Ethical Collaboration with Children and Young People in Research

PPI IGNITE NETWORK

Ethical Collaboration with Children and Young People in Research

Acknowledgements

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Participants at the launch of this guide, Barretstown Campus, 30th Jan 2025.

Foreword

On Tuesday, January 30, 2024, 55 attendees gathered at the Barretstown Campus 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, Prof. 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. Prof. Suzanne Guerin 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 Dr. Roisin Farragher (Tusla – Child and Family Agency), 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.

This toolkit developed from the insights gathered during the event we hope 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 (now Taighde Éireann - Research Ireland), and DCU. Thanks to all who attended and contributed their valuable expertise.

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

On January 30, 2025, the PPI Ignite Network at DCU, Barretstown, and Tusla

– Child and Family Agency launched the "Ethical Collaboration with Children & Young People in Research" resource at Barretstown Campus, County Kildare. The event opened with a welcome from John Mitchell of Barretstown, followed by a detailed presentation of the resource by Prof. Veronica Lambert from the PPI Ignite Network at DCU. A panel discussion, facilitated by Dr. Edel Tierney of Tusla Child and Family Agency, featured insights from experts Dr. Harry Shier, Dr. Roisin Farragher, and Prof. Suzanne Guerin. Keynote speaker Arthur Isaac, founder of Future Youth Impact, explored the challenges and opportunities of participatory research with children and young people. Attendees also engaged in icebreaker activities led by John Mitchell. The event concluded with closing remarks from Marian Brattman, National Manager for Research at Tusla Child and Family Agency National Research Office. Sincere thanks to all attendees for their participation and valuable contributions to the discussions, making the event a resounding success.

Prof Veronica Lambert, DCU, John Mitchell, Barretstown and Dr Edel Tierney, Tusla Child and Family Agency.

Purpose

This toolkit contains guidance when collaborating with children and young people in research, as well as how to plan, support, and implement their involvement effectively. 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. This guide includes a series of checklists designed to support anyone in planning or evaluating research and activities when collaborating with children and young people. These checklists are not intended as strict instructions but rather as suggestions and prompts to help guide your thinking and decision-making process. By considering these points, you can ensure that your activities are thoughtful, inclusive, and impactful.

For the purpose of this resource, the following definitions have been applied:

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)

Given the broad definition of children and young people, it is important to note that while the checklist can be applied across various contexts, the developmental differences and needs within children and young people must be considered. You can find resources covering the development of children and young people in more detail **here**.

The Toolkit is structured into sections corresponding to various stages of the collaboration timepoints across the research cycle. There are separate checklists for the different phases in collaboration process: PPI in Preparation; PPI in Action and PPI in Wrap Up, followed by useful resources, activity ideas containing icebreakers and games as well as references. The order of research items or elements is not prescriptive and can be used flexibly in any sequence that aligns with the specific requirements and context of a research project. This adaptability allows anyone to prioritise elements in a manner most relevant to their goals and circumstances.

The focus of this resource is on questioning prompts rather than providing direct instructions, encouraging a thoughtful and reflective approach to determining the best course of action. This approach recognises that the most suitable path forward will depend on the unique context and requirements of each individual project.

Each checklist is presented in a table format with several columns:

- Research Elements: This column outlines the key steps to consider throughout the research or collaborative cycle.

- Checklists: This column provides a detailed description of the elements to consider at each step.

- Yes/No Columns: These columns allow for marking whether each element has been completed or not. Sometimes, certain elements may not apply, and it's perfectly acceptable to mark "No" in those cases. Spaces are included throughout the guide for reflecting on why certain elements have been marked, providing room for deeper consideration.

- Top Tips: This column highlights important elements to keep in mind throughout each stage of the collaboration.

The rows in the table correspond to a specific step or task that needs attention within the collaborative cycle with the rows in place to guide you through the process by breaking down each key element, ensuring a comprehensive and organised approach to the entire PPI research cycle.

