

# NeurOX YPAG: SUMMARY OF PROJECTS & OUTPUTS

May 2021 – May 2022: by Vanessa Bennett

## 1. Promoting, supporting and developing ethical frameworks for young people's (YPs) involvement

The focus of the YPs PPIEP strategy is building capabilities and providing different options for YP to engage and be involved in research. Our core principles are:

- **Transparency and trust:** being clear on what is involved and why, and building trusting relationships
- **Accessibility:** inclusive involvement needs to be attractive, flexible and accommodating to many different YP, and their very different needs and experiences
- **Sustainability:** this is about commitment to the plan that involves structures and processes that offer a future working together

### Outputs

Our current cohort of young people are working on our co-produced strategy to engage with other groups of young people via communities. They will implement and evolve this peer-engagement strategy using their stories of involvement.

## 2. Understanding and defining 'meaningful involvement' & impact

We have been collating the experience of our young co-researchers over the past 2.5 to 6 years to better understand the ingredients of meaningful and inclusive involvement and how we can evaluate this to document the 'IMPACT'. We have described three areas of IMPACT in our accompanying report.

1. Promoting, supporting and developing ethical frameworks for YPs involvement
2. Direct impact for young researchers and researchers
3. Indirect impact (knowledge production) for research and other young people

We are working on outputs that describe our approaches responding to the core challenges outlined in our co-produced animation and further aspects to explore.

### Supporting publication in development:

Case-study publication in development: Bennett V, Gill C, Miller P, Wood A, Bennett C, NeurOX YPAG, Singh I. Co-production approach to understand on-line help-seeking for young people experiencing emotional abuse and neglect: methodology, evaluating meaningful involvement and impact. [Planned submission to Health Expectations, June 2022]

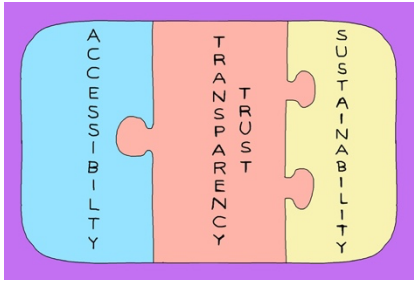
*Questions we have considered include:*

*How do we achieve inclusive and meaningful involvement?*

*How do we evaluate meaningful involvement?*

*What is impact, and for whom?*

*How can we build capabilities to support meaningful involvement?*



### 3. Co-produced animation on meaningful involvement

We have co-produced an animation to share our experience of working together and ideas on how to make involvement meaningful and inclusive for young people. This included input from the Oxford Health Biomedical Research Centre adult Patients Active in Research members as well as early career researchers.

#### Output

Co-produced animation: <https://youtu.be/4BkcwTVjCBM>

### 4. Evaluating YPs involvement in the BeGOOD research programme/NeurOX YPAG

The NeurOX YPAG started with the 5-year BeGOOD Wellcome Investigator Award (to Oct 2021), therefore it was important to evaluate the impact of young people's involvement. They were also integral to end of grant celebrations.

#### Outputs

**Storytelling Impact Report:** <https://bit.ly/StorytellingImpact>

- Impact of YPAG on young co-researchers and researchers (BeGOOD and Oxford Health Biomedical Research Centre projects)
- Independent review conducted by Arts of the Old Fire Station
- Stories from 5 young co-researchers and 3 researchers; opened to full group in discussion stages

**BeGOOD end of grant event (closed event involving 20 young people)**

- 3 YP presenting; 6 YP participating in discussion
- Presentation of storytelling impact and YPs involvement approach and strategy

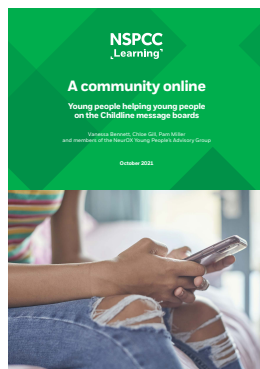
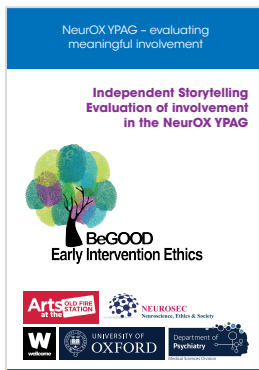
### 5. Co-producing dissemination outputs from Childline/NSPCC study

A focus for the year has included working together on various outputs from the Childline online message boards research projects.

