

Ethical Collaboration with Children and Young People in Research

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TÚSLA An Ghníomhaireacht um
Leanaí agus an Teaghlach
Child and Family Agency

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 **PPI** IGNITE
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 **IRISH RESEARCH COUNCIL**
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Foreword/Introduction

On Tuesday, January 30, 2024, 55 attendees gathered at Barretstown Castle in Co. Kildare, travelling from across Ireland for a workshop focused on collaborating with children and young people in research.

The event commenced with welcoming remarks from John Mitchell of Barretstown, Veronica Lambert from PPI Ignite at Dublin City University (DCU), and Marian Brattman from TUSLA Child and Family Agency.

During the event, Dr. Harry Shier engaged the audience with a discussion on PPI from a child rights perspective, leveraging his extensive international experience. Professor Suzanne Geurin from UCD emphasized best practices for conducting PPI in research involving vulnerable children and young people. Dr. Niall Muldoon, Ombudsman for Children, facilitated an engaging panel discussion featuring Roisin Farragher (TUSLA), Cameron Keighron (University of Galway), and Shannon Carey (Barretstown), where they shared valuable insights on ethical collaboration with children and young people.

Niamh Dillon from the PPI Ignite Network at RCSI guided attendees through the development of a statement on research ethics committee approval for PPI activities. Framed by the understanding that ethical approval is not required for the inclusion of children and young people in PPI activities, participants were asked to share their diverse and valuable expertise during a series of roundtable discussions. They were invited to express their thoughts and ideas on several topics, including: what constitutes good ethical practice in PPI involving children and young people; how to ethically engage children and young people in research; and what they envision a resource for ethical collaboration with children and young people should look like.

The toolkit developed from the insights gathered during the event will serve as a resource for all those involved in conducting research in collaboration with children and young people.

This initiative, part of the PPI Ignite Network Festival 2023, was organized by Barretstown, PPI Ignite Network at DCU, TUSLA Child and Family Agency, and the PPI Ignite Network at UCD, with funding from the PPI Ignite Network at DCU, supported by the Health Research Board, Irish Research Council, and DCU. Thanks to all who attended and contributed their valuable expertise.

The toolkit will be launched on the 30th of January 2025 in Barretstown.

Acknowledgements

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The authors would like to thank all of the representative from the following organisations for their attendance and input at the original event on the 30th of January 2024: The PPI Ignite Network at Dublin City University; TUSLA Child and Family Agency; Barretstown; The PPI Ignite Network National Office and Lead Sites; The PPI Ignite Network at University College Dublin; The Department of Children, Equality, Disability, Integration and Youth; Dublin City University; Children's Health Ireland, Children in Hospital Ireland, The Irish Cancer Society, Empowering People in Care, Children's Health Ireland at Crumlin; University College Dublin; University College Cork, Trinity College Dublin, Technological University of the Shannon, University of Galway, Royal College of Surgeons Ireland, Queens University Belfast and Atlantic Technological University.

Purpose

This toolkit contains guidance on considerations when involving children and young people as PPI contributors in research as well as how to plan, support and implement PPI with children and young people in research. The toolkit aims to empower users to create inclusive and respectful environments where young voices are genuinely heard and valued. It includes practical tools for facilitating engagement, as well as how to plan, support and include children and young people's voices across the research continuum.

The Toolkit is structured into sections corresponding to various stages of the research cycle, followed by useful resources, case studies, activity ideas containing icebreakers and games as well as references.

Resource Development

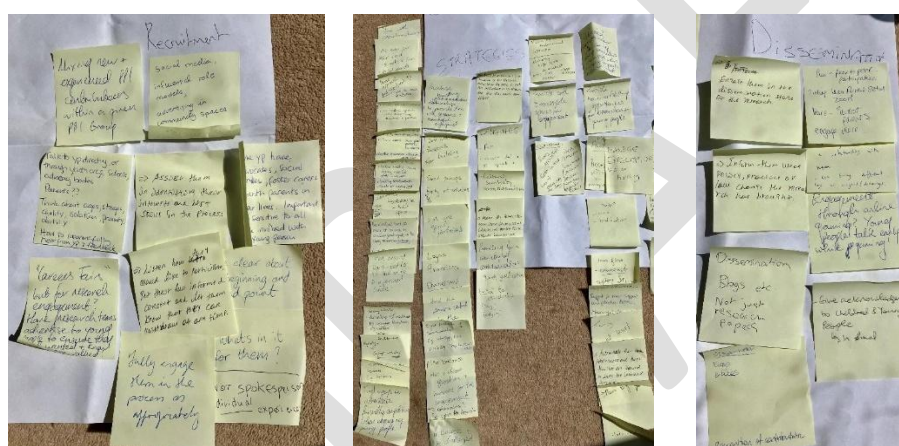
Following the event on the 30th of January 2024, thematic analysis of discussions surrounding ethical collaboration with children and young people in research from the event took place. This highlighted the key recommendations for best practices and the development of a new resource aimed at guiding researchers in Public and Patient Involvement (PPI) with young participants. A thematic analysis of presentations, panel discussion notes, roundtable discussions and scenario notes was conducted. The analysis, drawn from the roundtable notes, emphasized the importance of ethical considerations throughout the research process, from recruitment to dissemination.

