

Young people's advisory groups in health research: scoping review and mapping of practices

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ABSTRACT

Background Young people's advisory groups (YPAGs) for research are comprised of children or adolescents who work with researchers to shape different stages of the research process. Their involvement is expected to ensure studies better reflect the preferences and needs of targeted youth populations. However, despite their increasing use in health research, there is little systematic evidence on the methods and impacts associated with YPAGs.

Method To address this gap, we conducted a scoping review of YPAGs in youth-focused health studies. We systematically searched MEDLINE for empirical studies in populations between 12 years and 18 years of age published in 2019. If a potential YPAG was identified, authors were contacted for additional information about the activities and level of involvement of the YPAG.

Findings Of all studies that collected primary data from persons aged 12–18 years, only 21 studies reported using youth advice during their research. This represents less than 1% of all published empirical child and adolescent studies. There was variation in the type of research activity undertaken by YPAGs and their level of involvement. Most studies involved YPAGs in co-production of research design and/or in dissemination activities. The majority of authors that responded were positive about the impact of YPAGs.

Interpretation Recommendations for consistent reporting of YPAG involvement in empirical studies include reporting on the match between YPAG and study populations, frequency/format of meetings, and the nature and level of involvement.

INTRODUCTION

The last two decades have seen a shift towards the involvement of young people as 'co-actors' in the research process, as exemplified by participatory roles in co-designing research questions, developing tools and methods, and in the interpretation of results.^{1–3} The growing prioritisation of young people's voices, heralded by the UN Convention on the Rights of the Child,⁴ is now reflected in research guidance and funding body requirements for patient and public involvement (PPI) in many high-income nations, and also increasingly in low-income and middle-income countries (LMICs).^{5–7}

Often, adolescents' PPI in health research is through young people's advisory groups (YPAGs)—to work collaboratively with researchers at different stages of the research process. YPAGs are conceptualised as a way to improve acceptability and feasibility of research studies from the perspective of participants, as well as increasing the relevance

What is already known on this topic?

- Increasing emphasis has been placed on the involvement of young people as 'co-actors' (rather than passive subjects) in health research.
- A range of methods have been employed to enact young people's involvement in health research, often under the umbrella of 'Young People's Advisory Groups' (YPAGs).
- Systematic evidence on the methods and impacts of YPAGs in youth-focused health research is needed to maximise opportunities afforded by youth involvement.

What this study adds?

- This study provides systematic evidence on the methods and impacts of YPAGs in youth-focused health research.
- Fewer than 1% of published empirical child and adolescent health studies reported using youth advice during their research.
- Recommendations are provided for the consistent reporting of YPAG involvement in empirical studies

and impact of findings.⁸ There is also evidence from young people that their participation in such groups is motivated by a desire to make a difference and/or to develop relevant skills.⁹

Many iterations of YPAGs exist; groups vary in terms of how they are constituted, their remit and the methods used for involvement between researchers and YPAG members. There is also variation in terminology, such that 'Youth Advisory Boards (YAB)', 'Stakeholder Groups', 'PPI groups' and 'Focus Groups' (where young people are involved as advisors, rather than research participants) are sometimes used interchangeably with YPAGs. In this study, we will use the term YPAG to encompass all these ways to engage young people. As shown in [table 1](#), YPAGs also differ in whether they are project-specific (ie, established for a single research study) or provide input to a number of studies under the auspices of a host organisation (ie, an academic department or third sector organisation).

