Public Voice

service improvement
through user engagement

Young Person and Parent/Carer Participation and Engagement with Child and Adolescent Mental Health Services (CAMHS) in Haringey

REPORT

delivering healthwatch Haringey

Contents

Acknowledgements

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- Open Door
- Tavistock and Portman NHS Foundation Trust
- Barnet, Enfield and Haringey Mental Health NHS Trust
- Haringey Mind
- Ambitious About Autism
- Haringey Involve
- MAC UK
- The parent representative on the Haringey CAMHS Transformation Board

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REPORT

Executive Summary

Introduction

Background

A national programme of change is underway in child and adolescent mental health services (CAMHS), building on the three-year CYP IAPT project and cemented by the *Future in Mind* report, published by the Department of Health and NHS England in 2015. This report sets out the government's vision of what an effective, modern children and young people's mental health service looks like.
Future in Mind requires every area to develop its own Local Transformation Plan, reflecting these national ambitions and including commitments to transparency, service transformation and monitoring improvement.

Haringey published its own CAMHS Transformation Plan and 2015/16 Delivery Plan, identifying key areas for improvement within the borough[1]. These include expanding tier 2 capacity (early intervention) through the use of group interventions and digital solutions, improving access to parenting support and peer support, focusing on outcomes, improving information and accessibility of services, stream lining the transition between CAMHS and adult mental health support, and increasing engagement with BME families.

The findings of our current research combined with earlier studies and policy reports have informed our proposed framework for participation and engagement with parents and young people, as well as a toolkit aimed at helping in the monitoring and evaluation of participation and engagement activities.

[1] Haringey CCG (2015) *Haringey Child and Adolescent Mental Health Services and Transformation Plan: Executive Summary and 2015/16 Delivery Plan.* Accessible at http://www.haringeyccg.nhs.uk/downloads/publications/Haringey%20CAMHS%20Transformation%20Delivery%20Plan%2015-16.pdf

Participation in Practice: Engagement around the country

The Young Minds website identifies a series of good examples in promoting engagement. These include:

- Berkshire: Young people are involved in staff training by being asked to plan and deliver training sessions for staff at Berkshire CAMHS.
- Devon: Young people are involved in staff recruitment in a number of different ways - job candidates may be asked to prepare a presentation for a panel of young people on a given theme
- Surrey: Young people helped to design a training package, using their first-hand experience as CAMHS users to help make decisions on what should be included in the training package.
- Hampshire: A group of young people established the key indicators of a successful provider, evaluated bids for tender, visited sites run by the providers and conducted interviews with the bidders.

In addition, CAMHS providers in Haringey who we consulted in a workshop held on 14th March 2016 mentioned these examples:

- The Hive, Camden: A youth base was established where training and information was provided for young people in areas such as education, employment, housing and health and wellbeing. Young people were able to use this service to gather information on other services and to get help in life skills- design and delivery of the project involved a young people's board.
- Young People Cornwall: Young People Cornwall offers a variety of service to put young people in the driving seat and giving young people a voice. They may support the starting and management of youth groups, and run programmes and projects for a variety of causes, such as anti-bullying.

Furthermore, national charities working with young people and/or people with mental health issues have developed their own approaches for involving service users, which may be suitable for adapting to CAMHS services:

- Coram Voice, National: Coram Voice promotes young people holding services to account for the care they provide to young people. It seeks out the hardest to reach and most vulnerable and represents their voice within the care system.
- Ambitious About Autism, National: MyVoice is a project aimed at 16-25 year olds with autism, allowing them to connect with one another and promoting them having a say in their communities. Simultaneously it provides them with

numerous leadership roles on the project, such as Online Facilitator, Online Content Creator and Youth Consultant.

One important group that promotes participation and engagement work is the Participation Works Partnership, a collaborative effort between six agencies- British Youth Council, Children's Rights Alliance for England, KIDS, National Council for Voluntary Youth Services, National Youth Agency and Save the Children UK- and several partners. The Participation Works Partnership promotes children's and young people's participation across a variety of themes, including Children and Young People in Care, Training and Policy. Some notable work they have engaged in is the work they have conducted around Young Inspectors- young people who are trained to conduct inspections of services and providing findings and recommendations in conjunction with their review.

Method

In order to engage as many people as possible, Public Voice conducted a series of face-to-face interviews; focus groups and online focus groups; one to one interviews; and a parent's survey. This approach resulted in engagement with a far wider range of participants than initially proposed. This included individuals who were not involved with CAMHS, as well as CAMHS users from outside the borough. In fact, issues relating to those who did not use services were highlighted to Public Voice by other participants, prompting engagement with non-users to find out more about their experiences.

The participants in our study included young people (YP), parents or carers (Pa or E-Pa) and representatives of mental health service providers (Pr). Also included were professionals associated with mental health services and an adult who did not belong to any of these groups. It must be noted that some participants, who are unaccounted for, attended the focus groups as observers (see appendix I).

Results

Service Providers

The service provider representatives were asked to provide information about their current engagement methods against the nine IAPT CYP participation priorities.

Service provider opinions of their engagement using the nine participation priorities

	Priority	Strengths	Weaknesses
Feeling good	Initial assessments	Pr2: Done in timely manner according to commissioning standards, probably better than CAMHS nationally	Pr2: 8 weeks may still be considered a long time for parents/carers and young people Pr2, Pr3: Psychotherapy is a long wait Pr3: Waiting times too long
	Regular monitoring	Pr3: Generally good at output monitoring	Pr3: Should be more collaborative and integrated into the therapy
	Complaints procedure	Pr2: Easy to contact Pr3: Always available to be directed to it	Pr2: Could be more child orientated
Doing the job right	Staff training	Pr1: Module of training developed with young people	Pr3: Doesn't involve young people directly
	Recruitment and selection of staff	No comments made	Pr3: Young people not on recruitment panels
	Supervision and appraisal of staff	Pr1: Doctors required to receive feedback from parents or carers and young people Pr3: Done for service as a whole	Pr1: Not across staff team (ie. Doctors and some nurses only) Pr3: Not done for individual members of staff
Running the service well	Commissioning of services	No comments made	Pr1: Still trying to get something established
	Influencing of senior managers	No comments made	Pr1: Much more difficult to involve senior managers than frontline staff
	A mission statement	No comments made	No comments made

The findings appear to indicate that engagement around the 'Feeling good' and 'Doing the Job Right' areas of the nine participation priorities are better developed than the 'Running the service well' area. Pr1 made reference to a module of training developed with young people, as well as the fact that doctors were required to receive feedback from parents or carers and young people as part of their appraisal. Pr1 also made concessions as to the format this feedback was given, to make this

more interesting for the young people. Pr3 felt that whilst regular monitoring was incorporated into their service, they felt that this should be more collaborative and integrated into the therapy. Another example of promoting engagement and participation within the system was the development of a training module with young people (Pr1).

One particular area of interest is the engagement strategies employed by adult mental health service providers, highlighted by Pr4. Pr4 indicates that an accessible service user forum have become “an established part of” their work. Pr4 also indicates that the provider they represent utilises a steering group; a group of people who the providers can go to when “developing a project, or reviewing a service”.

There were examples of engagement outside Haringey that were highlighted in two of the focus groups. The first example was the use of parents/carers and young people on staff recruitment panels. This was seen as a very positive experience by people who were involved (Pa3, YP8, YP11). However, one person who had not undertaken such an activity, when asked about potential involvement in staff appraisals and reviews, stated that this activity would be useful if people were ready, but they “don't think it will happen while they are being treated or have serious problems of their own before trying to fix others” (YP2). YP2 was involved in a Young Inspectors project looking at CAMHS services in Dorset.

This self-assessment very usefully identifies areas for improvement and there is a willingness to address these issues amongst the providers. Some will be more easily tackled than others and perhaps an early priority could be a more child friendly complaints procedure which could potentially be developed jointly. There was complete agreement from the providers that they would benefit from a Haringey wide young peoples’ forum or council to widen their pool of young people to consult with; Haringey seemed to be less well served than other London boroughs in this respect and this was a disadvantage.

Parents survey findings

> "Every child and every situation is different – parents understand their own child best, but do not always know how to help them, so rely on services for this."
> "Opportunities for parents and young people to meet informally – regular meet-ups in different locations across Haringey."
> "Parents should be involved in strategic planning, all services should have guidelines for how they will place children at the heart of what they do. This should be across different agencies, not just CAMHS (schools, police, GPs)."

Fifty nine parents/carers in total responded to the parents/carers survey. However, only 29 of these (49%) had current or previous experience of children's mental health services in Haringey. Of those who had experienced services the majority (79%) had more than a year's worth of contact with Haringey CAMHS – and a quarter have more than 3 years' worth of contact (time since their child was first referred).

Overall, parents/carers feel that they have been more involved with their child's individual care, rather than with the running of the service more generally.