The questions asked during the roundtable discussions and a selection of post-it notes from the original answers are included below.

Question 1: What is good ethical practice in PPI in research with children and young people?



Question 2: How do you ethically engage children and young people in research?



Question 3: What do you want a resource for ethical collaboration to look like?



This resource, developed from the thematic analysis of the day, aims to provide both guidance and support to anyone involved in PPI activities with children and young people.

A further detailed breakdown of the resource development including feedback process to go [here](#) once finalised.

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Introduction to Public and Patient Involvement

The widely used definition of Public and Patient Involvement (PPI) in research is: 'research carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them' (National Institute of Health Research, 2020).

PPI ensures individuals who will be most affected by the research (e.g. patients, service users, family members, carers or members of the public) are actively and meaningfully involved in developing, designing, managing, conducting and communicating the research.

PPI contributors may serve as members of research advisory groups, they may advise on research proposals, research priorities or research design. They may be involved in research projects and provide independent advice over a period of time.

There is a clear distinction between being a PPI contributor and being a participant (or subject) in research studies. If a researcher seeks the views and experiences of patients/service users as data, it is not PPI. Patients/service users involved as collaborators and partners in research are asked to bring their views and experiences to the table not as data but to contribute to decisions about the design, conduct, reporting and use of research. PPI is an approach to research that fosters collaboration between people with lived experiences, researchers, and research institutions. The goal of PPI is to improve research and strengthen the impact of research on society. Involving patients or the interested public in research broadens a researcher's field of influence, generating novel ideas, challenges, and discussions (Dorris and Kroll, 2023).

Why is PPI Important

Public and Patient Involvement (PPI) can enhance both the quality and relevance of research by offering a lived-experience (Brett et al., 2014; Bakhtiar et al., 2023). Involving public or patient partners/contributors in research addresses the needs, priorities and preferences of people it is most likely to affect (Bakhtiar et al., 2023). PPI empowers individuals by giving them a voice in decisions that affect their health and well-being. By involving the public and patients, research is often more effective, transparent and trustworthy (Domecq et al., 2014). Additionally, incorporating a wide range of experiences and viewpoints can enrich research design. Engaging patients and the public can also enhance the research dissemination strategy to ensure the research is communicated in ways that are clear, meaningful and accessible to the intended audience.

PPI in Research with Children and Young people

Public and Patient Involvement (PPI) in research for [children](#) and [young people](#) is about making sure that children and young people have a say when it comes to research that could affect them, ensuring that their voices are heard and that the research meets their needs.

Article 12(1) of the UN Convention on the Rights of the Child (1989) states that children have the right to express their opinions freely on issues that affect them. This right should be recognized and considered based on the child's age and maturity. It highlights the significance of listening to children's perspectives and involving them in decisions that impact their lives.

When scientists or researchers are trying to learn more about things that affect children and young people, like new medicines or ways to stay healthy, it's important to hear from the people who will actually use these things, the children and young people themselves. By collaborating and partnering with children and young people, researchers can make sure that the results of their work are more useful, relevant, impactful and suited to the needs of young people.

The Lundy Model

The Lundy Model, developed by Professor Laura Lundy, is a framework for understanding and promoting children's participation in the decision-making processes in matters that affect them. Overall, the model advocates for meaningful participation, ensuring that children's rights are upheld and their perspectives are integral to decision-making processes (EU for Children, 2020).

It emphasizes four key elements:

Space: Creating an environment where children can express their views safely and freely.

Voice: Ensuring children's opinions are heard and taken seriously in decisions that affect them.

Audience: Identifying who will pay attention to and take into account children's perspectives, ensuring their voices reach the appropriate decision-makers.

Influence: Ensuring that children's opinions genuinely affect the decisions made, rather than being merely acknowledged.

Explanation of PPI for children

Imagine you're making a cake and want it to be the best cake ever. Before you say it's the best, you ask your family and friends to taste it and tell you what they think. They might say it needs more icing, chocolate, or sprinkles. Their help makes your cake even better.

Now, think about scientists who want to make something new to help people, like medicine. Before they know if it's good, they also ask people who might need the medicine for help. These people are like your family and friends tasting the cake. They share their ideas to help make the medicine better.

When we talk about PPI in research, it means people who might use the medicine help scientists decide if it's good and how to make it better. Their help is very important, just like your family and friends help you make the best cake!

PPI Throughout the Research Cycle

Below you can find checklists which are designed to help you keep track of tasks or steps by listing things that need to be done at each stage of the research process. There are separate checklists for the preparation, during and wrap-up phases of research

Preparation Phase

The preparation phase is a critical stage of research that lays the groundwork for a successful study. It starts at the point of research ideation and ends when you have everything in place and are ready to begin gathering information.

