

NeurOX Young People's Advisory Group (YPAG)

Terms of Reference

What is the NeurOX YPAG?

The Neuroscience, Ethics and Society (NEUROSEC) group at the University of Oxford seeks to explore the ethical and societal dimensions of advances in neuroscience and mental health, especially where these advances impact the lives of children and young people. To ensure that the voices of young people authentically drive the group's projects, it has convened the NeurOX YPAG in order to co-produce research that is relevant, responsive, and 'real' to their lives. The NeurOX YPAG (and PPI Lead) is a group of young co-researchers (aged 14–25 years) included as a pivotal strategic group within the core PPI function of the NIHR Oxford Health Biomedical Research Centre. Our role will be to offer governance and oversight, practical guidance on setting up YPAGs, peer-peer training, co-facilitation, and research training to motivate and increase young people's involvement in mental health research.

What does the NeurOX YPAG do?

The YPAG will work alongside the NEUROSEC team to develop a wide range of research studies exploring young people's attitudes surrounding mental health and ethics. The precise nature of the YPAG's involvement will differ from study to study but can include co-production, refining research questions, designing materials and research tools, recruiting participants, analysing data, disseminating findings, and providing consultations to other researchers.

What are the Membership Criteria?

Membership criteria are:

- A genuine interest in matters relating to youth mental health and mental health ethics
- Aged 14 – 25 years old
- Live in the UK

What are the responsibilities of YPAG members?

- Advise/ co-produce research development.
- Advising on or co-designing study protocols, tasks, interview/topic guides, data collection schedules, questionnaires and information sheets and YPAG recruitment.

- Contributing to data analysis and interpretation.
- Contributing to writing project reports and papers.
- Contributing to the dissemination of research.
- Consistently and punctually attend online meetings in the evenings at least once a month. Smaller groups of members who have expressed interest in supporting specific projects, and other opportunities, may meet more frequently to support that work.
- Listen to others and express views constructively and politely.
- Work respectfully and effectively with people from diverse backgrounds, perspectives and experiences.
- Maintain good communication, organisational and time-management skills.
- Keep in touch, reply promptly to emails and complete required tasks between meetings.
- Keep personal experiences shared by other members confidential and keep the meeting confidential by not taking screenshots or recording the sessions. YPAG members will be provided guidance about working securely with any personally identifiable data in advance.
- Do not share any personal data in the YPAG sessions. [Personal data](#) includes your email address, phone number, and home address.

What support is offered to YPAG members?

In order to support the activities of the YPAG, the facilitators will ensure that young co-researchers receive the relevant training they need to develop confidence in their roles. Members will learn about mental health, ethical research, the research process, and associated topics. YPAG members are provided with the opportunity to work with different universities, charities and professionals. It is hoped that young researchers will gain other skills that will help them during their future education/career, such as skills in organisation, presentation, teamwork, leadership, mentorship and research. To support career development of our YPAG members, we allow members to take on roles in line with their future career plans, such as social media managing or mentorship. In addition, we provide awards and guide YPAG members on how to include their YPAG membership on their CV. We also provide references for jobs, universities or other applications.

Members of the YPAG are encouraged to play an active role in public engagement and will be supported by researchers, who will highlight such opportunities. These include attending and presenting at academic conferences, writing blog posts about meetings and the group's wider activities, and attending other events to promote the group's work.

To support YPAG members, those who engage with YPAG members are required to:

- Keep jargon to a minimum (and provide explanations or a glossary of technical terms in advance where necessary).

- Provide administrative support and send out relevant documents by email.
- Circulate documents in advance of meetings and allow members time to read them and prepare for them.
- Provide training to members as needed.
- Provide adequate time and opportunity for YPAG members to discuss any difficulties that may arise due to their involvement.
- Ensure that everyone has a chance to have their voice heard.
- Provide each YPAG member with reimbursement. Provide additional reimbursement for additional optional activities.
- Keep personal experiences shared by YPAG members confidential and protect personal data.
- Disclose whether the meeting is being recorded at the beginning of the session.
- Update YPAG members on research studies and data they are involved in.
- Facilitate and notify YPAG members of additional opportunities.
- Highlight any triggering themes before the session. If possible, have these themes at the beginning or end of the session, allowing the YPAG members to avoid this section if need be.
- Work around the schedules of the YPAG members. After-school hours are the most appropriate.
- Provide screen breaks for digital meetings and during physical meetings, and provide lunch/ snacks.
- Do not elicit any personal data in the YPAG sessions. [Personal data](#) includes email address, phone number, and home address.
- Make the session engaging and fun!

The YPAG Manager, Lucienne Spencer, plays an active role in supporting YPAG members. In the first instance, specific support needs may be discussed with Lucienne. Lucienne will arrange and co-facilitate YPAG meetings. Occasionally, researchers from the Department of Psychiatry or other groups will attend meetings to co-facilitate a session. Experienced members of the YPAG will be encouraged to help co-facilitate and receive the necessary briefing, support, and guidance to carry out this function.