The impact of YPAGs on the research process may be dependent on the nature and level of youth involvement. [Box 1](#) illustrates the different levels of involvement that characterise YPAGs in youth-focused health research, reflecting the balance



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Table 1 Examples of non-project-specific young people's advisory groups (YPAGs) in health research⁵¹

YPAG name	Country	Group details
Generation R Alliance	UK	<ul style="list-style-type: none"> ▶ A network of YPAGs across the UK made up of members aged 8–19 years. YPAG views feed into the design and delivery of health research related to the same age cohort. ▶ YPAGs are funded by the National Institute for Health Research (NIHR) and/or other National Health Service organisations.
Kids and Families Impacting Disease through Science (KIDS)	Australia, France, Spain and USA	<ul style="list-style-type: none"> ▶ Comprised of acute or chronically ill children and adolescents, and healthy children; focuses on understanding, communicating and improving the process of medicine, research and innovation. ▶ Parallel groups for family members. ▶ A collaboration between the American Academy of Paediatrics (AAP), children's hospitals, universities, private paediatric groups and schools.
iCAN	Australia, Canada, France, Spain, UK and USA	<ul style="list-style-type: none"> ▶ A worldwide consortium of advisory groups working to provide a voice for children (all ages) and families in paediatric medicine and research. ▶ 26 groups worldwide.
McPin Foundation Young People's Network	UK	<ul style="list-style-type: none"> ▶ Young people aged 13–24 years interested in mental health. The network includes those with lived experience of a range of mental health problems. ▶ Part of the McPin Foundation, a specialist research charity dedicated to putting people affected by mental health problems at the heart of the research agenda.
National Children's Bureau Young Research Advisors	UK	<ul style="list-style-type: none"> ▶ Children and young people aged 7–18 years, recruited from across the UK. ▶ Funded by, and part of, the National Children's Bureau charity.
Youth Advocates, 'It's OK to Talk' programme	India	<ul style="list-style-type: none"> ▶ Young people aged 14–25 years, with lived experience of mental health difficulties and interests in technology and story-telling; participants recruited through an open call online and networks of NGO/academic partners. ▶ Advising on a national antistigma, public engagement and research programme, funded by the Wellcome Trust.

iCAN, the children's communication charity; NGO: non-governmental organisation.

of responsibility and ownership over the project between researchers and young people. At one end of the spectrum, full responsibility may be held by the researcher (ie, young people are consulted about decisions made by researchers). In contrast, responsibility may lie primarily with participating youth. Participatory activities also vary according to the research stage, from setting research priorities through to disseminating outputs (see figure 1). It is important to note that different levels of involvement are appropriate and can apply to different stages of the research process. For instance, researchers might engage in 'light consultation' over the research design, but 'coproduce' research

tools, use 'interactive advice' for data analysis, and then have YPAG-led public dissemination.

Despite their increasingly widespread and varied use, the implementation of YPAGs in health research has not been systematically mapped in previous reviews. In order to determine the extent of reporting on use of YPAGs and to provide a taxonomy of how YPAGs are used in studies of adolescents aged 12–18 years, we conducted a scoping review of all empirical youth-focused health studies published in the previous calendar year (2019).

METHODS

A scoping review was conducted to map YPAG reporting in academic medical journals and was followed the Preferred

Box 1 Levels of involvement of young people in health research

5. Youth-led: Responsibility for the research lies primarily with the young people; they lead each stage of the research process, for example, young people decide research questions, lead on data collection, analysis and public dissemination of findings.

4. Co-production: Researchers and young people work collaboratively to conduct research, with the young people taking on specific responsibilities, for example, generating themes in the coding and the interpretation of results.

3. Interactive advice: Researchers present information to young people and engage in discussions with young people, which help to guide the research, for example, advising on research questions to ensure alignment with youth priorities.

2. Light consultation: Young people provide input into materials proposed by researchers, in order to increase their relevance and comprehension, for example, commenting on research information sheets to ensure they are accessible for young people.

1. Affirmation: Young people approve decisions already made by researchers, for example, taking part in a one-off consultation to verify a certain approach.