Research Element	Checklist	Yes	No	Comments/Top Tips
Forming a research question (Adapted from NIHR Researcher PPI Checklist, 2019)	Have you worked alongside children and young people to develop your research question? If not, have you checked the appropriateness of your research with children and young people before seeking funding?			By actively involving children and young people in the formation of research questions, researchers can ensure they are creating research studies that are aligned with real-world needs and experiences of children and young people, ultimately leading to more impactful research outcomes.
Writing a research application	Have you checked the funder's specific expectations around PPI?			Involving children and young people in the funding application process can strengthen proposals and enhance their relevance. In Ireland, some funding bodies require PPI involvement in their application process and entire research design.
	Have you considered having a child or young person as your co-applicant?			
	Can children and young people get involved in writing the application? If yes, would it be appropriate for them to write/co-write the lay summary?			

	If no, is it appropriate for children or young people to give their feedback on the application?			
	Have you thought about what you need to know from collaborating with children and young people?			
	Have you thought about what you would you like to know/gain knowledge about from collaborating with children and young people?			
	Have you thought about how you are going to involve PPI within the research project?			
	i.e. Can children and young people collaborators help with the design, appropriateness, lived experience or dissemination throughout the project?			
	Have you adequately budgeted for collaborating with children and young people throughout the research?			
Forming a remuneration and recognition package	Have you adequately budgeted for children and young people contributors throughout any PPI activities? (e.g. remuneration of expenses; PPI honorariums; Cost of activities; cost of training opportunities; cost of travel)			<p>If possible, it would be helpful to involve parents or guardians, as well as the children and young people themselves, to discuss appropriate methods and amounts for remuneration.</p> <p>Resources that may be useful for budgeting for PPI activities can be found in the resources section.</p>
	Have you considered how to recognise and acknowledge the contributions of children and young people? (e.g. co-authorship of publications or dissemination materials; co-presenting materials; certificate of involvement; thank you letters; activity days; training opportunities)			<p>Acknowledging children and young people in research is essential to recognise their valuable contributions and ensure that their voices are heard.</p> <p>Recognition of their involvement</p>

				helps to highlight their role in shaping meaningful research outcomes. If possible, it would be helpful to involve children and young people and their parents to discuss appropriate methods of recognition.
Identifying Children and Young People to collaborate with	Have you thought about what you would like or need to get insights from children and young people?			
	Have you thought about what stage of your research would it be most beneficial to get help from children and young people or if the contribution is required throughout the entire trial?			
	Are you looking for children and young people with lived experience of what you're researching?			
	If so, is there anything extra you need to consider?			
	Are you striving for inclusivity, ensuring diverse voices are heard, including those from marginalized or underrepresented groups.			It may be useful to look at the PPI Ignite Network's Equality, Diversity and Inclusion Strategy .
	Do you need children and young people to be at a specific developmental stage or age to take part?			
	If so, is there anything extra you need to consider?			

Recruiting children and young people	<p>Have you thought about how you will recruit the children and young people to collaborate with?</p> <p>Have you considered if you need to advertise?</p>			<p>If possible, children and young people contributors should be involved in the recruitment process.</p> <p>Multiple methods for recruitment may be required.</p> <p>Create a plan for recruiting participants for the PPI activities, including defining the target population and strategies to reach them effectively.</p> <p>Re-recruitment or refreshing of the PPI panel may be required throughout the research process.</p>
	<p>Have you considered how you will reach your intended audience? (Is your advertising directed to children and young people, parents and guardians or organisations? Is your advertisement going to reach the right audience?)</p> <p>Do you need any permissions in place to advertise?</p>			
	<p>Have you considered multiple mediums of advertising (e.g. written/videos/posters)?</p>			
	<p>If you are advertising/contacting specific potential contributors, have you provided the following details?</p> <p>Project overview: brief description of the project: why it is important and how they will input to the project</p>			

	<p>Project timeline: Explain the overall duration of the project, the overall duration of the PPI involvement and whether it is a once off activity or they are expected to join for the entirety of the project.</p> <p>Who you are looking for: Have you stated who you are looking for? Do children and young people need to be of a certain age or developmental stage or have lived experience of a condition/situation being researched?</p> <p>What is required: Clarify the format of participation, such as whether it will be attending multiple meetings or a one-time activity (e.g. reviewing a trial document). Also provide details on the frequency of meetings, the expected duration of meetings and locations of meetings (e.g. in-person location or remote). Clarity should also be given on what to expect and specific start and end points. Do they need anything to be a PPI contributor (e.g. do they need a computer/Smart phone/Internet access?)</p> <p>Budget: Clarify if participants will be reimbursed for any expenses related to their involvement or if an honorarium will be provided and, if so, the amount and type of honorarium that will be provided.</p> <p>Contact Information: Have you provided information on how to ask questions? Is there an application process or how do they apply if they are interested? Have you provided multiple ways of applying (e.g. online/by post/by phonecall) to suit as many people as possible? Do you need anything from the PPI applicants? Do you need applications by a particular deadline, or do you have rolling recruitment?</p>			
	Is your advertisement using suitable language for the targeted audience. Have you made sure child friendly language is being used, that all materials are jargon free?			The National Adult Literacy Agency (NALA) and Health Information and Quality Authority (HIQA) have Guidance on Communicating in plain English for Children

	If you are using written materials, is the font size appropriate for children and young people?			For writing children's materials, it is recommended to use a minimum of 12pt. font size.
	Do you need to talk to children and young people directly? If so, you may need permissions to talk to children and young people directly through organisations, schools, hospitals or advocacy bodies.			
	Once you have identified members, have you listened to how they would like to participate?			You could assist children and young people in identifying their interests and roles they would enjoy in the process.
	Have you established a <u>partnership agreement</u> for all individuals involved in the research?			At each stage of PPI work with children and young people, it is beneficial to establish a partnership agreement that outlines everyone's expectations and to ensure the safeguarding of children and young people for the entire duration of their involvement.

