Peer Research on Mental Health in Our Communities

Connected Voice Haref

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Introduction

This report looks at knowledge, understanding, and thoughts about mental health and mental health services among ethnic minority communities in Newcastle upon Tyne, United Kingdom. Newcastle is a city in the North East of England. In Newcastle, around 11% of the population are from ethnic minority communities and this rises to 24% among school-age children (1) . The 2021 census data is not yet released but it is anticipated that these numbers have increased.

This project was started after a almost year of living with the pandemic and ran from January-June 2021. Although the focus of the research was not specifically about COVID-19, it is impossible to talk about mental health in this time without talking about the mental health impacts of the pandemic, quarantines, illness, death, financial difficulties, and increased health inequalities. The pandemic was on the researchers and participants minds throughout this project and plays a part in both the research questions and the data collected.

In the UK, minoritised groups experienced higher infection rates, hospitalisation, and death rates from Covid-19. In the first wave, Black African and Bangladeshi men ages 9-64 had 5 x the mortality of White men and Black African and Pakistani women had almost 4 x the mortality rate of White women (2). Towards the beginning of 2021, it was reported that the death rate for Black and Asian people in the UK was 3-4 times higher than the death rate of White people (3). Financially, people from minoritised backgrounds were hit harder during the pandemic than White people. Employment rates dropped 26 times for ethnic minority workers compared to White workers and in specific industries such as food and accommodation, job losses were significantly higher for minoritised groups (4). Ethnically minoritised groups had a greater likelihood of having their overall healthcare affected by the pandemic than White people and were more likely to say that issues with housing made their mental health worse (5, 6). The mental health impacts of the pandemic are yet to be fully understood but the impacts of stress, trauma, and poverty on mental health and wellbeing are well documented (7).

Average mental distress in the UK increased from pre-pandemic to during the pandemic and this increase was greater for women of all ethnicities and for men from minoritised communities compared to white British men. In the male sample, the increase in mental distress was greatest among Bangladeshi, Pakistani, and Indian men compared to White British Men (8).

For many minoritised groups, mental health services carry a certain amount of stigma (9). Many factors have an influence on whether or not mental health services are accessed including awareness, recognition and acceptance of mental health problems, difficulty talking about mental health, and negative perceptions of mental health (10) Stigma and mistrust of services can also delay help-seeking, which is linked to more severe presentation at contact

Stigma and mistrust of services can delay help -seeking.

Structural racism, inequalities and discrimination disadvantage individuals from minoritised backgrounds in terms of accessing mental health services and getting good quality care (12).

Black and Black British people face 10 x higher rates of Community Treatment Order use and Black Caribbean and Black African people were over 2 times more likely to be admitted to the hospital compulsorily when compared to White British people (13, 14). It is important to note that these higher rates are not explained by higher rates of serious mental illness or psychosis alone (although people from minority groups are more likely to be diagnosed with psychotic disorders(6)) but are related to perceived risk of violence, higher rates of contact with the police, lack of trusting relationships with GPs, and general inequalities (14). Service users from minoritised backgrounds are less connected with primary mental care services, tend to have worse outcomes with treatment, and are more likely to begin services through a criminal justice route versus through a primary health care system (15, 16)

The way that the current mental health care system is set up also presents barriers for accessing care. Factors impacting this include long wait lines, cultural and language barriers, lack of awareness of other services among service providers, and discrimination (10). Inpatient staff have identified lacking the skills, confidence, training, and knowledge to meet the religious and cultural needs of minoritised patients (17)

Researchers have called for tailored services to meet the needs of different community groups. Service users, their families and communities need to be part of reshaping interventions in order to remove some of the barriers (11).

There is very little research into the experiences and thoughts about mental health of the ethnically minoritised communities in Newcastle and even fewer projects that are designed and implemented by peer researchers who belong to these communities being studied. This project is a step towards filling that gap.

The results and recommendation from this research project should be used to inform policy around the design of mental health services and to encourage existing services to make needed changes. However, much of this project was also about speaking to community members around their own perceptions of mental health. We hope that this report provides a jumping off point to continue discussions around mental health, and in doing so, decreases stigma and increases engagement with the development of and improvement of services.

Why peer research?

Peer research is a research method in which members of the community being researched take part in designing, conducting, analysing, and disseminating the research. Peer researchers are able to use their insight and understanding of the community being researched to improve access to research projects for those who would not normally participate, and add a level of depth and nuance to the project that would otherwise be absent (18)

This project was commissioned by Newcastle Healthy Futures to look into the experiences people from minoritised communities have when accessing support for mental health issues. Haref was chosen to coordinate this process because of their network and community ties. Haref recruited four organisations to work on this project.

Who was involved?

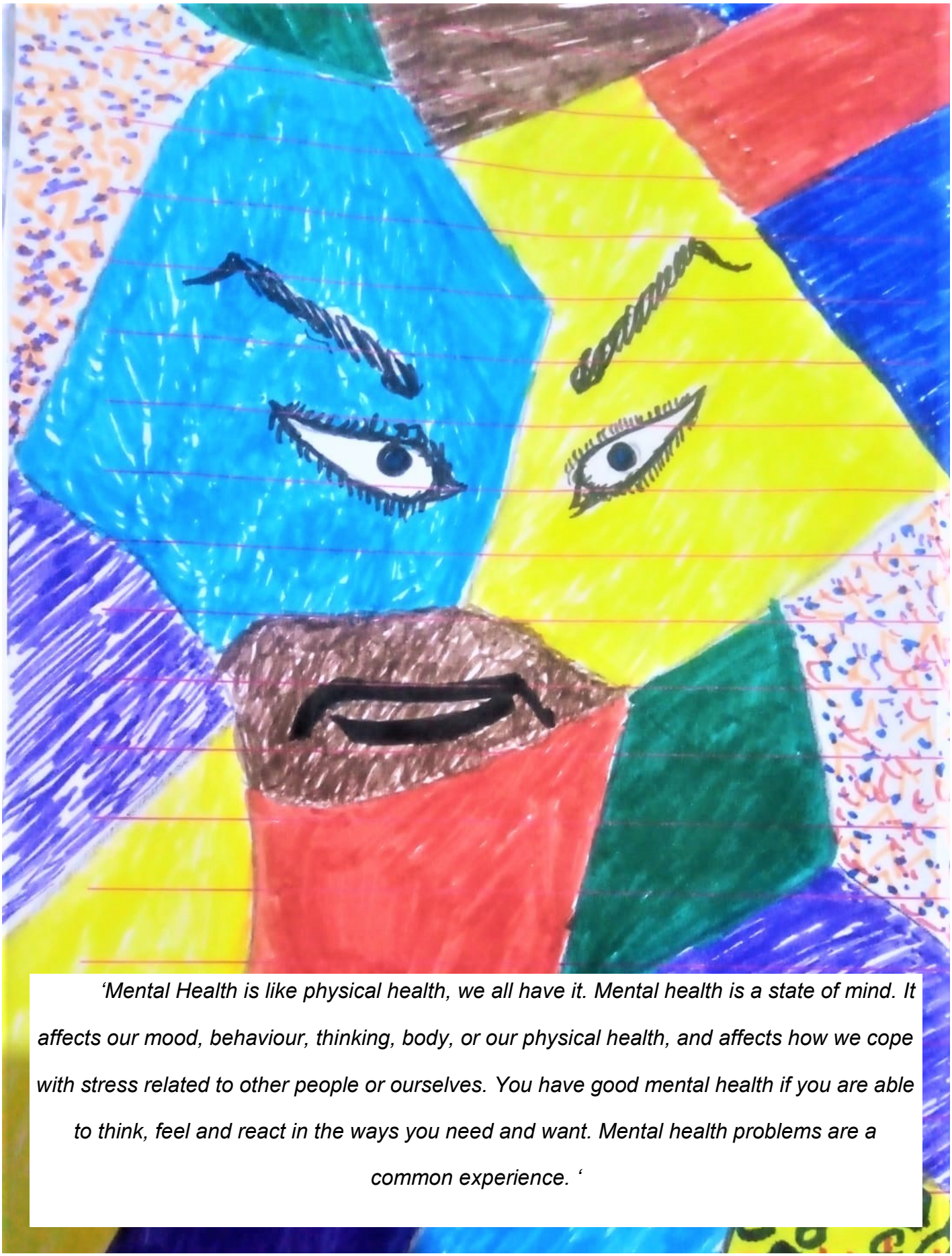
- Rainbow Home
- First Step
- Riverside Community Health Project
- West End Friends

