

How to involve children and young people in what is, after all, their research

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ABSTRACT

Third in a series of four articles addressing ethical approaches and issues in undertaking clinical research with children and young people.

INTRODUCTION

It is right that everyone with a legitimate interest in research should be able to contribute to its design, review, conduct and dissemination. Few would probably argue with this; however, the translation of this concept into practice is somewhat diverse, especially in the case of involving children and young people (CYP) in research, which is the focus of this article. Research should meet the needs of those who may ultimately use services or require care informed by the findings of such research, thus CYP who are directly or indirectly affected by research fundamentally have a right to say what research is undertaken and the manner in which it is done.¹ The Nuffield Council on Bioethics report endorses this standpoint, prompting for the involvement of CYP in all aspects of the research process²:

We recommend that research ethics committees should routinely require researchers to have involved children, young people and parents, as appropriate, in the design of their studies. Researchers who have not sought input in this way should be required to justify to the research ethics committee why this was not appropriate in their case, and be able to demonstrate an appropriate knowledge of relevant literature and guidance.

However, in accepting this, a robust process that enables everyone to contribute meaningfully to research is required, respecting and valuing the needs and priorities of all of the stakeholders who need to be 'around the table'. This is the ultimate aim of patient and public involvement (PPI) in research, an approach which has generated significant interest and has increased in momentum since the turn of the 21st century.³ PPI is now viewed as a crucial dimension of good research practice⁴ and research conducted in the UK involving CYP has been one of the pioneers in this field. The successful University of Liverpool bid that established the National Institute for Health Research (NIHR) Medicines for Children's Research Network proposed the involvement of CYP and their families throughout the entire research process.⁵ Yet, it is clear that there is a long way to go until the involvement of CYP in the design and conduct of research is routine, ethically sound and of a standardised quality.⁶ For example, Winch *et al* found that the majority of paediatricians felt that support for

undertaking PPI activities from their local organisation was inadequate.⁷ However, once established, it is then incumbent on the entire community to evaluate the impact and influence of PPI on research, service delivery and clinical care, not to forget the impact that PPI can have on the individuals and communities involved. Furthermore, PPI, including the involvement of CYP, must be constructed on a sound evidence base,⁸ hence why it is important for the research community to actively document, reflect and report on PPI, especially when involving CYP, since this will also add to the literature of best practices, facilitating the community in constructively moving forward with how PPI with CYP should be done.

Therefore, the aim of this article is to concisely review PPI in research involving CYP, with the main objective in providing practical guidance for researchers to build good PPI with CYP into their work (section 5). Second, this article aims to support reviewers of research applications in assessing this important part of the research proposal (section 6). The article has the following sections:

1. Defining PPI and describing common models and examples.
2. Reasons why CYP should be involved in research design, conduct and dissemination.
3. When and where it may not be possible to involve CYP in research.
4. How CYP are involved in research in the UK and internationally.
5. How to develop and build the involvement of CYP into research studies.
6. How to review and critique the involvement of CYP in research.

Defining PPI and describing common models and examples

What is PPI?

PPI is a collaboration between researchers/health-care professionals and CYP (and their families, depending on the nature of the research) in planning and managing research studies. According to INVOLVE, involvement is defined as 'research being carried out *with* or *by* CYP, rather than *to*, *about* or *for* them.'⁹ PPI with CYP may take many shapes, but it should ideally follow an established method and the process and should be more than a *tick box* gesture—not just *involvement for the sake of involvement*. Although this can involve consultation with CYP as research participants (eg, where CYP are asked their views on a specific issue in a qualitative study), the concept of involvement goes beyond this, since involvement actions should



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Table 1 Examples of CYP involvement at different stages in the research pathway