<p>Agree terms and commitments</p>	<p>Have you got an agreement document in place?.</p> <p>Your agreement document should include</p> <p>Scope of Involvement - Defines the extent and nature of participation.</p> <p>Roles and Responsibilities - Outlines the duties of both researchers and children and young people contributors.</p> <p>Confidentiality - Specifies how the identity of children and young people will be protected.</p> <p>Feedback - Describes how participants can provide input and receive updates.</p> <p>Compensation and Reimbursement - Details any payment or reimbursement for participation-related expenses.</p> <p>Right to withdraw - participation is voluntary and that they can withdraw from the study at any time without any negative consequences.</p> <p>Safeguarding practices - Physical and emotional safety practices/procedures and staff involved.</p> <p>List of researchers, institutions and funding bodies involved</p> <p>Duration of PPI activities - Timeframe for participation</p> <p>Acknowledgement of contributions - How the children and young people's contributions will be acknowledged (consider recognizing their contributions publicly, such as in publications or presentations).</p> <p>Reviewing and Reporting - if any data will be collected or reported on the effectiveness of PPI contributions. If so, how this data will be stored and managed is required.</p> <p>Termination of contract – any reasons why the agreement may be ended.</p> <p>Expectations – What is realistically expected to be achieved in timeframe of involvement.</p>			
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Voluntariness	Have you ensured that both children and their parents/guardians are aware that joining your PPI research team is voluntary and free from any external pressures or biases?			<p>Children and their parents need to be able to make an informed choice to participate or not without any undue pressure.</p> <p>Emphasize that participation is optional. Children should feel free to decline without fear of negative consequences. This can be reiterated regularly.</p>
	Have children and young people and their parents/guardians been informed that their initial and continued participation is voluntary and that they can withdraw from the study at any time without any negative consequences?			
Ethics	Have you received training/familiarised yourself with good ethical practices in research? These need to be followed throughout any PPI activities with children and young people.			<p>In Ireland, ethical approval when conducting PPI work is not usually required. The PPI Ignite Network statement on research ethics committee approval may be a useful resource to look at.</p> <p>Although ethical approval is usually not required, good ethical practice should be followed throughout any PPI activities (Mitchell et al., 2019). At each stage of PPI work with children and young people, it is beneficial to establish a partnership agreement that</p>

				<p>outlines everyone's expectations and to ensure the safeguarding of children and young people for the entire duration of their involvement. Additionally, it's important to obtain consent and assent from children or young people and their parents or guardians (if the child is under 18) regarding their involvement, even if this approach is less formal than informed consent (TUSLA, 2024).</p>
Consent	Has the concept of PPI been clearly explained to any collaborating parties (e.g.: children and young people and their parents or guardians)? Do you need any materials to assist with this (e.g. videos/booklets/leaflet)?			<p>If using written materials, have you thought about literacy requirements or accommodations that might be required? The National Adult Literacy Agency (NALA) and Health Information and Quality Authority (HIQA) have Guidance on Communicating in plain English for Children.</p>
	Have you clearly communicated the entire process of collaborating in any PPI activities to any collaborating parties (explained to any collaborating parties (e.g.: children and young people and their parents or guardians) in an age-appropriate manner, ensuring everyone understands their roles? Do you need any materials to assist with this (e.g. videos/booklets/leaflet)?			<p>If using written materials, have you thought about literacy requirements or accommodations that might be required? The NALA and HIQA have Guidance on Communicating in plain English for Children.</p>

	Have you informed children and young people contributors about the research topic and ensured that they are happy to discuss this topic and the research?			
	Have you ensured any PPI recruitment materials are written in suitable language for the children and young people or their parents/guardians. Any information provided should be accessible and clear.			<p>If using written materials, have you thought about literacy requirements or accommodations that might be required? The NALA and HIQA have Guidance on Communicating in plain English for Children.</p> <p>Other tips include, to use clear and concise language, minimise word count while maintaining all necessary details for the intended audience. Ensure that the vocabulary is age-appropriate, opting for simple words and providing examples to clarify concepts.</p> <p>Where possible, avoid using any jargon, acronyms or technical terms, unless they are explained. For written materials, no written font to be smaller than size 12pt.</p>
	Have you checked that children and young people, and their parents/guardians are made aware that becoming a PPI contributor is voluntary and that they are able to make an informed decision?			This should be reiterated across the entire duration of PPI activities.