The project started with 10 members of the NeurOX YPAG who are now involved in co-writing various outputs. This project led to the co-development of a new grant proposal to further develop the co-production and research methodology. It aims to amplify the analysis using artificial intelligence/machine learning approaches and develop evidence-based modelling for help-seeking.

#### Outputs

- Presentation for high-value funders: <http://oxfordhealthbrc.nihr.ac.uk/wp-content/uploads/2022/03/YPAG-presentation-on-The-Childline-Message-Boards-Project-2021.pdf>
- NSPCC Press interview and release: detailed in planned publication.
- BBC South Today TV interview (young co-researcher and researcher): aired three times on 10<sup>th</sup> Nov 2021 and on BBC Radio Oxford.



- Department of Psychiatry on-line news piece.  
<https://www.psych.ox.ac.uk/news/oxfordshire-young-people-involved-in-childline-research-project>
- NSPCC Co-produced external briefing report NSPCC external briefing Bennett, V, Gill, C. Miller, P and NeurOX Young People’s Advisory Group (October 2021) A community online: young people helping young people on the Childline message boards. London: NSPCC. [https://bit.ly/NSPCC\\_Bennettetal2021](https://bit.ly/NSPCC_Bennettetal2021)
- Collaborative Grant application for MRC/ESRC/AHRC Adolescence Mental Health and Developing Mind Methodological Innovation call (pending, Council ref: MR/X003213/1): submitted on January 20<sup>th</sup> 2022.
- Three publications involving young co-researchers as co-authors in development (planned submission May/June 2022).

Bennett V, Gill C, Miller P, Sayers C, NeurOX YPAG, Appleton J. ‘In their own words’: a naturalistic co-produced study of young people’s experiences of emotional maltreatment expressed in anonymous, peer-peer online message forums. [Planned submission to Child Abuse Review, June 2022]

Bennett V, Gill C, Miller P, Lewis P, NeurOX YPAG, Lavi I. Understanding help seeking of young people experiencing emotional maltreatment from ‘real-world’ conversations in online peer-peer communities. [Planned submission to Health Expectations, June 2022]

Bennett V, Gill C, Miller P, Wood A, Bennett C, NeurOX YPAG, Singh I. Co-production approach to understand on-line help-seeking for young people experiencing emotional abuse and neglect: methodology, evaluating meaningful involvement and impact. [Planned submission to Health Expectations, June 2022]

## 6. Collaborative research grant development: involvement

Members of the NeurOX YPAG, and collaborators developed the collaborative grant application for the UKRI/MRC Adolescent Mental Health Methodology call (Council ref:MR/X003213/1) to follow on from Childline/NSPCC study:

### **APPLICATION IN PROGRESS.**

- **Co-REACH: Co-producing Research on Emotional Maltreatment in Online Community Help-Seeking Settings**

#### **The proposed project is a collaboration between:**

- University of Bath, Oxford Brookes University, University of Oxford
- Project Partner: The Compassionate Mind Foundation
- Oxford Brookes Children and Young people’s Network & NeurOX YPAG

*The Co-REACH study* aims to build on the Childline Study to co-produce new research methods with young researchers with diverse care experiences. It would include novel computer-assisted approaches – machine learning – to enable us to analyse a large number of help-seeking conversations for YP relating to emotional maltreatment. This would enhance our understanding and provide a strong evidence base to develop a new help-seeking model. The study plans to develop methods that can be applied more broadly to other help-seeking research and modelling.

