

YOUNGMINDS

The voice for young people's mental health and wellbeing

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**Report on Children, Young People
and Family Engagement**

for

**The Children and Young People's
Mental Health and Wellbeing Taskforce**

December 2014

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Executive Summary

YoungMinds was commissioned to undertake the engagement of children, young people and families for the Children and Young People's Mental Health and Wellbeing Taskforce. Specifically the views of young people, parents and carers were sought on issues relating to the provision of mental health information and services.

During the engagement over 1,100 children and young people and over 400 parents responded to on-line surveys, 800 male respondents completed a poll, and 17 discussion groups were conducted as well as six telephone interviews.

The complete findings are available in the full report. A summary of the findings follows:

1. Findings relating to promotion and access

1.1 Mental health information

- Younger respondents to the survey and young carers were the least informed about their mental health, with 25% of 14 and 15 year olds and 24% of young carers saying that they do not know enough about how to look after their mental health.
- Mental health apps or websites, and friends were the two sources most frequently used by young people to access mental health information. Online information resources were also considered useful by 68% of those that used them. Information provided by charities was thought to be most useful with 73% of young people who had used it saying it was helpful.
- Digital services are popular for the speed, ease of access and preserving anonymity. But there are concerns about the quality and trustworthiness of information found online, and the lack of a well-known, trusted, central portal of information for young people.
- Young people want online information to be corroborated by professionals. When this is not the case, the information loses impact and value.
- Information should be normalised, easy to find and reliable - similar to the information on physical health. Several survey participants concluded that something similar to high profile healthy eating campaigns was required for mental health.
- There were some views that the issue was less about providing additional information and more about increasing awareness of, and access to, existing information.
- Parents felt least informed about how to support their child when they are struggling with their mental health or self-harming, and how to teach their child about looking after their mental health and emotional wellbeing.
- Mental health apps or websites, and health professionals other than GPs were the two sources most frequently used by parents to access mental health information. Charities are the information source that parents would be most likely to use.

- Participants across all audiences highlighted the need for information to be provided earlier. GPs, teachers, other professionals, parents and young people themselves should focus on prevention and spotting early signs to avoid intervention later.

1.2 Mental health services

- Online services, such as counselling, practical apps to manage mental health and mentoring are used less often than online information resources. Discussion groups highlighted concerns about confidentiality and knowing who is providing the support.

On-line counselling wouldn't really work because anybody could be a counsellor on the internet so if you go out to get help and it's just a bunch of kids mucking around they could make you feel worse - *Educational settings attendee*

- Parents have a clear preference for services to be delivered face to face rather than online. 94% of parents would be more confident in a service's value if it was delivered face to face rather than online.

I think any online provision without supervision and professional support via face to face meeting is potentially very dangerous - *Parent survey*

- All groups of young people agree that the most important factor in mental health service provision is that *"The person that gives me support is someone I feel comfortable talking to and can be honest with."*
- Professionals are encouraged to spend more time to get to know the young person and context better. A better balance between professionalism (confidential, respectful, private) and informality (friendly, appropriate language, suitable locations, a degree of flexibility) needs to be struck.
- The issue of trust appears important with all groups, but it was particularly highlighted by looked after children who talked about needing to be supported by *"a familiar face, somebody that understood me"*, and were clear that *"people you don't know, you are not going to start telling them all."*

1.3 The role of schools

- Many young people taking part in the discussion groups expressed concerns about the lack of support available in their school. The service user groups in particular concluded that schools do not typically have enough of the right people to help, and that they should be more understanding and do more to promote mental health.

When I got ill at school they treated it as a behavioural issue so I was formally suspended twice to things related to my mental health when in reality I didn't actually need to be punished for it, I needed someone to help me, which they didn't do, - *Service user attendee*

- The two forms of support provided by schools that children and young people find the most helpful – lessons about mental health run by an outside organisation and on-line counselling for pupils – are rarely provided. Online counselling is popular as it alleviates concerns about confidentiality.

- Similarly, forms of support considered to be helpful by parents namely information on the school intranet, evening sessions for parents looking after their child's mental health, lessons about mental health for pupils, and signposting to access support, are not provided by schools very often.
- It was generally agreed that mental health support requires full-time dedicated trained staff able to identify worrying signs and that mental health should be included in the curriculum, alongside physical health. Services should be delivered in an approachable way, with self-help and peer support available, as well as after school drop-in.

I just think that teachers in the schools need to be educated on mental health to spot things, so there's like some sort of support network that they [young people] can go to rather than them feel shit. - Vulnerable group attendee

1.4 GPs

- Young people and parents are often concerned they are not listened to – sometimes complaining that GPs are ignorant of mental health issues and turn a blind eye to worrying signs.

GPs are just very dismissive of parents and parental concerns... You are telling your GP and oh it's a parental issue, oh it's a behavioural problem at home, and your kid is trying to stab you with a knife - Parent group attendee

1.5 The image of CAMHS

- Children and Young People prioritise accessing CAMHS support over concerns about the specific name of the service. 78% agreed that *"It doesn't matter what CAMHS is called as long as young people know where to find it"* with only 8% disagreeing. The majority of CAMHS Service users are happy with the name.

It's not the name people are bothered about, it's the quality of service they receive and even receiving any service can sometimes be hard enough - CYP survey

2. Findings related to having a co-ordinated system

- Use of multiple services is greater amongst some vulnerable groups with 72% of those who have had looked after status, and 55% of those who have been a young carer have used four or more services.
- The main combination of services remains school (or educational establishment), GP, and CAHMS. It is often when this combination does not work well in practice that other services are used – for example private services, A&E, crisis teams and charities.
- 47% of young people who have used two or more services report that they worked poorly together with 42% saying they worked well together. Young carers have a worse experience with 52% saying services worked poorly together (only 36% saying they worked well).

Liaison between different services is really important, so if the GP and the A & E teams and the crisis teams and the school and the therapist and the counsellors they all like need to be informed, sometimes it can feel a bit bitty, you know so

you explain something like five times to five different people because they haven't got the information passed on - *Service user attendee*

- Parents report a worse situation. 72% of parents who have used services have had an experience of poorly integrated services, approximately three times as many as those who have an experience of well integrated services (26%).

I was getting pushed from pillar to post, from pillar to post, it was the school that had to assess her, no it was the GP, it was the school, it was the GP, and I gave up on that one in the end - *Parent group attendee*

- Key to services working together more effectively is improved communication, better liaison between professionals, clear lines of responsibility, and absolute clarity with young people about confidentiality – it is vital to be clear about what information will be shared with whom, and why, and in what circumstances information may need to be shared without the consent of the young person.

3. Findings related to data and standards

3.1 Experiences of mental health services

- The engagement revealed vastly different experiences of using mental health services. There were several examples of excellent service provision reported by some young people.

They [CAHMS] were amazing. I wouldn't be the person I am today. I've known this woman...and she's known me since the age of 5. And she's like a second mum to me. She listened, like me I stored up my feelings and I still couldn't talk in front of a big bunch of people... She's amazing - *Vulnerable group attendee*

- Positive experiences were less common amongst parents. Areas of dissatisfaction included getting an appropriate referral to a service in the first place (a feeling of having to fight their way into services and tell their story over and over again before professionals will believe that their child is ill) and, once referred, the amount of time prior to actually attending the appointment (the waiting time).
- The need to become quite ill before any service is made available was highlighted.
- Long waiting times were of particular concern to young carers, as was the distance from home to attend services and appointments as they were not often able to leave their caring responsibilities for a long period of time.
- Several comments revealed that on occasion activities were being “done to” service users, rather than being agreed with professionals

Even when I'd been through the same inpatient system once, made my feelings clear that psychologically I wasn't going to 'click' with recovery unless I was able to have input into my own treatment to make it individual and realistic to me but this was ignored purely as I was an adolescent – *CYP survey*.

3.2. An ideal CAMHS service

- Across the engagement, participants commented that the characteristics of an ideal service would include being accessible and available, providing support in a timely fashion, privacy and confidentiality – but with the option to have someone accompany you, clear communications, working with the same professional each time, being listened to and believed, having key information available, and the opportunity for an informal first meeting with professionals to get to know people.
- On a practical level, young people described the need for services to be available outside of school hours, or to be delivered in ways that didn't impact on learning or add to the stigma of needing to attend a mental health appointment.
- Children and young people also stressed the importance of the service being provided in a non-clinical building. An ideal setting would be bright, comfortable and relaxed.

The first time I went for counselling I went into the room and it was just like a plain room, and just like two seats ... I felt very uncomfortable because I didn't feel very welcomed to where I was and if there was a bit more like if the building was a bit more friendly I'd probably feel more comfortable to talk to the person -

Service User Attendee

- There is a preference for communication by text particularly for appointment reminders.
- Children and young people who have been discharged should be fast-tracked back in to the right part of the system should they relapse.

3.3. Transition to adult services

- Service users conclude that transition should not be when children and young people reach 18, but that a level of flexibility should be allowed right up to 25. Transition should be longer, individually suited, and later. More flexibility between child and adult services would diminish the requirement for such a formal 'transition' period.

The hand-over from child and adolescent services is immediate and almost brutal. A phasing of change to adult mental health services at 18 would be helpful. There should be a specific service for 18 to late 20s. These are no longer children but certainly not adult – *Parent survey*

1. Introduction

YoungMinds was commissioned to undertake the engagement of children, young people and families for the Children and Young People's Mental Health and Wellbeing Taskforce. The taskforce is chaired by the Department of Health and NHS England, and is looking at how children and young people's mental health services could be better organised, commissioned and provided. It is also looking at how to make it easier for young people and their parents and families to access help and support, including in schools, through voluntary organisations and online. The taskforce will report both to ministers and to the Children's Health and Wellbeing Partnership, and will publish its recommendations next spring.

To contribute to the work of the taskforce, YoungMinds is gathering the views of young people, parents and carers on issues including:

- The promotion of good mental health and wellbeing in children and young people
- Where young people would like to go to access help and support and how they would like services to be provided
- What services should be provided in universal settings like schools
- How current services can be improved
- Transition to adult mental health services

The taskforce is working across four task and finish groups.

- Prevention and Access
- A co-ordinated system
- Vulnerable groups
- Data and Standards

Data from the engagement has been organised under three of the task and finish group areas (Prevention and Access, A co-ordinated system, and Data and Standards). Findings relating to vulnerable groups have been included under those headings.

2. Methodology

The engagement of children, young people and families needed to address six lines of enquiry designated by the taskforce. To maximise the short time frame for the engagement the enquiries were divided across an online quantitative survey and four sets of discussion groups and interviews to ensure that enquiries were directed at the most relevant audiences, diverse voices were heard in the engagement, and data was collected relating to all six lines of enquiry:

Lines of enquiry	Methodology
What more could be done to promote good mental health and wellbeing in children and young people?	Online Surveys Discussion groups with vulnerable groups Parents & carer discussion groups
Where do children and young people wish to go for information, advice and counselling and how they would like these services to be provided, including the use of online services?	Online Surveys Discussion group in primary schools Discussion group in secondary schools Parents & carer discussion groups
What specific services are needed in settings such as early years settings, schools and colleges – both for individual children and young people but also collectively?	Online Surveys Discussion group in primary schools Discussion group in secondary schools Parents & carer discussion group
What needs to change in current services, including both universal and specialised services and how well they feel services work together?	Online Surveys Discussion groups with current and former CAMHS users Parents & carer discussion groups
How they access or would like to access preventive and early intervention support, including issues around visibility of services, barriers to services, and views on the terminology used such as 'CAMHS'?	Online Surveys Discussion groups with targeted groups of disadvantaged young people Discussion groups with current or former CAMHS users
Their views on transition – when is the best time to move to Adult Mental Health Services?	Discussion groups with current or former CAMHS users

An online poll was added to the methodology and conducted after the data collection period ended to address two gaps in the data- details are given below.

2.1 Quantitative Data

2.1.1. Online surveys

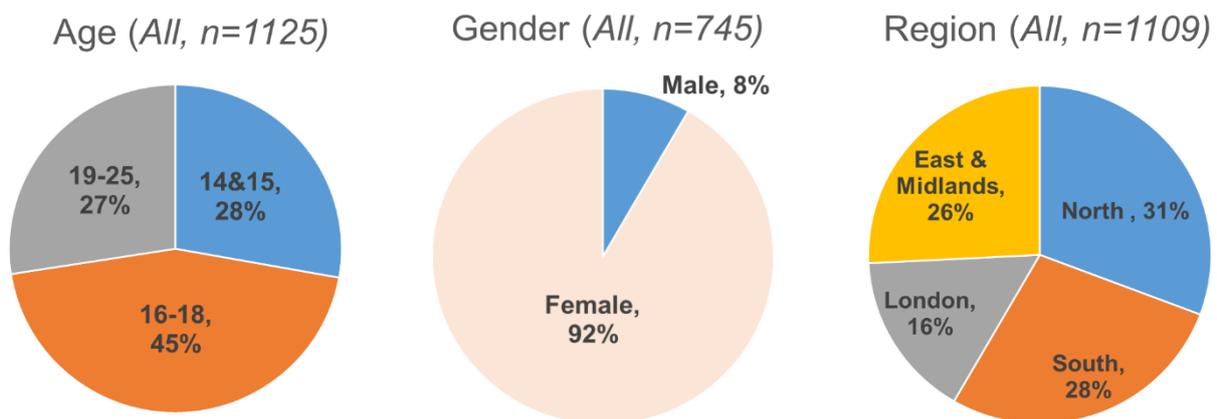
Two online surveys were conducted using Survey Monkey. Both surveys were self-selecting.

A children and young people's survey was in field from 25 November to 19 December 2014. In total 1136 responses were received. Two collectors were used. The first collector was distributed via email to a database of young people aged 14-25 that have previously engaged with YoungMinds. The second collector was accessible via a link on the homepage of YoungMinds website. The link was promoted on social media and sent to partner organisations in the mental health and voluntary sectors.

A parent and carer survey was in field from 1 December to 19 December 2014. In total 430 responses were received. The survey was distributed to YoungMinds database of parents and carers who have engaged with other work; the survey link was accessible on the homepage of the YoungMinds website and was distributed to sector partners.

Further information about survey design is provided in appendix one along with the survey questions.

The profile of respondents to the children and young people's survey was as follows ("n" denotes the number of respondents answering the relevant question).



Whereas the age and geographical splits are quite even, the gender split of respondents is heavily weighted towards females. This is to be expected in surveys on this subject. A more targeted recruitment exercise (requiring more time and resources) would be needed to increase the proportion of males in the sample.

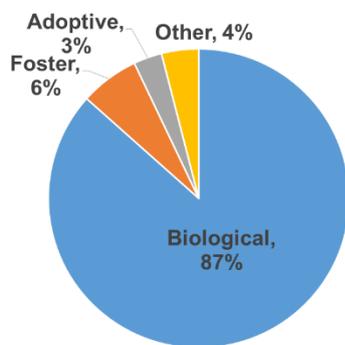
In terms of ethnicity 87% of respondents answering the relevant question (n=757) described themselves as "White English/Scottish/Welsh/Northern Irish/UK", with "Any other white background" next highest at 3%. No other group of the 18 listed represented more than 1.3% of the sample.

The survey was completed by a number of young people in vulnerable groups at risk of mental health problems.

