

Using Linked Data to Address Mental Health Questions:

Public Involvement with Young People

Aims

PPI with young people aimed to find out:

1. Which research questions and topics young people think we should focus on when using linked data.
2. How we should share and present research findings, so they are clear, understandable, and accessible to young people.

Methods

Young people aged 11-18 were invited to take part in a 1-hour group discussion about mental health and research priorities. The PPI opportunity was advertised on the McPin's (a charity dedicated to involving the public in mental health research) website and social media channels (<https://mcpin.org/>). In addition, four youth groups from the East of England were contacted directly by email.

In each session, the researchers provided a brief overview of:

- What is research?
- What is public involvement?
- The MHCYP dataset and National Pupil Database linkage
- Using linked datasets to answer questions about mental health

Following this overview, researchers showed participants a mind-map on a virtual whiteboard and used this to facilitate a discussion about mental health. The whiteboard was pre-populated with key topics that are related to mental health. These were drawn from the AfRI research questions. Young people were asked to discuss these topics, and to highlight any additional topics they felt were missing. Young people were then shown a second mind-map which was used to facilitate a discussion about how to present and share research findings.

Findings

Young people aged 13-22 (N=26) took part in PPI sessions in May and April 2025. There were four PPI sessions in total, each with unique participants. Three PPI sessions were arranged via McPin recruitment and took place online. One in-person session was arranged with a youth group.

During the online sessions young people contributed verbally and in written format using the MS Teams chat function. The virtual whiteboard was difficult to use on mobile devices so for the young people who were joining online meetings using their mobile

phones the researchers recorded the ideas on the whiteboard for them. Coloured paper was used in the in-person session for young people to write down their ideas.

1: Which research questions and topics do young people think we should focus on when using linked data?

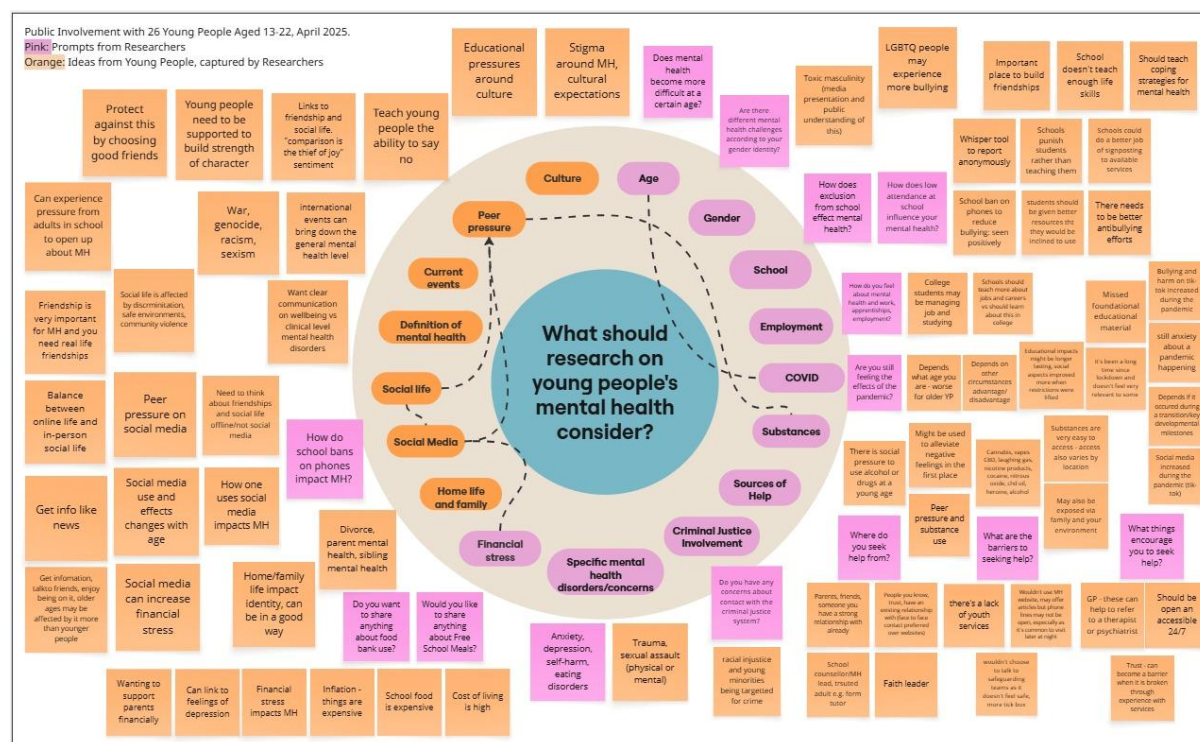


Figure 1. A virtual whiteboard co-created by researchers and young people to identify topics that should be prioritised in mental health research.

