

NHS Orthodontic Care:

Views and Experiences of Parents, Carers, Children and Young People

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About Healthwatch Hertfordshire

Healthwatch Hertfordshire represents the views of people in Hertfordshire on health and social care services. We provide an independent consumer voice evidencing patient and public experiences and gather local intelligence to influence service improvement across the county. We work with those who commission, deliver, and regulate health and social care services to ensure the people's voice is heard and to address gaps in service quality and/or provision.

About the Hertfordshire and West Essex Integrated Care System

The Hertfordshire and West Essex Integrated Care System (ICS) was established as a statutory body on 1st July 2022. Integrated Care Systems are geographically based partnerships that bring together providers and commissioners of NHS services with local authorities and other local partners to plan, coordinate and commission health and care services¹. The Hertfordshire and West Essex ICS is made up of two key bodies – an Integrated Care Board (ICB) and Integrated Care Partnership (ICP).

Integrated Care Board (ICB)

The Integrated Care Board (ICB) is an NHS organisation responsible for planning and overseeing how NHS money is spent across Hertfordshire and West Essex, with the aim of joining up health and care services, improving health and wellbeing, and reducing health inequalities. The board of the ICB includes representation from NHS trusts, primary care and from Hertfordshire County Council and Essex County Council².

This report will be sent to the Hertfordshire and West Essex ICB Primary Care
Transformation Group to suggest where orthodontic services should be located and how
access to NHS orthodontic care could be improved.

Integrated Care Partnership (ICP)

The Integrated Care Partnership (ICP) is made up of representatives from different organisations involved in health and care. This includes NHS organisations, local authorities and the Voluntary, Community, Faith and Social Enterprise (VCFSE) sector. The

¹ Integrated care systems: how will they work under the Health and Care Act? | The King's Fund (kingsfund.org.uk)

² <u>Health and wellbeing decisions – Hertfordshire and West Essex Integrated Care System (hertsandwestessexics.org.uk)</u>

partnership is responsible for developing an Integrated Care Strategy which will set out the priorities for Hertfordshire and West Essex for the next 10-20 years³.

Hearing Patient Views about Primary Care in Hertfordshire and West Essex

Healthwatch Hertfordshire and Healthwatch Essex have been commissioned by the Hertfordshire and West Essex Integrated Care Board (ICB) Primary Care Workstream to undertake a series of engagement projects. The aims of the engagement projects include:

- Gathering lived experiences to feed directly into the Hertfordshire and West Essex ICS Primary Care Workstream.
- Supporting and enabling the Hertfordshire and West Essex ICS to achieve wider participant engagement.
- Engaging patients and the public on programmes covering key priorities and areas of importance at a regional and local level.
- Making recommendations to the Hertfordshire and West Essex ICS Primary Care Workstream so improvements can be implemented.

Using patient and public feedback, this engagement project will focus on improving the relevant services within different areas of primary care by making recommendations to the Hertfordshire and West Essex ICB Primary Care Transformation Group.

From March 2024 to May 2024, the Director of Primary Care Transformation at the ICB has requested that Healthwatch Hertfordshire explore NHS orthodontic services with a specific focus on where services should be located, and how access to NHS orthodontic care could be improved.

Background

From April 2023, Integrated Care Boards took on delegated responsibility for commissioning pharmacy, general ophthalmic and dental (POD) services from NHS England. This is with the intention of being better able to design services around the needs of local communities⁴.

³ <u>Health and wellbeing decisions – Hertfordshire and West Essex Integrated Care System</u> (hertsandwestessexics.org.uk)

⁴ NHS England » Delegating commissioning functions to ICBs offers real opportunity to improve local health outcomes

Orthodontics is the care and treatment provided, usually to children, to straighten their teeth and/or correct how their upper and lower teeth meet and work together⁵.

Orthodontics correct existing teeth, jaw irregularities, and prevent problems that may occur later in life.

Orthodontics can also be used for aesthetics to create the "perfect smile" which can improve patients' self-confidence and wellbeing. Oral health also plays an essential role in physical health, given that malocclusion (misaligned teeth) can lead to serious and painful dental issues such as gum disease or tooth decay⁶.

Patients referred are assessed using the Index of Orthodontic Treatment Need⁷ and only those patients who have clinical need that is at or above the threshold defined in these regulations are eligible to receive orthodontic treatment under the NHS.