Research stage	CYP involvement and example(s)
Asking the right research question	CYP can be involved in the prioritisation of research topics and questions. Prioritisation exercises can take several forms, ranging from informal focus group discussions and questionnaires, through to more formal and structured processes, such as a James Lind Alliance Priority Setting Partnership. ³⁷ <i>Example:</i> CYP's beliefs about their research priorities for rheumatic conditions and whether and how young people would like to become involved in the research process were explored. ³⁸ Thirteen focus groups were undertaken with 63 CYP aged 11–24 years from all four devolved nations of the UK (England, Northern Ireland, Scotland and Wales). The results highlighted the importance of considering the spectrum of ages of CYP, as well as geographical diversity. The findings from this prioritisation work were used to inform the future research strategy of the Barbara Ansell National Network for Adolescent Rheumatology in the UK. ³⁹
Developing and planning a study	CYP can comment and advise on study protocols, including research questions, methodology, specific methods and research instruments used in the study, for example, consent and assent forms, participant information sheets and interview topic guides. In doing so, they are able to influence the design of the study so that it is more likely to be accessible and relevant to CYP. <i>Example:</i> As part of a feasibility study, face-to-face and telephone consultation exercises with CYP and families were undertaken prior to designing a trial of protocol-based ventilator weaning. The aims of this exercise were to: (1) ascertain views on the relevance and importance of the trial; (2) determine the important outcome measures for CYP and families; and (3) ascertain views on informed consent in a cluster randomised controlled trial. The trial objectives were deemed important and relevant, and CYP and families considered the most important outcome measure to be the length of time on ventilation. CYP and families did not consider informed consent to be a necessary requirement in the context of this trial, rather awareness of unit participation in the trial was important with the opportunity of opting out of data collection. This consultation provided useful, pragmatic insights to inform trial design. ⁴⁰
Research conduct and operations	CYP can be involved in the management and conduct of studies. This can take several forms, including as members of study/trial steering committees and advisory groups, through to CYP acting independently as coresearchers/peer researchers with management responsibilities. <i>Example:</i> As part of the Trials Engagement in Children and Adolescents (TRECA) study aiming to develop multimedia information (MMI) resources about research studies, CYP and families joined a Patient and Parent Advisory Group to play a key role in reviewing and providing input into various aspects of the study, including commenting on, and piloting documents to be used by participants. In addition, two members of the Patient and Parent Advisory Group also self-nominated themselves to join the TRECA Study Advisory Group alongside other academic and clinical professionals to provide strategic guidance for the overall study. These individuals were the liaison between the Study Advisory Group and the Patient and Parent Advisory Group. ⁴¹
Data collection and analysis	CYP can be involved in some, or all aspects of data collection and analysis. With regard to data collection, CYP can be involved in disseminating surveys to their peers, cofacilitating focus groups and conducting peer-to-peer interviews. With regard to data analysis, CYP may be involved in identifying and refining themes from qualitative data, commenting on quantitative analysis and how to portray these findings to CYP, and helping to draw conclusions to be exploited in future research. Appropriate training and support will be required for CYP for them to be able to conduct and analyse research in an appropriate manner. CYP may also be involved as researchers themselves, drawing on participatory action research methods. ^{42–44} <i>Example:</i> Barnardo's Yorkshire Young People's Research Group (The Originals) consisted of CYP trained as peer researchers. They collected data with CYP (aged 12–16) through questionnaires, drama, photography, observations and interviews at three research events. CYP split into two groups to analyse the questionnaires and interviews. ⁴⁵
Dissemination of study findings	CYP can play an integral role in the dissemination of study findings, ranging from contributing to press releases, website blogs and social media posts, through to coauthoring journal publications, funding reports and copresenting findings at conferences. CYP may have access to a wide range of contacts, based on their experience, and tend to be better suited to communicating information to their peers. In addition, CYP should be involved in reflecting on the impact of their involvement in the study, and the impact that their involvement has had on themselves. <i>Example:</i> As part of a study exploring the use of mobile apps to support self-management of long-term conditions, a young person was involved in conducting a systematic review. ⁴⁶ The young person submitted an abstract as presenting author for a large international conference, ⁴⁷ supported by academic and clinical colleagues. The young person and academic researcher also copresented findings from the study, and the partnership between CYP and researchers at a local Children's Hospital Conference. ⁴⁸ Dissemination also extended beyond traditional publication strategies, and included the preparation of blog posts and social media announcements about the findings of the study and next steps in the research pathway.

CYP, children and young people.

empower CYP to influence decision-making processes through their active involvement in the research planning process (see table 1).

Ideally, the process and impact of involvement of CYP in research should be reported and accessible in the public domain. As a rule of thumb, it could be proposed that any CYP involvement should withstand critical scrutiny and perhaps be publishable in peer-reviewed journals, in line with reporting frameworks such as the Guidance for Reporting Involvement of Patients and the Public, second edition reporting checklists¹⁰ and the Public Involvement Impact Assessment Framework,¹¹ which aim to improve the quality, transparency and consistency of the international PPI evidence base.

Models of CYP's involvement in research

Several models of CYP involvement in research have emerged over the last two decades.^{12–15} In summary, these include: consultation; collaboration and user led.

