionnaire findings and emphasise the interconnected pressures faced by families and staff. They underline the importance of consistent, adaptable, and anxiety-aware approaches that recognise both the clinical and emotional aspects of care.

# Travel, cost and hidden barriers

Survey responses showed that many families travelled long distances to attend specialist paediatric dental appointments. While most respondents said the travel distance was acceptable, awareness of the NHS Healthcare Travel Costs Scheme was low across all sites.

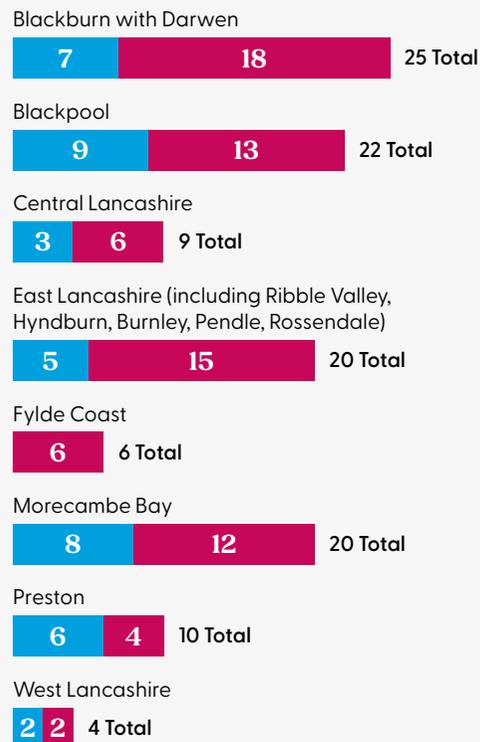
## Question from survey

People receiving some benefits, or on a low income, can apply for a refund of travel costs to specialist NHS services (NHS Healthcare Travel Costs Scheme (HTCS)).



Low awareness of the HTCS indicates that some families may be incurring avoidable financial costs when accessing specialist services.

## Where do you live?



In informal conversations, some parents expressed surprise that support was available and mentioned they had covered travel costs themselves. For some families, willingness to travel further did not necessarily mean they could afford to do so, due to financial constraints, time away from work, or reliance on others for transport.

These findings suggest that travel and cost may act as hidden barriers to access, particularly for families on lower incomes or those with complex needs.