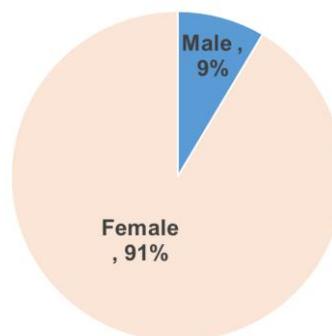
Group		n=	%
Lesbian, Gay or Bisexual	174	714	24%
Transgender	21	762	3%
Has had looked after status	36	764	5%
Experienced being a young carer	144	763	19%
Experienced unemployment	255	754	34%
Service users (Has used CAMHs)	347	858	40%

The profile of the respondents to the parent and carer survey was as follows:

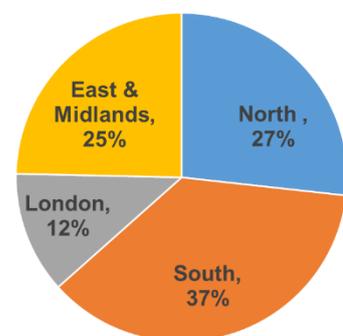
Parental Status (All, n=426)



Gender (All, n=282)



Region (All, n=426)



In addition, 226 parents (53% of all respondents) had children with experience of using CAMHs services.

When reporting on the questions below we have analysed the specific groupings within the data that are most relevant to the issue at hand. If necessary, it would be possible with more time and resources to undertake further data analysis and examine all the questions considering a wider range of respondent segments.

2.1.2. Poll

Two gaps were identified in the data collection from the online surveys, telephone interviews and discussion groups. The first was the low response rate from males. This was recognised prior to the survey closing and partner organisations with networks of male supporters were approached to support the survey. However, response rates from this demographic remained low as detailed above.

Secondly, a question requested for particular focus within the engagement was 'Are young people happy for the information they give about a health service they have used to be shared in order to help improve services and for this information to include their NHS

number?' This question had been discussed in telephone interviews and discussion groups but data was limited.

To address both of these gaps, after the online survey closed, a poll was conducted via a polling agency addressing five key questions from the online survey. These questions were agreed with the Department of Health and NHS England.

The poll had 2,000 respondents aged 14-24. 839 respondents were male and 1,161 were female.

Questions relating to the use of NHS number have been analysed for male and female respondents. Questions related to other aspects of the engagement have only been analysed for male respondents to address the gaps in the original engagement. With more time, an analysis of all respondents could have been undertaken.

2.2 Qualitative Data

2.2.1. Discussion groups

Four sets of discussion groups each with a different line of questioning were conducted: 1) CAMHS service users; 2) education settings (primary & secondary schools); 3) parents & carers and 4) vulnerable groups. We took as the definition of vulnerable the groups of children and young people identified by the taskforce and those with protected characteristics under the 2010 Equality Act. The line of questioning for each of the four sets is included in appendix 3.

In total 17 discussion groups were conducted in total by YoungMinds staff. Ten discussion groups were hosted by external organisations, including:

- Care Leavers' Social Group, Leeds
- Crossroads Care Gateshead Young Carers Service
- Labelled, Darlington (a social enterprise supporting young people with additional needs)
- Meanwood Church of England Primary School, Leeds
- Sunderland College
- Youth Focus: North East (a charity delivering youth employment, health, education, arts, and intergenerational programmes in the North East)
- Second Chance, London (a charity supporting young people not in education, employment or training)

Other organisations that hosted discussion groups and wished to be listed anonymously are: a secondary grammar school in South London; a secondary comprehensive school in Essex; a special school in Newcastle.

Additionally, at the time of this engagement, YoungMinds was undertaking commissioned work in two regions to engage children, young people and families in the development of CAMHS service specifications. Both commissioners and the participants in the engagement kindly gave permission for the content of their discussion groups to be added to this report

as the themes were highly relevant. These are CAMHS commissioners for Coventry City Council and Warwickshire County Council and the participants of three parent discussion groups held in their region, plus a commissioning support unit in the South of England.

Three discussion groups were held in London and attended by young people from London, Leeds and Newcastle who are part of the YoungMinds young activist network. One discussion group was held in London and attended by parents from within the YoungMinds parents and carers network.

2.2.2 Telephone interviews

YoungMinds conducted six telephone interviews: one with a parent who was unable to attend the discussion group but wished to contribute and five with young people who are current or former CAMHS service users specifically regarding the sharing of NHS numbers, as this had not been sufficiently addressed in discussion groups.

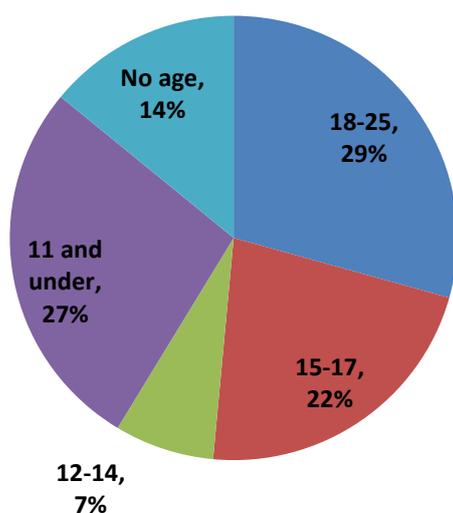
2.2.3 Analysis

Discussion groups and telephone interviews were audio recorded with the exception of groups that requested not to be recorded, where facilitator notes were taken and primary school groups where creative activities were used. A thematic analysis was undertaken of all transcripts and notes.

2.2.4. Demographics

20 participants attended the parent and carer discussion groups and one parent participated in a telephone interview.

Of the young people who participated in discussion groups and telephone interviews, participant ages were as follows:



Of those participants asked to state their gender, 41% (57) were male and 59% (81) were female.

In considering the ethical implications of conducting research amongst children and young people, YoungMinds adhered to the best practice guidelines as outlined by the European Society of Opinion and Market Research (ESOMAR). We imposed parental consent checks on respondents under the age of 14, however for a short period of the fieldwork, the screening question requiring parental consent for these respondents was not functioning. All respondents aged 13 and under who inputted responses during this period and who had provided an email address were contacted to seek parental consent.

Discussion groups and telephone interviews were undertaken by YoungMinds staff. Online survey design was undertaken by YoungMinds in consultation with NHS England and the Department of Health. Analysis of the online surveys, discussion groups and telephone interviews and the report writing was undertaken by Richard Donaldson and Justin Irwin from Fiveways. The poll was conducted by One Poll who adhere to the Market Research Society standards and guidelines. Poll analysis and report writing was undertaken by YoungMinds.

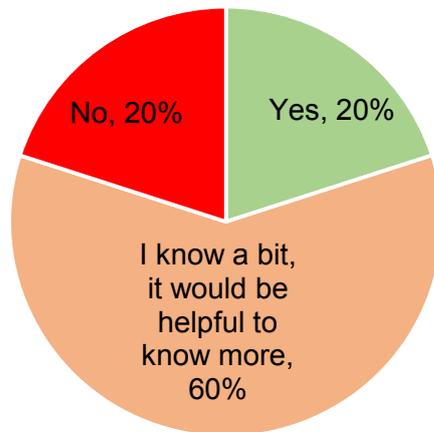
3. Findings relating to promotion and access

3.1 Being informed, stigma and promoting good mental health

3.1.1 How informed are the audience about their mental health?

Although one in five of the children and young people who completed the survey think that they know enough about how to look after their mental health, 60% feel it would be helpful to know more, and 20% of children and young people say that they do not know enough.

CYP - Do you think you know enough about how to look after your mental health? (All, n=957)



The survey captures responses from people who have chosen to participate in research into mental health. In the discussion groups that did not contain mental health service users, people struggled to define or explain mental health, or to separate mental health from mental illness, suggesting that they may not be well placed to manage their own mental health.

It is very confusing and actually how would a young person know that they've got mental health issues if they don't know what that is?
Vulnerable group attendee

It's not like you can say 'mental health' and just one thing pops up, there are so many aspects of it
Vulnerable group attendee

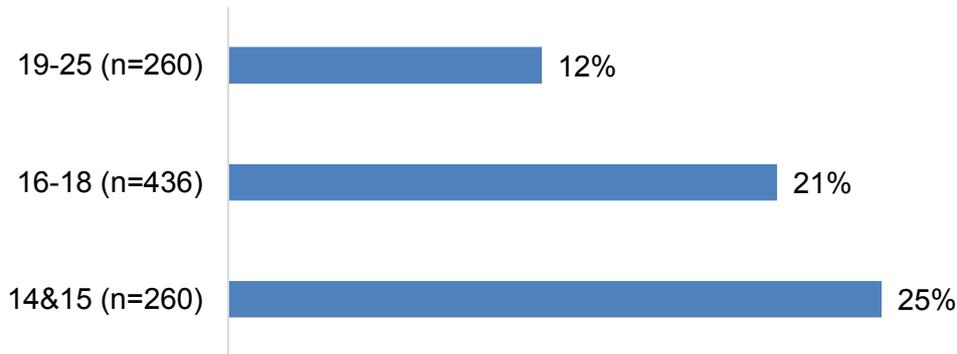
Indeed, children and young people that have used CAMHS are more likely to say they know enough about looking after their mental health. 28% answered “*yes I feel like I know enough*” (n=339) compared with 16% of those who had not used CAMHS (n=618).

It was generally understood in the discussion groups that mental health is complex and often misunderstood. In particular it was noted that mental health issues are often confused with general challenges of adolescence – primarily by adults.

Younger respondents are the least informed, with 25% of 14 and 15 year olds saying that they do not know enough about how to look after their mental health.

CYP - Do you think you know enough about how to look after your mental health?

Proportion answering "no" - by age



Although insight on this (and other) questions was difficult to gather from primary school age children, the groups illustrated a good understanding of mental health overall, and particular awareness that issues around mental health can be confusing and problematic. Insight into whether this group understands enough to look after their own mental health was not forthcoming.

The survey may have revealed an increased need amongst young carers to be more informed about their mental health. 24% (n=144) did not think they knew enough about their mental health, compared to 20% of all respondents. This may link to the suggestion from discussion groups that young carers have particular additional needs, as one of the key potential sources of information – their own parents – may be restricted.

When you are a young carer and you've got like a parent or someone who is like really mentally ill and physically ill that you can't really just go to them and say "I need to have a chat with you about how I'm feeling," because obviously they've got more like things to be dealing with; so the young carer could possibly not be feeling any support coming from their family if like the parent is like extremely ill and if they are having like anxiety or something.

Vulnerable group attendee

Parents felt most informed about *“Understanding my child’s development”*, *“Common types of mental health disorders”* and *“Recognising signs and symptoms of ill mental health/poor emotional wellbeing in my child”*.

The three areas parents felt least informed about were:

Parents - Area	n=	% saying they were "not very" or "not at all" informed
<i>What to do if your child is self-harming</i>	354	56%
<i>How to support my child when they are struggling with their mental health</i>	357	46%
<i>How to teach my child about looking after their mental health and emotional wellbeing</i>	357	45%

Parents of children who have used CAMHS services follow a similar pattern.

3.1.2 To what extent do the audience perceive or experience a stigma attached to mental health?

It is clear across all groups that considerable stigma is still attached to users of mental health services. Service users and others with particular knowledge of mental health services suggested that the level of stigma is reducing, but the concern amongst young people about confidentiality and about not being seen to be visiting or using services clearly illustrates a significant perception of stigma still exists.

*They're too afraid of what people might think...they're just too scared to ask for help, because they don't want like anyone thinking that oh they're crazy or something.
Vulnerable group attendee*

*I think mental health is like a really like unspoken subject
Educational settings attendee*

Groups with less experience of mental health services talked about stereotypes relating to people with mental health problems. Secondary school age children in one of the discussion groups agreed that mental health is a taboo subject and that they had never received information on it at school.

Parents also discussed how children and young people with mental health needs are stigmatised to a distressing level. They reported children and young people being described as dangerous, not able to be trusted, not stable, and at risk of causing physical or emotional harm to others.

3.1.3 What more could be done to promote good mental health and wellbeing in children and young people?

A common theme from the groups related to the need for better education around mental health and wellbeing¹. This ranged from changes to the curriculum within educational establishments, to public information campaigns, and to the (continued) use of role models. Groups discussed how other campaigns had successfully changed behaviour – ‘eating healthily, try to be green, try to recycle’, but there was no equivalent for mental health.

One suggested approach was to focus more on the positive benefits of knowing about rather than negative aspects. It was also felt to be important in encouraging people struggling with their mental health to accept that this was, in itself, fairly common.

I would make sure that [people with mental health problems] understand that it's OK that there's something wrong with them...It's OK to be mentally unstable.

Vulnerable group attendee

Promoting acceptance [is important], not just in sort of staff in schools, but students as well, I think it makes it a lot easier when your peers know what you are going through.

Educational settings attendee

In the survey, parents were asked to rate the importance of different organisations, programmes and people in promoting positive emotional wellbeing in their children. Consistent with the views of children and young people, they prioritised educational establishments and GPs; these bodies had the largest proportion of parents rating them “very important” or “important”.

- Secondary school - 92%
- College - 88%
- Primary school – 87%
- GP - 85%
- University - 84%

¹ This is considered further in the schools section below

3.2 Mental health information

3.2.1 Where do the audience go for mental health information?

Participants in the children and young people survey were asked about the different sources of information they had used and if they considered them to be helpful. The results for all respondents are in the table below.

CYP - Source	% used (n=967) (rank)	% of those used who found it helpful (rank)
Friends	64% (1)	53% (6=)
Online mental health app or website	63% (2)	68% (2)
Social media	63% (3)	56% (5)
Parents or other family members	56% (4)	43% (9)
From a mental health support service I used	54% (5)	60% (4)
My school/college teachers	52% (6)	40% (10)
My GP	52% (7)	32% (12)
Question websites like Yahoo answers	48% (8)	38% (11)
Another health professional besides a GP	47% (9)	61% (3)
Newspapers or magazines	32% (10)	30% (13)
A visitor to my school/college	32% (11)	47% (8)
From a charity I volunteered with or got support from	27% (12)	73% (1)
Youth group	16% (13)	53% (6=)

The top two - “*online mental health app or website*” and “*friends*” - made up two of the top three most frequently used sources of information across all age groups. For younger groups (14-15 and 16-18) “*social media*” completed the top three, and for the older group (19-25) it was “*My GP*”.

It was evident from the primary school groups that teachers play a pivotal role, along with parents, in any form of information provision.

The role of parents/grandparents/carers was highlighted in discussion groups. There was certainly considerable reticence about telling teachers or others in authority for fear of the consequences – including being removed from parents, having their parents told (if they are their carers), and everyone at school knowing about their problems. Similarly, some people may not seek any help at all – particularly bearing in mind the stigma that participants associated with mental health in general.

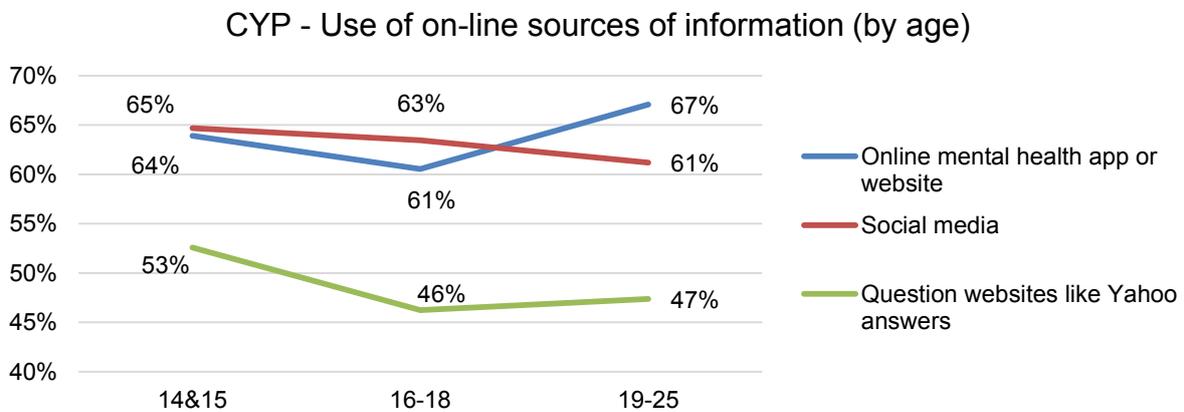
You know as well you know what I was worried about? I thought if they find out [that I've used a mental health information website] they're going to think I'm nuts and they're going to lock me up. And that's what, it deters you more even though.