Parents/carers tended to agree that they had felt emotionally supported as a parent (52% agreed), that they were kept well-informed throughout their child's referral and assessment (52%), and that their views were taken into account during their child's initial assessment (68%). However, two thirds of parents/carers (64%) felt that they had not been proactively asked for any feedback on the service and 60% had not been asked for their views on the overall strategy or vision for the service. More than half (56%) had not seen any visible improvement as a result of any feedback they had given, whilst only 4% said they had. Of parents/carers who had actually given feedback, 82% said they had seen no improvement as a result. Overall, 52% of parents/carers agreed that the service includes and listens to the views of parents/carers.

Parents/carers said it was most important for them to be involved by being asked for their feedback, being asked for their views to help shape overall service priorities and strategy and seeing visible changes in response to their feedback.

Parents/carers' preferred options for getting more involved and attending regular meetings (77%), sitting on a board or decision-making panel (59%) and carrying out research and consultation work with other parents/carers (41%). Conversely, parents/carers' least frequently preferred options are sitting on interview panels for new staff (18%), acting as an ambassador for the service (18%) and being involved in staff appraisals (14%).

Interviews and focus groups

The results emerging from the interviews, focus groups and workshops can be divided into three main areas. The first main area is "current engagement", which establishes what engagement practices are already occurring. The second main area is "engagement aspirations", which looks at the sort of engagement parents/carers, service providers and young people would like to see. The third area is "barriers to engagement", which are the problems and blocks to engagement that currently prevent or are anticipated to prevent engagement.

Current engagement

> "I think there is a willingness to work more closely with schools in some cases, to avoid clashing and a lack of communication in the progression of someone's treatment."
> "There's surveys and questionnaires and things but people just don't feel like that's very useful."
> "I really like doing the interview panels and stuff…they take away that scariness from interviews, because before I ever did one, I was really nervous to go to interview panels myself being on the other side…I like doing groups and talking to people rather than writing things down because sometimes you can't always get your point across…you can describe things more and get more heard…it's usually like once a month."

Engagement Aspirations

> "They [senior managers] need to come to the community. Stop hiding in offices!"
> "they have to do more stuff to stimulate the brain, like say sports…stuff to wake them up."

“I think there would be something in parents having some kind of solidarity…I think you could do that with mental health and they do have mental health groups, local groups.”

Barriers to engagement

“I think I found it quite confusing. When I first got referred it was all so complicated, and no one explained to me what was going on.”
“I never heard anything about mental health from school days and all of the stuff that was possibly traumatic for me when I was younger, I didn’t know how to deal with it.”
“There are projects which we have a voice in, but I don’t think the adults take it in because they’re busy coping with stuff.”

Table 1 summarises the themes that emerged from the interviews and focus groups and which are developed in more detail in the main body of the Report.

Table 1: Summary of themes emerging from the qualitative data.

Area	Major theme	Minor themes	
Current engagement	Engagement within mental health services	Surveys/Questionnaires Staff training Staff appraisals Service User forum	Steering group Thoughts wall Staff recruitment Young Inspectors (Dorset)
	Engagement outside mental health services	Schools and youth centres Groups	Skills and Activities
Engagement Aspirations	Service and groups	Authoritative youth groups	
	Service and user	Ambassadorial role Interview/recruitment panels	Staff training Senior managers
	Service and non-user	Family involvement Leisure activity Early intervention	Information and promotion Schools Senior managers
	User/parent and user/parent	Peer groups	
	Format of engagement	Digital Face to face	
Barriers to engagement	System	Accessibility Awareness Perceived status	Complexity Prescriptive Transition (CAMHS to Adult)
	Regional Context	Cultural Social	Professional Financial
	Beliefs about mental health services and mental health	Mental health: Not accepted Mental health: Dangerous	Mental health: Isolated Mental health services
	Personal	Time	Circumstance

Recommendations

Our study highlights both targeted recommendations of ways to improve engagement and also the importance of the underlying principles of all such engagement. A set of recommendations for improving future engagement have been developed. These are based on our initial findings of the current practice and engagement aspirations; barriers to engagement, and our own experiences from delivering the project. There are seven principles that should underpin engagement and participation which we consider important to improving effectiveness of engagement work. The emerging themes provide a framework for engagement activities based on what we believe parents/carers and young people would like from engagement and will encourage them to become involved rather than disengaged.

Seven Principles

The seven principles are important concepts to keep in mind while planning, undertaking and reviewing all engagement activities. These seven principles are:

Inform

Young people and parents/carers should always be made fully aware of what engagement activities are available as well as what to expect in those engagement activities. Activities should be advertised appropriately, with e-mail circulations and word of mouth methods promoted.

Free choice

Young people should be made aware that they are free to engage or not engage with the system. Young people and parents/carers, for example, felt pressurised and embarrassed about completing surveys when not given prior warning, especially in front of staff members.

Flexibility

Timing, nature of delivery (digital or face to face) and focus must all be considered for engagement to be inclusive and flexible yet thorough. Individuals had different views on individual and group engagement and the nature of digital engagement, and this range of viewpoints should be considered to promote engagement.

Confidentiality

Services should respect and understand the potential value of confidential feedback through all formats of engagement. It may be difficult for people to give honest feedback where they feel their responses are easily identifiable or visible to staff.

The flexible nature of engagement should allow participants the option of being able to give feedback directly or anonymously.

Confidence building
It is essential that all people attempting to engage with the services are confident enough to contribute in their own way, whether in a capacity as representatives of service users collaborating with service providers or as participants in focus groups with staff members looking to improve the service.

Reward
It is important that young people feel their contributions are valued through compensation for their time or rewards for contributions. These rewards do not have to be monetary or at financial cost to the service providers- simply seeing the outcomes of such engagement may be rewarding enough.

Feedback
It is extremely important that the outcomes of any engagement work are shared with everyone involved. Participants often felt that there was little or no noticeable change based on their feedback. It is important to also consider feeding back the results as well as the actions, potentially in the format of “You said, we did” reports.

Emerging Themes

The most salient themes that emerged from the research and which could have a significant role in both meeting the aspirations for engagement as well as overcoming some of the barriers to engagement are:

Accessibility to services
One of the biggest barriers to engagement is the lack of easy access to psychological services. The results indicated that this barrier not only stops people from getting into the service and therefore participating and engaging in activities, but also makes people sceptical of engagement as a way of attempting to do more for less. For engagement activities to truly have a significant impact on the way services are run, access to psychological services must be improved.

Collaboration with Young People's Groups

One of the key issues to emerge from our engagement with the providers was that it is difficult to develop meaningful engagement with young people who are using mental health services in the absence of a wider culture of engagement in Haringey.

There is at present no youth forum or other similar group able to represent young peoples' views on a range of issues and identify what is important for them.

Work is currently in progress to develop a Haringey Youth Council which could fulfil this representational role in relation to health and wellbeing and a range of other issues. A number of organisations have expressed an interest in including young people in how they shape their Health services and policies by using the Haringey Youth Council as a method for inclusion and co-production.

Digital and face-to-face engagement

Young people were far more positive about digital engagement and face to face engagement than they were about surveys. Utilising a variety of methods also increases the chance of individuals engaging at the level that they wish to engage- for example, some will feel more comfortable engaging through a moderated on line chat room rather than in a face to face discussion. The use of digital engagement in particular allows an opportunity to overcome some of the personal barriers, such as time related constraints by minimising travel time or even allowing engagement to be organised when appropriate (such as via e-mail correspondence).

School based engagement

The importance of school based engagement was highlighted by every stakeholder group we engaged with - service users, non-users, parents/carers and providers.

Many young people highlighted the fact that they did not know what mental health was until they entered the CAMHS system. Engagement with schools could not only be used to help overcome barriers such as stigma and issues related to awareness for non-mental health professionals, but to promote knowledge and understanding of mental health and potentially allow for early intervention.

Teachers are often the front line in identifying and having to deal with early signs of mental health problems. They need to access young peoples' mental health services on behalf of their students and the referral pathway process needs to be clearer and more responsive.

Parent and Carer Engagement

There is a demand from parents / carers to be more involved in the provision of the service. The parents/carers survey indicated that parents/carers are most interested in attending regular meetings, sitting on a board or decision-making panel and carrying out research and consultation work with other parents/carers. There is a demand for parent support groups and this should be an early priority.

There was a feeling that engagement was relatively good at the referral and assessment stage but not once the delivery of the service had started. This possibly reflects a view expressed by some parents that they felt excluded from the relationship with the doctor/therapist and this was a tension caused by the issue of patient confidentiality, which they often did not feel suitably prepared for.

Senior manager engagement

It is also important to understand that people felt strongly about senior managers engaging with people directly, which can be done in a number of different ways. One suggestion was direct access for parents/carers- which could be accounted for via parents/carers and service users attending board meetings, or being used as a sounding board for service changes. Methods that have been utilised in other boroughs should be considered here also, such as the concept of young inspectors, parents/carers and service users being involved with staff recruitment panels and staff training. With non-users, senior managers could work towards establishing links with the community and schools.

Provider collaboration

The providers are very committed to improving their engagement process and developing opportunities for participation for both parents / carers and young people. They have generally found it difficult to establish a cohort of young people to work with in Haringey despite a number of creative attempts to do so and are open to other ideas to maximise the level of engagement.

