



Eight ways to make a difference **Children and young people's mental** **health services**

About Healthwatch Gateshead and Healthwatch Newcastle

Healthwatch Gateshead and Healthwatch Newcastle are two of 152 local Healthwatch organisations established throughout England on 1 April 2013 under the provisions of the Health and Social Care Act 2012. We are the independent voice and champion of users of a range of NHS services and social care for adults, children and young people. We have a dual role to champion the rights of users, and to hold the system to account for how well it engages with the public.

We collect feedback on services from people of all ages and communities. We do this through our network of voluntary and community sector organisations; during events, drop-in sessions and listening events at a range of venues across Gateshead and Newcastle; online through the feedback centre on our websites; via social media; and from callers to our information and signposting helplines. As part of the remit to gather views, we also have the power to ‘enter and view’ services and conduct announced and unannounced visits.

Healthwatch Gateshead and Healthwatch Newcastle are part of Tell Us North CIC (company no. 10394966).

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1. Executive summary

This report presents the views gathered from children and young people aged 18 or under (or 25 or under if in local authority care) and their parents and carers in Newcastle and Gateshead. It illustrates their:

- a) Awareness of the self-referral process for children and young people's mental health services.
- b) Awareness of the single point of access for children and young people's mental health services.
- c) Awareness of Kooth (an online counselling and support service).
- d) Experiences of using children and young people's mental health services.

During 2015–2017 NHS Newcastle Gateshead Clinical Commissioning Group (CCG) led the 'Expanding Minds, Improving Lives' listening and consultation exercise. This heard from children and young people, and their parents and carers, about mental health needs and services in order to help transform services provided across Newcastle and Gateshead.

As a result, changes have been made to some children and young people's mental health services. A single point of access for referrals (from November 2017) and online consultations (Kooth, from May 2018) were implemented.

Newcastle Gateshead CCG carried out a further engagement exercise in June 2019 (using an electronic survey), to gather people's views on the single point of access and Kooth. A total of 67 people responded to the survey, most of whom were professionals. Two respondents were young people and five were a parent or carer.

As so few young people, parents or carers responded to this survey, we decided to gather more views from them. We created a different survey, available online and in paper format, and offered participants the opportunity to give further information in a one-to-one interview.

We also sent an information request to Newcastle Gateshead CCG requesting information on the progress made against the action plan stemming from Expanding Minds, Improving Lives.

We received 279 responses to our survey, but 45 of these responses were invalid and removed before data analysis. They were invalid because the responses either came from people outside of Newcastle or Gateshead or were from people who were not children, young people or their parents and carers. This left us with 234 responses to analyse.

We also spoke to 17 individuals via one-to-one interviews and a focus group. Sixteen were parents and carers and one was a young person.

Our main findings

Self-referral

Most people who gave their views were aware that they can self-refer into children and young people's mental health services and thought that they knew how to do this. However, during the one-to-one interviews and the focus group most said that they considered using their GP or another health or social care professional as a self-referral. We also found that, although some people were fully aware of what a self-referral is, they still mentioned using their GP.

When asked how they wanted the self-referral process to be promoted, the most common methods were via teachers and school staff or social media.

Kooth

Most people had not heard of Kooth and hardly anyone had used it, which meant we were not able to gather people's experiences of using Kooth.

When we told people what Kooth was, most felt that it was a useful resource and said it should be promoted more via teachers, schools and social media.

Single point of access for children and young people's mental health services

Most people we spoke to via one-to-one interviews and a focus group were aware of the single point of access, and most were happy with the service they received. They said that the service was good, provided useful information, was well organised and responsive. These people also highlighted that the staff were friendly, helpful, approachable and did listen.

Issues were highlighted around the lack of information provided by the single point of access once a referral was made and while waiting for a first appointment. Most people were not told about Kooth while waiting. Concerns were also raised about waiting times.

Experiences of other children and young people's mental health services

One-to-one interviews and the focus group highlighted the following key themes:

- How difficult it can be to get a referral and the support needed, and a diagnosis.
- Waiting times are a problem and experienced throughout the pathway. This has an impact on the wellbeing of the child or young person.
- Access to support between appointments and pre- and post-diagnosis is limited.
- Communication between services is poor, meaning that people have to tell their story numerous times or act as a liaison between services.
- The quality of service can be poor, with people highlighting poor school observations by the children and young people's service and poor behaviour plans as a result.

Recommendations

This report is called 'Eight ways to make a difference' because it makes 8 recommendations to improve the service user experience.

Our recommendations focus on: the promotion of the single point of access; self-referral and Kooth; improving information and pre- and post-diagnosis support; reducing waiting times; exploring issues around capacity and staff attitude; investigating issues around inaccurate plans for a child or young person. We also recommend further consultation with people who have used the single point of access or Kooth.

Our recommendations can be read in detail on page 29.

2. Introduction

In 2015–2017 the Newcastle Gateshead Clinical Commissioning Group (CCG) ran the ‘Expanding Minds, Improving Lives’ (EMIL) listening and consultation exercise. The aim was to hear from children and young people, and their parents and carers, about mental health needs and services and use that information to transform services provided across Newcastle and Gateshead.

EMIL pulled together the views of children, young people, parents and carers, and from voluntary and community sector (VCS) organisations across Newcastle and Gateshead. These views informed the design of some new models of service delivery. The new delivery models were then discussed with potential providers.

As a result, changes were made to children and young people’s mental health services, with the setup of a single point of access (SPA) for referrals and an online consultation service known as Kooth. Other work was also identified and is described in the Newcastle Gateshead CCG ‘Children and young people’s mental health and emotional wellbeing action plan 2017–19’.

What is the SPA?

The SPA is run by Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust (CNTW), the mental health trust covering the North East of England. It provides a service to all children and young people aged 0–18 years living in Newcastle or Gateshead who present with mental health difficulties.

The SPA is the first point of contact for all requests for advice and referrals for emotional health and wellbeing, mental health treatment and support. It provides information, advice, signposting and referrals, and is staffed by clinicians who can identify the most appropriate support for the child or young person.

Referrals are accepted from any professional working with a child, young person or their family. Self-referrals can also be made by parents or the child or young person. Referrals are accepted in written form or over the telephone.

What is Kooth?

Kooth.com is an online counselling and support service available to all young people in Newcastle and Gateshead aged 11–18 (and 25 and under if in local authority care).

Professional counsellors are available on the website from noon to 10pm on weekdays and 6pm to 10pm on weekends. The confidential service offers both drop-in and booked online chats with psychotherapists and counsellors, as well as providing life forums, self-help articles and peer support.

Why we did this work

In January 2019 we were busy identifying potential projects for Healthwatch Gateshead and Healthwatch Newcastle to take forward during 2019–2020. We were aware of the ‘Children and young people’s mental health and emotional wellbeing action plan 2017–19’ and the implementation of the SPA and Kooth, but uncertain about how far these areas of work had progressed. The services had not been running for long, so there had been no review of how well the SPA and Kooth were working for parents, carers, children and young people, or for health, social care and education professionals who work with children and young people.

We had also heard of issues from children and young people about mental health services. These were mainly about waiting times and difficulties getting the right support.

It was felt timely to get an update on progress and to review how well the new services were performing. This proposal was shortlisted as a potential project by the Committees of Healthwatch Gateshead and Healthwatch Newcastle. A prioritisation exercise took place throughout spring 2019 via a public survey and a prioritisation activity at our annual conference. This proposal was subsequently chosen as a Healthwatch priority.

Around the time this decision was made, Newcastle Gateshead CCG carried out a survey on the SPA and Kooth. It sought views from young people, parents and carers, teachers, GPs, school nurses, social workers, and anyone who worked with children and young people. Newcastle Gateshead CCG received 67 responses, mostly from professionals, with two from young people and five responses from a parent or carer.

As so few young people, parents or carers responded to the CCG survey we felt able to continue with our plans, focusing on hearing from children and young people, their parents and carers.

We aimed to get an understanding of their:

- a) Awareness of the self-referral process for children and young people’s mental health services.
- b) Awareness of the single point of access for children and young people’s mental health services.
- c) Awareness of Kooth.
- d) Experiences of using children and young people’s mental health services.

We also wanted to get an update on the progress made against the action plan arising from EMIL, which was being implemented by Newcastle Gateshead CCG, CNTW, Newcastle City Council and Gateshead Council.

3. Methodology

We used three techniques to gather information: survey, one-to-one interviews and focus groups.

We also made an information request to Newcastle Gateshead CCG for an update on actions relating to 'Expanding Minds, Improving Lives' (EMIL), as detailed within the 'Children and young people's mental health and emotional wellbeing action plan 2017–19'.

Survey

We heard from 279 people in total via the survey, but 45 of these responses were invalid and removed before data analysis. They were invalid because the responses either came from people outside Newcastle or Gateshead or were from people who were not children, young people or their parents and carers. This left us with 234 responses to analyse.

The survey we developed was different to the one designed by Newcastle Gateshead CCG. Our survey gathered the views of children and young people aged 18 or under (or 25 and under if in local authority care), and parents and carers of children and young people. The survey was just for Newcastle and Gateshead residents and aimed to get an:

- a) Understanding of the awareness of children, young people and their parents and carers of the self-referral process into children and young people's mental health services.
- b) Understanding of the awareness of children, young people and their parents and carers of Kooth.
- c) Idea of how children, young people and their parents and carers would like the self-referral process and Kooth to be promoted to them.

We also asked if people had used these services and if they wished to take part in a one-to-one interview. The survey gathered demographic information (age, ethnicity, gender, etc.) where people were willing to provide it – details are in the appendix on page 31.

The survey was launched in October 2019 using SurveyMonkey, with a closing date of 31 December 2019. It was promoted in various ways including: Healthwatch Newcastle and Healthwatch Gateshead social media channels, websites and newsletters; third party newsletters and websites; Radio Tyneside; Spice FM; and on Healthwatch information stalls.

We emailed a publicity pack asking organisations to promote the survey for us. The publicity pack was sent to 85 organisations across Newcastle and Gateshead that work with children, young people and/or parents and carers. It was also given to further selected organisations where we thought this might encourage participation. It was sent to all mainstream, independent and special schools in Newcastle and Gateshead (187 schools in total).

The survey was available online and on request as a hard copy with a FREEPOST envelope. As an incentive to complete the survey, respondents had the option to be entered into a prize draw for a gift voucher.

One-to-one interviews

Thirty-nine people (23 parents, 14 young people and two children in the care of the local authority) stated in the survey that they were happy to tell us more about their experiences. We got in touch as soon as possible to arrange a one-to one-interview.

Twelve interviews were completed: 11 with parents and one with a young person. These were structured based on the person's survey responses and typed up in full for qualitative data analysis.

Focus group

Archibald First School responded to the email we sent to all schools and arranged for parents to attend a focus group – five parents participated.