Note: Based on work by Arnstein,⁵² Hart⁵³ and Faithfull *et al.*³⁹

Research Design
1. Aims
2. Methodology
3. Material development
Conducting Research
1. Piloting
2. Recruitment
3. Data collection
Data Analysis
1. Coding data
2. Analysing data
3. Interpretation of results
Outputs and Dissemination
1. Recommendations for future research
2. Public dissemination of findings e.g. via media interviews
3. Dissemination of findings to academic and clinical audiences e.g. at conferences
4. Policy recommendations

Figure 1 Research stages that young people's advisory groups (YPAGs) might be involved in (adapted from Gaillard *et al.*⁵⁴ and with interactive advice given by the University of Oxford Neuroscience, Ethics and Society Research Group YPAG (NeuroX YPAG)).

Original research

Who	<ul style="list-style-type: none"> Number of YPAG members involved Age range Relevant characteristics e.g. did the YPAG have 'lived experience' relevant to the research question or reflected demographics of the research population?
Frequency	Report whether YPAG contributed: <ul style="list-style-type: none"> As a one-off session/activity OR At regular intervals OR At key points of the research cycle
Methods and nature of involvement	If relevant, report: <ul style="list-style-type: none"> Whether the involvement was online or face-to-face Whether YPAG participated as a group, one-to-one with facilitators, or independently The stage(s) of the research cycle the YPAGs involved in Methods used (e.g. survey, focus group, open discussions)?
Parental involvement	<ul style="list-style-type: none"> If applicable, report if parental consent was granted, or if parents/guardians contributed in other ways
Recognition of involvement	<ul style="list-style-type: none"> Describe YPAG involvement in Methods section Consider reporting in Methods or Results the influence on research and actions taken as a result of the YPAG input Include the YPAG (or named YPAG members) in Acknowledgements. If YPAG members' contribution was substantial, (co)-authorship of outputs is expected (often agreed early in the research process).

Figure 2 Recommendations for reporting young people's advisory groups (YPAGs) involvement in studies Note: Designed by the authors with interactive advice given by the University of Oxford Neuroscience, Ethics and Society Research Group YPAG (NeuroX YPAG).

Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews guidance.¹⁰

YPAG involvement in the present study

We met with two separate groups of young people who participate in the University of Oxford Neuroscience, Ethics and Society Research Group (NeuroX) YPAG. This mental health focused YPAG consists of young people aged 14–18 in Oxfordshire, who work with the Neuroscience, Ethics and Society team at the University of Oxford. Some members have lived experience of mental health challenges. We met with each group once, at key stages of conceptualisation and dissemination; each session lasted approximately 40 min.

The first meeting of six young people aged 17–18 years was face to face, the second meeting of 21 young people aged 14–17 years was virtual using a videoconferencing platform. The YPAG activities covered different domains. The group offered interactive advice on figures 1 and 2. The group also designed a youth-led dissemination strategy and commented on the benefits and disadvantages of YPAGs.

Identifying eligible studies

Search strategy and selection criteria

MEDLINE was searched on 20 January 2020 by ES for articles from 1 January to 31 December 2019 using a search strategy that combined terms for YPAGs, PPI, and children and adolescents (see online supplemental appendix 1). There were no language restrictions. Papers were included if they reported on an empirical health study where the majority (>50%) of research participants were likely to be aged between 12 years and 18 years (from either descriptions of age range or frequencies of ages), and would potentially benefit from a YPAG because the research addressed adolescent applied health research (ie, was not related to the prenatal, perinatal or postnatal period, infancy or reported on basic science research). Editorials, commentaries, viewpoints and papers reporting on secondary data analysis were excluded. After running the database searches, we carried out initial screening based on titles and abstracts of identified

articles, and then retrieved full-text copies of potentially eligible studies.

To ensure that we had not missed any other forms or descriptions of YPAGs, we also conducted a hand search of all journal articles published from 1 January to 31 December 2019 in the 20 top ranking Pediatrics, Perinatology and Child Health journals using *Scimago Journal and Country Rank* for 2018¹¹ (the most up-to-date ranking) (see online supplemental appendix 2). The search investigated the number of papers in each journal that were empirical, applied health studies focused on the target age range and the number of papers that actually involved a YPAG in their study. We also contacted three experts in the field and accessed the NeuroX YPAG database of studies on YPAGs to try and identify any additional studies.

