Understanding children and young people's experiences of primary care

Research for NHS England

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Contents

1 Executive summary

In order to improve the future health of the population, it is crucial to ensure that children and young people (CYP) have a positive experience when using health services. Yet, research about children and young people's experience of primary care is scarce, and much of the research exploring patient experience of primary care does not capture their views.

Engaging CYP and their parents through a range of qualitative methods, this research project – commissioned by NHS England and conducted by Ipsos MORI – was not only designed to begin to fill this gap in knowledge, but also aimed to understand the most effective methods of seeking feedback on primary care from CYP.

Experiences of primary care

Aside from feelings of nervousness and unease, CYP generally held few strong opinions about using primary care services. In contrast their parents often displayed strong and animated views about primary care services and the care their children received.

Yet, when probed, CYP were able and willing to talk in more depth about the factors that influenced their experiences of primary care. Indeed, CYP across all age groups went further than just identifying issues, and in many cases suggested ideas for improvement[1]. Notably, females aged 13- to 15-years-old held consistently strong opinions about certain aspects of their primary care experiences and were especially keen to suggest measures to enhance them.

Taking steps to make CYP feel welcome when using health care services was recognised as an important factor in improving CYP's experiences of care, with CYP across all age groups describing feeling out-of-place when using primary care services. **The time that CYP spend waiting for their appointment**, and the physical environment of the waiting area was also perceived as having a critical influence over whether or not CYP have a positive experience of primary care.

Feeling pressured and anxious when speaking to clinicians was commonly reported by CYP as they valued the **quality of communication between them and clinicians.** CYP, and to a lesser extent their parents, placed a high importance on clinicians being friendly and approachable, and using language and other forms of communications that CYP can understand. Female CYP also felt clinicians should not ask sensitive questions at the beginning of a consultation, and in front of their parents.

CYPs often **didn't feel engaged in their care** as clinicians' focus was primarily on their parents, which could lead to miscommunication. This was not widely recognised by parents who often felt that clinicians engaged with their child fully in the appointment. The **lack of consistency of care** and **the inability to see a doctor alone** were also reported, to have a negative impact on experiences of primary care of CYP (and especially older female CYP).

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[1] These can be found throughout the report and the full list in the conclusion.

Collecting feedback from CYP

While there was consensus among the stakeholders who were consulted - including experts within the voluntary and primary care health sectors - that the collection and use of patient experience data from CYP was of critical importance, the picture was more mixed among parents and CYP. Some parents were keen to have the voices of their children heard, but others believed that CYP lacked objectivity and critical thinking skills, and this could impair the quality of the data collected.

Strikingly, CYP often felt initially reluctant to the idea of giving feedback but often changed their minds throughout the groups or interviews, concluding they would like to be given the opportunity, although they did not want to be pressurised into doing so. They recognised not only that their primary care needs might differ from adults', but also that their own parents might have biased perceptions of their care and might not be best placed to feedback about their experiences. And despite concerns over anonymity and giving negative feedback, CYP believed that the feedback collected could be used to drive change and improve primary care at both national and individual-practice levels.

While participants' views on the most appropriate timing, frequency and location for CYP to be asked to feedback about their experiences of primary care varied, CYP across all groups expressed a preference for paper questionnaires.

2 Introduction

In order to improve the future health of the population, it is crucial to ensure that children and young people (CYP) have a positive experience when using health services. Research has demonstrated that the attitudes and behaviours that are developed while young are likely to influence interactions with health services throughout the life-span[2]. Linked to this, there are potential benefits to be gained from introducing young people to the importance of giving feedback, and empowering them to do so as they approach adulthood, as a basis for their future relationship with the NHS. Yet, the ability to understand CYP's experiences is inadequate, and much of the research exploring patient experience of primary care[3] – the health service most utilised by CYP – does not capture the views of CYP.

Most existing patient experience surveys are restricted to adults or, where children and young people's experiences are measured, parents or caregivers are asked to respond on their behalf. A review of data about experiences of CYP using the NHS noted that, of 38 national surveys identified by the Department of Health and Social Care as having been undertaken or planned between 2001–2011, patients under 16 were included in only one – the Young Patient Survey 2004, which was confined to inpatient and day care[4]. While the 2016 CQC Children and Young People survey[5] is a welcome addition to this small body of evidence, it only focuses on their experiences of inpatient and day case care. And although this year's GP Patient Survey was open to 16- and 17-year-olds for the first time[6], CYP's feedback is not currently being regularly and nationally collected and analysed. This lack of evidence is even more striking considering it is estimated that CYP constitute an estimated 40 per cent of GPs' workload[7].

This lack of robust insight into CYP's experiences of primary care is problematic for those planning and delivering primary care services for children. Additionally, some evidence suggests that children and young people tend to report more negative experiences of patient care than their older counterparts. In this year's GP Patient Survey, for example, just 77 per cent of 16- to 24- year-olds said they felt their overall experience of their GP surgery was 'good' or 'very good', compared to an overall average of 84 per cent[8].

The research detailed in this report – commissioned by NHS England and conducted by Ipsos MORI – was designed to begin to fill this gap in knowledge. It had three key objectives:

1. To understand what matters most to CYP when receiving primary care;
2. To identify ways in which CYP's experiences of primary care can be improved; and,
3. To understand the most effective methods of seeking feedback on primary care from CYP.

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[2] Hargreaves D S, Viner R (2014) Children's and young people's experience of the National Health Service in England: a review of national surveys 2001–2011. Arc Dis Child 2012;97:661-666, available at: https://adc.bmj.com/content/archdischild/97/7/661.full.pdf [accessed 7 September 2018]

[3] Primary care services provide the first point of contact in the healthcare system and includes general practice, community pharmacy, dental and optometry services.

[4] Ibid. 2.

[5] https://www.cqc.org.uk/publications/surveys/children-young-peoples-survey-2016

[6] NHS England (2018) *GP Patient Survey, National Report, August 2018 Publication*, available at: http://www.gp-patient.co.uk/surveysandreports [accessed 24 August 2018].

[7] Department of Health (2013), *Improving Children and Young People's Health Outcomes: a system wide response*.

[8] NHS England (2018) *GP Patient Survey, National Report, August 2018 Publication*, available at: http://www.gp-patient.co.uk/surveysandreports [accessed 24 August 2018].

Following a scoping phase, the research entailed qualitative research, including depth interviews, focus groups and a real-time mobile exercise with CYP, parents and stakeholders. Full detail of the research methodology can be found in the appendices.

While this research aims to provide initial insight into ways in which CYP's experiences of primary care can be improved, and recommendations about how primary care services might strive to collect feedback from CYP, it is clear that it will need to be supplemented by substantial efforts at both the national and local level to ensure that CYP's opinions on primary care are increasingly heard.

Structure of this report

The report is structured around the research key objectives. It presents findings around three main themes, namely:

1. Participants' attitudes towards primary care;
2. Participants' views on which factors affect their experiences of primary care;
3. And participants' views on giving feedback about their experiences of primary care, and their favoured feedback mechanisms.

Acknowledgements

Ipsos MORI would like to thank the team at NHS England for their help and guidance with this study. We would also like to thank all of those who participated in the research and shared their views with us. The research would not have been possible without them.