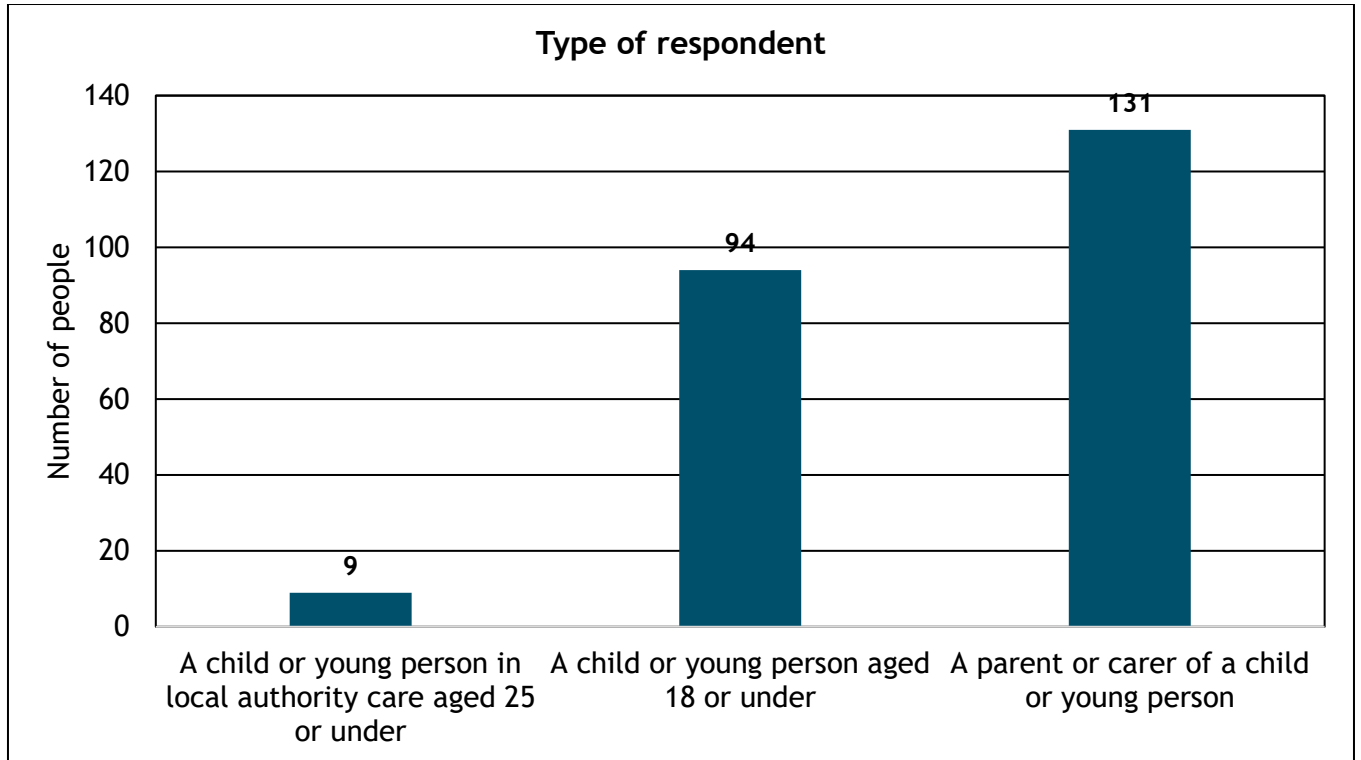
Information stalls

We ran stalls encouraging young people to complete the survey at venues that included:

- Gateshead College
- Jesmond Park Academy
- Newcastle College (two stalls)

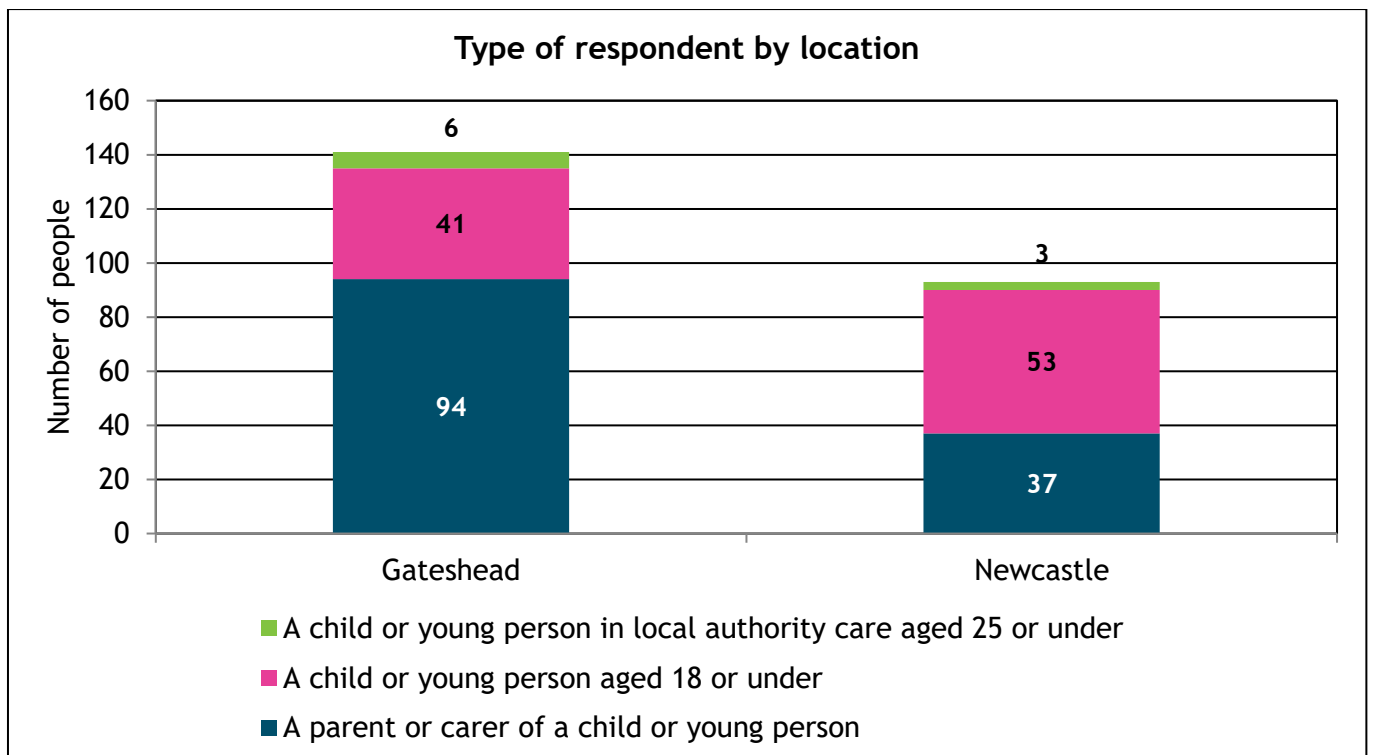
4. Findings

The graph below shows who responded to the survey.



Most responses came from parents and carers, followed by a child or young person aged 18 or under. We were particularly pleased to get some responses from children or young people in local authority care.

The next graph shows where these responses came from.



Most responses were received from people who live in Gateshead (141, compared to 93 from Newcastle).

In Gateshead, most responses came from parents and carers and in Newcastle most from children and young people.

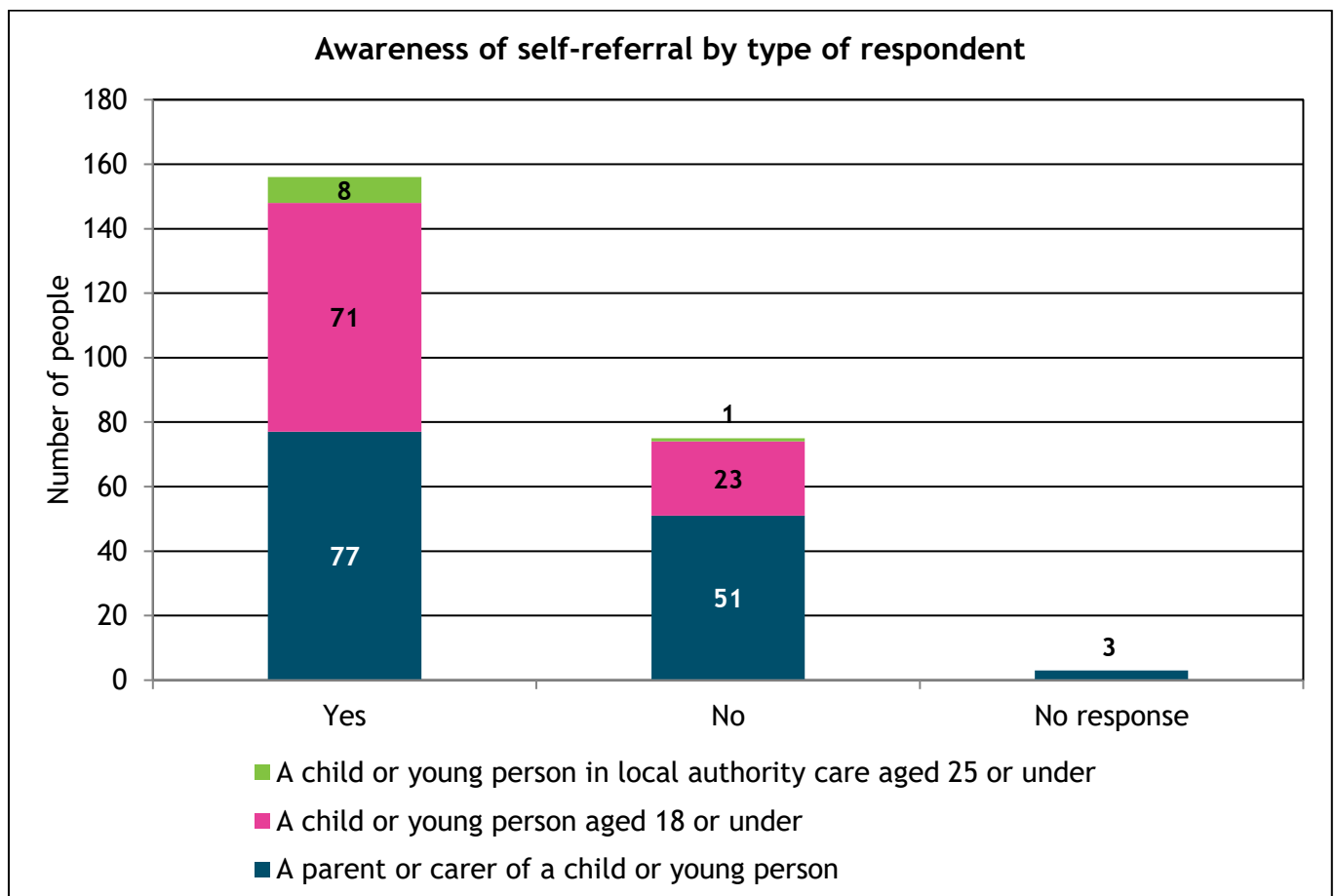
The number of responses from children and young people were representative of the populations of Newcastle and Gateshead, considering the sample size. There were an adequate number of views gathered from young carers, children and young people with disabilities, and children and young people from the lesbian, gay, bisexual and transgender community.

To improve representation, it would be good to gather more views from boys and the Asian community (Bangladeshi, Chinese, Indian and Pakistani in particular). Responses from parents and carers were less representative, with more views needed from fathers and the black and minority ethnic community (BAME).

The demographic data can be seen in the appendix on page 31.

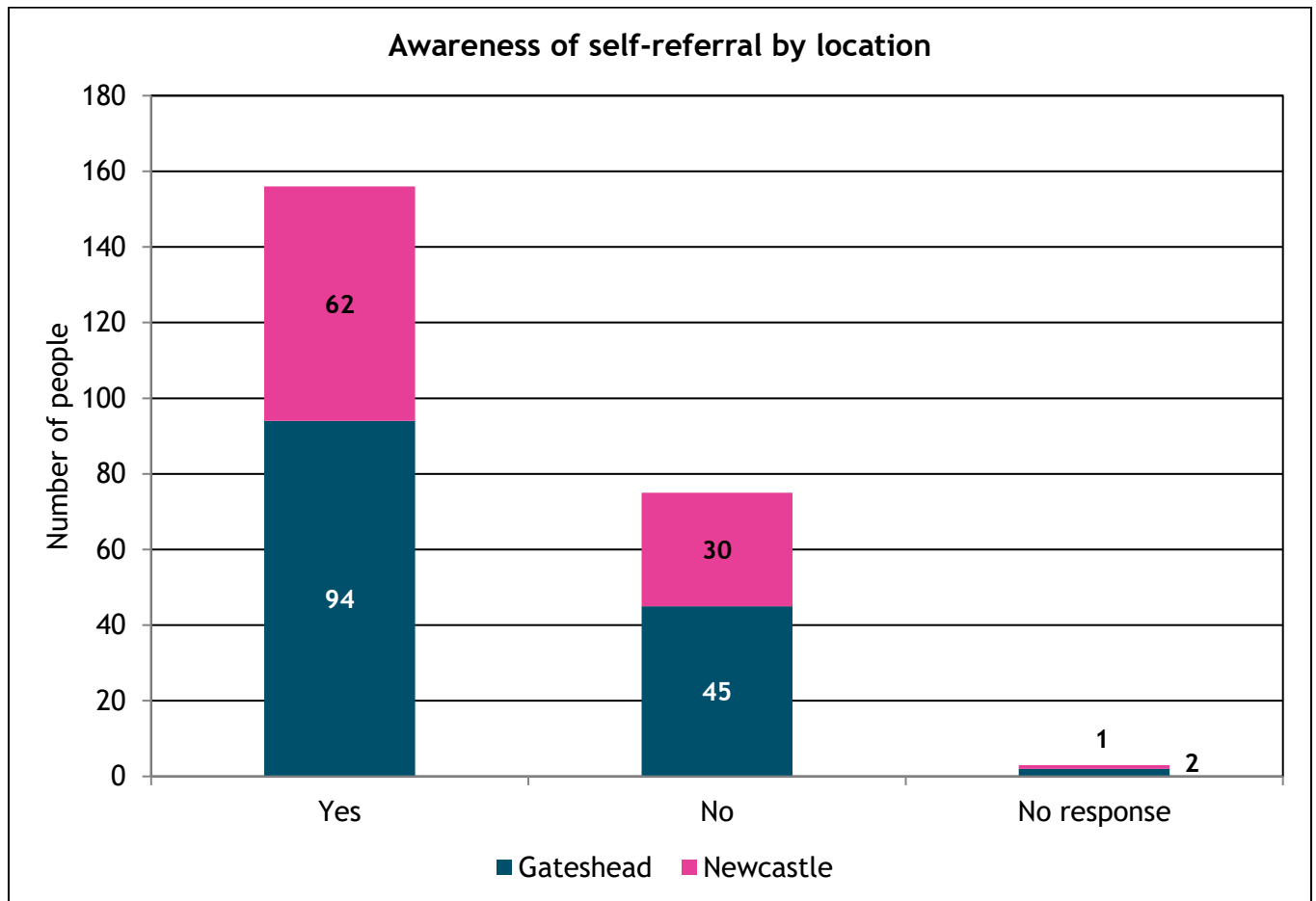
4.1 Awareness of self-referral

We asked respondents to the survey if they were aware that they could self-refer to children and young people’s mental health services. The graph below shows the survey responses by type of respondent.