	<p>Have you given them an appropriate amount of time to decide on participation?</p> <p>Are they aware that their confidentiality will be protected and they have right to withdraw at any time?</p>			
	Have you provided contact details for the researcher in charge of communications to ensure questions or concerns can be dealt with.			
	Have you given children and young people and their parents/guardians the opportunity to ask questions or discuss the PPI activities/research in more detail?			
	<p>Have children and young people agreed to take part in all PPI activities (this needs to be confirmed at each activity for the entire duration of their involvement in research)?</p> <p>If you are involving children, have their parents or guardians provided permission for their child to take part in PPI activities (this needs to be confirmed at each activity for the entire duration of their involvement in research)</p>			
	Have you communicated the remuneration and compensation procedures? This should state the amounts given for each activity and which expenses will be reimbursed.			
	<p>Have you considered any other permissions that you may need to take into consideration?</p> <p>Examples:</p> <ul style="list-style-type: none"> • If you are using photography or videography, do you have permission to do so? • If you are recording any of the sessions, do you have permission to do so? • Have you gotten permission to include names of children and young people in outputs or do the children and young people or their parents/guardians wish for them to remain anonymous? 			

Communications	Have you agreed on the format of contacts to be used throughout the PPI activities with children and young people and their families?			Have you given varied options for communication?
	Have you agreed on language to be used throughout the PPI activities with children and young people and their families?			
	Is there someone to manage PPI activities/communications throughout the research entirety or activity?			
	Have you provided contact details for the researcher in charge of communications to ensure questions or concerns can be dealt with?			
	If children and young people were involved in the application stage, have you communicated that your funding application has been submitted?			
	If children and young people were involved in the application stage, have you communicated the outcome of the funding application?			
Child safety	Have you all necessary safeguarding procedures, child safety protocols and distress reporting procedures in place prior to collaborating with children and young people?			Familiarize yourself with Tusla's guidelines on safeguarding children , safeguarding resource list and the Children First Programme . More information can be found on their website .
	Have you received and made yourself aware of the distress protocols within your organisation prior to commencing any PPI activities with children and young people?			
	Do you have a dedicated support worker or support mechanisms in place?			Recognise that discussing certain topics may be emotional for children and young people. Provide access to a safe outlet for any feelings that arise during the process.

	<p>Have all researchers or facilitators received necessary Garda vetting documentation prior to commencing any PPI activities with children and young people?</p>		<p>Garda Vetting in Ireland is a process designed to check whether an individual has a criminal record, especially when applying for roles that involve working with children, vulnerable adults, or other sensitive positions. This process is managed by An Garda Síochána. It is important to check your institutions processes surrounding Garda vetting.</p> <p>Once Garda Vetting has been obtained, ensure all Garda Vetting documentation is stored securely.</p>
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Training Opportunities	<p>Are the researchers/facilitators confident in running PPI activities? If no, it is important to avail of any training opportunities that are available to you.</p>			<p>There are several different groups in Ireland offering support or training for collaborating with PPI contributors, some of which can be found here.</p> <p>The PPI Shared Learning Group on Children and Young People, organized by the PPI Ignite Network at DCU, gathers for one hour on the last Thursday of every other month. The group's goal is to enhance understanding and raise awareness of public and patient involvement (PPI) in research involving children and young people by presenting and discussing best practices and real-life examples. You can register here to stay informed.</p>
	<p>Are the researchers or facilitators trained in working with children and young people?</p>			
	<p>Have children and young people been offered training and support to help them understand PPI and their involvement?</p>			
	<p>Have you completed an introductory session for any children and young people to explain what their collaboration means?</p>			<p>An introductory session for children and young PPI contributors should create a welcoming, supportive environment where they understand the purpose of their</p>

				<p>involvement. It should include introductions, an explanation of PPI, and why their input matters, with real-life examples of how their opinions can make a difference. The session help the entire team set clear ground rules for respectful behaviour and confidentiality, outline roles and responsibilities and time commitments and explain how decisions are made with their input with opportunities for questions and discussions. The session should conclude with a summary, a preview of the next steps, and appreciation for their participation.</p>
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Research Phase

The **research phase** of research is when you actually start gathering and exploring information.

Research Element	Checklist	Yes	No	Comments/Top Tips
Voluntariness	Have you reminded collaborating children and young people about the research topic and ensured that they are happy to discuss this topic and the research? This is required across the entire research cycle.			
	Have you informed/reminded children and young people that their participation is voluntary and that they can withdraw from the study at any time without any negative consequences. This is required across the entire research cycle.			
	Have the research team declared any conflicts of interest and how they will be managed?			This should be shared with any children and young people and their families. Managing and addressing conflicts of interest in PPI is crucial for maintaining trust and integrity in research. All researchers should disclose any personal, financial, or professional interests that could influence their involvement. This should be done openly and regularly. Any potential conflicts of interest should be identified at the beginning of the project. Check your institutions policies and procedures regarding conflicts of interest? Keep a record of any disclosures and taken steps to address them?