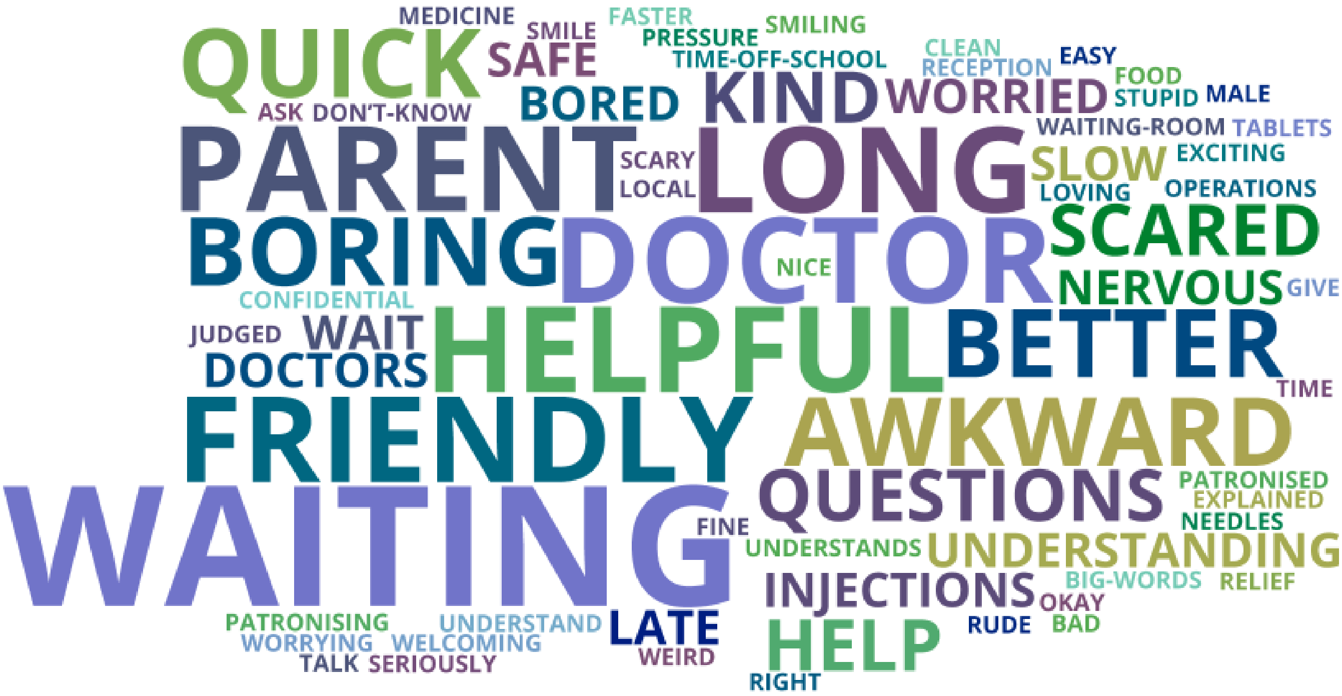
3 Attitudes towards primary care

This section explores CYP's and their parents' or carers' (hereafter referred to as parents) overall attitudes towards using primary care services. In doing so, it sets the context for the following sections which look in greater detail at the factors which affect CYP's experiences of using primary care services.

In order to gather CYP's overall impressions of using primary care services, participants were asked to reflect on what first came to mind when they thought about visiting a GP practice. The word cloud below shows the words that were mentioned by CYP who participated in the focus groups. The most frequently word mentioned was 'waiting'. As will be discussed in the following chapter, CYP's experience of waiting for their appointment can have a huge bearing on their overall experience of primary care.

Aside from the focus on waiting, other words mentioned tended to pertain to interactions with staff (e.g. doctor, helpful, friendly, awkward, understanding) and CYP's own feelings about using primary care (e.g. scared, nervous, safe, worried).

Figure 1: Words that came to mind when CYP were asked to think about visiting a GP practice.



Turning to look at CYP's feelings about using primary care services more closely, CYP and their parents tended to express two contrasting emotions; nervousness and indifference. It is worth noting that while parents often misjudged what their children thought about the consultation itself, their perceptions of their children's overall experiences of using primary care were generally accurate.

CYP and their parents associated feelings of nervousness with:

- The potential pain that might be experienced. Parents of younger CYP explained how their children tended to associate primary care with needles and vaccinations which made them feel particularly anxious.

- The worry about being asked questions that they couldn't answer, or misunderstanding what was being discussed during the consultation.
- Concerns about being placed in awkward situations, or being asked awkward questions, by the doctor.

Aside from these feelings of nervousness, CYP generally showed few strong opinions about using primary care services. This stood in stark contrast to their parents, many of whom displayed strong and often animated views about primary care services and the care their children received.

CYP's indifference was likely to be largely because, regardless of age, they tended to rely heavily on their parents, most of whom took a high level of responsibility for organising primary care for their child. CYP appeared to be somewhat passive agents throughout every stage of the visit: from their parents assessing the seriousness of an illness and booking appointments, to them taking control of the conversation with clinicians throughout the consultation. Overall, CYP's narratives suggest that GP visits happened *to* them.

"They're worried. They don't know what's going to be asked of them, and they're very quiet, you have to speak on their behalf." *Parent*

Parents also suggested that one of the reasons CYP had few opinions on their experience of primary care was because they had limited relevant experiences to compare it to. The research methodologies enlisted in this study supported this suggestion; it was notable that CYP were more critical in the focus-groups, which enabled them to compare their own experiences to those of other participants, than in the depth-interviews. This finding in itself has important implications for the way in which feedback is collected from CYP.

"I don't think a child would necessarily know what's good and bad, because they don't have anything to compare it to." *Parent*

Despite this general passivity, when probed, CYP were able to talk in more depth about the factors that influenced their experiences of primary care, whether for the better or worse. Indeed, one notable exception to the trend towards passivity was seen among females aged 13- to 15-years-old, who held consistently strong opinions about certain aspects of their primary care experiences.

The topics that were spontaneously raised by the CYP during the real-time feedback exercise closely mirrored those which were raised during the focus groups and in-depth interviews, validating the findings from these strands of the research. However, there was some indication CYP more frequently raised negative feedback in the real-time exercise. This may be because they were more likely to remember these issues a short time after their appointment, or it may be a consequence of their heightened awareness, having previously participated in a focus group or in-depth interview.

The following chapters detail the key factors that were identified as having an important influence over CYP's experiences.

4 Factors which affect CYP's experiences

This chapter explores the factors which have the greatest impact, whether positive or negative, on CYP's experiences of primary care. While some factors were raised by certain groups of CYP more than others (whether dependent on age, gender or frequency of use of primary care services), all were frequently mentioned in our interactions with CYP.

Throughout the chapter, recommendations for improving CYP's experiences of primary care are provided. In the majority of cases, these recommendations were suggested by the CYP themselves. Although most of the suggestions are common-sense and straightforward to implement, feedback from CYP highlights that in many cases they are not currently being met. Consistent implementation of these recommendations across primary care services will help to ensure that CYP have positive experiences of primary care, with benefits to the CYP themselves, individual primary care services and the wider health sector.

4.1 Being made to feel welcome

Taking steps to make CYP feel welcome when using health care services has been recognised as an important factor in improving CYP's experiences of care. The CYP consulted in the research supported this, with some CYP across all age groups describing feeling out-of-place when using primary care services.

The feeling that CYP are not welcome can start as soon as the CYP arrives at the GP practice. The majority of CYP reported that they preferred their parents to check-in with reception staff upon arrival, either because they did not feel that reception staff would take them seriously, or because they were concerned that they would not be able to provide the receptionist with the required information.

In the few cases where CYP had spoken to the receptionist themselves - whether by choice or necessity - they often reported facing barriers. For example, one CYP reported being turned away by the receptionist and asked to return with her parent. Another had been referred to alternative services - including a website - when she had asked to speak to a GP without a parent present.

"I ask for my mum to speak to the receptionist because I've been up before and they've said, 'Can we speak to your mum?'. If your parents couldn't get there, I feel like they wouldn't want to see you. I feel like they'll only take me seriously if my mum's there." *CYP, female, 13-15 years*

Although these experiences were mentioned most frequently by female participants aged 13- to 15-years-old (who were more likely than younger and male participants to have attempted to visit a GP without a parent), there was a widespread perception across all groups of CYP that it was not possible to visit a GP practice alone. This implies that the GMC's guidance to doctors—that doctors "*should make it clear that they are available to see children and young people on their own if that is what they want. Doctors should avoid giving the impression (whether directly, through reception staff or in any other way) that they cannot access services without a parent*."[9]—is not currently being met for those who participated in the research.

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[9] https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/0-18-years/communication

Recommendation: Reflecting the GMC guidance, primary care services should aim to accommodate CYP who wish to see a clinician without parental accompaniment. Primary care services should ensure that policies in this area are applied and communicated consistently by all staff.

More generally, CYP appeared sensitive to the perceived friendliness of reception staff. Especially among parents, there were criticisms of receptionists who were perceived as difficult or rude. CYP's views of reception staff often echoed the negative ones of their parents. However, as the CYP admitted having very little contact with receptionists themselves, it is worth questioning the extent to which they repeated what they had overheard their parents discussing, rather than having been affected negatively themselves. Additionally, these views weren't shared by every CYP with some describing receptionists as 'nice' and 'friendly'.

4.2 Waiting for the appointment

While research on children's experiences of primary care is scarce, those studies that exist have mainly focused on the relationships between children and primary care staff. Strikingly however, the time that CYP spend waiting for their appointment was mentioned frequently by both parents and CYP as an important influence over whether or not CYP have a positive experience of primary care. In the real-time feedback exercise, waiting times were frequently mentioned by CYP when describing their experiences of appointments. Specifically, the physical environment of the waiting area, can play a crucial role in ensuring that the CYP feels welcome and comfortable when using primary care services.

Although there appeared to be variation between primary care services, CYP often described waiting rooms as 'boring' with few age appropriate recreational activities to engage in while waiting to be seen. In many cases they felt any toys and games that were provided were suitable only for very young children, and that magazines and books tended to be suitable only for adults.

> ***"There's no colour in the doctor's waiting room. It has benches and is bland. There's nothing stimulating."*** *Parent*

Parents echoed these views, with some reporting that they had noticed the availability of recreational activities within waiting rooms decrease over the years. This caused some to wonder if toys and books might be source of cross-infection. Some parents and CYP also contrasted hospital waiting rooms, which tended to cater well for children compared with GP practices.

However, even provision of modest entertainment was often enough for CYP to report positive experiences of the waiting area—and in some cases to look forward to visiting their GP. For example, water coolers, BMI machines, educational posters on walls and regularly refreshed comics were all described positively by CYP.