These organisations were: Rainbow Home, First Step, Riverside Community Health Project, and West End Friends (Search.) The organisations and individuals have very strong ties within their communities. Each organisation recruited 2-3 peer researchers from minoritised communities and also provided a member of staff to support the researchers. Fulfilling Lives Newcastle Gateshead was brought in to facilitate a 4 week course on Zoom covering the basics of doing peer research and support the researchers throughout the project. There were 9 researchers and 4 staff members in total.

The Zoom course covered an introduction to research, ethics and bias, to survey design, interview techniques, data analysis, and reporting. Zoom was also used in the following weeks to further develop the research, analyse the data and write the report.

Online whiteboards were used to brainstorm topics, themes, and research questions. The group decided to focus on Experiences and Thoughts of Mental Health as the theme.

During this time, the issue of what to name the project arose. Some of the researchers felt that because the words ‘mental health’ are so stigmatising in their communities, some potential participants might immediately decide they didn’t want to be part of the research after only seeing the title. We had lengthy discussions about this issue, eventually deciding for ethical reasons, and to decrease stigma around the topic, it was important to use the term ‘mental health.’ The group also thought it was important to both ask participants what they thought of mental health, and provide our own definition of mental health, to encourage people to think of it in a more broad, less negative sense. We agreed on the definition on the following page.



'Mental Health is like physical health, we all have it. Mental health is a state of mind. It affects our mood, behaviour, thinking, body, or our physical health, and affects how we cope with stress related to other people or ourselves. You have good mental health if you are able to think, feel and react in the ways you need and want. Mental health problems are a common experience. '

Methods

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Completed Surveys

Online Surveys

- Surveys were created by the peer research team and sent out via **email, Whats-App and text.**
- Surveys were sent to **peers, family, friends, colleagues**, and others who are part of **ethnic minority groups in Newcastle**
- Survey was available in **English and Arabic** and translated back into English by a researcher
- Peer researchers supported participants who did not speak English by **translating or by filling out the survey alongside participants.**
- Researchers supported those **without digital access** by reading questions aloud and filling out survey for participants.
- The survey was administered to better understand participants **experience and knowledge of mental health, access to mental health services, and demographics**.

Interviews

- Researchers opted to do **1:1 interviews** as well to support the survey results and get more detailed answers.
- The research team wrote **15 interview questions** (see appendix)
- Many interviews were done in **languages other than English** when participant and researcher shared a common language.
- Interviews were done **face-to-face, over video call, or phone call.**

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Interviews

Ethical Considerations

- Due to the sensitive nature of the topic, it was important to consider the **wellbeing of both researchers and participants**.
- Researchers were **supported by staff and coordinators**
- Participants were **advised of any risks** in advance of participation and **provided a list of mental health resources** as well as an email contact for the research team.
- Research team considered the **ethical implications of recruiting known participants.** We decided that knowledge of communities, trust, and personal relationships would **increase participation and help decrease stigma** about mental health.

Things to Remember

- The research was **developed, conducted, and analysed** by a team of **peer researchers.**
- The researchers surveyed and interviewed predominantly **familiar peers, family, friends, and community members.** Therefore **the sample is not random** and we make **no claim that the results are representative**.
- Because the researchers spoke to **known participants** who were willing to talk about mental health, the answers might be skewed.
- Although we spoke to people from **many different ethnic backgrounds**, there were **very small numbers of some groups.** Therefore, **we avoided breaking down data into specific groups. The recommendations represent the views of many diverse groups.**
- The vast **majority of participants were female.**
- Because the **numbers of men are so small,** any results where men and women are split comes with that caveat.

