

'What' matters to 'Who' in mental health research with young people?

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Introduction

Young people are increasingly involved in health research; however, what the true impact is and how to define this is less well understood [1-3]

Impact could be explained as the meaningful change or benefits that arise through involvement across three different perspectives: [1,3]

1. Promoting, supporting and developing ethical frameworks for young people's (YP) involvement
2. Direct impacts for young co-researchers, and researchers
3. Indirect impacts (knowledge production) benefiting research and other diverse YP

This co-produced poster reports on our collective perspectives of the involvement of young people in the NeuroX Young People's Advisory Group (YPAG) across a range of research projects over 3-5 years. Full details of all projects the YPAG has been involved in, including advisory sessions and consultations, are available in references [3-12]. The aim is to illustrate what young people believe matters to who or what in mental health research.

Context and Methodology

The NeuroX YPAG was started in 2015 with a Wellcome Grant for the BeGOOD study.[4] A new cohort of 26 young co-researchers (YCoR; aged 13-16 years) joined in November 2019. From March 2020, the group were involved in additional projects supporting research within the University of Oxford, other Universities and third-sector partners.

This work was funded by the Department of Psychiatry/Oxford Health Biomedical Research Centre, other research grants (Emerging Minds UK) and external collaborators (NSPCC). [6,7]

The projects YCoR have been involved included:

- approaches to involvement: co-production, single advisory sessions and multiple consultations
- stages of research and applications: study conceptualisation, design, analysis, interpretation, recommendations for service development, dissemination, research grant proposal development.

This poster summarises the perceptions of YCoR from their/group experiences on projects selected by young co-authors to illustrate benefits. Not all members of the full NeuroX YPAG have been involved in all projects; YCoR chose to be involved in different projects.



OUR POSTER, OUR VOICE

FEATURED PROJECTS

● YOUNG CO-RESEARCHER BENEFITS ● OTHER YOUNG PERSON BENEFITS ● RESEARCH & RESEARCHER BENEFITS



CHILDLINE MESSAGE BOARD [3, 12-14]

Co-production with NSPCC evaluating the 'message board' feature on their website. The project was focused on emotional abuse and neglect.

We met via Zoom over a few months. Collecting, analysing and interpreting message threads, then giving feedback to Childline about the message boards and making recommendations about how they could be improved.

Developing skills in study design, sampling data, data analysis and dissemination

Feeling as though it was making a difference (Included in NSPCC 35th celebration and BBC news)

Experience of wide range of communication activities

Collaborating and learning about different aspects of NSPCC work: policy and funding

Being understood by researchers

Highlighting gaps in research

Insights to improve message boards/resources

Support further research in this area of help-seeking and peer support

Explore an under-researched area of YPs help-seeking

Gaining insight into language used by YP and their priorities

Clear feedback on the message boards (via presentation, discussion and recommendations across all impact areas)

ANTIDEPRESSANTS FOR YOUNG PEOPLE WITH DEPRESSION AND ANXIETY [15, 16]

YPAG members and young researchers from The McPin Foundation joined 3 on-line workshops and involvement in animation with researchers and discussed initial thoughts and feelings on antidepressants called Selective Serotonin Re-uptake Inhibitors (SSRIs).

Learn about antidepressants

Express opinions and views to researchers

Speak in a group

Record audios for animations

Co-produce an animation

Animation that accurately represent YP

Dissemination is clear

De-stigmatising antidepressant/SSRI usage for other YP

Discover the gaps in knowledge and research relating to SSRI use for YP

Received feedback from YP on their research and how to accurately communicate YPs perspectives

The young people also provided insight and supported the production of an animation video for the review. It was really nice to include some of the young people's voices in the video to add meaning to the video content and to make it more valuable and accessible for other young people watching.

TRENDS IN ANTI-DEPRESSANT PRESCRIBING UNIVERSITY OF NOTTINGHAM [17]

Two consultations were carried out online - 15 months apart

Session 1 - Looked at seasonal trends in a year for different mental health conditions - design phase

Sessions 2 - Looked at results and patterns of trends - interpretation phase

Learn about quantitative research, such as relative risk and trends on graphs

Learn more about mental health conditions

Understand seasonal trends in mental health and prescribing of medicines

Understand more about large complex database studies

Improving knowledge, future research and potentially better use of antidepressants to support YPs mental health

Listen to YCoRs views on anxiety and depression

Understand issues which they may not have heard of situated in the context of YPs lives and experiences with antidepressants

Helping people understand how database studies work, and showing the useful information they can provide, as well as gaining insight into our results are incredibly important. We'd strongly encourage researchers from all backgrounds to consider involving the public as much as possible in their projects.