Vulnerable group attendee

I was threatened that my parent would be told about me and I was scared that this would affect them

Vulnerable group attendee (young carer)

Use of digital services generated mixed feelings in the discussion groups. The survey revealed a slight fall in the use of social media and online 'question websites' with age.



Digital services were popular for the speed, ease of access and preserving anonymity. But there was a lack of trust in some cases, and the provision of information without support was unpopular to some. One secondary school group discussed the use of Wikipedia for mental health information; others had experienced cyber-bullying and were very reticent about using digital services unless they were certain they knew who they were seeking information from.

In terms of the helpfulness of the information, “a charity I volunteered with or got support from” is the source considered most helpful by those that used it, followed by an “online mental health app or website” – these made up two of the top three most helpful sources of information across all age groups, and for the group of service users (i.e. those that have used CAMHS).

CYP - Three sources of information considered most helpful by those that used them (% of users who considered them helpful)						
		Age			Service use	
		14&15 (n=264)	16-18 (n=445)	19-25 (n=260)	Service Users (n=344)	Non Service Users (n=606)
1	Online mental health app or website (64%)	A charity I volunteered with/ got support from (70%)	A charity I volunteered with/ got support from (84%)	A charity I volunteered with/ got support from (74%)	A charity I volunteered with/ got support from (71%)	
2	A mental health support service I used (57%)	Online mental health app or website (68%)	Online mental health app or website (71%)	Online mental health app or website (68%)	Online mental health app or website (68%)	
3	A charity I volunteered with/ got support from (55%)	Another health professional besides a GP (63%)	Youth group (69%)	A mental health support service I used (64%)	Another health professional besides a GP (63%)	

The survey revealed that there are a number of sources which children and young people found particularly helpful, but which are generally underused – notably charities, health professionals besides a GP, and youth groups. Conversely, friends, parents, other family members and teachers are well used for seeking mental health information – with each being used by at least half of all respondents – but they were typically not found to be as helpful.

As with children and young people themselves, the majority of parents also use online apps or websites to find information relating to their child's emotional wellbeing and mental health. The three most used sources of information for parents are:

- Online app or website - 56%
- Another health professional besides a GP – 52%
- A mental health charity - 49%

Parents involved in discussion groups, whilst aware that 'there's so much rubbish on the internet', were typically confident in using and trusting appropriate digital information sources, and in making their own assessment of where they could find correct information.

*What I've done in the past is look at the ones that are associated with no profits and look at the ones associated with hospitals.
Parent group attendee*

3.2.2 What other mental health information is needed?

Some young people highlighted the need for more information about mental health in general. There was also a need for a clearer roadmap of what to do at different stages – from initial consultation to crisis, including help to identify which stage a young person was in and guidance about where best to get specific information and support.

I'd say a lot of young people don't really know how to address mental health, they see it as a problem on the inside so when it comes to addressing it they don't know how to, they don't know who to go to, and if they did know who to go to how would they address it to the person to get help and support?... More information needs to be digged up and researched more and these young people need to know exactly what mental health is.

Vulnerable group attendee

There were some views that the issue was less about providing more information and more about increasing awareness of, and access to, existing information. This may be particularly relevant noting concerns about the quality of information available online, and the lack of a well-known, trusted, central portal of information for young people.

I think it's just addressing the situation and promoting the services that are out there because people are aware of what's out there for mental health.

Educational settings attendee

Parents generally felt that more information would be very useful about a number of subjects, particularly relating to how they could support, teach or manage their child, and where they could find additional help.

Parents - Type of information	% parents (n=355) who consider more information to be "very useful"
How to support my child when they are struggling with their mental health	79%
Where to take my child for support if they are struggling with their mental health and emotional wellbeing	76%
How to teach my child about looking after their mental health and emotional wellbeing	75%
Managing my child's challenging behaviour	75%
Where to go for advice and guidance if I am concerned about my child's emotional wellbeing	74%
What to do if your child is self-harming	73%

3.2.3 Who should be providing this information?

Participants in the children and young people survey and poll were asked how likely they would be to go to various sources for more information about mental health. The table below shows "net likelihood to use" which is the proportion of respondents who would consider using that source of information minus the proportion that wouldn't. Therefore positive percentages (in bold) indicate that more respondents are likely to go to this source of information than not. A negative percentage indicates more respondents are unlikely to go to this source of information.

The survey results indicate that information should be provided online. Across all age groups online apps and websites are the most likely sources to be used to find out more information.

The oldest age group (19-25) are likely to draw on more sources than the younger groups, only the youngest group is more likely to use social media than not, and school and college aged children are more unlikely than likely to see their teachers as potential information sources.

Results from male poll respondents whilst broadly following trends from the survey results to this question, differed significantly regarding the likelihood of seeking information about mental health from a parent or other family member. Whilst all survey groups were more unlikely than likely to seek information from a parent, male survey respondents listed their parents or other family members as the group they would be most likely to seek information about mental health from, by a sizeable margin. With more time and had these results been available earlier in the engagement, this issue would have been valuable to explore within discussion groups with males.

Source of information (net likelihood to use)	14&15 (n=259)	16-18 (n=440)	19-25 (n=256)	Male poll respondents (n=839)
Online (mental health) app or website ²	46%	42%	56%	29%
Friends	15%	16%	19%	15%
From a mental health support service I used	7%	19%	36%	16%
Social media	2%	-8%	-7%	-13%
Question websites like Yahoo answers	-2%	-21%	-29%	10%
Parents or other family members	-12%	-30%	-13%	54%
My school/college teachers	-20%	-20%	n/a	12%
Another health professional besides a GP	-22%	6%	20%	25%
My GP	-23%	-7%	22%	42%
A visitor to my school/college	-41%	-42%	n/a	-7%
From a charity I volunteered with or got support from	-45%	-28%	12%	5%
Youth group	-54%	-54%	-59%	-5%
Newspapers or magazines	-59%	-56%	-41%	-20%

Where information is provided by an individual, a key theme apparent throughout the discussion groups is the importance of people that can be trusted, that they listen, that they have time to spend with the young person, and that they are not judgemental.

² This combines the responses for answer options "Online- app or website" and "Online mental health app or website".

I'm not fussed what kind of worker I get, it's just how they approach you and stuff.
Vulnerable group attendee

Parents are likely to draw on a much wider range of information services, but as with children and young people, online sources are ranked highly. Charities are the source that parents would be most likely to use.

Parents - Source of information (net likelihood to use)	Parents (n=358)
A mental health charity	78%
Online- app or website	76%
Books	64%
Another health professional besides a GP	61%
NHS website	60%
A helpline	52%
My GP	47%
GP	41%
Speak to my child's school/college	30%
Speak to friends or other family members	26%
Friends	24%
Parents or other family members	13%
Newspapers or magazines	-25%
Parenting programme	-31%

The parents in the discussion groups were more concerned about making information consistent, approachable and easy to understand, than with who provides it.

Theoretically the information should be the same from whatever agency it is being disseminated from right? So what you want is something that people can read and understand, so if that means a non-profit [which] really can understand parents.... So I mean I think that really ends up being a 'who can do a better job' given the audience that it is targeted to.
Parent group attendee

3.2.4 How should this information be provided/what should it look like?

Participants across all audiences highlighted the need for prevention and information being provided earlier. GPs, teachers, other professionals, parents and young people themselves should focus on spotting early signs rather than intervention later.

But it's too late, starting at 18; that's like saying I'm going to teach you about sex education when you've gone way, way past a point where anyone can tell you anything, , you would have gone out and taught yourself. It's too late; you need to get it when it starts and when you can actually address the problem... so you should start much younger.
Vulnerable group attendee

I just think that teachers in the schools need to be educated on mental health to spot things, so there's like some sort of support network that they can go to rather than them feel shit.

Vulnerable group attendee

Information should be normalised, easily available and akin to the information on physical health. Several participants talked about healthy eating campaigns; some concluded that something similar was required for mental health, focussing initially on stigma and normalising mental health.

It's not just the subject of mental health and mental illness but the highlighted point that everyone has mental health and how every single person whether they have a problem or not can manage their mental health better

Service user attendee

More generally, participants spoke about information being simple, jargon free, warm and personal, non-judgemental, factually correct, and straight to the point.

3.2.5 What barriers to accessing information exist?

Two particular themes were highlighted as barriers to accessing information – that people don't know enough about mental health to understand what to look for, and that young people and parents are put off by professionals dismissing their concerns, making judgements, and not listening to them.

I think that teachers could be a bit more observant about issues with their students and not just make judgements on things

Service user attendee

Consistent with other digital services, it is typical that young people want information they read online to be corroborated by people – ideally professionals. When this is not the case, the information available, be it online or in print, loses impact and value. It would seem that the significance of individual professionals in providing mental health information should not be underestimated.

3.3 Mental health support

3.3.1 Where do the audience go for face to face mental health support?

78% of respondents (n=858) said they had used one or more of the full list of support services detailed in the survey³. The services most commonly used by children and young people were as follows:

- GPs (53%)
- School counsellors (42%)
- CAMHS (40%)

³ These are detailed in full in the Appendices

- School teachers (39%)

Within the 19-25 age group (n=225) 47% of respondents had used Adult mental health services and 36% had used Community based counselling services or youth information advisory and counselling services.

The survey revealed that some vulnerable groups were more likely to have used services. 92% (n=36) of respondents who had had looked after status and 85% (n=143) of respondents who said they had been a young carer had used one or more the support services listed.

Although the sample is small, there is evidence that respondents who had had looked after status were more likely to use more intensive and acute services, 72% had used CAMHS and 61% A&E.

87% of parents (n=309) had used services to provide support for their child. When asked to select particular services (n=215) the most commonly used were as follows:

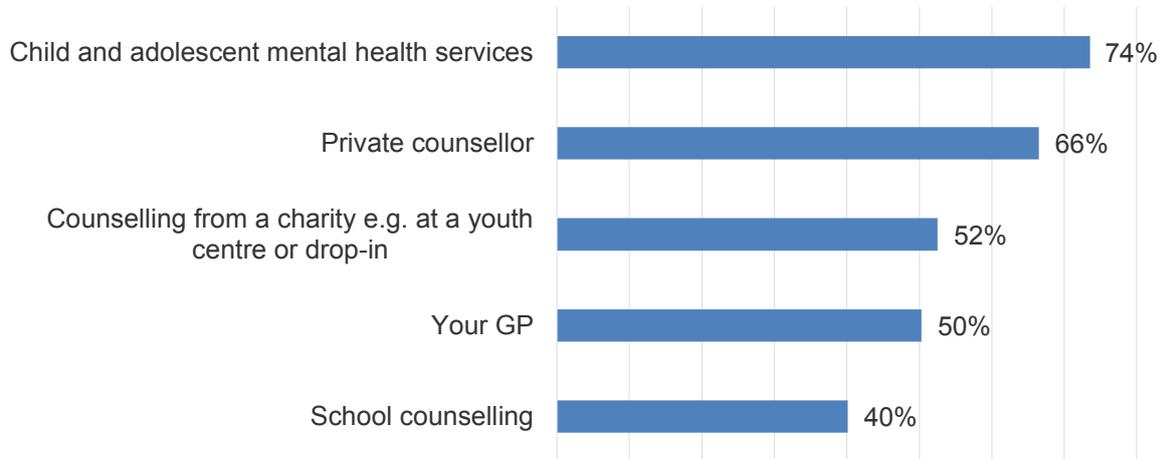
- NHS Specialist child and adolescent mental health services – CAMHS (67%)
- GP (55%)
- School teaching staff e.g. teachers, headteachers, pastoral care teachers (54%)

3.3.2 Who should be providing this support?

Those respondents to the children and young people's survey that had not used a service previously (n=188) were more likely to consider CAMHS services for help with their mental health should they need support.

Non service users considered that sources of support that are commonly used by others (GPs and school counsellors, see above) would not be as helpful as CAMHS and counselling.

CYP - Services non-service users would consider using (n=188)



Amongst male poll respondents private counselling and counselling from a charity retained the same positions as within the survey results and school counselling continued to rank lowly as a source of support respondents would consider using. The significant difference between survey results and male poll respondents results was the exchange of positions between GP and CAMHS with male poll respondents ranking their GP as the place they'd be most consider using for support and CAMHS the least. This could potentially be linked to stigma of accessing designated mental health services and this could be valuable to explore further in discussions with males.

Male poll respondents (n= 839)	Used this type of support	Have used this and would use it again	Have not used this but would consider using it
Your GP	26%	12%	45%
Private counsellor	22%	11%	44%
Counselling from a charity e.g. at a youth centre or drop-in	21%	9%	41%
School counselling	27%	12%	36%
CAMHS	31%	13%	34%

Perhaps not surprisingly, the discussion groups in general felt mental health support should be provided by specialists in mental health, although this was at least partly due to concerns around the quality of support provided within schools⁴.

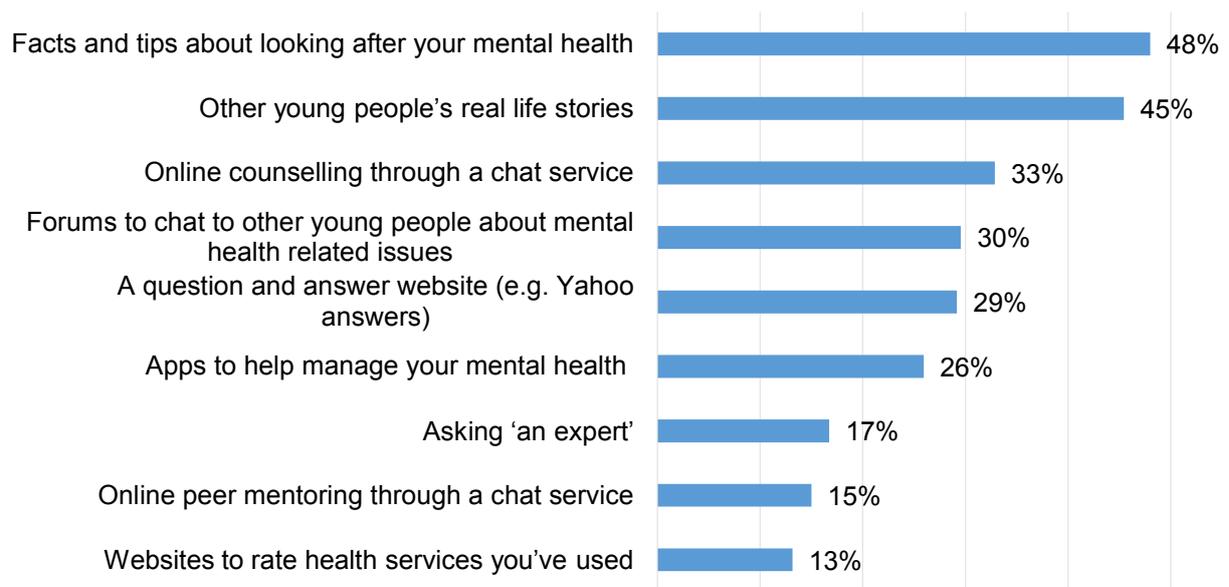
3.3.3 How do the audience access and use digital support?

The most popular devices for accessing on line support for children and young people (n=785) are a phone (79%) and a laptop or computer (76%). Understandably shared computers are much less popular – only 7% of respondents said they would use these.

Parents (n=321) are more likely to look for information using their computer or laptop (77%) and tablet (51%) than their phone (46%). As above, shared computers are the least popular option (11%).