Results

Demographics of survey participants

Gender

85% female

14% male

2% prefer not to say

Disability Status

89% non-disabled

10% disabled

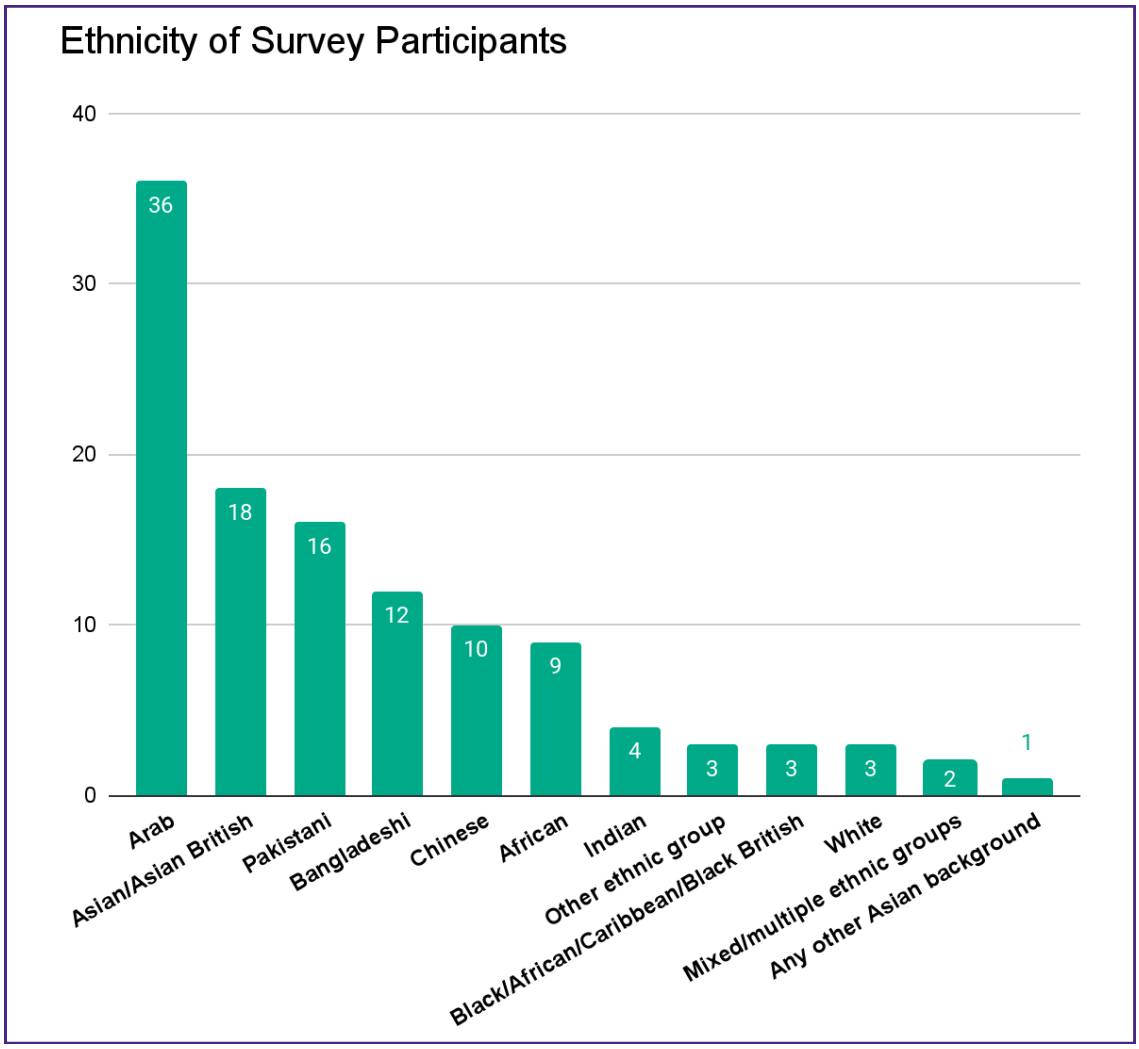
1% prefer not to say

Home Life

87% live with others

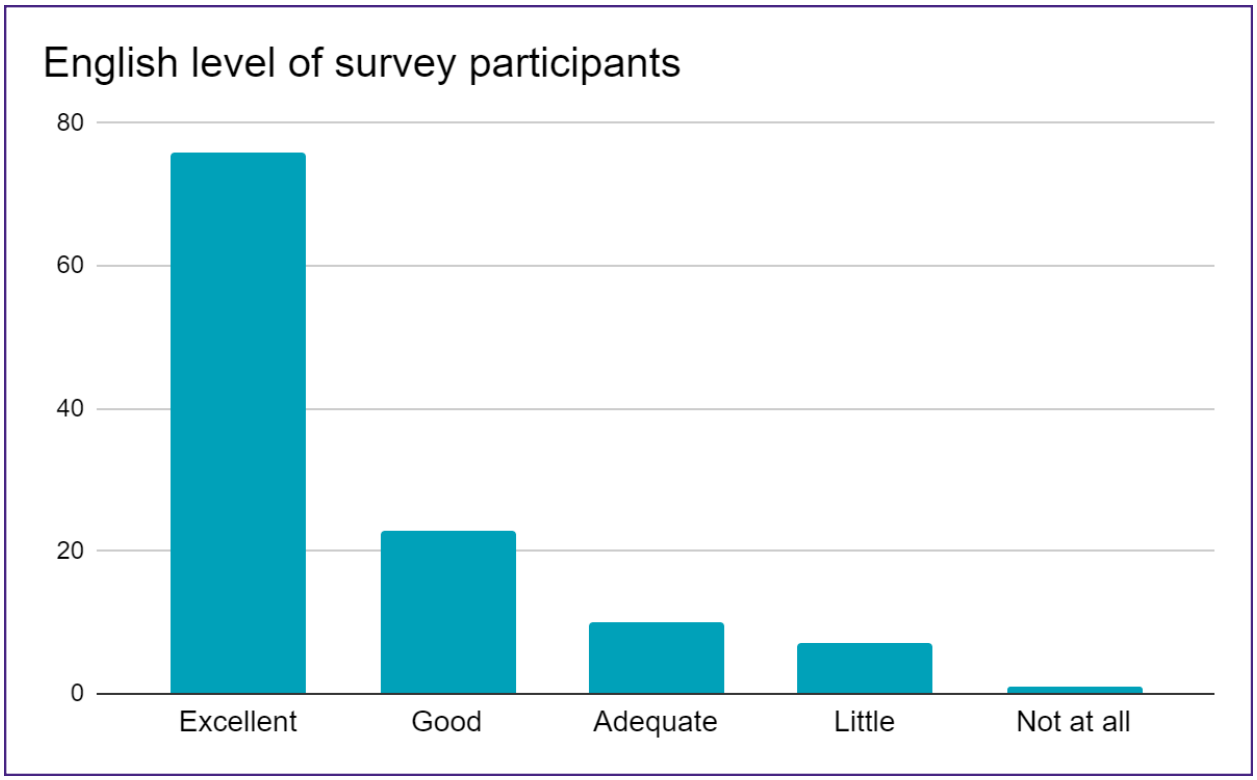
10% live alone

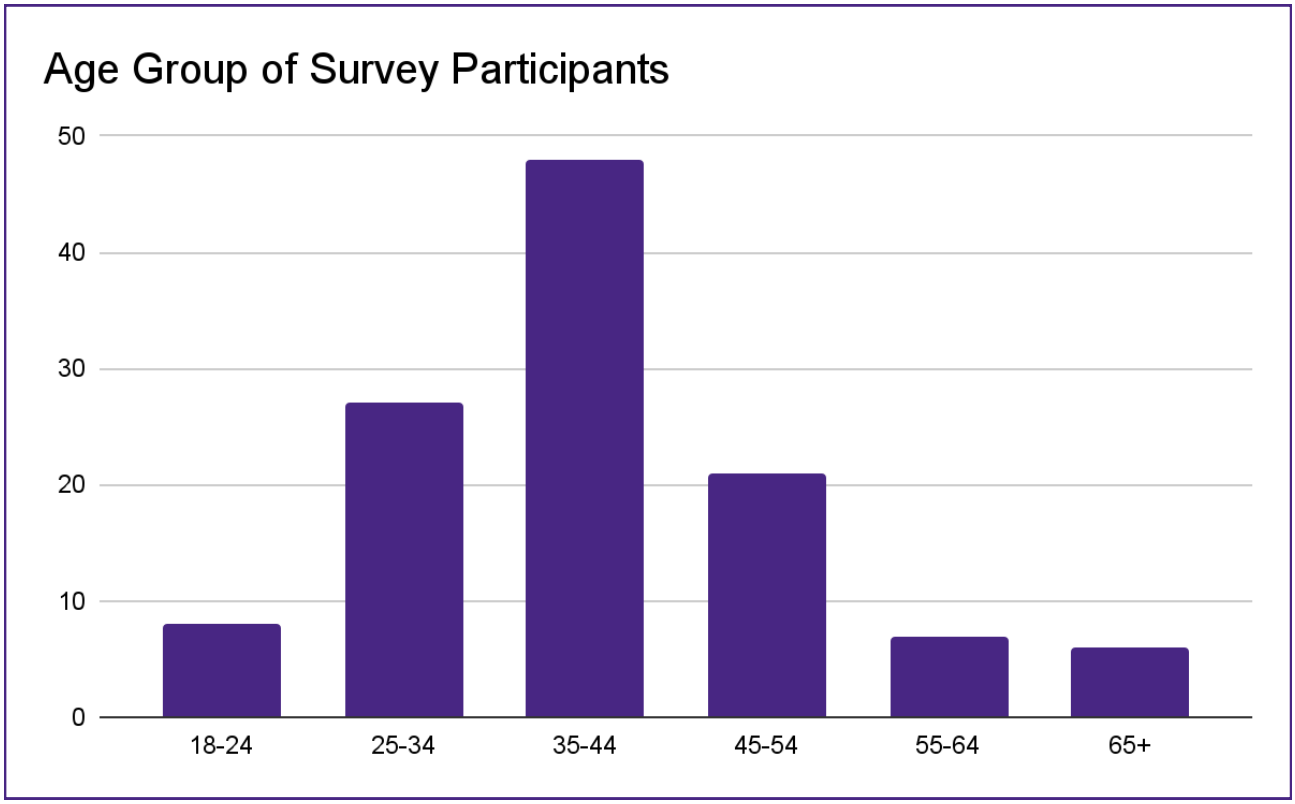
3% live alone part time



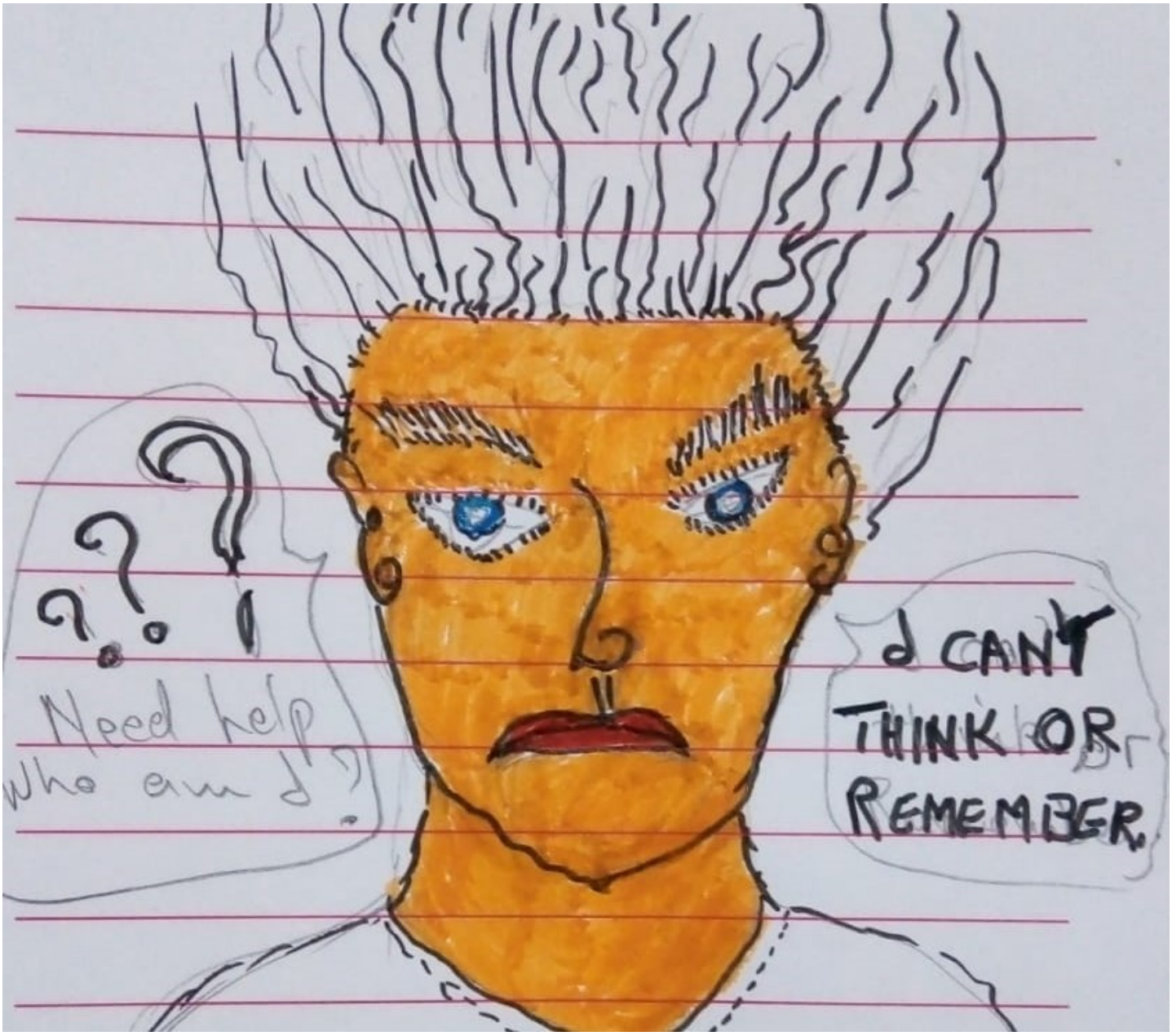
**Due to limitations with the survey design tool, the ethnic group heading (such as Asian/Asian British) was clickable as an option and some people chose this vs. selecting a more specific ethnicity. It is unclear whether this was purposeful or not.*

Demographics of survey participants





Demographics of Interview Participants



Interview Participants

- 13 Interviews
- Incomplete demographic info
- **Majority female, non-disabled, live with others.**
- Identified as **Arab, Asian, Asian British.**
- Most between the ages **of 34-45**

- Results from **interviews and surveys** were **interwoven** in the remainder of the sections.
- Where necessary, results are **identified as coming** from either **surveys** or **interviews**.
- Where interview and survey questions were the same, **answers were combined i**n the results.

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Mental Health Knowledge, Awareness, and Coping

- The majority of survey participants were familiar with common mental health disorders like **depression and anxiety**
- Definitions of mental health ranged greatly.
- Some defined it as **sadness, anxiety, or the inability to cope**; some felt mental health was more **neutral and fluctuating;** others thought it was more related to wellbeing **such as feeling happy, balanced, and the ability to think positively.**
- For certain participants, mental health was about coping and being able to **maintain ones' responsibilities** while for others it was **the exact opposite.**
- Some participants felt that **mental health meant being 'crazy.'**
- Others defined mental health **by listing specific mental illnesses or symptoms.**
- Only a **small number** of people were **unable to define** mental health at all.

