

**Hearing the voices of looked after children:  
Considering the challenges of obtaining feedback on healthcare services**

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**Abstract**

The voices of Looked-After Children (LAC) are rarely heard in health services or research. Obtaining feedback on services from children and adolescents and involving them in decision-making is important; yet communicating with vulnerable groups, like LAC, is not straightforward. Improving communication practices and ways of gaining feedback can facilitate quality improvement across healthcare. Using focus groups with 49 LAC aged 5-17-years, we identified three core themes. First, feedback tools need to be child-centred and LAC-friendly; second, tools should be gender-neutral and developmentally appropriate; and third the current UK feedback tool was not fit for purpose. If feedback tools for children and adolescents are unfit for purpose, then any quality improvement and changes to services made are not sufficiently paying attention to this important population.

## Introduction

Constructions of children and childhood have changed, as have values and expectations of them. Children and adolescents are now afforded autonomy in various contexts, including healthcare. Such changes reflect the international human rights treaty, the UN Convention on the Rights of the Child (1989), granting rights to those 17-years and under. For example, Article 12 stipulates they have the right to have their opinions accounted for when adults are making decisions affecting them. This means children are treated as competent to integrate information and communicate effectively with professionals (McPherson, 2010).

Consequently, services needed to find child-centred ways of listening to their views to achieve quality improvement. If only adult viewpoints are sought, then insightful ideas from children are missed (Lindeke, Nakai & Johnson, 2006) and therefore it is helpful to respect children as agents (Coyne, Hallström & Söderbäck, 2016).

Providing space for young voices in healthcare, has however not been fully realised in practice. For example, although children are an important consumer group and their views can help services communicate more effectively, they are frequently not given opportunities to participate (Dickinson, Wrapson & Water, 2014). Dickinson et al. argued that in New Zealand, children rarely exercise opportunities to comment on their hospital care. Likewise, in a review of 38 UK surveys about experiences of healthcare children were mostly excluded (Hargreaves & Viner, 2012). Hargreaves and Viner showed patients under 16-years were only included in one-of-38 surveys, although 16-24-year-olds fared better. This is important, as 16-24-year-olds rated their care lower than adults, demonstrating a failure to listen to young populations mean services are not achieving a full understanding. This suggests a gap

between the *aims* of services to listen to young people, and *practices* in services and research to hear their voices (Hargreaves & Viner, 2012).

Despite emphasising involving children in healthcare communication, they are still not given sufficient opportunities to participate in decisions or research to inform quality improvement (Coyne & Gallagher, 2011). Arguably, this is especially important for vulnerable populations. Some groups are especially likely to be excluded because of protectionist positions and Looked-After Children (LAC) are one such group. There is an absence of research infrastructure and culture in social care, as well as limited research funding (Mezey, Robinson, et al., 2015).

Those in care historically have been subjected to high levels of social exclusion and they struggle to sustain social networks, making them an especially vulnerable group (Ridge & Miller, 2002). LAC face unique challenges in school (Aldgate, 2009), may have limited or no contact with biological parents and have greater levels of mental health need (Hussey, Falletta & Eng, 2012). LAC are likely to have experienced a range of adverse circumstances, including trauma (O'Reilly Bowlay-Williams, Svirydzenka, & Vostanis 2016) and therefore children within this group have a greater likelihood of poorer life outcomes, like unemployment and involvement in the criminal justice system (Gaskell, 2010). Including LAC voices in healthcare communication, services, policy and research is crucial to empower them. However, such communication is challenging, and listening to vulnerable groups is difficult (McLeod, 2007) which is clearly reflected in the lack of evidence informed by LAC's experiences (Davis & Wright, 2008; Winter, 2010). This means they become marginalised as a group which reduces their likelihood to be heard, so services and researchers need to be patient, build trust, and pay attention to their own adult-centric agenda

(McLeod, 2007). Listening to LAC is not straightforward, but healthcare providers and researchers have a lot to learn by engaging them.