Identifying YPAG reporting

Among eligible papers, we searched for evidence of YPAG reporting. Papers were considered as reporting YPAG use if they contained at least one mention, anywhere in the paper, of some form of YPAG involvement whose members were: (1) Predominantly aged between 12 years and 18 years (>50%) and (2) Involved in any stage of the research process.

Characterising YPAG use

If a potential YPAG was identified, study authors were asked to complete an online questionnaire asking them details about YPAG use in their study, including level of involvement as per box 1; and on YPAG impact on the study (a great extent, a small extent or not at all). If there was no response, as much detail about the YPAG as possible was extracted from the paper.

RESULTS

Identifying and quantifying YPAG reporting

As illustrated in figure 3, our search yielded 1563 unique papers. Our initial title and abstract screening excluded 873 papers which were either found not to be empirical (e.g., reviews), or not involving young people as participants. The full texts of the remaining 690 articles were assessed for eligibility. Out of these, 420 were eligible, all of which involved primary data collection with young people predominantly aged 12–18 years. No new studies were identified in the NeuroX YPAG database. The hand search of 20 journals identified 3030 potentially relevant studies, from which no new YPAG studies were identified. The included studies therefore represent less than 1% of all relevant papers (estimated from the hand search).

Out of the 420 eligible studies, we flagged 27 studies as possibly including a YPAG. The corresponding authors of all 27 studies were contacted; 21 authors replied. From these, 15 of the 21 studies confirmed they included a YPAG;^{12–26} the remaining 6 either did not use a YPAG (n=3)^{27–29} or had YPAG members who were all aged over 18 years (n=3).^{30–32} For the six studies where authors did not respond, we assumed a YPAG was used based on information provided in the paper.^{33–38} The final number of 21 studies comprises 5% of all 420 studies (figure 3).

Characterising YPAG use in research

The identified studies that used a YPAG covered a range of topics such as cyberbullying,¹³ supporting young people in their decision to join a clinical trial,²³ sexual health,^{17 21 24} exploring novel mental health treatment options,^{12 19} healthy eating interventions,²⁵ and treatment for conditions such as arthritis¹⁴ and diabetes.²⁶ All but two of the studies were conducted in high-income countries.^{24 37} Table 2 summarises YPAG use in the 15

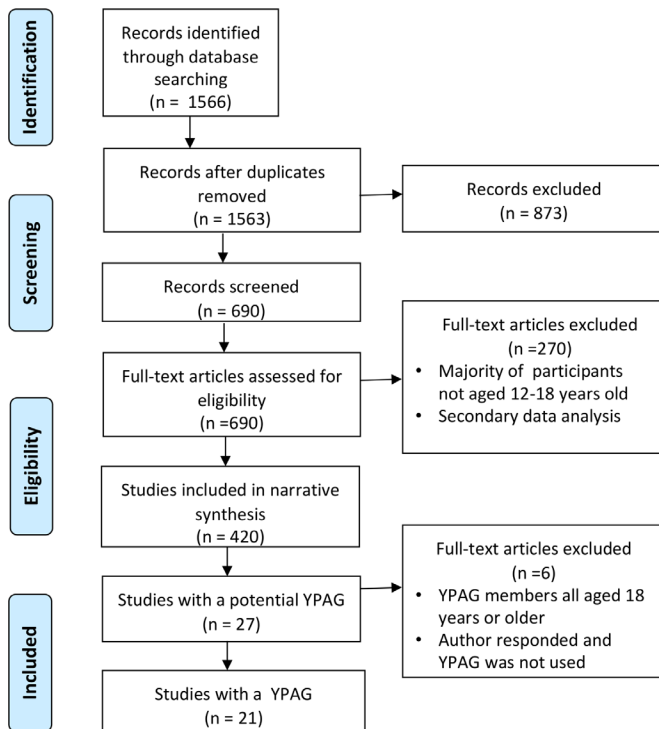


Figure 3 Scoping review flow chart, using the PRISMA reporting template (adapted from Moher *et al*⁵⁵). Young people's advisory groups (YPAGs).

studies whose authors responded to our survey. YPAGs varied with regards to number of youth members and frequency of meetings.