Most respondents (156) said they were aware they could self-refer. Although awareness appears to be evenly divided among children and young people, and their parents and carers, when the sample size of each type of respondent is considered, awareness was lower among parents and carers (59% said 'yes', compared to 76% for children and young people).

The next graph looks at the level of awareness of the self-referral process in Newcastle and Gateshead separately.

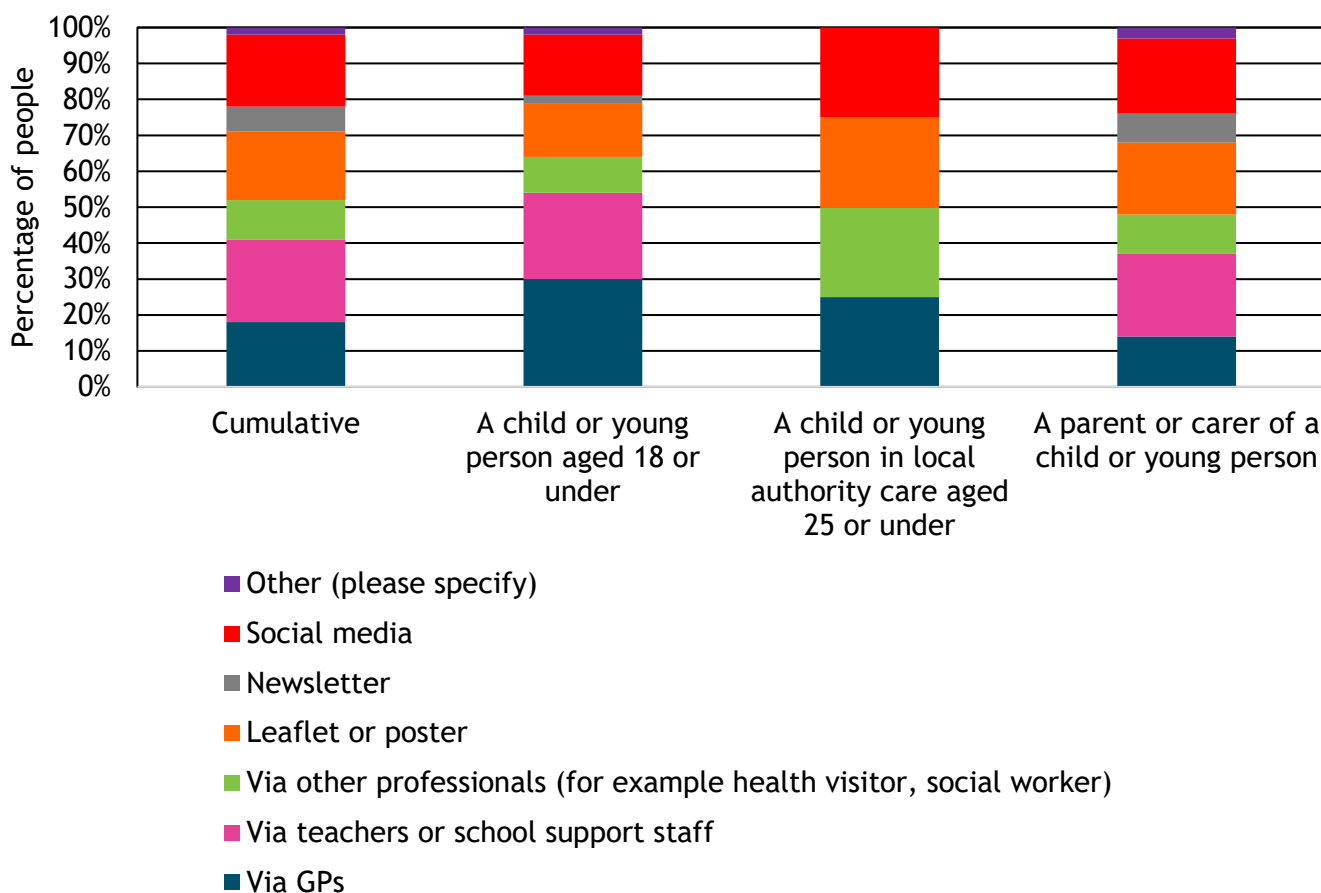


When the sample size for each area is considered, awareness was the same across both areas; 67% of people responded 'yes' and 32% responded 'no'.

We also asked nine of the people we interviewed (eight parents or carers and one young person) and all of those from the focus group (five parents or carers) if they were aware of the self-referral process. Twelve said they were aware they could self-refer, including the young person we interviewed.

When the 75 respondents to the survey who said they were not aware of the self-referral process, were asked how they thought the self-referral option should be promoted in the future, 70 gave an opinion. The next graph displays the results.

How should the self-referral option be promoted: by type of respondent



Overall, the most popular method for promoting the self-referral option was via teachers or school support staff, followed by social media, leaflet or poster, and then GPs. The most popular method for parents and carers was via teachers or school support staff, followed by social media and leaflet or poster. Children and young people wanted to hear about self-referral via their GP, followed by teachers and school support staff and social media.

Promotion of the self-referral option via GPs received a low response from parents compared to children and young people. Newsletters also received a very low response rate from all types of respondents.

The people who selected ‘other’ specified the following:

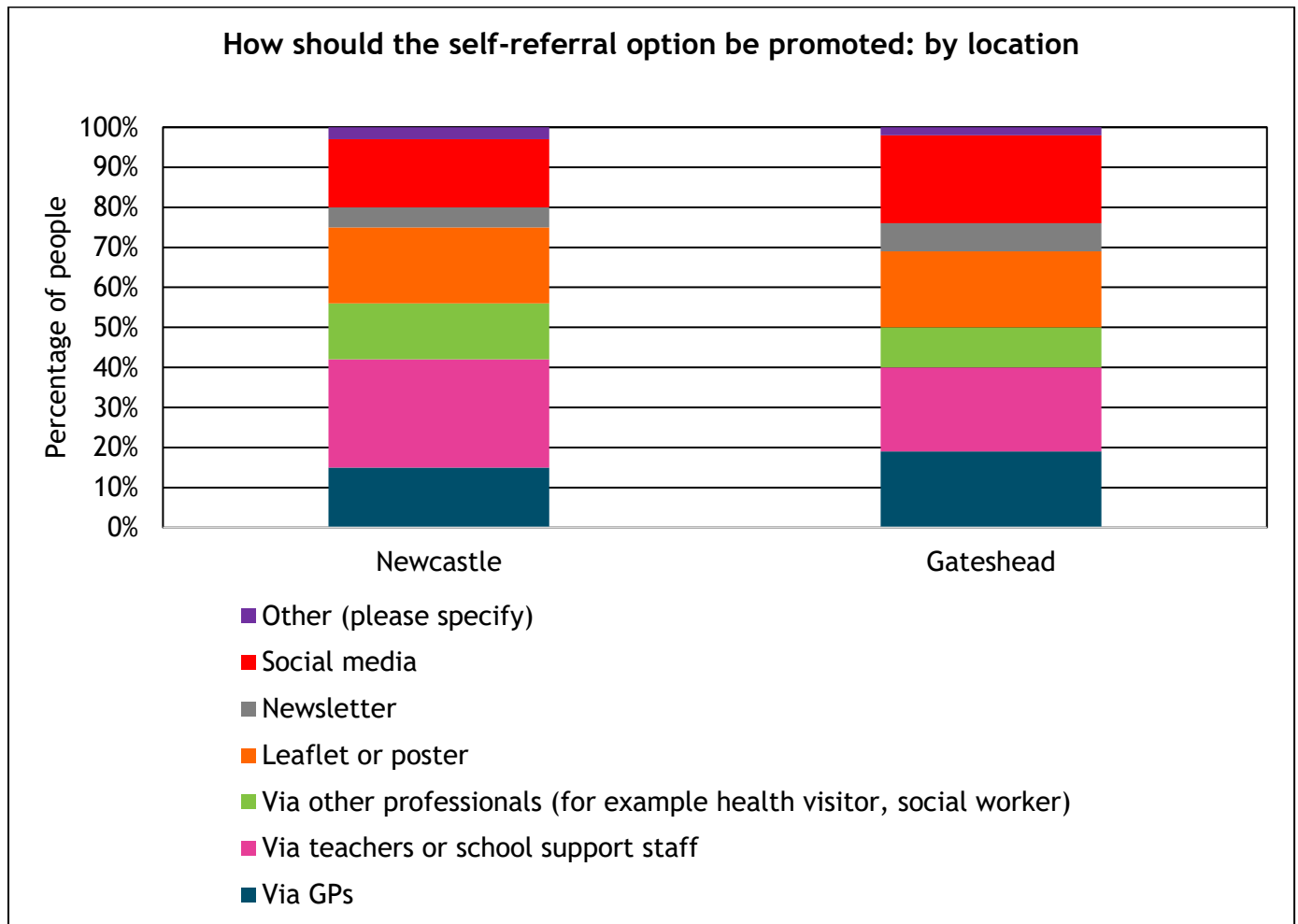
“Lots of publicising.”

“Bloggers, ambassadors and mental health campaigners, MPs.”

“All of the above but especially schools, and perhaps advertise in the regular booklets schools give out about what’s on locally.”

“Text.”

The next graph looks at promotion preferences separated across Newcastle and Gateshead.

