Young People's Advisory Group (YPAG): Our Mental Health Priority Setting in Northwest London Engagement Project

Findings Report

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We, as YPAG members, all contributed to the project and created this report together.

CONTENTS

1. Background and Introduction

In 2024, the Young People's Advisory Group (YPAG), a mental health network coordinated by Inclusion Barnet within the ARC Outreach Alliance (AOA) Mental Health research programme, began a new chapter in our journey. We carried out an engagement project to discover what young people feel are the important questions and priorities in mental health research in Northwest London (NWL), build an understanding of how access to mental health support differs amongst our diverse community and to improve their involvement in shaping research. Our overarching aim is to create sustainable infrastructure for young people's voices to be heard, considered and meaningfully involved in research.

Our approach

Eight of us took on paid roles as Project Leads and Assistants to achieve our goal, with support, training and guidance from the AOA team. To achieve this, we built alliances locally (e.g. with groups such as CNWL Youth Ambassadors) and recruited new young members from across the NWL region to join our work.

The project was collaborative and youth-led, and we were all involved in the areas of the project that matched our interests or skills we wanted to develop e.g. creating content and resources, data collection, data analysis and working with specialist software. We used a collaborative platform throughout to help us manage all of the project tasks and stay in regular contact via our WhatsApp group, drop ins and group meetings.

We decided the best way to achieve our goal was to create a survey by young people, for young people.

2. Methods

Survey design

We started by considering what we wanted to ask young people in one of our group workshops. We discussed what topics come up consistently in our conversations as a YPAG and with our peers in relation to mental health support, service provision and access. With input from the AOA team from a clinical and research perspective, we agreed on the following themes:

- Crisis care
- Attitudes towards self-diagnosis
- Role of education in mental health
- Prevention
- Support Systems

Next, we created ‘a long list’ of all the potential questions we wanted to ask in relation to the themes generated after the initial brainstorms and then voted on the questions we considered most important - aiming for 2-4 questions per theme. Through a shortlisting technique, we agreed on 22 questions for the final survey. We also agreed on some initial questions designed to capture young people’s age, ethnicity, borough and gender and a question seeking parental consent for under 16-year-olds.

When writing the questions, we worked together with the AOA team to think about how to make the questions as accessible as possible. For example, when asking about highly sensitive matters like crisis care, we thought the question should not be too direct, so we used “How challenging do you think it would be to get help if you or someone you know had a mental health crisis?”. We grouped the questions by theme (e.g. Support Systems) and ensured we defined the topic area before asking any questions.

As a group, we decided that the survey should be split into two sections. The first part would include a mixture of multiple-choice questions and questions where young people could rate their response on a scale e.g. 1-5, strongly disagree to strongly agree. The second part included open-ended questions where young people could express freely how they felt about the given topic. All of the themes mentioned above were covered in both parts. We decided on this structure to make it flexible - to allow young people to have options on how they wanted to answer. Our aim was to increase the completion rate - we thought respondents would be less likely to be overwhelmed with this approach, and therefore more likely to answer all the questions.

After further discussions and due to content length restrictions with the platform we used, we agreed to have two separate surveys with two different links for part 1 and part 2, with a link to part 2 at the end of part 1 of the survey.

We chose to use Qualtrics as the survey platform. Some of us had experience with using it for university projects, so it was a platform we were familiar with and were also aware that the AOA team had expertise to support us. The process of generating questions and survey design was incredibly streamlined, and it has some great features. For example, there were ‘breakout’ questions enabling us to group answers to one question with answers from another e.g. seeing how people rate professional communication according to how strongly they agreed with self-diagnosis.

Another consideration for us was whether or not to make the questions compulsory. Ultimately, we decided not to. This was because a big part of our approach was to create a space where there was no pressure to answer. It was important to us that in gathering the life experience of young people that their involvement was optional.

We also created an 'Easy Read' version (available upon request) for young people with learning disabilities. We formed a sub team to create this survey, and it was created following guidance from the Advocacy Project and Healthwatch England.

Additional content: putting young people first

We thought about what would make the survey attractive, relatable, and inclusive for our peers. We agreed we could do this by including a detailed introduction to who we were, why we were doing it and why it was important young people got involved.

We felt it was very important to clearly state in the introduction that responses would be anonymous and confidential and that data could be withdrawn at any point - we felt requesting people's information might have been stressful and we wanted to make people as comfortable as possible.

We also included a consent form in the introduction to be completed that required parental consent for young people under 16 which we built into the survey - we agreed that this should be the only mandatory section in the survey as consent was a priority for us. We were conscious that the questions we were asking were sensitive and the wellbeing of respondents was important to us. We therefore included links to mental health support services and our contact details at the end of the survey in case young people wanted to debrief on anything they found challenging in the survey in a supportive peer-to-peer format.

Ahead of data collection, we piloted our survey with a local Youth Ambassadors group to ensure the survey was inclusive and accessible. The AOA team also reviewed it to ensure there was agreement on all aspects of it.

Data collection

Our target group was young people aged 14-25 from across North West London. We created a contact list together, drawing on our own connections and relevant organisations in our own Boroughs that we are associated with or were familiar with. We also performed searches online

and asked in our communities what groups we could contact that we weren't aware of, to ensure we were reaching a diverse and representative sample of young people.

We used different forms of media to distribute the survey, including a flyer with a QR code and links attached to emails so that the approach was as accessible and convenient as possible. What was consistent though was providing information along with the survey, ensuring that anyone who wanted to respond was well informed.

Some examples of the groups we contacted included:

- Our school and educational networks
- West London NHS Trust CAMHS Youth Ambassadors
- Harrow Young Carers
- Hounslow Youth Council
- North Paddington Youth Club
- Hammersmith, Fulham, Ealing and Hounslow Mind
- Central and North West London (CNWL) Youth Ambassadors

We also met with groups to introduce the project and encourage participation, including the West London NHS Trust CAMHS Youth Ambassadors and the NIHR Imperial Biomedical Research Centre Community Researcher event.