- ▶ *Consultation* involves asking CYP about their views on a research proposal or project on a one-off basis. For example, by hosting a focus group, interview or survey. These views are then used to inform the researchers' work, but CYP tend to not be actively involved in the decision-making process, or in other aspects of the given research.
- ▶ *Collaboration* involves active, ongoing partnerships with CYP who are actively involved in the planning and process of research. For example, CYP may become co-researchers

and/or members of a study/trial steering committee or advisory group, working alongside researchers to design, undertake and/or disseminate the results of a research study.

- ▶ **User-led** research is a model where decision-making is led by CYP, rather than researchers. In essence, CYP are the researchers. For example, there may be a small user-led element of a larger study, such as evaluating the experiences of study participants, in which CYP become peer researchers, conducting interviews and/or focus groups with the support from other members of the research team.¹⁶ User-led research ultimately changes the power dynamic and relationship between researchers and CYP.

Reasons why CYP should be involved in research design, conduct and dissemination

We propose two broad reasons as to why CYP should be involved in research: because it is morally (and ethically) the right thing to do, and pragmatically, it will improve research and pave the way for future services, care and support for CYP.

Moral reasoning as to why CYP should be involved in research

Since the introduction of the United Nations Convention of the Rights of the Child (UNCRC),^{17 18} there has been a move towards engaging CYP directly in research, as opposed to relying on parents or carers to represent them, and a change in emphasis from research on children to research with children.¹⁹ This point is underpinned by Article 12 of the UNCRC, with regard to respecting the views of children, ensuring that they have the right to express their feelings and wishes in all matters affecting them.¹⁸ More importantly, their views must also be considered and taken seriously. This extends from participation in research through to involvement, since CYP with a legitimate interest in research should be able to contribute to its design, review, conduct and dissemination—should be seen as a partnership between everyone involved. Such collaboration promotes the engagement of the scientific community with the public, with the benefits extending beyond the more immediate impact on the quality of research. The impact of involving CYP in research can indeed influence intermediate and longer term research outcomes, but it can also impact on those directly involved in research, since it upholds their rights, fulfils legal responsibilities, enhances democratic processes and supports CYP in developing skills, while empowering and enhancing their self-esteem.^{6 20 21}

Pragmatic reasoning as to why CYP should be involved in research

The second broad reason is a practical but more contended one. To thrive, research must be a fair partnership; however, whether research outcomes are improved as a result of PPI is less clear. While there is evidence that PPI can positively impact on research, particularly by improving elements of research quality such as recruitment materials and dissemination,²² there is little empirical evidence to substantiate whether PPI enhances the quality of research, the outcomes observed and the impact of PPI on clinical practice and service delivery in the longer term. Understanding the quality of PPI and how well it has been undertaken is just as important as understanding the scope and impact of PPI.²³ Similarly, there are limited examples in the literature specifying the most successful and efficient ways to undertake PPI, particularly with CYP. Further work is needed to develop a stronger evidence base detailing how to successfully embed the involvement of CYP in research more widely and effectively.

When and where it may not be possible to involve CYP in research

Even though we are firm advocates of involving CYP in research, we do recognise that it is not always possible or feasible to do so, particularly at the desired level one may hope for. In some circumstances, it may also not be appropriate to involve CYP in research for a variety of reasons, some of which are outlined below. While PPI may not be seen as an absolute requirement by everyone, an increasing number of funding bodies are now enforcing mandatory questioning as part of the application process.²⁴ Therefore, those who do not intend to involve CYP in their research must be ready to provide a very clear justification for their decision,²⁵ since this will be something that reviewers should certainly pick up on.

Some examples of when PPI with CYP may not be possible or feasible include:

1. Funding limitations.
2. Time constraints.
3. The nature of a study, for example, a basic science or observational/database research study.

These factors may limit the need for, or benefit of involving CYP in research, though researchers should be able to clearly articulate why this is the case. After all, PPI should be done for the right reasons, not just for the 'sake of PPI'. For example, it would be inappropriate to invite CYP to simply sit at a group laboratory meeting discussing preliminary preclinical research results, simply in order for the research team to say that they have *involved* CYP in their research. This is just one of many

Box 1 Top tips for involving CYP in research from CYP's point of view, developed by INVOLVE