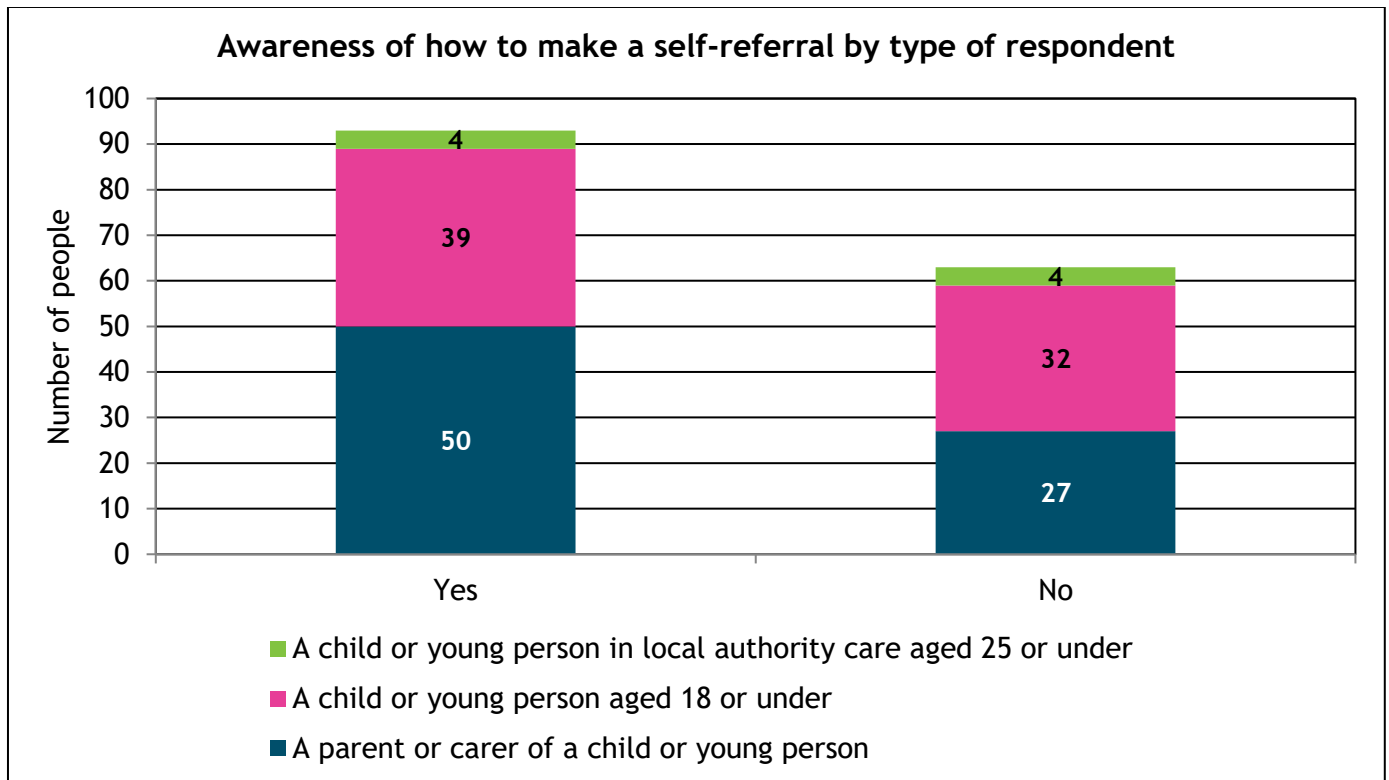


The differences across Newcastle and Gateshead were very small, but the biggest difference was seen within ‘via teachers or school support staff’, with Newcastle respondents having a higher preference for this method.

A difference was also seen within ‘social media’, with Gateshead residents selecting this more often than Newcastle residents.

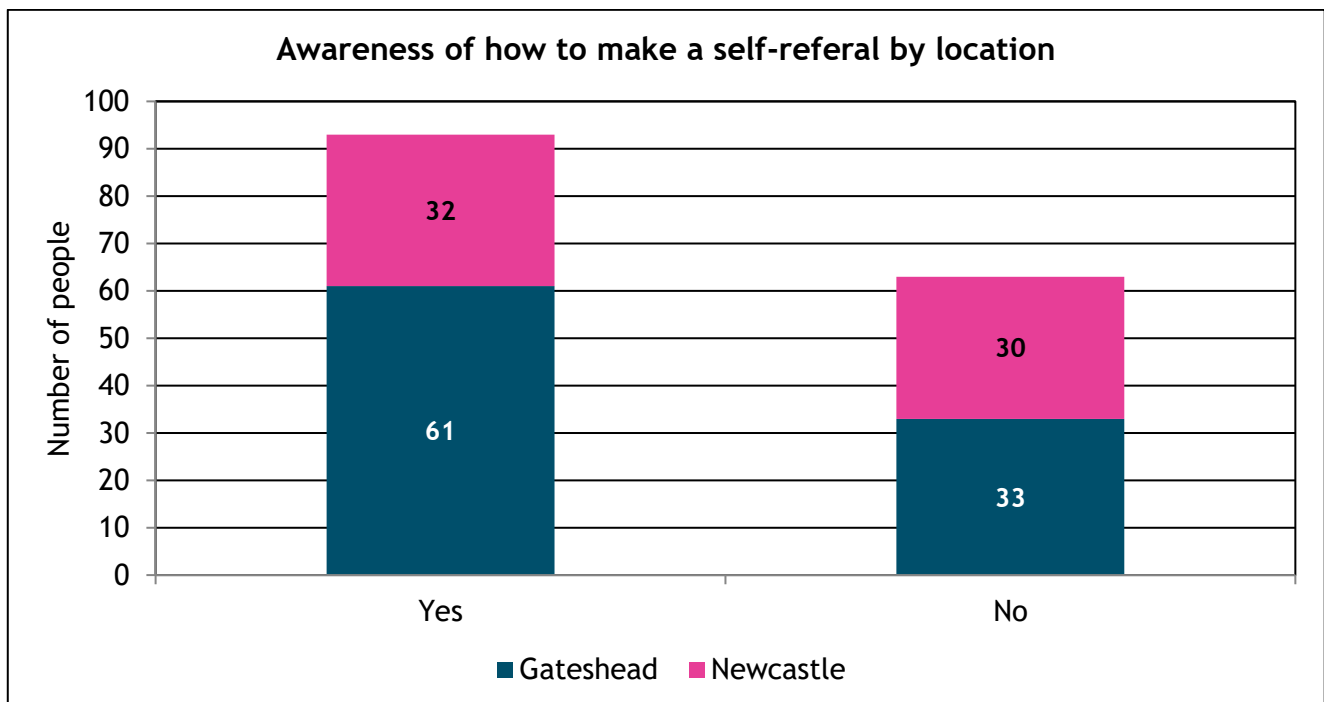
4.2 Awareness of how to make a self-referral

The respondents to the survey that stated that they knew about self-referral into children and young people’s mental health services (156 people), were then asked if they were aware of how to do this. The next graph shows how people responded.



Most (60%) stated that they knew how to make a self-referral. When the sample size for each type of respondent is considered, more parents and carers (65%) knew how to make a self-referral for the child or young person they care for, compared to children and young people themselves (54%).

The next graph looks at the awareness of how to make a self-referral by location.



Awareness of how to make a self-referral is higher in Gateshead (65%) in comparison with Newcastle (52%).

However, when we explored people's understanding of self-referral via one-to-one interviews and the focus group, we found confusion about what a self-referral is. Twelve people shared their views and only five of those (all parents and carers) understood what a self-referral was. Two of these specifically mentioned the SPA, and showed an understanding of who can use the SPA and the fact that referrals can be made online:

“I am aware now that we use the single point of access, I tend to do that online... but I have spoken to them over the phone.”

“I completed a referral for assessment of my child. I understood anybody could refer i.e. teachers/GP/family or the young person.”

It is important to note that both these people felt that they were aware of the process mainly because of the job they do. The other three people who understood what a self-referral is said:

“Know about the process because I am a teacher but also know because I did it for my daughter. GP would not refer so I made a referral myself after badgering the service I was trying to refer into multiple times.”

“Got a list of services that felt child could use and contacted them directly. Knew someone who worked in the field.”

“You can self-refer but it is much quicker via your GP.”

While these three people did not reference the SPA specifically, it is interesting to note the references made to their employment or knowing someone in the field.

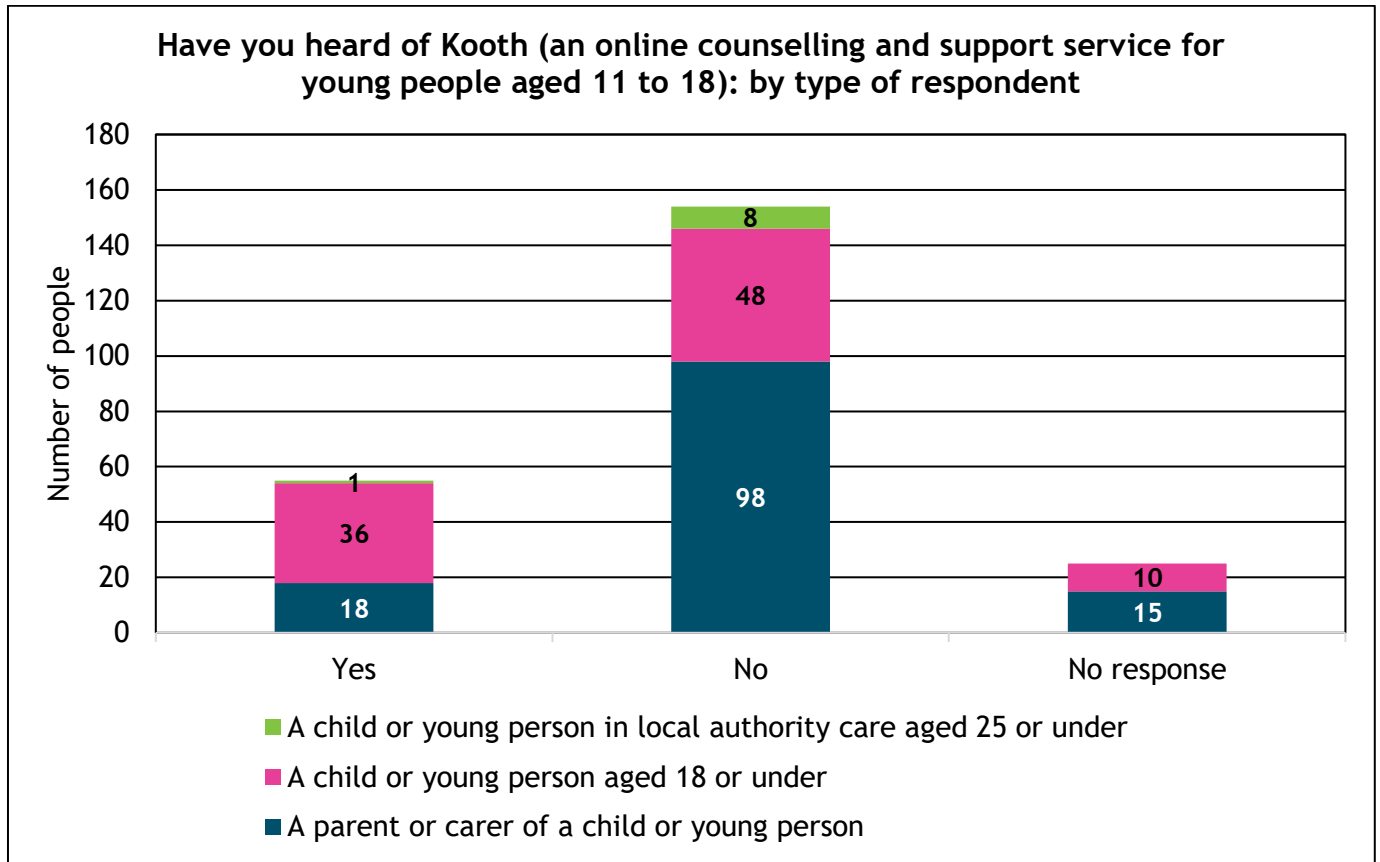
The other seven people had a different understanding. All mentioned returning to their GP, and two of these people also referred to using schools, health and social care professionals and hospitals, etc.

“I would start with a GP visit for my child to explain the issue and ask for the appropriate contact so I could refer them into the service, or if they felt my child needed a GP intervention. I imagine the contact numbers are also available online through an NTW children's mental health services search.”

“My understanding is to refer back to my GP stating that I would like to go back into the services or speak to talking therapies to make a self-referral back into therapy.”

