

NEUROSEC/NeurOX YPAG research involvement update

March 2020 – April 2021

NEUROSEC Covid-19 projects – supporting young people’s views and priorities through the pandemic

Covid-19 consultations: March to April 2020

Aim: Consultations with young people at the start of the covid-19 pandemic, when ‘lockdown’ restrictions were first put in place, intended to determine key areas to support young people’s mental health and wellbeing through research during the pandemic.

How young people were involved...

- ⦿ Survey design: 6 NeurOX YPAG members and input from The McPin Foundation
- ⦿ Survey: 15 NeurOX YPAG members; 15 young people from The McPin Network
- ⦿ Review of results: NeurOX YPAG, Global Young Leaders and McPin young people
- ⦿ NeurOX YPAG on-line session: 29 young people

What young people told us...

Main worries at the start of lockdown were loss of connection and wellbeing relating to social isolation, anxieties around education and dealing with uncertainty.

They felt it was important to respond to young people’s needs to connect, share experiences, and support each other. They suggested equipping young people with knowledge, capability and means to support each other in an on-line community.

What gives you hope and comfort during this time of crisis?

How can young people support each other?

| | | | | |
|--|---|--|--|-------------------------------------|
| Talking on-line Connecting via social media Knowing friends going through the same | Looking forward to 'normal' life Thinking about future events Focus on happy thoughts Can still socialise via digital Nature outside continues Spring! Having extra time to try new things Solution focus Friends giving hope | Communities Helping family Acts of kindness Helping each other 'In it together' On-line community | China – hope Measures working | Globally united 'In it together' |
| | | | Positive experiences/ other countries | Not alone/ global |
| | | | Family support | Planning |
| Friends | Positive future thinking | Support each other | Reassurance | Relaxing exercise |

| | | | | |
|--|---|--|---|---|
| Staying in contact Maintaining relationships All going through same things Check in with each other regularly | Combat isolation fears Avoiding loneliness Reaching out to friends/ those struggling Safety net Conversations Sharing thoughts and emotions 'Stick together - unified' Listening On-line support groups – MH and school Talking: how we feel | Combat isolation – distractions Encouraging others to try new activities Supporting vulnerable people Sharing experiences broadly | Talk about other things Positive talking and thinking Non-covid focus | Keeping each other safe/ following rules |
| | | | Positive support/ thinking | |
| | | | Exercise Hobbies Creativity | Supporting vulnerable people |
| Contact/talking to friends and group chats | Emotional support/ talking peers | Social media interactions | Share coping strategies | Supporting community Support learning |

http://oxfordhealthbrc.nihr.ac.uk/wp-content/uploads/2021/05/YPAG_McPin-COVID-survey-pilot-consultation_summary_final.pdf

Solutions developed together...

- ⦿ Community and peer-to-peer initiatives were seen as the most valid to approaches to enable young people to empower and support each other. Young people explored various options including on-line platforms, training and what peer support would need to offer.
- ⦿ Successful collaborative grant application between NEUROSEC (Department of Psychiatry), The McPin Foundation, Imperial College London and Youth Era.

Covid Peer Support Study: May to Sept 2020

Aim: This co-designed randomised wait-list controlled study evaluated the impact of a Peer Support Training Course (the “Uplift Programme”) on those being trained as peer supporters.

Funded by: Higher Education Innovation Fund and ESRC Impact Acceleration Account through the University of Oxford’s COVID-19: Economic, Social, Cultural, & Environmental Impacts – Urgent Response Fund.

How young people were involved...

- © Co-production involving young people from NeurOX YPAG (2), Global Young Leaders (2), and The McPin Foundation
- © Five interactive on-line sessions with off-line follow up, review of training materials and on- and off-line qualitative analysis

What we found...

Using quantitative (standardised measures) and qualitative analyses we found that:

Young people who completed training generally experienced both higher levels of well-being and civic engagement, compared with those who did not.

This included greater self-awareness and self care; improved support giving skills; and empowerment.



More on findings: <https://oxneurosec.com/coping/>

The outputs...

- © Young person’s blog about their involvement in the research: <https://mcpin.org/peer-support-training-for-young-people/>
- © Communicating the research and young people’s perspectives within the scientific community to guide further research:
 - Poster presented at: Grand Challenges Canada Annual Meeting
 - Peer-reviewed publication (in draft).

The outcomes...

- © Young people described what it meant to be participants in the study (they called themselves ‘Uplifters’) and of peer support training for an Instagram campaign. This gave them an opportunity to tell others about the experience and what it meant to them. **#uplifttomorrow**
- © The findings supported a successful application for a follow-up study: *Peer-to-Peer Support to Help Adolescents Cope with Moral Distress during COVID-19.*

Peer-to-Peer Support to Help Adolescents Cope with Moral Distress during COVID-19: Sept 2020 – ongoing

Aim: The co-designed follow-up project (to the Covid Peer Support Study) involved testing the peer-to-peer intervention delivered by the participants (or Uplifters) in the previous study, who have now been trained in peer support.