Recommendation: The reception and waiting area should be welcoming and provide a variety of recreational activities which are age appropriate for a range of CYP, including older CYP. For example, educational posters and regularly refreshed magazines or comics.

CYP's and parents' concerns about waiting rooms were compounded by delayed appointments. Parents, and often CYP, were sensitive to the pressures faced by primary care services. However long waits for appointments were a recurrent frustration. Given the frequency with which GP appointments run behind schedule - around one in three patients (31%) report that their last GP appointment was at least 15 minutes late[10] - this is an issue that is likely to impact a large number of CYP.

CYP described how the uncertainty about when they would be called to their appointment could cause extreme boredom and exacerbate any anxiety they were feeling. Parents also noted that CYP were far less able to deal effectively with these feelings than an adult in the same situation, and that delays were therefore likely to have a disproportionally negative impact on CYP.

Parents also complained that having to wait for long periods surrounded by unfamiliar and sick people could trigger challenging behaviour from their children. Several CYP also stressed how they worried about getting ill if they stayed too long in the waiting room. It was notable however, that mentions of these issues were limited to a very small number of CYP in a single focus group, indicating that this was not a widely shared concern among CYP.

Both parents and CYP suggested that primary care services could do more to forewarn patients about delays to appointments. Some parents described their practice calling patients to warn them if appointments were delayed by more than 30 minutes, so that they could wait at home, thereby minimising distress caused to children. A number of CYP suggested that they would like to be told on arrival how long they were likely to have to wait. In any case, a more proactive approach to updating patients about late-running appointments would be welcomed.

> ***"If I'd known the doctor was going to be so late, I could have gone home and come back. I was there and nobody was telling me what was happening. I was the one who had to keep going and asking. It was very frustrating, especially because my daughter wasn't very well and she was getting more and more agitated"*** *Parent*

Recommendation: Primary care services should communicate about late-running appointments when CYP arrive at reception, if not before. If possible they should provide estimates of lengths of delays.

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[10] NHS England (2018) *GP Patient Survey, National Report, August 2018 Publication*, available at: http://www.gp-patient.co.uk/surveysandreports [accessed August 2018]

4.3 Communicating with the clinician

The quality of communication between CYP and clinicians is crucial to giving CYP a positive experience of primary care and ensuring that both the CYP and clinician get the most out of the appointment. However, the latest Health Behaviour in School-aged Children (HBSC) survey reported that only half of young people (52%) feel able to talk about personal things with their doctor[11], implying that there is still significant progress to be made in this area. Indeed, the way in which clinicians spoke to CYP was raised by all groups of participants as having a large impact on their experiences of primary care.

A key theme emerging from the research was the pressure felt by many CYP when speaking to clinicians. CYP reported feeling worried about wasting clinicians' time, not understanding what clinicians were saying to them, or saying the wrong thing. It was notable that CYP with long-term conditions, who attended primary care on a more regular basis, reported being more confident communicating with clinicians.

"They are friendly, but if any doctor spoke to me, I'd be nervous. Because they're a doctor. It seems really important." *CYP, female, 11-13 years*

These concerns underlie many CYP's communications with clinicians and, perhaps linked to this, CYP placed a high importance on clinicians being friendly and approachable. Parents also recognised that the friendliness of clinicians could have a large impact on their child's confidence during the appointment.

"It wouldn't hurt for staff to have training on being warmer to children. Then children would know it's fine to see the doctor. When they're older, if they've had a bad experience growing up, they're going to be nervous. If the staff are warm and friendly, just a bit of personality, just a smile, the whole experience is more relaxed." *Parent*

In particular, the importance of greeting the CYP, as well as their parent, at the start of the appointment has been noted in previous guidance to clinicians[12]. In the focus groups, many CYP were able to report instances where they had not been acknowledged by the clinician. However, when clinicians took the time to greet them kindly and professionally, they reported that it made them feel more at ease.

The importance of quality of communication was also highlighted in the real-time feedback exercise. The friendliness of those in positions of authority, whether a clinician or otherwise, was often the first aspect of appointments that CYP chose to feed back about, reinforcing the importance of communication-style in all interactions with CYP.

"She was a bit sharp and patronising to begin with but when we started talking she was nice." *CYP, female, 13-15 years*

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[11] Brooks R, Magnusson J, Klemera E, Chester K, Spencer N and Smeeton N (2015) *Health Behaviour in School-aged Children English national report 2014*. Hatfield UK: University of Hertfordshire, available at: https://www.researchgate.net/publication/282857118_HBSC_England_National_report [accessed 24 August 2018].

[12] Public Health England, NHS England and Department of Health (2017) *You're Welcome Pilot 2017: Refreshed Standards for Piloting*, available at: http://www.youngpeopleshealth.org.uk/yourewelcome/standards/ [accessed 24 August 2018].

Recommendation: Clinicians should greet CYP, as well as their parent, personally at the start of the appointment to help them feel at ease and involved in the appointment.

A second factor which influenced the quality of communication between CYP and clinician was CYP's ability to understand what the clinician was saying, without their parent explaining it to them. CYP emphasised that they wanted to be able to understand what the clinician was saying, even when they were speaking directly to the CYP's parent. The speed of the clinicians' speech, as well as the complexity of the language used, had an impact on their ability to do so. CYP also wanted clinicians to check their comprehension with them, and offer them the chance to ask questions. Some CYP felt that they would not be confident enough to ask the clinician questions unless prompted to do so.

Recommendation: Clinicians should use language or other forms of communication that CYP can understand; moderating the speed with which they talk, as well as the language they use. To ensure comprehension, they should proactively ask CYP whether they understand what has been said, rather than wait for CYP to ask questions independently.

"Are you sexually active? Do you have a boyfriend? They say it as soon as you walk in."
CYP, female, 13-15 years

Finally, many of the older female CYP involved in the focus groups reported feeling embarrassed when asked sensitive questions by their GP, particularly when these questions were asked in front of their parent. There was a perception that clinicians asked these questions very early in the conversation, jumping to conclusions before exploring other potential explanations. In some cases, CYP reported finding this so embarrassing that they had resisted returning to see the GP in order to avoid these questions. CYP suggested that, to avoid having to be asked these questions in the consultation, CYP could be provided with a form to complete and return to the clinician.

Recommendation: Clinicians should aim to avoid asking potentially sensitive questions early in the consultation, particularly when other people are present. Where possible, clinicians should offer CYP the opportunity to provide necessary sensitive information by completing a form.

4.4 Feeling involved in care

As discussed earlier in this report, for many CYP the use of primary care services was passive, with parents playing a leading role at all stages of the patient journey. Some CYP, particularly younger and male CYP, reported that this was their preference, and that they did not wish to have a larger role in their care.

However, a significant proportion of young people did want to be fully engaged with their care, and to feel that they had a say in decisions that were made about them. The extent to which CYP felt this was possible varied, and a number of barriers to being fully involved in care were identified.

Across all groups, a significant proportion of CYP reported that during appointments, clinicians' focus was primarily on their parents rather than on them. In some cases, CYP described this as being overt, with clinicians speaking directly to the CYP's parent and making little effort to engage with the CYP. However, CYP also picked up on subtler cues that they were being overlooked. For example, one CYP described how, although the GP was making eye contact with him while speaking, questions were directed to his parent.

"He normally looks at me, but talks to my mum. He says, 'Oh, how is he feeling?" *CYP, male, 7-11 years*

Recommendation: Clinicians should speak directly to the CYP, rather than the parent, wherever possible. They should consider how they use non-verbal communication to ensure that the CYP feels engaged and listened to.

CYP explained that, by engaging with their parent rather than the CYP - even in cases where this was the CYP's preference - it could lead to miscommunication. A significant number of CYP, across all groups, reported incidents where their parent had explained something inaccurately, or said something that the CYP disagreed with, and they had felt unable to correct them. This finding is linked to the earlier point about the pressure that CYP feel when speaking to clinicians; CYP reported being concerned that to correct their parent would be seen to be wasting clinicians' time (especially when clinicians immediately made a note of what their parent had said), or that their interjection might not be taken seriously.

"Sometimes my mum tells the doctor how I'm feeling, but I think it'd be better if I told them. It would be better if I said it because I can't then tell her that she's wrong and tell the doctor something different." *CYP, female, 7-11 years*

Recommendation: Where parents speak on behalf of their child, clinicians should give CYP the opportunity to agree or disagree with what their parent has said before taking note of it. Clinicians should be aware of the effect that the presence of a parent can have on CYP.

This concern that CYP's opinions would not be taken seriously was another key barrier preventing CYP from becoming more involved in their own care. Some CYP reported that when they had contributed or raised concerns with clinicians, they had felt dismissed. CYP were aware that, in some cases, this might be due to the time pressures that primary care clinicians face.