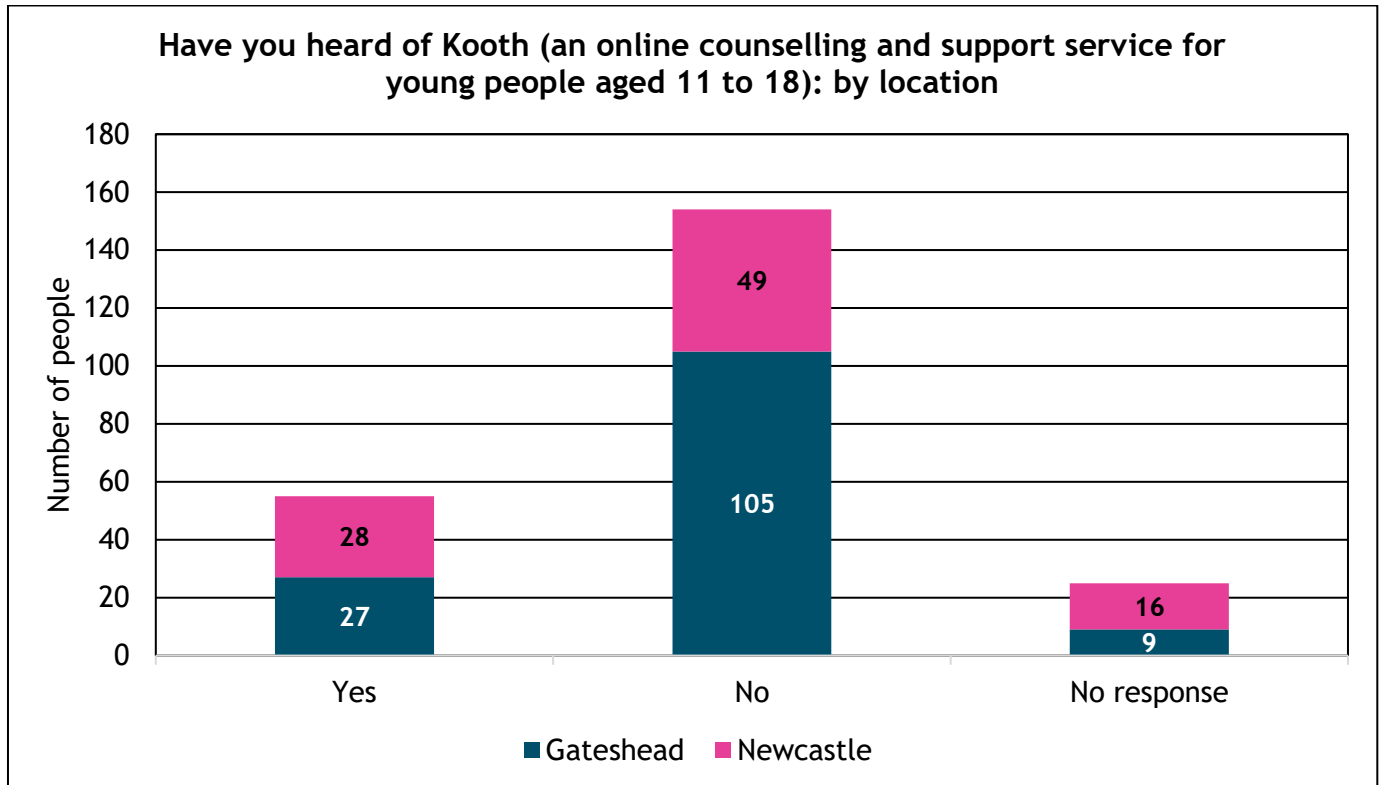
4.3 Awareness of Kooth

We asked respondents to the survey if they were aware of the Kooth online service. The graph below shows responses by type of respondent.



Most people had not heard of Kooth. This was the most common response within all three groups and was particularly the case among parents and carers.

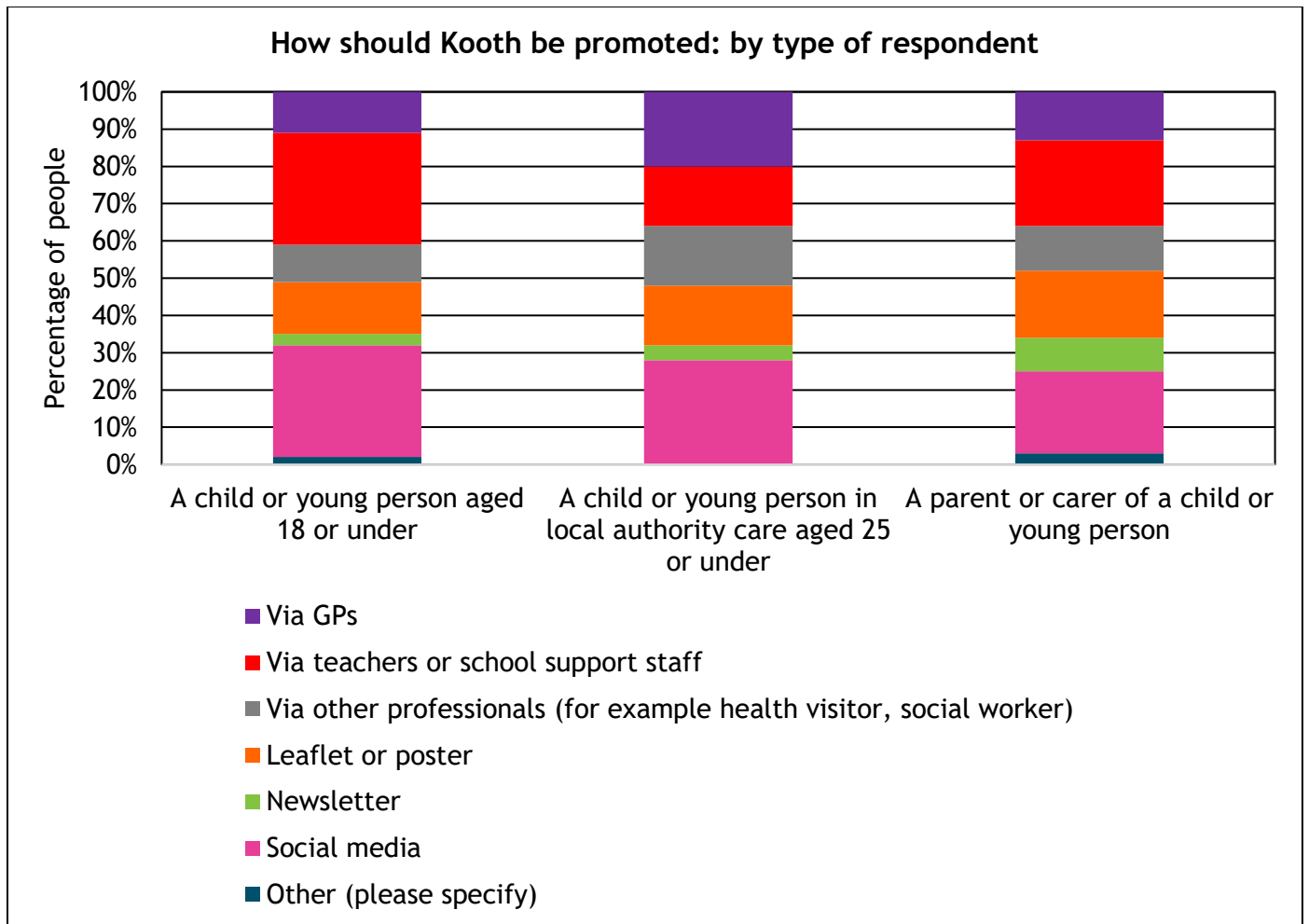
The next graph looks at the awareness of Kooth across Newcastle and Gateshead.



Awareness of Kooth is higher in Newcastle (36%) compared with Gateshead (20%).

Only three out of the 12 people we interviewed had heard of Kooth. These people were all parents and carers, and two of these had heard about Kooth through their work and one through Healthwatch Newcastle.

We asked respondents who answered 'no' to this question (154) how they thought Kooth should be promoted in the future. The next graph displays the results.



Collectively, the most popular promotional method was via teachers or school support staff, followed by social media.

The most popular method for parents and carers was via teachers or school support staff, followed by social media and leaflet or poster. Children and young people wanted to hear about Kooth mainly via social media, closely followed by teachers or school support staff.

Hearing about Kooth via newsletters received a very low response rate from all types of respondents. The people who selected ‘other’ specified the following:

“NHS website.”

“MPs, Local designated ambassadors, school councils, bloggers, school buddy systems, mental health campaigners, YouTubers, local celebrities.”

“Emails through the college system.”

“TV advert.”

“Text.”

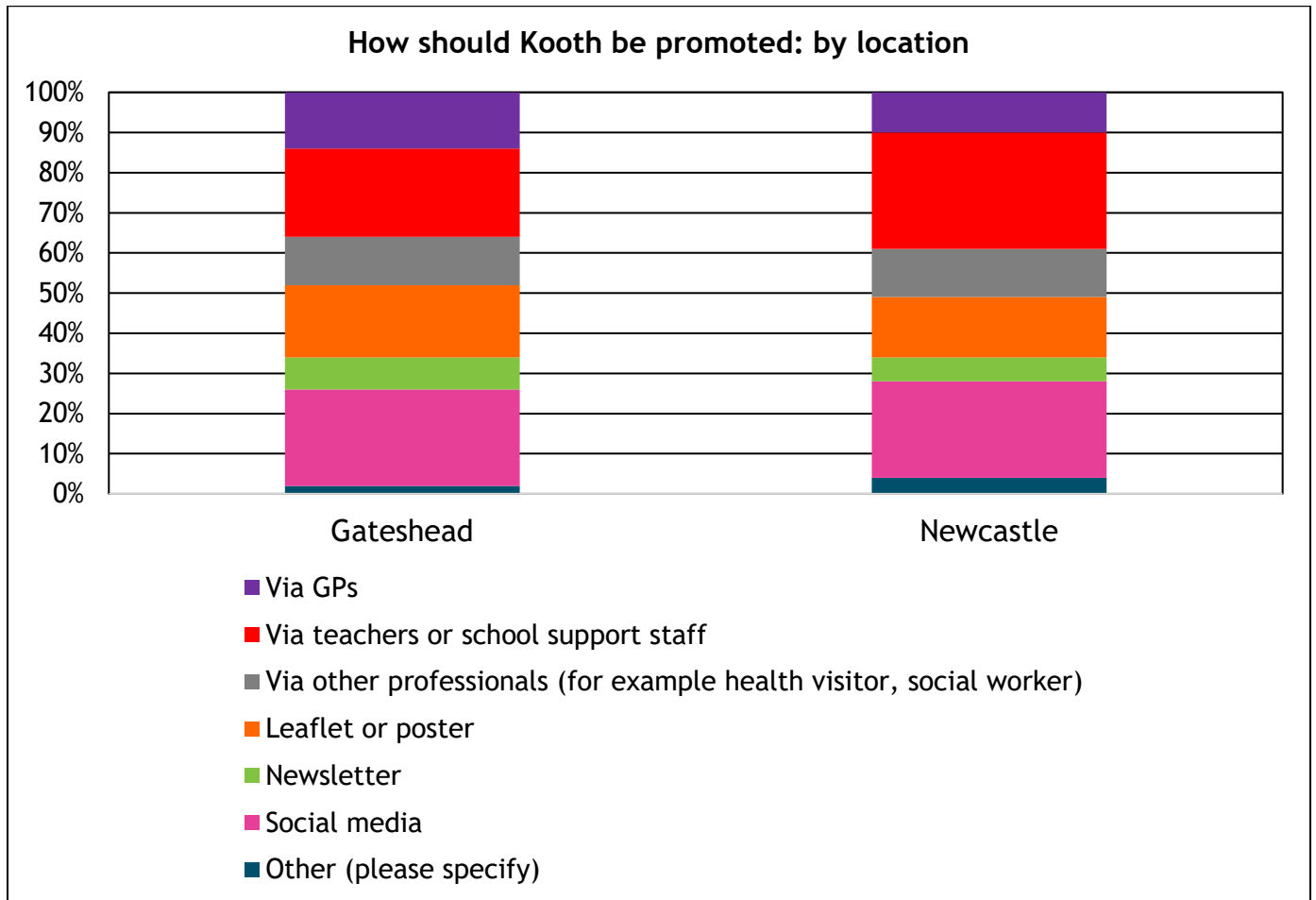
“Meet and greets.”

“Ideally school to send letter home with child about this service.”

“All above and Special Educational Needs and Disabilities information and advice services for children and young people.”

“I don't know.”

The next graph looks at how Kooth should be promoted by location.