Data analysis

Data analysis and reporting on both parts of the survey were carried out by a sub team within our group. It was their role to lead on providing a clear picture of the findings and to reflect on what we found. For part 1, we thought it was important to think about how the data could help us pinpoint certain groups of people that needed more support, e.g. by age, the borough they lived in or ethnicity. We agreed that highlighting improvements by demographic and categorising their responses to a particular theme from the survey would be the best way of doing this. You will see in the Results section how we approached this, but we have also reported the other key findings from the data.

For part 2 of the survey, we wanted to highlight the direct quotes from the young people in creative ways to identify and comment on themes that appeared so that we could make recommendations. We also used Microsoft Office to create groupings and themes in the form of percentages from the data.

We used the reporting function on Qualtrics, as well as Microsoft office features to analyse our data and used platforms like Canva to create our resources for reporting on Part 2.

3. Results

Response rate

- 236 young people started part 1 of the survey. We found a response rate of 37%, which is 87 young people completing the questions
- 84 young people started part 2 of the survey. We found a response rate of 28% which is 23 young people completing the questions

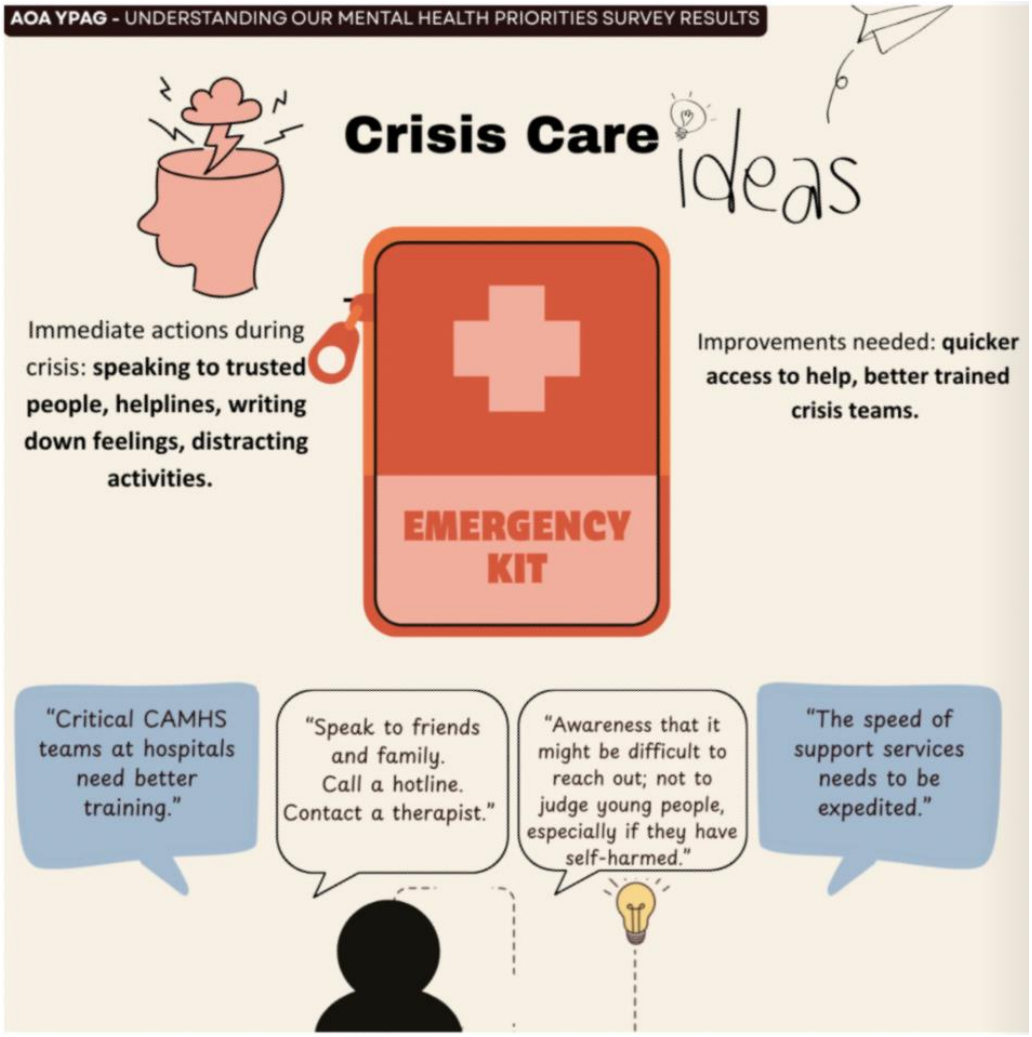
Characteristics of respondents

- Of the 106 who reported their gender, 45 were cisgender male, two were transgender male, 38 cisgender female, one transgender female, three were agender, eight chose not to answer and nine selected other.
- Of the 106 who reported their ethnicity, 28 were White, six were Black/African/Caribbean, 49 were Asian (Indian, Pakistani, Bangladeshi, Chines, any other Asian background), 11 were Mixed two or more ethnic groups, 3 chose not to say and nine were Other (Arab or any others).
- Of the 106 who completed this question, seven were 14 years old, six were 15 years old, 34 were 16 years old, 24 were 17 years old, seven were 18 years old, 11 were 19 years old, six were 20 years old, four were 21 years old, two were 22 years old, two were 23 years old and three were 24 years old.
- Of the 106 who reported their borough, 11 were from Brent, 24 from Harrow, 31 from Ealing, 6 from Hammersmith and Fulham, 18 from Hillingdon, three from Hounslow, seven from Kensington and Chelsea and six from Westminster.