Although treatment can begin at any age, it usually starts once most of a child's adult teeth have started to come through. The British Orthodontic Society recommends that children are treated at the "optimum time in their development" which is around the age of 12 when their jaw bones are still pliable⁸. For adults, treatment can also begin at any age, however adults are usually not eligible for NHS orthodontic care⁹.

Depending on the problem, treatment is usually between 6 and 30 months. Once treatment is finished, individuals tend to wear a retainer for at least 12 months. NHS orthodontic treatment is free for those under the age of 18 who need treatment for their future health. However due to high demand, there can often be long waiting lists¹⁰. In addition, not every child has equal access to NHS orthodontic care, with research finding that children from more deprived areas are less likely to receive NHS orthodontic treatment¹¹. Care leavers are also less likely to have access to NHS orthodontic care and are more likely to experience poor oral health¹².

Additionally, if children and young people do not qualify for NHS treatment or feel they cannot wait for treatment, they have the option of choosing private care¹³. However,

⁵ Orthodontics - NHS (www.nhs.uk)

⁶ <u>Misaligned teeth and jaws: Overview - InformedHealth.org - NCBI Bookshelf (nih.gov)</u> <u>Misaligned teeth and jaws: Overview - InformedHealth.org - NCBI Bookshelf (nih.gov)</u>

⁷ Index of Orthodontic Treatment Need (IOTN) explained. - St Michael's Orthodontics (stmichaelsorthodontics.co.uk)

⁸ <u>Ridgway Dental - Blog (weebly.com)</u>

⁹ Orthodontics - NHS (www.nhs.uk)

¹⁰ <u>Barriers and facilitators in the orthodontic treatment of teenagers with neurodevelopmental disabilities - ScienceDirect</u>

¹¹ Inequality in uptake of orthodontic services | British Dental Journal (nature.com)

¹² <u>Dentistry Journal | Free Full-Text | Access to Dental Care for Children and Young People in Care and Care Leavers: A Global Scoping Review (mdpi.com)</u>

¹³ Orthodontics - NHS (www.nhs.uk)

although waiting lists for private treatment tend to be shorter, it can be expensive. Treatment typically ranges from £2,000 to £6,000 depending on the treatment needed; in some cases, fees can be even higher.

Barriers to Accessing Orthodontic Treatment

There are a number of barriers which can prevent children and young people from accessing orthodontic treatment.

Waiting lists: The NHS has experienced staffing shortages and high demand for orthodontic treatment. This has prevented children and young people from getting orthodontic care at the recommended age, with the current waiting time for NHS braces between 6 to 30 months¹⁴. This also means that children aged 16 on the waiting list risk surpassing the age of eligibility, and they may have to pay for private treatment. As with many other NHS services, orthodontics is also still recovering from the COVID pandemic and the impact this had on waiting lists.

Duration of treatment: Another key concern for those undergoing treatment is its duration. One study found that 40% of participants said the length of treatment had caused them to refrain from visiting the orthodontist¹⁵. Another study found that while shorter treatment duration may be attractive, thorough and more complex treatment takes longer. As a result, economic pressures on orthodontic practices to produce high turnover may be counterproductive when striving for better outcomes overall¹⁶.

Location: NHS orthodontic practices are often stretched out and may be a significant distance from where the patient lives. Moreover, children from deprived and rural areas are less likely to receive orthodontic treatment. Some people may also have mobility issues that prevent them from accessing services, and most orthodontic practices may not offer home visits¹⁷.

Opening hours: Opening hours of orthodontic practices may be inconvenient for parents, especially those who work and do not have much flexibility around their working hours. Opening hours also tend to be within school hours, meaning that children and young people tend to miss education to access treatment.

¹⁴ How Long Is The NHS Waiting List For Braces? | Bhandal Dental Practice

¹⁵ AlAnzan-et-al.pdf (donnishjournals.org)

¹⁶ https://onlinelibrary.wiley.com/doi/abs/10.1034/j.1600-0528.2001.00010.x

¹⁷ Barriers in Access to Dental Services Hindering the Treatment of People with Disabilities: A Systematic Review - PMC (nih.gov)

Language and communication: Some studies found that people may face language and communication barriers when accessing services and face difficulties finding interpreters¹⁸.