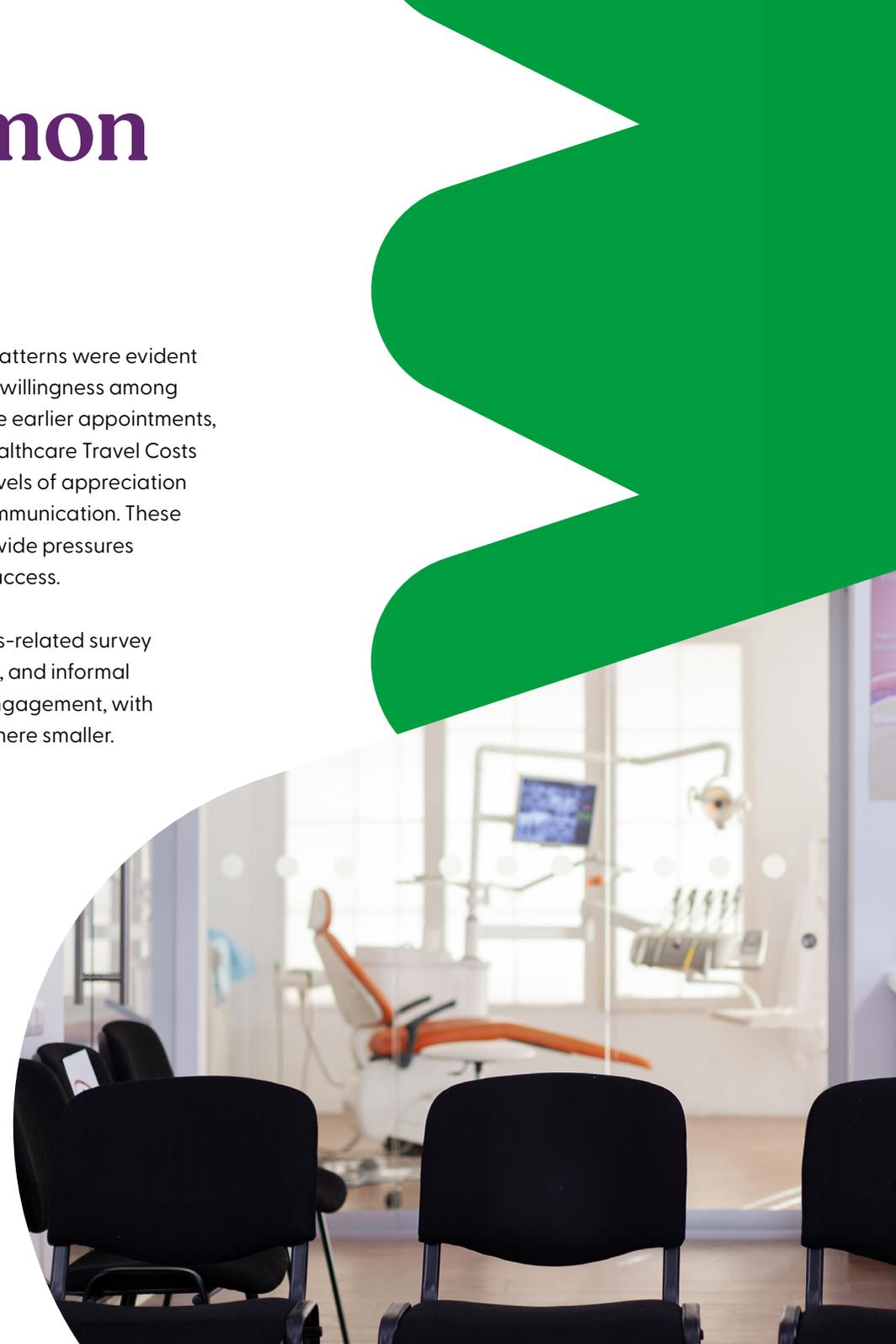
**“Staff very nice and accommodating. We were 10 mins late but they still saw us. They also spent time going through my daughter X-ray. Explaining what is going to happen next.”** Parent

# Differences and common patterns across sites

Experiences of care were consistently positive across all service locations; however, access pressures varied by site. Analysis of access-related survey responses and qualitative feedback shows that Blackburn with Darwen and Blackpool faced the greatest strain, especially regarding referral pathways, appointment availability, and waiting times. Burnley and Morecambe experienced more moderate access pressures, while fewer access concerns were reported by respondents attending services in Kendal, though this should be viewed cautiously due to the smaller number of responses from that location.

Despite this variation, common patterns were evident across all sites. These included a willingness among families to travel further to secure earlier appointments, limited awareness of the NHS Healthcare Travel Costs Scheme, and consistently high levels of appreciation for staff's care, patience, and communication. These shared themes suggest system-wide pressures alongside localised variation in access.

This assessment draws on access-related survey responses, qualitative comments, and informal observations captured during engagement, with response volumes considered where smaller.



# What this engagement tells us

## The question for the system is

How can we keep the quality of care families value, while making access simpler, more predictable, and less stressful for families?

Families are generally positive about the specialist paediatric dental care their children receive. They trust the staff and feel their children are well cared for. What causes frustration is not the care itself, but the effort it takes to get it. For many families, this includes the financial and emotional strain of attending appointments, as well as the uncertainty created when appointments are changed or cancelled.

Parents are realistic about pressures on services. What they are asking for is clearer communication, more predictable processes and systems that recognise the realities of family life and complex needs.

# Implications for service delivery and commissioning

## The question for the system is

How can services respond in ways that genuinely improve the family experience, using insights to improve access, communication, reduce inequalities and flexibility for families?

The findings highlight opportunities to improve the experience without altering clinical care. Providing clearer referral information, improving communication about waiting times and next steps, increasing appointment flexibility where possible, and regularly sharing details about travel cost support could significantly enhance patient experiences. These insights are directly relevant to the Paediatric Oral Health Needs Assessment, aiding in identifying unmet needs, disparities, and inequalities that are not apparent from activity data alone.



COLLABORATION + INNOVATION = IMPACT



Lancashire and  
South Cumbria  
Integrated Care Board