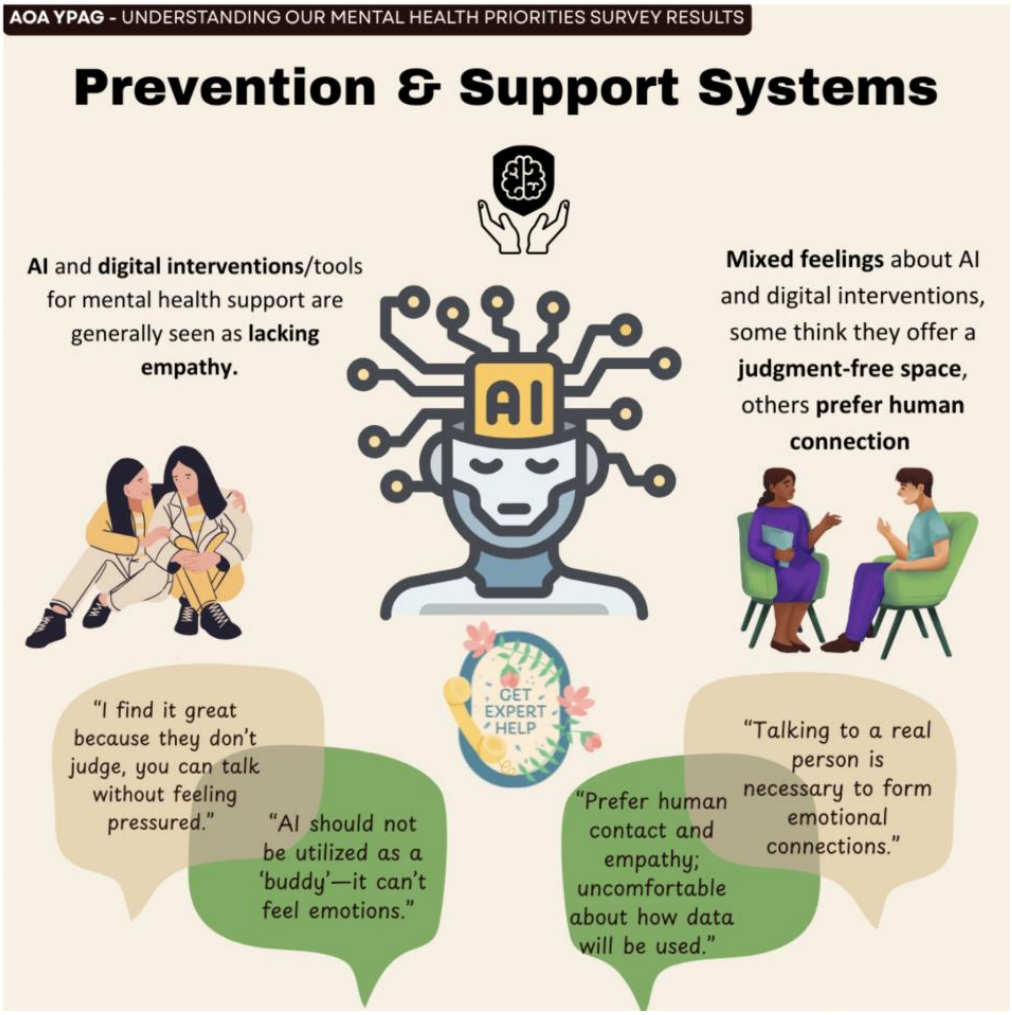
Overview of results

The graphics below summarise the analysis we did to highlight the results by theme across the two parts of the survey. This is supported by some direct quotes from Part 2 of the survey:

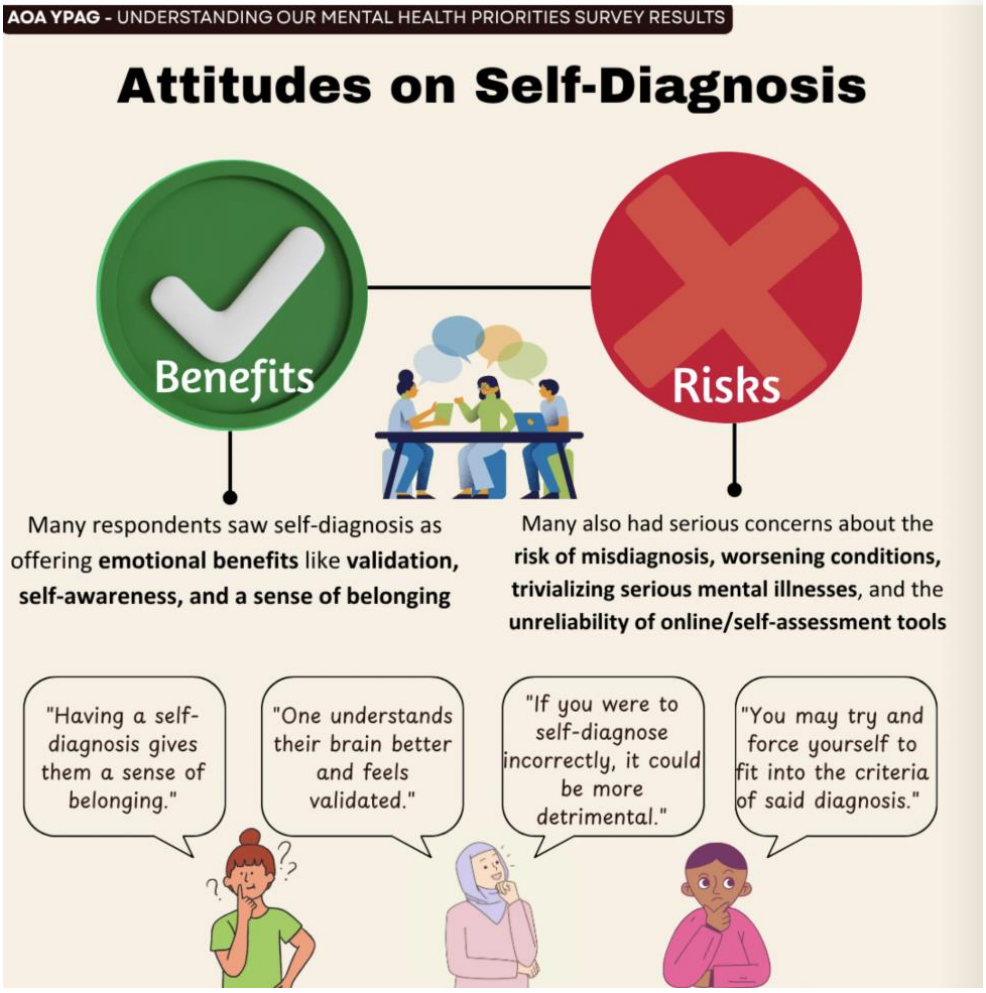
a: Quotes and key points on crisis care



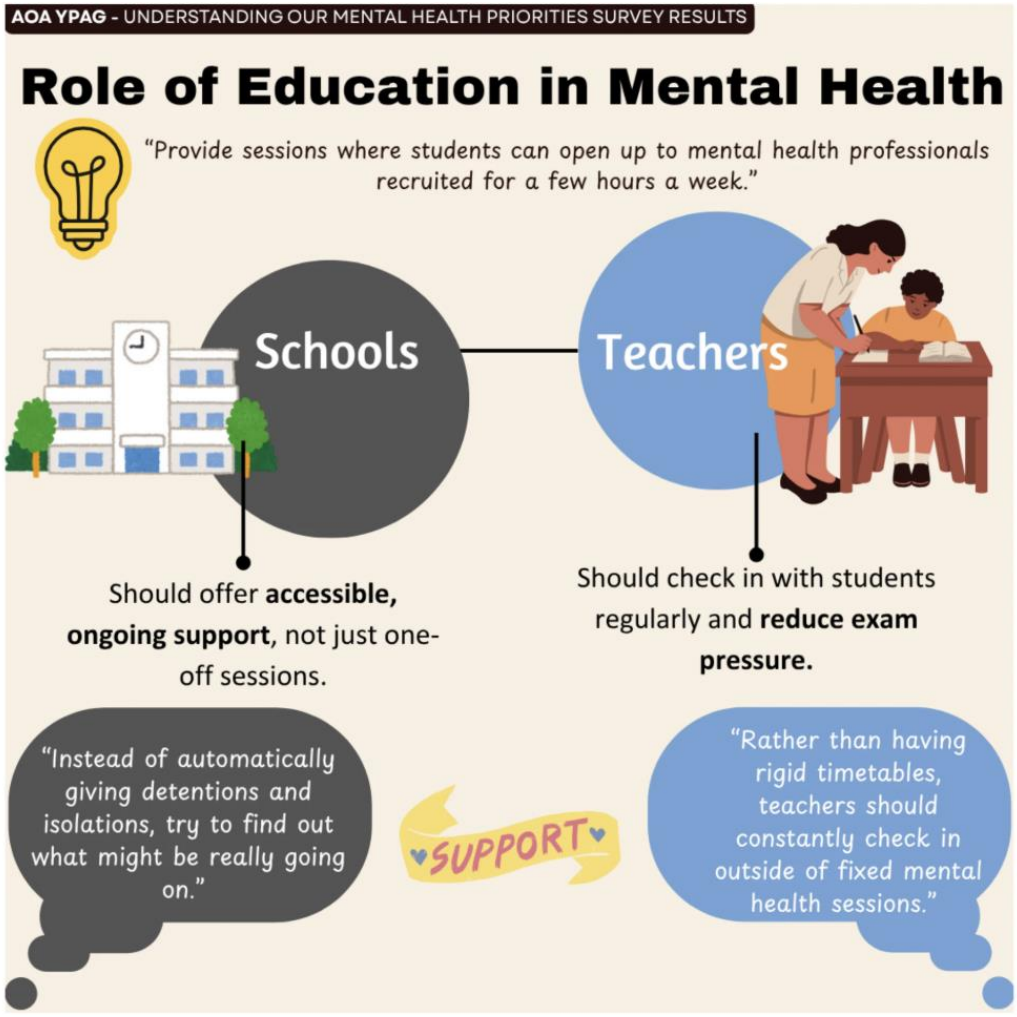
b: Quotes and key points on prevention and support systems



c: Quotes and key points on attitudes towards self-diagnosis



d: Quotes and key points on the role of education in mental health



Part 1 Quantitative results

We are sharing our findings for Part 1 of our survey below in line with our data analysis approach, along with additional findings across the questions for this part of the survey:

e. Insights on support in education based on the borough respondents live in

Borough vs Support in Education

How effective do you think your school/college/university is when: - Supporting students' mental health overall?

2.71 Overall average

We looked at how young people from each borough responded to this question.

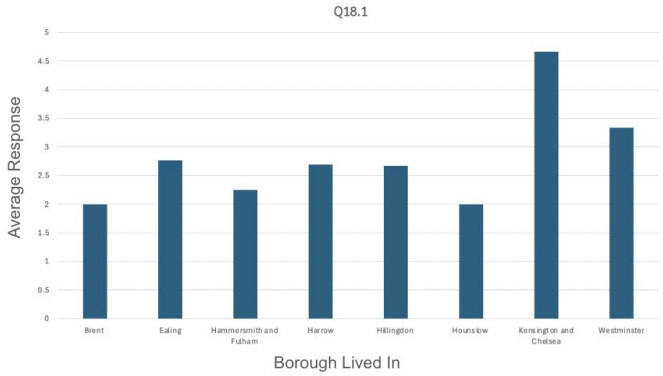
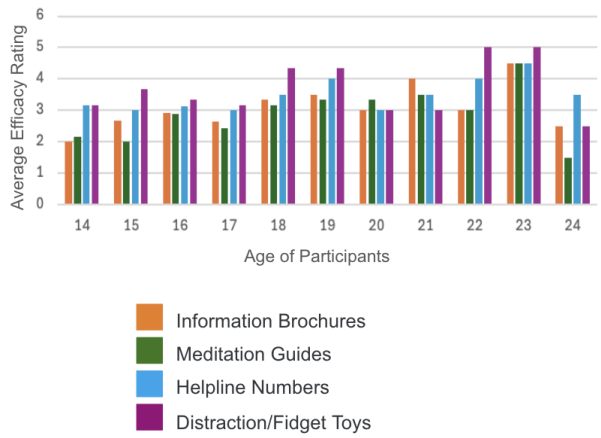


Figure e shows that young people attending education in Kensington and Chelsea had the best experience of support and Hounslow was the least effectiveThe overall rating was 2.71 out of 5, 5 being very effective.

f. Insights based on age of respondents on what would be beneficial as part of 'care package' while waiting for professional support and as a preventative measure

Age vs Prevention/Support systems

Would you find a ‘care package’ helpful while waiting for professional mental health support?
Which of the following items…