<p>Agree terms/commitments</p>	<p>Have you got an agreement document in place.</p> <p>Your agreement document should include</p> <p>Scope of Involvement - Defines the extent and nature of participation.</p> <p>Roles and Responsibilities - Outlines the duties of both researchers and collaborating children and young people.</p> <p>Confidentiality - Specifies how the identity of children and young people will be protected.</p> <p>Feedback - Describes how participants can provide input and receive updates.</p> <p>Compensation and Reimbursement - Details any payment or reimbursement for participation-related expenses.</p> <p>Right to withdraw - participation is voluntary and that they can withdraw from the study at any time without any negative consequences.</p> <p>Safeguarding practices - Physical and emotional safety practices/procedures and staff involved.</p> <p>List of researchers, institutions and funding bodies involved</p> <p>Duration of PPI activities - Timeframe for participation</p> <p>Acknowledgement of contributions - How the contributions from children and young people' will be acknowledged (consider recognizing their contributions publicly, such as in publications or presentations).</p> <p>Reviewing and Reporting - if any data will be collected or reported on the effectiveness of PPI contributions. If so, how this data will be stored and managed is required.</p> <p>Termination of contract – any reasons why the agreement may be ended.</p> <p>Expectations – What is realistically expected to be achieved in timeframe of involvement.</p>			
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Child Safety	For in-person activities, have you checked the physical space is safe and secure, free from hazards, and appropriate for children's activities.			Always prioritize the physical and emotional safety of all children and young people.
	Have you checked child-to-adult ratios for support and supervision to ensure you have the necessary supports in place for any activity? In Ireland, child-to-adult ratios vary depending on the type of childcare setting.			
	Have you all necessary child safety protocols and distress reporting procedures in place?			Familiarize yourself with Tusla's guidelines on safeguarding children , safeguarding resource list and the Children First Programme . More information can be found on their website .
	Do you have a dedicated support worker or support mechanisms in place?			Recognise that discussing certain topics may be emotional for children and young people. Provide access to a safe outlet for any feelings that arise during the process.

<p>Creating a safe and empowering space for children and young people</p>	<p>Have you created a safe and supportive environment where children feel secure expressing their views?</p>		<p>Prioritize the physical and emotional safety of all participants.</p> <p>Informal spaces may work best.</p> <p>Treat all participants with respect, valuing their opinions and contributions. Their views and preferences should be considered and listened to throughout the entire research process.</p> <p>Be sensitive to their individual needs and experiences.</p> <p>Be aware of and respect cultural differences that may influence perspectives.</p> <p>Encourage children and young people to express their opinions and ideas openly and ensure they feel that their contributions are heard and valuable.</p> <p>Be open minded, flexible in approach and do not pass any judgment.</p>
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	Are your planned activities inviting and engaging for young participants.			Use age-appropriate methods for engagement, ensuring that activities are suitable and accessible for the age group involved. There are some examples of icebreaker activities here .
	Are you using age-appropriate language to ensure children and young people understand the discussions?			The National Adult Literacy Agency (NALA) and Health Information and Quality Authority (HIQA) have Guidance on Communicating in plain English for Children
	Have you empowered the voices of children and young people?			<p>Acknowledge the unique expertise that children and young people bring to the table. Shift the perception that professionals hold all the knowledge and emphasize the value of lived experiences.</p> <p>Be open and flexible in your approach.</p> <p>Ensure that all children and young people feel confident to share their perspectives and that their opinions are listened to.</p>

				<p>Establish mechanisms for ongoing feedback.</p> <p>If possible, involve children and young people in decision-making processes at every stage (e.g. co-develop project aims, methods, and outputs).</p>
	For any activities, have you thought about only including facilitators who are experienced/received training in working with children and can create a child-friendly atmosphere?			
	Maintain communication with both children and young people and their parents/guardians about the involvement process, schedule and any outcomes.			
	Have children and young people been informed about the outcomes of PPI activities and how their contributions are making a difference. This should include any research developments, changes in policies, practices and law changes.			
	Have you thought about in-person/online options and if so, how will you support this?			
	Have you chosen venues that are easily accessible for all children and their guardians, considering transport, access and safety.			
	Have you made any activities child friendly?			Are you providing enough time to talk, time for fun activities, using icebreaker activities ?
	Have you provided multiple options for engagement during sessions? (e.g. expression through play, expression through art, talking, communicating on phones or electronic devices)			

Remuneration	Have you engaged with parents or guardians, as well as the children and young people themselves, to discuss appropriate methods and amounts for remuneration.			
	Have you checked if the legal restrictions on how many hours children and young people under 16 years can undertake paid activities?			
	Do children and young people have to claim any expenses (submit receipts for costs) or submit invoices for their time? If so, have you put together a step-by-step plan/demonstrated how this needs to be done or will you help with this process? If so, have you had the children and young people set up as a payee with your finance office?			
	Have you checked the timeframe in which payments will be made and informed children and young people and their families of this?			
	Have you established a payment process with your finance or HR office on how you are going to pay children and young people contributors before the involvement activity starts. Check with finance and HR departments that it is accurate and can be implemented.			
	Have you established a process if the child or young person does not have a bank account?			
	If you intend on monetary payments (e.g. vouchers), have you checked that this is possible with your finance office?			
	If the children and young people and their parents/guardians are in receipt of social welfare and they accept payment or rewards for research participation, have you made them aware that their social welfare payment may be affected.			
Confidentiality/Privacy	Have you developed confidentiality agreements?			
	Have all researchers involved in the project signed confidentiality agreements to protect children and young people's information?			Everyone involved should understand their responsibilities

				regarding confidentiality of children and young people.
	Have all children and young people involved in the research signed confidentiality agreements?			<p>Confidentiality agreements for PPI involving children and young people should clearly outline how children and young peoples identity and confidentiality will be protected, while ensuring that participants understand their rights and the limits of confidentiality, especially in situations where safety is a concern.</p> <p>It can help to develop this agreement alongside children and young people.</p> <p>Ensure the agreement is child-friendly, uses appropriate language and is transparent.</p>
	Have you agreed that personal information is kept confidential?			<p>Any research staff and volunteers must receive training on confidentiality practices, data protection laws, and ethical standards.</p> <p>If any information is stored, it must be securely in accordance with the 2018 General Data</p>