Items on the whiteboard shown in pink are those that were pre-populated by researchers based on AfRI research questions. All items shown in orange are ideas that were contributed by young people (captured/written by researchers). The dotted lines also show connections that young people identified between topics. The board can also be viewed here (with the option to zoom in):

https://miro.com/app/board/uXjVI_4wlul/?share_link_id=735210195245

Topics added by young people

Young people added seven topics that they felt should be a focus of research into young people's mental health. These included: peer pressure, social media, social life, home and family life, current events, culture and the definition of mental health.

Peer pressure

Young people agreed that peer pressure was a strong influence on their behaviour when growing up. They felt that young people need to be supported to build strength

of character and feel it would be helpful for schools to teach and encourage the ability to say no. They highlighted the importance of choosing good friends and felt this could help to protect young people against negative effects of peer pressure.

Social media

Young people felt that social media should be a key focus of research. They felt that social media was not inherently bad for their mental health, and that it could have both positive and negative influences, depending on the way in which it is used. For positive effects, young people said they get information, news, enjoy being on it, and talk to their friends. They noted that social media use and effects change with age and in particular, older ages may be more negatively affected by it than younger ages.

Social life

Young people wanted research to explore their offline social life and friendships. They feel that this is a really important component of their wellbeing and mental health, but adults often speak more about social media and their online environments. Young people felt that their ability to engage with an offline social life was impacted by discrimination, the availability of safe environments, and level of community violence. They emphasised that friendship is very important for mental health and that they need real life friendships.

Home and family life

Home and family life included examples such as divorce, parent mental health and sibling mental health. Young people felt that home and family life impact their identity and that this could be in both good and bad ways.

Current events

Examples of current events included war, genocide, racism and sexism. Young people described wider social conditions and international events as being able to bring down the general mental health level, and that this in turn could affect their individual mental health.

Culture

Young people highlighted that cultural background can be a key influence on mental health. In particular, they felt that some cultures place strong expectations and educational pressures on young people and also stigmatise mental health.

Definition of mental health

Young people asked what we mean by mental health and thought that it was important to receive clear communication about wellbeing vs mental health

disorders. We described mental health as a continuum, where everyone's feelings and mood vary on a regular basis and that mental health includes this daily variation. We then explained that some people experience more consistent challenges that start to regularly effect their daily life and people with more persistent challenges may receive a diagnosis of a mental health disorder (with examples such as anxiety, depression, self-harm, eating disorders). When speaking about specific mental health disorders, young people wanted to add trauma and sexual assault (physical or mental) to the research focus.

Key ideas added to topics originally identified by the research team:

Of the topics that were pre-populated by researchers, the most widely discussed by young people were school, sources of help, COVID, substances and financial stress.

School

Young people agreed that school was an important influence on their mental health. They recognised it as an important place to build friendships and highlighted some school-based strategies that had positive effects on their wellbeing, such as a whisper tool to anonymously report concerns and a school ban on phones to reduce bullying. On the other hand, young people felt that schools: do not teach enough life skills, punish students rather than teach them, need better antibullying efforts, could do a better job of signposting to available services, should teach strategies for mental health.

Sources of help

Young people primarily seek help from someone they know, trust and have a strong existing relationship with, such as parents and friends. Second to their close friend and family circle, some young people said they would seek help from trusted adults such as their form tutor, school counsellor, mental health lead, or their faith leader. Others said they wouldn't choose to talk to safeguarding teams because it doesn't feel safe and instead feels like a tick box response. All groups expressed a preference for face-to-face contact over websites. When asked about the barriers to seeking help, young people said there is a lack of youth services, and many wouldn't choose to use a mental health website. A key barrier to using mental health support websites was that it is common to visit these later at night and many of their phone lines are not open. This doesn't align with their preference for direct contact with a person for support. Young people were also asked what things encourage them to seek help, and this included trust, support being open and accessible 24/7, and GPs as they can facilitate referrals.

COVID

With regards to COVID, a minority felt that it has little relevance to their mental health now. However, the majority felt that it was an important area for research and the impacts were likely to depend on your age, socioeconomic circumstances, and whether the pandemic occurred during any key transitions or developmental milestones. Some young people suggested that social impacts improved when restrictions were lifted, but that educational impacts might be longer lasting due to missing key foundational educational material. Some noted that online bullying and social media use increased during the pandemic and others shared that they have anxiety about another pandemic happening.

Substances

Substances were described as readily available to young people, including cannabis, vapes, CBD, laughing gas, nicotine products, cocaine, nitrous oxide, CBD oil, heroine and alcohol. Many young people agreed that vape use should be a key focus for researchers. They described different reasons for young people trying substances, including to alleviate negative feelings, peer pressure, and exposure from the family environment.

Financial Stress

Young people agreed that financial stress can lead to feelings of depression and negatively impact their mental health. They described the significant impact of the cost of living crisis, school food as expensive and of poor quality and some young people described a need/want to support their parents financially.

Links identified by young people

Young people identified connections between topics including:

Age and COVID

The effects of COVID depend on what age you were when it happened and whether you were in a key transition or developmental milestone. They speculated that the impacts would be worse for older young people (e.g. those doing their GCSEs, A-Levels, in university, first jobs or seeking their first job).