Participants at the workshop in 2024
developing the ideas and insights for this toolkit

Resource Development Methods

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. This feedback informed the development of a new resource aimed at guiding researchers on collaborating with children and young people. To further refine the guide, the authors sought feedback from a diverse range of stakeholders, including initial event attendees and speakers, as well as members of the PPI Shared Learning Group on Children and Young People which is hosted by The PPI Ignite Network at DCU, key organisations and departments that work alongside children and young people and children and young people themselves. Children and young people were invited to review the resource and provide feedback by individuals or professionals known to them The feedback we gathered, has been crucial in shaping this toolkit, which aims to provide both guidance and support to anyone involved in PPI activities with children and young people.

For the final steps, the authors gathered additional feedback during the resource launch on January 30th, 2025. The launch brought together another wide range of stakeholders who provided valuable insights that further refined and enhanced the resource. The authors would like to sincerely thank all event attendees for their contributions and support.

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?**
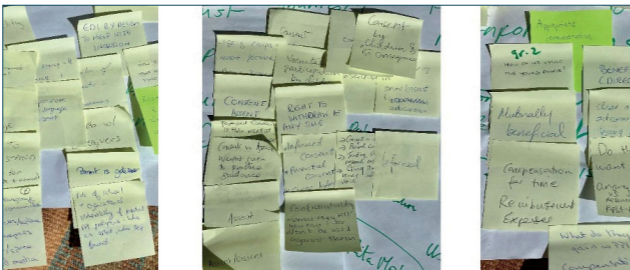
Question 2: **How do you ethically engage children and young people in research?**
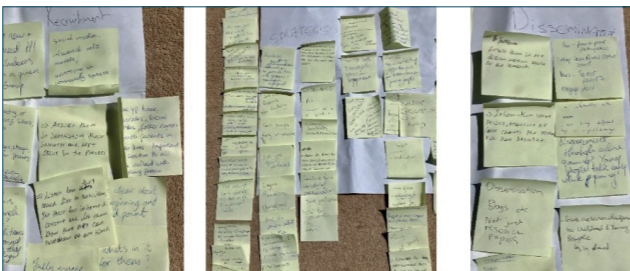
Question 3: **What do you want a resource for ethical collaboration to look like?**
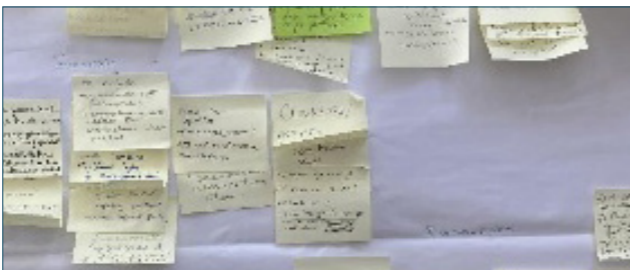
Introduction to Public and Patient Involvement

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, 2024).

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/collaborators 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/collaborator 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/collaborators 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.

Reflection: why do you believe PPI in collaboration with children and young people is important?

PPI in Research with Children and Young people

Public and Patient Involvement (PPI) in research with 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. Their unique perspectives help ensure the research is more useful, relevant and aligned with the needs of the target population, improving its overall quality and impact (Molloy et al., 2019). Researchers also gain valuable insights that can enhance study design and appropriateness. Additionally, engaging young people fosters trust within the community, supports ethical research practices, and broadens the researchers' own skills in communication and collaboration. This inclusive approach ultimately strengthens the research and its connection to the communities it aims to serve.

Engaging young collaborators offers a wide range of benefits that support their personal, educational, and social development. Collaboration can boost their confidence, enhance communication and public speaking skills, and foster a sense of empowerment as they see their input valued and acted upon (Preston et al., 2023). They gain critical thinking and teamwork, exposure to research and professional environments and recognition for their contributions (Mitchell et al., 2019). Additionally, being involved allows young people to make a meaningful impact on decisions that affect their peers and communities, fostering a sense of belonging and validation. These experiences not only support their personal growth but also empower them as advocates for issues that matter to them.

The Lundy Model of Participation

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's important to note that although the Lundy Model of Participation is not specifically designed as a PPI participation model for collaborating with children in PPI research, its principles can be effectively applied in this context.

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.

Space

HOW: Provide a safe and inclusive space for children to express their views

- Have children's views been actively sought?
- Was there a safe space in which children can express themselves freely
- Have steps been taken to ensure that all children can take part?