1. *Do not make assumptions* about what we are interested in or what we are capable of—ask us.
2. *Our involvement needs to benefit us* too—such as by learning new skills, vouchers, payment, activities, meals out, references or having fun.
3. Provide *training and support* so we can get fully involved.
4. Give us *feedback* on what happens after our involvement—show us what difference we are making, so we know our involvement is worthwhile.
5. Use *words that we can understand*, but without trying to sound young and cool!
6. *Involve us early* on in as many parts of the research as possible.
7. Always provide *decent refreshments*—not just sandwiches, pizza too!
8. *Show respect* for our contribution—make us feel included and like an equal part of the team.
9. Find ways to *ensure we can all contribute* as much as we want to, whatever our age, needs or abilities.
10. *We have busy lives* and our circumstances, interests and availability might change. Reassure us if we have to miss a session and fill us in afterwards.
11. *Organise meetings* at times and places that are easy for us to get to and where we feel comfortable.
12. If there is a gap between meetings, *keep in touch* and give us updates.
13. *Communicate with us in different ways* such as online, text, social media, phone and post—ask us what we prefer as we do not all use social media or email.

CYP, children and young people.

Box 2 PPI guidance, adapted for CYP from the UK's Health Research Authority to support applications for review by research ethics committees

1. Have CYP shaped the research question and been asked what they deem important?

It is not acceptable to merely state that CYP thought it was important. *'We started our work with a priority setting partnership involving healthcare professionals, CYP and families to define the right questions.'*

2. Have CYP shaped the intervention and decided which outcome measures to use in clinical trials?

'Our priority setting partnership which included CYP said these... were the most important issues for them so we shaped our research outcomes around them.'

3. How were CYP's input used to minimise the burden on future research participants?

'We developed the study with CYP and families, minimising the amount of trips they would need to take to the hospital. The agreed number of visits were felt to be broadly acceptable. We also took this to larger patient groups at each proposed research centre.'

4. How did CYP influence the ethical design of a trial? For example, whether the use of placebo would be acceptable?

'We provided research ethics training and linked with the website reviewingresearch.com and then discussed ethical dimensions of the study in the steering group, which included CYP and parents/carers. It was agreed that CYP experience a flare of their condition would not be eligible to take part in the trial, because it would be unethical for them to receive a placebo while experiencing significant symptoms.'

5. How were CYP views acted upon? For example, if they identified that participants might potentially experience distress, and if there were practical considerations.

'We listed comments made by our CYP's group and how we responded. As the study also involved CYP, we discussed this with one of the GenerationR YPAGs and followed their suggestions. We decided to minimise time off school and fixed appointment after school hours or in the holidays, if they wished - although some CYP preferred to attend the hospital over school!'

6. How were recruitment processes changed to be sensitive to the emotional and practical needs of potential participants?

'These methods were debated in our steering group and also in wider patient consultation. We listed how their suggestions were adopted, showing our initial ideas and what we decided to go with.'

7. How were CYP involved in deciding what questions to ask in interviews and focus groups?

'We discussed our interview schedule with CYP from an existing YPAG. CYP worked in pairs and using role play, acted out the interviews with each other. They felt that some of the questions were too specific, and decided to change the wording so that it felt more familiar and comfortable for CYP. They also didn't like the term 'interview', and asked us to change this term for 'chat'.'

8. How were CYP involved in designing the protocol and patient facing information?

'CYP and families are members of our trial group, and with one researcher, held a writing workshop day where they wrote and designed the first drafts of patient facing information, including participant information sheets, consent/assent forms

Continued

Box 2 Continued

and signposting leaflets. These were then reviewed by hosting four patient focus groups at the proposed research sites.'

9. How would CYP continue to be involved in the project at different stages, with a clear explanation of what input was expected and how it might shape future decisions?

'We have CYP and families represented on our trials steering group. When they joined the group, they received terms of reference to help them understand their role within the group, and the contributions they may make. One example includes dissemination, whereby CYP wanted to get involved in producing a series of short videos reporting the results of the research, to share with their peers—they wanted to lead on this with the support of the researcher. They will also contribute to the writing of conference proceedings, but felt that the researcher should lead on this because they are more familiar with writing abstracts.'

CYP, children and young people; PPI, patient and public involvement; YPAG, Young Person's Advisory Group.

examples of ensuring that PPI with CYP is meaningful and done with the right intentions, respecting the rights, commitment and contributions of CYP. Where certain situations may initially prevent involvement of CYP in research, there may well be simple strategies that could be employed. For example, where there is limited (or no) funding for PPI activities as part of a grant application, it may be most feasible to approach an existing organisation to request attendance at one of their existing meetings. Similarly, building in sufficient time to undertake PPI with CYP from the outset, including the provision of time reserves, could prevent time constraints from negatively impacting on the quality and indeed ability, for CYP to be involved in research. For these reasons, the overlap between *engagement* and *involvement* may be more prominent, reflecting the nature of the activity planned. For example, for a basic science study, it may be more appropriate to invite CYP into the laboratory to explore some of the concepts addressed by the research using creative and interactive techniques. This is traditionally viewed as an *engagement* activity, but could pave the way for closer involvement with CYP.