"I feel like they ask your mum, but if you say something and they don't think it's relevant to the problem but you think it's relevant they're just like, 'Whatever.'" *CYP, female, 14-15 years*

Recommendation: Clinicians should take CYP's views seriously and not dismiss or appear to dismiss their concerns or contributions.

Interestingly, the extent to which CYP felt barriers to being involved in their care was not widely recognised by parents. In contrast to the experiences reported by CYP, many parents felt that clinicians engaged with their child fully in the appointment. Supporting this apparent disconnect, a recent analysis of national survey data - comparing CYP and parent responses about the same inpatient admission - found that CYP were less likely than their parents to report feeling they had involvement in decisions about their care.[13] This indicates that clinicians should not always take the parent's lead in the extent to which the child is involved in the consultation, as the parent themselves might not be aware of how their child views their involvement.

4.5 Seeing the preferred clinician

As previously detailed, almost all CYP reported that their parents booked their primary care appointments for them. As a result, CYP had limited opportunity to choose which clinician they saw. This barrier to choice has the potential to negatively affect CYP's experience of primary care as it was apparent that many had clear preferences.

Both male and female CYP, of all ages, expressed a preference to have a same-sex clinician where possible. CYP said that they would prefer a clinician of the same gender because this prevented any awkwardness they might otherwise feel.

"'I don't like it when I go to a male doctor and they ask me to take my t-shirt off." *CYP, female, 7-11 years*

Recommendation: Receptionists should be sensitive to gender preferences and ask parents when they are booking appointments whether their child would prefer a same-sex clinician. Clinicians should also be aware that CYP, of all ages and genders, may have preferences which have not been accommodated and offer them the chance of seeing a same-sex clinician where appropriate.

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[13] Hargreaves DS, Sizmur S, Pitchforth J, et al, *Children and young people's versus parents' responses in an English national inpatient survey,* Archives of Disease in Childhood 2018;103:486-491, available at: https://adc.bmj.com/content/103/5/486 [accessed 24 August 2018]

"It's better to see the same one, because then you don't have to feel awkward going in and wondering which doctor it is. They don't ask you the same questions. They've got a record and they don't have to keep repeating the same things." *CYP, female, 7-11 years*

Both parents and CYP said that consistency of care was important to them and that they would rather have the same clinician at each visit. As has been mentioned, feeling awkward during an appointment was a common occurrence. This was a particular issue for teenage girls. According to a recent survey, a quarter of girls (24% of Year 8 and 25% of Year 10) reported feeling 'quite uneasy' or 'very uneasy' with their doctor on their last visit, while boys reported more ease[14].

CYP thought that, by having the same clinician, they were less likely to feel awkward as they would not be asked questions about their medical history. They also thought that they would be more likely to feel comfortable having had the opportunity to build a rapport with the clinician. These issues were felt even more acutely by CYP who visited the GP regularly due to a long-term condition. These CYP generally reported that they saw the same clinician at each appointment, and felt that this was important element in managing their condition.

Parents also felt it was important for CYP to have consistency of care. They said that this made their children feel more at ease during their appointments as CYP would like to see a 'familiar face'. They felt this was more important for CYP than it is for adults, because adults were less likely to experience anxiety surrounding visits to primary care, whereas CYP need to feel as comfortable as possible during their appointments.

4.6 Being able to see a doctor alone

As discussed earlier in this report, there was a widespread belief among CYP that they were not allowed to attend primary care unaccompanied by an adult. For the majority of CYP, this was not an issue - most said that they wanted their parent to accompany them to the appointment in order to offer support.

However, some CYP said that they felt unable to speak openly with their clinician while their parent was in the room. This was sometimes because they felt that their parents would control the conversation with the clinician – describing situations inaccurately or in ways that they did not agree with. As discussed, CYP often lacked the confidence to correct their parents in front of a clinician.

"When I went to the doctor before, my aunt was telling him what was wrong with me. She didn't even know what was wrong." *CYP, female, 14-15 years*

Other CYP suggested they did not want to discuss certain sensitive topics in front of their parents. Again, this was largely reported by girls aged 14- to 15-years-old but was also mentioned by CYP in other groups.

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[14] Balding A and Regis D (2016) Young people into 2016. Exeter: Schools Health Education Unit, unpublished report

When in these situations, CYP often felt unable to tell their parent that they wanted to go to see the clinician alone. They suggested that they would prefer for the clinician to explicitly ask the CYP if they would like their parent to join their appointment, so that they had an opportunity to see the clinician alone, without having to raise the issue themselves.

"If it were coming from my doctor, it would be better." *CYP, female, 14-15 years*

Recommendation: Clinicians should ask CYP before beginning the appointment, or at any point in the appointment where the conversation turns to sensitive subjects, whether they would like their parents to remain in the consultation room.

5 Collecting feedback from CYP

This chapter explores the views of CYP and their parents about giving feedback on CYP's experiences of primary care. More specifically, it looks at whether they think giving feedback about such experiences is important, their favoured feedback mechanisms, and how the resultant insight should be used and communicated back to them. It also explores concerns held by both groups about giving feedback.

5.1 Attitudes towards collecting feedback

Among the stakeholders who were consulted from the primary care and voluntary sectors, there was a very strong consensus that the collection and use of patient experience data from CYP was of critical importance. They believed such information could help inform both the delivery of care and the overall experience of primary care for this group.

Crucially, there was a strong feeling that the patient experience data needed to be collected from CYP themselves, rather than by using parents as a proxy. Stakeholders cited the UN Convention on The Rights of the Child which states that the opinions of CYP should be considered when making decisions about things that affect them, and that they shouldn't be dismissed out of hand on the grounds of age[15].

> ***"Although the parent is very important, ultimately you're delivering care to the child and not the parent. I think it's important to get feedback from the person whom you're trying to target the care at."*** *Stakeholder*

However, the picture was more mixed among parents and CYP. While both groups believed that giving feedback about their experiences of primary care was a worthwhile exercise, which could be used to bring about tangible improvements, there were clear differences between participants.

Parents were often keen to have the voices of their children heard, but with some caveats. Most parents welcomed the collection of information about their children's experiences of primary care, but some questioned the quality of the information that could be collected from CYP for a number of reasons.

Some parents thought that children, especially younger children, had not developed the critical skills necessary to provide useful and relevant feedback. Some felt that CYP did not have enough relevant comparable experiences to have developed expectations, and therefore be in a position to provide meaningful feedback. Some concerns were also raised about CYP's lack of objectivity; some parents thought feedback given by their children would be driven by their mood, rather than their actual experiences. As a result of these concerns, some parents thought that they were in a better position to give feedback about their children's experiences, that the CYP themselves were.

> ***"I think we're more critical as adults than children. Sometimes it's wiser for an adult to give feedback."***
> Parent

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[15] UN General Assembly, *Convention on the Rights of the Child*, November 1989, United Nations, Treaty Series, vol. 1577, p. 3, available at: http://www.refworld.org/docid/3ae6b38f0.html [accessed 24 August 2018]

Yet throughout the course of this research, CYP of all ages demonstrated that they were not only capable of thinking critically about their experiences of primary care, but also able to suggest practical ways in which improvements could be made. There were some parents who, reflecting this, felt that it was highly important that CYP were given the opportunity to give their opinions and suggest improvements. They felt that CYP would be appreciative, that it would make them feel listened to, and that they would therefore be more likely to trust and be open with staff.

There was no clear consensus on the lower age at which feedback should be collected from CYP. Due to the concerns around collecting feedback that have been outlined, some parents felt that only CYP aged 7 or older would be able to complete a feedback form without their parent's input. However, other parents suggested that, if the feedback tool was designed with younger children in mind, much younger children would be able to provide feedback. Stakeholders also emphasised that, in order to ensure that feedback exercises are as inclusive as possible, there should be no lower limit on the age range asked to complete the survey.

> ***Don't limit the age range – try to make it as inclusive as possible. Even if CYP can only complete some elements. If it's drawing that can be any age. A very creative 5-year-old could create something really powerful. A 7-, 8- or 9-year-old might be very eager to write and explain.***
> Stakeholder

It is important to note however, that making the feedback mechanism accessible - whether through the feedback tool, the feedback mode or both - may affect the quality of the data that is collected. This could have implications for the way in which it is possible to use the data. For example, some forms of feedback, such as drawings, could only be analysed qualitatively.

Recommendation: Feedback mechanisms should be as inclusive as possible, incorporating feedback tools (for example drawing) that allow young children to express their experiences of primary care, without limiting the extent to which older CYP can provide detailed feedback.

Turning to CYP, there was a marked lack of enthusiasm about being given the opportunity to give feedback about their experiences of primary care. This was for a range of reasons:

- **Indifference**: some participants simply felt like giving feedback was '*not important*'. The same participants often felt disengaged during GP visits, and that these played a very minor part in their lives.

- **Trust in staff:** some participants discussed how they strongly trusted their GPs and GP nurses so they did not think that their feedback would be beneficial for them.

- **Lack of engagement**: while noting the potential benefits of collecting information from CYP, many participants also felt that they did not want to do it themselves and would decline the opportunity to do so if they could.