Young co-researchers provided:

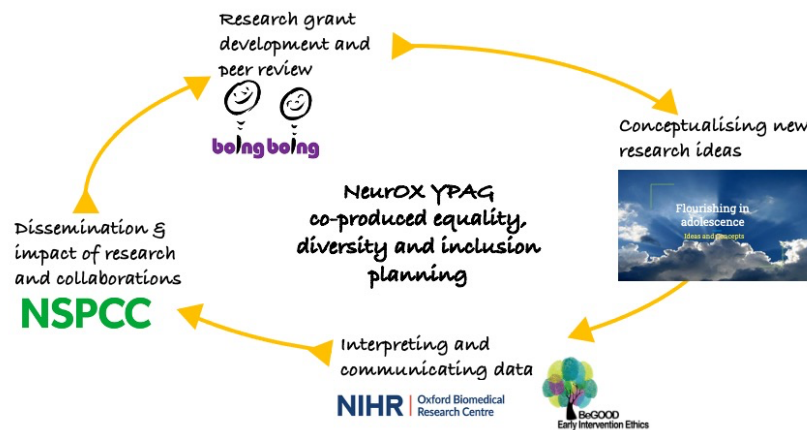
- Peer review feedback/advisory input.
- Co-development of Young Reviewer attachment.

## 7. Work experience research and YPAG training

### Work experience week

In total 10 NeurOX YPAG members participated in this paid online work experience week. This involved internal and external guest sessions from NSPCC and BoingBoing.

- Key project: researching and developing young people's perspectives and ideas on Flourishing research
- Childline dissemination outputs – presentation for High value funders
- Peer review session with BoingBoing charity
- Guest researchers – PPI input



### Output

Read our report and feedback: <https://oxfordhealthbrc.nihr.ac.uk/neurox-ypag-virtual-work-experience-week-26-30-july-2021/>

### Building capabilities over the year: embedding YPAG training

To build capabilities we have embedded training and support through all sessions to extend knowledge and have provided the additional training sessions.

### Outputs

*Optional training workshops provided by (June 2021):*

- Jessica Lorimer – research design
- Vanessa Bennett – qualitative data projects
- Tessa Reardon – quantitative and mixed data projects
- Andrey Kormilitzin – AI/big data approaches

*Story collecting training (March 2022)*

- In person training with Arts of the Old Firestation: 4 YP, 2 researchers
- On-line training session (planned)

*Podcast training (April 2022)*

Peer-peer training session by Eve Lownds (NeurOX member and podcaster: How are you (really)?): 4 YP

## 8. Implementing an inclusive YPs PPIEP strategy

Preparing for involvement of diverse YP in communities, we have co-produced a peer-engagement and recruitment strategy. The overarching aim is to improve accessibility of research to include all YP, ensure trust and transparency and make YPs involvement in research sustainable.

### Objectives

- Engage and recruit more YP from diverse groups to join the YPAG.
- Develop engaging ‘content’ to communicate about our work/experiences to diverse groups of YP.
- Engage through sharing stories and experiences of being in a YPAG and benefits of being involved for YP (and for the research/other YP) – through their own storytelling.
- Help young people to understand what research is about and different options for them to be involved in research:
  - engagement
  - participation (in studies)
  - involvement – advisory and co-production (YPAG)
  - advocacy and activism.
- To bring together different communities of YP through peer-peer engagement and involvement in research.

### Outputs

Development of the peer-peer engagement programme will continue through to summer 2022 and includes.

- Instagram campaign and website development
- Developing individual stories of involvement experience and impact for YP: various media including podcasts
- Planning taster sessions with community groups and youth worker leads

## 9. Internal Department guest researcher YPAG sessions and PPI consultations

We have provided PPI consultations to researchers keen to understand how to involve young people throughout their research projects, and more involved sessions with our young co-researchers for others. In our online workshops with young people, we have continued to use breakouts, padlets and other online whiteboard tools.