To maximise the potential for engagement and participation and utilise it to its full potential, CAMHS providers could consider more collaboration with one another. Providers could support one another's work by sharing data collected about engagement, such as what methods are working well. When the Haringey Youth Council is operational some collaboration between providers would avoid duplication of effort and too many demands being made of the same group of people. Commissioners could encourage more collaboration through commissioning some engagement work jointly, perhaps with a lead provider in each case.

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Introduction

Background

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Haringey published its own CAMHS Transformation Plan and 2015/16 Delivery Plan, identifying key areas for improvement within the borough[2]. These include expanding tier 2 capacity (early intervention) through the use of group interventions and digital solutions, improving access to parenting support and peer support, focusing on outcomes, improving information and accessibility of services, stream lining the transition between CAMHS and adult mental health support, and increasing engagement with BME families.

There is a strong push for children, young people and parents to be more involved in shaping the future of children's mental health services at a national level, as demonstrated in *Future in Mind*, as well as the earlier CYP IAPT programme.
One of the six key strategic recommendations outlined in Haringey's transformation Plan is for services to 'promote participation of children, young people and families in all aspects of prevention and care'. Haringey CCG commissioned Public Voice to help understand how they can best promote participation of children and young people and their parents and carers in CAMHS, in line with the aspirations set out in the Haringey CAMHS Transformation Plan.

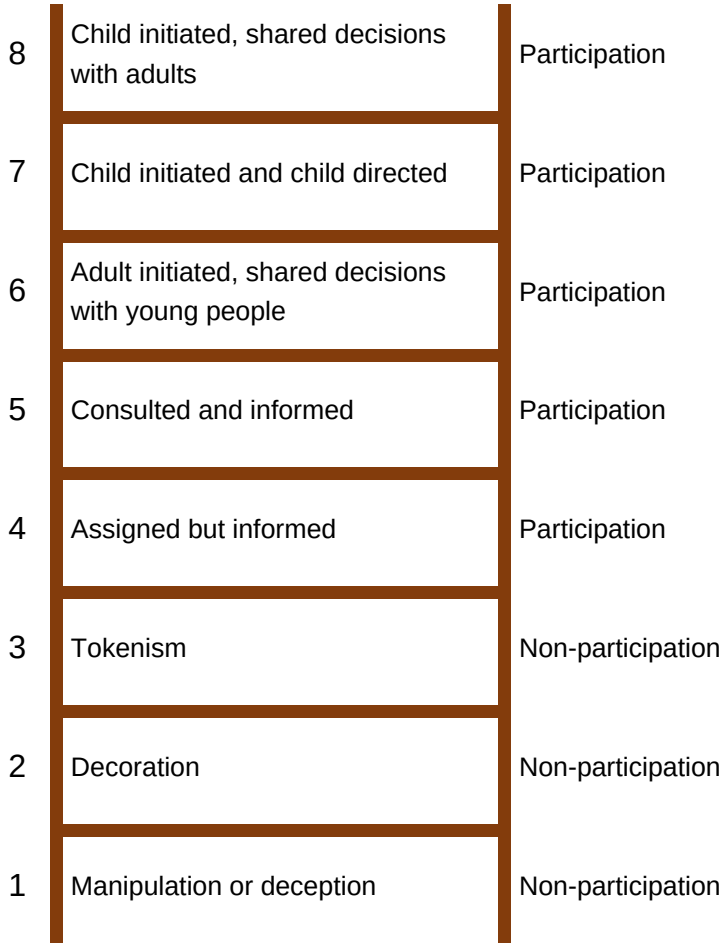
Public Voice spoke to young people who have accessed CAMHS, parents, CAMHS provider organisations, schools and other stakeholders working to promote participation of young people in Haringey. The findings of the research will therefore contribute to a framework for participation and engagement with parents and young people, as well as a toolkit aimed at helping in the monitoring and evaluation of participation and engagement activities.

[2] Haringey CCG (2015) *Haringey Child and Adolescent Mental Health Services and Transformation Plan: Executive Summary and 2015/16 Delivery Plan.* Accessible at http://www.haringeyccg.nhs.uk/downloads/publications/Haringey%20CAMHS%20Transformation%20Delivery%20Plan%2015-16.pdf

Participation in Theory: Ladder of Participation (Hart, 1992)

One simple way of considering effective engagement and participation is through Hart's (1992) ladder of participation[3] (fig. 1). This utilises the ladder metaphor whereby the higher rungs of the ladder imply a more child initiated engagement and participation process. Conversely, the lower rungs of the ladder refer to non-engagement which may guise itself as engagement or participation.

Fig. 1: Summarised ladder of participation (Hart, 1992)



Hart (2013)[4] states that participation and engagement does not necessarily need to be at the highest ends of the ladder to be effective as long as young people are informed about the nature and effect of their engagement. However, the non-participation levels must be avoided. This is important to remember in all engagement- participation activities designed merely to meet service requirements may potentially be counter-productive. For example, if young people feel as if their contributions have been manipulated, decorative or tokenised, it may discourage them from future engagement work.

[3] Hart, R. (1992) *Children's Participation: From tokenism to citizenship, Innocenti essays* (4, p. 5) UNICEF International Child Development Centre

[4] Hart, R. (2013) *Children's Participation: The Theory and Practice of Involving Young Citizens in Community Development and Environmental Care*. Routledge, New York

Participation in Practice: Engagement around the country

It is important to highlight good engagement practices from CAMHS around the country. Young Minds were tasked with supporting children and young people's participation in the CYP IAPT programme, which they did through a survey distributed to young people and a one-day workshop event[5]. Young Minds and the Department of Health also developed nine participation priorities "to facilitate change and drive young people's participation in the Children and Young People's IAPT"[6].

The nine priorities are:

1. Get Initial Assessments Right
2. Make Sure Session Monitoring involves the Young Person
3. Provide Easy Access to Complaints and Advocacy
4. Make Sure Staff Have the Right Skills and Knowledge
5. Involve Young People in Recruitment
6. Involve Young People in Staff Appraisals
7. Involve Young People in Commissioning
8. Help Young People Influence Senior Managers
9. Have a Strong Mission Statement

[5] Young Minds (2011) *Talking About Talking Therapies – Thinking and planning about how best to make good and accessible talking therapies available to children and young people*. Accessible at http://www.iapt.nhs.uk/silo/files/talking-about-talking-therapies.pdf

[6] http://www.youngminds.org.uk/training_services/vik/children_young_peoples_iapt/the_nine_participation_priorities

The Young Minds website identifies a series of good examples in promoting engagement in these nine priority areas. These include:

- Berkshire: Young people are involved in staff training by being asked to plan and deliver training sessions for staff at Berkshire CAMHS.
- Devon: Young people are involved in staff recruitment in a number of different ways- job candidates may be asked to prepare a presentation for a panel of young people on a given theme
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Furthermore, national charities working with young people and/or people with mental health issues have developed their own approaches for involving service users, which may be suitable for adapting to CAMHS services:

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numerous leadership roles on the project, such as Online Facilitator, Online Content Creator and Youth Consultant.

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Methodology

The initial proposal sought to hold numerous co-design groups with different sets of participants- namely representatives of service providers, parents of young people involved with CAMHS, 9-13 year olds involved with CAMHS and 14-18 year olds involved with CAMHS. However, participant recruitment in itself posed many challenges for Public Voice. Problems with participant recruitment were in fact anticipated by the representatives of the service providers, who had alerted us to potential issues we faced prior to recruitment. Initially, there were very low engagement rates from young people, especially from the north and east of the borough, and even when people were interested in engaging, significant challenges were posed in finding universally suitable times and locations.

In order to engage as many people as possible, Public Voice conducted a series of interviews and focus groups- both digitally and face-to-face- and a parent's survey. This approach involved a far wider range of participants than initially proposed, including individuals who were not involved with CAMHS and CAMHS users from outside the borough. In fact, problems relating to non-users were highlighted to Public Voice by other participants, prompting engagement with non-users to explore the issues.

To help in participant recruitment, several of the main providers in Haringey put out e-mail notices to the young people who access support from them, as well as their parents, informing them of the research taking place. A note was included in the parent newsletter of two secondary schools in Haringey, inviting parents to take part in upcoming events and surveys. Haringey Involve also contacted their members – all of whom are parents of children with disabilities – about the work. The majority of the parents of survey respondents were gathered through one of the schools. The online discussion group was arranged through Ambitious About Autism, who host regular online groups with young people, and the Tavistock agreed to let us come along to their monthly pizza group to speak to some of the young people who attend regularly. MAC UK allowed Public Voice conduct focus groups with their service users.

The interview schedules both for the interviews and focus groups were initially designed to capture participant's opinions on engagement with CAMHS at a service level. These specifically focussed on Young Mind's nine participation priorities, utilising some of the examples of good engagement highlighted by them. However, similar to the issue of participant recruitment and availability, this proved to be more

difficult to put into practice. Although some participants were able to provide opinions on some of the more formal levels of engagement services currently provide, such as utilising young people for staff recruitment panels, many young people found answering such questions difficult, either due to their perceived lack of relevance to the young person's mental health or due to lack of any involvement in the system. Consequently, all of the interviews and focus groups required a far less structured approach, often based on more general questions about how best to engage with young people and the barriers to engagement, with questions having to be appropriately adapted to the audience.