				Protection Regulations. This could include information such as contact information, emergency contact information or medical information (allergies or medication). This information must be deleted once the children and young people are no longer involved. Information can be found on the Data Protection Commission website.
	Have you discussed the limitations to confidentiality prior to initiating any activities? (e.g. Identified or potential risks to, or concerns regarding, children or young people)			It is important to have clear and detailed conversations informing children and young people about the limitations of confidentiality at the outset of the working relationship.

Wrap Up Phase

Research Element	Checklist	Yes	No	Comments/Top Tips
Communication	Have you communicated what happens once the PPI activity/activities have been completed?			
	Have you communicated about the outcomes of the PPI activities and any impact they had?			
	Have you communicated the research findings and developments?			Information about the research should be communicated in a clear, age-appropriate manner to

				both children and their parents or guardians.
	Have you communicated any next steps?			
	If you are having any research events, have you invited any children and young people PPI contributors and their families?			Ensure venue is child friendly
	Have you collected any feedback on the PPI process itself from children and young people?			
Dissemination of research	Have you worked with children and young people to tailor your research messaging.			They could help craft messages that resonate with their aged-matched counterparts, ensuring that information is relevant and engaging.
	Have you worked with children and young people to ensure that you are using the right methods of public dissemination to target your audience (e.g. articles, videos, social media posts, posters)?			
	Have you worked with children and young people to create dissemination materials?			
	Have you thought about children and young people co-authoring publications? If that is not possible, provide input on the clarity and accessibility of dissemination materials, helping to ensure that content is understandable and relatable.			

Closing the loop	<p>If you're PPI activities are coming to an end, have you communicated the end of the involvement well in advance. This provides children and young people time to adjust and ensures they don't feel blindsided.</p> <p>Also, have you let them know the specific reason for winding down, such as the completion of the project, changes in funding, or the end of a particular phase of the research.</p>			
	<p>Have you thanked the children and young people and/or their families for their time and insights?</p>			<p>Take time to formally thank participants for their time and insights. This would provide children and young people with a sense of closure and reinforces that their contributions are recognized and valued.</p>
	<p>Have you provided feedback on how their involvement has contributed to the research?</p>			<p>This could be in the form of a report or presentation that highlights their specific impacts and what their contributions changed.</p>

	Have you formally recognised the efforts of the children and young people contributors in ways that are meaningful to them?			<p>It is important to check the ways children and young people would like to be recognised and acknowledged with both children and young people and their parents/guardians (if confidentiality may be an issue).</p> <p>Ideas for how children and young people efforts could be recognised include certificates, public acknowledgment, co-publications, presentations or day trips.</p>
	Have you checked if children and young people have any concerns or feedback about the process before finishing?			
Remuneration and Compensation	Have you finalised all honorariums/remunerations for children and young people PPI contributors after all activities have been completed?			There is additional information on remuneration and compensation here .
	<p>Have you communicated to children and young people and their families that all expenses or invoices must be claimed by a certain date to ensure they receive compensation before the end of funding?</p> <p>If so, have you ensured that all payments have been finalised before the project end.</p>			

Follow-up	<p>Are you completing any follow-on research?</p> <p>If yes, have you thought about maintaining the same children and young people PPI team that you have established.</p> <p>If yes, are they aware of this and happy to be contacted?</p> <p>If yes, have you ensured that you have made it clear that this continued participation is again voluntary?</p>			
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Glossary

Children: According to the United Nations Convention on the Rights of the Child, children are defined as anyone under the age of 18 years of age (United Nations, 1989)

Young People: The World Health Organisation defines young people as those between 10 and 24 years of age. World Health Organisation, 2014)

Resources

General Information and Resources

- The [PPI Ignite Network](#) in Ireland is funded by the Health Research Board and Irish Research Council to promote excellence and encourage innovation in PPI in health and social care research nationally. The PPI Ignite Network is a partnership amongst 7 Irish Universities, 10 National partners and 53 local partners.
- [DCU PPI Ignite Resources Page](#)
- [PPI Ignite Network Involving Children and Young People in shaping research](#)
- [TUSLA Public and Patient Involvement](#)
- [HSE Useful Links and Resources for PPI](#)
- [Barnardo's Young Researchers: Guidance](#)
- IPPOSI is a patient-led organisation who work with patients, scientists, government, academia and industry to ensure patients are represented at the forefront of health policy, health care, research and innovation in Ireland. They offer courses for patient contributors and have resources available on their website: <https://www.ipposi.ie>
- [NIHR: Briefing notes for researchers - public involvement in NHS, health and social care research](#)
- [NIHR: Involving children and young people as advisors in research](#)
- [NIHR PPI \(Patient and Public Involvement\) resources for applicants to NIHR research programmes](#)