Research contact: gabrielle.pavarini@psych.ox.ac.uk

Funded by: *Westminster Foundation*

How people were involved...

- © Co-design involving: 2 on-line YPAG sessions to brainstorm and then design the study with 11 NeurOX YPAG members and some young people previously trained on peer support (Uplifters)
- © Co-delivery of intervention with 21 Uplifters
- © Further involvement in interpretation of data planned

The study...

Design and methodology: RCT using quantitative (standardised measures) and qualitative methods involved 21 Uplifters co-delivering 'Coping During COVID-19' to 100 young people.

- © Our partners, Youth Era provided training materials while young people facilitated small groups to participate in hands-on impactful activities, engage in small group discussions, and build relationships with other supportive young people.
- © Assessed the impact of participating on adolescents' well-being, coping and sense of connectedness.

Findings and outcomes are currently being prepared...

- © Further information: <https://oxneurosec.com/coping/>

Young people's feedback on the programme...

- © During a focus group discussion with the uplifters, they each chose 3 words to describe the programme:



Oxford Health BRC EDI project – widening involvement of YP in mental health research

Research and consultations with YP, researchers, collaborators: Oct 2019 – Aug 2020

Aim: Initial theoretical desk research and consultations to inform an inclusive capacity building approach to widen involvement of young people in research. This aimed to capture insights into what young people feel is important to consider to ensure young people's involvement is diverse and meaningful.

Research contact: vanessa.bennett@psych.ox.ac.uk

How young people were involved...

- ⊙ NeuroX YPAG pre-work and on-line session in April (29 young people) to explore digital approaches to widening involvement of young people in research – brainstorm session
- ⊙ NeuroX YPAG on-line workshop held in June (22 young people) to further explore digital approaches to widen involvement of YP in research – workshop
- ⊙ Guest session with a researcher and young people from the National Children's Bureau (NCB)

Young people explored the following questions in groups...

How could involving more diverse young people affect ethics of co-production in research?

What is important in deciding which young people to involve in research?

How should a diverse group of people be involved?

How is involvement meaningful to young people?

How could a digital approach increase diversity of young people in mental health research?

A summary of their discussion...

http://oxfordhealthbrc.nihr.ac.uk/wp-content/uploads/2020/10/NeuroX-YPAG-June-2020-meeting_diversity.pdf

Additional consultations...

- ⊙ Researcher and YPAG member presented and discussed a draft strategy with:
 - OU Experimental psychology group
 - Oxford Brookes Children and Young People's Health Research Network
 - Oxford Health Foundation Trust CAMHS Participatory Experience Lead
 - Oxfordshire third sector groups: Oxfordshire Youth, Discovery College

Outputs... considering inclusivity and digital involvement with young people

- ⊙ Resources to guide researchers on how to meaningfully involve young people in their research and enhance accessibility of the research while using digital involvement for young people:
 - Young people's podcasts: what's important to young people and how to run digital sessions
 - Guidance on running a digital meeting
 - Digital safeguarding protocol (for local adaptation)
 - Animation (in development)
 - <https://oxfordhealthbrc.nihr.ac.uk/patient-and-public-involvement/young-peoples-involvement/>
 - Researcher and YPAG member co-authored the following book Chapter. Rosemary Musesengwa, Vanessa Bennett, Kiran Manku, Biggy Dziro, Sapfo Lignou,

Kudzai Kanyere, Peter Lewis, *COVID-19 and Co-production in Health and Social Care Research, Policy and Practice Volume 2: Co-production Methods and Working Together at a Distance*. In: *COVID-19 and Co-production in Health and Social Care Research, Policy and Practice*. Edited by: Oli Williams, Doreen Tembo, Josephine Ocloo, Meerat Kaur, Gary Hickey, Michelle Farr, Peter Beresford. (Open Access)
<https://policy.bristoluniversitypress.co.uk/covid-19-and-coproduction-in-health-and-social-care-1>

Outcomes...

- © Development of the *NeurOX YPAG EDI widening involvement strategy*.
- © Supported set up of additional 2 Oxford YPAGs through resources and consultations: 2020-2021
 - Co-RAY YPAGs (University of Oxford/ Experimental Psychology):
<https://emergingminds.org.uk/co-ray-project/>
 - Wellcome Global Mental Health Databank UK YPAG (University of Oxford/Department of Psychiatry) <https://www.psych.ox.ac.uk/research/wellcome-global-mental-health-databank>

NeurOX YPAG EDI widening involvement strategy and implementation: 2021 – 2022

Following consultations and digital experience working on research projects, and through collaborations over the past year, a proposed capacity building model is designed to respond to an EDI strategy through focussing on three core principles: Accessibility, Sustainability, and Trust and Transparency.