There are also a number of challenges when it comes to involving CYP in research. There are constraints regarding the routes as to how researchers involve CYP in research, limited largely by the availability of suitable groups with adequate resources. There are also difficulties in reaching diverse groups of CYP, some of whom may be less frequently heard. For example, in a systematic review of studies involving CYP with disabilities, Bailey *et al* concluded that more needs to be done to improve the way in which CYP with non-verbal communication are involved in research.²⁶ However, we believe these difficulties should not be the case, and are the founding reasons for this article—to make PPI with CYP easier for the entire community.

How CYP are involved in research in the UK and internationally

The UK has guided the way in engaging and involving CYP in the design and delivery of research.^{14 16} One model developed and adopted by the NIHR Clinical Research Network: Children's Specialty group was through the forum of a Young Person's Advisory Group (YPAG), which first emerged in 2006 at Alder Hey Children's NHS Foundation Trust. Here, a model of working with CYP was piloted to feed into the research process, in partnership with researchers, so that the research that was

developed better met the needs of CYP and families. It was led by the principle that group activities should transform CYP from research subjects into research partners, enabling them to take an active role and contribution to research projects. The pilot was successful and led to the establishment of a further five YPAGs in England, and one in Scotland, forming a national YPAG under the umbrella name of GenerationR (R for Research).¹⁵ Across Europe, YPAGs now exist in Albania (KIDS Albania), France (KIDS France), Italy (KIDS Bari) and Spain (KIDS Barcelona). The commitment to growing YPAGs across Europe is now facilitated by a virtual European YPAG network.²⁷ Beyond Europe, YPAGs also exist in North America, Africa and Asia-Pacific regions, united under the International Children's Advisory Network.²⁸

Involving CYP through the forum of a YPAG can be successful because they are designed to fit around the lifestyle of CYP, as meetings mostly take place during weekends and the school holidays. Reimbursement of travel and subsistence to attend meetings are provided, as are gift vouchers as a 'thank you' for contributing to YPAG meetings. Learning and teaching activities are created to tap into the creative and artistic skills among the groups, avoiding jargon and, most importantly, inviting researchers to the sessions so that CYP can ask them about particular studies. Inviting researchers to meetings and gaining written feedback from researchers as to what happened as a result of their input is also essential for formally measuring and assessing the impact of CYP's involvement in research. For example, if CYP suggest changes to a patient information leaflet, it is important to know whether those comments were taken on board, and if so, how researchers and ethics committees regarded those changes.

How to develop and build the involvement of CYP into research studies

Involving CYP in research studies can be practical and feasible for a variety of situations and researchers. Whether researchers are conducting a survey as part of an undergraduate degree, designing a qualitative study as part of a doctorate degree, identifying a research question for pump priming project or leading a multicentre randomised controlled trial, there are ways in which CYP can be involved. Importantly, researchers should tailor their involvement strategies to the current study or topic. What may have worked in the past may not work now, hence why it is important to take a bespoke approach for each project. Here are some steps to facilitate the process of involving CYP in research:

1. *Identifying local/regional/national YPAGs:* Is there a YPAG in the local area? If so, one should establish contact with the YPAG facilitator—they will have practical ideas and guidance on how to go about establishing a YPAG, or how to attend one of their YPAG meetings to involve CYP in research. Researchers may need to be willing to travel to YPAGs if there are none in the locality or region.
2. *Identifying institutional/organisation YPAGs and youth forums:* Does the researcher's organisation have a YPAG or youth forum? If the answer is 'yes', one should make use of it and approach the organiser to seek support from CYP. If the answer is 'no', it may be worthwhile to establish a new group, which could benefit future research and the ability for CYP to have a louder voice within the organisation.
3. *Forming project-specific advisory groups:* It is sometimes favourable to identify CYP to join the project team, for example, as members of an advisory group, members of a steering group, or in a coresearcher role. For this, researchers could advertise vacancies for these roles, with a call for expres-

sions of interest and/or applications for the role(s) on offer. Researchers could ask colleagues to facilitate the process of establishing contact with CYP they already know, or family groups that they may be contact with. Researchers could also approach charities, other not-for-profit organisations, community volunteer services and support groups, relevant to the community, condition and/or service area under investigation in the research project. Researchers should plan how they will select CYP, maintaining transparency in the process, for example, listing any key criteria for shortlisting and interviews if that is felt to be appropriate, as well as choosing who to invite to the role. Being clear about the selection process in promotion materials is important, so that people know what to expect from the outset.²⁹