"Scared, anxious, depressed, frustrated, uneasy, not confident, hide away from the world, stressed."

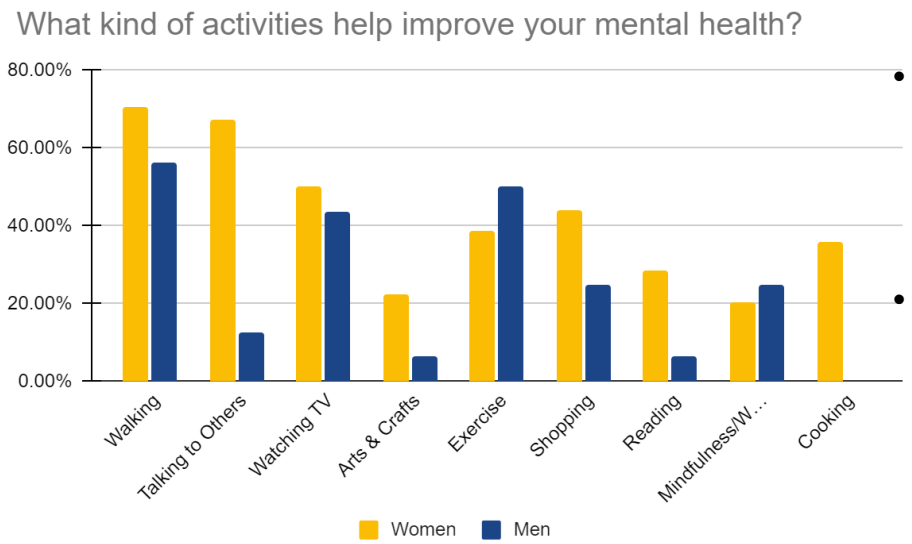
'To me it's a state where I can perform all of my duties of my life like work, relationship, duties of my dependents, religion, hobbies, etc. capabilities with confidence.'

'It means when a person is confused can't make proper decisions, lots of his behaviours are not his real natural self, can not take even his own responsibility'

"Thinking right, making the right decisions, dealing with any problem as a whole and trying to address it in the right way."

'Crazy person, lunatic, out of his head! '

Activities to help mental health



- In Surveys, **men identified fewer activities** than women
- **Women** were significantly **more likely than males to use cooking, reading and arts & crafts** to help them with their mental health
- **Men** were **slightly more likely** to use **exercise and mindfulness/wellbeing** tools such as yoga to improve their mental health.
- In interviews, 5 people mentioned talking to **God, praying, or reading the Quran** as coping tools.

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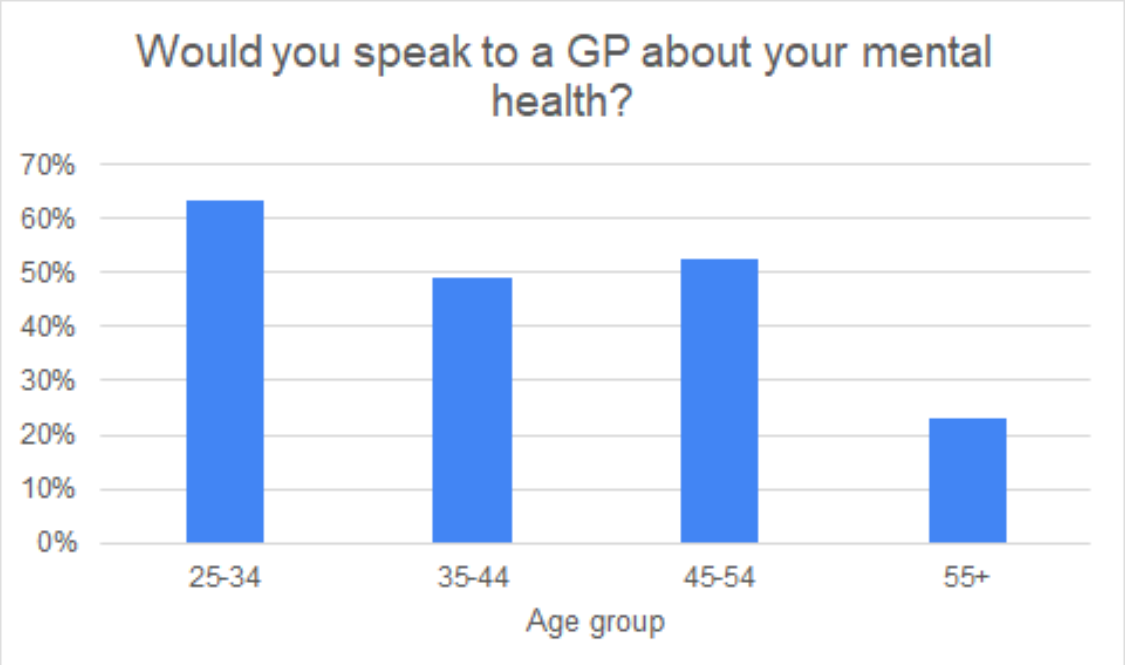
Who would you talk to about your mental health? (survey question)

**The total represents all participants and the male and female rows represent those who specified their gender.*

Contact to speak to	% Total n=116	% female n=98	Male n=16
Friend	62%	63%	56%
Family (daughter/husband/sister)	51%	53%	31%
GP	46%	46%	50%
Colleague	14%	14%	12%
Counsellor / therapist / psychologist	3%	3%	0%
Teacher	3%	4%	0%
Religious Leader	3%	3%	6%
God	1%	1%	0%
No one	16%	14%	19%

- Although our sample of men is limited to only 16 males, it appears that **males are less likely than females to speak to friends and family.**
- Interestingly, both **men and women were very unlikely to speak to a counsellor** about their mental health.
- **Men also appear more likely to report that they will not speak to anyone** about their mental health; One fifth of men said they would speak to no one.
- **Women named more contacts** that they would talk to compared to men.
- **Older people appeared less likely to talk to a GP** about their mental health



Talking about/dealing with your own mental health

Benefits:

'getting to know yourself better,'

'not keeping it to yourself, it gives relief.

'I know what I should be doing but it is difficult, I have to wait, be patient, but this is easy to say and hard to do. For other people I can recommend few things to do, so you can talk easy but for me, it's hard to act.'

