Research Involvement and Engagement

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How to talk to young people about their mental health: a co-produced psychoeducation video

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Abstract

Background When creating resources, such as psychoeducational materials, for children and families, it is essential to consult all stakeholders. By asking service users what they would find helpful, we can ensure that psychoeducational materials developed are directly addressing a need. This report summarises the process of co-developing a psychoeducational video with young people for the adults in their lives.

Methods and results The idea for a psychoeducational video originated from discussions within a Youth Advisory Group in a South London Child and Adolescent Mental Health Service. The group shared that they wanted a way of letting the adults in their lives know what is and is not helpful to hear when they are experiencing mental health distress. A workshop was held with young people to gather ideas for the content and style of a psychoeducational video resource. Through co-design methods, themes were identified including prioritising the young person's lived experience, the importance of listening, respecting and validating, adults not making assumptions about a diagnosis, and actively involving young people in care planning. A script and accompanying video were produced over several co-design sessions and shared via multiple online mass communication channels.

Conclusions This project was co-produced at all stages by young people with lived experience of mental health difficulties to develop a digital resource that they considered necessary and meaningful. Centring the voices of young people when producing materials concerning their mental health results in valuable resources and can bring autonomy to those involved.

Keywords Child mental health, Co-production, Patient and public involvement, Psychoeducation, Digital mental health, Co-design

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Background

In the UK, approximately 18% of young people between the ages of 7 to 16 have a probable mental health difficulty, with over 1.2 million young people referred for mental health support in 2022 [1]. As well as offering direct support, Child and Adolescent Mental Health Services (CAMHS) play a key role in sharing psychoeducational resources which might benefit children and their families. Resources can include information, advice, and coping strategies for both young people and their families. Parents and caregivers are often invited to play an active role in their child's treatment at CAMHS. For example, caregivers can be invited to join appointments or even take on a 'co-therapist' role [2], and many psychoeducational materials have parents as their target audience. Consultation with parents and carers revealed that they want resources to give them an understanding of their child's diagnosis, the services they were accessing, and how to identify symptoms in their child [3].

Psychoeducational materials are often presented from a theoretical model which can describe a mental health difficulty, its maintenance factors and potential interventions [4]. Fewer materials have been created which centre the lived experience of young people experiencing mental health difficulties. Such a resource would benefit caregivers by providing them with an understanding of a young person's experience, and would benefit young people since they may be able to relate to and share the resource.

To develop effective and engaging resources for families who are accessing CAMHS, it is important to combine professional expertise with the lived experience of young people. Co-production processes involve services users in the conceptualisation, design, implementation and evaluation of projects [5]. Asking service users what they would want and find useful ensures that the resources developed can match their needs and that their voices are centred in the development. Resources like psychoeducational materials aim to provide an explanation for mental health distress, however too often they do not include lived experience. By involving young people with lived experience of mental health difficulties in the development of psychoeducational materials, we can ensure that they are targeted towards the needs of the young people and their families.

The aim of this project was to develop new psychoeducational material through consultation with young people with lived experience of mental health difficulties. This report summarises the process of co-developing a psychoeducational video resource with young people for the adults in their lives.

Methods and results

This project is described using the Double Diamond Design Model [6], which depicts a general template for the steps taken in any design project. The model consists of four stages: (1) The Discover Phase, (2) The Define Phase, (3) The Develop Phase and (4) The Deliver Phase. In the Discover Phase, an idea is established, which is then further refined into specific goals in the Define Phase. The aim of the Develop Phase is to iteratively consult and redefine the product until all stakeholders are satisfied. The Deliver Phase then consists of finalisation and dissemination [6].

The discover phase

The idea for a video resource originated from discussions in a Youth Advisory Group (YAG) held within a South London CAMH service. The YAG holds monthly meetings and is attended by both current and former service users of CAMHS and facilitated by clinicians (authors AB, JD, NK and JR). The young people attending the YAG expressed a desire to communicate to the adults in their lives what is and is not helpful to hear when they are experiencing mental health distress. It was thought that developing a novel resource that captured these messages would be an important way of supporting young people in their mental health recovery. During the YAG meetings, it was agreed that the first stage would be to facilitate a discussion between young people to generate ideas for the video content and style.

The define phase

A 90-minute workshop was held with authors AB, JR and RB and five young people to discuss ideas for the video. The young people's ages ranged from 15 to 17. The first 60 min of the workshop was dedicated towards discussing ideas for the video content, which would then be developed into a video script. The remaining 30 min were dedicated towards discussing the style of the video, which would then guide the CAMHS Digital Clinical Team (JD and RB) in creating the first iteration of the video. For those who expressed interest, written consent for recording was sought before the workshop from young people who were 16 years and over, and consent from their caregiver was sought for those who were under 16 years.