Where efforts have been made, LAC's perspectives have been insightful. For example, when vulnerable children (including LAC) were listened to about their healthcare, they identified the importance of improved planning and resources, as well as age-appropriate facilities and good communication (Curtis et al., 2004). Likewise, in a review of mental health and LAC, children provided meaningful comments about treatment and service provision (Davies & Wright, 2008). Similarly, LAC have reflected on their experiences of social care. In early work in the West, adolescents in care articulated they want to be involved in decisions but felt this was rarely provided (Cashmore, 2002); yet they emphasised their desire to exercise choice and control when seeking support (Stanley, 2007). Failure to listen can leave them feeling helpless and impact on their confidence as they realise the lack of decision-making opportunities available (Leeson, 2007).

This is especially important in research contexts as it is social workers who frequently act in LAC's best interests. Problematically, when they allow LAC to be approached for research, they tend to select those who they feel are most capable, which denies others the opportunity to have their views included (Dixon, Biehal, et al., 2013). A balance between protection and autonomy is crucial (Mezey et al., 2015), but simply denying opportunity based on perceived vulnerability and competence maintains marginalisation and disempowerment.

## ***Aims***

Quality improvement and patient safety are central to many healthcare systems in the West as legislation and policies are in place to deliver high quality care to patients. Across many western countries, listening to patients is important and different ways of seeking feedback are utilised, such as questionnaires and feedback forms. In the UK, the health service uses a standardised paper-based feedback procedure. This is the Friends and Family Test (FFT), described by NHS England (2013) as a tool for obtaining feedback for quality improvement, to highlight good and poor patient experience. Problematically, the idea of such universality across patient groups and services has been critiqued. It has been constructed as ‘unreliable’ (Kmietowicz, 2014) with its single question considered ambiguous leaning toward social desirability (Lynn, 2013); "*how likely are you to recommend our service to friends and family if they needed similar care or treatment?*" (NHS England, 2013). These criticisms have led to professional unease about using results for local quality improvement and calls for a change of wording (Manacorda, Erens, Black & Mays, 2017).

Patients are not homogenous, and obtaining feedback from children requires different mechanisms to adults. Furthermore, even within populations there is variation and LAC’s needs and experiences vary (Ward et al., 2005), which is also true of their experiences with healthcare services. Arguably the FFT is unlikely helpful when it seems to target adults, and fails to account for the unique circumstances of LAC. In this paper, we aim to represent LAC’s views to understand their perspective on communicating with healthcare services, the challenges they perceive in giving feedback, and their opinions of the FFT. The research question was ‘*what are the most appropriate ways for healthcare providers to elicit feedback from LAC?*’

## **Method**

As the voices of LAC are limited in health research, and the value of the FFT has not been fully examined, a qualitative exploratory approach was suitable. Qualitative approaches are well-suited for doing research *with* children (O'Reilly, Ronzoni & Dogra, 2013) and for examining topics related to health (Wilkinson, Joffe & Yardley, 2004). In this way children's voices are placed at the centre of the study, treating them as autonomous competent agents with expertise in their own lives, rather than relying on adult (by-proxy) narratives, which is consistent with our sociology of childhood perspective.

### ***Participants***

We included children and adolescents in care in the Midlands (UK). We define LAC as those who are removed from biological parents, either foster care or Local Authority/private residential care. Participants were recruited via the Looked-After-Children's nursing service, with support from Social Services. Forty-nine participants aged 5-17-years participated.

### ***Data collection***

To provide space for collaboration and consultation we used focus groups, as these are an effective method for fostering discussions about health (Wilkinson et al., 2004). Due to possible vulnerability we ensured each group contained small numbers (average #3, no more than #5) to encourage free dialogue, and 14 focus groups were conducted (see table1).

Sampling adequacy was achieved through saturation, within and across groups (Hancock, Amankwaa, Revell, & Mueller, 2016), as appropriate for the approach (O'Reilly & Parker, 2013).

The focus group schedule was designed to ensure dialogue was participant-driven and child-centred with questions reflecting the aims and research question. All groups were asked semi-structured open questions to ascertain appropriate strategies for healthcare services to communicate with LAC, obtain feedback on services, the FFT, and possible ways to improve communication. Focus groups took place in safe, private spaces within schools and Children in Care Council environments. All were audio-recorded and transcribed verbatim.