The most common uses of online resources amongst children and young people (n=783) are information-based – *“Facts and tips about looking after your mental health”* (48%) and *“Other young people’s real life stories”* (45%).

CYP - Online resources - % used (n=783)



Online services, such as counselling, practical apps to manage mental health and mentoring are used less often, perhaps reflecting some of the concerns about confidentiality and knowing who is providing the support highlighted in discussion groups.

Broadly the pattern of use above is similar in all age groups. Certain resources increase in their use with age – *“Asking ‘an expert’”*, *“Apps to help manage your mental health”*, *“Forums to chat to other young people about mental health related issues”* and *“Facts and tips about*

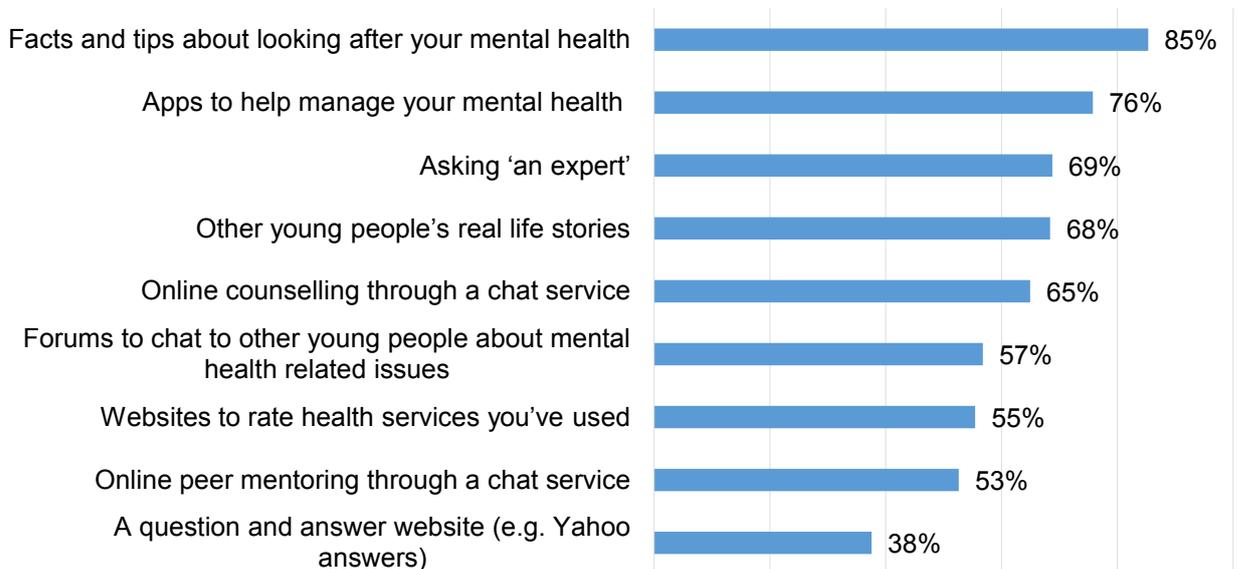
⁴ This is considered further in the schools section below

looking after your mental health". The only resource to decrease in use with age is "A question and answer website (e.g. Yahoo answers)".

When those who have not used them previously are asked if they would consider using various on-line services, "Facts and tips about looking after your mental health" remains the most popular option (85% of those who had not yet used this would consider using it).

However "Apps to help manage your mental health" (76%), "Asking an expert" (69%) and "Online counselling" (65%) are also popular amongst those who have previously not used them, indicating a latent demand for these services.

CYP - Online resources - % who would consider using if not used



As with use of these resources, the pattern of which resources respondents would consider using if they haven't used them already is similar in all age groups. Interest in some resources increases with age – namely "Other young people's real life stories", "Asking an expert" and "Websites to rate health services you've used".

As previously, overall the pattern of use of digital services is somewhat mixed. For example, some young people involved in the discussion groups were concerned about the suitability of online counselling.

On-line counselling wouldn't really work because anybody could be a counsellor on the internet so if you go out to get help and it's just a bunch of kids mucking around they could make you feel worse.
Educational settings attendee

However, the vast majority of the large number of 'free text' comments on the survey about this subject were very positive about using digital services, in particular those run by charities. Respondents shared positive experiences of using Beat, Bipolar UK, Rethink, YoungMinds and in particular Mind and ChildLine amongst others, with the only negative

comments typically relating to difficulties in accessing the services due to high demand. Other services that are regularly used include mood Apps and the NHS Choices website. Criticism and concerns generally were expressed in relation to unmoderated services or user generated content, such as Yahoo answers or Wikipedia, and to information provided by organisations not working in the field of mental health – such as websites of national newspapers.

I think Child Line is phenomenal - they were there for me when I needed it most and were extremely helpful.

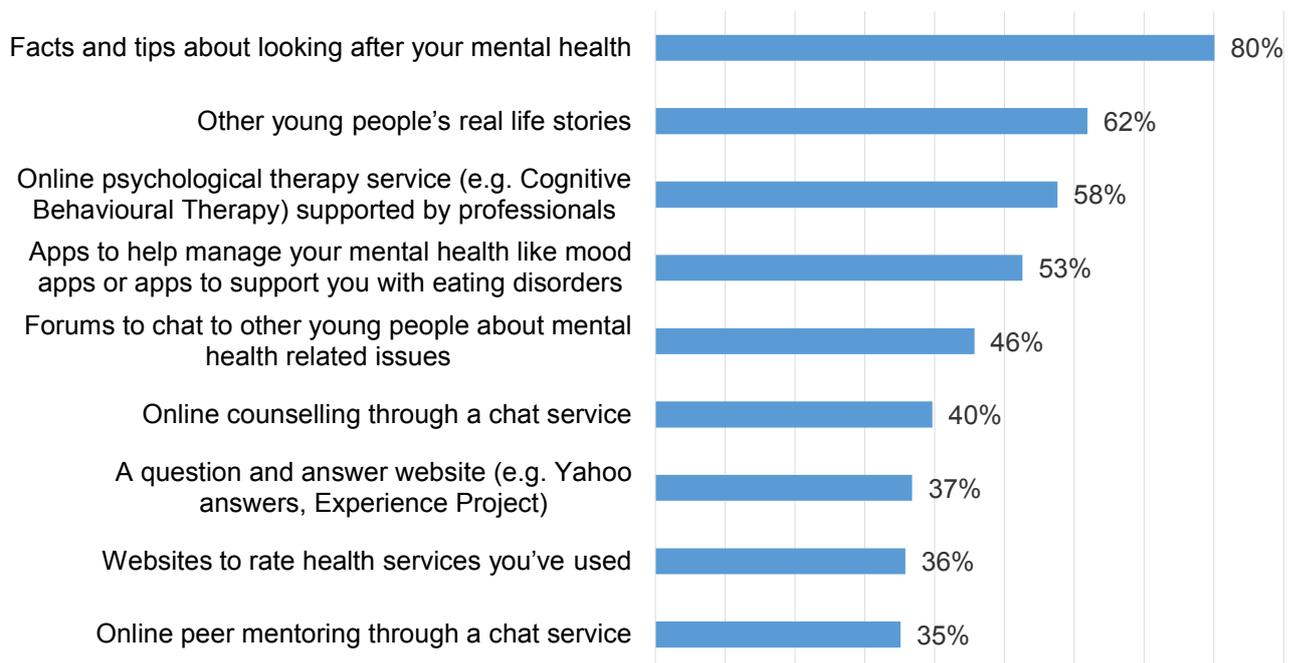
Mind is great as it talks about issues objectively so sufferers don't feel patronised, but it also offers supportive information.

Mind and YoungMinds has been a valuable resource.

Free text responses (CYP survey)

The pattern for parental use of online resources is similar to that of children and young people. 80% of parents would consider using “*Facts and tips about looking after your mental health*” for themselves or their child.⁵

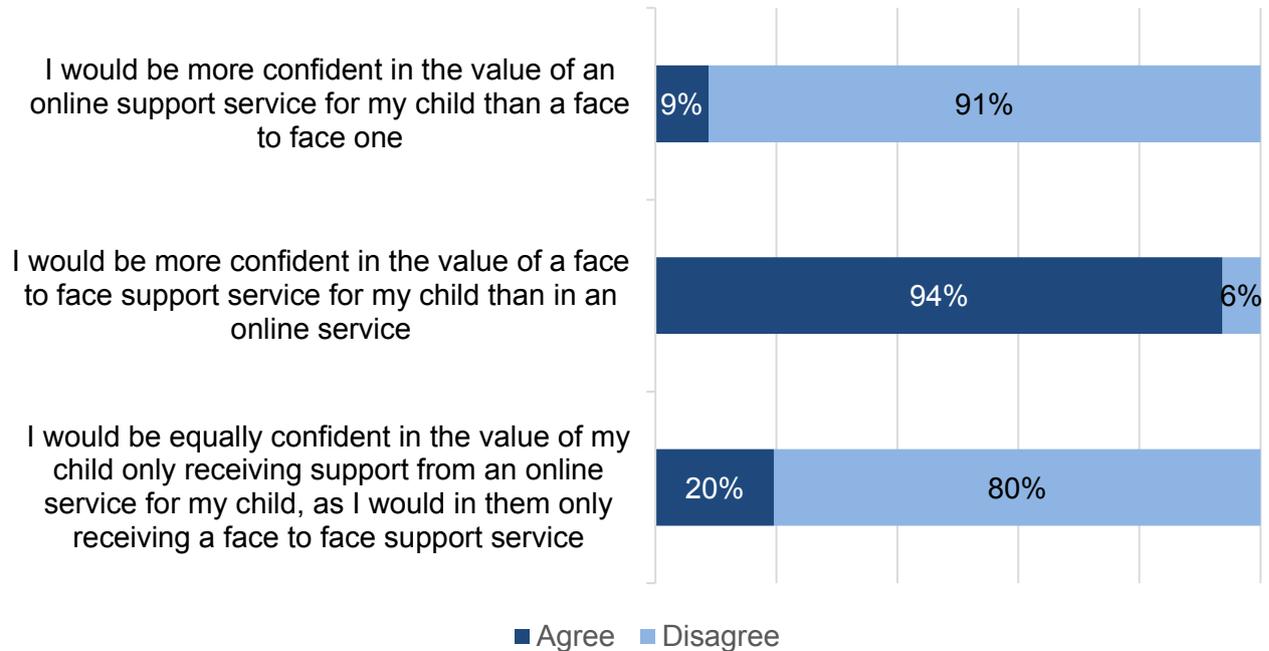
Parents - Online resources - % parents who would consider using themselves or with their child (n=302)



⁵ Unlike the children and young people's survey, the parents' survey design does not allow reporting on the proportion of parents who haven't previously used these online resources that would consider using them. These figures are the proportions of all parents who would consider using these online resources, whether they have used them previously or not.

However, parents have a clear preference for services to be delivered face to face rather than online. 94% of parents (n=322) would be more confident in a service's value if it was delivered face to face rather than online – only 9% of parents would be more confident in the value of a service if it was delivered online rather than face to face.

Parent's confidence in online and face to face services (n=322)



I am cautious of the support online as not all health websites are well run or well regulated.

I think any online provision without supervision and professional support via face to face meeting is potentially very dangerous

All are a bonus but should never be used in replacement of one to one support

Free text responses (parent survey)

3.3.4 How should this support be provided and what should it be like?

When asked to rank statements about mental health support provision in order of importance all groups agree that the most important factor is that *“The person that gives me support is someone I feel comfortable talking to and can be honest with”*. The least important quality for all groups is *“The support looks and feels like it’s designed for people my age”*.

The priority order is very similar across all groups – with only slight changes in the relative positions of confidentiality (ranked 2nd by those who have had looked after status and females) and speed of support (ranked 2nd by CAMHS users, those who have been young carers, LGBT respondents and males).

CYP	All	CAMHS Users	Young Carers	Looked after	LGBT	Male	Female
n =	861	343	143	35	183	62	672
The person that gives me support is someone I feel comfortable talking to and can be honest with	1	1	1	1	1	1	1
The support is confidential and private and no one would know I have used it	2	3	3	2	3	3	2
I can get help quickly when I need it	3	2	2	3	2	2	3
The support is provided somewhere I can get to easily and quickly	4	4	4	4	4	4	4
There is a choice of ways I can get support and I get to help decide what's best for me	5	5	5	5	5	5	5
The support looks and feels like it's designed for people my age	6	6	6	6	6	6	6

The male poll respondent results differ from the overall survey results and male survey results. The top four priorities are re-ordered in the poll results with the top two priorities becoming confidentiality and someone I feel comfortable talking to. The bottom two priorities remain service design and choice and involvement in decision making about the support provided.

Male poll respondents (n= 839)	
The support is confidential and private and no one would know I have used it	1
The person that gives me support is someone I feel comfortable talking to and can be honest with	2
The support is provided somewhere I can get to easily and quickly	3
I can get help quickly when I need it	4
The support looks and feels like it's designed for people my age	5
There is a choice of ways I can get support and I get to help decide what's best for me	6

The discussion groups fully support the survey and poll results, with young people repeatedly talking about the need to find approachable people who will listen and who can make them feel comfortable without needing to work in a formal and 'clinical' manner.

Sometimes, if you are not getting it from home you need someone to sit down with you and be able to have a conversation with you.
Service user attendee

Professionals are encouraged to spend more time to get to know the young person and context better, and not just leap in with "what's your problem?" A balance between professionalism (confidential, respectful, private) and informal (friendly, appropriate language, suitable locations, a degree of flexibility) needs to be struck.

The issue of trust appears important with all groups, but it was particularly highlighted by looked after children who talked about needing to be supported by 'a familiar face, somebody that understood me,' and were clear that 'people you don't know, you are not going to start telling them all.'

On a practical level, participants discussed the need for services to be available outside of school hours, or to be delivered in ways that didn't impact on learning or add to the stigma of needing to attend a mental health appointment. Further flexibility about who should accompany young people to appointments was also important, as was the clothes and approach of the professional.

Staff with shirts and name badges puts you off straight away
Vulnerable group attendee

I have a friend who on her first appointment her mum was there and she didn't want her mum to be there because it ended up being [...] the mum talking to the specialist
Service user attendee

The top qualities of a service prioritised by parents, ranked by the proportion of parents (n=287) that considered them "very important", were as follows:

- I am provided with advice and information about how to support my child at home (85%)
- My child has a good relationship with the staff they work with (82%)
- I am involved in decisions about the treatment and support my child will receive (82%)
- It is quick for my child to get an appointment (80%)

Being given information and being involved in the support being provided is clearly vital to parents. Many respondents in the survey highlighted poor communication, not being listened to, and their children not being listened to as major frustrations. There is a possible conflict between delivering a young-person centred service and the needs or wishes of parents, but the impact on parents and siblings is significant for many, and, poorly managed, this can contribute to a lack of support for the young person.

The whole family and the impact that the child with the mental health problem is having on their family needs to be considered from the outset.

That the staff are knowledgeable, compassionate and skilled. That the service has children and families at the heart of what it does- most services say they do they but they don't. That parents are trusted and not automatically assumed that they are to blame. That parents are involved in their child's care.

Free text responses (parent survey)

3.3.5 What barriers to accessing services exist?

Key barriers identified via discussion groups related to getting an appropriate referral to a service in the first place, and, once referred, the amount of time prior to actually attending the appointment (the waiting time). Related, the need to become quite ill before anything is actually made available was highlighted on more than one occasion.

You tend to only get access to support if your case is quite severe so not everyone gets support.

Service user attendee

I've been ringing my GP for 2 weeks, 2 weeks I've been ringing them for an appointment for 10 minutes, and I can't, every single day at half past 8 I am ringing them and I won't get through till 9 o'clock. And when I get through at 9 o'clock they're like, "Oh yes, we don't have any appointments." And I ring every single day... It drives me insane. I have lost my trust in the NHS. I have lost my trust, I have lost my trust in everything. Sorry.