### Outputs

- Eating disorders (Dr Rebecca Murphy)
- Full online YPAG consultation session with 5 young researchers

Read the researchers’ blog: <https://oxfordhealthbrc.nihr.ac.uk/involving-young-people-in-planning-a-study-to-evaluate-a-new-treatment-for-binge-eating-disorder/>

### Consultations with PPI Leads

- NIHR DSE award application – panic disorder (Prof. Polly Waite)
- ARC doctoral fellow proposal – self harm (Dr. Stella Botchway)
- Wellcome grant submission – anxiety and panic disorder (Dr. Andrea Reineke)

## 10. External collaborative advisory input: Nottingham seasonal depression in adolescents

This was our second online consultation session with Dr Ruth Jack, and Dr Rebecca Joseph from the Centre for Academic Primary Care at the University of Nottingham, and Debbie Butler, a public contributor.

- They shared the findings from their study of seasonal trends in antidepressant prescribing, depression, anxiety, and self-harm in adolescents and young adults using UK primary care data.
- 5 young researchers participated in this online session.

### Outputs

Read the researchers' blog: <https://oxfordhealthbrc.nihr.ac.uk/involving-young-people-in-studies-using-large-health-databases/>

## 11. Consultation for academic institutions setting up new YPAGs: Anglia Ruskin University

We held a consultation with two representatives from Anglia Ruskin University (Prof Grace Spencer and Prof Niamh O'Brien), as part of their broader consultation exercise on setting up their own YPAG.

- Online consultation.

## 12. Strategic engagement: YP's perspectives on Oxfordshire County Council mental health and wellbeing strategies

As part of a wider consultation with a range of community groups, we held an online consultation session with Jack Gooding (Senior Public Health Principal) to review and discuss OCCs prevention strategy for young people's mental health and wellbeing in Oxfordshire.

The young people provided feedback on:

- How Oxfordshire could engage earlier and better to support YPs mental health and wellbeing.
- How online platforms could best help YPs wellbeing.
- What school support is effective/helpful for young people's mental health and wellbeing.

They offered ideas on:

- A longlist of opportunities from children and young people.
- The vision, aims, and objectives of the new strategy.
- What would work to support children and young people's emotional wellbeing and mental health.

Jack Gooding, a Senior Public Health Principal in the Public Health Team at Oxfordshire County Council, fed back:

*“It was a privilege to spend some time with members of the Oxford YPAG and have a rich conversation about strategies that could improve their wellbeing and help to prevent mental ill health. The group were articulate and were able to provide invaluable insight into the themes and topics we discussed including on how to engage children and young people in wellbeing and mental health support. The insight gained from the focus group will be used to inform the direction of the new wellbeing promotion and mental ill health prevention strategy for Oxfordshire and it would be great to come back together at a later date to co-produce the interventions that are taken forward over the next year.”*

### **13. Involvement in the British Sociological Association Youth Ethics Working Group**

On behalf of the NeurOX YPAG, Vanessa Bennett, is involved in a collaboration across academic Institutions contributing to and shaping the development of a set of ethical guidance for research with children and young people. So far, this has involved initial work scoping the remit and approach to the process and content. It will involve consultations with a range of professionals and diverse young people.

- We are planning our first workshop in Sheffield on 16<sup>th</sup> June involving a range of stakeholders.
- It is hoped that members of the NeurOX YPAG will have the opportunity to be involved soon.

Please see our accompanying IMPACT which can be downloaded from:  
<https://bit.ly/NeurOXYPAG>

For further information please contact: [vanessa.bennett@psych.ox.ac.uk](mailto:vanessa.bennett@psych.ox.ac.uk)

NEUROSEC, Department of Psychiatry, University of Oxford.