INSERT TABLE1

### ***Data analysis***

Our approach to analysis was thematic, conceptualised as an umbrella term for approaches that identify salient issues and patterns in data (Clarke and Braun, 2018). This is a data-driven strategy to understand issues from participants' perspectives (Boyatzis, 1998). Researchers are active agents who select, code, organise and categorise data into themes (Clarke & Braun, 2018). This is appropriate to identify salient issues from LACs' perspectives and ensure their voices are central to analysis. To ensure robustness, a coding framework was developed by multiple team members (Boyatzis, 1998).

### ***Ethics***

This project was provided approval from Manchester and Derby Research Ethics Committees (NHS). Adult gatekeepers were three Local Authorities covering the Health Trust geography,



and all foster carers, children and adolescents also provided consent/assent. They were assured of their rights, given age-appropriate information and opportunities to ask questions.

## **Findings**

Our LAC felt they should have a role in decision-making about their healthcare and believed they had an important contribution to make for improving communication. The general culture of the focus groups was of excitement and taking the task seriously. They were talkative, open and made helpful contributions represented through analysis. While they were open and enthusiastic, for many, their levels of cognitive and literacy skills, meant facilitators sometimes needed to encourage, ask short questions, and rephrase/repeat questions to encourage answers. Nonetheless, all participants had a lot to say, opinions and experiences to express, and were motivated to join in. Overall, three themes were identified; 1) tools need to be child-centred and LAC-friendly; 2) tools need to be developmentally appropriate and gender-neutral; and 3) the current FFT was not fit for purpose.

### ***Theme one: Child-centred and LAC-friendly***

Despite the UNCRC, children's rights have been treated by some as tokenistic, and many have had their rights ignored, trivialised or overridden (Alderson, 2008) and children's rights are often overlooked in health and social care situations (Carter, 2014). However, efforts have been made to ensure that healthcare communication is child-centred, i.e., engaging, child-friendly, and developmentally appropriate. To obtain feedback on services that is insightful, meaningful, and honest from children and adolescents, healthcare providers need to find

mechanisms to do so. Our participants reported that an essential factor in obtaining feedback from LAC is that the methods were child-centred and LAC-friendly.

An essential feature was that feedback tools should have an appropriate balance of images and text. Overall the feeling was that images helped to make the tool look more appealing, but also helped children understand the content and function. The participants in most groups felt that the addition of pictures was crucial.

*P2-More pictures needed*

*P3-I'd say more pictures but less words*

(Group2)

*P1-You could like put more good pictures on*

(Group14)

*P1-It's not as fun as you'd make it for children. You like them to have fun*

(Group6)

Evident here was feedback tools that were too text-heavy would not be appreciated by children and adolescents, as they felt that feedback mechanisms needed *less words*. Furthermore, participants reported they would largely ignore standardised leaflets requiring them to provide feedback as they felt they were unappealing and unnoticeable. Participants reported that children like to *have fun* which should be represented in the way healthcare providers seek feedback from them. Participants argued that the tool needed to stand out, make them notice it and appeal to them for them to take the time to respond.

*P2—It will not stand out. You look at it and you go, “oh it’s just another leaflet”.*

*You’re not going to necessarily walk past it and pick it up and think “yeah, I’m going to”, cuz people aren’t going to notice it; it’s not going to stand out.*

(Group7)

Evidently, participants felt for services to access their opinions the way in which they were communicated with needs to *stand out*. They argued it was insufficient to put a feedback card on a table and expect children to take the initiative to fill them in. They did offer ways for healthcare providers to make tools more appealing and child-focused. For example, alongside adding images, they felt colours were important, but also wanted the process to be more interactive.

*P1—I think for young people it should be more colourful and things like that really, so it’s more eye catching*

(Group1)

*P2-Colours*

*P1—Games...a game to play*

*P3—Educational and non-educational*

(Group2)

While the visual appeal of the tool itself was considered central for child-centred communication, the content was also important. Not having too many words was a recurrent narrative across groups, but the exact nature of the words was also seen as important. They felt feedback tools were adult-centric when they failed to use a vocabulary that could easily

be understood. Notably, they felt clarity should be provided that the function was indeed to obtain their feedback, arguing the word ‘*feedback*’ should stand out and be clearly written.