Service user attendee

I was on a waiting list after being referred and it had to you know being on that waiting list it got to the point on both occasions where I had to be hospitalised because the waiting list was so long and things got that bad before I was seen.

Service user attendee

If you like need counselling or something sometimes you have to wait like months and months to get the help and you can like self-deteriorate in those times.

Service user attendee

The considerable waiting times were of particular concern to young carers, as was the distance from home to attend services and appointments as they were not often able to leave their caring responsibilities for a long period of time (this tended to be an inconvenience for other young people, but not an overly problematic one).

Several practical barriers were also highlighted. Communication should be by text, not letter – particularly for appointment reminders; buildings should be easily accessible with user-friendly waiting areas; children and young people who have been discharged should be fast-tracked back in to the right part of the system should they relapse, and buildings should be appropriate to the user.

The first time I went for counselling I went into the room and it was just like a plain room, and just like 2 seats, sit down, and I felt very uncomfortable because I didn't feel very welcomed to where I was and if there was a bit more like if the building was a bit more friendly I'd probably feel more comfortable to talk to the person
Service user attendee

The key barriers experienced by parents are broadly the same – being listened to in the first place, receiving an appropriate referral, and accessing the service.

Once he was finally accepted by the service, his consultant has been brilliant. CAMHS have finally helped us and have finally acknowledged that my daughter needed help.

I can't really comment on CAMHS as we have waited 16 weeks for a appointment
Free text responses (parent survey)

3.3.6 What should schools be doing?

69% of all respondents to the children and young people's survey (n=904) reported that counselling for pupils was provided in the school or college; when provided just over half of respondents (55%) considered it to be helpful.

The two forms of support provided by schools that children and young people find the most helpful – lessons about mental health run by an outside organisation and on-line counselling for pupils – are rarely provided.

CYP	Provided	If provided, % who considered helpful
Counselling for pupils- in school or college	69%	55%
Posters about mental health	36%	45%
Peer mentoring programme	32%	52%
Provided leaflets about mental health	27%	51%
Lessons about mental health run by teachers	20%	43%
Lessons about mental health run by an outside organisation	16%	68%
Counselling for pupils- online	12%	62%
Information on school intranet about mental health	11%	53%

When services aren't provided by the school, the two forms of support considered to be most helpful by school and college aged children 14-18 (n=660) are lessons about mental health run by an outside organisation and counselling for pupils.

CYP	When not provided, % of school aged children (n=660) who consider it would be helpful
Lessons about mental health run by an outside organisation	93%
Counselling for pupils- in school or college	91%
Provided leaflets about mental health	86%
Lessons about mental health run by teachers	85%
Counselling for pupils- online	82%
Information on school intranet about mental health	79%
Posters about mental health	77%
Peer mentoring programme	63%

Results from male survey respondents varied to survey results. One key difference is that overall, a smaller proportion of those who hadn't used a type of support or information provision within school considered that they'd find the listed types of support and information helpful. Another key variation was that the survey results ranked face to face counselling in second place as the type of support they'd find most useful in school and ranked online counselling as fifth they'd find most helpful; male poll respondents reversed this and their results ranked online counselling as the first they'd find most helpful and face to face counselling as the sixth:

Results from male poll respondents (n=839)	Provided	If provided, % who considered helpful	When not provided, % of who consider it would be helpful
Counselling for pupils- in school or college	46%	23%	29%
Provided leaflets about mental health	37%	16%	29%
Posters about mental health	37%	16%	29%

Peer mentoring programme	35%	16%	33%
Lessons about mental health run by teachers	35%	14%	31%
Lessons about mental health run by an outside organisation	34%	16%	35%
Information on school intranet about mental health	33%	13%	33%
Counselling for pupils- online	29%	12%	37%

Many of those taking part in the discussion groups expressed concerns about the lack of support available in their school. The service user groups in particular concluded that help in school is poor, that schools do not typically have enough of the right people to help, that they should do more to promote mental health, and that they should be more understanding.

I think the schools need to do more to reduce the stigma of mental health and I think that has to start with the teachers so I would definitely advocate more mental health training for teachers in school so that they can understand our needs
Service user attendee

We've got 1,000 students in our school and 1 nurse
Service user attendee

People in groups that were not service users did not necessarily know if the school had a counsellor, or access to one, and some were unaware of anyone in their school who could help.

It was generally agreed that mental health support requires full-time dedicated trained staff, and that mental health should be included in the curriculum, alongside physical health. Services should be delivered in an approachable way, with self-help and peer support available, as well as after school drop-in. Online counselling was popular as it could alleviate concerns about confidentiality – an important issue for this audience, particularly noting some examples of pupils with mental health problems being treated seemingly extremely harshly.

When I got ill at school they treated it as a behavioural issue so I was formally suspended twice to things related to my mental health when in reality I didn't actually need to be punished for it, I needed someone to help me, which they didn't do, and before I came back to school they told me I was only allowed to return to school if I promised not to talk to my peers about the problems I was having
Service user attendee

Specific location(s) in educational establishments for students to relax or seek help were considered to be a sensible idea, as was improved signposting within schools, both for internal and external support.

Overall there was concern that children with mental health issues who meet their learning targets go unnoticed and are not seen to be a priority.

According to parents (n=320) the most common forms of support offered by schools are counselling for pupils in school or college (55%) and meetings if their child needs support (54%).

However there are several other forms of support that when used, parents consider to be helpful that are not provided by schools very often, namely information on the school intranet, evening sessions for parents looking after their child's mental health, lessons about mental health for pupils, and signposting for parents on where to get support.

Parents	Provided	If provided, % who considered helpful
Counselling for pupils- in school or college	55%	56%
Meetings with parents if their child needs support	54%	72%
Signposting for parents on where to get support for their child if needed	27%	75%
Peer mentoring programme	27%	55%
Evidenced psychological interventions or treatment in response to identified need	26%	66%
Lessons about mental health for pupils	23%	74%
Provided leaflets about mental health	20%	60%
Posters about mental health	18%	65%
Evening sessions for parents about looking after child's mental health	16%	78%
Information on school intranet about mental health	12%	79%
Counselling for pupils- online	9%	69%

In every case, when the above services aren't provided by the school, over 80% of parents would consider them to be helpful.

The training of staff in schools is a key issue for parents. Most seem to think that staff need more training about mental health, in particular so that they can identify worrying signs. Some are concerned about un-trained staff (including teachers) becoming involved in their child's mental health, and would prefer to see an increase in dedicated full-time mental health experts within the school.

As with other services, parents report poor communication and a lack of information – this, of course, may conflict with their children who are concerned about information they share confidentially within a school based service being shared with their parents.

3.3.7 What should other staff across the children and young people's workforce be doing?

The key concerns reported by young people tend to be about being listened to, being given some time to build trust and to get straight answers (from people who 'don't take any crap').

Parents share the key concern about listening. They complain that teachers and GPs are ignorant or dismissive of mental health issues and turn a blind eye to worrying signs.

GPs are just very dismissive of parents and parental concerns... You are telling your GP and oh it's a parental issue, oh it's a behavioural problem at home, and your kid is trying to stab you with a knife.
Parent group attendee

Other staff should pay particular attention to issues around confidentiality and sharing information. Children and young people express concerns that information about them will be shared against their will; parents often want to know more, but feel that they are not told enough. This may reflect a confusion faced by staff about what information can be shared with both parents and organisations – certainly confidentiality and data protection were cited by young people as reasons for not sharing information between services, notably between schools and mental health services. From the perspective of a young person, the key thing is that they are made aware what will happen with any information that they share prior to sharing it.

3.3.8 How does the promotion/image of CAMHS need to change?

Overall, children and Young People (n=763) prioritise accessing CAMHS support over concerns for the specific name of the service.

Statements about naming CAMHS	Agreement	Disagreement	Net agreement
"It doesn't matter what CAMHS is called as long as young people know where to find it"	78%	8%	70%
"The name 'CAMHS' is fine- it's clear enough"	50%	26%	24%
"A more young-person friendly name for CAMHS would be better"	49%	25%	24%
"I don't have a view on what CAMHS is called."	27%	27%	0%
"The name 'CAMHS' sounds intimidating."	31%	41%	-9%

Although these remain the priority for every group – there are some differences between different segments of respondents.

- Only in the 14-15 year old group do the majority of respondents agree with the statement *"The name 'CAMHS' sounds intimidating"* - although it is only a small majority of the group agreeing rather than disagreeing. They are also the group who agree most with the statement *"A more young-person friendly name for CAMHS would be better"*
- The majority of CAMHS Service users are happy with the name – *"The name 'CAMHS' is fine- it's clear enough"* has a net agreement of 54% in this group. Also more CAMHS service users disagree with the statement *"A more young-person friendly name for CAMHS would be better"* than agree.

Statements about naming CAMHS – Net agreement (negative figures mean more disagree than agree)	Age			Service Users	Vulnerable Groups		
	14&15	16-18	19-25	CAMHS	LGBT	Young Carers	Looked after status
<i>n=</i>	199	366	197	312	183	144	36
"It doesn't matter what CAMHS is called as long as young people know where to find it"	75%	70%	63%	72%	70%	68%	69%
"A more young-person friendly name for CAMHS would be better"	30%	20%	24%	-6%	14%	26%	-11%
"The name 'CAMHS' is fine- it's clear enough"	14%	33%	18%	54%	32%	21%	67%
"I don't have a view on what CAMHS is called."	5%	5%	-16%	6%	1%	-4%	19%
"The name 'CAMHS' sounds intimidating."	3%	-14%	-13%	-25%	-14%	-8%	-39%

Many of the free text comments relating to the name further clarify this point.

Improving the quality of care that they provide matters more than improving their name.

It's not the name people are bothered about, it's the quality of service they receive and even receiving any service can sometimes be hard enough.

Free text responses (CYP survey)

Those who think the name should be changed generally propose either that the service should be more visible, normalised and with a less clinical name – maybe more around wellbeing – in an attempt to minimise stigma, or that it should be clear, direct, and unfussy, such as *Mental Health Services for Young People*.

Within the results from male poll respondents, the three statements with the highest level of net agreement remain the same, however the most agreed with statement becomes "A more young-person friendly name for CAMHS would be better":

Statements about naming CAMHS- Poll results male respondents	Agreement	Disagreement	Net agreement
"A more young-person friendly name for CAMHS would be better"	55%	6%	49%
"It doesn't matter what CAMHS is called as long as young people know where to find it"	50%	11%	39%
"The name 'CAMHS' is fine- it's clear enough"	45%	24%	21%
"I don't have a view on what CAMHS is called."	34%	16%	18%
"The name 'CAMHS' sounds intimidating."	34%	18%	16%

4. Findings related to having a co-ordinated system

4.1 What combination of services do people access⁶?

78% of respondents to the children and young people's survey (n=858) had used one or more of the 19 services listed, 66% had used two or more, 52% three or more and 39% four or more⁷.

Usage of multiple services is greater amongst some vulnerable groups with 72% of those who have had looked after status, and 55% of those who have been a young carer have used four or more services.

The main combination of services remains school (or educational establishment), GP, and CAHMS. Feedback from the groups suggested that it is often when this combination does not work well in practice that other services are used – for example private services, A&E, crisis teams and charities.

86% of parents had used two or more of the 22 services listed in the survey, with just over one-third (36%) using five or more.

4.2 How do the audience feel services work together?

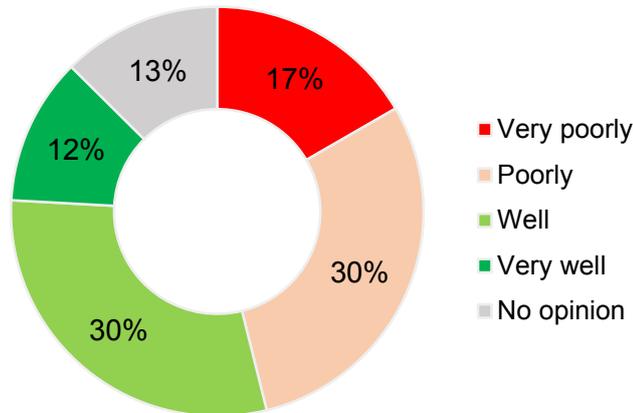
Just under three-quarters (73%) of children and young people who have used a service (n=603) feel that it is "extremely important" that services that support young people's mental health work together to provide care. This rises to 77% amongst those that have used CAMHS (n=323),

42% of those who have used two or more services (n=518) report that services worked "well" or "very well" together – however 47% report that the opposite was the case saying services worked together either "poorly" or "very poorly". In other words, more people thought that services worked poorly together than worked well.

⁶ The relative use of different services by children and young people is covered above (section 3.3.1 *Where do the audience go for mental health support?*)

⁷ This shows the proportion who have used multiple services at any time – it does not mean using services simultaneously.

CYP- How well services work together
(Those who have used two or more services, n=518)



This pattern is mirrored amongst some vulnerable groups. Young Carers being more likely to report services working together poorly.

- CAMHS service users (n=325) – 42% services work together “well” or “very well”, 48% “poorly” or “very poorly”
- Young Carers (n=119) – 36% services work together “well” or “very well”, 52% “poorly” or “very poorly”

Liaison between different services is really important, so if the GP and the A & E teams and the crisis teams and the school and the therapist and the counsellors they all like need to be informed, sometimes it can feel a bit bitty, you know so you explain something like five times to five different people because they haven't got the information passed on so for me that kind of liaison link would be really important.

Service user attendee

You are shoved from a psychologist to a psychotherapist to a counsellor to a doctor

Service user attendee

Reflecting the figures above, the free text responses relating to this survey question show a vastly mixed experience. There are plenty of examples of good communication between services, but the survey generated numerous examples of poor or non-existent communication between services, and, in some cases, the impact of these. A flavour of these responses across a range of ages follows:

There could have been more communication between services and there should have been something that parents can access for advice or for comfort.

Had to keep on repeating myself I was worrying constantly that I missed something a lot if things were happening behind my back which I didn't and don't appreciate.

They didn't work together at all.

My inpatient care team were amazing in liaising with my outpatient DBT n&s team but all my other teams have been awful. They all think that they know what's best and are blissfully unaware that the person they are making decisions about is in the middle of their little ego trip!!!!

Eventually they worked well together but having to be referred to cahms by your school nurse instead of your GP, we went to the GP who referred us to the school nurse, who assessed us and then decided if we should be referred to CAMHS.

Multiple services involved but a complete lack of communication between CAMHS, social services, school, and most importantly me.

There was never enough communication between my social worker or camhs which I think led me to become so unwell I ended up being sectioned.

All parties did not have great contact between each other and I felt continuously worried about what was going to happen regarding my treatment. It was very uncertain.

No one ever communicates with each other which makes me have to tell each one of them difficult things, which is hard. But if I don't do it then the professionals moan at me for not telling them.

To be honest I've never really had any experience of services working together to support me.

No one communicated with each other so I constantly had to repeat very horrible periods in my life. The people would change a lot so they never really knew me. They never contacted me, I always had to get in touch with them. I told them I was extremely suicidal and self-harming and they didn't get back in contact with me for 6 weeks.

There has been no communication or similarities between different services, which is ultimately very confusing and difficult to manage.

Camhs didn't interact with school who didn't connect with gp.

No one ever communicates with each other which makes me have to tell each one of them difficult things, which is hard. But if I dont do it then the professionals moan at me for not telling them.

GP and CAHMS worked reasonably well together, little or no interaction with school and GP/CAHMS.

They communicated with each other well; the NHS youth counsellor kept my GP up to date with what was going on and the GP and eating disorder service have maintained good contact.