In total, 89 individuals contributed to the data in this report in a variety of different ways (Appendix I). The participants consisted of young people (YP), parents or carers (Pa or E-Pa), representatives of mental health service providers (Pr), and an adult who did not belong to any of these groups (but was included as a young person). It must be noted that some participants, including professionals associated with mental health services who are unaccounted for, attended the focus groups as observers.

The challenges encountered with participant recruitment and material design allow for important notes to be made about the method used and an opportunity to learn lessons. Firstly, engagement was only made possible through the efforts of the aforementioned organisations, and such organisations may be exceptionally useful for engagement both within and outside the mental health services. Secondly, that the numerous methods of engagement were dependent on the form of engagement preferred by participants, and that people will only engage if the method is suitable for them. Thirdly, individual levels of experience and knowledge must be accurately reflected in engagement work, avoiding a one-for-all approach to engagement. These three lessons point to a need for a user-led approach to engagement, forming the basis of many of the findings and recommendations in this report.

Results

Due to the volume of the data from focus groups and interviews the results have been categorised into three sections:

1. Providers and the nine Participation Priorities: The providers' opinions on their current levels of engagement within the nine Participation Priorities, which were identified during the Provider focus group.
2. The Parents survey: The results of the parents' survey and what could be identified from the data.
3. Interviews and focus groups: All of the themes that emerged from the interviews and focus groups conducted. These can be divided into two major themes- Engagement and Barriers to Engagement.

Providers and the nine participation priorities

The service provider representatives were asked to provide information about their current engagement methods against the nine participation priorities (fig.1).

Fig. 1: Service provider opinions of their engagement using the nine participation priorities

	Priority	Strengths	Weaknesses
Feeling good	Initial assessments	Pr2: Done in timely manner according to commissioning standards, probably better than CAMHS nationally	Pr2: 8 weeks may still be considered a long time for parents/carers and young people Pr2, Pr3: Psychotherapy is a long wait Pr3: Waiting times too long
	Regular monitoring	Pr3: Generally good at output monitoring	Pr3: Should be more collaborative and integrated into the therapy
	Complaints procedure	Pr2: Easy to contact Pr3: Always available to be directed to it	Pr2: Could be more child orientated
Doing the job right	Staff training	Pr1: Module of training developed with young people	Pr3: Doesn't involve young people directly
	Recruitment and selection of staff	No comments made	Pr3: Young people not on recruitment panels
	Supervision and appraisal of staff	Pr1: Doctors required to receive feedback from parents or carers and young people Pr3: Done for service as a whole	Pr1: Not across staff team (ie. Doctors and some nurses only) Pr3: Not done for individual members of staff
Running the service well	Commissioning of services	No comments made	Pr1: Still trying to get something established
	Influencing of senior managers	No comments made	Pr1: Much more difficult to involve senior managers than frontline staff
	A mission statement	No comments made	No comments made

The findings appear to indicate that engagement around the 'Feeling good' and 'Doing the Job Right' areas of the participation priorities appear to be better developed than the 'Running the service well' area. Pr1 made reference to a module of training developed with young people, as well as the fact that doctors were required to receive feedback from parents or carers and young people as part of their appraisal. Pr1 also made concessions as to the format this feedback was given, to make this more interesting for the young people. Pr3 felt that whilst regular monitoring was incorporated into their service, they felt that this should be more collaborative and integrated into the therapy. Another example of promoting engagement and participation within the system was the development of a training module with young people (Pr1). One particular area of interest is the engagement strategies employed by adult mental health service providers, highlighted by Pr4. Pr4 indicates that an accessible service user forum have become "an established part of"

their work. Pr4 also indicates that the provider they represent utilises a steering group - a group of people who the providers can go to when “developing a project, or reviewing a service”.

There were examples of engagement outside Haringey that were highlighted in two of the focus groups. The first example was the use of parents/carers and young people on staff recruitment panels. This was seen as a very positive experience by people who were involved (Pa3, YP8, YP11). However, one person who had not undertaken such an activity, when asked about potential involvement in staff appraisals and reviews, stated that this activity would be useful if people were ready, but they “don't think it will happen while they are being treated or have serious problems of their own before trying to fix others” (YP2). YP2 was involved in a Young Inspectors project looking at CAMHS services in Dorset.

This self-assessment very usefully identifies areas for improvement and there is a willingness to address these issues amongst the providers. Some will be more easily tackled than others and perhaps an early priority could be a more child friendly complaints procedure which could potentially be developed jointly. There was complete agreement from the providers that they would benefit from a Haringey wide young peoples’ forum or council to widen their pool of young people to consult with; Haringey seemed to be less well served than other London boroughs in this respect and this was a disadvantage.

Parents survey

> "Every child and every situation is different – parents understand their own child best, but do not always know how to help them, so rely on services for this."
> "Opportunities for parents and young people to meet informally – regular meet-ups in different locations across Haringey."
> "Parents should be involved in strategic planning, all services should have guidelines for how they will place children at the heart of what they do. This should be across different agencies, not just CAMHS (schools, police, GPs)."

59 parents/carers in total responded to the parents/carers survey. However, only 29 of these (49%) had current or previous experience of children's mental health services in Haringey. The majority (79%) had more than a year's worth of contact with Haringey CAMHS – and a quarter have more than 3 years' worth of contact (time since their child was first referred).

Overall, parents/carers feel that they have been more involved with their child's individual care, rather than with the running of the service more generally.

Parents/carers tended to agree that they had felt emotionally supported as a parent (52% agreed), that they were kept well-informed throughout their child's referral and assessment (52%), and that their views were taken into account during their child's initial assessment (68%). However, two thirds of parents/carers (64%) felt that they had not been proactively asked for any feedback on the service and 60% had not been asked for their views on the overall strategy or vision for the service. More than half (56%) had not seen any visible improvement as a result of any feedback they had given, whilst only 4% said they had. Of parents/carers who had actually given feedback, 82% said they had seen no improvement as a result. Overall, 52% of parents/carers agreed that the service includes and listens to the views of parents/carers.

Parents/carers said it was most important for them to be involved by being asked for their feedback, being asked for their views to help shape overall service priorities and strategy and seeing visible changes in response to their feedback.

Parents/carers' preferred options for getting more involved are attending regular meetings (77%), sitting on a board or decision-making panel (59%) and carrying out research and consultation work with other parents/carers (41%). Conversely, parents/carers' least frequently preferred options are sitting on interview panels for new staff (18%), acting as an ambassador for the service (18%) and being involved in staff appraisals (14%).

Interviews and focus groups

The results emerging from the interviews, focus groups and workshops can be divided into two main areas - engagement and barriers to engagement. The findings within these main areas then form the basis of the recommendations for future engagement, including seven underpinning principles of engagement and recommendations for improving engagement and participation from parents/carers and young people.

> "There's not a lot of engagement with young people." YP7

The engagement area includes all areas and forms of engagement, currently undertaken or aspirational, whether viewed positively or negatively, highlighted by participants in the interviews and focus groups.

Forms of engagement

> "Everything we're doing is through technology. Try and get into technology more, and social media…it's a difficult thing to do but once you manage to get started, it will really get you somewhere." YP8

One of the most prevalent forms of engagement in CAMHS was the use of surveys and questionnaires, both to ask users how they felt their treatment was, and to seek feedback for how the service was running. However, feedback for this method of engagement was generally negative- YP10 stated that they did not feel they were very useful, whilst Pa3 felt that the questions were too generic. Another problem with this method of engagement was the perceived lack of action from the service providers upon receiving responses (Pa3, YP7). There were some positive comments about this format - YP15 felt that feedback surveys could potentially be helpful, although they couldn't specify when this would be the case.

All of the various types of engagement should be considered in the various forms of engagement - that is, if the form of engagement is not suitable, many people will not get involved. Digital forms were seen in a very favourable light, with a range of formats within digital forms suggested. These included the use of app's, specifically to log complaints anonymously (YP5), the use of social media to promote activities and events and engaging discussion (YP7, YP8), the forming of online groups (Pa1, Pa2) and interactive e-mail contact between providers and users (YP15). Less prominent was the promotion of face-to-face groups (YP8, YP10), whilst surveys were not generally considered engaging, although there may be use for them if utilised appropriately.

Staff recruitment and staff training

> "I think they should get more feedback from young people that are in the services, and people involved in staff training more…it would improve the young people involved and it would improve the staff that's being trained experience as a whole." YP6

Involvement in staff recruitment panels was seen as a positive experience by individuals who had previously engaged with it (Pa3, YP7, YP8, and YP11) although others were less enthusiastic about the method of engagement. YP6 felt that whilst it would be "great" for young people to be involved in staff recruitment, it would not be particularly detrimental if they were not. Similarly, two individuals mentioned the advantages of involvement with staff training (YP6, YP10), whilst YP5 mentioned such projects did occur but that people did not consider the results of such engagement appropriately. YP2 stated that this activity would be useful if people were ready, but they "don't think it will happen while they are being treated or have serious problems of their own before trying to fix others".