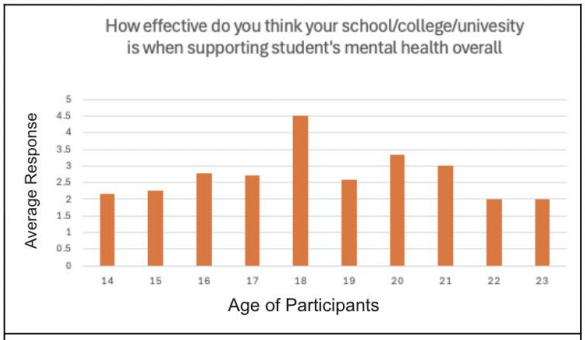


- We looked at the preference of items in a care package vs age
- As age increases, the popularity of informative methods like **helpline numbers** and **information brochures** increases
- For teenagers and young adults **distraction** and **fidget toys** are especially popular
- Meditation guides seem to be the least popular of the care package items

Figure f shows that as age increased, resources like helplines and information brochures increased in popularity. Distraction and ‘fidget toys’ are especially popular for 18 and 19 year olds and 22 and 23 year olds.

g. Insights based on age on the levels of effectiveness of general support and specialised support in education

Age vs Support in Education



- Each bar represents the score between 0 and 5 of support provided by an educational institution to students' mental health, in that age group
- Average rating of 2.78
- Support seems to be greatest when the participant is around the age of becoming of adulthood

- Each bar represents the score between 0 and 5 of support provided by an educational institution to students with more mental health needs, in that age group
- Average rating of 3.01
- Again, more support for ages 18, but also later at 23. For teenagers, support is greater for those with mental health needs than overall mental health

Figure g shows that young people feel most supported in education for their overall mental health and for those who have more needs at the age of becoming an adult. It is also clear that over 21-year-olds (rating of 3, 5 being the best) do not feel well supported for their general mental health and wellbeing, but 23 year olds with additional mental health needs feel very well supported in education

h. Insights based on ethnicity on how challenging it would be to get help in a mental health crisis

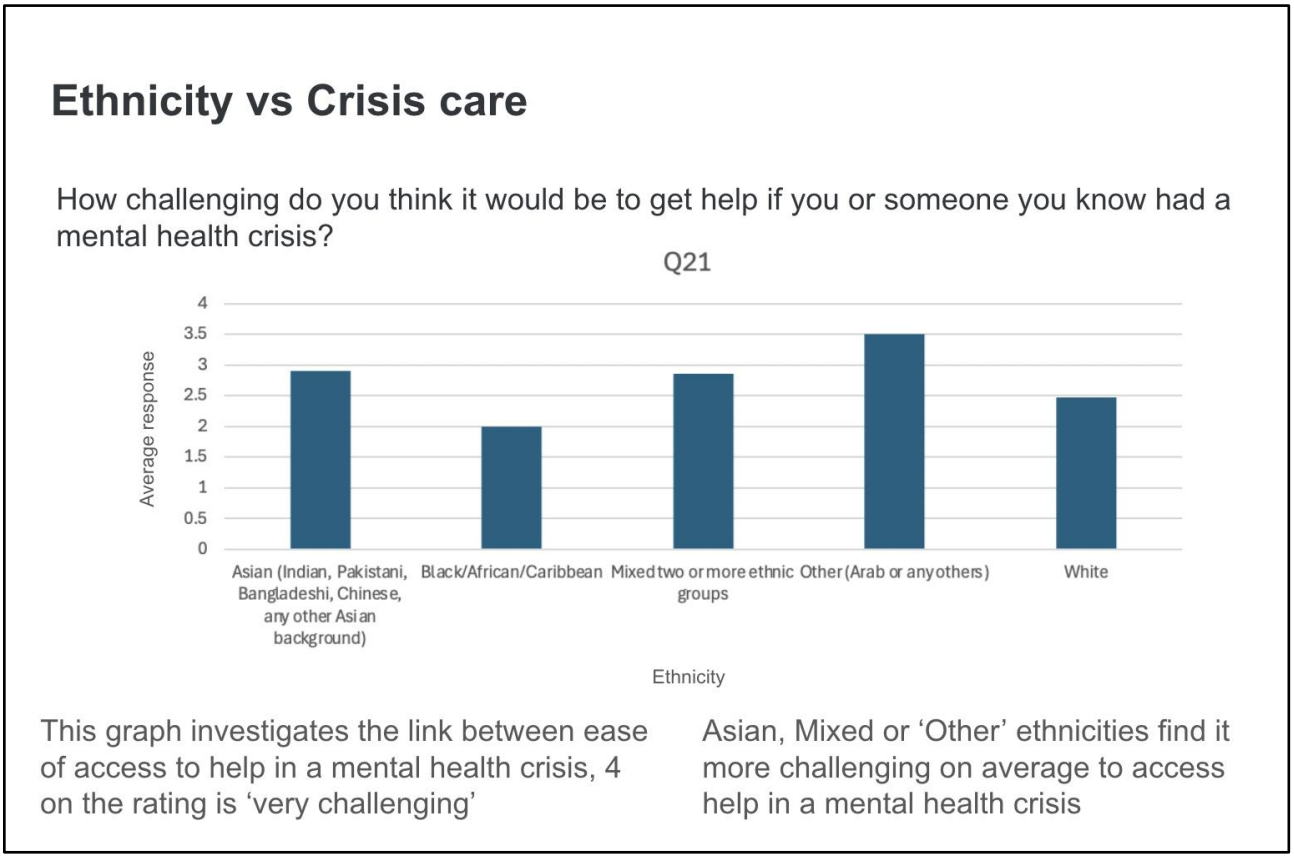


Figure h shows that young people who identified as 'Other (Arab or any others)' would find it the most challenging to get help in a crisis and 'Black/African/Caribbean' young people would find it the least challenging.