The capacity building approach intrinsically addresses each of the NIHR UK Standards for Public Involvement. The implementation plan is to be reviewed by groups of young people.

Strategic aims:

1. Building knowledge and empower young people to amplify their voices in research offering social accountability
2. Widening 'inclusion' within mental health YPAGs to offer researchers the perspectives from a broader population of young people, and/or those most relevant to their research
3. Developing a collaborative capacity building approach to mental health-focussed YPAGs that is responsive to researchers' and young people's needs
4. Improving the researcher experience and attitudes towards PPI to facilitate broader YPAG involvement
5. Recognising the value and utilise the expertise of third-sector organisations to enhance accessibility and expand inclusion of YP

Objectives of the implementation plan:

- © Determine mechanisms needed to involve more young people in collaborative research, including: communication, governance, training and support to amplify youth voice.
- © Demonstrate benefits and opportunities to young people, researchers, and collaborators from inclusive, meaningful involvement.
- © Benefit researchers through offering researcher and young people's insights into effective working with young people.
- © Expand the number of young people involved and capable of contributing to mental health research through a focus on accessibility via collaboration, support and learning.
- © Produce a schema/work flow and continuous assessment protocol that is responsive, YP-focused and YP-friendly and supports researchers to incorporate good involvement practices.
- © Co-design robust methodological approaches that enable wider involvement of young people in research.

BeGOOD projects: legacy of a 5-year programme involving young people in research

Consultation on BeGOOD design bioethics tools: March 2021

This session was aimed at reviewing the 5 Citizens Early Intervention Ethics: BeGOOD design bioethics tools that have been co-produced with NeurOX YPAG members over the past 5 years to inform interpretation and guide planning for further research. The tools were designed to reach, amplify and explore diverse young people's voices on questions that are important to guide the development of mental health interventions.

How young people were involved...

- © Young people were sent a brief background summary for the 5 BeGOOD projects; some had been involved since the start of the programme.
- © 17 NeurOX YPAG members joined an on-line workshop and participated in small breakout sessions (3-4 young people) without and adult researcher.

Young people discussed...

They started by thinking about the communication, context and approaches for the tools:

How they want to communicate, and language they want to use, when talking about their mental health (and in research).

Why and how young people want to be involved in shaping support for their/others mental health through research.

How we should explore/capture different young people's experiences and views.

What engages, empowers and prevents them from being involved in mental health research and activism.

Who they feel needs to listen to their ideas and what makes them feel listened to.

- © Young people provided feedback on which methods were most interesting, practical and appropriate tools, how these could reach different groups of young people and how to evaluate the tools given the research findings with broader groups of young people.
- © Members critiqued the approaches taken for each of the 5 BeGOOD digital tools designed to explore young people's preferences around communication of their mental health, their rights, and treatment approaches with regard to the potential application of predictive digital technologies and AI-based support (i.e. chatbots).

Next steps...

- © We are currently planning on- and off-line sessions and activities to engage with more young people; to complete in October 2021.

A blog and summary of their discussions will be available soon

NeurOX cross-sector projects

Childline/NSPCC Cross-sector placement: Sept to Dec 2020

The aims for this collaborative project were to inform further research and the development of the Childline message board platform. The focus was characterising the barriers and facilitators to help seeking and exploring how peer-peer interactions facilitated support and help-seeking for young people who had experienced emotional abuse and neglect. Integral to this co-production project we wanted to demonstrate the meaningful role that young people can play as co-researchers through their lived experience and contextual perspectives and to explore ways to support and extend their involvement in analytical methodology.

Research contact: vanessa.bennett@psych.ox.ac.uk

Funding: *Emerging Minds UKRI Network*

<https://emergingminds.org.uk/understanding-online-help-seeking-of-young-people-via-the-childline-moderated-online-peer-peer-message-boards/>

How young people were involved...

- ⊙ 3 workshops involving 10-14 NeurOX YPAG members using a blend of virtual, digital and off-line approaches.
- ⊙ Working independently, in groups and in pairs, on- and off-line.
- ⊙ Over the 3-month period, contributed over 130 hours to the research project.
- ⊙ Guided scaffolding facilitated involvement in: data sampling, data selection, thematic analysis, a conversation analysis approach, application and interpretation to help-seeking theory.
- ⊙ 1 on-line interactive session with 10 senior members of the NSPCC research/ Childline teams: interpretation and discussion of findings and recommendations from young people.
- ⊙ Final feedback session from NSPCC/Childline to young people (in preparation)

Outputs...