The discussion began by creating a word cloud in response to the question "What are some common misconceptions or myths about mental health?" Fig. 1 displays the word cloud created by the young people in attendance in answer to this question. It contains elements around stigma such as 'it's your fault', 'victims are weak', 'try harder', 'it's curable', 'trend', 'shameful', 'attention seeking', 'embarrassing' and 'failure', as well as unhelpful advice that had been previously heard such as 'cheer up' and 'just be positive'. Young people also noted

Fig. 1 Word cloud produced at workshop

Table 1 Themes and quotations for 'what not to say'

Themes	Quotations
Unsolicited advice	"Any advice that begins with just, you can safely assume that the person has already thought of it, or already tried it and that perhaps it hasn't worked." "The majority of comments that, like, I received when I was really struggling with my mental health were comments that I did not ask for."
Assumptions of understanding of someone else's experience	"People need to stop assuming things in general for people because you just don't know, like, what someone… what someone wants support wise or if someone just doesn't want your support and, like, that's fine too." "I feel like a lot of people, especially adults, they will actually educate themselves a little bit on mental health. They will try because they want to help you, but they will forget that it is really different for everyone."
Minimising experiences	"I tell people I have OCD and they say 'Oh I'm like that' because they are organised. It's not sort of done intentionally; it's done to relate but it all ends up feeling a bit insulting." "They almost… they basically see depression, sad anxiety, worried and worried is natural because you have exams."
Not listening to me or respecting my request	"And they weren't really helpful in the sense to, like, leave me alone type thing even when I explicitly said can I have this or whatever. I feel, like, unheard in a way."
Not involving me in my care	"Schools, they come up with schemes to try and help the problem but they never kind of involve students in the schemes."

misunderstandings they had heard about mental health difficulties such as 'OCD equals cleanliness' and 'neurodiversity is illness'.

Then a number of follow-up questions were asked, including: "What has been helpful to hear when you've been experiencing a mental health difficulty?" Discussions centred around what young people have felt is unhelpful to hear when they are experiencing mental health difficulties, and what they would prefer to hear instead. The transcript from the workshop was anonymised and analysed for key themes using content analysis, which is a method used to distil text into overarching themes or categories [7]. JR then arranged themes into a video script and direct quotes from the workshop were included to illustrate key themes from the discussion.

The key themes that were identified from discussions in answer to the question: 'What not to say to young people experiencing mental health distress' and accompanying quotations which were used in the script can be found in Table 1:

The young people who attended the workshop also thought that the video resource should not only include ideas on what *not* to say to young people experiencing mental health distress, but also what *to* say so that it can become a more helpful resource for those who watch it. The key themes that were discussed and accompanying quotations can be found in Table 2.

These themes were then compiled and synthesised into five key messages that were illustrated throughout the

Table 2 Themes and quotations for 'what to say'

Themes	Quotations
Involve me in communication about me	"There's been a lot more communication involved and actually… been talking to me and my parents about what's going on… so it's not just like I'm a subject. I'm, like, involved in the conversation."
Listen to me and don't jump to give me advice	"I think long term it's usually just listening cause each case is so different"
Validate my experience	"Even saying 'I don't fully understand what you're going through because I haven't been through that but like… and I can see that it's really difficult for you.'"
Don't make assumptions; ask me	"I feel like people aren't gonna get offended if you say that you don't quite understand. Like it's better than pretending you do understand if you don't."

video and summarised at the end. These can be seen in Fig. 2.

The develop phase

Four pre-existing short psychoeducational videos were shown to the workshop attendees. These four videos demonstrated different styles and formats of video to generate discussion around preferences for the style of the video. The workshop attendees expressed a preference for animations to appear human-like rather than something more abstract (e.g., shapes), and highlighted the importance of diversity in terms of gender, ethnicity and ability within the animated characters. The attendees discussed how narration and subtitles are important to ensure the video is accessible, and that colour in the video is important to make it engaging. It was discussed that the video should be shorter than 5 min in order to maintain viewer engagement. Young people emphasised that it needs to feel realistic and authentic rather than scripted. The CAMHS Digital Clinical Team (authors RB and JD) used PowToon to create the animated video. The title was finalised as "*Talking to young people about mental health*". A screenshot of one of the frames of the animated video can be seen in Fig. 3.