Further findings

- 49% said they or someone they know as self-diagnosed a mental health condition or as neurodiverse
- 30% reported that a lack of availability of resources would be the biggest contributor to self-diagnosing rather than seeking a professional diagnosis
- 48% said they had accessed support in education and while 34% said they hadn't
- Overall, respondents said they would find it 'neither easy nor difficult' if they or someone they know needed helped in a mental health crisis (3 out of 5 on the scale)
- 67% of respondents said they would either 'to a large extent' or 'to some extent' be interested in exploring digital tools to prevent mental health issues
- Asian was the only ethnicity where more respondents reported they had not accessed

support in education than those who had. Other ethnicities had more than double reported use of support in comparison to not seeking it

- Black/African/Caribbean young people reported the most difficulty of accessing crisis care (2 out of 5 on the sliding scale with 5 as most challenging), and their experience of communication with staff was the worst (1 out of 5 equating to'poor')

Part 2 Quantitative results

We are sharing our findings for Part 2 of our survey below in line with our data analysis approach, along with additional findings across this part of the survey

i. Insights on the benefits and risks of self-diagnosing mental health conditions

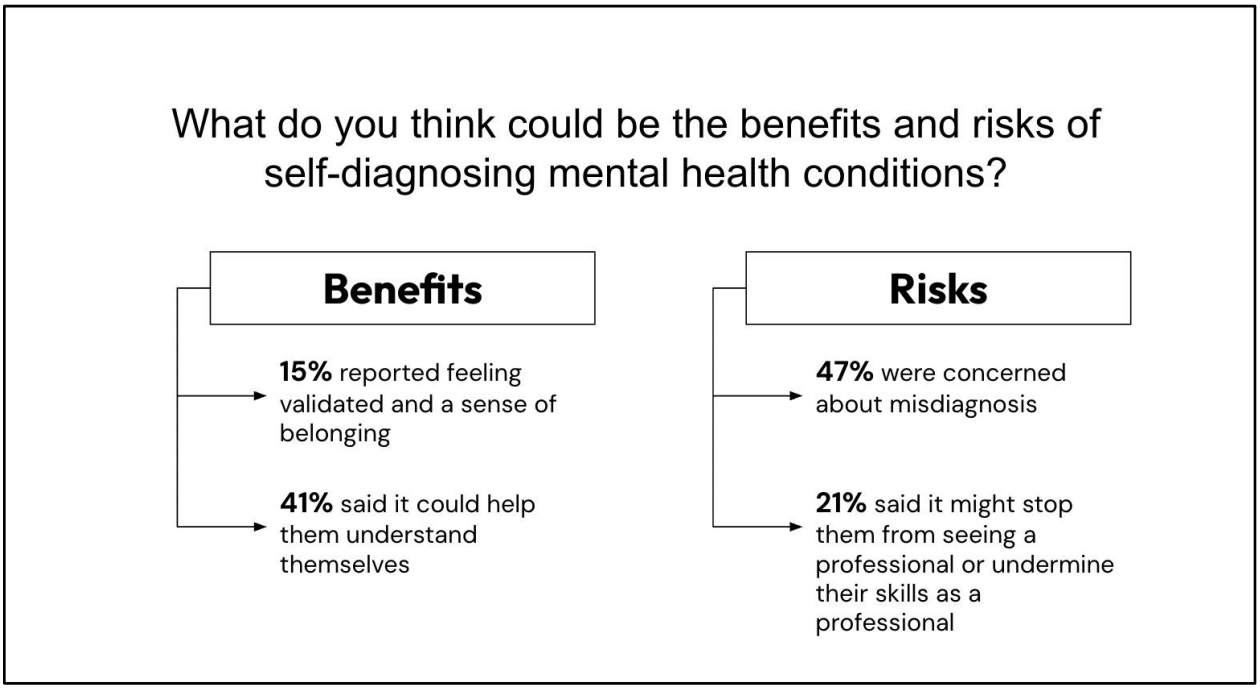


Figure i shows a similar amount of young people feel there are benefits and risks in self-diagnosing a mental health condition. 21% reported it may stop them seeing a professional while 15% said they would feel validated and a sense of belonging from a self-diagnosis.

i. *Insights on the steps respondents might take to manage a mental health crisis*

Figure i shows 69% of young people would talk to a trusted person to manage a mental health crisis while 28% would call a helpline and 21% would delay or distract themselves.

j. Insights on how respondents feel about using AI as a method of support for their mental health