Internal NSPCC/Childline peer reviewed report with recommendations from the research, including:

- ⊙ Enhancing the design, organisation and functionality of the message boards
- ⊙ Further research on interactivity and their impact on young people's help seeking journeys
- ⊙ Approaches to develop capabilities of help seekers and peer supporters to enhance the quality of supportive interactions: focussing on 'conversational features' and compassionate responding
- ⊙ Exploring needs of all community members: determining how they can be supported throughout their journeys given the natural evolution of membership and anonymity of the relationships

Impact of research...

- ⊙ Recommendations to be considered in NSPCC/Childline's medium and long-term planning.
- ⊙ Reflection and evaluation from young people on their involvement in the research.
- ⊙ Development of co-produced research design and methodology involving young people through digital platforms and off-line work.

***"I enjoyed feeling that I had made a difference and helped improve the service"
(young researcher)***

Additional outputs (to be completed)...

- ⊙ Young person's blog
- ⊙ Researcher blog
- ⊙ Research paper detailing involvement methodology, insights from young people, reflection and co-production evaluation

NeurOX collaborative research involvement

Supporting the Oxford PERL Lab Young people's insights into antidepressants for the Wellcome Trust: Sept to Dec 2020

The aim of this Oxford PERL Lab project was to involve young people in a review to highlight what is known about the effects of antidepressants for this age range and what outstanding questions still remain. Working together with a group of young people with relevant lived experience from the NeurOX YPAG and The McPin Foundation was important to get their insights on this very relevant topic.

Research contact: susannah.murphy@psych.ox.ac.uk

Funding: Wellcome Trust

How young people were involved...

- ⊙ 3 on-line workshops with 12 young people (aged 15-24 years) from the NeurOX YPAG and The McPin Foundation.
- ⊙ The group included 11 females, 1 male, 2 trans males, 1 person identifying as non-binary, and included individuals from different backgrounds and ethnicities.
- ⊙ Experienced young co-facilitators led breakout sessions supported by PERL, NEUROSEC and The McPin Foundation researchers.

Findings and outputs...

- ⊙ Review article accepted for publication: *Lancet Psychiatry*
- ⊙ Mental elf blog and podcast about review:
<https://www.nationalelfservice.net/treatment/antidepressants/antidepressants-and-psychotherapy-for-adolescent-depression-can-they-be-compared-activeingredientsmh/>
- ⊙ Animation: youtu.be/hL4q1R53CWI
- ⊙ Researcher blog about involvement: <https://oxfordhealthbrc.nihr.ac.uk/involving-young-people-in-research-about-the-use-of-antidepressants-a-researchers-experience/>

Nottingham University study on seasonal use of antidepressants: Dec 2020 – tbc

- ⊙ 3 workshops planned involving 6 NeurOX YPAG members (1 session completed Dec 2020)
- ⊙ YPAG training included in each 2 hour session on quantitative data interpretation

Additional Advisory research consultations in 2020/2021:

- ⊙ 7 Guest Advisory consultations with other Oxford University researchers across Department of Psychiatry and Department of Experimental Psychology

Publication on co-production with young people (Dec to May 2021)

Peter Lewis, member of NeuroOX YPAG...

- © Reviewed and commented on text and contributed a personal reflection on his experience. As well as the regular YPAG sessions, Peter has been involved in the Covid Peer Support study and the Childline Cross-sector research project.

“The shift to an online YPAG came with advantages and disadvantages, most notably affecting our ability to connect with each other, and the number of opportunities available to us.

Digital meetings increased our ability to connect, allowing us to hold meetings with people from around the world, which was previously impossible. Throughout our Peer Support Project, we had Zoom calls with people and organisations from the US Peer Support Trainer and a Young Leader for the Lancet Commission on Global Mental Health from Barbados for example. In our regular meetings, we have connected with other UK-based youth organisations, with the aim of building a lasting network of connections, a possibility highlighted by the digital focus.

We have also used blog posts, podcasts and Instagram accounts to boost connectivity. Inevitably, there have been downsides, such as technical issues and the difficulty of interacting with another person over a screen.

Perhaps most significantly, we have had an increased number of opportunities. I’ve digitally met with researchers from Nottingham University, senior Childline representatives, and interestingly a researcher looking to use virtual reality in schools to improve mental health. It seems unlikely that so many opportunities would have been available had we not gone online; probably it was lockdown increasing concern for young people’s mental health that played a part.

There are many takeaways from the digital period, which I expect will feature in the future once we have returned to in-person meetings.”

Rosemary Musesengwa, Vanessa Bennett, Kiran Manku, Biggy Dziro, Sapfo Lignou, Kudzai Kanyere, and Peter Lewis Chapter 16: International perspectives on the impact of COVID-19 on community engagement of young people for involvement in mental health research

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<https://policy.bristoluniversitypress.co.uk/covid-19-and-co-production-in-health-and-social-care-1>

For further information about the NeuroOX YPAG please contact vanessa.bennett@psych.ox.ac.uk

