A Practical Guide to Involving Young People in Research

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The involvement of young people in research is an important ethical imperative (UNCRC 1998) and has been called for by young people themselves (RCPCH 2005). 'Involvement' can be defined as when researchers collaborate with young people in the planning and management of studies to input from young people at ALL stages of the research process including research priority and question setting, project development, advisory board membership, virtual user groups, co-researcher roles through to dissemination of results.

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Considerations when involving young people in your research

<u>Planning and supporting involvement</u>

- ✓ It takes considerable resource to set up and establish a young people's group, so bear this in mind before setting one up. Try to use existing groups and networks where possible.

- ✓ Develop a plan for involving young people which considers:
    - *What the existing evidence tells us already about young people's opinions with regards to the issue being studied.*
    - *Why young people should be involved.*
    - *What will be the role and remit of the young people in relation to the research?*
    - *How will young people be involved*, (e.g. what method of involvement would best suit the aims, objectives, resources and participants of the project). It is preferable to use a variety of methods and involve young people in the choice of methods to be used.
    - *How will you ensure that their involvement is not tokenistic* (e.g. clearly defining roles, establishing what will support young people's involvement, how their views will be incorporated and what will support those doing the involving).
    - *How and why the involvement of young people is likely to add value.*
    - *What is the best environment?* The ethos, culture, and environment in which young people participate should be safe, accessible, age and developmentally appropriate.

- ✓ Be mindful of young people's time constraints (e.g. school, college, family, social life) and arrange meetings accordingly (e.g. not during exam periods; afternoon rather than morning meetings etc). Ideally, ask the young people involved what is best for them.

- ✓ It is important to try to attract a good mix of young people from across society. Try to consider different socioeconomic backgrounds, genders, ethnic minority backgrounds, young people with disabilities and marginalised young people such as those in care.

- ✓ If you establish a group, it is best to recruit continuously. For individual activities ensure there is good written publicity about the activity so that young people feel properly informed before they agree to take part.

- ✓ Remember input from one young person or ten young people, is still only a few young people – PPI provides in-depth insight not vast opinion.

- ✓ Offer further opportunities, if possible, when young people get older and "age-out" out of group (e.g. adult advisory groups, volunteering opportunities etc).

- ✓ Consider how to maximise accessibility, safety, and ethical standards.

- ✓ If the focus of the project is adolescent (10-19), ideally involve adolescents rather than young adults (in their twenties) recalling their adolescence.

- ✓ Consider the target age group of the project and developmental social interactions of different ages across the adolescent (10-19 years) and young adult (15-24 years) spectrum. For example, a project which spans the adolescent and young adult spectrum may consider holding two groups for 10-15 years and 16-24 years.

- ✓ Identify a staff member with the necessary skills to effectively facilitate the involvement. They should be responsible for briefing of both young people and key professionals (e.g. chair of a steering group) prior to the activity and be available for de-briefing of the young people after.

- ✓ After the activity, summarise discussions in an anonymised report.

- ✓ Plan how and when to send a project update to the young people involved.

- ✓ Consider ways of how the young people can be involved in the presentation of the research, for example, analysis of the data, future abstract writing and presenting.

- ✓ Ensure researchers acknowledge the involvement of young people in any publication arising from their research.

Approach to involvement

- ✓ Be flexible in your approach - often it is more productive to have a mix of short and long term aspirations to maintain engagement.

- ✓ Listen to what the young people really want - do not assume you know. Clarification of their views if required should be done in a non-judgmental way. Professionals should consider the words they use and avoid the use of jargon.

- ✓ Find a facilitator who is welcoming, and an excellent communicator with young people. Make this person a long-term point of contact for the young people so they can develop a positive relationship over time.

- ✓ Think about how you can help the participants to introduce themselves and build trust and openness between each other (e.g. ice-breaker games, designated social time).

- ✓ Peer support is a key aspect of any group meeting of young people so always allow some unstructured time in face-to-face meetings.

- ✓ It is important to reward and incentivise where appropriate (e.g. social events, certificates, awards, vouchers) and provide necessary information for the young people to include in their career portfolios etc. Travel expenses should be covered as a minimum.