*P2–If it was asking for feedback, it should have something clearly that says  
feedback....*

*P3–It’s over-complicated*

(Group7)

In response to questions about the specific words needed, participants argued the language used should be simple.

*P3–They wouldn’t understand the word comparison and recommend, or the word  
services, friend, family or treatment.*

(Group2)

For LAC, the premise of vocabulary is particularly important. Research shows that children in care are typically behind their peers in terms of educational attainment (Evans, Brown, Reese & Smith, 2017). Indeed, one problem that arose in the groups was that several participants lacked literacy skills.

*P3–I can’t read*

(Group 4)

*P3–You can’t read D*

*P4–I ain’t got my glasses on*

(Group9)

*P3-He doesn't know how to read*

(Group12)

Although educational difficulties may account for some literacy problems encountered by some respondents, it may be that the reading comprehension skills of younger children is also limited when asking for feedback. Making assumptions that all people can read was not considered to be child-centred and our participants offered alternatives.

*P2-It's better to have words, so you can hear it, so you don't have to read it*

(Group13)

*P3-If the kid was reading the book and they could have like this button they press that reads it for them*

(Group6)

*P2-It's difficult because if you're visually impaired...*

(Group7)

Participants recognised the need to read a leaflet/card to provide feedback was inappropriate in isolation. They argued that alternative ways to provide their perspectives was necessary, particularly as many of their peers could not read. Indeed, they also recognised that disabilities, such as the visually impaired would be excluded through the traditional feedback mechanisms.

## *Theme two: Developmental appropriateness and gender-neutrality*

We have noted that children and adolescents are not a homogenous group, and neither are LAC. Children do not all speak in one voice, and if we are to promote children's rights, we need to take their perspectives seriously and provide opportunities for them to speak out (Lundy, 2007). Developmentally, children are conceptualised in different chronological ways, from infant, child, adolescent, to young adult. They have different cognitive, social, emotional and academic abilities at different points, and the circumstances for LAC can have detrimental impacts on their growth and transition to adulthood. If we are to fully engage LAC, then tools used must be developmentally appropriate. Although our participants did not differentiate in detail, only classifying a difference between *younger kids*, from *older kids*, they did recognise age as an important factor.

*P3-Cuz primary kids don't know as much as secondary kids*

(Group2)

*P1-Make it based on age, maybe. Like if it's a small kid it might only be like one question*

(Group3).

Participants drew attention to differences in knowledge between younger children, those in primary education (elementary), compared to older children, in secondary (middle/high) education. They argued feedback tools needed to be simpler and less demanding for younger

children and could be more sophisticated for older children who had more knowledge. They felt overall that young children would simply not understand the requirement.

*P2-If you're getting a five-year-old to answer, then a five-year-old's going to be like, well what's a ward?*

(Group7)

While drawing on a specific age, five-year-old, to illustrate her point, the participant articulated she felt young children would not understand certain words and argued this was an inappropriate way of engaging young children. When groups were questioned about more engaging ways to involve younger children they consistently mentioned techniques like using *characters, cartoons, images, superheroes* and other familiar visual phenomenon.

Additional to age-appropriate materials, participants were also clear that gender appropriateness should reflect contemporary understandings of gender identities. Overall, they were keen that healthcare providers should not express sexism, stereotyping or inappropriate colours in their feedback tools. Although two participants in group11 felt different styles and interactive tools would appeal differently to boys and girls, the consensus was that feedback tools should be gender-neutral. Interestingly, for some there was discussion before reaching this consensus, consider below:

*P1-Most of the time with girls, it's pink and stuff*

(Group3)

*P3-Anything that's not pink....with girls, people stereotype that we like pink, but not all of us do!*

(Group3)

Despite occasional stereotyping around gendered colours, overall, respondents advocated for gender equality. They argued that males and females should receive the same feedback tool and that this should not discriminate. In response to whether there ought to be different versions for girls than boys, common responses included:

*P4-No, that's just kind of sexist*

(Group4)

*P3-cuz everybody's the same*

(Group8)

*P1-It should be equal because nowadays it should be about equality, not whether you're a boy, girl, Asian, White, Black, it doesn't matter*

(Group13)

Notably, some respondents also identified that some adolescents may experience gender identity issues and raised this as a challenge for gendered feedback.