Youth empowerment group

> "Empowering things that are already established and giving them the true authority of power." Pr2

The most passionately discussed component of the aspired level of engagement amongst provider representatives was the concept of formation of a youth empowerment team. The youth empowerment team would consist of young people across Haringey, not just service users. One of the principles behind the formation of such a team, according to Pr1, would be to avoid the "flock of seagulls" effect, which

involves CAMHS, social services, education and others “diving in”. This would be done by putting the “young people in charge” and using their views and “guidance and support” to help with engagement strategies. Pr1 also suggested that “you don’t just want to focus on their mental health experiences”, as this may be dependent on external factors such as bullying at school. Furthermore, the formation of a youth empowerment group was seen as combatting the “real danger of expecting people” to fall within the CAMHS framework.

Pr2 pointed out those similar concepts are already run in other boroughs, utilising people from youth parliament who had some experience with mental health, “empowering things that are already established and giving them the true authority of power”. Pr2 also asks how youth were involved in the commissioning of the current project, expressing the view that an active youth empowerment group could be driving the project if one existed. Pr4 believes this issue is related to the lack of joined up youth organisations, and that this means that the concept of a youth empowerment team has to be considered due to this lack of youth organisations in the borough. Pr4 also believed this team could “call out to young people on any issue”, highlighting another borough in which they could utilise the youth organisations there to call upon if a similar project was undertaken there. Pr1 reiterated the belief that this should not solely be about CAMHS and mental health if aiming for a “really authentic sense of representation”.

Senior managers

> **“**They need to come to the community. Stop hiding in offices. How are people going to find you if you’re hiding in offices? Take a walk, ten of you lot, just walk down the high road, you’ll see it!” YP16 (Non-user)

Influencing senior managers was also considered critical to engagement (Pa1) in relation to formal and established links between users and the CAMHS board. It is important here to note that a substantial number of suggestions regarding provider and non-user engagement were made in the MAC UK focus group, who had no access to CAMHS and therefore had a different understanding of engagement. Engagement from senior managers with non-users was considered an essential aspect of provider and non-user engagement, and that without senior managers interacting with local communities, they would not know the realities of the issues local communities are dealing with (YP16, YP17).

Schools

> "I think there is a willingness to work more closely with schools in some cases, to avoid clashing and a lack of communication in the progression of someone's treatment." YP2

Engagement with schools was seen as central by both users and non-users alike- potentially the most recurring theme from all of the data was the suggestion that schools need to be engaged more (E-Pa4, YP2, YP7, YP16, and YP19).

Suggestions made as to what this engagement could consist of included training staff in basic counselling, service providers giving talks on mental health and providing information about statutory and non-statutory mental health services in the community. Pr1 felt there was a "huge number of people out there who won't go anywhere near a mental health service" and stated that they were interested in engaging young people that do not go to CAMHS. This could be done through the involvement of schools, to promote a dialogue with young people.

Peer groups

> "It would be good to me if there was a regular place to meet them [other parents]…so having peer groups, places to meet people, I'd find it really useful to regularly meet with parents just to navigate my way through all of this." Pa2

Users/parents engaging with other users/parents was seen as useful for engagement by both parents/carers (Pa1, Pa2) and young people (YP7). Parents/carers believed that peer groups that met up would be helpful to them, although Pa1 warned that these had a habit of dropping off due to other commitments. Both Pa1 and Pa2 also stated that whilst they were interested in this type of group, they did not have the time or the energy to start or maintain them themselves. YP7 believed talking to someone also going through their own mental health problems "can reduce a lot of your embarrassment".

Non-service based activities

> "They have to do more stuff to stimulate the brain, like say sports…stuff to wake them up." YP17 (Non-user)

Pr2 said that the nine CYP IAPT participation priorities do not consider young people who do not go to CAMHS nor represent anything that engages people "as an offshoot or side shoot to any treatment or work". Examples of engagement outside the mental health service include "groups where young people can hang-out and at the same time be part of something, feedback groups, events, digital design groups, activities, jobs to young people and parents" (Pr2). Pr1 similarly reported more casual instances of engagement outside the mental health system, such as integrating football with well-being - "people want to come together to play football", but "you can introduce, develop and explore" a link between football and well-being.

Young people also expressed largely positive sentiments towards the current engagement occurring outside the mental health services. YP8 said that group engagement outside of the service such as PizzaNChat "are quite good because you have more people listening and you can get updates". YP8 also added that the nature of group work makes it less intimidating, whilst YP10 felt that groups such as PizzaNChat were "definitely helpful". There was also a desire for such groups to be held outside the service provider venues, with YP8 suggesting that "maybe considering having them somewhere else like a library".

The non-user group also suggested several ways that they could be engaged prior to accessing CAMHS, potentially reducing the need for it, including family involvement (YP18), leisure activities (YP18) and a generic statement on early intervention (YP19).

Miscellaneous

> "You walk through Tottenham, you won't see one flyer about mental health, you won't see no poster or none of them big billboards about mental health, so how are people going to know about it?" YP16 (Non-user)

YP15 also highlighted the use of a whiteboard, allowing service users to express their thoughts and suggestions. There were two examples of engagement outside Haringey that were highlighted in two of the focus groups. YP2 was involved in a

Young Inspectors project looking at CAMHS services in Dorset. Another proposal for provider and user research was utilising of users or parents/carers of users as ambassadors for CAMHS (Pa2), but this would only be effective if there was a very positive view of the service (Pa1). Advertising and publicising mental health was also seen as important in promoting engagement and participation, particularly as non-users were not aware of these issues (YP16, Y19).

Barriers to engagement

> "too prescriptive around what the service is after as opposed to what the young people are after…constantly needing to almost validate what we're doing ourselves" Pr1

Identifying the barriers to engagement are essential to understanding the best way to deliver any engagement process. The barriers highlighted were substantial and action must be taken to overcome them in order to make engagement work meaningful.

System barriers

> "From the beginning I felt there was a flaw in the system. By the time I was called for an appointment I'd forgotten I was referred." YP7
> "I think I found it quite confusing. When I first got referred it was all so complicated, and no one explained to me what was going on." YP3
> "Transition to adult services shouldn't be imposed upon people at 18. Should be a thought out plan of gradually introducing that change over time." YP2

Barriers within the system proved the most numerous and often quite complex feedback. The first barrier to engagement and participation that individuals may find initially is the issue of **accessibility**. Interesting findings related to this barrier emerge from all categories of participants (E-Pa3, YP17, Pa1, Pa2, Pr3), who believed waiting lists were too long. Pr3 believed some of the individuals on waiting lists wished to engage but these long waiting times immediately prevented them from doing so.

Once individuals were within the system, another barrier arose - the **complexity of the system** posed significant barriers to engagement for parents/carers and young people (Pa2, YP3, YP6, YP15), with a lack of information and inaccessible language about the process contributing to confusion about CAMHS. Some of the issues around the system highlighted by non-users were related to the perceived status of CAMHS as "too involved" (YP17), powerful (YP16, YP19, Pa1) and unrelatable (YP18, Pa1). The culture of the system also contributed to the barriers as far as providers were concerned, often perceived as "too prescriptive" whilst the staff felt it was their primary duty to be there for "the sake of the young person rather than for the sake of the service" (Pr1).

However, ultimately, one of the biggest problems with engagement and participation work was the **lack of awareness** of engagement and participation opportunities that was happening (YP7, YP8, YP10, YP11), whether this was engagement outside the service or within the service. The final, but very significant system related barrier was the transition from CAMHS to adult mental health services, which was often perceived as very sudden and forced with a big culture change (YP1, YP2, YP5, YP7). This is problematic as it means that many people who have experience within the CAMHS system are no longer able to contribute their views as to how to improve the services.

Wider context barriers

> "You've talked about this herd of elephants and the elephant is budgets… all the engagement in the world will not replace the need to have longer sessions nearby more frequently with someone who's got more time and is more relaxed." Pa1
>
> "I don't think they are trained enough to deal with young people who are suffering, all my school teacher did was give me a leaflet." YP7
>
> "The issues that they have are being clowned by the people around them so they can't come forwards, they're forced to keep it to themselves." YP19 (Non-User)

Barriers related to numerous aspects of the wider context were highlighted numerous times by providers, parents/carers and young people. The most frequently recurring issue highlighted was related to the **financial landscape** of Haringey (Pa1, Pa2, Pr3, YP7), with some participants believing this to be the ultimate issue with any mental health related work. Some participants were sceptical of the concept of engagement and participation work itself as "trying to do more for less" (Pa2). Some

participants also believed another barrier to engagement was the **cultural background of Haringey** (Pr2, YP5, YP17), noting the mental health system was based on a "very reductionist, westernised model of distress" (Pr2), and "the majority of NHS people be white people" (YP17). There were also **social issues** identified as barriers, either because they were not perceived to be understood by providers despite their deep understanding of mental health (YP5), or social issues that made discussing mental health problematic (YP19). The final barrier identified as one related to wider context was the **training of non-mental health professionals**, such as teachers, in Haringey (E-Pa4, YP7, and YP19).