- In interviews, **9/13 participants** clearly stated that they were **comfortable speaking** about their **mental health.**
- Participants were able to identify **benefits to speaking to others about mental health.**
- Those who were **not comfortable** talking about their mental health cited reasons such as **discomfort, familial pressure** not to disclose mental health issues due to **fear of medical professionals,** and **assumptions** professionals make when you don't speak English.
- **6** interview participants said that they **knew how to deal with their own mental** health and **2 said that they did not.**
- Participants identified ways to **cope** with mental health such as **speaking to counsellors, GPs, talking to others, and activities**.
- One participant identified knowing what to do, but **finding it difficult to act.**

Supporting others with their mental health

- **12 out of 13** interviewees stated that they felt that they **either knew what to say or where to direct someone struggling with their mental health**
- **5** people specifically mentioned that they **knew services to direct people to such as the GP, or Samaritans**
- **6** participants described feeling **confident** about **supporting someone** through various means such as encouragement, problem-solving or kindness.
- However, **4** participants stated that they **would want to tell someone where to go but did not know where to find help** and mentioned asking organisations they are working with or googling it.

'I will advise that he should be positive and try to advise positive vibes like doing a workout, running because it reduces the stress, afterwards I will advise contacting mental health service.'

I don't know where are those mental health support services but we can find out if we google it.'

Impact of lockdown /mental health in recent years

- For survey participants, the most common themes were **fear and anxiety, depression, stress and loneliness.**
- **12** interview participants stated lockdown had **negatively impacted their mental health**
- People were **frightened** to go out and of **catching Covid-19.** They were worried about the **future, their safety, and their health.**

'Hearing many people die caused us to be terrified as I am away from home and have small children, I had fear and anxiety.'

- Most stated that **lockdown had a negative effect** on their emotions. Some people mentioned **gaining weight, feeling lazier, or caring less about their appearance**. It was difficult to maintain physical health.

'It felt like I was in a prison with no money, we don't have anything, during the pandemic you have more time thinking about problems so everything felt worse.'

- **Financial concerns** were widely cited with specific concerns about community **businesses and loss of income.**

As kids are growing so does the worries- want them to see successful in life. Expenditures have been rising but not the income. Jobs are getting less secure, so all these things do contribute to the mental health.

- There were also significant concerns related to **children**, both the **added stress of taking care of/schooling children** during quarantine and the fear of **passing the virus onto children.** the importance of school support became apparent.

'the children are at home all the time. I had to call school and say I am not coping - you have to take them so now they are at school."

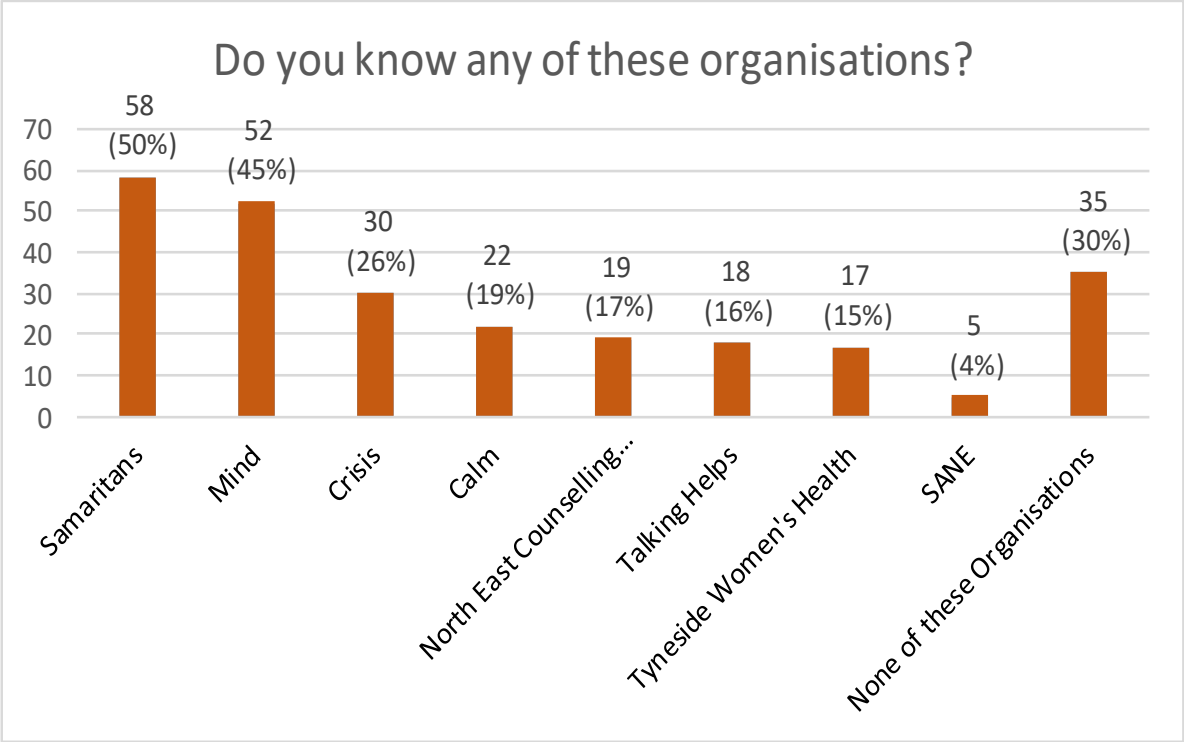
- For some people, their routine **hadn't changed** and others were **helped by friends and/or family.** It was noted that those able to **work from home**, who were **furloughed**, or whose work received **extra funding** were **not as negatively impacted** by the pandemic.
- A fewer number of people found **benefits to lockdown**, and enjoyed having more **time alone or with family.**

"Mentally drained me but spiritually enhanced me.'

- It seemed **easier to talk about mental health** when it was attached **to a particular event** such as the pandemic, a death in the family, financial stress, or difficulty navigating the asylum process.
- The majority of interview participants said their **mental health had gotten worse in recent years** in relation to the aforementioned stressors.

Previously I had no worries but now during the lockdown, I am unwell, I think of unsolved problems, our house is too small for my family I worry a lot, I feel helpless I can't change anything.

Familiarity with mental health services



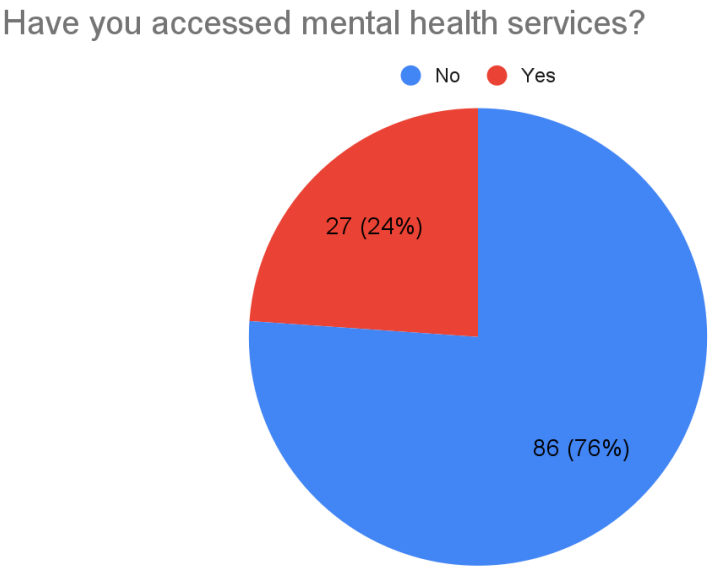
*Please note that this list of services is in no way exhaustive. This was the list of services generated by the research team and some services familiar to the participants may have been left off.