CAMHS didn't really work with the school councillor at all, at one point I was on a safety plan but the school weren't kept up to date and didn't follow up when they said they would have a chat with me.

No communication made everything really difficult and held things up.

Communication between the services was very slow and took ages to get referred to the correct people.

Sometimes there has been no communication between A&E and CAMHS; CAMHS would not even know that I had been to A&E.

I ended up playing messenger between people and having to repeat the same old stuff and answer the same questions time and time again.

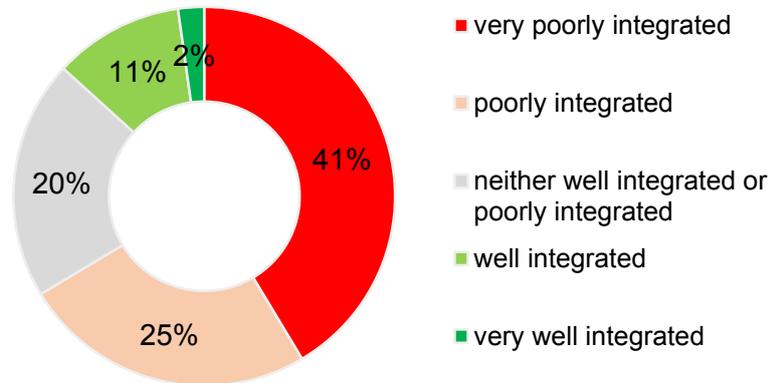
There was a massive lack of communication which eventually led to a lot of confusion.

Not surprisingly, the same issues are highlighted by parents. 87% of parents who have used services (n=195) feel that it is “very important” that there is integration between services that support young people’s mental health. 72% of parents who have used services (n=208) have had an experience of poorly integrated services, approximately three times as many as those who have an experience of well integrated services 26% (n=201).

Indeed, parents’ impressions of services working well together are less positive than those of children and young people (which, considering the depth of feeling in the list above, is of significant concern).

Only 13% describe services as “well” or “very well integrated” – 66% describe them as “poorly” or “very poorly integrated”. Parents who have used CAMHS (n=175) answer in similar proportions (67% poorly/very poorly; 15% well/very well)⁸

Parents - How well services work together
(Parents who have used two or more services, n=185)



The free text responses give another 120 pieces of feedback about poorly integrated services, with just 40 responses relating to well integrated services. They are along the same themes, primarily based around communication, with no clear functions and responsibilities, nor easy referral protocols.

⁸ There is likely to be a big overlap in the respondents of both for these segments.

I was getting pushed from pillar to post, from pillar to post, it was the school that had to assess her, no it was the GP, it was the school, it was the GP, and I gave up on that one in the end
Parent group attendee

Parents don't know how to navigate the system, do not feel listened to, and can find themselves in desperate and frustrating situations.

So you have got a kid who has a mental health issue, you think your kid is depressed. You go to your GP and you through like tenacity have convinced your GP to write a CAMHS referral. So then you get, finally you wait three months for your CAMHS referral and then you get to the CAMHS referral and they've decided that unless the kid is suicidal they're not getting any help.....So I think there needs to be some kind of acknowledgement that the system isn't working and an honest and clear cut path for people that is a reality based path.
Parent group attendee

4.3 How could services work better together?

For the majority of young people the priority area is effective integration between school/college, GPs in primary care and CAMHS. When asked to prioritise the five services that most need to work together to make sure young people and their families get the best possible care and support for their mental health, children and young people who have used a service (n = 596) identified the following seven most often:

- CAMHS - 80% selected it in the top 5 priority services (93% of CAMHS users n=316)
- GPs - 71%
- School counsellors - 60% (65% of school/college aged children n=417)
- School teacher - 60% (65% of school/college aged children n=417)
- Community based, or youth information advisory and counselling services - 47%
- Adult mental health services - 43% (59% of 19-25 year olds n=179)
- Hospital paediatrician/doctor working with a psychologist or psychiatrist - 40%

Key to services working better together is improved communication, better liaison between professionals, clear lines of responsibility, and absolute clarity with young people about confidentiality – it is vital to be clear about what information will be shared with whom, and why, and in what circumstances information may need to be shared without the consent of the young person. These rules of engagement should be in place prior to any significant contact.

This has implications for any considerations about using identifiers (such as the NHS number) to share information or improve communication. When asked about sharing data in this way, there was some reticence in the discussion groups.

My first experience of adult services I felt very strongly that I was let down by them and I didn't do anything about it, I didn't actually comment or make a complaint or anything because for fear of I guess being identified and potentially still using the service in the future, and having made that complaint feeling that I can't go back because I've said this. So I don't think being identified is necessarily a good thing.
Service user attendee

The resource issue is also relevant to relieve one of the causes of poor service integration – long waiting times.

Although not in the priority list, particular consideration may need to be given to how services work with the police, as the impact of spending time in a police cell or being arrested can be significant. Again, this needs to be based on clear protocols, and resource needs to be made available for this to be effective.

We shouldn't have to be shoved into a police cell just because we've got some issues. I think there should be some specialist available at the police or local somewhere, where someone can go rather than being locked up at 3 o'clock in the morning.
Service user attendee

The treatment of children like that by the police is just compounding the problem, it is just ruining them, it ruins any tiny bit of self-worth that they have left and it can be built on, it's just taken away from them.
Parent group attendee

It should also be noted that where there are examples of services working well together, these are typically due to the hard work and diligence of individual professionals, working against a cumbersome or non-existent system.

Parents (n=216) identify the same services as children and young people to be the priorities for effective integration. Again schools/colleges, GPs and CAMHS are considered the services that need to work together well.

- NHS Specialist Child and adolescent mental health services (CAMHS) – 77% selected it in the top 5 priority services (84% of parents whose children had used CAMHS n=172)
- School teaching staff - 73%
- GPs – 68%
- Community based, youth information advisory and counselling services – 42%
- School counsellors - 38%

Again parents highlight communication as a key barrier to services working together, and many appreciate the requirement for additional financial and human resource to resolve this issue – whilst again noting the achievements of individuals.

Individuals within services are often the reason why things move forward, not the service as a whole
Free text responses (parent survey)

Some parents think that more is required than tinkering around the edges of the existing systems. For them a complete overhaul of the mental health support is required so that services are genuinely designed for young people, that young people and parents are listened to, that professionals have time and resources to provide an appropriate service, and that the services can be provided in a timely fashion.

5. Findings related to data and standards

5.1 What are the audience's experiences of using different services?

As has been seen in the responses to the survey, the audience has vastly different experiences of using services. It is to be expected that some of the people who respond to such a survey may have a particularly extreme story to tell, but the number of people who describe disappointing experiences, both when responding to the survey and in discussion groups, reflects the state of the services overall.

There are, of course, many examples of excellent service provision.

I always found that the practitioners have always been very sort of friendly and easy to talk to, so don't sort of change them or the way they act
Service user attendee

I went to CAMHS and they helped me a lot and I'm not nearly as bad as I used to be, yeah.
Vulnerable group attendee

I think it's quite amazing how people go out of their way to help people who have problems, to be honest with you, it's really nice the support that you get, because some people think you're not going to get the support, and they think they're just going to gang up on you but they're here for you, to help.
Vulnerable group attendee

Nobody was ever able to make any real progress and they turned the situation around in less than, they did it in less than 6 months so we are definitely the poster child for positive NHS inpatient experiences in my household.
Parent group attendee

Young people also spoke of the importance of other non-clinical interventions, such as volunteering, exercise and peer support.

Positive experience of using services was less prevalent from parents, who generally report the feeling that they have to fight their way in to services and tell their story over and over again before professionals will believe that their child is ill. Parents also complain that sometimes the refusal to treat their child is done without actually seeing the person or speaking to them.

Parents feel they have to jump through hoops to get even the simplest mental health service.
Parent group attendee

I feel that I am doing all the work and I want the professionals to meet us half way.
Parent group attendee

5.2 How well do staff in different services work with children and young people?

Again, few conclusions can be made about how staff in different services work as so much depends on the approach of the individual. As a starting point, when staff listen to, respect and believe what young people are saying, they are typically viewed as working well.

In discussion groups NHS mental health teams were described as both 'clinical, officious and detached' and 'welcoming and tactful', indicating the range of experiences people can have when interacting with CAMHS staff. Police were described as 'completely inadequate and not competent', reflecting the concerns highlighted above.

It is rare, however, that the blame for poor service is directed towards individuals, and clear that there are many dedicated individuals changing children and young people's lives for the better.

They [CAMHS] were amazing. I wouldn't be the person I am today. I've known this woman and she's called [] and she's known me since the age of 5. And she's like a second mum to me. She listened, like me I stored up my feelings and I still couldn't talk in front of a big bunch of people. But if it weren't for her I wouldn't be the person I am today.
She's amazing.
Vulnerable group attendee

There are some fantastic individuals working in the area of children's mental health but they aren't able to do what they want to for people because the support services, such as therapy, aren't available or demand is so high that waiting lists are too long.
Free text responses (parent survey)

5.3 What does the audience want to change about these (CAMHS) services?

The audience typically wants the following changes

- More available services
- Shorter waiting times
- Flexibility in service delivery
- To be treated as individuals, listened to and respected
- Consistency in approach
- Appropriate funding for all services, but particularly 24/7 365 days a year crisis teams
- Clarity about confidentiality
- More communication between services and service users
- Improved coordination of services
- To be communicated with in a contemporary way
- Language appropriate to the age of the patient (no long words or adult clinical language)
- Not to be patronised

- Straight-talking
- Where appropriate, gradual, casual, non-obtrusive interventions
- More time with professionals
- Appropriate signposts and links to other services when treatment ends
- Easy routes back to treatment when required
- To be placed at the heart of the service

5.4 What would an ideal (CAMHs) service look like?

Children and young people in the discussion groups stressed the importance of the service being provided in a non-clinical building. An ideal setting may include the following characteristics:

- Being colourful, not bland
- Relaxed, informal, warm, comfy (like a coffee shop or canteen – where appropriate)
- Taking place in a 'room of, kind of bright, fun things to do and like people that have been through what you are going through so you can talk to them whenever and have fun at the same time' (educational settings attendee)
- Taking place in a building that allows some anonymity, or that is chosen by the young person
- Where all are welcomed by friendly staff on arrival.

Overall characteristics of an ideal service could include the following:

- Accessible without having to battle to be referred
- Provided in a timely fashion, within a couple of weeks
- Have an option for an informal first meeting with professionals, to have a chance to get to know people
- Private and confidential – where agreed – but with the capacity to be joined by a friend or family member if desired by the child or young person
- Having clear lines of communication with parents and carers
- Having clear lines of communication with other services
- Working with the same professional each time, who is knowledgeable, compassionate and skilled
- Having key information available so that there is no need to tell the story over and over again
- Forms completed only once, and only digitally
- Centred around the young person, who is listened to, believed, respected, and, where appropriate, challenged
- If the service is not working for a young person, with an opportunity to feedback why and to seek suitable alternatives.

These characteristics are consistent across all groups. In addition:

- Looked after children may have particular additional support needs based on particular impacts of their childhood, and, potentially, less access to support from their families than other young people
- Young carers may be particularly sensitive to confidentiality as they may be concerned about the impact of any information being shared with their parents. They also need services to be accessible in such a way that they do not impact on their caring role
- Primary school children may have even greater requirements to have access to safe warm, colourful and calm locations, and may have particular need to involve both teacher and parent alongside other professionals.

5.5 To what extent are the audience engaged in decisions about their treatment?

There is limited evidence in the survey responses or discussion groups about children and young people being involved in decisions about their treatment. Certainly young people mention that they are not involved in decisions about medication – both in relation to being given a prescription that they don't want, and not being given medication when they want it (in one instance of each, both the result of medical protocols rather than patient needs).

The GP said that the policy for the practice was not to prescribe medication for Under 18s. [...] They didn't particularly take me seriously
Service user attendee

Many general comments on the survey describe activities being “done to” service users, rather than being agreed with professionals.

Even when I'd been through the same inpatient system once, made my feelings clear that psychologically I wasn't going to 'click' with recovery unless i was able to have input into my own treatment to make it individual and realistic to me but this was ignored purely as i was an adolescent.

i felt i wasnt listened to and they didnt really understand me or my illness.

They didn't support me in the decisions I wanted to make. Cahms could have listened to me and not spoke over me and tell me how I am feeling.

They could have asked me if I wanted to stay with a parent/guardian or conduct the appointment alone.

The mental health services need to take young people seriously. Just because i don't have a proper diagnosis doesnt mean the voices I hear don't scare me and make me depressed.

They should listen to young people instead of thinking they know what's best for you when they really don't.

Parents have an additional battle of not always being included in information shared with their children, but then being expected to care for them. Whilst balancing the need to respect the choices of children and young people, parents need to know as much as possible about what decisions are being made and why.

They never explained anything about the medication which I've since found out actually they can make suicidal tendencies worse
Parent group attendee

On a very practical level, parents need to be engaged when their child misses appointments or leaves hospital without supervision. Improved communication would be beneficial.

5.6 How should transition to adult services be improved?

It is generally accepted that transition to adult services is a crucial and problematic time.

I've just turned 17 so it's my transition year, there's been no talk of it yet and I'm terrified about what's going to happen [...]. There is not enough information, no support out there for that phase in your life, even though they should really get the adult counsellor or psychiatrist come in and meet you with your current one you don't actually have one until like possibly a year after you leave child services because of the waiting lists.
Service user attendee

The hand-over from child and adolescent services is immediate and almost brutal. A phasing of change to adult mental health services at 18 would be helpful. There should be a specific service for 18 to late 20s. These are no longer children but certainly not adult.

Free text responses (parent survey)

Service users conclude that transition should not be when children and young people reach 18, but that a level of flexibility should be allowed right up to 25. Transition should be longer, individually suited, and later. It should take into account that not everyone is at the same stage, and should stop focussing on an arbitrary age and instead focus on the person – making sure that any change – if required – takes place when the service user feels ready and is in an emotionally stable position.

More flexibility between child and adult services (i.e. transitional overlapping) would diminish the requirement for such a formal 'transition' period – the need for such a divide between child and adult services seems to be based on the requirements of those delivering the service, and not those receiving it.

5.7 What do the audience think about the use of their NHS number?

Questions on this issue were asked in the poll and responses gathered from 2,000 respondents. Two questions were provided by the Department of Health who also provided

background information which had been co-produced with young people to explain this issue to other young people.. This information was provided within the poll and within interviews and discussion groups.

Whilst overall there was a net positive response (Yes responses minus no responses) to the question 'Do you think you would be happy for information you give about a health service you have used to be shared in order to help improve services and for this information to include your NHS number?', this was by a very small amount (3%). Positive responses increased in older age groups and males had a slightly higher negative response rate.

	14-15	16-17	18-19	20-21	22-24	Female	Male
Yes	32%	25%	39%	39%	39%	33%	34%
No	39%	37%	25%	33%	31%	33%	38%
Not sure	29%	38%	36%	28%	30%	34%	28%

In interviews and discussion groups, once participants discussed the potential concerns and risks they had about the sharing of their NHS number, all agreed that all factors considered they would be happy for it to be shared on information they give about a health service. The discussion groups and interviews raised a number of key concerns on this issue and it may be the case that had information been provided on these areas in the survey, positive response rates would have been higher.

These issues were clearly reflected in the poll responses to the question: 'If you were to share feedback about a service, is there any information you think should be provided about the feedback?' The type of information most respondents said they wanted was about how their identity would be kept confidential and the next two most highly ranked were who would see the information and how it would be used. As in discussion groups and interviews, poll respondents were less concerned about where and for how long the information would be stored.