Voice

HOW: Provide appropriate information and facilitate the expression of children's views

- Have children been given the information they need to form a view?
- Do children know that they do not have to take part?
- Have children been given a range of options as to how they might choose to express themselves?

Audience

HOW: Ensure that children's views are communicated to someone with the responsibility to listen

- Is there a process for communicating children's views?
- Do children know who their views are being communicated to?
- Does that person/body have the power to make decisions?

Influence

HOW: Ensure that children's views are taken seriously and acted upon, where appropriate

- Were the children's views considered by those with the power to effect change?
- Are there procedures in place that ensure that the children's views have been taken seriously?
- Have the children and young people been provided with feedback explaining the reasons for decisions taken?

Lundy, L., Kilkelly, U., Forde, L and Kelleher, D. (2020).
The Right of Children to Participate in Public Decision-Making Processes. London: Save the Children.
Available https://resourcecentre.savethechildren.net/library/right-children-participate-public-decision-making-processes

What is PPI and Why Does it Matter to children or young people?

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.

Another way to improve your cake, besides letting friends and family taste it, is to get them involved in helping to bake the cake. This could involve comparing recipes, finding the best ingredients, measuring and mixing ingredients, baking and decorating the cake.

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!

By analogy, children and young people can help adult researchers to develop research questions, develop and test research methods and instruments, collect data (e.g., peer-to-peer interviews), analyse findings, draw conclusions, produce reports, disseminate and raise awareness of outcomes (Shier 2019).

Arthur Isaac - a children's rights and youth participation consultant based in Wales has created a resource called *"Is research right for me? A Guide for Young People"*. He draws upon his own experience as a peer researcher and founder of a youth-led research organisation to create an honest, well-rounded guide for other young people. Arthur is currently working on *"the Participation Speedometer"*, a conceptualisation encouraging

organisations and practitioners working with young people to identify the form of engagement right for their project.

You can stay up-to-date with his work o LinkedIn (Arthur Templeman-Lilley) or Instagram (@Arthurisaac04).

The *"Is research right for me? A Guide for Young People"* resource provides young people with the information and reflection opportunities that they need before getting involved in research. It breaks down the research process using real-world examples, explains the different roles in research, and summarises the skills that they could develop. The guide puts a focus on youth participation, empowering readers through rights-based language. Through the use of diagrams and graphics, young people with varied learning styles can get what they need from the resource. Whether or not research is something they have explored previously, young people can take a look and find their own answers to the question "is research right for me?"

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 considered at each stage of the research process when collaborating with children and young people. There are separate checklists for the preparation, action and wrap-up phases of research.

Components of the resource can also be applied to support ethical practices in research involving children and young people, particularly during phase 2: conducting the research. Additionally, the resources and icebreakers provided are versatile tools that can enhance engagement and communication, making them valuable beyond the context of public and patient involvement (PPI). These elements can be effectively utilized in various research settings to foster a respectful and inclusive environment when working with children and young people.

PPI Throughout the Research Cycle

- Identifying & Prioritising
- Design
- Undertaking / Management
- Analysing and Interpreting
- Dissemination
- Implementation