Several versions of the video in development were brought to CAMHS YAG meetings over a course of five months. Feedback was sought over a series of iterations until a consensus amongst the consulting young people had been reached on the style and content of the video. The video was then shared with a Parent Advisory Group (PAG), a pre-existing group similar to the YAG, to gather feedback from its intended audience. Feedback from the members of this parent group was positive, and members noted that they found it a helpful resource. The final video was 3 min in length.

Fig. 2 Helpful things to remember (five key messages)

Fig. 3 - Screenshot of the animated video

The deliver phase

The young people involved in the production of this video identified their target audience as parents, carers, teachers and health professionals. It was agreed that in order to reach the maximum number of parents, it would be helpful to utilise mass communication channels including the NHS Trust's social media channels, targeting parents and carers. The video was also added to myHealthE, the Trust's online platform for parents to access resources whilst they wait for the child to be seen by CAMHS [8]. Finally, it would be distributed digitally across the Trust's schools network, GP and school nursing networks, and displayed on waiting room screens in CAMHS clinics.

Conclusions

Young people too often feel disempowered in their environments at school, home and in mental health settings [9]. Involving young service users in resource production and supporting the amplification of their voice can bring them more autonomy, a key factor in mental health recovery, in a system which can too often feel disempowering [10]. This project also appeared to have a secondary result of enabling young people who had experienced frustration with adults in their lives to feel heard and validated. One young person demonstrated this in their feedback: "*I am so happy to be part of this beautiful project to help young people with mental health.*"

This project additionally revealed how important it is to consider a young person's wider system when thinking about their mental health. Young people in the YAG faced many challenges in their daily lives, yet their priority for this project focused on wanting to be better supported by the people in their lives, primarily their parents and teachers.

A discussion throughout this project focused on the help or hindrance of using diagnostic labels when speaking about their mental health. Psychiatric diagnosis labels often carry stigmatised associations [11], yet young people, in particular, have increasingly been found to not carry stigmatising beliefs when using psychiatric labels [12]. As well as discussing how a diagnostic label can be potentially stigmatising, young people highlighted how diagnosis can bring understanding and help with access to treatment. The young people involved in this project were keen to acknowledge this dual nature of diagnosis, and not take a stance for or against. This was carefully considered within the final production of the video's script. For example, one of the 'helpful things to remember' points was rephrased from 'I'm not my diagnosis' to 'I'm more than my diagnosis'.

This project demonstrated the utility of creating digital resources and using digital channels for dissemination as well as the value of embedding a Digital Clinical Team within CAMHS to provide co-design expertise and enable and facilitate this process of digital co-production

with service users. A digital resource was of particular interest to the young people involved and meant that as soon as it had been created, it was possible for young people to share it with their networks and for existing mass communication channels to be used for its dissemination within and outside of the NHS Trust.

Co-design is becoming increasingly common especially when it comes to developing digital resources, and results in interventions which are tailored towards the needs of the communities they aim to benefit [13]. An important future direction for co-design in digital mental health has been suggested for clinicians and researchers to consider a wider range of methods to involve young people, for example 'design jams' and 'hackathons' [13].

Importantly, the idea and creation of this resource was co-produced at all stages by young people with lived experience of mental health difficulties. It is essential that co-production is not tokenistic, whereby individuals are merely informed or consulted. Rather, individuals with lived experience should be involved in the complete lifecycle of a project from conceptualisation to design, evaluation, dissemination and implementation [5]. Most importantly, for healthcare professionals, this project demonstrates how we can use the power of our positions to centre and amplify the voices and experiences of young people to support recovery and promote wellbeing.

Limitations

Although this project centralised the voices of young people, it is important to note that the young people who engaged in this project consisted of those who felt confident enough to join an advisory group, and therefore there are likely many experiences that this project does not capture. Future projects would benefit from using a wider range of involvement methods.

Abbreviations

CAMHS	Child and Adolescent Mental Health Services
PAG	Parents Advisory Group
YAG	Youth Advisory Group

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Author contributions

JR: Conceptualisation, Methodology, Writing – Original Draft. AB: Conceptualisation, Methodology, Reviewing and editing manuscript. RB: Methodology, Resource creation, Reviewing and editing manuscript. NK: Conceptualisation, Methodology, Reviewing and editing manuscript. KB: Conceptualisation, Methodology, Reviewing and editing manuscript. JD: Conceptualisation, Resource creation, Methodology, Reviewing and editing manuscript.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

Written consent was sought from young people who were 16 years and over, and consent from their caregiver was sought for those who were under 16 years to take part in the workshop.

Consent for publication

Written consent was sought from young people who were 16 years and over, and consent from their caregiver was sought for those who were under 16 years for anonymised quotes to be used in publications.

Competing interests

The authors declare no competing interests.

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