

Understanding how young people want to communicate about their mental health

Written by Vanessa Bennett

Reviewed and edited by Caitlin Brookes and Amelia Crook (NeuroX YPAG members)

As part of the March BeGOOD session, young researchers offered their perspectives across a broad range of challenging topics, some that they feel are avoided or not openly spoken about. These included preferred communication approaches about their own and peers' mental health; and what methods and language may appeal most for different mental health challenges, personal psychologies and life experiences.

The context for this session was primarily on what language and means of communication and research young people felt most appropriate when involving young people in research. Inevitably this also crosses different contexts for young people though!

What language and approaches should we use in mental health research and interventions?

“Prefer more empathy and less clinical”

“Anxiety is often trivialised and the extent to which it affects many people not understood, which can be invalidating”

“Talking more about little things adding up(?) or what it means to the person – rather than anxiety and depression being caused by big things – may prevent invalidating young people’s problematic experiences.”

Young researchers strongly expressed a desire to shift the language used away from clinical terminology with greater empathy for ‘all’ experiences of their mental health in research and mental health interventions to enable young people to feel more “at ease”, environment. They discussed the language used around mental health – they felt that this needed to be more age-appropriate (but not patronising) and empathetic to gain a better understanding of young people’s problems, engage more to reduce stigma/barriers in a safe, comfortable environment to talk about mental health and how this can have an impact on society and the individual...

Clinically focussed approaches and terminology potentially trivialises and invalidates some young people’s experiences, particularly if they are told they are ‘not eligible’ for support. For example, they may perceive their problem is ‘not serious enough’ if they do not meet clinical thresholds. To young people (and adults), this may translate to being told that their experiences of poor mental health are not out of the ordinary.

Personalisation and individualisation are terms riddled through their feedback and clearly important. They indicated that setting a better balance between a wellbeing and clinical focus in both research and interventions is important to be more inclusive of the individual’s conceptualisation of their own

experiences. Critically, this may not match that of the adult researcher or clinician, no matter how hard we try? Although, the use of more open-ended questions asking to describe or explain personal experiences could help young people to explain in their own way.

Enhancing knowledge, discourse, and personalising research and intervention approaches for specific mental health challenges, self-harm and suicide

“Suicide is an extremely sensitive subject, so therefore it should be the person’s choice on what and how they talk about it. Uncomfortable talking about self-harm and suicide if not expecting it.”

The young people didn’t seem to hold back and broached some very intense, emotive topics. But I’m not surprised. In fact, ‘not avoiding them’ is one of their main messages. They feel talking more helps you feel less alone and remove the stigma associated with self-harm and suicide, and better prevention. However, they also point out that sadly this often comes too late and feel it is frequently avoided due to these aspects of mental health being avoided and unspoken particularly by older generations. They acknowledged sensitivity and good practice not to spring such topics and conversations on people, particularly those in recovery who may be easily triggered. They highlighted a need for empathy and understanding but also creating safe opportunities, forums or methods for individuals to communicate these thoughts and be included in research.

Adopting diverse approaches and methodologies to include more voices in research

“Some people might want to talk about their mental health face to face with someone who can perhaps provide comfort, reassurance or support. However, others may be uncomfortable with the idea of an interview or talking to someone else and would perhaps prefer a survey or a more automated form of talk. Depends on the person.”

Further discussion broached different methods for young people to ‘talk’ and give a voice to their experiences without feeling judged or patronised which is more likely to produce a positive outcome for the young person. Young people discussed human as well as automated technological approaches such as ‘bots’ and apps’ to include diverse voices. Confidentiality and anonymity are key to opening up and finding a voice for some young individuals, and maybe even more so for different sex and gender identities. However, young people with different gender identities noted that they don’t want to be labelled and singled out; they want to be included rather than becoming more isolated. Important points to be mindful of in setting our equality, diversity and inclusion approaches!

Key points they noted:

- *Research involving human interaction may offer a source of comfort, reassurance and support; talking to a real voice and knowing someone is listening.*

- *Others may be uncomfortable with the idea of an interview or talking to someone else and may prefer a more automated form of talk where you can message instead of speaking.*
- *Some may feel more comfortable with tick box, multiple choice questions, particularly for many men or those who find it more difficult to openly discuss mental health topics.*
- *Anonymity may also be important to allow people to engage and/or open up.*

Investigating earlier preventative approaches – system of help/advice

“System of help/advice addressing pyramid of needs from bottom level ways to make you feel better to higher level advice.”

“Being taught how to self-soothe”

“Being taught how to properly soothe or talk to others when they are distressed/sad.”

Young people described their wishes to advocate for earlier help more closely aligned with an individual’s needs; following a ‘pyramid of needs’ approach. Although prevention may be the focus of much research at the moment, awareness of such approaches in life or research among young people may be low or perhaps inadequately communicated. They gave some thoughts on what preventative approaches could look like including: being taught self-care and self-soothing techniques to support their own wellbeing as well as gaining skills on how to support others.

Development of ‘resilience’ is widely reported to be protective when encountering mental health challenges. Interestingly, despite the following prompt on the Padlets, *“What does resilience mean to you”*, ‘resilience’ was not recorded. There could be many explanations to this. They may have just decided not to talk about it, avoided the term or not jotted it down on the Padlet! Part of the leap of faith for a researcher – you can’t have everything! Exploring how well understood and salient ‘resilience’ is for young people can go on the next agenda.

In terms of information and sources of systems for getting help and advice, they feel that a large variety of resources are available, but the downside is that this could easily become overwhelming as you may be unsure what kind of support is right for you. Young people seem to want to be involved in improving their own and other's wellbeing and mental health but training, resources and availability of information is potentially a barrier and not spoken of or offered enough.

How do young people want to be involved in shaping their/other young people’s mental health?

“Maybe YP want to offer mental wellbeing schemes.”

(What would help is...?) “Advocating for therapy as a preventative measure rather than just once things have already gone wrong”

Many YPAG members have been involved in research around peer support¹ with the Neurosec Team and other researchers over the past year, and so we were also keen for them to discuss this topic without us present. Some of their suggestions are summarised in the accompanying report. They identified types of support and resources they think may be helpful and/or would like to be involved in, and make social media a place where mental health is not stigmatised. Anonymity, privacy and flexibility are important features of peer approaches to support mental health. While asking for advice was important, flexibility to offer advice offered perceived benefits to some young people. They noted that helping others can also be a means to improving their own wellbeing skills, self-care and mental health.

Facilitators and barriers to engagement, participation and involvement in research

“Showing that involvement can create a positive change”

“People coming together to help others allowing adolescents to have a voice”

“Clear demonstration that they are being heard”

“There is only so much we can do without adults properly engaging first (e.g. schools, the NHS) – YP want their voice to be heard so there's no disconnect between generations”

The young researchers provided an extensive list of facilitators and barriers to being involved in research or its outputs, offering great insights for researchers (and all adults) on what being involved and feeling heard means to them as an individual! They also give some great advice on what stops them interacting and contributing.

In their own words... who you think needs to listen, why and what makes you feel heard?

The young researchers compiled a comprehensive list of stakeholders that they would like to listen to their views. They expanded on the role that each of these agents have in improving the mental health of young people and what they felt needed to happen to demonstrate change.

1. ¹See our previous Covid consultation with young people on supporting young people's agency in Covid-19 here: http://oxfordhealthbrc.nihr.ac.uk/wp-content/uploads/2021/05/YPAG_McPin-COVID-survey-pilot-consultation_summary_final.pdf