Personal barriers

> "The actual barrier is the illness." YP7
> "If you're looking after a kid with all these problems, 80% of your emotional energy is taken up with the whole thing, and you have to limit and choose your battles very carefully." Pa1
> **"**The timing of the groups needs to be looked at as well, I've never been able to make it to the parents group meeting here because it's always the morning after this group, so I've got to take the afternoon off work." Pa3

The theme of personal barriers affected providers, parents/carers and young people alike in a range of ways. Issues around time and personal circumstance were recurring, with the time pressures of working life (Pr2, Pa1, and Pa3) and the timing of engagement based activity posing a challenge (YP12). **Personal circumstances** also provide a significant barrier to both parents, who find their energy consumed by caring (Pa1) and the young people suffering from mental health issues (YP7). YP2 stated that they did not think that engagement such as young people on recruitment panels or helping with staff appraisals "while they are being treated or have serious problems of their own". One young person even identified that these personal barriers are not only affecting them but staff members, who do not take on board the results of engagement work as they are "busy coping with stuff" (YP5).

Belief based barriers - harboured by the participants or other members of the community about the mental health services or mental health - also emerged. Amongst both parents and users, mental health issues were perceived as not accepted (Pa1, YP8), with people generally finding it very difficult to understand.

Other participants viewed mental health as a threat to others, where you do not know what to expect (YP16, YP17) whereas one told us that they'd been previously asked if they sit in a corner at home and cry (YP7).

What is extremely interesting is the fact that the non-users from the North and East of the borough highlighted different stigmas than CAMHS users from elsewhere - whilst mental health was perceived by the non-users as potentially threatening and unpredictably aggressive, the CAMHS user believed the stigma about them was as an isolated individual who cries in a corner of their house. Non-users from the North and East of the borough indicated their own beliefs about mental health services that would be problematic to engagement. YP18 stated that they would not refer anyone to mental health services as they do not believe in putting people on drugs, whereas YP17 believed the NHS should be more supportive instead of trying to section people instantly. Some of these ideas were based on previous experience of family members- YP19 had a relative who was sectioned, which was "everyone's fear".

Recommendations:
Relationships, principles and actions

Based on the initial findings, as well as our own experiences from conducting the project, a set of recommendations for improving future engagement were developed.

There are three components to these recommendations:

1. **Seven Principles**
2. **Framework of Relationships**
3. **Key Actions**

We have identified seven principles that should underpin engagement and participation work and will maximise its effectiveness. The relationship component consists of a series of complex relationships between service providers and four major constituencies. The actions provide a realistic basis for engagement activities based on what we believe parents/carers and young people would like from engagement work and overcome some of the barriers to engagement highlighted by participants.

Principles

The results highlighted the need not only for targeted recommendations of ways to improve engagement, but also the importance of underlying principles of all such engagement. These are important concepts to keep in mind while planning, undertaking and reviewing all engagement activities.

There were seven principles that emerged from the data, which must be considered just as essential to engagement as the processes themselves. These seven principles are:

1. Inform
2. Free choice
3. Flexibility
4. Confidentiality
5. Build confidence
6. Reward
7. Feedback

Inform

> "I think just more awareness of what's actually available…you won't really know unless you actually go and search properly and find places." YP7

Young people and parents/carers should always be made fully aware of what engagement activities are available as well as what to expect in those engagement activities. Some young people reported knowing that others were not engaging in activities as they were unaware of them. This information can be communicated in a variety of ways, such as through posters, leaflets, newsletters, e-mails or even word of mouth.

Free choice

> "Make it less of a compulsory thing…don't know how you should word it but just make it clear it's not something you have to do." YP8

Young people should be made aware that they are free to engage or not engage with the system. Some participants highlighted that this was very important as individuals may see engagement as an obstacle to dealing with their own issues, especially those early in the CAMHS treatment process. Indeed, pressurising individuals to become engaged may be counter-productive, especially where they perceive themselves to be on the lower rungs of the participation ladder.

Flexibility

> "I do feel as if the problems I have in my experience are probably quite specific to the situation." YP15

One of the most important lessons learned from this research was that engagement must be tailored around individuals. This became evident when attempting to organise workshops - some individuals were not available except at specific times whilst others were not comfortable contributing in groups. Consequently, various avenues of engagement were utilised - individual face to face interviews, focus groups, online based focus groups and online based interviews were all conducted to gather the required feedback. Often the questions posed within each of these also differed - whilst some tasks and questions were appropriate for focus groups as they facilitated discussion, they were not appropriate for the focussed nature of an

interview. This level of flexibility is required for any engagement with parents/carers and young people - timing, nature of delivery and focus must all be considered for engagement to be inclusive and flexible yet thorough.

Confidentiality

> "Every time I've been given a survey, it's been upstairs in one of the services, the office is quite small, so it's quite personal and when they hand you one of those forms you feel quite shy to give it back…even if they just glanced down a second by accident they'll see exactly what you've said." YP8

Whilst it is clear that confidentiality is an important aspect of the care patients receive, it should also be clear that some individuals feel they are able to engage more where confidentiality is expected. Individuals may inhibit their responses more if they feel that they may be offending members of staff when feeding back on a service, especially when the responses to requests for feedback go directly to any staff members involved. Services should respect and understand the potential value of confidential feedback through all formats of engagement.

Confidence building

> "Everything is confusing and I'm too scared to approach the service with my questions." YP3

Confidence building is a principle of great importance for numerous reasons, providing the basis for honest feedback and suggestions for improvement both from young people and parents. Some parents expressed a lack of confidence in approaching senior managers with their opinions, and the daunting nature of the challenge, potentially leading to a culture of divide between professionals and non-professionals. It is essential that all people attempting to engage with the services are confident enough to contribute in their own way, whether in a capacity as representatives of service users collaborating with service providers or as participants in focus groups with staff members looking to improve the service. Important elements of this principle include an appropriate build up to group activity for the first time and a positive feedback culture, encourage by staff of all roles within CAMHS.

Reward

> "Situations where there's an incentive…If you just tell someone to come for an hour to sit in a room and talk about something, you wouldn't really want to do that." YP12

Young people and parents also have lives outside of the service and would like to feel the rewards of engagement. It is important that young people feel their contributions are valued through compensation for their time or rewards for contributions. These rewards do not have to be monetary or at financial cost to the service providers. For example, one young person mentioned the use of participation on interview panels helping ease the anxiety of their own interviews, whilst a parent similarly believed they were rewarding as they gave an insight into the culture of the providers.

Feedback

> "I don't know how far they go to actually analyse these surveys because I know I've done loads and…I've never seen the feedback from my surveys" YP7

It is extremely important that the outcomes of any engagement work are shared with everyone involved. This helps to avoid participants feeling that their involvement is merely at the token, decoration or manipulation rungs of the ladder of participation, all of which are counter-productive and may see swift drop-out rates for future engagement. Feedback may also be strongly related to the fifth principle, Reward, as young people will see the fruits of their engagement. It may also see more engagement as a result, as participants are happy that their contributions are acknowledged and valued.

Relationships

The results indicated that engagement work would be required to involve a complex framework of relationships between the service providers and four other groups. It is extremely important that senior managers are involved in establishing these relationships as well as having an input to them. This includes relationships service providers are directly responsible for (1 and 2 below) and two other others:

1. CAMHS Service users.
2. Parents/carers of service users.
3. Young people's groups: specific focus on a young people's representative group.
4. Non-users accessible through schools and community based engagement.