In terms of level and type of involvement, YPAG contribution was identified across all different phases of the research process, but most commonly in the research design phase (figure 3). YPAGs were usually involved in more than one research phase. For example, one study¹⁴ reported 'the youth panel initially inputted into in depth needs analysis ... They advised on and helped recruitment. They reviewed all the intervention materials ...' (S O'Higgins, personal communication). Another author²¹ commented that YPAG members were '... equal partners in our research activities. They are viewed as experts of their lived experiences, and thus vital to the research process from design through evaluation' (B Brawner, personal communication).

Table 2 Characteristics of young people's advisory group (YPAG) use in included studies (questionnaire responses for 15 studies)

Characteristic	Number of studies
Number of young people in the YPAG	
<5	1 ²⁶
5-10	7 ^{14 15 18 20-23}
11-20	4 ^{12 13 16 25}
>20	3 ^{17 19 24}
Frequency of meetings	
Only once	3 ^{20 24 25}
<5	4 ^{17 19 23 26}
5-10	3 ^{12 13 16}
11-20	0
>20	2 ^{15 21}
Unspecified->1	3 ^{14 18 22}

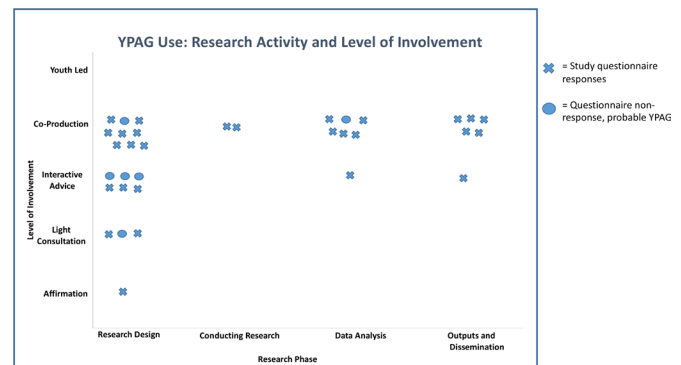


Figure 4 Research activities and levels of young people's advisory group (YPAG) involvement.

The level of involvement varied between and within research phases (figure 4), from affirmation to co-production; none of the studies were youth-led. The phase of research design had the widest variation for level of involvement and the phase of conducting research had the least variation. The majority of research phase activity was conducted at the level of co-production (71% of reported activities).

Perceived impacts of YPAG involvement

The question of how to describe and measure the impact of PPI is a complex one that remains an area of active discourse and development. Impacts may be observed on the research, the researchers, the service users, the community, on policy and funders. It can be both positive and negative, although negative impacts are not commonly reported in the literature.

All but one respondent of the questionnaire to study authors reported that including a YPAG impacted their study 'to a great extent'. Examples of such responses included: 'their [the YPAG's] voices and views were critical in helping us to shape the intervention' (K Stasiak, personal communication);¹² 'It also is a positive experience for researchers working with young people to ensure their research is more accessible to the young people they are working with' (S Spence, personal communication)²⁵ and 'The work would not have been possible without their contributions' (B Brawner, personal communication).²¹

This positive influence also extended to future research; for example, Mmari *et al*²² reported that 'since the study, the YAB (Youth Advisory Board) has made food insecurity a key issue. They have even designed their own project, called the 'granny project' to train 'grandmas' in the community to teach young people how to cook and share their food with community. The project has received funding now to implement that' (Dr K Mmari, personal communication).²²

These identified benefits of YPAGs were consistent with the expressed views of NeurOX YPAG members. A key benefit to the research identified by the group was being able to identify and prioritise questions reflecting the needs and interests of young people, as members felt that '[research] can be more focused on things youths need'. NeurOX members thought they had improved self-esteem because the experience 'feels like you're involved in something important'.