We recognise that some of the research topics discussed at meetings or the nature of the involvement offered could potentially be emotionally demanding, triggering or upsetting for individual members. YPAG members are offered involvement, not employment, and there is no obligation to participate in any involvement activity. Members may decline to attend

meetings or choose to step out of particular discussions as they wish, without needing to give a reason. Declining involvement in an activity or choosing not to attend a meeting at any one time will not influence future offers of involvement. If a YPAG member anticipates that a particular session may be upsetting or difficult, they can contact Lucienne Spencer in advance. She will find out more information about the potentially triggering aspects of the sessions to help the YPAG member decide whether to take part.

Ethos

The group is founded on core principles of Accessibility, Transparency, Trust, and Sustainability. We achieve this through flexibility, collaboration, transparency, responsibility, empathy, respect for all group members, responsibility, and commitment. The researchers will also seek opportunities to ensure the group's sustainability. These principles guide the group's operations, decision-making procedures, and activities.

How are meetings/activities arranged and run?

Members will meet at least once a month online using Teams or another password-protected digital platform. Smaller groups of members who have expressed interest in supporting specific projects and other opportunities may meet more frequently to support that work. We will also hold in-person meetings at least twice per year.

The YPAG Manager, Lucienne Spencer, arranges and co-ordinates the involvement of YPAG members in meetings and activities. YPAG members are informed of forthcoming opportunities for involvement via e-mail and asked to respond to inform Lucienne whether they are interested and/or available. Typically, a deadline is set for responses and once this deadline has passed, Lucienne will allocate opportunities to those that have expressed interest before notifying YPAG members via e-mail.

The exact level of involvement offered to YPAG members cannot be guaranteed. Involvement will vary according to the number of projects that require involvement in any given month, the specific needs of individual projects and any limitations on the number of YPAG members required to be involved in projects.

Meetings are run to the agreed ground rules to ensure a safe, inclusive space where everyone feels comfortable contributing. Please see "*Ground Rules*" for more information.

Procedure for complaints, concerns or changes to personal details from group members

Feedback of any kind is very welcome and encouraged. We value any feedback you have about how we are working, including things that are going well and those we could improve.

Any complaints or concerns should be directed to the YPAG facilitators' team by contacting Lucienne Spencer (lucienne.spencer@psych.ox.ac.uk). At the start of each academic year, a senior YPAG designated contact person will be appointed and communicated to YPAG members if, for any reason, they do not feel comfortable sharing their concerns with the facilitators.

If you need to change any of your personal details, please contact Lucienne Spencer (lucienne.spencer@psych.ox.ac.uk) at your earliest convenience. Please be aware that in certain situations, we might be unable to update your personal details. Once records are archived for legal compliance, such as financial records required to be retained in their original form for a specific period, updates to these records cannot be made. Updates may also be restricted during the processing of active transactions to ensure their integrity.

If you feel more comfortable raising concerns outside of the YPAG facilitator group, members can contact Ilina Singh (ilina.singh@psych.ox.ac.uk).

Confidentiality

Full, open discussion about mental health may sometimes involve participants disclosing sensitive information about their own experiences (though it is not required). Such disclosures can be valuable but only occur within a mutual understanding that confidentiality will be respected. Group members must not communicate any personal narratives or confidential information they learn due to being a member of the YPAG. They must also conduct online meetings in a private space where others cannot see or hear the meeting. In summary:

- Identities and names of YPAG members will not be shared without permission
- Personal information about any member will not be disclosed
- Activities or people should not be described in a way that might identify individuals

Individual YPAG members are encouraged to inform people of their own boundaries and if they want their membership of YPAG to remain confidential. We respect individual choice on this matter and will not seek an explanation.

YPAG members may be involved in collecting or analysing data and will be invited to review draft papers and reports from researchers. Members are expected to treat any information of this nature as confidential and not to share it with others outside of the YPAG or use it for any other purposes. YPAG members will be provided with guidance about working securely with any personally identifiable data in advance. Where any information about government policy initiatives or findings from the research are shared with YPAG members at meetings, or elsewhere, we will state clearly if these are not yet in the public domain and should not be discussed outside of the YPAG.

NEUROSEC will collect personal data from YPAG members (e.g. personal contact details, emergency contact details, payment details and support needs). This will be stored securely on the University of Oxford network, used only for NEUROSEC purposes as agreed at the time

of collection, and not shared with others. The group will adhere to Oxford University GDPR regulations and the Data Protection Act 1998. When a YPAG member leaves the group, we permanently delete files from hard disks, using software that meets recognised erasure standards, such as BCWipe, WipeFile, or Permanent Eraser. Any physical data will be shredded and disposed of in secure bins.