Peer pressure and substances

Some young people may turn to substances to alleviate stress or negative emotions; however, others may be drawn into trying or using substances due to peer pressure. They felt that the majority of young people engage with substance use due to peer pressure.

Social media and peer pressure/financial stress

Young people linked financial stress to social media and peer pressure. They felt that social media perpetuated expensive lifestyle ideals that they felt pressured to keep up with. Many described feeling the need to earn money in order to emulate the lifestyles that they see on social media (e.g. travel, fashion).

2. How should we share and present research findings, so they are clear, understandable, and accessible to young people?

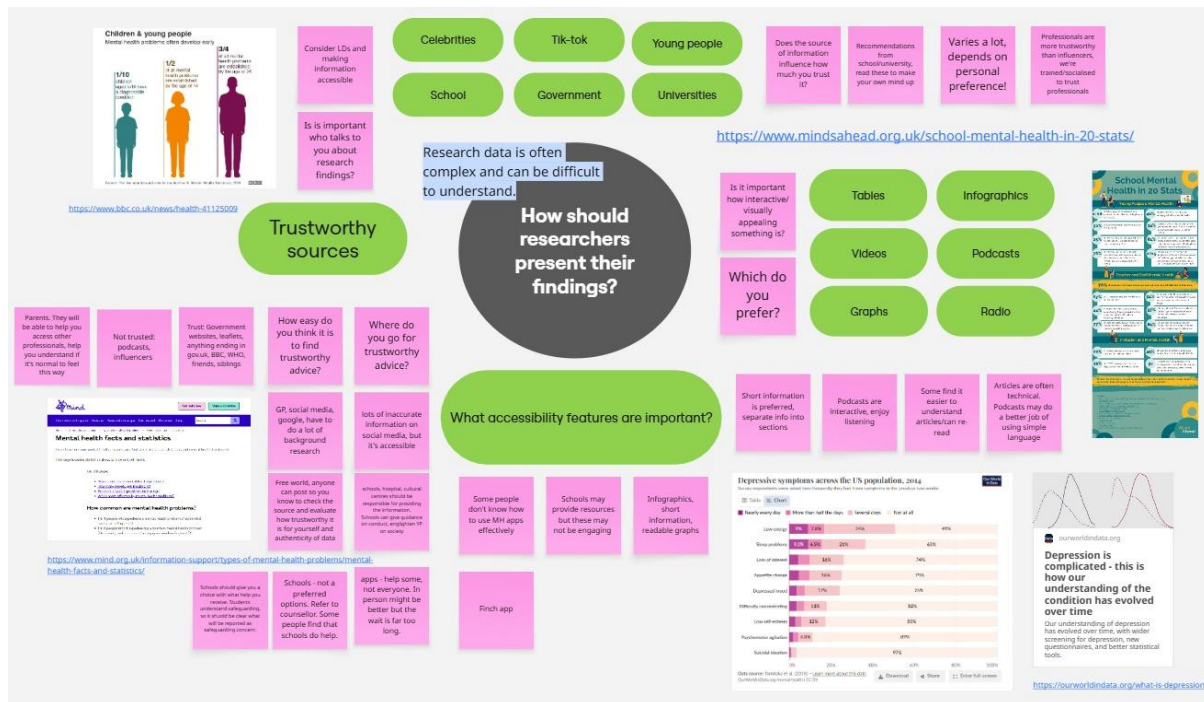


Figure 2. A virtual whiteboard co-created by researchers and young people to note preferred methods of presenting research findings.

Format of research findings

There were a wide range of opinions on how research findings should be presented. They valued all major formats for different reasons (written, graphs, numbers, infographics, podcast, videos, tables) and agreed that researchers should present findings in a wide range of formats in order to cater to different preferences.

- For written text, there was a preference for short information separated into sections.
- Articles can often be too technical, but they like having written information because they can re-read it to help their understanding.
- Confident reading graphs if they are clearly labelled and described.
- Infographics and visually appealing graphs were more engaging than traditional line graphs or bar charts.

- Podcasts were popular as they are interactive and are often good at pitching the content to the right audience and using appropriate language.
- Researchers should consider learning difficulties when sharing their findings and make the information accessible.

How trustworthy information is

Young people felt very confident in their ability to assess how trustworthy a source is. They felt very aware that anyone can post information online, so it's necessary to do background research, check the source and evaluate how trustworthy it is for yourself. Examples of sources that they do not readily trust include podcasts, influencers and social media. Examples of sources that they do trust include parents, friends and siblings, government, professionals, leaflets, websites of well-known organisations such as WHO, BBC, and websites including gov.uk.

Importance of human contact as opposed to websites

Young people felt that organisations such as schools, hospitals and cultural centres should be responsible for providing reliable information regarding mental health. They emphasised that human contact is important in the communication of mental health information.