DISCUSSION

Despite the increasing priority given to PPI by major funding bodies,⁵⁻⁷ fewer than 1% of empirical studies for those aged 12-18 years reported on the involvement of YPAGs. There was considerable variation in the type and extent of research activity

YPAGs were involved in, as well as their level of involvement: some YPAGs were involved in all stages of the research process with regular meetings over the course of a programme, whereas others met just once. Activities typically clustered at the beginning (research design) and data analysis and dissemination phase of the research process, with little involvement in conducting research. The majority of study authors, when surveyed, reported significant positive research impacts of YPAG involvement.

The striking lack of reporting of YPAG use in child health research points to the need to better understand barriers and enablers to youth involvement. Studies exploring researcher views on using YPAGs highlighted barriers at the researcher, academic organisation and funding body levels.^{39–41} At the level of the researcher, barriers included a lack of understanding of how youth can participate and be engaged in research. Organisational barriers included lack of resources (time and money) for genuine youth participation, challenges in accessing young people, delays if ethical approvals or safeguards are needed and youth participation not seen as part of the workplace culture. Having a dedicated staff member who was responsible for supporting young people and answering researchers' questions about youth participation was seen as an important structural facilitator to involvement. Funding bodies increasingly mandate PPI involvement in proposal development without making funding available to conduct early and formative development work with YPAGs. This development work might take place a few years before any funding is awarded (and at which stage co-producing YPAG members might have left school/moved away/reached the maximum age for that YPAG).

A key strength of this paper is the application of systematic methods of evidence synthesis to a mandate in applied health research that is widely advocated but rarely scrutinised. However, a number of limitations should be noted. First, we included YPAGs of those aged between 12 years and 18 years, to be able to quantify and identify the relevant research and also because the newer definitions, proposing to extend the age of adolescence, had not been implemented fully by 2019. However, although methodologically challenging, including older adolescents would have expanded the generalisability of our findings to all adolescent populations.⁴² There is some research to suggest that children under 12 years can reliably report on their experiences, although very few studies include them.⁴³ Second, since our analysis of the frequency of YPAG use was based on published papers, it is possible that the low rate of YPAG use reflects a lack of reporting rather than a lack of involvement per se. This could be due to a lack of consensus on how to report YPAG involvement in research. Furthermore, if multiple publications have emanated from one study then maybe only one of these will include details of the YPAG.

Stages and levels of involvement for YPAG activity can assist in pragmatically facilitating mapping activities and comparisons between projects. However, there will be some nuances that may be missed using this approach, including the wider context as to why young people might get involved. There is an assumption that the the quality and the quantity of research will improve with greater involvement and responsibility given to young people. This assumption was supported by the qualitative feedback we gathered, however, there have been other views questioning this shift to greater involvement.^{44 45}

Similarly, our review did not specifically consider the intricate differences in power and status that can arise between YPAG members and adult researchers. The extent to which a young person feels 'involved' depends on how researchers address such power imbalances, for instance in terms of communication

strategy and session structure. To facilitate the agency of young people, involvement activities should take place in locations they feel are familiar, rather than traditionally adult-led spaces, such as educational and research institutions.⁴⁶

YPAGs in LMICs

Despite the known underrepresentation of LMIC research in academic health literature, it was nevertheless striking that we identified only two YPAGs from studies conducted in a LMIC. There are a number of challenges and implications of involving YPAGs in these contexts, potentially amplifying difficulties encountered in high-income countries where mental health is often less stigmatised⁴⁷ and young people's opinions might more commonly be sought. Capacity building must lie at the heart of any programmes trying to improve youth involvement in research in lower resource settings, to find ways to strengthen the young person's voice in contexts where this might not be as easily heard, in ways that are mindful of the power imbalances that might impact on a young person's ability to speak openly and freely to a researcher (particularly, for example, if the young people have stigmatised health conditions). There is a body of work in the social sciences on how to empower communities and disadvantaged groups which can be applied to health research,^{48 49} for example, highlighting the potential of group work, technology use and the arts to enable young people's involvement. Finally, it is important to determine what appropriate incentives might be for participants who live in very socioeconomically deprived contexts, for example, how remuneration might be perceived by non-participants.