Safeguarding and Disclosure

If, during interactions with researchers, YPAG members indicate a risk to their safety, we have a duty to protect them. We will first discuss their concerns with them, reassure them and try to get appropriate support. We will provide them with details of trained professionals to talk to, but we would also need to contact some external services if:

- The YPAG member asks us to.
- We believe their life or someone else's life is in danger.
- The YPAG member is being hurt by someone in a position of trust who can hurt other children like a teacher, religious leader, sports coach, police officer or doctor.
- The YPAG member tells us that they're seriously hurting another person.
- The YPAG member tells us about another child who is being hurt and is not able to tell someone or understand what is happening to them.
- We are told we have to by law, for example, for a court case.

If a YPAG member tells NEUROSEC staff something or does something that makes them believe there is a serious risk to their or someone else's safety, ideally, we would discuss these concerns with the YPAG member. If it is not possible to discuss our concerns with the YPAG member (for example, if they have left the premises and we cannot get hold of them) and the YPAG member has a nominated emergency contact, we will contact that person to try and ensure that the support they need is in place to ensure their safety.

Reimbursement

YPAG members play an indispensable role in the research process, and as such, the time and effort they commit to the group must be appropriately recognised. As such, junior members will receive a stipend of £15 monetary compensation per hour for online (to include preparation, online attendance and post-meeting work). In addition, we will reimburse travel expenses. Senior members of the YPAG, who have accrued a significant amount of experience and expertise, are expected to support the facilitators in designing and running sessions, and these additional contributions will likewise be recognised with a £20 per hour stipend. Expenses incurred when travelling to and from meetings outside of Oxford will be reimbursed separately.

Internal Evaluation

Periodically, members will be asked to reflect and consider the progress of the YPAG in its key focus activities, and its overall direction. This information will be collated and fed back to the relevant parties. The facilitator team will collate the findings and discover ways to best incorporate feedback into future sessions.

Leaving the YPAG or Termination of Involvement

YPAG members may withdraw from the role at any time. In a situation where YPAG members are unable to continue as members, we ask that they notify the facilitators as soon as possible. Resigning group members may be asked to provide feedback on their experience in writing to help guide the future running of the YPAG.

Although YPAG members have the right to withdraw from their roles at any point, we recommend a minimum term of 18 months.

If any YPAG member behaves in a way inconsistent with the agreed ground rules, the YPAG manager will arrange a meeting with the YPAG member to discuss this incident. Wherever possible, we will seek to find a way to resolve the situation. However, in the event of a very serious breach, or repeated breaches of the ground rules, it may be necessary to withdraw the offer of involvement in the YPAG immediately. We will prioritise ensuring the YPAG is a space where people feel safe and respected.

Accessibility

We are keen to provide adjustments to ensure that people from the widest range of backgrounds can participate fully in the YPAG. This may include resources being in a particular format, closed captions, and so on. If a YPAG member requires an adjustment, they should contact Lucienne Spencer who will endeavour to accommodate them.

Ground Rules

As we often cover some sensitive topics, we all must create a safe non-judgmental space to share our thoughts and conduct research. We must also have some safeguarding processes in place to ensure there is no harm done to members in addressing the research topics. Here are some ground rules:

1. You are not required or expected to disclose personal information to the group and do not need to validate your view with your experience if you do not want to. You may use the third person if you wish to give an example.
2. Respect one another:

- Create a non-judgmental space.
 - Everyone has their own/different experiences; all are valid and important.
 - Respect that we are individuals with different backgrounds and identities.
3. If you feel concerned or uncomfortable at any point, let the session leader know. If you are on an online platform, you can use the private chat function. If you would prefer to communicate in a different way, please let us know.
 4. Avoid jargon or overly scientific language/acronyms. Researchers will also avoid this too.
 5. No question or response is silly. We want to make sure everyone understands and feels able to contribute and have a range of different ages and levels of understanding.
 6. In some breakout sessions, the researchers will be off-camera and largely non-participatory. They will be there purely for support but the YPAG facilitators can ask if there is something 'technical' they need clarifying.
 7. Everyone in the room is equal, there are no hierarchies. We want you to feel comfortable; our young facilitators are also here to guide you. The researchers are here to learn from you too!
 8. Take as many breaks as you want but let a staff member know if you're leaving the meeting for good and that you are ok. If you are NOT OK please message Lucienne or other facilitators during the meeting and the researcher will try to help you. This is very important to ensure everyone is safe. If you drop off because of a connection we will give you 5 minutes and then drop you an email to check you are ok.
 9. If you have cameras on, we ask that your call is private so nobody else can see or hear the meeting.
 10. If you notice anyone/anything suspicious during the meeting please let us know immediately. This is important to keep everyone safe; the Chair will remove anyone joining uninvited.
 11. Members should not record or take photos of the rest of the group without explicit permission or forewarning.

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Further Information

For more information about NeurOX Young People's Advisory Group (YPAG) and how you can get involved please contact:

- Prof Iliana Singh – PI: ilina.singh@psych.ox.ac.uk
- Lucienne Spencer – PPIEP lead: lucienne.spencer@psyc.ox.ac.uk