- We asked survey participants if they had **heard of a list of 9 mental health** services.
- Around **50% of the participants were familiar with Samaritans and Mind** and around **25% were familiar with Crisis.**
- **Fewer than 20%** had heard of Talking Helps, Tyneside Women's Health, and North East Counselling Services
- This suggests that the respondents **were more familiar with information-based or Crisis services**, and less familiar with longer term mental health support services or more traditional counselling services.
- Notably, **30% of participants had not heard of a single one of those services**
- **5 interview participants** said they knew how to direct people to services but the **GP, Mind, and Samaritans** were the only services specifically named.
- **The majority** of interview participants **did not know where to go to access support-** 3 people said they would have to **google services** to know where to direct someone to find help.

'I have not heard of any of the above mental health services, I think there needs to be a national campaign by the government to bring more attention to this subject.'

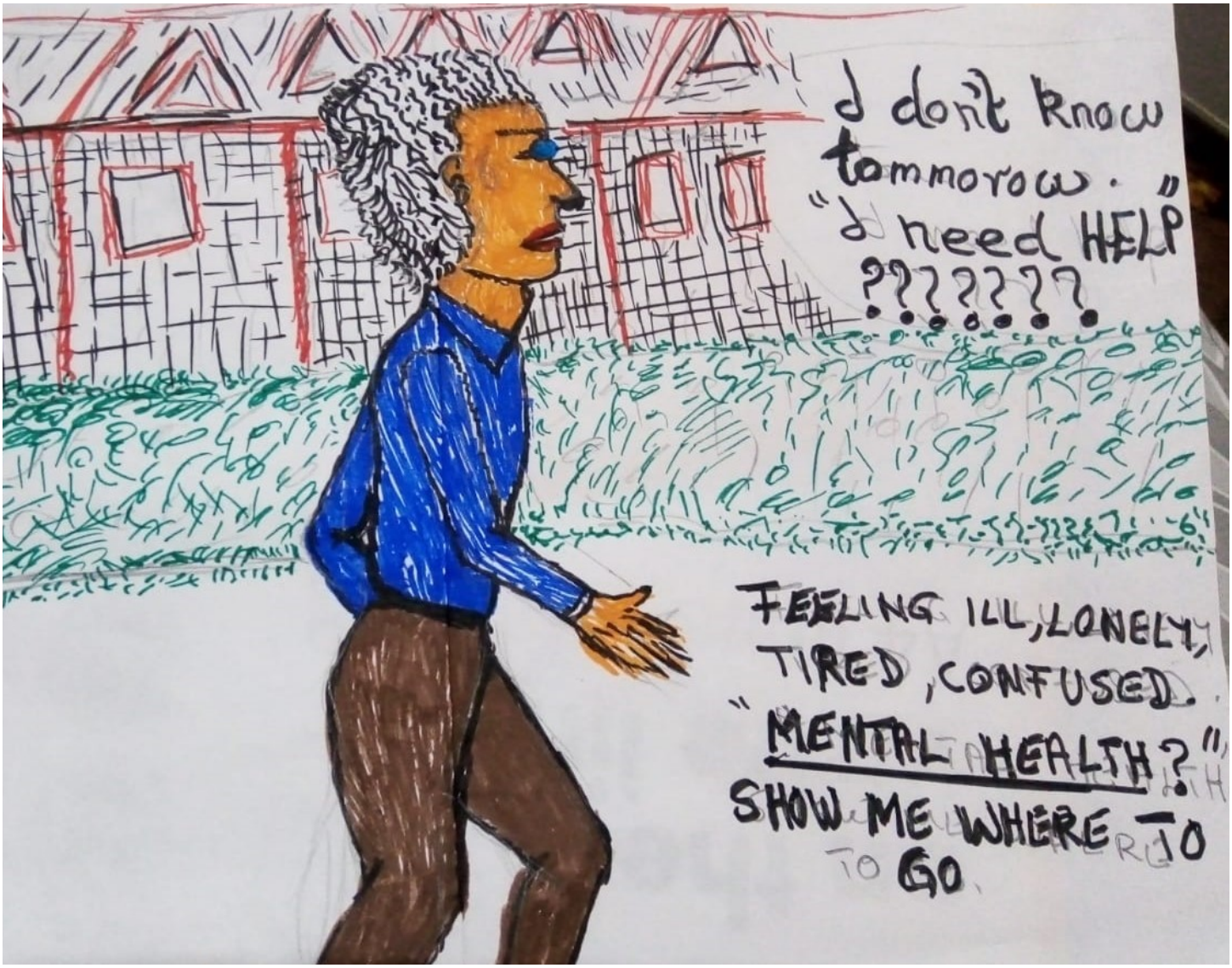
Use of mental health services

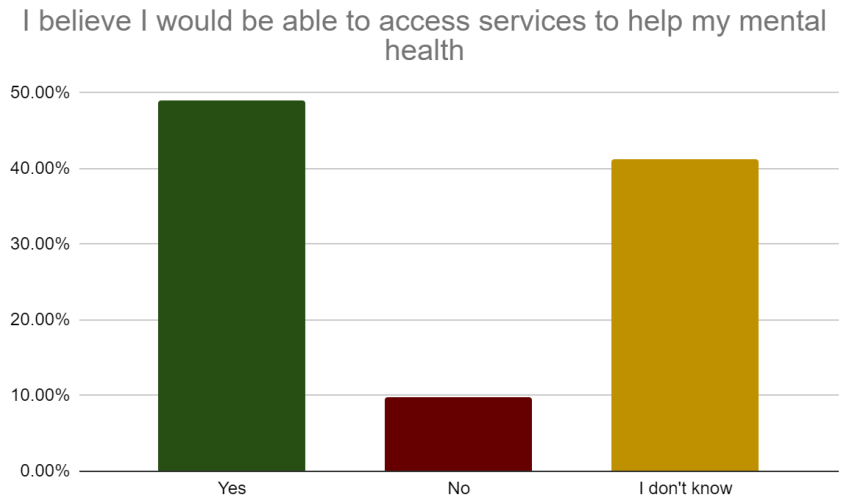
- Slightly **fewer than one quarter** of survey participants have **used a mental health service previously.**
- The number of people who had **accessed mental health services decreased with age.**
- There was **significant variation in the number of people who had used services when this was broken up by ethnicity** but it is important to note that the total number of participants were relatively small, and more so when broken down by ethnicity.



Have you used mental health services?