4. *Securing funding and support for involving CYP:* It is important to try and build funding and capacity for involving CYP in research. This is often a major stumbling block for many researchers and organisations. It may be possible to cost for CYP's involvement in a grant, especially in project-specific grants, and there is guidance available to aid researchers in budgeting for involvement.³⁰ In addition, researchers should reference supporting evidence to reinforce proposals and actions, for example, referring to the Nuffield Council report.²
5. *Referring to guidance and best practice examples:* Refer to current guidance and be able to answer any potential questions that reviewers and independent assessors may ask when looking at research proposals. Some suggestions are provided in [box 1](#), [box 2](#) and section 6 of this article 'How to review and critique the involvement of CYP in research'.
6. *Recording and reflecting on the involvement experience:* Record the entire journey of involving CYP in research, from start to finish, and publish it using a variety of mechanisms, such as original journal articles, reflection/editorial articles, conference proceedings/posters/presentations, blog posts, social media tweet chats and video blogs... but do not forget to involve CYP in the process! Recording and reflecting on the experience improves the outputs from the research, and helps other researchers and reviewers to learn from specific experiences, as well as informing and educating wider audiences about the research.

In addition, INVOLVE has published some 'top tips for researchers', developed by CYP following a review of existing information and guidance on involving CYP in research.⁹ As shown in [box 1](#), the underlying message from CYP was a request for researchers to talk to CYP, bringing them into the conversation.

How to review and critique the involvement of CYP in research

From a practical perspective, the involvement of CYP in research, and indeed PPI more broadly, does not require prior ethical approval. According to INVOLVE, patients and members of the public, including CYP, who are actively involved in research, are acting as advisors, through the sharing of their lived experience and knowledge. Therefore, ethical approval is not required for the active involvement element of research.³¹ However, it would be naïve to overlook the notion that the way in which some researchers undertake PPI may be unintentionally unethical,³² thus prompting researchers to continuously reflect on the way in which they involve CYP in research (see [box 1](#) and [box 2](#)). In doing so from the outset, sound involvement of CYP in research should smooth and simplify the ethical review process for a given study, in light of potential ethical challenges having

already been discussed between CYP, other relevant stakeholders and the research team. There may well be incompatible viewpoints between the research team and CYP; however, this should be viewed as a constructive aspect of developing good quality research, in the same way that peer review operates. Good quality involvement of CYP, articulated in a transparent, explicit and reflective manner, with clear rationale and explanations for decisions, will undoubtedly be a strong supportive argument in any research application or proposal, making it more difficult for a reviewer to raise contradictory points. Box 2 provides a list of useful questions that a reviewer may ask when assessing and interpreting research applications. Any applicant should be ready to answer these in a balanced and transparent manner.

DISCUSSION

This article began with a broad overview of PPI in research involving CYP, navigating through some of the more practical issues and challenges facing researchers when wanting to build good PPI with CYP into their work, while reflecting on the difficulties reviewers may face when assessing the level of PPI within research proposals. We see PPI, particularly with CYP, as a self-evident benefit that fair and equal partnerships in research require. Everyone with a legitimate interest in research should be able to contribute to its design, review, conduct and dissemination, otherwise our venture with CYP in the driving seat will fail to thrive. Involving CYP in research takes us up Arnstein's ladder of citizen participation, towards a place where 'Citizen control, delegated power and partnership' is a reality.³³

It is hoped that this article will help the paediatric and adolescent community to contribute more actively towards research involving CYP. The article largely discussed some of the more practical issues and steps to take with regard to involving CYP in research. It was a deliberate intention not to delve deeper into the theoretical and conceptual issues relating to PPI more broadly, since these have previously been discussed extensively within the literature.^{3 34–36} By discussing practical strategies and possible resources available for researchers to build PPI with CYP into their work, it is anticipated that this article will be used as a reference guide by researchers to enable more CYP to become involved in research, while helping those who review research applications to assess this important and fundamental component of any research proposal associated with the health and well-being of CYP.

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