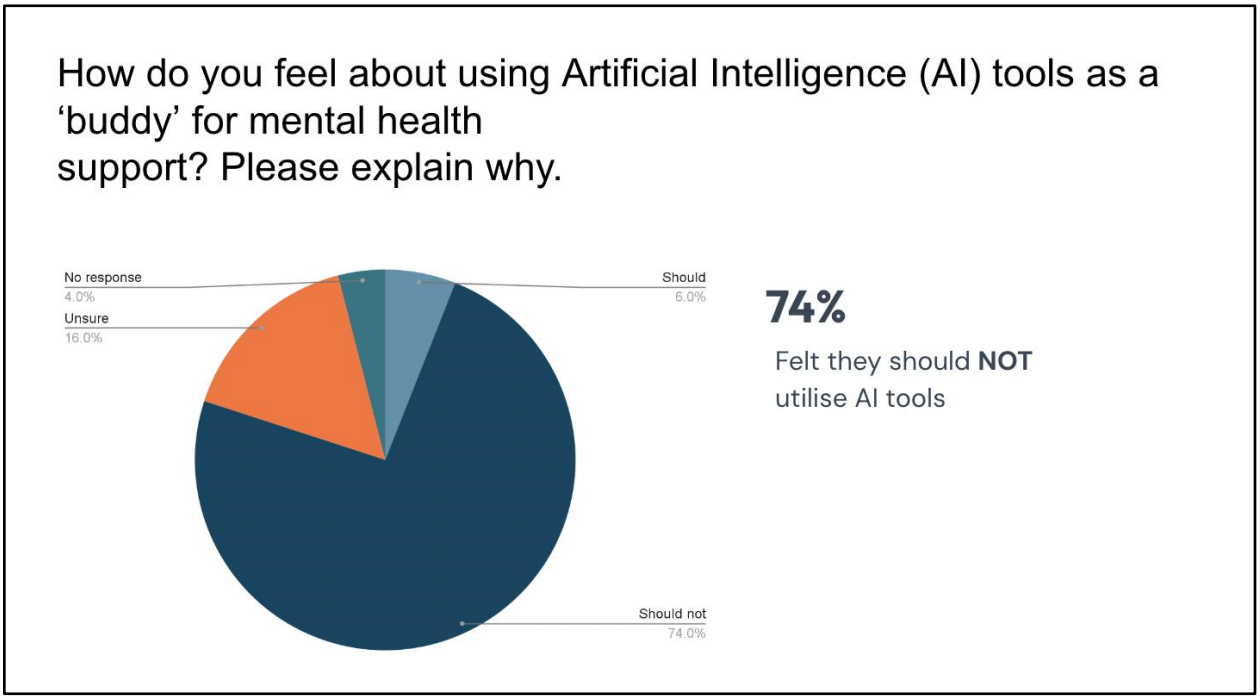


Figure j shows 74% of respondents felt they should not use AI tools as a 'buddy' (or support) for their mental health while 16% were unsure and 6% said they would use AI.

k. An infographic we created to summarise some of the direct quotes from young people across the survey's themes

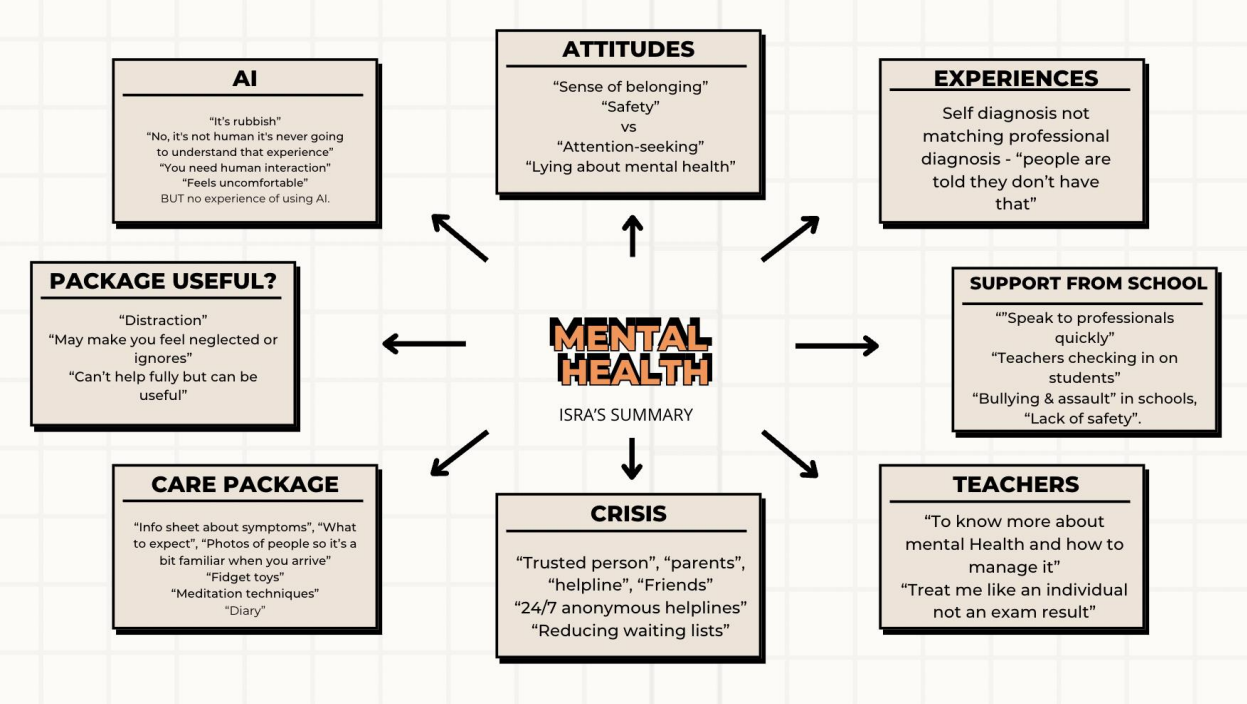


Figure k is a graphic we made to summarise young people's feelings across the survey's themes including advice for teachers: "Treat me like an individual, not an exam result".