Pain and discomfort: Children and young people often have reservations about orthodontic treatment which can prevent them from accessing services. This includes concerns about pain, discomfort whilst eating, and the appearance of braces¹⁹.

Information and awareness: For both parents and children, lack of awareness and information about orthodontic procedures can prevent patients from seeking orthodontic care.

Aims

The aim of this engagement was to hear from children and young people, parents and carers about experiences of receiving NHS orthodontic treatment. This was limited to children and young people who had accessed NHS orthodontic care within the last 2 years.

- To explore patient views and experiences of NHS orthodontic services in Hertfordshire.
- To understand the barriers patients may face when accessing NHS orthodontic care, and how they could be addressed.
- To make recommendations to the ICB Primary Care Transformation Group on where NHS orthodontic services should be located, and how access to services could be improved.

Methodology

To achieve these aims, a mixed methods approach was adopted. An online survey was created and targeted towards parents and carers to gather their views and experiences of NHS orthodontic care. In-depth interviews were held with parents and carers, as well as children and young people, to explore this. Interviews took place online or via telephone to accommodate needs and preferences.

The engagement period ran from March – May 2024. The survey and opportunities to take part in interviews were promoted via social media. They were also shared with the NHS,

¹⁸ FULL_TEXT.PDF (manchester.ac.uk)

⁽PDF) Barriers and challenges faced by orthodontists in providing orthodontic care and implementing new innovative technologies in the field of orthodontics among children and adults: a qualitative study (researchgate.net)

other statutory services, and the Voluntary, Community, Faith and Social Enterprise sector across Hertfordshire to distribute via their networks, contacts, and social media channels.

In total we heard from **60** parents and carers through the online survey, and **10** parents and children and young people through the in-depth interviews.

Key Findings

Demographics

Please note that the demographics below relate to the online survey only. Demographic information was not collected during the interviews.

Age of child

- Under 10 4%
- 10 years old 2%
- 11 years old 12.24%
- 12 years old 10.2%
- 13 years old 10.2%
- 14 years old 18.37%
- 15 years old 20.41%
- 16 years old 10.2%
- 17 years old 10.2%
- 18 years old 2%

Age of respondents

- 18-24 years: 2%
- 35-44 years: 30%
- 45-54 years 58%
- 55-64 years 8%
- 65+ years 2%

Gender of respondents

- Female 96%
- Male 4%

Area participants live in

- Borough of Broxbourne 14%
- Borough of Dacorum 14%
- District of East Hertfordshire 11%
- Borough of Hertsmere 2%
- District of North Hertfordshire 11%
- City of St. Albans 20%
- Borough of Stevenage 4%
- District of Three Rivers 5%
- Borough of Watford 7%
- Borough of Welwyn Hatfield 5%

Ethnicity of respondents

- White British respondents: 71%
- Ethnically diverse groups: 29%

Accessing NHS Orthodontic Care

43% of participants said they and their child did not face any difficulties accessing NHS orthodontic care. These participants shared their positive experiences, including short waiting lists, quick referrals, flexible appointments, and high-quality treatment.

"We were very fortunate that our dentist referred my daughter early and so by the time she needed the treatment the space was available."

"Really good with my daughter, she's had moulds done and awaiting braces to be fitted."

"Fast, quality care and support."

"We were referred without a problem."

However, the majority of participants (57%) said they and their child experienced challenges when accessing NHS orthodontic treatment. The challenges and barriers they faced are detailed in this section.

Waiting Times

The most common challenge cited amongst participants was waiting times. Participants felt that the time it took from the point of referral to starting orthodontic treatment was too long, with many experiencing up to a 2-year wait before their child had their first appointment.

"We had a year's wait just to be assessed and to confirm if eligible for NHS braces. To then be told we have at least another year to 18 months to wait to potentially start treatment."

"My son is currently 16 years of age turning 17 years of age in September of this year. He has been on the waiting list for braces for nearly a year and is not likely to get them based on the waiting list for another year or more."

"After being 'accepted' for orthodontic treatment for a severe overbite on an autistic child, we then had to wait several months for the first appointment."

Some participants felt their child needed urgent treatment but still faced a long wait. For example, one parent said their child still had baby teeth which needed extracting by their dentist, while another parent said their child required oral surgery, despite facing a 3-year wait.