- ✓ Manage expectations. Ensure that the young people understand that research is a lengthy process and there are often no immediate tangible benefits. Explain that not all ideas or projects will succeed or be feasible or practical.

✓ Try to provide short and basic research training. A good starting point is explaining the research cycle (https://bit.ly/rescycle) (e.g. from setting the research question to dissemination of results and evaluation).

✓ Try to avoid putting individual young people on the spot. Some young people can be very quiet but often getting a lot out of the experience personally. Use pairs/small group when working face-to-face or breakout rooms when virtual, to facilitate discussion even with the quieter young people.

Involvement of young people in adult predominant meetings

Role of the Meeting Chair

✓ Ensure the young people are welcomed and introduced, as well as introduced to all the other meeting participants including their name, what they do and why they are there.

✓ Ensure the facilitator can sit with the young people to explain anything during the meeting.

✓ Is attentive and actively involves the young people, acknowledging some may be less confident, so that they are given time to have input on discussions.

✓ Directs questions to the young people, when appropriate, to ascertain their views and ideas on the topic.

✓ Ensure questions that are directed at young people are clear and precise.

✓ Ensure participants avoid jargon and explain any medical terms or abbreviations during the meeting.

✓ Ensure the young people are clear about the decisions that have been made at the end of the meeting.

Role of the facilitator

✓ The facilitator is a designated person who provides support to the young people before, during and after all meetings (face-to-face and virtual meetings).

✓ The facilitator should ensure the young people understand the purpose of the meeting, their particular remit in the meeting, who else will be there and what will happen at the meeting(s), including how differing opinions will be heard.

✓ The facilitator should discuss with the young people beforehand how they would like to participate in the meeting(s) and ensure that they have the necessary information to enable them to be prepared and think of issues beforehand.

Manner of Involvement of young people in an adult predominant activity

- ✓ Ideally, the young people should have a choice over how they are involved including timing, pacing etc. Just inviting young people to an adult activity does not result in meaningful involvement and can be tokenistic without ensuring they are able to participate meaningfully.

- ✓ Ensure the process is accessible to the young people. If it isn't, can it be made so? (E.g. could a separate exercise run with young people, the results of which can then be presented to the adult-led group, ideally by representatives of the youth-led group)?

- ✓ Take care with long meetings and ensure adequate breaks to accommodate their long-term conditions and acknowledging the attention spans of young people.

- ✓ Ensure young people have enough time to formulate and/or express their opinion.

Post-activity considerations

- ✓ Ensure the young people have an opportunity to talk about how they thought the activity went. This should be fed back to the organisers.

- ✓ Ensure that young people are clear as to what happens next and who will do what.

- ✓ Ensure feedback is provided on both their involvement as well as the research outputs/minutes.

- ✓ Ensure expenses are covered and evidence of their involvement (certificate for their cv) provided.

- ✓ Consider offering 'token of thanks' if possible to further acknowledge their time and input for example vouchers.

FAQs

Q. How long does it take to plan a PPI activity?
A. This depends on many factors including, what type of activity you plan to carry out (e.g. group vs individual, online vs in-person); who is involved in planning the activity with you; how much experience you have conducting PPI and are you planning this activity in addition to carrying out your 'job'. The key is early planning.

Q. Who needs to be involved in planning and conducting a PPI activity?
A. It is very useful and good practice to have at least one other person input or at least proofread your PPI planning. Group activities, regardless of whether in-person or online, need two facilitators – one lead facilitator and the other support. This is very useful when it comes to breakout activities, technical or admin support and safeguarding.

Q. How long should an activity take to complete?
A. We would suggest individual online activities should take no longer than 30 minutes for a young person to complete. Group online meetings should last for around one hour and group face-to-face meetings should last from three hours - half a day (with breaks), to enable travel to and from the meeting.

Q. When should I approach a PPI group?
A. If you can work with an established PPI group, contact the group coordinator as soon as you know you want to conduct PPI. It is very common for groups to plan their activities a year in advance, and it is common for group coordinators to chat to those wanting to work with the group, even if PPI planning is at a very early stage.

