

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:



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