"I don't think it's that important [to give feedback] because I think the doctor knows what he's doing."
CYP, male, 11-13 years

However, there was also a view among some CYP that giving feedback was very important as it could improve their own and others' experiences of primary care. They recognised not only that their primary care needs might differ from adults', but also that their own parents might have biased perceptions of their care and might not be best placed to feedback about their experiences. Girls aged 13- to 15-years-old were the most enthusiastic about giving feedback. This was because they were often most likely to report negative feedback due to issues around access to care and how they were addressed by practitioners.

"Adults might not understand how children feel and children might not understand how adults feel"
CYP, female, 13-15 years

Interestingly, CYP with long-term health conditions did not appear more inclined than other CYP to give feedback about their experiences, despite GP practice visits being more frequent and playing a more central part in their day-to-day lives. This might be because they felt more satisfied with their care and treatment, being more skilled at managing consultations and dealing with GP practice staff.

It is important to note that, throughout the interviews and group discussions, CYP's views often evolved: after an initial reluctance, CYP often changed their minds and concluded they would somewhat like the opportunity to give feedback, although they did not want to be pressurised into doing so.

5.2 Preferred feedback mechanisms

Having explored CYP's appetite for reporting back on their experiences of primary care, participants were asked to think about what would be their favoured feedback mechanism. Interestingly, both parents and CYP spontaneously associated giving feedback with filling in a questionnaire - whether online or on paper. As such, most of the discussion around feedback revolved around the key features to take into consideration when designing and delivering a questionnaire.

Method of collection

Participants were asked their opinions on the most appropriate timing, frequency and location for CYP to be asked to feedback about their experiences of primary care. There was a notable lack of consensus, with clear differences in opinion between parents and CYP. This indicates that using a flexible approach to collecting feedback, which maximises convenience, may be most fruitful.

Timing: while participants agreed on the importance of considering timing when gathering feedback, there was disagreement over whether children and their parents should provide feedback at the point of care - when their experience is fresh in their minds - or later - so they have had time to reflect.

"Children forget things, don't they? They're goldfish. Half an hour after the appointment and they'll have forgotten about it already" Parent

A common opinion among parents was that children should give feedback just after their appointment, as they felt children would not be able to remember their experience accurately if there was a delay between the appointment and provision of feedback.

Among CYP, views were more mixed, with some participants explaining they would prefer to leave the GP practice as soon as possible, and therefore would be unwilling to remain at the primary care service to complete a questionnaire. However, others thought differently and were worried they would forget about their experiences if they did not give feedback shortly after their appointment.

Frequency: there was no clear consensus about the frequency of feedback collection. Some participants argued that they should be asked after every single appointment, while others suggested that they should only be asked to provide feedback each quarter or every six months. Parents expressed concern that, if feedback was collected on this less frequent basis, CYP would not recall their experiences accurately. However, CYP thought that giving feedback too frequently could be detrimental, leading to greater disengagement.

Location: linked to discussions on timing and frequency, participants also reflected on where their feedback should be delivered; at the primary care service straight after an appointment, at home, or at school. Again, there was no clear consensus among parents and CYP. While CYP were mostly happy about giving feedback at school (although a few were worried that other pupils might see private information), some parents were uncomfortable with their children doing so. They expressed concerns that CYP's feedback could be influenced by teachers or other students, and might not reflect their opinions accurately.

Some CYP expressed a preference for completing a questionnaire at home. Reasons for doing so varied: some reiterated that they would just like to leave the GP practice as soon as possible after their appointment, while others voiced concerns about privacy, and felt that providing feedback while at home would better ensure confidentiality than if they were to give feedback at their GP practice.

"At home I could stay anonymous and truly express my opinions without worrying about other people seeing what I'm writing." CYP, female, 11-13 years

Recommendation: Given the lack of consensus among parents and CYP, primary care services should choose an approach to collecting feedback that is as flexible as possible, allowing CYP and parents a choice of when, and how frequently to provide feedback.

Mode of collection

Given the high level of digital literacy among CYP, it could be assumed that young people would prefer to provide feedback using an online method. Increasingly however, research suggests that this assumption is incorrect. For example, a review of literature pertaining to reading preferences found insufficient evidence to support the assumption that adolescents prefer to read on screen[16]. Our research supported this contention; CYP across all groups expressed a preference for paper questionnaires, with a few not showing a preference for one method over another. CYP gave a number of reasons for this preference, highlighting a confusion about how different data collection methods work.

Online questionnaires are too restrictive: a recurrent reason for mentioning their preference for paper was the view that online questionnaire would enforce word limits and would therefore be too restrictive to allow CYP to share their opinions fully.

Paper questionnaires are easier to complete: there was a commonly held view that paper questionnaires would be more convenient to fill out, as they would not require CYP to access the internet but could be completed at the point of care, just after an appointment.

Paper questionnaires carry more weight: An isolated view held by some of the older children was that any results from online feedback would be aggregated and therefore their individual feedback would not carry any weight. They believed it would not be possible to aggregate results if they were collected via paper and that their responses would therefore be given more attention.

> ***"With the ones online, I feel like the amount of people that do them, they just average the answers, so it wouldn't be looked at properly. If you did them on paper and gave them I think they'd be looked at more."***
>
> CYP, female, 13-15-years

Interestingly, given the preference for a paper questionnaire, CYP stressed that they would not be prepared to return paper surveys in the post, even if provided with a pre-paid envelope. Overall, paper questionnaires were viewed as a convenient option as they could be filled in at the GP practice, after an appointment and then forgotten about.

Recommendation: Although CYP expressed a preference for paper, it seems that this was largely driven by perceived convenience and because it would address privacy concerns. Therefore, whichever mode is used to collect feedback, it should be ensured that it maximises the ease of completion, and that clear messages about confidentiality and how the data will be used are provided.

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[16] Merga, M.,K., *Do Adolescents Prefer Electronic Books to Paper Books?*, August 2015, Publications 2015, 3, 237-247.

Feedback tools

Participants - both parents and CYP - were in agreement that children represented a hard group to engage, and that feedback tools should be specifically tailored to different age groups. The research highlighted that gathering meaningful feedback requires consideration of a number of factors.

Language: the use of simple language was recurrently mentioned as an important feature to enable CYP to give accurate feedback. Participants - both adults and children - felt that the language used should be as simple as possible to avoid any confusion or misunderstanding, especially for younger children. Coupled with this, the text should be minimised as far as possible – with questions and instructions kept short.

Brevity: the survey length was also a key factor to consider for the vast majority of participants. Both parents and CYP thought that the longer the questionnaire was, the less engaged children would become. As such, parents recommended including no more than five questions. CYP were also critical of long surveys, stressing how they reminded them of exams.

Design and age-appropriate graphics: participants agreed that any feedback tool should be made as child friendly as possible through the use of elements of 'gamification'. For example, the use of symbols (smiley and sad faces, or traffic light systems) was considered to be an efficient and fun way for children, especially young children, to indicate levels of agreement or disagreement with statements. Some participants had come across such designs in secondary care settings. Smiley face push-button survey and feedback devices - such as the HappyOrNot feedback kiosks - were favoured among parents. However, they raised concerns about the accuracy of the feedback collected through such devices as they cautioned that young children may be 'tap happy' and press buttons 'for fun'. Finally, parents of younger children also suggested incorporating audio features.

Comments box: While parents stressed the importance of the design of the feedback tool, CYP tended to focus more on the content of the tool. Many shared a strong desire for a free-text comment box, as they thought closed-questions alone would be too limiting, and that a comment box would allow them to give feedback on issues not covered by the questionnaire.

> ***"I think forms are limited, so if there's something you don't agree with, you can't put that in. I'd want a box to fill in with my thoughts."*** *CYP,* male, 7-11-years

Recommendation: Feedback tools should be designed with CYP's needs in mind. They should contain as few questions as possible, with both questions and any other text written concisely and clearly. The graphic design of the questionnaire should incorporate elements of 'gamification' such as smiley face rating scales or traffic light systems.

5.3 Concerns about giving feedback

When discussing feedback collection and mechanisms, both parents and CYP spontaneously raised a number of concerns. These included:

Concerns that feedback would be based solely on negative experiences: a commonly held view among parents was that parents would only give feedback on negative experiences of primary care. Some participants mentioned that they could not think of an instance where they would choose to give feedback on a positive experience whereas they would want to complain if they had a particularly negative experience.

"It doesn't seem very important to give feedback unless there's something very bad about the service." Parent, London focus group

Concerns that CYP would worry about giving negative feedback: In contrast to parents, CYP were almost unanimously concerned about giving negative feedback, not only about their primary care experience but also in general. For example, children reported that they would only give positive feedback to their peers at school, and omit any negative feedback they might otherwise give.