Q. How should I thank the young person for their involvement?
A. Certificates are free and fantastic way to recognise the young person's work. They can use these as part of their CV or work portfolios. Providing ad-hoc job or placement references is also important. We would also recommend monetary recognition in the form of vouchers. Vouchers may range from £10-£40 per person per activity, depending on factors such as, the amount of time and input young person has given and the research budget. It is important to consider this in any grant costings.

Q. Where should I advertise my activity?
A. If relevant to a specific setting (e.g. healthcare) word of mouth via professionals or physical posters. Online via social media platforms such as Twitter, Instagram, Facebook, or via relevant websites and networks or forums.

Q. What method of communication should I use with young people?
A. Email. Keep your message short and to the point; use simple language; do not send too many emails; and never share email addresses (between young people or with other professionals) unless you have consent to do so. Text or WhatsApp message (group or individual) may be useful especially if relating to those attending a face-to-face meeting.

Q. Do I need to do anything once my activity has taken place?
A. Besides the obvious report write up and sharing your findings, it is extremely important to ensure you have planned how and when you will provide a research project update to the young people involved.

Q. What if adults (other than the facilitator and researcher) want to observe the involvement session?
A. It is important to try to keep the number of adults to a minimum at meetings to avoid inhibiting discussion amongst the young people. If there is an observer, ensure that they are introduced at the beginning and encouraged to explain their role is as an observer rather than participant.

Q. How can I and when should I acknowledge the involvement of young people in my research?
A. Outputs from your work which may include but are not limited to, publication, presentation, abstract, should acknowledge the young people's involvement – this may reference a group (and their logo) or named individuals (with their permission).

Icebreaker games

Face-to-face meeting games
Human bingo - Think of random questions (e.g. find someone who is left-handed, plays a musical instrument etc) and write them down on paper handouts. Everyone has a handout and goes around the room asking the questions to complete the handout first.
Find your pair - Create card sets of pairs (e.g. Batman and Robin, Micky Mouse and Minnie Mouse, salt and pepper). Task is to find your partner and get to know them. At the end each person introduces their partner to the larger group.
Paired interviews - Participants pair up with someone they don't know and for 5 minutes find out 5 pieces of information about each other that they will be happy to share with the whole group. After 5 minutes, everyone introduces their partner to the larger group.
Birthday line-up - The group must line up in order according to their birthday. No one can speak, use only non-verbal communication. The facilitator then goes down the line as the participants call out their birthdays.
Speed-dating - 3-5 minutes to chat per pair. Either set questions or just allow it as free time to get to know each other.
Spider web / Hot potato - In a circle, to start someone holds the ball of wool at one end picks another person to throw it to and asks them a question (ask anything or just introduce yourself). Keep going until everyone has asked a question. Everyone keeps hold of a bit of the wool until you have made a giant web in the middle of the circle. To make it extra fun you can rewind the wool - throw the wool back to the person who threw it to you and ask another question. NB avoid if any participant has limited hand function/arthritis flare in hands. Also if no wool, use a small bean bag and play hot potato instead.
Everyone Change - Chairs in a circle, one less than the number of participants. The person starting the game is without a chair and stands in the middle of the circle. It is their aim to find a chair/space in the circle. The person in the middles says for example, everyone wearing jeans, change your seat. Everyone wearing jeans must leave their seat and cross the room in order to find a seat on the other side of the circle. They cannot return to their own seat or to one on either side of it. The person in the middle also tries to occupy one of the seats in the circle.
Virtual meeting games
Wordle - The host thinks of a word and shares their screen with blank boxes representing each letter of the word they have chosen. The group must guess the word. Host to give a clue to help everyone get started.
Treasure hunt - The host tells everyone to go and get an object that is something to do with the theme you have set (e.g. something you think of when you think summer). To make this game more fun think of a difficult theme or provide a short time limit, or the object should be in the room you are sitting in. Depending on time, you can go around each person and explain their object or just ask everyone to hold their object up.
Name Graffiti - Each member of their group writes their name on a sheet of paper and then write or draw something around their name that says or shows something about themselves (e.g. a football, a musical note etc).