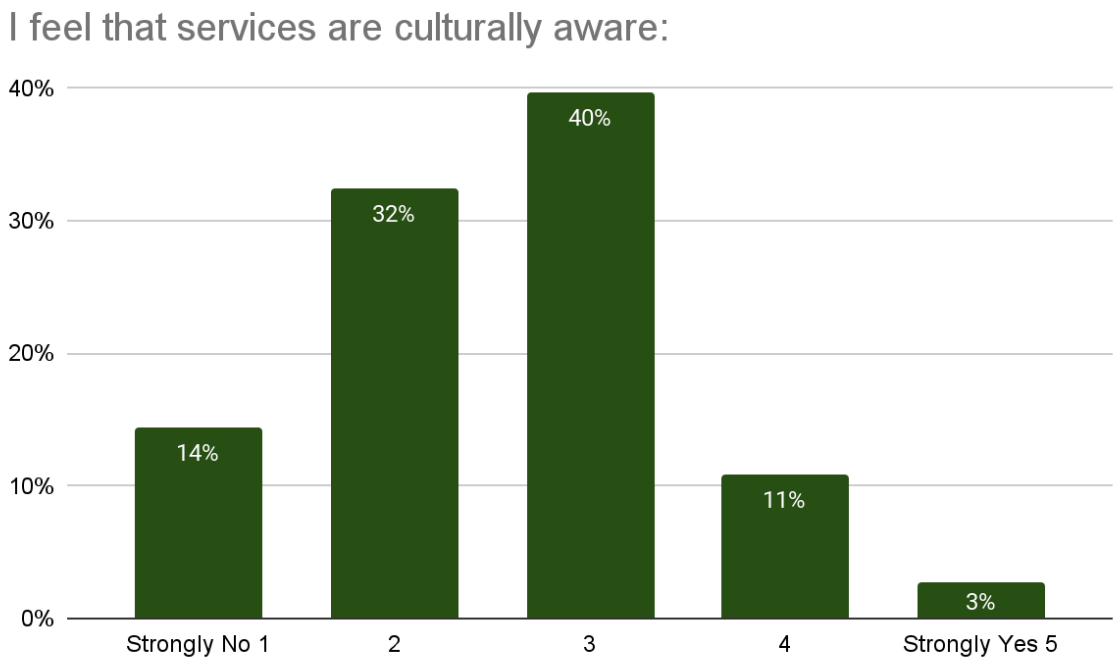
Ethnicity	No	Yes	% Yes	Total
Black/African/Caribbean/Black British	9	3	25%	12
Arab	30	6	17%	36
Asian/Asian British Overall	43	17	28%	60
Bangladeshi	9	3	25%	12
Chinese	10	0	0%	13
Indian	2	2	50%	4
Pakistani	10	5	33%	15





- When those who had not accessed mental health services were asked **if they felt that they would be able to if needed**, **50%** felt they would be able to, **10%** said they would not be able to and **40%** said they didn't know.
- Although there were very few respondents in the **18-24** age group, almost **40% of them had used mental health services** while in 65+ respondents, none of them had.

Cultural awareness of mental health services



Cultural awareness was defined as, "they are knowledgeable about my religion. They understand the norms, customs, traditions, and needs of my community .'

- **14% of survey participants felt strongly that services were not culturally aware** while **only 3% felt strongly that they were**. 32% were leaning towards services not being culturally aware. 40% were neutral and 11% leaned towards yes.

'Counselling on basis of western culture may create further friction for a child for example in a household as behaviour change in child may increase the tension within that particular household '

'Make it easy for those who seek help to choose the person who can understand his needs, at the same time it removes the embarrassment that he has to explain his culture to people'

- Many **interviewees** stated that they **did not know if services** were culturally aware and **3 assumed they were not.**

'They should be aware of our current situation, as we come from countries that are totally different in terms of religion, customs and tradition.'

- **3** interview participants felt **that they were culturally aware,** give advice, provide interpreters, and keep data confidential

My personal experience is positive, they did understand my needs plus I can speak English that makes a huge difference.'

"They need to consult with specialist services by and for racially minoritised groups.'

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Participant Recommendations

Decrease stigma:

- Increase awareness of **anonymity** of services.
- **Embed** mental health services in other services as opposed to separate clinics
- **Avoid** patients needing to **explain their culture**
- **Avoid label of mental health problems** when appropriate.
- **Clarify thresholds** for use of services: you don't need to be in a crisis to access services

Cultural awareness/diverse practitioners:

- Mental health services should develop **familiarity with different local cultures** and **adapt their services** accordingly to people's cultural needs rather than making service users assimilate.
- **Increase awareness of cultural differences in understanding mental health,** gender roles, family structures, cultural or religious restrictions, taboos, and traditions.
- Service providers from **different cultural and ethnic backgrounds** as well as the need for **practitioners who speak multiple languages**
- **Interpreters** should be **widely available and advertised as such.**

Alternatives to more traditional services:

- Offer **options for services that focus on collective/community wellbeing** versus only individual mental health. Some cultures are less focussed on the individual as the focus of intervention.
- **Include family members and family therapy** if the cultural norm is to deal with issues within the family-
- **Provide services to family members supporting someone with mental health problems** (including awareness building and information)
- **Creative/holistic approaches to mental health services** such as the use of social groups, entertainment groups, team building for whole families, buddy systems, and financial/housing/education support.

ParticipantRecommendations

Community engagement:

- **Increase awareness of mental health in different communities** via awareness building in schools, jobs, colleges, etc., by putting literature in religious buildings, using community ambassadors, compulsory courses and more.
- **Increase awareness of mental health services through targeted advertisement** in community newspapers or flyers, promotion in community groups
- **Use schools** to build awareness, increase conversations around mental health, and connect to services.

Normalise use of mental health services:

- Make **services more accessible or built into existing physical health** systems by **implementing mental health checks at annual GP appointment,** putting **mental health services into GP practices**, or having walk-in mental health services.
- Clarify that **mental health services are for anyone and everyone** and should be engaged with at the onset of symptoms, not just at crisis stage.
- **Decrease fear of consequences** of engaging with services such as **children's services become involved, hospitalisation, etc.**
- **Clarify impact and treatment options.** Services are more than medication prescribers.

*All recommendations came directly from comments made in either the surveys or the interviews.

Researcher Recommendations

The following recommendations were specifically highlighted by the peer research team to reflect the recommendations that they felt were the most important or additional recommendations not reflected in this research.

- More information available in **multiple languages** about how **to contact and access services. Use of leaflets**
- Reduce stigma by **incorporating mental health services into other services** so that service users don't have to go to a special building and be identified as in need of mental health support.
- **Awareness of language used when describing mental health services to avoid further stigma.**
- **Increase awareness of mental health** in general.
- **Demystify what happens** when you access mental health services.
- Develop a **training programme to train parents on how to deal with mental health challenges**
- Service providers could send **weekly tips** on mental health
- Service providers could hold **monthly sessions on mental health to reduce stigma**

Future Research Directions:

- **Repeat peer research biannually** or annually to track changes that might happen in the future.
- Similar research could be done to understand what the **impact was on children** so that parents/service providers can understand how to deal with children's challenges.

References

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