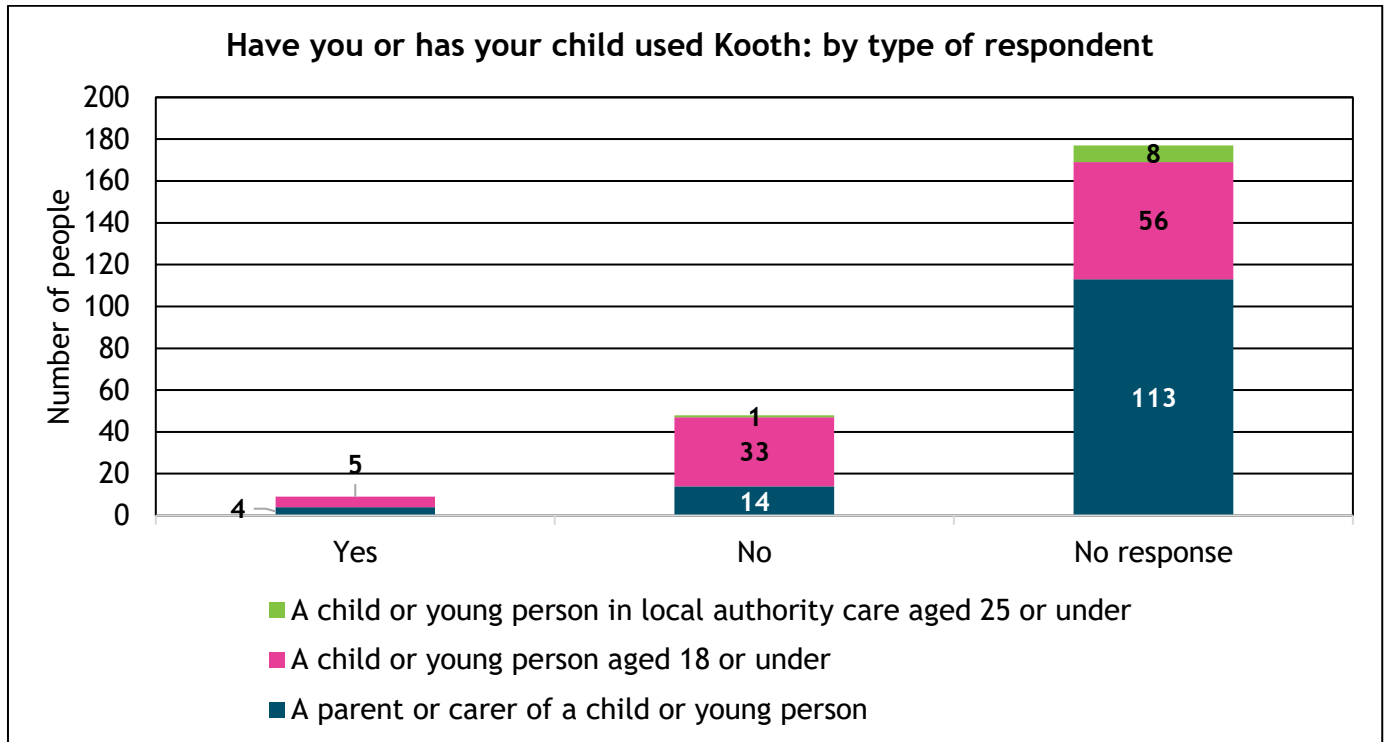


The differences across Newcastle and Gateshead were very small. The largest difference was seen within ‘via teachers or school support staff’, with Newcastle respondents having a higher preference for this method.

A difference was also seen within ‘GPs’, with Gateshead residents selecting this more often than Newcastle residents.

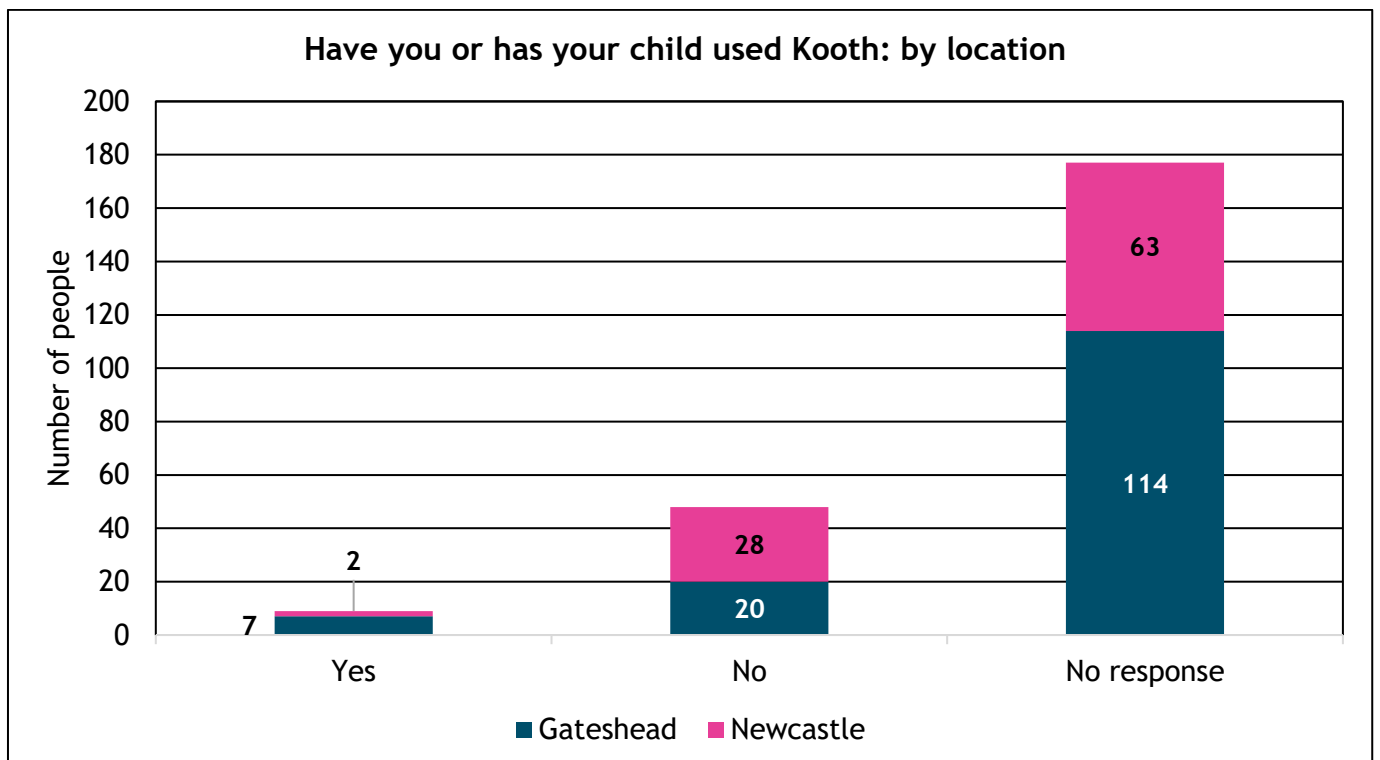
4.4 Use of Kooth

We asked respondents to the survey if they or their child had used Kooth. The graph below displays the results.



The majority (177) did not respond to this question, most of whom were parents. Only nine people answered ‘yes’, four were parents or carers supporting a child and five were children or young people. The rest (48) answered ‘no’ and were mostly children or young people.

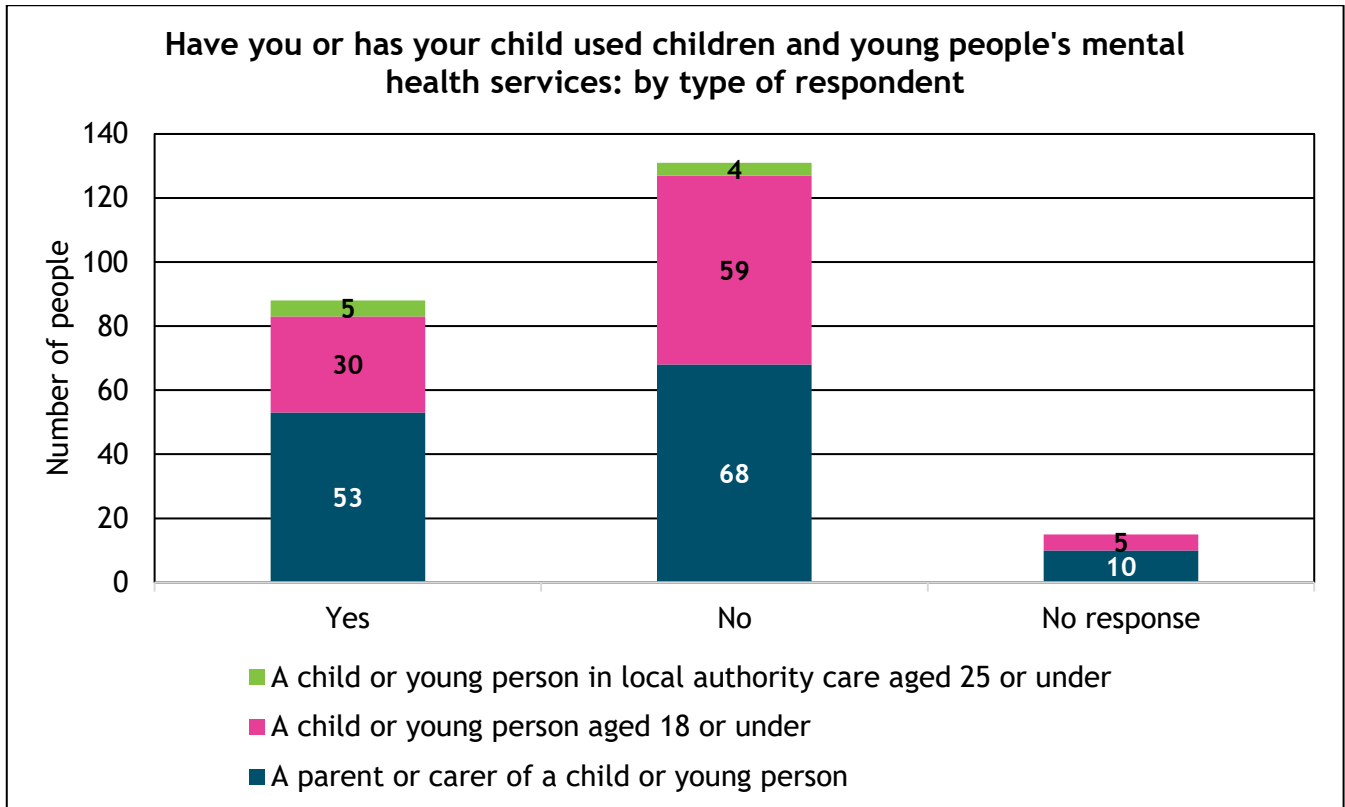
The next graph shows how many people had used Kooth by location.



More people from Gateshead chose to not respond to this question compared to Newcastle. A very small proportion of people said they had used Kooth in Newcastle; the proportion of 'yes' respondents was slightly higher in Gateshead.

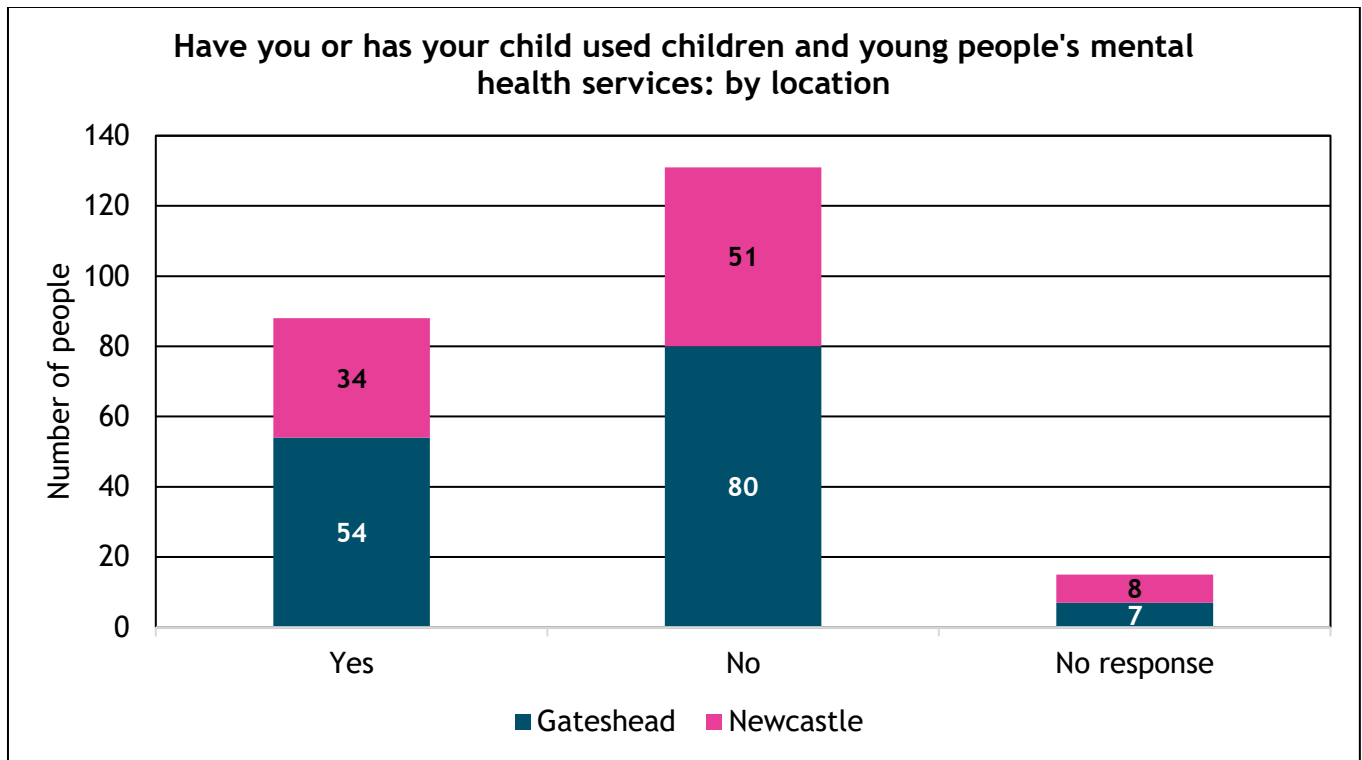
4.5 Use of children and young people's mental health services

We asked respondents to the survey if they had used children and young people's mental health services themselves or through supporting a child. The graph below displays this information.