There was another breakout session where we asked about the reasons they thought might explain the patterns we found. This produced a really fascinating discussion where the groups raised lots of issues that hadn't occurred to us, as well as focussing on aspects that we hadn't considered as so important.

NEW TREATMENT FOR BINGE EATING DISORDER [18]

Young people met in a single advisory session (with pre-reading). In breakout groups, YP discussed supportive digital approaches to treatment for binge eating disorders. Fed back and discussed with the researchers.

Learn more about binge eating disorders

Have discussions with researchers

Provide a safe space for young people to talk about sensitive topics

Future studies and treatments for binge eating disorders will be better informed and shaped due to including YPs perspectives in this research

Learn young people's opinions about different treatments

Hear young people's opinions on designing a study to evaluate new treatments for binge eating disorder

The young people provided useful insights into their priorities, preferences, and concerns about our research. They articulated clearly the advantages of digital treatment for Binge Eating Disorder in terms of it being discreet and something which could be discussed to help avoid potential embarrassment and judgement from others.

CO-AUTHORING PEER-REVIEWED PUBLICATIONS [3, 12, 13]

Evidence for evaluation and the triad of benefits are reported in detail in the case study and published papers.

Four members from the YPAG are co-authors on papers published papers

They started to develop skills in academic writing

Involved in each stage; gained a first-hand account of the publication process from outline to publication

PODCASTING + BLOG WRITING [19-21]

Five of the YPAG made their own podcast chatting and reflecting on joining the group, what had changed and what they felt they had gained from being members. They utilised some of their Story Collecting Training.

Some YCoR members have written blogs about their experiences.

Improve confidence

Learn how to structure and record podcasts

Reflect on our experiences

Come together as a team to discuss our experiences

Talk about involvement research & co-production

Improved writing skills

Expressed our thoughts, opinions, views on YPAG

Time and project management

Working with other organisations: Co-Production Collective

The co-production process allows researchers and young people to share views, opinions, and beliefs on a wide range of mental health related topics. It is a positive forum where everyone's perspectives are heard, and all views are listened to - without judgement. Because of this it can really increase your self-confidence to talk in front of a large group. It also helps you think about your views and hear different perspectives.

Educate other YP on what a YPAG is, what the benefits are what they could be involved in

Talked about the welcoming, safe environment

Encourage diverse YP to join regardless of ability or knowledge

Listen to young people's opinions and experiences of being in a YPAG

Listen to what young co-researchers enjoy about being involved in research; what works and what doesn't

Understand involvement processes and practices from YCoR perspectives

Dissemination and evaluation: communicating and capturing the benefits using a range of media for different audiences

WORK EXPERIENCE [22]

Online multitude of activities; worked with BoingBoing, NSPCC and BeGOOD.

Flourishing

A new potential research project: discussed elementary ideas on what should be pursued and how to go about this.

BoingBoing

Giving objective peer feedback on how to improve their research strategy. Given an outline of how to assess whether activism can improve the mental health of YP facing multiple systemic disadvantages.

NSPCC: policy group session

Discussed politics of making laws, campaigning and funding. Created a presentation to communicate the Childline project to funders.

Variety of different exercises and experiences

Developed plenty of skills

Ability to work in groups thoroughly practised

Encouraged to put your point across: discussed and felt heard

Quality of conversation and encouraged higher participation

I learned to not be as afraid to give my view on things, and it was nice for my contributions to have an effect on the overall result. To work well and function within a group. A stronger ability to find a problem or a question and being able to break it down so it's more manageable, also an enhanced belief on how important and useful this skill is.

Ways of working in involvement and co-production

The relationship between YCoR and researchers is reliant upon YCoR feeling listened to and respected by the researchers (evidenced by quotes and publications). Although YCoR may not yet have technical experience, the value from lived experience is still important.

Therefore, researchers need to support and build YCoR's abilities and skills to participate fully, and use language that is age-group appropriate, not patronising but also not assuming 'technical' knowledge.

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What matters to who?

When YP feels as though they are being listened to and respected, the involvement or co-production can embed what the YP actually think, rather than what they believe the researchers want to hear. This in turn means that research being done is more accurate and researchers gain better feedback/information on their projects. This then leads to more accurate and better research and mental health support for YP as a population.

The cyclical relationship across the different perspectives encompasses factors that 'make a difference' and can demonstrate meaningful benefits or change across the three impact areas.

Transparency and trust

Regardless of the level of involvement from YP, there needs to be transparency and trust built by the researcher/facilitator respecting YCoR's views.

Trust, transparency and respect can be created in a YPAG through mutual respect for each other & from the facilitators.

This respect includes: inclusion of different backgrounds (equality); acknowledging each other's time (understanding that YP have other commitments and pressures and therefore their capacity changes); fair benefits for YCoR; ensuring YCoR understand the difference that their involvement in the research will make.