"2 year waiting list and then two times 6 months waiting list as my child still has baby teeth."

"A long waiting time for initial appointment, then oral surgery was required before the orthodontic treatment could start. Over 3 years wait for the surgery."

"Too many delays and no one cares for kids who need urgent care."

Similarly, two parents shared how waiting for orthodontic treatment has significantly impacted their child's confidence and self-esteem and has led them to facing bullying at school.

"Told to wait but too long and keep chasing them up. Second tooth is stuck behind front tooth which is causing him pain. These major issues need to have priority as he can be bullied at school for not having a front second tooth."

"Family and friends that have their kids referred in the past have had treatment start much earlier, such as dental blocks. Our daughter is suffering with bullies over her teeth and the wait time is making this worse."

When participants were asked what they would consider an acceptable time to wait to start treatment, no one selected any time after 12 months. 21% said 7-12 months while the majority (77%) said between 0-6 months.

Reducing waiting times was therefore essential for participants, with **37%** stating this was one of the most important factors when choosing an NHS orthodontist. Unsurprisingly then, many participants called for the NHS to prioritise reducing waiting lists for children and young people, and for orthodontic practices to be transparent about the expected waiting times and to provide updates to keep parents, carers and children informed.

Moreover, a few participants suggested that orthodontic practices should explain the reasons behind treatment decisions such as watchful waiting, to enable parents and carers to understand why their child may have an extended wait to start treatment.

"Make the wait times shorter. 1-2 years for an orthodontist appointment isn't acceptable."

"We may need teeth removed under anaesthetic (autistic child, care leaver) for which there will be an additional waiting list. More clarity and shorter waitlists would be helpful."

"I think if they explain why there's watchful waiting then I think parents accept it more and they're less angry and frustrated."

"I don't mind waiting if I'm kept informed about what's going on."

<u>Appointment Times</u>

Lack of choice and flexibility regarding appointment times was also a significant barrier for respondents. Participants highlighted the limited availability of appointment times which often caused their child/person they care for to miss school.

Due to the typical age of orthodontic patients, this was particularly problematic as many children and young people are completing their GCSE or A-level examinations. This can also put strain on parents and carers who have to take their child to appointments during their working hours.

"We're trying to time it so he's not getting his braces tightened while he's got exams. I know they have to work during the day, but you think of all those children missing all of those hours of school, it's an enormous amount of schooling impacted by this."

"Our nearest orthodontist is a 20–30-minute drive away and appointments are only available in the school day which means that my son regularly misses 1.5 hours of school and I miss work to take him to appointments."

"Timing of appointments was difficult – school didn't want appointments in school time but orthodontic appointments often weren't available out of school time."

However, one participant had a positive experience, recalling that their orthodontic practice offered appointments after school to accommodate their child who was sitting exams. This is an example of good practice that other NHS orthodontic practices should intend to adopt.

"Clearly Baldock had thought 'This kid's in year 11 now so we'll try to make sure appointments don't interfere with their schooling much' – whereas none of other practices have been able to do that."

Parents and carers also expressed dissatisfaction with NHS orthodontic practices that offered greater flexibility with appointment times and after school/weekend appointments exclusively to private patients, which was a common occurrence.

"Unfortunately the way they run their business is that they give the evening and weekend appointments to those who pay for it."

Case Study: Discrepancies in Care

Sue* had varied experiences with four of her children who received orthodontic treatment from different practices across the county. Sue's experiences were coloured by a lack of information from some practices regarding waiting times and the uncertainty and inconveniences that arose as a result.

"I don't mind waiting if I'm kept informed about what's going on. What I don't like is having to chase my dentist and me then – once they've had their teeth removed – ringing up and saying, 'They've had their teeth removed,' and then having to chase again for an appointment."

Sue also highlighted the discrepancy in the communication she received which seemed dependent on whether her child was an NHS or private patient. For her child who was an NHS patient in another town, the communication was lacking. Comparatively, her other child who was receiving private care at the same practice was communicated with promptly.

"It seems I'm always having to chase at the practice if you're on the NHS, whereas if you're a private patient at the practice, everything is sorted out and they phoned us and told us, and everything was just communicated to us better."