Interactive activity ideas

Important points before you start

- At the start of any meeting, always clearly state the ground rules in terms of respect for each other, confidentiality etc. Give contact details of someone who the young people can contact if anything upsets them etc during the meeting and that they would like to discuss further in private.
- Maximise time for discussion over presentation of research. Keep PowerPoint slides to a minimum.
- Give clear, concise instructions.
- Give warning if sensitive issues are to be discussed (e.g. mortality, sexual health, mental health).
- As well as taking notes, take photos of activity outcomes/games this is an extremely helpful way to document your PPI work and can be added to a report or future presentation.

Activity ideas

1. Board game

Inventing your own board game can be a fun and creative way to engage young people in conversations and discuss complicated topics (e.g. RCTs, study design, study participant process). Also useful for people who are visual learners, providing visual answers or touchable objects, can help players think about their answers, the concept you are discussing and possible/impossible alternatives. A board game can be very simple a bit like a visual quiz, or it can be more complicated and involve false answers and bonus questions.

2. Card sorting exercise

Providing physical cards with discussion items/points on them (e.g. study outcomes) to choose or rank in order. Use in pairs or small groups to generate debates, questions and problem solving.

3. Word clouds & voting

Using tools such as Mentimeter (www.menti.com), Google JamBoard etc., are great ways for people to provide anonymous answers in a group setting – particularly for virtual activities. They can really help those who are quieter or less confident to speak in front of others. They also tend to generate lots of food for thought.

4. World café style

In a face-to-face setting, world café style activities (moving around the room in small groups), help a large group comment on / critique multiple items in a friendly and non-intimidating way. Use paper tablecloths to write ideas on or stick post-it notes to large sheets of paper. Each group can then see what the others have been discussing.

5. Working in pairs

If you have simple tasks to complete such as designing an event poster or a website page, working in pairs can be effective and straightforward.

6. Group discussions (spider, web, speed dating, hot potato)

Working in groups, preferably several small breakout groups if a lot of attendees, are quick to get going activities that can produce a mix of ideas and generate many great questions. However, they do require planned facilitation to ensure everyone can participate, that the conversation stays on track and if needed, boundaries reinforced. Use post-it notes to collect ideas/thoughts and arrange on a wall during discussion.

Speed dating, spider web and hot potato ice breaker games listed in the previous section, are also good activities to do in groups to help with discussing topics and sharing experiences.

7. Roundabout

If a large group, participants form an outer and inner circle and then play music. Each circle moves round in opposite directions and when the music stops, discuss/introduce each other in pairs for 3-5 minutes then repeat. This is a useful activity to share experiences if an experienced group.

Resources

Your Rheum
- Involvement resource bank https://yourrheum.org/involvement-resources/
- Your Rheum animation https://bit.ly/yourRHEUM
- Research cycle explained animation https://bit.ly/rescycle

GenerationR Alliance
- Involvement resources including a list of YPAGs across the UK https://generationr.org.uk/
- RCT animation https://generationr.org.uk/?video=randomisation-explained-in-1-minute

NIHR
- Involvement resource bank https://www.nihr.ac.uk/documents/ppi-patient-and-public-involvement-resources-for-applicants-to-nihr-research-programmes/23437

RCPCH & Us
- Involvement resource bank https://www.rcpch.ac.uk/work-we-do/rcpch-and-us
- *Recipes for engagement* with young people https://www.rcpch.ac.uk/sites/default/files/2018-09/recipes_for_engagement_2018.pdf
- A game which could be adapted depending on focus of research *chatterbox game* on 5 ways of healthy well-being (facts vs myths surrounding mental health) https://www.rcpch.ac.uk/resources/chatterbox-game-five-ways-healthy-wellbeing

Visualization in Participatory Programmes VIPP
- Person-centered approach to planning, training and other group events https://www.unil.ch/files/live/sites/euteach/files/Takeuchi/PDF%20documents/VIPP_Unicef.pdf