Ethics

- [PPI Ignite Network statement on research ethics committee approval](#)

Training and Support

- Children and Young People Shared learning group: The PPI Shared Learning Group on Children and Young People, organized by the PPI Ignite Network at DCU, gathers for one hour on the last Thursday of every other month. The group's goal is to enhance

understanding and raise awareness of public and patient involvement (PPI) in research involving children and young people by presenting and discussing best practices and real-life examples. Register [here](#) to stay informed

- PPI Ignite - [Digital Badge: Public and Patient Involvement in Research \(instructure.com\)](#)
- [Introduction to PPI Video by the PPI Ignite Network](#)
- Many of the [PPI Ignite Network Lead Sites](#) offer introductory sessions, and some also offer modules focused on public and patient involvement. For more details, you can contact your local PPI Ignite Network site.
- PPI Ignite Network [Digital Badge: Public and Patient Involvement in Research](#)

Budgeting

- [PPI Ignite Network at DCU Budgeting for PPI advice](#)
- [Payment guidance for researchers and professionals | NIHR](#)

Child Safety

- [Child and Family Agency Act 2013](#)
- [UN Convention on the Rights of the Child](#)
- [TUSLA Signs of Safety - Information Leaflets for Children, Parents and Professionals](#)
- [Tusla Child and Family Agency: Children First Programme](#)

Communication

- [Plain English writing, structure and design tips - NALA](#)
- [Writing Child-friendly Versions of Research and Evaluation Reports](#)
- Additional Icebreaker activities can be found at the following links by: Session Lab; Ultimate Camp Resource or Team Building

Tools

Icebreaker Activities

Below you can find different Icebreaker activities. Icebreakers are a way to help groups feel more comfortable, connected, and ready to engage with each other in a productive way.

Ideas for forming partners:

- Find someone with the same eye color as you.
- Find someone who had the same thing you had for breakfast.
- Start hopping on either your left foot or right foot and find a partner who is hopping with the same foot you are.
- Find a partner who has a different number of brothers and sisters than you do.
- Find a partner who is wearing one item of clothing the same color as you are.
- Put either your pinky or thumb in the air. Find one other person who is doing the same thing you are, and that person is your partner.
- Would you rather eat an apple or an orange? Find someone who would rather eat the same thing you like.

Human Knot

Category: Problem-solving, team building

Materials: None

Preparation: None

Instructions: Everyone stands in a circle. Tell everyone to reach across the circle and shake hands with someone (the person cannot be standing next to them.) After shaking hands, they should not let go of that person's hand. Then, tell them to use their free hand to grab the free hand of a different person – not the same person that they shook hands with the first time. Now that the group is all knotted up, ask the children to unravel the knot by unthreading their bodies without letting go of each other's hands.

Discussion: What strategies worked best for unraveling the knot? If we were to do it again, how could we be more efficient?

Giants, Wizards, Elves

Category: team building, physical activity, energizer

Materials: None

Preparation: None

Instructions: Before you begin, explain the three rules to the participants:

1. Giants conquer wizards. To be a giant, raise your arms high above your head.
2. Wizards conquer elves. To be a wizard, make a triangle with your arms over your head.
3. Elves conquer giants. To be an elf, place your hands alongside your ears with index fingers extended.

Divide the participants into two teams with a space of about 4 feet between them. Direct each team to retreat a few feet for a huddle to decide which they will be giants, wizards, or elves. In their huddles, each team decides what they will be, plus a backup choice. Then they come back to their 4-feet-apart stance. On a count of three, each team yells what they are. If one team yells "Elves!" and the other yells "Wizards!" The wizard team will chase the elves to their safe zone (you can mark these with cones or use a tree or other found object). Anyone who is tagged becomes part of the opposing team. If both teams yell the same creature, they do it over-using their backup choice.

Birthday Circle

Category: Energizer, teambuilder

Materials: None

Preparation: None

Instructions: Ask the group to place themselves clockwise in order of their birthday months and days. Give more specific directions and demonstrations if your group is young or confused.

What Am I?

Category: Guessing game, energizer, time filler

Materials: Sticky notes, marker

Preparation: On each sticky note, write a noun. It can be a place, an object, a color, or a food. Make sure that there is one sticky note for each participant.

Instructions: Place the sticky notes on the participant's backs so that they cannot see their own sticky note. Tell them that their sticky note could be a place, an object, a color, or a

food. They must walk around, go up to other participants, and ask Yes or No questions about their sticky note. Once they guess what they are, they can sit down.

Discussion: Which were the hardest things to guess?

Tips: Don't make the items too difficult to guess, this will make the game more frustrating than fun.

My Name Is...

Category: Icebreaker, physical activity

Materials: None

Preparation: None

Instructions: Gather participants in a large circle. Tell them that they must think of a movement to accompany their name. Begin the game by demonstrating a movement with your own name (for example, say "Peter!" and spin around once.) The next person must repeat that name and movement, then add their own name and movement. This continues around the circle. The last person will have to do the names and movements of everyone else in the circle! Help the participants if they have trouble remembering the names and movements.

Discussion: Which movements and names were the easiest to remember?

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