Due to this, when participants were asked when they would prefer their child to have an orthodontist appointment, the majority (74%) said they would like appointments to be before 9:00am, after school hours or at the weekend. Only 13% said they would prefer an appointment during typical school and working hours (9:00am – 3:00pm).

Therefore, a large number of participants suggested that more appointments should be made available outside of school and working hours and at weekends to improve access to NHS orthodontic care.

"Saturdays and Sundays because my son goes to an out of county specialist school a long distance from home which means any appointments during the week requires him to miss a whole day of school."

"Having later appointments would help because I'm having to take the time off to take them, so more flexibility with appointments would be good."

"We would like the option of some flexibility to reduce the amount of time missed from school."

"Appointments that are not within the school day. My daughter was in year 10 at the time and had to always miss some of school."

Travel and Location

Almost half of all participants (46%) said the location of services was a key factor when choosing an NHS orthodontic practice. However, some had to travel long distances to their child's appointment and would prefer to access an orthodontic practice more local to them. Nonetheless, most participants (67%) were happy to travel up to 30 minutes to appointments, while 21% would be willing to travel up to 15 minutes.

"By the time I've driven them to school, done the wait, come back, dropped them back at school and then I've got back to my work, that's a 2-hour turnaround."

"Referred to a practice in Watford when we live in Berkhamsted – 14 miles away."

"Have to travel from Ware to Stevenage – every time we go it's a minimum of two hours."

Some parents and carers were willing to travel further afield, with 11% stating they would travel up to 45 minutes for appointments. These participants were happy to travel if it meant their child would receive high-quality treatment, a better choice of appointment times, and/or shorter waiting lists.

"We went to the orthodontist which our normal dentist recommended, so they're in Watford which is a bit of a pain but I'm happy to travel to Watford if it gives her the best treatment."

"If the appointment was at a weekend then I'd be happy to go further, or after school. But when it's during school hours which the majority of them have been, I think the maximum I'd be prepared to travel is 20-30 minutes from their school."

"I would rather go to the best orthodontist in the area in Watford than the second best in Hemel."

Most participants were able to travel further, with the majority (79%) stating they and their child would travel to their orthodontic practice by car. However, 20% used other means such as public transport, taxis, and walking, meaning that services need to be within a reasonable distance to their home, work and/or school – particularly if appointments are only offered within school and working hours.

Understandably then, when participants were asked where they would prefer their orthodontic practice to be located, almost half (49%) said near their home while 35% said near to their child's school – both with the intention to reduce the distance to travel, and time out of school and/or work.

"The most important thing for me is somewhere close enough so that it disrupts their education the least."

"Also the opportunity to move closer to my child's school so she could be more independent and it would not impact the working lives of my husband and myself quite so much."

Appointment Availability

Appointment availability was essential to a large number of participants, with **40%** stating it is one of the most crucial factors for them when choosing an NHS orthodontic practice.

However, some participants experienced limited appointment availability which in many cases led to disruptions to progress and delays in the completion of treatment.

Participants also shared that they are given little choice regarding appointments and have to simply "accept what they are given."

"Orthodontic practice has very limited availability for appointments so he can only be seen every 3 months."

"Appointments are 12-14 weeks apart instead of 6-8 weeks and we have little choice in what's given."

"We are very aware that should we need to change an appointment we would then have a long wait for the rescheduled appointment."

Positively however, most participants who required urgent or emergency appointments were able to access support in-person, over the phone or via text from their orthodontic practice. Each case was dealt with effectively and in a timely manner.

"I had to get an emergency appointment and they were able to arrange that really quickly for me."

"She did have a bracket that came off but they got her an appointment and put it back and they help and give advice over the phone."

"The practice has a really great system where you can text because one of my son's braces broke once when we were away and it cut into his tongue and we got advice by text because we were actually in Northern Ireland at the time visiting family so that was really good."

Quality of Care

Participants were asked to rate the level of care their child received during treatment from 1-6 (with 1 being very bad and 6 being very good).

★: 7%

★★: 7%

★★★: 10%

★★★★: 15%

★★★★★: 21%

★★★★★★: 40%

As shown in the diagram above, most participants said the treatment their child received was very good and they were satisfied with the care their child received. Of these participants, many shared that the practice staff had good communication and were kind, helpful, informative, and professional. As a reflection of this, **82%** of participants said they would recommend their orthodontic practice to family and friends.