	14-15	16-17	18-19	20-21	22-24	Female	Male
How your identity will be kept confidential	2	1	1	1	1	1	2
Who will be able to see it	1	2	3	3	3	2	1
How the information will be used	3	3	2	2	2	3	3
Where it will be stored	4	4	5	5	4	4	4
How long it will be kept for	5	5	4	4	5	4	5

In discussion groups and interviews, the concern most frequently highlighted about the potential use of an individual's NHS number on information they share about a service, was about whether the person providing their treatment would see their feedback. There was a

feeling that if there was any chance the person who had treated you could see your feedback (and know it was from you), it would compromise your honesty when providing feedback. Additionally, participants expressed concern about offending the staff member if they provided any negative feedback.

But I think especially with it being mental health and so on, I would expect a lot of people probably to be quite worried about whether the people they were immediately in contact with would then have, and use, that information. Or - you know - whether they could do anything with it to, I suppose, impact my service negatively
Service user interview

Well obviously you don't want to be off on the wrong foot with anyone who is... so say for example you said that you didn't really like your therapist – you know, a lot of mental health services are based around a relationship with you and your therapist, or whatever, or GP, basically any professional.
Service user interview

The second key theme within discussions was whether the information you shared would be used to improve services generally or your specific care and treatment. Interviewees felt clarity about this was important and that it was fair to let young people know whether the information they shared would have any impact on their personal experience of using services rather than just generally stating it would 'improve services.'

In terms of, say something didn't go so well and you'd like it to be better in the future. The form should be clear on whether this information can be used to maybe impact upon future services and experiences of services that you personally use, or whether it would go into the wider pool of service experience. So knowing whether your feedback will actually make an impact on your particular case, or whether it's just going to be taken into account in the general perspective of things.
Service user interview

Well I, personally, would want to know that what I'm saying was... what's going to be done with the feedback? More than confidentiality, more than anything else, I'd want to know that it is going to be taken seriously, and I'd want to know who is going to be taking it seriously. And what's going to happen –like, ok, I've given the feedback. What's going to be the next thing that's going to happen?
Service user interview

Amongst interviewees there was strong support for anything that could make their personal experience of using services more joined up, including extended use of NHS numbers if this helped achieve this. It was also raised amongst survey respondents and in other discussion groups that young people have to repeatedly tell their story when they access a new service or meet a new worker and that this needs to change.

I have been seen by a few different services, and the one issue I've found is that I have to repeat my story every time I see someone new. And personally I would rather they just access my file from a centralized database. I'd rather risk the idea of confidentiality and all of that for practically, when I'm in a state of need, and I really need someone to look at my notes, I might not be in the best state to explain everything, I'd rather there were a centralized database for people to be able to see my notes..

Service user interview

Appendices

Appendix 1: Children & Young People Survey

Survey Design

The survey was designed in collaboration with Department of Health and NHS England. It was requested that the survey included questions from a survey simultaneously being conducted by NHS England with parents relating to integration of services. YoungMinds adapted these questions for use with young people. As a means to maximise the response rate, respondents could enter into a free prize draw for £200 of high street shopping vouchers if they wished. Entry was not dependent on completion of the survey. In considering the ethical implications of this we ensured that in the case of a winning respondent being aged 15 and under, YoungMinds would contact their parents/carers to notify them and receive consent before delivery of the prize.

Survey Questions

Screening Questions

1. Please select the statement that is true for you:

I am 14 years old or older
I am 13 years old or younger

It's very important to us that we hear what children and young people of all ages want to say about the questions in this survey. If you are aged 13 or under, we just need to check with an adult, normally your parent or carer before you take part. This helps make sure that you have the chance to talk with an adult about the survey before you take part.

2. If you want to take part in the survey please tell us the contact details for a parent or carer below and we will contact them.

The name of your parent/carers
Their relationship to you (like dad, nan, foster carer)
Their phone number or email address

Demographic Questions

3. Please pick the area in the list below that best describes where you live :

North
London
East & Midlands
London

4. What is your age now (in years)?

Question related to participant experience with mental health

Everybody has 'mental health' – it includes things like: how we feel about ourselves; how we cope when things are difficult; our ability to make and keep friends and relationships; and how we learn and develop as we grow up.

Sometimes people experience mental health problems and have difficult thoughts and feelings that make it hard to enjoy or even to do the things they usually do like sleeping, eating, going to school or spending time with their friends.

5. Please tick any of the following statements that are true:

- I have experienced a mental health problem in the past
- I am currently experiencing a mental health problem
- Someone close to me has experienced a mental health problem

Enquiry 1 Questions: What more could be done to promote good mental health and wellbeing in children and young people?

Just like we can look after our physical health by doing things like eating healthily and exercising - there are things we can do to help us look after our mental health too.

We want to find out if you think you know enough about your mental health and where young people should go to get information about important things like their mental health.

6. Do you think you know enough about how to look after your mental health?

- Yes, I feel like I know enough
- Maybe, I know a bit, but it would be helpful to know more
- No, I don't think I know how to look after my mental health

7. There are lots of ways you might get information about mental health-it could be from a person, a leaflet, a school lesson or assembly, online, etc.

Have you received info about looking after your mental health from:

- Parents or other family members
- My school/college teachers
- A visitor to my school/college
- From a charity I volunteered with or got support from
- Youth group
- From a mental health support service I used
- Friends
- My GP
- Another health professional besides a GP
- Online- app or website
- Social media
- Newspapers or magazines
- Anywhere else? Please tell us anywhere else you've got information about mental health from:

Yes, and it was helpful

Yes, but it wasn't that helpful

No

8. If you wanted some more information about mental health, for you or maybe to help a friend, how likely would you be to go to each of the following for information:

Parents or other family members

My school/college teachers

A visitor to my school/college

From a charity I volunteered with or got support from

Youth group

From a mental health support service I used

Friends

My GP

Another health professional besides a GP

Online- app or website

Online mental health app or website

Question websites like Yahoo answers

Social media

Newspapers or magazines

Anywhere else? Please tell us anywhere else you would get information from:

Very likely
unlikely

Quite likely

Neither likely or unlikely

Quite unlikely

Very

Enquiry 3 Questions: What specific services are needed in settings such as early years settings, schools and colleges – both for individual children and young people but also collectively?

Schools and colleges can play an important role in supporting young people's mental health. They can help pupils to get help if they are having mental health problems and things like exams, friendships, and bullying can all impact how pupils might feel when they are at school. We want to find out what's already happening and what you'd like to see in schools to support your mental health.

9. Please tick any of the following that your school or college provided or that you think schools and colleges should provide to support pupil mental health:

Counselling for pupils- in school or college

Counselling for pupils- online

Peer mentoring programme

Lessons about mental health run by teachers

Lessons about mental health run by an outside organisation

Posters about mental health

Provided leaflets about mental health

Information on school intranet about mental health

Anything else? Please tell us about any other ideas you have for how schools and colleges could support pupils mental health:

Yes- it was provided and it was helpful

Yes- it was provided and it wasn't helpful

No- but I think it would be helpful

No- and I don't think it would be helpful

Enquiry 2 Questions: Where do children and young people wish to go for information, advice and counselling and how they would like these services to be provided, including the use of online services?

Sometimes people need help with their mental health. We want to know where young people would like to go for help in this situation and what's most important to you when you get help.

10. If you needed support with your mental health, rank the following to show what would be most important to you:

The support is provided somewhere I can get to easily and quickly

I can get help quickly when I need it

The support is confidential and private and no one would know I have used it

The support looks and feels like it's designed for people my age

The person that gives me support is someone I feel comfortable talking to and can be honest with

There is a choice of ways I can get support and I get to help decide what's best for me

11. Please tick any of the following you have used for to get support and help for your mental health. If you haven't used any- please select the box at the top 'None of these'

None of these

CAMHS – Child and Adolescent Mental Health Service

School teacher

Police, youth justice

Child development centre

Inpatient or day patient CAMHS

Foster care services

Children's social care

School nurse

Occupational therapist

Speech and language therapist

Dietician

Learning disability service for young people

Community based counselling services or youth information advisory and counselling services

GP

School counsellors

Adult mental health services

Hospital A & E team

Adoption services

Hospital paediatrician/doctor working with a psychologist or psychiatrist

Enquiry 5 questions: What needs to change in current services, including both universal and specialised services and how well they feel services work together?

12. When did you first have contact with a service to get help with your mental health?

Within last 6 months

6 months to 1 year ago

1 to 2 years ago

2 to 4 years ago

Longer than 4 years ago

13. Are you still using a service to get support with your mental health?

Yes

No

14. What was helpful about the service(s) you used?

COMMENT BOX

15. What could have been better about the service(s) you used?

COMMENT BOX

When we access support with our mental health, we often use more than one service. When the services and people supporting us work well together, it can help us get better care. We want to know about your experiences of services working well together to support you.

16. Thinking about the services you used to get support with your mental health- how well did they work together to provide the care you needed?

Very poorly

Poorly

Well

Very well

No opinion

Please tell us about your experiences around services working together and what went well and not so well:

17. How important do you think it is that services that support young people's mental health work together to provide care?

Not Important
Slightly Important
Quite Important
Very Important
Extremely Important
No opinion

18. Out of the services we list below, please pick five that you think most need to work together to make sure young people and their families get the best possible care and support for their mental health

None of these
CAMHS – Child and Adolescent Mental Health Service
School teacher
Police, youth justice
Child development centre
Inpatient or day patient CAMHS
Foster care services
Children's social care
School nurse
Occupational therapist
Speech and language therapist
Dietician
Learning disability service for young people
Community based counselling services or youth information advisory and counselling services
GP
School counsellors
Adult mental health services
Hospital A & E team
Adoption services
Hospital paediatrician/doctor working with a psychologist or psychiatrist

First priority Second priority Third priority Fourth priority Fifth priority

19. Please describe what it would look like for you and your family if services worked together well to provide you with care and support

There are lots of things online (including apps) that have been created to help you with your mental health. By online we mean anything you could access on a phone, tablet or computer, such as websites, social media, apps, forums, etc.

20. If you wanted help with your mental health, please tick any of the following you would consider using for support:

Child and adolescent mental health services

School counselling

Private counsellor

Counselling from a charity e.g. at a youth centre or drop-in

Your GP

Anywhere else? Please tell us anywhere else you think you would go to for help:

I'd consider using it

I wouldn't consider using it

I don't know what it is

21. If you were going to use something online for help with your mental health- what device would you be most likely to use to access these resources?

Phone

Tablet

Own laptop/computer

Shared or public laptop/computer

22. We have listed some online mental health resources. Please tick any that you have used or would consider using.

Online counselling through a chat service

Online peer mentoring through a chat service

Other young people's real life stories

Facts and tips about looking after your mental health

Apps to help manage your mental health like mood apps or apps to support you with eating disorders

Asking 'an expert'

A question and answer website (e.g. Yahoo answers, Experience Project)

Websites to rate health services you've used

Forums to chat to other young people about mental health related issues

Anything we've missed that you've used online? Tell us here:

I have used this

I would consider using this

I wouldn't use this

23. Please tell us about any online resources you've used related to mental health that you particularly like or didn't like and why:

COMMENT BOX

Enquiry 4 Questions: How they access or would like to access preventive and early intervention support, including issues around visibility of services, barriers to services, and views on the terminology used such as 'CAMHS'?

24. At the moment services to help children and young people with their mental health are called 'CAMHS'- this stands for 'Child and Adolescent Mental Health Services.' Here are some things young people have said about the name 'CAMHS'- how much do agree or disagree with these comments?

"The name 'CAMHS' is fine- it's clear enough"

"The name 'CAMHS' sounds intimidating."

"A more young-person friendly name for CAMHS would be better"

" It doesn't matter what CAMHS is called as long as young people know where to find it"

"I don't have a view on what CAMHS is called."

If you have any ideas for a better name for these services, please tell us here:

Strongly agree
disagree

Agree

Neither agree nor disagree

Disagree

Strongly

Demographic Questions:

We would like to know about who has taken this survey so we can make sure we are hearing the voices of a wide range of young people.

Please complete the questions below by selecting the options that apply to you. You can select the 'prefer not to say' option for any that you don't want to tell us about. This information will not identify you and everything you say will be kept confidential.

25. How do you describe your ethnic origin?

Black British

Caribbean

African

Other Black

Asian British

Bangladeshi

Pakistani

Indian

Chinese

Other Asian

Mixed & Black African

Mixed & Black Caribbean

White & Asian

Other mixed ethnicity

White English/Scottish/Welsh/Northern Irish/UK

White Irish

White Gypsy or Irish Traveller

Any other White background

Other ethnic background

Prefer not to say

26. How do you describe your sexual orientation?

Straight
Gay man
Gay woman/lesbian
Bisexual
Prefer not to say
Other- please state:

27. What is your gender?

Male
Female

28. Does the gender you identify as match the gender you were assigned at birth?

Yes
No
Prefer not to say

29. Have you ever had 'looked after' status, or lived in care or in a foster home?

Yes
No

30. Do you have any other thoughts or comments that you would like to tell us?

Appendix 2: Parent & Carer Survey

Survey Design

The survey was designed in collaboration with Department of Health and NHS England. It was requested that the survey questions from a survey simultaneously being conducted by NHS England with parents relating to integration of services. Within the survey parents could opt-out of responding to these questions by indicating they had already completed the integrated services survey. As a means to maximise the response rate, respondents could enter into a free prize draw for £200 of high street shopping vouchers if they wished. Entry was not dependent on completion of the survey

Survey Questions

Demographic Questions

1. Please pick the area in the list below that best describes where you live :

North
South
London
East & Midlands

2. What is your parental status?

Biological parent
Stepparent
Mother's unmarried partner
Father's unmarried partner
Adoptive parent
Brother/sister
Foster parent/carer
Grandparent
Other (please specify):

Everybody has mental health – it includes things like: how we feel about ourselves; how we cope when things are difficult; our ability to maintain healthy relationships.

Sometimes people experience mental health problems and have difficult thoughts and feelings that make it hard to enjoy or even to do the things they usually do like sleeping, eating, going to work or spending time with their friends.

Questions related to participant experience with mental health

3. Please tick any of the following statements that are true for you:

I am currently experiencing a mental health problem
I have experienced a mental health problem in the past

4. Please tick any of the following statements that are true in relation to the mental health of your child:

My child is currently experiencing a mental health problem
My child has experienced a mental health problem in the past

Enquiry 1 Questions: What more could be done to promote good mental health and wellbeing in children and young people?

We want to find out how well informed parents feel they are about issues related to the mental health of their child. Additionally, we are interested in what families would like more information about and how they would prefer to access that information.

5. Please indicate how well informed you feel about the following areas related to your child's mental health:

How to teach my child about looking after their mental health
Where to go for advice and guidance if I am concerned about my child's mental health
Where to take my child for support if they are struggling with their mental health
Recognising signs and symptoms of ill mental health in my child
Managing my child's challenging behaviour
How to promote good mental health in my child from birth onwards
Understanding my child's development
How to support my child when they are struggling with their mental health
What to do if your child is self-harming
Common types of mental health disorders

Very Informed
Informed
Fairly Informed
Not very informed
Not at all informed

6. Please indicate how useful you think more information about each of the areas listed below would be to you. Information about:

How to teach my child about looking after their mental health
Where to go for advice and guidance if I am concerned about my child's mental health
Where to take my child for support if they are struggling with their mental health
Recognising signs and symptoms of ill mental health in my child
Managing my child's challenging behaviour
How to promote good mental health in my child from birth onwards
Understanding my child's development
How to support my child when they are struggling with their mental health
What to do if your child is self-harming
Common types of mental health disorders
Please tell us about any other information you would find helpful

Very useful
Useful
Quite useful
Not very useful

Not at all useful

There are different ways that parents might receive information about how to look after their child's mental health- including information about recognising if your child needs support and where to find that support.