Phase 1 PPI in Preparation Phase

Phase 2 PPI in Action Phase

Phase 3 PPI in Wrap Up Phase
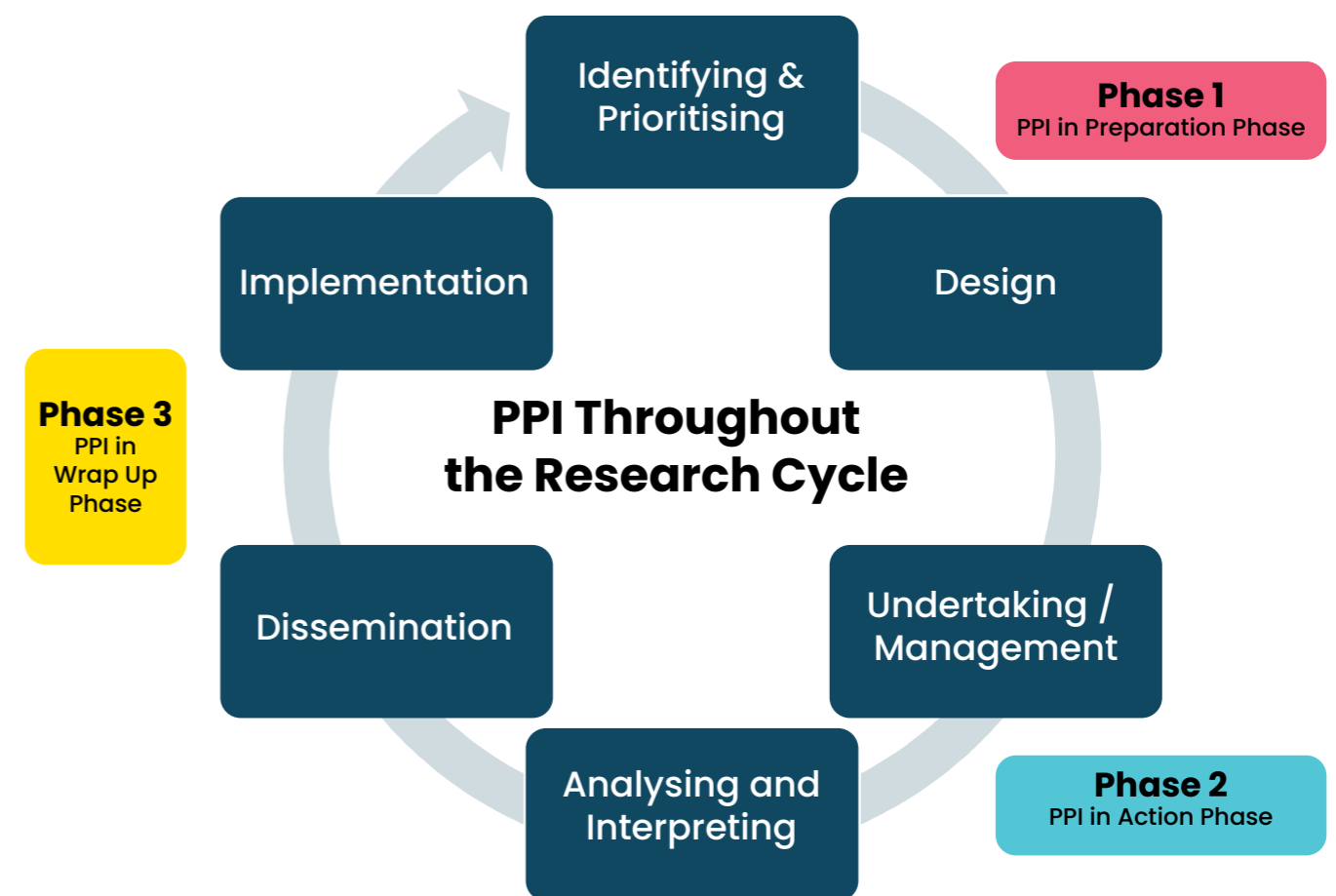
Phase 1:
The Preparation Phase

The preparation phase is a critical stage of PPI that lays the groundwork for a successful collaboration. It starts at the point of research ideation and ends when you have everything in place and are ready to begin. Establishing a committee/advisory group can take time and should be considered at the very start of the research planning process.

Identifying & Prioritising

Phase 1
PPI in Preparation Phase

Design

Research Element	Checklist	Yes	No	Top Tips
Forming a research question	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.

Reflections:

Research Element	Checklist	Yes	No	Top Tips
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 like to know/gain knowledge about from collaborating with children and young people?			
	Have you thought about how you are going to collaborate with children and young people within the research project? i.e., Can collaborating children and young people 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?			

Phase 1: PPI in Preparation Phase

Research Element	Checklist	Yes	No	Top Tips
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 research process?			
	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?			
	What arrangements need to be taken to ensure the **safeguarding of children** and young people involved?			
	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?			

Research Element	Checklist	Yes	No	Top Tips
Recruiting children and young people	Have you thought about how you will recruit the children and young people to collaborate with? Have you considered if you need to advertise?			If possible, children and young people should be involved in the recruitment process. If you currently do not have children and young people available to assist, consider reaching out to existing Young People's Advisory Groups (YPAGs) for support with this. Multiple methods for recruitment may be required. Create a plan for recruiting children and young people to collaborate with, including defining the target population and strategies to reach them effectively. Re-recruitment or refreshing of the collaborators may be required throughout the research process.
	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?) Do you need any permissions in place to advertise?			