"The practice was amazing. Lovely people. Well organised. Always got an appointment that suited us."

"We have been very happy with the care that has been given – all staff have been professional and knowledgeable."

"The orthodontist is good at explaining what they are doing and putting my child at ease."

However, some participants said their child received inadequate care from practice staff and felt they could have involved their child more and communicated more effectively with their them.

"The beside manner of the provider was very poor. I complained and things improved."

"My poor children who know nothing about NHS healthcare or dentistry are just sitting there – they're not stupid boys but they're completely not involved in these conversations at all."

"You should have it set up so that every single child that comes in fully understands what you are doing."

Similarly, a few participants felt that the care their child received was "rushed" and impersonal. They commented that the orthodontic practice seemed to be prioritising efficiency over personalised care, with one parent viewing the service as a "conveyor belt."

"The care was fine. However it felt very "rushed" and "that'll do" rather than thorough and personalised."

"Listening to individual patient's needs and not worrying about the fact the appointment slot is x time so they have to rush and traumatise children."

"I feel as though my daughter was a means to receiving funding rather than a patient that was valued and to be cared about. I appreciate the funding difficulties of dentists and orthodontists who provide services for NHS patients but we felt we were an inconvenience."

"It wasn't very clear when things were happening and what was going on."

Communication

Linked to the above, improving communication was a priority for participants, with many sharing that they did not have the opportunity to raise concerns or to ask questions. This included technical questions about the treatment process, and how particular conditions will be fixed. In particular, children and young people said they would like more information about how to care for their braces and managing pain and discomfort.

"What is this 'cross jaw' or 'cross bite'? I've got no idea, they didn't explain it to me, they didn't show me a diagram, I barely even heard the word."

"After they put the braces on I feel like maybe they could have explained a bit better how to look after It because it was just a one minute conversation. They gave me the cleaning kit but it had no instructions, there was no piece of paper or anything."

"My youngest will potentially still have braces when he goes to university, how's that going to work? Can you transfer the treatment over? How long is it for? Can you have them taken off early? I just don't have any of that information."

Parents and carers also commented that staff should involve and communicate with parents, as well as their child. Many parents did not feel adequately involved in their child's care and were not informed about key decisions. Parents and carers called for greater involvement so they could understand how best to support their child.

"Sometimes the orthodontist spoke to my child but did not talk to me so I did not know what advice was being given and that makes it hard to support my child."

"No space for parents to attend the appointment so my child has to go in on their own and for some children this is daunting and they would like their parent/carer with them."

"As my son is an older teenager he was briefed about caring for his new braces without me being present. He wasn't prepared with any questions to ask and didn't remember the information he was given. Neither of us were prepared for the discomfort that followed his first appointment – if we were, we would have had painkillers ready."

Case Study: Lack of Choice and Information

Carys* had a mixed experience of orthodontic care with her two sons in Hertfordshire. She felt that the process was efficient, but the orthodontist's rigid approach to treatment removed the sense of choice for her and her children.

"You're going to have braces come hell or high water, and at no point was there any kind of time – which I would expect of my team – where you sit down with the patient and parent and say, 'This is what we've found, it looks like this on the X-ray, these are the options.' ... It's like a well-oiled machine, but it feels like it's a well-oiled machine that's pushing through a thousand teenagers to the end point, which is to put braces on so everyone has perfect teeth, but I'm not quite sure we all need that."

The lack of flexibility and communication also resulted in confusion about timescales and treatment options. Carys recalled how she and her children felt they had to research what was said during appointments as they were not directly informed. Carys felt that there needs to be more consideration for the patients and their parents to ensure that they are informed about their treatment.

"I know what it's like – when you're in an area you know it inside out, but there's a complete disconnect from the people working in the practice and where I'm at as an individual knowing nothing about what the implications are... I'm not sure if we had all the options, we would have chosen to have braces."

Please note a pseudonym has been used to protect the participant's identity.

Choice of Treatment

Linked to choice and information, a number of participants felt that NHS orthodontic practices should offer parents, carers and children and young people more choice of treatment options. Some participants said they were not informed or consulted about whether the orthodontic treatment was necessary and/or were not presented with any choices or alternatives.

"It was almost like it was a done deal because you were referred and you're quickly through the process."