I. An infographic reflecting on the themes identified in figure 8

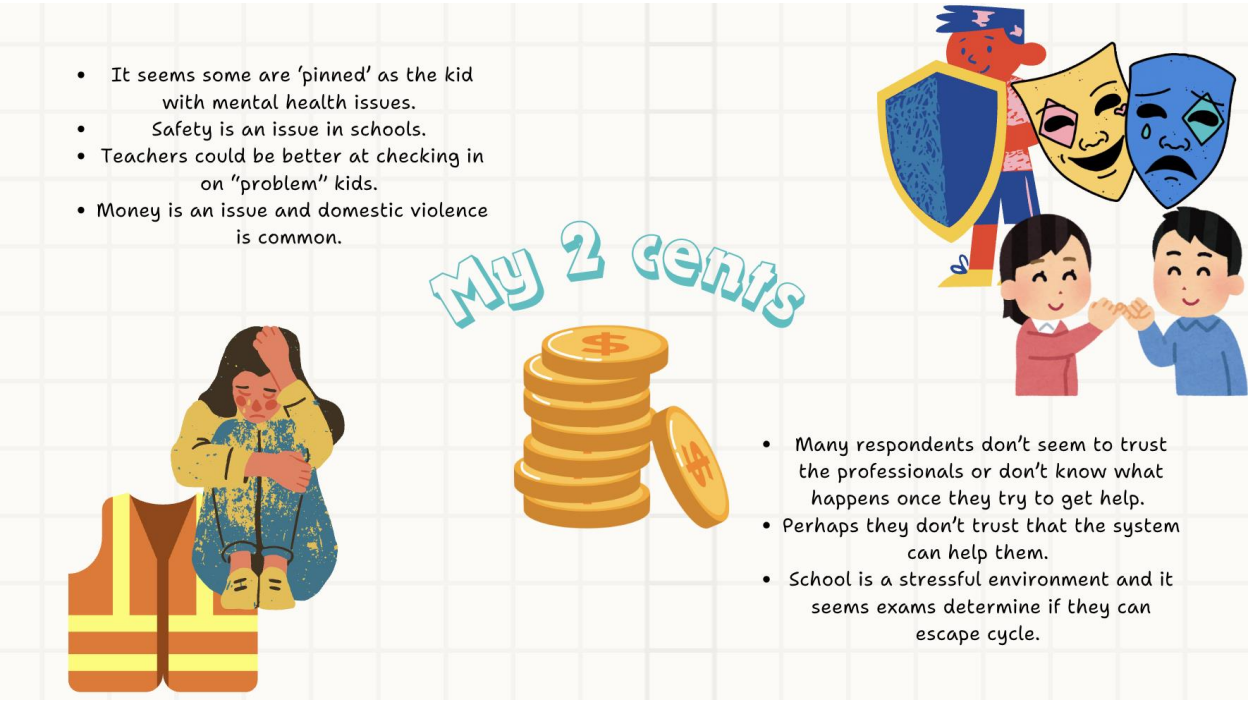


Figure I highlights our feelings about what we found, including the potential issue of trust in the education system.

Further findings

- 50% of respondents made comments suggesting support like counselling and therapy would be the best way to support students in education, while 31% suggested more training for staff would help
- 57% reported a negative experience of using digital tools
- 81% made comments suggesting they would feel more valued by receiving a care package while waiting for professional support
- 32% made comments suggesting they would like reduced waiting lists to improve support during a crisis while 23% proposed better training

4. Discussion

Summary of findings

Attitudes towards self-diagnosis

- **49%** reported self-diagnosing or knowing someone who had done so.
- **30%** identified lack of resource availability as a key reason for self-diagnosing rather than seeking professional help.
- **21%** said self-diagnosis might deter them from seeing a professional, while **15%** felt it provided validation and belonging

Support in Education

- **48%** had accessed mental health support in education; **34%** had not.
- **Asian respondents** were the only demographic where more reported *not* accessing support.
- **50%** suggested counselling and therapy would best support students, while **31%** recommended more staff training.

Crisis care

- On average, respondents rated the difficulty of accessing crisis help as neutral (**3/5**).
- **69%** would talk to a trusted person in a crisis, **28%** would call a helpline, and **21%** would delay or distract themselves.
- **Black/African/Caribbean youth** reported the *least difficulty* accessing crisis care (**2/5**) but had the *worst communication experience* with staff (**1/5**).
- **32%** advocated for reduced waiting lists, and **23%** suggested better crisis training.

Support systems and Prevention

- **67%** were open to exploring digital tools for mental health prevention.
- However, **57%** had negative experiences with existing digital tools.
- **74%** felt AI should *not* be used as a mental health support "buddy"; only **6%** supported its use.
- **81%** wanted care packages while awaiting professional help.

We were very interested in some of the findings related to ethnicity in crisis care and what the factors involved in perception of difficulty in accessing care and experience of communication of staff might be. We were also surprised to see that there was only one group who reported not having accessed support in education more than those who had. We are interested in what role stigma and culture may play in this. We were also surprised to see that such a high proportion of young people wouldn't feel comfortable with AI as a tool to support them. And finally, we were interested to see the success in Kensington and Chelsea in terms of supporting young people in education and wondered what lessons could be learned.

Strengths and imitations

We found that of the 320 young people who began the survey, a large proportion didn't complete all of the questions. This could be because we didn't make the questions mandatory or perhaps the survey was too long. However, we wanted to reach a specific quality with our content and didn't want to compromise on that. We felt that for it to be good quality, it needed to be a certain length and if all questions were mandatory this may have increased the drop-off rate further. We don't think this was a specific issue with this survey, but with surveys in general.

Although we did our very best to make the questions inclusive and accessible in the main survey, the content may still have been off-putting for some young people. We were very pleased with the Easy Read survey and we received good feedback, but as it was created and shared after our main survey we found it difficult to generate interest in completing it.

Our results show that some ethnicities were not well represented in the survey (for example, Black/African/Caribbean, young people from Hounslow, Transgender young people, under 16-year-olds) which may limit how applicable our findings are. We faced some challenges when extracting the data from Qualtrics, some of the data was missing but the skills we had within the team meant that we were able to overcome this and still report on the majority of the lost data.

What would we do differently next time?

- We could have included more ethnicity options in the 'Characteristics of respondents' questions e.g. Middle Eastern. If there were more options maybe some young people would have felt more comfortable answering as they would have felt included.
- Perhaps we were over-ambitious with the initial timeline; we could have benefitted from more time designing the survey and collecting data
- Regarding the young people that were not represented, perhaps we could have done more to reach out to engage with them in their own spaces and through their networks if we had more time to focus on this.
- Perhaps we could have created and shared an Easy Read survey at the same time as the main survey to maximise the data collection potential

5. Recommendations

We set out to discover what young people feel are the important questions and priorities in mental health research in Northwest London, build an understanding of the diversity in experience of accessing support and to embed young people's voices in influencing research. Overall, we believe we have achieved this by highlighting lots of questions and priorities that are important to young people and potential routes to address them. We have embedded young people's voices in influencing research, not only with the responses we gathered but in the approach to this project as truly youth-led – by young people, for young people. Our recommendations for the next steps are to:

- Explore barriers to seeking support in education and what role ethnicity, culture and stigma plays in this
- Review the specific methods used in Northwest London to support young people in education and its effectiveness and if it is age-specific in line with our findings
- Explore how the risks of self-diagnosis can be mitigated to ease the fears of young people
- Explore how to upskill the people young people trust to help them manage a potential mental health crisis
- Explore what can be done to mitigate mistrust of AI/digital tools as a form of support and prevention
- Review the feasibility of developing 'care packages' to support young people while they wait for professional help
- Review the successes in Kensington and Chelsea in supporting young people in education and what can be done to replicate this

A big thank you to the AOA research team and all of the young people who completed our survey and the organisations and groups who supported us along the way.

If you would like to learn more about us, discuss the report or our findings in more detail, you can join our network or contact us via our webpage. You can also read our recent newsletter (insert link when available).