Research Element	Checklist	Yes	No	Top Tips
Recruiting children and young people *(continued)*	Have you thought about barriers that may prevent some groups from collaborating and attempted to mitigate these?			This may include barriers that prevent people hearing about the opportunity; barriers that prevent people from accessing the opportunity; social barriers; financial barriers; health barriers; barriers that prevent people from feeling welcome and included when they decide to take part.
	Have you considered multiple mediums of advertising (e.g. written/videos/posters)?			
	If you are advertising/contacting specific potential collaborators, have you provided the following details?			
	Project overview: brief description of the project: why it is important and how they will input to the project			
	Project timeline: Explain the overall duration of the project, the overall duration of the collaboration and whether it is a once off activity or they are expected to join for the entirety of the project.			
	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?			

Research Element	Checklist	Yes	No	Top Tips
Recruiting children and young people *(continued)*	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 collaborator (e.g. do they need a computer/Smart phone/Internet access?)			
	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.			
	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 potential collaborators? Do you need applications by a particular deadline, or do you have rolling recruitment?			
	Is your advertisement using suitable language for the targeted audience. Have you made sure child and young person 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](#)

Phase 1: PPI in Preparation Phase

Research Element	Checklist	Yes	No	Top Tips
Recruiting children and young people *(continued)*	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 parents/ guardians, organisations, schools, hospitals or advocacy bodies.			If you are collaborating with children, parents or guardians need to give their permission for a researcher to approach any child about collaborating in research activities.
	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 **partnership agreement** for or all individuals involved in the research?			At each stage of the collaboration 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.

Research Element	Checklist	Yes	No	Top Tips
Forming a remuneration and recognition package	Have you adequately budgeted for collaborating children and young people throughout any PPI activities? (e.g., remuneration of expenses; PPI honorariums; Cost of activities; cost of training opportunities; cost of travel)			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. Resources that may be useful for budgeting for PPI activities can be found in **the resources section.**
	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)			Acknowledging children and young people in research is essential to recognise their valuable contributions and ensure that their voices are heard. Recognition of their involvement 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.

Research Element	Checklist	Yes	No	Top Tips
Agree terms and commitments	Have you got an agreement document in place? **Your agreement document should include** **Scope of Involvement** - Defines the extent and nature of participation. **Roles and Responsibilities** - Outlines the duties of both researchers and collaborating children and young people. **Confidentiality** - Specifies how the identity of children and young people will be protected. **Feedback** - Describes how participants can provide input and receive updates. **Compensation and Reimbursement** - Details any payment or reimbursement for participation-related expenses. **Right to withdraw** - participation is voluntary and that they can withdraw from the study at any time without any negative consequences. **Safeguarding practices** - Physical and emotional safety practices/procedures and staff involved. **List of researchers, institutions and funding bodies involved** **Duration of activities** - Timeframe for participation **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). **Reviewing and Reporting** - if any data will be collected or reported on the effectiveness of the collaborations. If so, how this data will be stored and managed is required. **Termination of contract** – any reasons why the agreement may be ended. **Expectations** – What is realistically expected to be achieved in timeframe of involvement.			

Research Element	Checklist	Yes	No	Top Tips
Voluntariness	Have you checked that children and young people, and their parents/guardians are made aware that becoming a collaborator is voluntary and that they are able to make an informed decision? Have you given them an appropriate amount of time to decide on participation? Are they aware that their confidentiality will be protected (within the limits of child protection) according to their preferences and that they have the right to withdraw from the collaboration at any time?			This should be reiterated across the entire duration of any activities.
	Have you ensured that children are aware that collaborating with your research team is voluntary and free from any external pressures or biases?			Children need to be able to make an informed choice to participate or not without any undue pressure. Emphasize that participation is optional. Children should feel free to decline without fear of negative consequences. This can be reiterated regularly.
	Have children and young people been informed that their initial and continued collaboration is voluntary and that they can stop at any time without any negative consequences?			