"Inflexible treatment. There was one option which wasn't suitable for my child (SEN). So told would have to wait a year and then ask for a referral to the hospital. We have now gone private and are doing Invisalign which is being done at my child's pace with a very caring dentist."

"Preventative care is not mentioned as an option which is available at some private orthodontists. This could save a lot of money e.g. myobrace."

Two respondents suggested there should be a wider choice of treatments, particularly for children and young people with disabilities and/or additional needs. Because of this, some participants had no choice but to access private orthodontic care for their child due to the lack of treatment options available on the NHS.

"I think the NHS orthodontist could perhaps be a bit more flexible with their approach. The reasoning they gave was that the bite wouldn't align, then having spoken to the private orthodontist he said yes that is the sort of gold standard but that isn't the only improvement that could be made."

"We had to go down a different route and go private. She's having Invisalign because the regular orthodontist wouldn't do it another way. The private one said it won't be the perfect result but it will be an improved result which to be honest after that experience, she was happy with."

In addition, participants expressed a lack of awareness regarding their choice of orthodontic practice. **51%** of the participants surveyed were not aware they had a right to choose which orthodontic practice their child accessed, with many commenting that being able to transfer to a practice of their choice could allow greater flexibility and accessibility.

"When we were sent to Hitchin with my son, that was the only other option presented to us by the dentist. We weren't really given much choice."

"We didn't really have a choice, we just went with the one they said."

"We have a more local orthodontist to my child's school but have been unable to transfer there, despite it being the same practice with 2 branches."

Continuity of Care

Continuity of care refers to connected and coordinated care for patients as they move through the healthcare system. This was an area for improvement cited by participants. Communication between different professionals was poor for some, which often caused delays to referrals and extended the overall length of their child's treatment. For a few participants, delays, and miscommunication about whether their child qualifies for NHS treatment caused them to opt for private orthodontic care.

"Daughter was referred to one practice and told she did not qualify for NHS care even though she had a 6mm overbite with functional impairment. We asked for an explanation from the practice and this was not forthcoming. We then asked for a second opinion for which there was another wait and they agreed that she did qualify for NHS care."

"He was initially refused an orthodontic referral by the mainstream dentist but then he was seen by a special care dentist and was referred."

"We spent a lot of time going back and forth between the dentist and orthodontist."

Some participants had to chase their orthodontic practice to book follow-up appointments and receive essential information about their treatment. Parents and carers often had to facilitate communication between different professionals, leaving some to feel they had been forgotten in the system.

"The dentist said I'm going to have to refer her to a specialist clinic so we said ok and we went away and waited. Then after about two, three months I rang and it transpired that they hadn't referred us, they had forgotten."

"Coordination between orthodontics and oral surgery was lacking prior to surgery resulting in unnecessary appointments."

"If the orthodontist doesn't send the letter to the general dentist you're then phoning up these two people trying to get them to communicate with each other."

As such, participants called for greater continuity of care and better communication regarding referral pathways.

"Clarity from the dentist at the point of referral. We were told several different things and wasted time we don't have as carers trying to pursue referral to different orthodontists in St. Albans and Harpenden when it transpired he actually needed to be under the hospital orthodontics."

"Communication of referral pathways. Dentist told us different things and it was unclear that we needed hospital orthodontics team and the reason why was not given."

Understanding of Additional Needs

A number of participants felt that their child's orthodontic practice did not have an adequate understanding of how to support children and young people with additional needs, such as autism or learning disabilities. Participants called for NHS orthodontic practices to have more training and greater awareness of these needs to improve the quality of care provided.

"Better communication with my child. More flexibility for children with additional needs.

More consideration given to disabled children needing braces."

"They really need to have a better awareness of autism and learning disabilities."

"More autism training for orthodontists so they know how to communicate better with autistic people."

In addition, one parent shared that their child struggles to physically access their orthodontic practice, resulting in them receiving inadequate care. This further highlights the need for NHS orthodontic practices to improve accessibility and the provision of reasonable adjustments.

"My son is in a wheelchair and it is very difficult to access the orthodontist from the parking to physically entering the building and getting him in the chair. They had no way of taking X-Rays."

Summary

This research aimed to explore patient views and experiences of NHS orthodontic services in Hertfordshire. The findings from the survey and interviews show that while around half of all participants were satisfied with the treatment they received, half also felt there was room for improvement.