*P1-Can I just say, what if you're transgender?*

(Group5)



### ***Theme three: FFT is not fit for purpose***

The foundation for discussions was on the specific design of the nationally utilised UK health service FFT. Interestingly, there is limited work ascertaining patient perspectives on this tool for feedback to health services. This is especially problematic for younger patients, as the FFT is arguably adult-centric. We asked our participants specifically about the FFT, showing them a real card example of one. They felt this was not fit for purpose, was inappropriate for younger patients, and needed to be reconstructed.

Fundamentally it is crucial that the person answering the question on the card can understand a) what is being asked and b) the meaning of the words. The respondents argued that many LAC would not understand the question, with some participants reporting that they themselves did not.

Facilitator-*Do you understand it?*

P2-*Not really, no*

(Group3)

Facilitator-*Do we understand the word 'recommend'?*

P2-*No*

P1-*No*

P3-*No*

P4-*I don't have a clue*

(Group9)

P2-*What does 'recommend' mean?*

(Group11)

What may seem simple to adults is not necessarily understandable to children and adolescents. When health services are designing tools to gain feedback from young groups it is essential that they include their voices and perspectives in doing so. Evident from the lack of understanding of the core concept on the FFT, '*recommend*' the health service have not utilised language which is child-centred. Furthermore, many felt there were too many words and felt the wording in the question was unclear.

*P1-Probably not the clearest or best wording*

*P3-I'd put it a bit simpler*

*P4-too wordy for kids*

(Group5)

Not only were the words criticised, but the overall visual appeal of the feedback card was felt to be inappropriate for their age group. Participants argued the card was *boring* and they would not be enticed to fill one in. In such a way, therefore, it failed its primary objective.

*P1-I don't like it*

*P3-It looks no fun*

(Group4)

*P3-It looks quite boring to be honest*

(Group7)

*P3-No boring*

(Group13)

*P1-What is the NHS Friends and Family Test? I'm 16 and I couldn't care less*

(Group7)

The level of disinterest from participants became evident from their comments and their expressed attitudes toward it. The young people expressed articulately that they did not like the FFT, that they simply did not care about filling it in and felt the design was boring. Perhaps more concerning however, was that some simply did not understand its function, and when presented with the card thought that it was an actual test, like a health test.

*P1-Is it like when you have a test that you're okay and healthy?*

(Group9)

Consequently, participants felt no demographic group would engage with the feedback tool. This is concerning, when this is the primary mechanism that UK health service uses to gain comments from service users. Participants argued the FFT would not be used by children and adolescents, but it would not appeal to adults either.

*P1-Yeah, but an adult wouldn't even pick that up. I don't know any adults now-a-days that read, except my grandma and grandad, and even they still have phones!*

(Group14)

*P3-I think in general people just wouldn't answer it*

*P1-It's just another few seconds out of your life*

(Group7)

To be effective, health services need respondents to take time to comment, see value in responding, and provide platforms that are appealing. Comments about filling in the FFT were mostly negative, in that they would not pick it up, with only a small number saying they *might* pick it up. Response rates to feedback questionnaires for services are generally low and to transform services in a patient-centred way, children's voices need to inform care. To achieve this, feedback mechanisms need to be modern, after all these young people's grandparents even *have phones*. Perhaps therefore a more interactive digital platform is needed.

## **Discussion**

There is only a limited research representing the voices of LAC. There is some evidence suggesting that accessing LAC for research can be challenging, because of concerns about vulnerability and because professionals and carers seek to protect them from harm, including unwarranted approaches by researchers (Murray, 2005). Equally, obtaining feedback from LAC in healthcare services can be difficult and has rarely been achieved. However, with the rise of a children's rights agenda, improvements to child-centred care, and a rising rhetoric of inclusion, we need to redress the balance and start listening. Qualitative research provides an appropriate mechanism to do so, and qualitative approaches focusing on children's voices are continuing attempt to empower children. Our work has actively sought to reflect the views of one under-represented group and informs healthcare services across the

globe of the types of concerns these young people have in terms of communicating with providers.