"Normally, I'd only say the good things. If I only had bad things to say, I wouldn't really answer."
CYP, female, 11-13-years

Linked to this, there was a common perception among CYP that their feedback would be seen directly by clinicians. As such, CYP reported feeling worried that they would either offend them or be penalised for giving negative feedback. CYP went further, explaining how they might feel guilty or awkward if they saw the same clinician after giving poor feedback. As a result, some suggested that they would feel pressurised to give positive feedback.

Recommendation: Feedback tools should explain clearly to CYP and their parents that their responses will be kept anonymous, and that any feedback provided will not adversely affect the care individuals receive.

Parents had reservations about the quality of feedback CYP would give: Parents reiterated that they felt children needed a certain level of maturity in order to give meaningful feedback. Some parents suspected that their children may feel obliged to give feedback when they didn't want to – which could lead to feedback being less reliable. Others were unsure of the capacity of young children to understand the concept of feedback.

"I don't agree with feedback from the children, because I think they might not be ready or they might not understand."
Parent

Concerns about funding: among parents there was a high level of awareness of the financial challenges that primary care and the wider NHS is under. Because of these pressures, some parents raised concerns about the amount of money which would be spent on implementing a feedback mechanism for CYP and whether this should be a priority for the NHS.

Recommendation: Feedback tools should present a clear narrative about the long-term and short-term benefits to the health care system of collecting feedback from CYP. Benefits identified by CYP included improvement of clinicians' and other staff's behaviours towards CYP and of GP practices' arrangements, but also empowering CYP to make their voices heard.

5.4 Preferred use of feedback

When asked to reflect on how the feedback data collected should be used, both CYP and their parents thought that it should be used to drive change and improve primary care at both national and individual-practice levels. This demonstrates that, although participants had mixed opinions about whether the collection of feedback should be prioritised, there was seen to be value in its collection. CYP of all ages were able to differentiate between potential uses of the data, and articulate the respective benefits of each use.

Creating national guidelines: Both parents and CYP thought that their feedback could be helpful for creating national guidelines to help clinicians improve the way in which they work with children and young people. More specifically, they thought feedback could be used to produce guidance outlining what's important to CYP, and giving advice on approaches to communicating with CYP and their family or carers. Such views were also shared by stakeholders.

Practice-level improvements: There was a widely held expectation among CYP and parents that feedback would result in direct improvements to their own GP practice. Some CYP discussed how they thought their feedback would be more beneficial at an individual-practice level than a national level because some of their comments and opinions may relate specifically to individual staff members.

Parents were more sceptical. There was cynicism that collected feedback would be useful, or that actions would be implemented based on the findings. This led some parents to believe the endeavour could be a waste of money. Others believed that, for any changes to happen, the information collected would need to be publicly displayed, for instance on a notice board in their GP practice, with clear actions that had been taken as a result of the feedback. This practice-level information would provide parents and CYP with reassurance that their data was being used, and would encourage them to engage with giving feedback on an ongoing basis.

Recommendation: Aggregated feedback data should be made easily available to patients in an accessible format. Clear actions that the primary care service is taking as a result of the feedback should be provided. Where possible, patients would also welcome information about the any cost-savings that the primary care service has accrued as a result of the feedback patients have provided.

6 Conclusions and recommendations

This research project has sought to explore CYP and their parents' experiences of primary care, and to understand the most effective methods for seeking feedback from CYP. It has supplemented the limited information that is currently available by providing **some key learnings around CYP's experiences of primary care, and principles for the development of a feedback tool**. In order for the findings from the research to be useful however, substantial efforts will need to be made at both the national and local level to ensure that recommendations are adopted and that CYP's opinions on primary care are increasingly heard.

6.1 Improving CYP's experience of care

Although, when initially engaged on the subject of primary care services, CYP generally showed few strong opinions, they were able to discuss their experiences in great depth when probed. This was particularly the case in the focus groups, where CYP were provoked to respond to opinions and experiences voiced by others in the group

In doing so, they identified a range of factors that have influenced their experiences of primary care – for the better and the worse - leading to a number of recommendations about how primary care services might seek to improve CYP's experiences.

- ✓ **The reception and waiting area should be welcoming and provide a range of recreational activities which are age appropriate for a range of CYP, including older CYP.** The time that CYP spend waiting to see their GP has as an important influence over whether or not CYP have a positive experience of primary care. The physical environment of the waiting area, can play a crucial role in ensuring that the CYP feels welcome and comfortable at the GP practice.

- ✓ **Primary care services should communicate about late-running appointments when CYP arrive at reception, if not before. If possible, they should provide estimates of lengths of delays**. Uncertainty about when one would be called to their appointment can cause extreme boredom and exacerbate any anxiety CYP might be feeling. In addition, waiting for long periods surrounded by unfamiliar and sick people can trigger challenging behaviour from their children.

- ✓ **Clinicians should greet CYP personally at the start of the appointment to help them feel at ease and involved in the appointment.** Friendliness of clinicians could have a large impact on their child's confidence during the appointment.

- ✓ **Clinicians should use language or other forms of communication that CYP can understand; moderating the speed with which they talk, as well as the language they use. To ensure comprehension, they should proactively ask CYP whether they understand what has been said, rather than wait for CYP to ask questions independently.** CYP might not feel confident enough to ask the clinician questions, and they want to understand what the clinician say.

- ✓ **Clinicians should aim to avoid asking potentially sensitive questions early in the consultation, particularly when other people are present. Where possible, clinicians should offer CYP the opportunity to provide necessary sensitive information by completing a form.** This is especially important for older female CYP who might not want to be asked certain questions in front of their parents.

- ✓ **Clinicians should speak directly to the CYP, rather than the parent, wherever possible. They should consider how they use non-verbal communication to ensure that the CYP feels engaged and listened to.** Engaging with parents rather than CYP can lead to miscommunication.

- ✓ **Where parents speak on behalf of the child, clinicians should give CYP the opportunity to agree or disagree with what their parent has said, before taking note of it. Clinicians should be aware of the effect that the presence of a parent can have on CYP.**

- ✓ **Clinicians should take CYP's views seriously and not dismiss or appear to dismiss their concerns or contributions.**

- ✓ **Primary care services should aim to accommodate CYP who wish to see a clinician without parental accompaniment. Primary care services should ensure that policies in this area are applied and communicated consistently by all staff.**

- ✓ **Clinicians should ask CYP before beginning the appointment, or at any point in the appointment where the conversation turns to sensitive subjects, whether they would like their parents to remain in the consultation room.** Some CYP might feel unable to speak openly with their clinician while their parent is in the room. They might be especially reluctant to discuss sensitive topics.

- ✓ **Receptionists should be sensitive to gender preferences and ask parents when they are booking appointments whether their child would prefer a same-sex clinician. Clinicians should also be aware that CYP, of all ages and genders, may have preferences which have not been accommodated and offer them the chance of seeing a same sex clinician where appropriate.**

6.2 Collecting feedback from CYP

CYP and their parents were also asked their views on giving feedback about their experiences of primary care - and notably whether they thought giving feedback about such experiences was important, - their favoured feedback mechanisms, and how the resultant insight should be used. Interestingly, while CYP initially suggested they would be reluctant to give feedback, they often changed their minds and concluded they would like the opportunity to give feedback, although they did not want to be pressurised into doing so. In order to maximise engagement and impact, a range of recommendations were made by both parents and CYP:

- ✓ **CYP feedback mechanisms should be as inclusive as possible, incorporating feedback tools that allow young children to express their experiences of using primary care, without limiting the extent to which older CYP can provide detailed feedback**. There should be no lower limit on the age range asked to complete the survey.

- ✓ **Given the lack of consensus among parents and CYP, primary care services should choose an approach to collecting feedback that is as flexible as possible, allowing CYP and parents a choice of when, and how frequently to provide feedback.** Timing, frequency and location of feedback collection should all be taken into consideration when designing feedback tools in order to widen engagement.

- ✓ **Whichever mode is used to collect feedback, it should be ensured that it maximises the ease of completion, and that clear messages about confidentiality and how the data will be used are provided**. Although CYP expressed a preference for paper, it seems that this was largely driven by perceived convenience.

- ✓ **Feedback tools should be designed with CYPs in mind. They should contain as few questions as possible, with both questions and any other text written concisely and clearly**. The graphic design of the questionnaire should incorporate elements of 'gamification' such as smiley face rating scales or traffic light systems. Children represented a hard group to engage, and that feedback tools should be specifically tailored to different age groups.

- ✓ **Feedback tools should explain clearly to CYP and their parents that their responses will be kept anonymous, and that any feedback provided will not adversely affect the care individuals receive.** CYP tend to worry about giving negative feedback and often feel pressurised into giving positive feedback.

- ✓ **Feedback tools should present a clear narrative about the long-term and short-term benefits to the health care system of collecting feedback from CYP**. There is a high level of awareness of the financial challenges faced by primary care and the wider NHS and it is important for people to realise the benefits of collection meaningful feedback.