Most respondents to the survey (131) stated they had not used children and young people's mental health services. However, 88 people said that they had and most of these were a parent or carer of a child.

The next graph shows how many people had used services by location.



Most of the people who had used children and young people's mental health services were from Gateshead, but when the sample size of Gateshead (141) and Newcastle (93) is taken into account, the proportion of those who have used children and young people's mental health services was similar (38% for Gateshead and 37% for Newcastle).

4.6 Experiences of the SPA and Kooth

People who wished to speak to us after completing the survey were asked to provide contact details so we could get in touch. Thirty-nine people (23 parents, 14 young people and two children in the care of the local authority) said they would be happy to tell us more about their experiences.

We carried out 12 one-to-one interviews in total, 11 with parents and one with a young person. Unfortunately, the other 27 people we contacted by phone or email either did not respond or were not able to find the time to meet.

Archibald First School also arranged for parents to attend a focus group, and five parents participated.

This section summarises the information gathered about the SPA and Kooth from these one-to-one interviews and the focus group.

People's awareness of the SPA

We asked all 17 people if they had heard of the SPA. Thirteen had heard of the SPA and four had not. The one young person we spoke to had not heard of the SPA.

Seven of these people could tell us how they had heard of the SPA. Five people had heard of it because of their line of work (i.e. teaching assistant, school counsellor, CNTW employee). The other two had heard of it via an online search and through Healthwatch Newcastle.

Experiences of using the SPA

Out of the 17 people we spoke to, 13 people had made use of the SPA and five wished to make comments specifically about it. These people mentioned that the service was good, well organised and responsive. They also highlighted that the staff were friendly, helpful, approachable and did listen. This was satisfying to hear, as this is what people said they wanted from new services as part of 'Expanding Minds, Improving Lives' (EMIL).

Two people mentioned that the service was a bit slow and sometimes call-backs didn't happen as promised. One person suggested the following:

“The only thing that would have been helpful was a list of different support services that may have been helpful to the family, with a worker who has the time to assess which services might be most beneficial to a patient and putting their name down, rather than the parent having to explore it all. Just having that single person to help navigate the system and be a hub of knowledge and support.”

Referrals

Eleven people shared their experiences of referrals made by the SPA on their behalf. The most common issue was the lack of contact or support available to them while waiting for the referral to go through. We asked these people if they were given information about other services that could be used while waiting for the referral to go through. All the people who responded (seven) said that they were not given any information.

“Left to deal with things alone.”

“None at all despite ringing to chase up the referral with clear evidence of distress and carer stress.”

It was disappointing to hear that this is still happening for some people, as this is something that parents and carers said they wanted to see improved as part of EMIL.

Five people also reflected on problems with waiting times.

“They are not quick and there is a lot of paperwork. At one point, paperwork went missing and had to wait 4–5 months because of it.”

“You have to wait for a long time.”

Finally, four people gave their opinions on the appropriateness of referrals. All four of these people (all parents or carers) said that the referrals were appropriate.

Information

Twelve people gave views on the information and advice provided while using the SPA. The majority (eight) felt that information and advice was poor. They highlighted that:

- Information was given before anyone had met the child, so it was often irrelevant.
- Information was limited.
- Information was often given verbally, which was difficult to take in.
- They often had to explore further before acting on any information received.

“Have been told to buy own books, buy own resources for behaviour control after not meeting the child or knowing about the situation. Books bought have been irrelevant.”

“There was limited information given post-diagnosis.”

“Got snippets of information but family had to follow through, explore and find out more.”

“Mostly poor. Often just told rather than passed information. It is hard to take it in that way.”

The remaining four people said that the information they received was good:

“Really good, they provided us with good, helpful information.”

“I always receive correct letters and referral letters to GPs. There are lots of brief awareness of autism and access to classes, etc.”

“She was told to go to the right places.”

“Yes, it wasn’t all relevant to my child, but it was relevant across the board.”

One parent highlighted an issue about access to an autism parent support group. Parents were told about this group after diagnosis and found it useful. They felt it was a shame that this group was not open to parents waiting for a diagnosis, as they would have found it helpful.

Would you recommend the SPA?

We were able to ask 10 people if they would recommend the SPA based on their experience. Four people said ‘yes’ and six said ‘no’. For those who said ‘yes’ reasons included good staff, less hassle for parents, and a good service generally.

Those who said ‘no’ highlighted that they had had a bad experience due to long waits, poor staff attitude and poor information. One person said:

“No, it sounds more beneficial than it is. In my experience it was just call handlers who emailed the correct person. No advice or support given.”

Usefulness of Kooth

We were able to describe this service in more detail to 12 people who had not used Kooth and asked them whether they thought it would be useful to them or their child. Only one of these people was eligible to use Kooth.

Seven people thought their child or young person would find it useful and two did not. Of the two who did not think it useful, one was a young person eligible to use Kooth, who said:

“I don’t like using online forums to chat and discuss things with. I sort of prefer my mental health to be dealt with by set meetings with a counsellor because then I can really say the things I want to say. If I was to use Kooth, I feel like I would not say the truthful answer always.”

The other person said ‘no’ because their child was not yet old enough.

The remaining three people were unsure whether it would be useful for their child. They highlighted the following from their own experience with their child:

- A need for the service to be sold to children before they would use it.
- Hard for children who have difficulties communicating their thoughts and feelings.
- Stigma attached to mental health could put children off.
- Children lacking understanding or being too overwhelmed at the time to engage.

When and how would you like to be told about Kooth?

Only five people who had not heard of Kooth gave views on this. They highlighted the following:

“As soon as possible after turning 11 by single contact or keyworker.”

“On starting school and via the school app.”

“As soon as possible after it had come into place, either at the next appointment or for someone to call those waiting for a service to tell them about this new service available whilst they wait.”

“At CYPS (Children and Young People’s Service) appointments.”

“Whilst waiting to be seen at point of referral.”

Concerns about Kooth

We asked 12 people if they had any concerns about Kooth and 10 people responded. The concerns people highlighted were:

- Management of safeguarding issues.
- Inappropriate sharing of information online by children and young people.
- Effectiveness of the service without seeing the young person, especially if they have high needs and require more intensive support.
- Service not widely known.
- Accessibility of the site for people who struggle to read.

4.7 Experiences of using other children and young people's mental health services

When completing one-to-one interviews and the focus group, we were also able to identify some themes that extend beyond people's experiences of the SPA or Kooth.

It can be a battle

Eleven of the 17 people we spoke to described their experience as a battle to be accepted by a service, referred to a service and/or receive a diagnosis.



“At first gaining access to the service was very slow but have found you have to pursue constantly.”

“From November 2017 until present it has taken two years and we are finally at the point of diagnosis and treatment, but this has felt like a battle.”

One parent at the focus group told us that their GP had referred them to the Children and Young People's Service (CYPS) but the service refused the referral. The parents decided to push further and CYPS agreed because the parents would not take no for an answer. CYPS explained that the first attempt was rejected because it was overburdened and could not take on another case. This entire process took three months, with a significant push by the parents.

Some parents followed this by explaining the significant impact they felt the delay had had on their child.

“Now she has a diagnosis and can start to get some of the support she deserves it is essentially too late now. It is hard for my daughter to comply, whereas if she had had support workers from an early age, it would have been normal to her.”

Waiting times

Eight of the 17 people we spoke to described problems with waiting times.

“Lots of time battling, then lots of time waiting.”

“I did re-refer in May 2018 with increased carer stress and further deterioration in symptoms. We unfortunately didn't receive any input until September 2018.”



“Various waiting times within the system pushing to get help (2 years, 2 ½ years, 1 year), most are still waiting for a diagnosis.”

Parents also mentioned long waits once on a pathway. Parents and their children often had to wait weeks or months for an initial appointment, with further lengthy waits between each appointment as they moved along the pathway. Parents often felt abandoned with no contact or support from services while waiting.

“At the end of this (initial appointment) I was told I would receive a phone call, they told us they would have a discussion about which route this would go down. Then I spent all summer from June to September trying to get through to them because I didn't get a phone call. I emailed CYPS and told them the situation as at this point, we were getting frustrated because no one was in contact with us.”

Parents in the focus group talked about watching their child deteriorate and develop more issues while waiting for help.

Waiting times were a concern highlighted by children, young people and parents and carers during EMIL. It is, therefore, disappointing to hear that parents and carers are still experiencing these problems.

Access to support

Seven of the 17 people we spoke to talked about difficulties getting help and support while waiting for a diagnosis and after diagnosis.

One parent of a child with anxiety sought further support from a GP. The child was receiving counselling at the time, but her condition was getting worse. The GP was very apologetic but said that there was no other support available. The daughter's condition was not severe enough to access other services that were currently overwhelmed.

When waiting for a diagnosis, parents often found they could not access support groups because they were only open to parents whose child had received a diagnosis.

“We found out there was an autism hub at Barnardo’s but we could not use it until diagnosed.”



After diagnosis, we heard the following:

“Things have got much better after diagnosis. At the moment, it hasn’t really helped in respects to getting support, but it has really helped the family unit and my daughter with acceptance and understanding.”

“Also, could not access the autism hub at school until post-diagnosis, but then could not access it anyway as daughter was ‘not autistic enough’.”

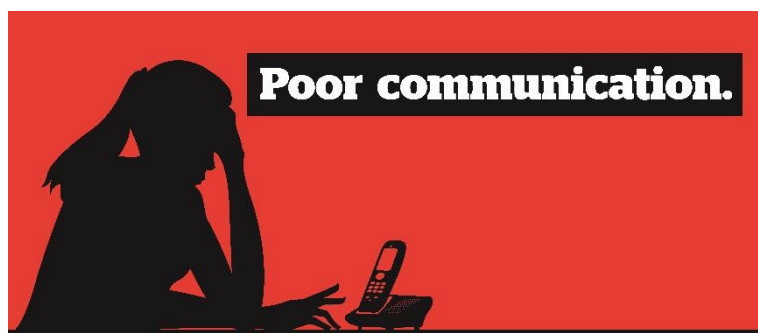
One parent also highlighted the need for more family support post-diagnosis:

“Needs to be more support for parents and siblings post-diagnosis too. Groups to go to for peer support, etc.”

Knowledge of patient and information sharing

Eight of the 17 people spoke about problems relating to professionals not reading patient notes or information not being shared between services. Parents felt they had to share their history multiple times.

“The nurse hadn’t read any of our history so when we mentioned harm in the past, she didn’t know what we were talking about. Then I had to re-traumatise myself because of having to explain what had happened and that annoys me because they didn’t check.”



In the focus group we also heard about professionals asking questions about the child when they were already two years into the process, which made the parents feel like they were going right back to the start. In these instances, the parents felt that staff did not demonstrate they knew the child.

Parents in the focus group also mentioned that there was often an information-sharing problem between agencies and the family often had to act as the go-between.

Quality of service

Nine of the 17 people we spoke to mentioned problems with the quality of service. Some parents in the focus group highlighted issues with the way observations of their child were conducted, as shown in these focus group notes:

- Nurse observing one child, didn't try to engage or play with the child.
- Nurse from CYPS came to observe but was distracted and not taking in anything useful. No real interaction between child and nurse. Resulted in a very generic behaviour plan with some instances of getting the child's name wrong.
- Child was meant to be observed by staff. Staff were making small talk between themselves and didn't notice when the child left the room. Lack of awareness, not doing their job.