7. Please tick any of the following that you have provided you with information related to your child's mental health:

Speak to staff at children's centre or nursery

Speak to my child's school/college

Parenting programme

GP

Health visitor

A mental health charity

A helpline

Speak to friends or other family members

Parents or other family members

Friends

My GP

Another health professional besides a GP

Online- app or website

Newspapers or magazines

Books

Anywhere else? Please tell us anywhere else you've got information about looking after your child's mental health from:

8. If you wanted information about mental health, how likely would you be to look for information from each of the following:

Speak to staff at children's centre or nursery

Speak to my child's school/college

Parenting programme

GP

Health visitor

A mental health charity

A helpline

Speak to friends or other family members

Parents or other family members

Friends

My GP

Another health professional besides a GP

Online- app or website

Newspapers or magazines

Books

Anywhere else? Please tell us anywhere else you would look for advice and guidance:

Very likely Likely Unlikely Very unlikely

Enquiry 3 Questions: What specific services are needed in settings such as early years settings, schools and colleges – both for individual children and young people but also collectively? and Enquiry 4 Questions: How they access or would like to access preventive and early intervention support, including issues around visibility of services, barriers to services, and views on the terminology used such as ‘CAMHS’?

Many services have a role to play in supporting positive emotional wellbeing in children and young people.

- 9. Please state how important you believe the following are in promoting positive emotional wellbeing in your child by: informing them about looking after their emotional wellbeing; recognising signs your child might be struggling; helping you get support for your child when it's needed.**

Children's centres
 Health visitors
 Antenatal classes
 My child's friends
 Primary school
 Playgroup
 Nurseries
 GP
 Parenting programmes
 University
 College
 Secondary school
 Youth services and youth clubs

Very Important Important Fairly Important Of Little Importance
 Unimportant

- 10. Please tick any of the following that your child's school provides/d or that you think schools and colleges should provide to support pupil mental health:**

Counselling for pupils- in school or college
 Counselling for pupils- online
 Peer mentoring programme
 Lessons about mental health for pupils
 Posters about mental health
 Provided leaflets about mental health
 Information on school intranet about mental health
 Evening sessions for parents about looking after child's mental health

Meetings with parents if their child needs support

Signposting for parents on where to get support for their child if needed

Anything else? Please tell us about any other ideas you have for how schools and colleges could support pupils and their families:

Yes – and it was helpful

Yes- but it wasn't helpful

No- but I think it would be helpful

No- and I don't think it would be that helpful

Enquiry 2 Questions: Where do children and young people wish to go for information, advice and counselling and how they would like these services to be provided, including the use of online services?

There are growing numbers of websites and services online related to mental health. By online we mean anything you could access on a phone, tablet or computer, such as websites, social media, apps, forums, etc.

11. Please show how far you agree with the following statements:

I would be equally confident in the value of my child only receiving support from an online service for my child, as I would in them only receiving a face to face support service

I would more confident in the value of a face to face support service for my child than in an online service

I would be more confident in the value of an online support service for my child than a face to face one

Strongly agree

Agree

Neither agree nor disagree

Disagree

Strongly disagree

12. If you were looking for information about mental health online- what device would you be most likely to use to access these resources?

Phone

Tablet

Own laptop/computer

Shared or public laptop/computer

Other (please specify):

13. We have listed some online mental health resources. Please tick any that you would consider using yourself or with your child, if you needed information and/or help related to your child's mental health:

Online counselling through a chat service

Online peer mentoring through a chat service
Other young people's real life stories
Facts and tips about looking after their mental health
Apps to help manage their mental health like mood apps or apps to support them with eating disorders
Forums to chat to other young people about mental health related issues
Anything we've missed that you've used or would use online? Tell us here:

Enquiry 5 questions: What needs to change in current services, including both universal and specialised services and how well they feel services work together?

We want to hear parents and carers views on how mental health services could be improved.

14. If your child has received any support with their mental health, please tick all of the services below that have been involved in providing that support.

**If you haven't accessed services, please select 'None' from the top of the list.
If the support you used is not listed please include it in the 'other' box at the bottom.**

None
Child and adolescent mental health services
School counselling
Private counsellor
Counsellor in voluntary sector
Service from your GP
Other

15. What was helpful about the service(s) you used?

COMMENT BOX

16. What could have been better?

COMMENT BOX

17. Have you completed the Parents Say survey about Integrated Services?

Yes
No
Not sure

If yes, skip to Q XX

18. When did you first have contact with services that support children and young people's mental health? Note: this refers to your first ever contact (in the long term) and not for the most recent episode of care (unless that was your first ever contact).

Within last 6 months
6 months to 1 year ago
from 1 to 2 years ago
from 2 to 4 years ago
Longer than 4 years ago

19. How long did you/have you used services that support children and young people's mental health?

Within last 6 months
6 months to 1 year
from 1 to 2 years
from 2 to 4 years
for longer than 4 years

20. Is your family still accessing services that support children and young people's mental health?

Yes

No

COMMENT BOX

21. From the list below, please select the services that were/are involved in helping your child address his or her mental health issues: (Tick all that apply)

Note: if the services you want to select are not listed or if you are uncertain which categories apply, please use 'other' to describe the services you wish to select)

NHS Specialist child and adolescent mental health services- CAMHS
School teaching staff (e.g. teachers, headteachers, pastoral care teachers)
School nurses
School counsellors
Community based counselling services or youth information advisory and counselling services
General practitioner
Healthcare professional in Accident and Emergency Departments
Adult mental health services
learning disability service for young people
Speech and language therapist
Dietician
Occupational therapist
Child development centre
Behavioural support services
Paediatric health services, including neurological services
Paediatric psychiatric liaison
Paediatric psychology liaison
Foster care services

Adoption services
Children's social care
Forensic mental health services, youth justice system, police
Inpatient or day patient child and adolescent mental health services
Other

22. From your experience, how well integrated or poorly integrated were the services that support your child or young person's mental health (e.g. services selected in response to question 21)?

very poorly integrated
poorly integrated
neither well integrated or poorly integrated
well integrated
very well integrated

23. How important or unimportant do you think it is that there is integration between services that support your child or young person's mental health?

Very important
Important
Neither important or unimportant
Unimportant
Very unimportant

24. Have you had an experience where services to support children and young people's mental health have been poorly integrated?

Yes
No
If yes, please describe one or more of these experiences:

25. Have you had an experience where services to support children and young people's mental health have been well integrated?

Yes
No
If yes, please describe one or more of these experiences

26. Listed below are 22 services that support children, young people and families, please read the list and then select the FIVE most important services that you feel need to work together to meet the needs of children, young people and their families effectively.

Note: Your response is limited to one tick per column. Once you have selected five services, in order of priority, you can move onto question 13. The response options are set to randomize for each completion so the numbering will not be in sequence.

Children's social care
Adoption services
Adult mental health services
School counsellors
Paediatric psychiatric liaison
General practitioner
Paediatric health services, including neurological services
Dietician Forensic mental health services, youth justice system, police
Community based counselling services or youth information advisory and counselling services
Paediatric psychology liaison
School teaching staff (e.g. teachers, headteachers, pastoral care teachers)
Speech and language therapist
Child development centre
Learning disability service for young people
School nurses
Foster care services Behavioural support services
Inpatient or day patient child and adolescent mental health services
Healthcare professional in Accident and Emergency Departments
Occupational therapist
NHS Specialist Child and adolescent mental health services
Other (please specify)

First priority
Second priority
Third priority
Fourth priority
Fifth priority

27. Are your responses to the above questions:

specific to the needs of your child?
could be generalised to a range of needs?
Other:

28. What do you think are the barriers to integration between services that support children and young people's mental health?

Comment box

29. What do you think are the main factors that would help improve integration between services that support children and young people's mental health?

Comment box

30. What do you think are the main factors that would help improve integration between services that support children and young people's mental health?

Comment box

Enquiry 2 Questions: Where do children and young people wish to go for information, advice and counselling and how they would like these services to be provided, including the use of online services?

31. If your child needed support with their mental health, please tell us how important each of the following factors would be about the service they use for support:

The service is easy for me and my child to get to

The service is age-appropriate for my child (e.g. if they are young there are toys and if they are teenage the service looks like it is for teenagers)

I am provided with advice and information about how to support my child at home

I am involved in decisions about the treatment and support my child will receive

My child has a good relationship with the staff they work with

It is quick for my child to get an appointment

I am able to refer my child for an appointment without going to a GP or another professional for referral

Please tell us about anything else that would be important to you about the service you and your child used:

Very Important

Important

Fairly Important

Of Little Importance

Unimportant

Demographic Questions:

We would like to know about who has taken this survey so we can make sure we are hearing the voices of a wide range of parents and carers.

Please complete the questions below by selecting the options that apply to you. You can select the 'prefer not to say' option for any that you don't want to tell us about. This information will not identify you and everything you say will be kept confidential.

32. How do you describe your ethnic origin?

Black British

Caribbean
African
Other Black
Asian British
Bangladeshi
Pakistani
Indian
Chinese
Other Asian
Mixed & Black African
Mixed & Black Caribbean
White & Asian
Other mixed ethnicity
White English/Scottish/Welsh/Northern Irish/UK
White Irish
White Gypsy or Irish Traveller
Any other White background
Other ethnic background
Prefer not to say

33. How do you describe your sexual orientation?

Straight
Gay man
Gay woman/lesbian
Bisexual
Prefer not to say
Other- please state:

34. What is your gender?

Male
Female

35. Does the gender you identify as match the gender you were assigned at birth?

Yes
No
Prefer not to say

36. Have you ever had 'looked after' status, or lived in care or in a foster home?

Yes
No

37. Do you have any other thoughts or comments that you would like to tell us?

Appendix 3: Discussion Groups & Interviews

Lines of questioning were developed for the four sets of discussion groups. Group facilitators adapted them during groups to suit the age and understanding of different groups.

Parents & Carers

- What words, images, or thoughts come to mind when I say the phrase 'mental health'?
- Where or who do you think parents and carers get information about mental health from? If unknown, where do you think they SHOULD be getting this information from?
- Thinking of the services your family has used (From nursery right up to University) – What do you think these services should do to help young people and their families?
- From your experiences of services that treat mental health within NHS or charity organisation, how could these experiences been improved?
- What do you think could make it easier or harder for young people to find or access help outside of family and friends? Think of atmosphere, environment, type of staff, time etc. The Where and When.
- When a child is in Children and Adolescent Mental Health Services (CAMHS), what factors do you think should be taken into consideration when deciding when to transition a young person into adult services?
- More and more information and support is online. This includes online counselling. What do you think are the positives and negatives about this type of approach for getting mental health help online?
- How do you think parents and carers could be better prepared to give emotional support when their child is suffering from mental distress?

Service Users

- What words, images, or thoughts come to mind when I say the phrase 'mental health'?
- What services or support have you used in relation to mental health?
- Thinking about your school, college or university- we all spend lots of time there. So what do you think should be done there do to help young people with their mental health?
- Thinking about your experiences of using mental health services- how could the services you have used, be made better?
- Imagine if someone was going to use a service for the first time. What might be the things that would make it easy or difficult for them to find and access help? Think of atmosphere, environment, type of staff etc.
- Thinking about when we move on from services- how should services decide when it's the right time for someone to move to adult services?

Education settings

- What words, images, or thoughts come to mind when I say the phrase 'mental health'?
- Where or who do you get information about mental health from?
- Thinking about school now. You spend a lot of your time in school- so what do you think schools should do to help pupils with their mental health when they are here?
- If someone you knew was struggling with their mental health at school, what do you think the school should do to help them?
- Imagine you are in a situation where you were really struggling and that the support of your family and friends isn't helping. So where else could you go for help elsewhere in the community or city? Or if you could create such a service, what would this look like? Think of type of staff, environment and atmosphere.
- More and more information and support is online. This includes online counselling. What do you think are the positives and negatives about this type of approach for getting mental health help online?

Vulnerable groups

- What words, images, or thoughts come to mind when I say the phrase 'mental health'?
- In what ways do you think the mental health of young carers/
- /young people in care etc. might be impacted differently to other young people?
- Where and/or how do you think young carers/
- /young people in care etc would best like to access information and help with their mental health?
- Just like our physical health- there are things we can all do to look after our mental health before we become unwell and need help. What sort of actions or coping mechanisms do you think could help young carers/ young people in care etc. young people look after their mental health?
- If a young carers /young people in care etc was looking for somewhere to get some support with their mental health- what sort of environment, atmosphere and type of staff, do you think would make them feel safe and ok about using a service?
- Thinking about your experiences of using mental health or other health services – how do you think these services could better for young carers /young people in care etc

Appendix 4: Poll questions

1. If you needed support with your mental health, which of the following would be most important to you? (Select top 3)

The support is provided somewhere I can get to easily and quickly

I can get help quickly when I need it

The support is confidential and private and no one would know I have used it

The support looks and feels like it's designed for people my age

The person that gives me support is someone I feel comfortable talking to and can be honest with

There is a choice of ways I can get support and I get to help decide what's best for me

None of the above / I don't know

2. If you wanted some more information about mental health, for you or maybe to help a friend, how likely would you be to go to each of the following for information:

Parents or other family members

My school/college teachers

A visitor to my school/college

From a charity I volunteered with or got support from

Youth group

From a mental health support service I used

Friends

My GP

Another health professional besides a GP

Online- app or website

Online mental health app or website

Question websites like Yahoo answers

Social media

Newspapers or magazines

Very likely

Quite likely

Neither likely or unlikely

Quite unlikely

Very unlikely

Not applicable

3. Please tick any of the following that your school or college provided/provides or that you think schools and colleges should provide to support pupil mental health:

Counselling for pupils- in school or college
Counselling for pupils- online
Peer mentoring programme
Lessons about mental health run by teachers
Lessons about mental health run by an outside organisation
Posters about mental health
Provided leaflets about mental health
Information on school intranet about mental health

Yes- it was provided and it was helpful
Yes- it was provided and it wasn't helpful
No- but I think it would be helpful
No- and I don't think it would be helpful
I don't know if they provide this

- 4. At the moment services to help children and young people with their mental health are called 'CAMHS'- this stands for 'Child and Adolescent Mental Health Services.'** Here are some things young people have said about the name 'CAMHS'- how much do agree or disagree with these comments?

'The name 'CAMHS' is fine- it's clear enough'
'The name 'CAMHS' sounds intimidating.'
'A more young-person friendly name for CAMHS would be better'
'It doesn't matter what CAMHS is called as long as young people know where to find it'
'I don't have a view on what CAMHS is called.'

Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree

- 5. Every person using the NHS has a unique number which can identify them called an NHS number. At the moment, any feedback you give about any health service you have used (for example a feedback questionnaire) has this number removed when it is stored in order to make the data anonymous.**

In future, the NHS would like to change this and keep the NHS number on any feedback you give. This would mean that they could use your feedback to see what different services you have used and see your views of those different services so they know what works best or not so well for you. This could help the NHS understand better the different range of services young people use; help those services work better together and help those services meet your needs better.

This would not mean your identity would be made public- your name would never be used in public in relation to any information you share.

Do you think you would be happy for information you give about a health service you have used to be shared in order to help improve services and for this information to include your NHS number?

Yes

No

Not sure

6. If you were to share feedback about a service, is there any information you think should be provided about the feedback? Please tick all that apply

How your identity will be kept confidential

How the information will be used

Who will be able to see it

Where it will be stored

How long it will be kept for

Other - please explain.....

None / no

7. Which of the following have you used for support/would you use for support in regards to mental health?

Child and adolescent mental health services

School counselling

Private Counsellor

Counselling from a charity e.g. at a youth centre or drop-in

Your GP

I have used, and I'd use it again

I have used, but I wouldn't use it again

I haven't used, but I'd consider using it

I haven't used, and I wouldn't want to

I don't know what it is

Not applicable