- ✓ **Aggregated feedback data should be made easily available to patients in an accessible format. Clear actions that the primary care service is taking as a result of the feedback should be provided.**

6.3 Research implications and future options for collecting CYP feedback

Broadly, there are two potential approaches to collecting feedback from CYP about their experiences of primary care; a national survey delivered centrally or local data collection. The approach used will depend on the aims of the exercise. For example, whether it's for national comparison and benchmarking of primary care providers, or for local service improvement. This section sets these options out, and uses findings from the research to outline the respective considerations and areas for further exploration for each option.

National survey

If the purpose of the feedback exercise was to gather views that are representative of individual or collective GP practices at a national level, a centralised survey would ultimately be required.

- CYP would likely be randomly sampled from an existing sampling frame (as is the case for GPPS), and questionnaires would be sent to home addresses.

- Reflecting the preferences identified in this research, the response mode would ideally be paper, with an online option available for those who do prefer to complete surveys online.

- However, further exploration (via experiments) would be needed around expected response rates and the most appropriate contact and reminder strategies for CYP. As noted in the research, CYP expressed a wish for convenience and reported that they might be unlikely to return a questionnaire by post.

- In order to encourage response, a strong and well evidenced communications strategy would be needed to justify the need to collect this information, given the likely significant NHS resource such an exercise would require.

- The questionnaire would need to be short, to encourage response. It would also need to focus only on the areas relevant to CYP, for example *how friendly the doctor* was, rather than collecting information that CYP would not be able to provide insight on. For example, the experiences of booking the appointment.

- Comparable questionnaires would need developing for different ages (i.e. comparable indicators, but different questions). As identified in the research, there was demand for any data collection tool to be as inclusive as possible.
- Consideration would need to be given around how the data would complement the existing GPPS data. For example, whether – where appropriate – the questions should cover similar measures.
- There would also need to be consideration around whether indicators from such a survey would feed into outcome frameworks, and how the data would be published or made available (for patients to decision makers).

Local data collection

If the interest was instead around supporting local service improvement, a tool kit could be developed for GP practices to help them implement local data collection, in a standardised way.

For example, suggested questionnaires, invitation letters or supporting leaflets.

- For example, suggested questionnaires, invitation letters or supporting leaflets.
- Practices would need to be given guidance around how to administer the survey, with regards to how to sample CYP, the likely levels of resource involved.
- Given the reliance on practice staff, the role of the administrative and support staff would need exploration, for example to print and distribute questionnaires that could be given to CYP as they leave the surgery following an appointment. However, given what the research showed in terms of CYP's assumptions that the feedback will be linked directly with the doctor they saw, practices would need to provide clear explanations around this.
- Practices would need to understand, and possibly be supported around, the data entry and analysis requirements and how to collate potentially large volumes of qualitative responses in order to use the feedback.
- Consideration would need to be given around how the data would complement the existing Friends and Family Test data.

Appendix: Research Methodology

The research was undertaken in two main phases; a scoping and review phase and a data collection phase.

Scoping phase

This stage of the research was intended to provide context surrounding the collection of feedback data from CYP, and inform the focus of the rest of the research. It involved:

- **a desk review** exploring and evaluating the range of strategies in use within the NHS, and internationally, for encouraging and collecting feedback from CYP about primary care.

- **eight in-depth stakeholder interviews** to understand the appetite for collection of feedback data from CYP, the ways in which the data could be used and potential barriers to collecting feedback.

Data collection phase

Directly informed by the scoping phase, this phase formed the bulk of the research leading to the findings detailed in this report. The purpose of this stage was to explore CYP's experiences of primary care and their attitudes towards collecting feedback. It involved:

- Six focus groups with CYP aged 7- to 15-years-old.
- Three focus groups with parents of CYP aged 7- to 15-years-old.
- Four in-depth interviews with parents of CYP aged 0- to 6-years-old
- Eight in-depth interviews exploring specific issues which may affect CYP living with a long-term health condition (LTC) or those who speak English as a second language (ESL).
- A real-time feedback exercise with eight CYP using the Ipsos App Life mobile application.

Further details of each of the key stages of the research are provided below.

Telephone interviews with stakeholders

Eight in-depth interviews with stakeholders were carried out. Stakeholders were identified by NHS England and included experts within the voluntary and primary care health sectors. The stakeholders we talked to worked for the following organisations:

- Association of Young People's Health (AYPH)
- National Network of Parent Carer Forums
- NHSE
- RCGP Adolescent Health group
- School and Public Health Nurses Association (SAPHNA)
- Tower Hamlets CCG

The topics explored in the interviews included:

- Benefits and challenges of collecting feedback from CYP;
- Factors which affect CYP's experiences of primary care (including factors which affect those with long-term conditions or those who speak English as a second language);
- Methods of collecting feedback from CYP; and,
- Existing feedback mechanisms for CYP.

Engagement with stakeholders was key to developing this research and ensuring that the outputs were recognised as legitimate and actionable in terms of driving service improvement through insight.

Focus groups

Nine focus groups were conducted; six with CYP aged 7- to 15-years-old, and three with a sub-set of their parents. These groups were held in three locations around England in June 2018. In line with best practice, the groups were split into three age-groups (7- to 11-years-old, 11- to 13-years-old and 14- to 15-years-old). CYP in the two younger age-groups (aged 7- to 11-years-old and 11- to 13-years old) were in mixed gender groups and the older age group (14- to 15-years old) were in single gender groups.

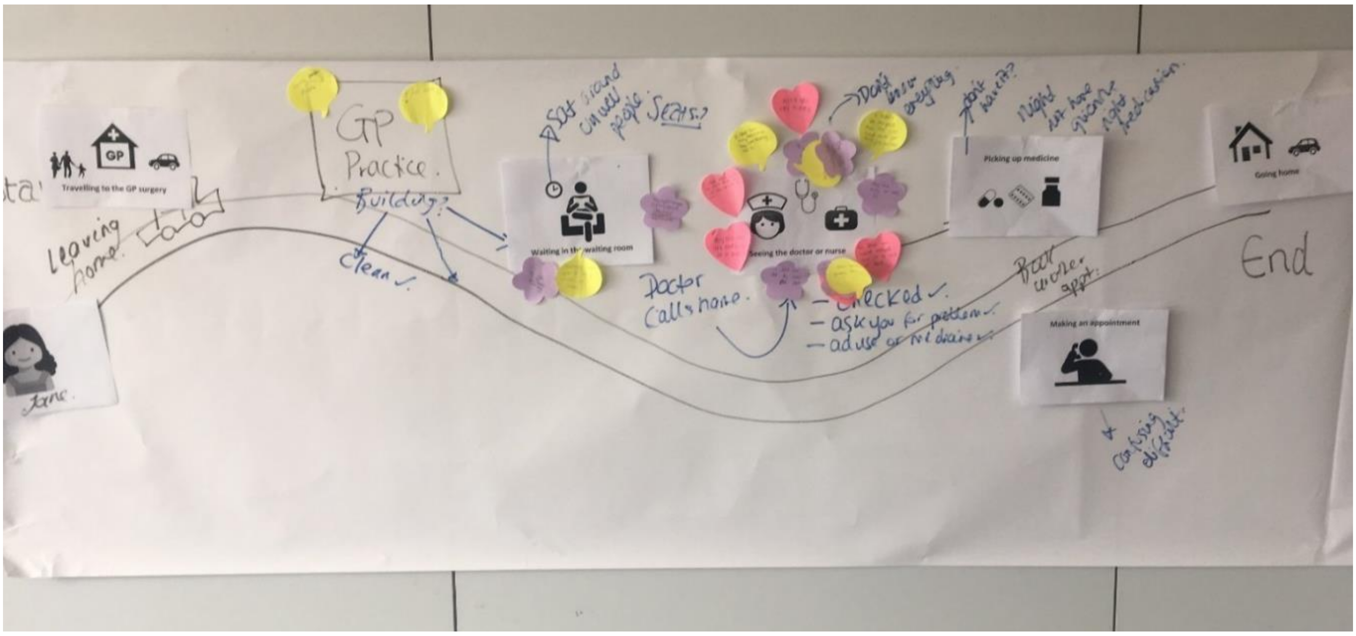
Each group was led by two moderators. In addition, the groups were digitally recorded (with participants' permission).

The table below shows the age profile of each group, the location of the groups and the number of participants:

Group	**Primary Respondent Quota**	**Location**	**Number of participants**
1	CYP, 7- to 11-years-old, mixed	Manchester	5 females 4 males
2	CYP, 7- to 11-years-old, mixed	London	3 females, 4 males
3	CYP, 12- to 13-years-old, mixed	Birmingham	6 females, 3 males
4	CYP, 12- to 13-years-old, mixed	London	5 females, 6 males
5	CYP, 14- to 15-years-old, female	Manchester	10 females
6	CYP, 14- to 15-years-old, male	Birmingham	7 males
7	Parents	London	4 females, 5 males
8	Parents	Birmingham	10 females
9	Parents	Manchester	7 females, 2 males

Each participating CYP was recruited based on the requirement of having visited their GP practice in the three months prior to the group.