Focus group parents also highlighted problems they had with the plans written for their child, as shown in these focus group notes:

- One parent received no separate intervention/behaviour plan for home and school. The plan ended up being useless for both situations.
- Copy and pasted plan, with no attention to detail. Child's name incorrect.

One parent was told that their child had been seen in school for a few weeks by a professional, but this was not correct. Due to record-keeping, some children's names had been mixed up and the child had not been seen.

5. Areas to explore further

This work has highlighted some areas that are worth exploring further.

Self-referral

Although our sample size was small, the issue of understanding the process for self-referral was very noticeable in our discussions.

We think it would be beneficial to explore how the SPA and the self-referral process can be promoted to parents, carers, children and young people so they feel assured enough to use the SPA and self-referral process instead of their GP.

One professional working in schools said:

“Some parents still believe that you have to go through a GP to get a referral but that isn't the case anymore.”

This work must ensure the message reaches as wide a population as possible. If done effectively, this would result in children and young people, and parents and carers getting in

touch with the right people much quicker, saving time and resources within primary care (recommendation one).

Access to information and support

People highlighted that they felt unsupported between their initial contact and first appointment, and between appointments while waiting for assessment and diagnosis.

We were surprised by the number of people we spoke to who had not been told about the Kooth service when in contact with the SPA. People told us they would have welcomed that information. It would be beneficial to do further work on this so that more people are aware of the Kooth service (recommendation two).

There appears to be a perceived lack of support while families wait for an autism or ADHD diagnosis, and a lack of support following a diagnosis. There were autism hubs that families could not access before diagnosis that they would have found useful, and hubs they could not access after diagnosis because the child was ‘not autistic enough’.

We are aware there is some support out there, including:

- Rollercoaster, which runs support groups for parents and carers who are supporting a child or young person with any kind of emotional or mental health problems. There are plans to expand this in Newcastle and Gateshead.
- The Gateshead Autism Hub, based in the Elgin Centre in Gateshead, which offers an information hub and parent/carers support groups for people across the region pre- and post-diagnosis.
- The Children, Young People and Parents Mental Health Trailblazer Project and a mental health support team, active in 108 Newcastle and Gateshead schools.

However, people’s responses when asked about support available suggests that either there is not enough, or that it is not well promoted.

It was also suggested to us that there needs to be more support for parents, carers and particularly siblings post-diagnosis, such as peer support groups (recommendation three).

Waiting times

Issues around waiting times extend beyond the frustration of having to ‘battle’ and long waits to receive a diagnosis. Parents noted the impact these waits had on their child’s willingness to accept diagnosis and treatment and on their life chances. Some parents commented that by the time of diagnosis, the child had accepted their situation and did not wish to accept help, noting that if they had received the diagnosis earlier, their child may have been willing to accept the support they were entitled to.

We know that Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust (CNTW) has been working on reducing waiting times and the results can be seen in the trust’s 2018–2019 Quality Account. This account highlights a reduction in the size of the Newcastle and Gateshead CYPs waiting list, and a reduction in the number of people waiting more than

18 weeks for Gateshead CYPS. The account also highlights a commitment to continue working on improving waiting times. With this in mind, and our findings, we would like to see this work continue as a high priority so that children and young people can receive the support they are entitled to much quicker (recommendation four).

Capacity issues

Feedback suggests that children, young people, parents and carers are experiencing the impact of capacity issues within CYPS (referrals not being accepted because it is overburdened) and services provided by the voluntary and community sector (VCS), which are overwhelmed. We would like to know more about what Newcastle Gateshead CCG and CNTW are doing to resolve this issue and what is being done to support VCS providers (recommendation five).

Further work

It is worth noting that there are some people whose voices still need to be heard. Although we received a good number of responses from children and young people, we did not speak to enough on a one-to-one basis (only one person) to hear their experiences in more detail.

Although three of the people we interviewed had heard of Kooth, unfortunately none had used it. Therefore we were unable to ask what experiences anyone had had of this service.

We also want the views of children, young people, fathers and people from black and minority ethnic communities to be heard more (recommendation six).

Finally, we did receive a response to our information request for an update on actions relating to EMIL as detailed in the 'Children and young people's mental health and emotional wellbeing action plan 2017–19'. This highlighted that actions from EMIL are being progressed and that some have been completed. We understand that:

- Further work is planned to evaluate the SPA.
- Numerous pathways have been reviewed, focussing on making them more streamlined with less bouncing around the system and fewer waits. This has improved in some areas but further work is needed in others.
- Further work is planned to co-produce a sustainable model for Young Commissioners so that young people can always be involved in the commissioning and development of children and young people's mental health services.

6. Recommendations

Based on the information we have gathered we make the following recommendations:

1. Newcastle Gateshead CCG and Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust (CNTW) should explore how the SPA and self-referral process can be promoted to parents, carers, children and young people so that they feel assured enough to use the SPA and self-referral process instead of their GP. This work should ensure that key messages reach a broad range of communities.

2. Newcastle Gateshead CCG and CNTW should ask parents, carers, children and young people who have been in contact with the SPA about the information and support they received while waiting for their first appointment, and work with them to review what information is shared and how. Any solutions identified should then be implemented, including the provision of more information about the Kooth service.
3. Newcastle Gateshead CCG and CNTW should ask parents and carers about their experiences of accessing support before and after an autism or ADHD diagnosis, and work with them to decide how best to promote any support services that are available to children, young people, parents, carers and siblings.
4. Newcastle Gateshead CCG and CNTW should continue to prioritise and put resources into reducing waiting times for the benefit of children, young people and their parents and carers.
5. Newcastle Gateshead CCG and CNTW should reflect on the capacity issues identified in this report and inform Healthwatch Newcastle and Healthwatch Gateshead about current plans or actions that are or could be taken to rectify these issues.
6. Newcastle Gateshead CCG, CNTW and Kooth should consult with and hear the experiences of children, young people, fathers and people from the black and minority ethnic community who have used either the SPA or Kooth.
7. Newcastle Gateshead CCG, CNTW, and Kooth should work closely with schools and colleges to promote the SPA, the self-referral process and Kooth, because according to our survey this was the most preferred method for hearing about these services.
8. Newcastle Gateshead CCG, CNTW and Kooth should also consider running a social media campaign to promote the SPA, self-referral and Kooth.

7. Acknowledgements

We would like to thank all the people who gave their views to inform this report.

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We are grateful to Archibald First School, Gateshead College, Jesmond Park Academy and Newcastle College for helping us reach out to children, young people and their parents and carers.

Appendix

Anonymised case studies

It was a long battle to get a diagnosis and support...

In 2008, when Esme's daughter, Olivia, was five, Esme noticed that Olivia had some behavioural issues. Esme started to work with the child and adolescent mental health service at the Queen Elizabeth Hospital.

Whilst working with this service Esme really felt as though her views as Olivia's mother were dismissed. She did not feel listened to and was really made to feel like the problems stemmed from her parenting.

In the end, Esme found using this service so exhausting and such a battle. She felt discouraged enough to stop using the service and continued without support.

Esme managed in this way for five years (until about 2013 when Olivia was 10). Esme thinks that she should have gone back sooner, but she quite simply could not face the battle.

Eventually, when Olivia turned 14 (2017), social services became involved and Esme and Olivia were allocated a social worker. Esme really hadn't wanted it to go that far due to the stigma attached to having a social worker, but in the end, the involvement of social services was very positive.

With the support of social services, Esme and Olivia started working with the children and young people's service (CYPS), where the battle to get a diagnosis began.

Eventually, by the age of 15 and a half (October 2018), Olivia received a diagnosis of Autism.

In total, Esme and her family had been coping for 10 and a half years before eventually receiving this diagnosis. Coping because, initially, Esme did not feel listened to, and fobbed off and blamed as a parent. Coping because of the time it took to get to the right service and on the right pathway to a diagnosis.

It was a real battle.

After the diagnosis Olivia was finally able to receive some of the support she deserved, but the family found it very hard to get Olivia to engage in the support she was offered.

Esme feels that if Olivia had been diagnosed much earlier and offered support, she may well have engaged with it then, as she hadn't experienced years of getting by without it.

The family also feels really let down. If Olivia had received support earlier, this may have helped the family avoid some of the stressful experiences they've had to endure.

Esme felt that the information provided post diagnosis was limited. Small pieces of information were often shared verbally but Esme had to follow the suggestions up herself and in doing so came across new information.

Esme would have found it helpful if a list of different support services could have been made available to her. It would also have been really good to have a single worker who would have the time to assess which support services might be best for the family and put their name down, rather than the parent having to explore it all.

Esme and her family did attend some parent support groups which she found very useful. These parent support groups were just for people who had children with an Autism diagnosis. Esme feels that this is a shame as she would have found the group useful before diagnosis.

Overall, the experience for Esme and her family was a battle and very challenging. It would have been a much better experience had the family been listened to more and provided with more support throughout the process.

Wait... wait and wait some more...

Rosie and her son, Archie, first accessed children and young people's mental health services via the single point of access in February 2019.

After the first referral went in, the parents were told that they would be contacted within 12 weeks and they were invited to a welcome event within that time. This was pleasing.

However, once at the welcome event they were informed that there was about a 12 to 15 month wait.

This was really hard to take in. The family were surprised that the welcome event happened so quickly, and it had made them think that the next steps would follow on quite quickly too. Being told about the long waits at the welcome event was quite a shock and a disappointment.

However, very soon after this welcome event, they did receive an initial appointment which went very well. Rosie was told that they would assess the case, decide which route Archie needed to take through the system and that Rosie would then receive a phone call about the next steps.

Rosie did not receive the phone call. Throughout June to September Rosie was trying to get through to the children and young people's service (CYPS). Rosie eventually ended up emailing CYPS as she was getting very frustrated with the wait, lack of information, and lack of a phone call.

After this Rosie did receive three phone calls which resulted in Rosie having a better understanding of the process and which route Archie would be taking through the system. An occupational therapist also got in touch and gave some advice. Rosie found this useful.

Since then, Archie has had a developmental assessment, followed by another long wait. Because of this, Rosie ended up having to speak to other people for support, like the Gateshead Occupational Therapy service.

Archie is now on another waiting list for a school observation. The family won't know if he needs an assessment until after that. Rosie says that it is an incredibly slow experience and it has had an impact on Archie, who feels forgotten, confused and frustrated.

Survey respondents - children and young people demographic data

Gender		Sexuality	
Male	26	Heterosexual	56
Female	47	Bisexual	7
Transgender	0	Gay man	2
Unknown	30	Gay woman	2
Age		Other	0
17 and under	63	Unknown	36
18-24	14		
25-49	0	Ethnic groups	
50-64	0	British	63
65-79	0	Irish	0
80+	0	Gypsy or Irish Traveller	0
Unknown	26	Other white background	3
Disability		Indian	0
Yes	13	Pakistani	2
No	65	Bangladeshi	1
Unknown	25	Chinese	1
Carer		Other Asian background	0
Yes	6	White & Black Caribbean	0
No	71	White & Black African	0
Unknown	26	White & Asian	2
Employment status		Other mixed background	1
Student	72	Caribbean	0
Employed/self-employed	4	African	1
Not in paid employment	1	Other Black background	0
Retired	0	Arab	0
Unknown	26	Other ethnic background	0
Marital status		Unknown	29
Single	68		
Divorced	0		
Married	0		
Civil partnership	2		
Living with partner	0		
Widow	0		
Unknown	33		

Survey respondents - parents and carers demographic data

Gender		Sexuality	
Male	6	Heterosexual	99
Female	97	Bisexual	1
Transgender	0	Gay man	0
Unknown	28	Gay woman	0
Age		Other	0
17 and under	2	Unknown	31
18-24	3		
25-49	89	Ethnic groups	
50-64	10	British	102
65-79	0	Irish	1
80+	0	Gypsy or Irish Traveller	0
Unknown	27	Other white background	1
Disability		Indian	0
Yes	8	Pakistani	0
No	94	Bangladeshi	0
Unknown	29	Chinese	0
Carer		Other Asian background	0
Yes	28	White & Black Caribbean	0
No	76	White & Black African	0
Unknown	27	White & Asian	0
Employment status		Other mixed background	0
Student	0	Caribbean	0
Employed/self-employed	83	African	0
Not in paid employment	20	Other Black background	0
Retired	1	Arab	1
Unknown	27	Other ethnic background	0
Marital status		Unknown	26
Single	36		
Divorced	8		
Married	55		
Civil partnership	5		
Living with partner	0		
Widow	0		
Unknown	27		

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