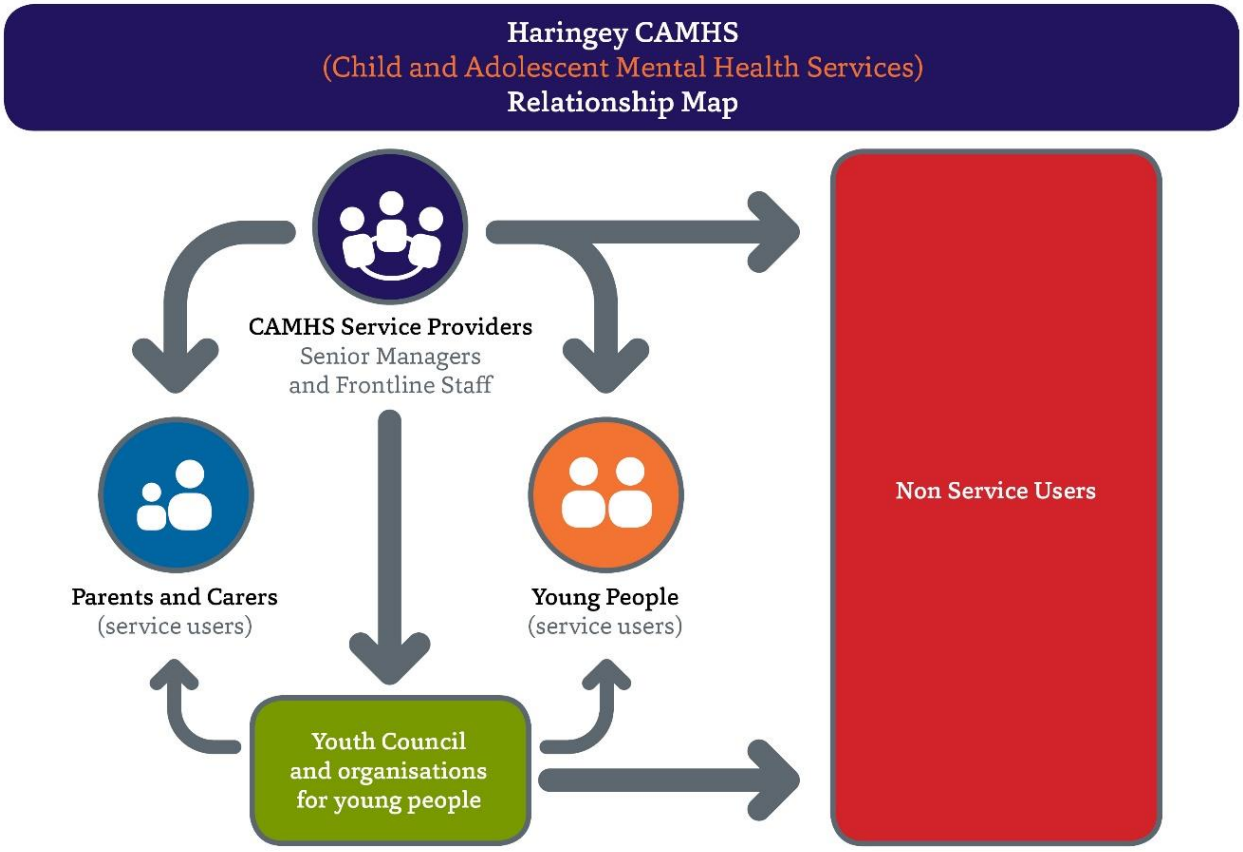
It is anticipated that as engagement improves and people participate more, relationships between these four groups might also be established.

The provider's relationships with these four groups may be as follows:

- The providers will want to establish an ongoing relationship with as many CAMHS users as possible, exploring numerous avenues for engagement as well as establishing the needs of the users. This relationship may utilise formal engagement methods, such as establishing user panels, attending meetings, and formalising user involvement in staff training and staff recruitment, and informal methods, such as outside service groups, group chats and support groups.
- Similar to the relationship between Providers and Service Users, providers should seek to establish an ongoing relationship with parents/carers of service users, addressing their needs and concerns where appropriate. However, it is important to note that the issue of patient confidentiality did arise as a barrier for parents, and it is difficult to know how this barrier may be completely overcome. However, opportunities for parents to be involved in both their child's experiences of the service as well as being involved in parent support groups and contributing to management of the CAMHS service will go some way to meeting their needs for involvement.
- Young people's groups: The providers may seek a reciprocal relationship with a young people's representative group, such as the Haringey Youth Council when it is established, based on mutually beneficial relationship of informing, supporting, advertising and publicising each other's work and functions and using this to get as many people involved with both organisations as possible.

This relationship will highlight what is important to young people as well as allowing for a wide reach of non-users, and promoting events and issues highlighted by CAMHS providers.

- Those not using CAMHS services may be accessed through many avenues, potentially the most important of which is schools. However, establishing links with the young people's groups, particularly the young people's representative group, may allow for a wider range of young people to be reached. Providers may publicise the CAMHS services at events, and organise talks and activities outside the service for professionals and young people.



Actions

There were several aspects of engagement that emerged from the research that should be considered as actions of particular importance. These are the most salient themes that emerged from the initial findings of the research and could have a significant role in meeting the engagement aspirations as well as overcoming some of the barriers to engagement.

Improve accessibility to services

One of the biggest barriers to engagement is the lack of easy access to psychological services. The results indicated that this barrier not only stops people from getting into the service and therefore participating and engaging in activities, but also makes people sceptical of engagement as a way of attempting to do more for less. For engagement activities to truly have a significant impact on the way services are run, access to psychological services must be improved. Areas that were highlighted by participants include a clearly communicated and effective referral system from schools to CAMHS, increasing the capacity of therapists with manageable workloads and reducing waiting lists.

The barriers to engagement that improving accessibility to services may help overcome include:

- System (Accessibility): By improving accessibility, this system barrier will be overcome, allowing users to engage earlier.
- Personal (Beliefs about mental health services): Scepticism amongst parents appears to be particularly high, with them believing that the focus should be on appropriate clinical treatment with engagement work as secondary. Improving accessibility may change people's perceptions about mental health services.
- Personal (Time): Improving capacity will increase the time available for staff to promote in engagement activity through reduced workloads.

Collaborate with Young People's Groups

Arguably the most important action to consider is supporting and working with a youth group that is a representative group for all young people across Haringey, highlighting their issues and representing what is important to them. This could be mutually beneficial, with both parties supporting each other and promoting one another's work, as well as informing one another about the activities and events they are organising and promoting them accordingly. Furthermore, it could allow for a wider range of non-service users to be accessed, especially in under-represented communities.

The Haringey Youth Council is currently being established and Jean-Pierre Moore, youth engagement co-ordinator for Haringey Council, has explained that:

> "The Haringey Youth Council is a body that represents youth voice in the decision making processes for the borough of Haringey. It is made up of over 20 young people aged between 11-19 with the intention to seek representatives from every youth club, youth group and secondary school in Haringey. The focus of the Council is to empower young people to influence decisions taken on their behalf and to promote engagement from the wider community on their identified 5 key priorities. Health sits high on this priority list with its own action group and Health champion to be elected from the represented Youth Councillors. This Action Group will campaign and work on projects developing a strong partnership relationship between services such as CAHMS and the Whittington to help provide a young people's perspective on services and to help quality assure services. These organisations have expressed an interest in including young people in how they shape their Health services and policies by using the Haringey Youth Council as a method for inclusion and co-production."

Working with the Haringey Youth Council also goes some way to mitigating the effects of barriers related to the wider context of Haringey and beliefs about mental health. The barriers to engagement that working with the Haringey Youth Council may help to overcome include:

- System (Awareness): Awareness of the mental health services and what they do may be improved through the Youth Council promoting the work of the mental health system and being able to inform people about the process.
- Personal (Stigma): The youth council informing young people about mental health issues and making discussion about it more mainstream and acceptable may be an effective way of combatting stigma.
- Personal (Beliefs about the mental health system): By using the youth council to promote engagement, beliefs about the distant nature of the mental health system may be addressed.

Parent and Carer Engagement

There is a demand from parents / carers to be more involved in the provision of the service. The parents/carers survey indicated that parents/carers are most interested in attending regular meetings, sitting on a board or decision-making panel and carrying out research and consultation work with other parents/carers. There is a demand for parent support groups and this should be an early priority.

There was a feeling that engagement was relatively good at the referral and assessment stage but not once the delivery of the service had started. This possibly reflects a view expressed by some parents that they felt excluded from the relationship with the doctor/therapist and this was a tension caused by the issue of patient confidentiality, which they often did not feel suitably prepared for.

The barriers to engagement that parent and carer engagement may help overcome include:

- System (Awareness): Awareness of the mental health services and what they do will help an understanding of the process and reduce anxiety
- Personal (Beliefs about mental health services): Scepticism amongst parents appears to be particularly high about the benefits of engagement.
- Wider Context (social and cultural issues): will aid understanding through shared experiences

Utilise digital and face-to-face engagement forms

People were far more positive about digital engagement and face to face engagement than they were about surveys. All engagement work should be considered in the form of at least these two major formats. Developing a range of methods within these two major groups - such as face-to-face focus groups or moderated online chat rooms - to engage is informed by the seven principles of engagement, especially flexibility. Utilising a variety of methods also increases the chance of individuals engaging at the level that they wish to engage. The use of digital engagement in particular allows an opportunity to overcome some of the personal barriers, such as time related constraints by minimising travel time or even allowing engagement to be organised when appropriate (such as via e-mail correspondence).

The barriers to engagement that digital and face-to-face forms of engagement may help overcome include:

- Personal (Circumstance): Utilising a variety of engagement forms, with special focus on digital forms of engagement, may allow for people with particular

circumstances to engage where they would otherwise find it difficult to do so. Those lacking confidence to engage in face to face group discussions may be happy to be involved in a moderated chat room.

Engage with schools

The importance of school based engagement was highlighted by service users, non-users, parents/carers and providers, with many young people highlighting the fact that they did not know what mental health was until they entered the CAMHS system. Engagement with schools could not only be used to overcome barriers such as stigma and issues related to awareness for non-mental health professionals, but to promote knowledge and understanding of mental health and potentially allow for early intervention. School based engagement may involve talks about mental health and what to do if you think you need to talk to someone , some basic information about the CAMHS process and system, and basic staff training and drop in sessions.