It was clear that many people felt the level of **communication and information** provided by their orthodontic practice was lacking. Patients were often left feeling uninformed about their treatment, or unaware of how long they would be waiting to start treatment. Therefore, ensuring patients and their parents or carers are informed ahead of their first orthodontist appointment and allowing for time at the end of appointments to ask questions or discuss concerns is vital.

For the majority of participants, **waiting times** was a significant barrier to accessing orthodontic treatment. The lack of communication and information provided compounded this, as many were left not knowing whether they had been referred by their dentist. As a result, providing information and general updates ahead of the initial appointment would prevent parents and carers from needing to take on the responsibility

of chasing for updates. Moreover, some parents and carers expressed greater willingness to wait for their child to start treatment if they were kept informed.

Some felt that the **continuity of care** was lacking, due to a disconnect between their dentist and orthodontist. Some people were sent to appointments without having had extractions, which created further delays to treatment. Setting up greater communication between service providers would ensure that individuals are referred appropriately and are prepared to start their treatment.

Many had difficulty with **appointment availability**, as most appointments were only available during school and working hours. As most people travelled to their appointments by car, this resulted in inconveniences due to scheduling. Moreover, missing school was a primary concern for parents and carers, as the majority of orthodontic patients are at the age where they are sitting GCSE and A-Level exams. Providing equal access to flexible appointment times outside of school hours for both NHS and private patients would reduce the pressure on children and their parents and carers to attend their orthodontic appointments at difficult times.

Several participants also raised concerns around **accessibility** and reasonable adjustments for those with additional needs. For some, it was difficult to attend appointments due to a lack of functional disability accommodations, such as for wheelchair users. For others, inadequate communication for those with autism or learning disabilities caused a lack of clarity in terms of treatment progression. Ensuring clearer communication for those with additional needs is crucial to ensuring the level of care is equal for all patients. Also, offering alternative treatment options to people with sensory processing difficulties and other differences would enable everyone to have equal access to orthodontic treatment and care that is personalised to their needs.

Recommendations

The findings have highlighted a range of suggestions for improvements regarding access to NHS orthodontic care. This includes reducing waiting lists, greater flexibility in appointment times, more appointment availability, and the provision of more local services. However, participants also made several other recommendations for how NHS orthodontic care could be improved. These recommendations are listed below.

Improving communication from orthodontic practices to ensure individuals are adequately informed about their treatment. This could be achieved by:

- Ensuring information is provided prior to first appointments to allow patients to ask questions about their treatment.
- Allowing time for patients and/or parents and carers to ask questions during appointments.

- Explaining the orthodontist's choice of treatment and providing details of any viable alternatives.
- Clear explanations about NHS eligibility and guidance on aftercare, such as caring for braces.

Improving the level of information provided by orthodontic practices to enable patients to ensure autonomy and involvement in treatment decisions as appropriate. This could be achieved by:

- Informing patients of their right to choose which orthodontic practice they attend.
- Allowing patients to opt out or change service providers, particularly when treatment involves functional corrections or treatment to reduce pain and discomfort.

Improving transparency around expected waiting times from the point of referral to starting treatment. This could include:

- Explaining reasons behind treatment decisions, such as watchful waiting.
- Providing updates regarding waiting times and making people aware of their right to move practices to access treatment sooner if desired.

Improving the continuity of care between dentists and orthodontists would reduce the number of patients whose referrals are forgotten or lost. This could be achieved by:

- Communicating with patients and their parents or carers about the progress of their referral and providing timely updates. This would ensure individuals are aware of where they are in the system and make it easier for people to be tracked throughout the system and reduce the risk of being forgotten or left waiting.
- Making sure any prior treatment (such as extractions) is complete before patients attend their first appointment.

Ensuring greater appointment flexibility for patients would reduce the difficulty some face with taking their child to orthodontist appointments. This could be achieved by:

- Consulting with parents and carers regarding the days and times that are most suitable for them.
- Providing practice transfers to those who have been referred to a practice that is
 far from their home, school, or place of work, and prioritising those who experience
 the most difficulty with attending appointments.

Enhancing appointment availability for patients would make it easier for individuals to attend their appointments. This could be achieved by:

 Offering appointments outside of school hours, particularly for patients who are sitting exams, to ensure the amount of school missed is kept to a minimum.