CONCLUSION

The individual and organisational factors involved in setting up YPAGs are substantial, yet, based on the very small number of empirical studies that report on the use of YPAGs in their research processes, they appear to make important contributions throughout the research cycle. In addition to the wider use and evaluation of YPAGs, it is critical that there is greater consistency in the reporting of YPAG involvement.

Consistent reporting on methods of involvement and outputs of YPAGs in publications will help develop a better understanding of the influence of YPAGs in adolescent health research, enabling better systems for meaningful youth involvement in research. In figure 2, we suggest reporting guidelines for publications involving a YPAG as reporting would be improved if journals begin to mandate reporting on YPAG use (or the lack thereof), in a manner similar to the necessary reporting of ethical approvals, in both study protocols and publication of findings. The included studies provided very little information on the methodology used for YPAG involvement, an issue the GRIPP guidelines⁵⁰ tries to address, though not commonly used in YPAG research. The Guidance for Reporting Involvement of Patients and the Public (GRIPP) guidelines⁵⁰ could complement our guidelines, for example, by recommending a 'critical perspective' on aspects of involvement that went well, as well as those that did not, to ensure that subsequent studies are able to build on the PPI experience.

In order to make full use of YPAGs across the range of research activities, youth will need expertise through training about research methodology and knowledge of the study area (either through lived experience or by further education). YPAG members should also be reimbursed for the time spent in training and giving input. As such, substantial investment in YPAGs is

required (notably, one of the included studies met with their YPAG over 60 times).

Going forward, greater breadth in how studies engage young people and incorporate involvement of a YPAG across all stages of research is needed. There are many creative ways young people could provide input into studies, beyond a static panel sitting in a room. Employing different media and tools will likely increase the scope of YPAG involvement and enable more diverse young people to contribute.

Reflections on YPAG involvement in this study

In conducting this review, we were committed to ensuring young people's involvement was meaningful however the rapid nature of the study and financial constraints meant we needed to take a pragmatic approach to involvement. We were mindful of the need to ensure that YPAG involvement should be proportionate to the resources available, in terms of time, finances, and that we involved the YPAG in areas where they had particular knowledge and expertise. Therefore the YPAGs were consulted at key stages in the research, specifically study design, interpretation of results and dissemination.

In relation to study design, we had initially intended to co-produce the levels of YPAG involvement in research, however the YPAG had only a few suggestions regarding dissemination (incorporated into figure 1). They contributed more to the advantages and disadvantages of YPAG participation and to the recommendations on reporting YPAGs (figure 2) by determining how they would like to be acknowledged.

In relation to dissemination, we met with the YPAG a second time using remote technology to share our findings and to try and understand what youth-led dissemination of research could entail beyond purely academic publications. These are essential implementation activities although often subsequent to the main published findings. For example, our strategy for dissemination of our findings to young people centred around contacting schools and presenting findings during assemblies or lessons, perhaps using an animated infographic, focusing on the benefits of YPAG membership for young people. Using social media influencers to disseminate the results was suggested, as well as incorporating the topic of YPAGs into undergraduate psychology courses on research methodology. As a result, the study authors have contacted a university department to explore including PPI in research methods courses, with positive initial responses.

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Contributors MF designed the study and drafted the manuscript. ES designed the study, drafted the manuscript, conducted the scoping review and coordinated the NeurOX YPAG involvement. GP coordinated the NeurOX YPAG involvement and helped refine the study and manuscript at all stages of the work. DM and CC helped refine the study and manuscript at all stages of the work. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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