The barriers to engagement that school based engagement may help overcome include:

- Personal (Stigma): Utilising schools as a method of communication allows for discussions about mental health to occur in a familiar, safe and comfortable environment.
- Wider context (Professional): Training teachers and frontline staff in handling mental health issues, specifically what to do when you suspect mental health problems, allows for professionals, parents and young people to be more comfortable reporting issues.
- Personal (Beliefs about mental health services): Engaging with schools through giving talks and holding events allows for people to understand more about both mental health and the work of mental health services.

Senior manager engagement

It is important to understand that people felt strongly about senior managers engaging with people directly, which can be done in a number of different ways. One suggestion was direct access for parents/carers - which could be accounted for via parents/carers and service users attending board meetings, or being used as a sounding board for service changes. Methods that have been utilised in other boroughs should be considered here also, such as the concept of young inspectors, parents/carers and service users being involved with staff recruitment panels and staff training. With non-users, senior managers could be involved in community events and attend as well as establish links with community organisations and schools.

The barriers to engagement that senior manager engagement may help overcome include:

- System (Perceived status): Senior managers engaging with service users and non-users may reduce the perceived status of CAMHS as being detached from the community or overly powerful.
- Wider context (Cultural, Social): Senior manager engagement may prompt a better understanding of the local circumstances and demographics and allow them to respond to the needs of Haringey appropriately.

Collaboration between providers

To maximise the potential for engagement and participation and utilise it to its full potential, CAMHS providers could consider collaborating more with one another. Such collaboration could be used to increase engagement with non-users, through a collaborative effort of working with community based organisations and schools as well as advertising and canvassing in areas of particular interest. Providers could support one another's work by sharing data collected about engagement, such as what methods are viewed most favourably. Furthermore, providers could provide each other information about establishing formal engagement methods, for example, staff recruitment panels and service user panels, to maximum effect.

Commissioners could consider encouraging more collaboration through commissioning some engagement work jointly, perhaps with a lead provider in each case.

The barriers to engagement that provider collaboration may help overcome include:

- System (Awareness): Provider collaboration involving data sharing and collaborative research may result in a wider awareness of activities organised by providers across the borough and with a range of organisations.
- Wider context (Financial): Reciprocally communicating effective and efficient ways of promoting engagement could reduce duplication and reduce costs.

Monitoring And Evaluation Toolkit

The monitoring and evaluation toolkit seeks to inform service providers about the level of participation and engagement with young people. There are three aspects of engagement that need to be monitored, and the monitoring and evaluation toolkit considers each of these. The three aspects are the nature of the engagement activity, the participant's feedback from the activities and the demographic background of the participants in the engagement activity. The toolkit is based both on the recommendations and principles that arose from the research. It is intended to allow for both quantitative data and qualitative data to be collected and analysed.

The components are as follows:

1. **Activity log**
    - To log every instance of engagement activity.
    - To be completed by the person responsible for the engagement activity.

The first component of the toolkit is a brief set of questions that look at how the engagement activity was conducted and the number of participants involved. This is to be completed by the practitioner or responsible person for the engagement activity and is to be conducted for every instance of engagement. It has been designed to be as succinct as possible.

2. **Participant Feedback**
    - To collect feedback on engagement activity.
    - To be completed by the participants as and where appropriate.

The second part of the toolkit requires the individuals engaging to give feedback on the experience. There are two different versions of the participant feedback component- a version to be used for service users and parents/carers, and a version to be used by non-users. It is important to note that participants of the study generally expressed negative or indifferent sentiments towards questionnaires and surveys. The feedback part of the survey has therefore been designed to be brief but also to encapsulate as much qualitative data on engagement activity as possible, whilst simultaneously capturing some quantitative data. This is not intended to be completed for every instance of engagement, but to be used according to the instance of engagement- for example, weekly informal groups do not require feedback forms to be completed on a weekly basis, as this may be seen as tedious or merely tokenistic by the people involved.

3. **Demographic data**
    - To collect demographic data on all participants.
    - To be completed by participants wherever possible.

One of the most important steps to monitoring participation and engagement is the collection of demographic data. For each participation and engagement activity or event, important demographic data must be collected to ensure fair representation. The most important demographic data to collect is related to the ethnicity of participants and the postcode area and district of participants place of residence. This will allow for the participation and engagement of underrepresented groups- people from the North and East of the borough and Black British and Black African communities- to be monitored. Such data should be collected at all engagement and participation events where possible.

All of the data collected from the three components of the toolkit should be input into a database consisting of quantitative and qualitative spreadsheets. The quantitative data can then be analysed statistically, whilst the qualitative data can be analysed for emerging themes. These results can then be fed back to participants where required.

There are also some notes that must be made regarding the toolkit:

- The toolkit should be flexible to amendment following feedback.
- The toolkit should be administered in different ways where possible- digital engagement activities should be accounted for through e-mail administration of the toolkit.

Activity log

Activity:
Date:
Location (including postcode):
Estimated number of participants engaged:

1. **What type of engagement activity was conducted?**

2. **What format of engagement activity was conducted?**

- Digital
- Face-to-face
- Survey/Questionnaire
- Other……

3. **Was the activity formal or informal?**

- Formal
- Informal

4. **Who was the activity aimed at (indicate all applicable)?**

- Parents/Carers of Service Users
- Service Users
- Organisation/Group
- Non-Service Users
- Other

5. **Any additional comments?**

Participant feedback

We are looking for feedback on our activities to see what people think is important and what people want. Please complete this form as honestly as possible.
Please indicate below to what extent you agree or disagree with each statement.

Statement	**Strongly Disagree**	**Disagree**	**Neither Agree nor Disagree**	**Agree**	**Strongly Agree**
I knew what to expect from the activity.					
I was aware that taking part in the activity was not compulsory.					
The activity was suitable for my personal needs (timing, format).					
My responses are confidential.					
I felt confident taking part in the activity.					
I felt the activity was rewarding.					
I feel like there will be outcomes to my feedback.					

Have you got any comments you would like to make about the activity? (How useful/enjoyable was it?)

Demographic data

1. **How old are you?**

2. **What is the first part of your postcode (whole postcode if unsure)?**

3. **Are you:**

- ☐ Male
- ☐ Female
- ☐ Transgendered
- ☐ Prefer not to say
- ☐ Other (please specify in the comment box

4. **How would you describe your sexual orientation?**

- ☐ Homosexual/Gay or Lesbian
- ☐ Heterosexual/Straight
- ☐ Bi-Sexual
- ☐ Prefer not to say
- ☐ Other (please specify in the comment box)
- ☐ None of the above

5. **How would you describe your ethnicity?**

White

- ☐ English/Welsh/Scottish/Northern Irish/British
- ☐ Irish
- ☐ Gypsy or Irish Traveller
- ☐ Any other white background

Mixed/multiple ethnic groups

- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other Mixed/multiple ethnic background

Asian or Asian British

- ☐ Indian
- ☐ Pakistani

- Bangladeshi
- Chinese
- Any other Asian background

Black/African/Caribbean/Black British

- African
- Caribbean
- Any other Black, African or Caribbean background

Other ethnic group

- Arab
- Any other ethnic group
- Prefer not to say

6. Do you consider yourself to be a disabled person or do you have a long-term health condition?

- Yes (please specify below)
- No
- Prefer not to say

Appendices

Appendix 1

Participants in each instance of engagement

Engagement method	Borough based	CAMHS user status	Participants
Parent/Carer Survey	Haringey	Parent/Carer of former or current CAMHS users.	59 respondents, of which 29 were eligible to respond.
Parent/Carer e-mail correspondence	Haringey	Parents/Carers of non-users	E-Pa1, E-Pa2, E-Pa3, E-Pa4
1 x face-to-face provider focus group	Haringey	Mental Health Service providers	Pr1, Pr2, Pr3, Pr4 (Adult provider)
1 x face-to-face parents focus group	Haringey	Parents/Carers of current	Pa1, Pa2
1 x online young people's focus group	Haringey & Non-Haringey	Current Former Non-users	YP1, YP2, YP3, YP4
3 x face-to-face young people's individual interviews	Haringey	2 current 1 former	YP5, YP6, YP7
1 x face-to-face participants focus group	Haringey & Non-Haringey	Current Parent/carer of current	YP8, YP9, YP10, YP11, YP12, YP13, YP14, Pa3
1 x online young people's individual interview	Haringey	Current	YP15
1 x face-to-face young people's focus group	Haringey	Non-users	YP16, YP17, YP18, YP19

Appendix 2

Master table of themes

Area	Theme	Examples
Engagement	Forms of engagement	Surveys, Questionnaires Face-to-face Digital
	Staff based	Staff training Staff recruitment
	Youth empowerment group	-
	Senior managers	Direct link to parents/carers Interaction with local communities
	Schools	Staff training Talks Information providing
	Peer groups	Parents/carers groups Young people's groups
	Non-service based activities	Groups Activities
	Miscellaneous	White board Young Inspectors project Advertising and publicising
Barriers to engagement	System	Accessibility Awareness Perceived status Complexity Prescriptive Transition (CAMHS to Adult)
	Regional Context	Cultural Social Professional Financial
	Personal	Stigma Beliefs about mental health services Time Circumstance

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