Our research not only directly included LAC to represent their perspectives, but also explored their views on how to better acquire feedback on healthcare services. Communicating with LAC about their care is crucial to advance services and for quality improvement, and that means we need tools that are child-centred, and account for the unique profile of this group. Although our research was built around the UK feedback tool of FFT, the lessons learned are relatively universal (at least in Western healthcare), as core recommendations from our LAC suggest that *all* services seeking feedback should use images, not be overly wordy, use child-friendly language, appeal to children, and maybe include interactive and digital means of communication.

Through our group discussions, it was evident that the respondents felt that any feedback mechanism should also be LAC-friendly, be developmentally appropriate by accounting for age, and be gender neutral. They strongly asserted that the current UK tool for obtaining feedback on services was inappropriate for young populations and needed redevelopment. This is important as the FFT is currently the main mechanism for obtaining feedback from *all* patients across *all* services in the UK.

Although our participants occasionally referenced their LAC status, by making comments about their carers or orienting in some way to their disadvantage, overall, they simply responded as children and adolescents, rather than specifically as LAC. As such, these young people noted the use of language failed to address younger populations in its vocabulary, syntax and semantics. Many participants failed to understand the meaning of the primary

question, and the specifics of the word ‘recommend’. If the central meaning of the FFT is misunderstood by children and adolescents, then the reliability and validity of the results yielded from it are questionable and fail to inform practice in any meaningful way. This suggests that any healthcare feedback tool should pay attention to the language used.

Problematically for this group more specifically, is the potential insensitivity of the focus on friends and family. The unique social and familial circumstances of this potentially vulnerable group have implications for who is supporting them in attending any healthcare appointments and in terms of how they might answer a question directly focusing on family. We have shown that our LAC mostly avoided making specific reference to their care status, but some did misunderstand the purpose of the feedback tool and did at certain points report they had no parent to help them give feedback. Through listening to these young people, we can start to understand and consider why and how feedback might be more usefully gained from children generally, but also how services might want to adapt or be sensitive to their LAC status so that they can do so autonomously, without needing adult support.

Evident from the discussions is that health services, and any practice-based services wanting to learn from children and adolescents about the value and limitations of practice are threefold. First, we need to listen to children and adolescents about their service experiences and to do that the mechanism or tool for doing so needs to be child-centred and age appropriate. Second, we need to listen to them through research and provide a suitable platform for their voices to be heard. Third, any feedback tool needs to be gender neutral, non-discriminatory and be visually appealing to capture the attention of the young.

Engaging children and adolescents who spend their lives in care is challenging and difficult for researchers and service providers alike. However, it is crucial that researchers and healthcare services find the patience, perseverance and skills to engage them in dialogue and learn from them. This group are not well-versed in being listened to by adults and therefore time needs to be taken to build rapport, show genuine unconditional positive regard for their voices, and find ways to help them express themselves. Opportunities to provide feedback on services has potential to be truly enlightening and ensure meaningful quality improvement, but time and care needs to be taken to ensure spaces are provided to allow them to openly express what they really think about their services. If the tools used are currently unfit for purpose this is problematic as any changes to services are only based on adult articulate voices. It is clear accessibility and opportunity must be provided to hear the voices of groups that might otherwise be limited, ignored or unyielded, not only LAC, but all children, and other groups who may be marginalised or disempowered with adult-centric text-based feedback forms.

We acknowledge this research does have some limitations, as the sample size of 49 LAC is not necessarily generalisable to all children and adolescents in this group. However, saturation within and across groups was assured with significant repetition and agreement on issues relevant to the research question. Furthermore, there is very little other work in the field and therefore the exploratory findings warrant further work. The views expressed in this research are arguably transferable in the qualitative sense given the broader thematic issues identified by the groups. Further research could promote a synthesis of perspectives and provide a stronger argument for how feedback can be gathered. However, the findings in this paper are strong and clear, the FFT is failing and NHS England need to be responsive in terms of how to identify patient feedback from younger age groups. Healthcare

communication with LAC especially, needs considerable improvement and the most appropriate way to do this is to listen to them.

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