Throughout the focus groups, CYP participated in a range of interactive activities to elicit conversations and help CYP share their experiences of primary care and views on giving feedback. For example, one of these tasks involved journey mapping a visit to the GP to better understand what aspects of primary care stood out to CYP.



(Journey map- CYP, 12- to 13-years-old, mixed- Birmingham)

In-depth interviews

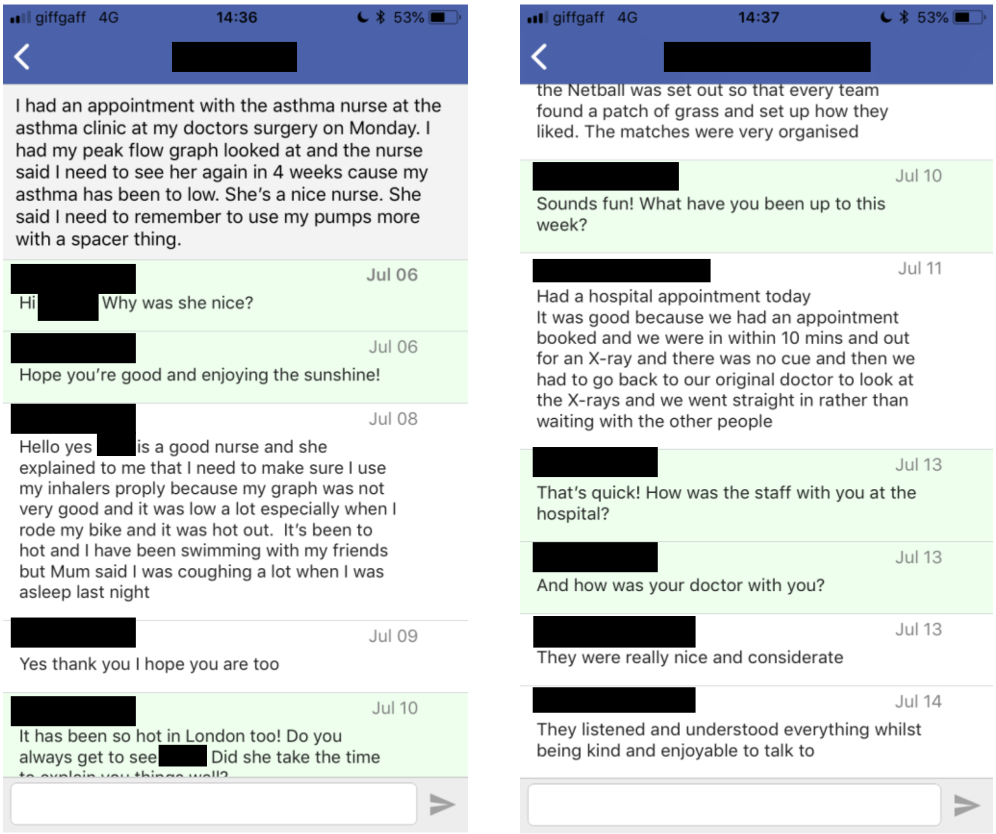
Following the focus groups, additional in-depth interviews were conducted with four parents of young CYP, and eight CYP who were either living with a long-term condition or who spoke English as a second language. The additional interviews were carried out to explore the views of potentially under-represented groups and to identify any issues which may affect them specifically.

Real-time feedback exercise

To supplement the findings from the groups and interviews, a mobile application was used to collect real-time feedback on any appointments they attended over the three-week period following the focus group. The findings from this strand of research have been used to validate and reinforce the findings from the discussion groups and interviews.

CYP were recruited and asked to download the Ipsos App Life mobile application - a cross between a social network and an online discussion board – on which participants each have a profile and take part in a series of discussions with the moderator. A total of eight participants actively took part in the exercise and were t asked questions about any appointments they had recently attended, to assist them in filling in a diary over the course of three weeks. Participants received notifications to encourage them to respond and moderators were able to respond in real time to any comments made by participants.

While some of the appointments discussed were not directly related to the healthcare, they helped answer the research question by providing useful insight into the way CYP conceptualised good and bad experiences, as well as how they prefer to provide feedback about their experiences.



[redacted]

I had an appointment with the asthma nurse at the asthma clinic at my doctors surgery on Monday. I had my peak flow graph looked at and the nurse said I need to see her again in 4 weeks cause my asthma has been to low. She's a nice nurse. She said I need to remember to use my pumps more with a spacer thing.

[redacted] Jul 06
Hi [redacted] Why was she nice?

[redacted] Jul 06
Hope you're good and enjoying the sunshine!

[redacted] Jul 08
Hello yes [redacted] is a good nurse and she explained to me that I need to make sure I use my inhalers proply because my graph was not very good and it was low a lot especially when I rode my bike and it was hot out. It's been to hot and I have been swimming with my friends but Mum said I was coughing a lot when I was asleep last night

[redacted] Jul 09
Yes thank you I hope you are too

[redacted] Jul 10
It has been so hot in London too! Do you always get to see [redacted] Did she take the time

[redacted]

the Netball was set out so that every team found a patch of grass and set up how they liked. The matches were very organised

[redacted] Jul 10
Sounds fun! What have you been up to this week?

[redacted] Jul 11
Had a hospital appointment today
It was good because we had an appointment booked and we were in within 10 mins and out for an X-ray and there was no cue and then we had to go back to our original doctor to look at the X-rays and we went straight in rather than waiting with the other people

[redacted] Jul 13
That's quick! How was the staff with you at the hospital?

[redacted] Jul 13
And how was your doctor with you?

[redacted] Jul 13
They were really nice and considerate

[redacted] Jul 14
They listened and understood everything whilst being kind and enjoyable to talk to

(Anonymised screenshots from Ipsos App Life)

Recruitment

All participants were recruited by professional recruiters using a screening questionnaire to identify the target groups. Recruitment screeners, participant information leaflets, and consent forms were provided to participants and their parents where appropriate. All participants were offered a financial incentive to thank them for taking part.

Ipsos App life participants were directly recruited by Ipsos MORI researchers after a group or an interview. It is interesting to note than despite expressing an initial interest and, the prospect of a thank you payment at the end of the task, and a number of reminders, only a third of the participants who signed up to Ipsos App life actively took part in the exercise. This suggests that while some CYP might be willing and interested in giving feedback, the enthusiasm can be short-lived. Overall, it appears that the less demanding and time consuming a feedback tool is, the more engaging and inclusive it is.

Fieldwork and analysis

Discussion guides containing topics and prompts were used by researchers to facilitate discussion during the groups and the interviews. The guides were developed by Ipsos MORI in conjunction with NHS England.

Prior to fieldwork, all interviewers and moderators received a detailed briefing from the core project team to ensure a common understanding of the purpose of the groups and interviews.

Given the depth of the qualitative research conducted it was important to undertake thorough and systematic analysis. During each group, notes were made by moderators on flipchart paper and these were photographed and the originals kept for analysis later. Professional note-takers took detailed notes during the groups, and interviews were digitally recorded.

An analysis framework was created structured around the key themes identified at an interim analysis session. Detailed notes and verbatim were added to the analysis framework. A final analysis session was held, attended by all interviewers and moderators, to discuss the key themes in more detail from across the groups and interviews, and identify key findings and recommendations.

Profile of CYP engaged in the research

While CYP were not specifically prompted about why they accessed primary care, CYP often spontaneously discussed their reasons for doing so. This revealed that the CYP involved in the research had used primary care for a broad range of different health issues; some of which were long-term conditions and some of which were acute illnesses.

All participating CYP had visited their GP practice within the previous three-month period and the majority reported visiting their GP several times per year. The CYP with long-term health conditions tended to go to their practice on a more regular basis, for routine appointments.

No CYP involved in the research, even those aged 13-15, reported having been to the GP practice by themselves. Most were accompanied by one of their parents. There were also some instances when an older sibling or another family member took them.

Interestingly, only a very small number of CYP reported ever having been to the consultation room by themselves - even though some of them expressed a desire to do so.

Interpreting the data

Qualitative research is not by its nature designed to be statistically representative. It is intended to be illustrative, providing detailed insight into a research topic. Therefore, claims cannot be made about the extent to which the conclusions may be generalised to the population. Instead, we present the broad range of views given by the participants, and where appropriate make reference to overall balance of opinion or general consensus.

Verbatim quotes are used throughout the report in order to illustrate particular bodies of opinion, but these should not be taken to define the opinion of all participants. It should also be borne in mind that this study is relatively small and findings are based on small number of focus groups, interviews and online diaries.

Michelle Mackie
Research Director
michelle.mackie@ipsos.com

Sylvie Hobden
Associate Director
sylvie.hobden@ipsos.com

Camille Aznar
Research Manager
camille.aznar@ipsos.com

Lauren Gower
Research Executive
lauren.gower@ipsos.com

For more information

3 Thomas More Square
London
E1W 1YW

t: +44 (0)20 3059 5000

www.ipsos-mori.com
http://twitter.com/IpsosMORI