Phase 1: PPI in Preparation Phase

Research Element	Checklist	Yes	No	Top Tips
Ethics	Have you received training/familiarised yourself with good ethical practices in research? These need to followed throughout any collaboration activities with children and young people.			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. 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 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 16) regarding their involvement, even if this approach is less formal than informed consent (https://www2.healthservice.hse.ie/organisation/national-pppgs/hse-national-policy-for-consent-in-health-and-social-care-research/) HSE National Policy for Consent in Health and Social Care Research (V2.0, 2024)).

Research Element	Checklist	Yes	No	Top Tips
Consent and Assent	Has the concept of PPI/collaboration in research been clearly explained to any children and young people? Do you need any materials to assist with this (e.g. videos/booklets/leaflet)?			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.
	If you are collaborating with children below the age of 16, are parents or guardians aware of any activities and have provided their consent for children to take part?			If you are contacting children about research, parents or guardians need to give their permission for a researcher to approach any child about collaborating in research activities. The HSE has recently released Version 2.0 of its National Policy for Consent in Health and Social Care Research, which defined a child as person under 16 years old. The guidance can be found at the following link: https://www2.healthservice.hse.ie/organisation/national-pppgs/hse-national-policy-for-consent-in-health-and-social-care-research/. This guidance should be examined further if you are collaborating with particularly vulnerable groups. 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. Additionally, it's important to obtain consent and assent from children or young people and their parents or guardians (if the child is under 16) regarding their involvement, even if this approach is less formal than informed consent. The decision to take part rests solely with the child, who provides assent based on their understanding and willingness. This process ensures that the child's autonomy is respected while involving them in research PPI activities.

Research Element	Checklist	Yes	No	Top Tips
Consent and Assent (continued)	Have you clearly communicated the entire process of collaborating in any PPI activities to children and young people in an age-appropriate manner, ensuring everyone understands their roles? Do you need any materials to assist with this (e.g. videos/booklets/leaflet)?			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.
	Have you informed collaborating children and young people 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. Any information provided should be accessible and clear.			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. 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.
	Have you given children and young people an appropriate amount of time to decide on participation before providing assent?			

Research Element	Checklist	Yes	No	Top Tips
Consent and Assent (continued)	Are children and young people aware that they have right to withdraw at any time without any repercussions?			This should be reiterated across the entire duration of the collaboration.
	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 the opportunity to ask questions or discuss the PPI activities/research in more detail?			
	Have children and young people agreed and assented to take part in all PPI activities (this needs to be confirmed at each activity for the entire duration of their involvement in research)?			
	Have you communicated the remuneration and compensation procedures? This should state the amounts given for each activity and which expenses will be reimbursed.			
	Have you considered any other permissions that you may need to take into consideration? Examples: 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?			If you are using photography or videography, ensure that all photos and videos are managed responsibly. To this end, only retain these materials for the retention period specified, after which they need to be securely deleted.

Research Element	Checklist	Yes	No	Top Tips
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?			

Research Element	Checklist	Yes	No	Top Tips
Child safety or Safeguarding	Do you have all the necessary safeguarding procedures, safety protocols for children and young people, and distress reporting procedures in place before collaborating with them?			Familiarise 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 all researchers completed any necessary child protection training?			In Ireland, the Children First Programme training is essential for individuals working with children and young people, focusing on recognising and reporting child abuse. Additionally, be sure to check your institution's specific requirements for child protection training, as some organizations may have their own guidelines or certification processes that align with national standards.
	Have you received and made yourself aware of the distress protocols within your organisation prior to commencing any collaboration 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.

Research Element	Checklist	Yes	No	Top Tips
Child safety or Safe-guarding *(continued)*	Have all researchers or facilitators received necessary Garda vetting documentation prior to commencing any collaboration activities with children and young people?			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. Once Garda Vetting has been obtained, ensure all Garda Vetting documentation is stored securely.
	After any consultation, confirm that children have access to suitable support systems. This includes: • Identifying an appropriate adult they feel comfortable talking to (e.g., a parent, guardian, teacher, or trusted mentor). • Ensuring they are aware of external support resources, such as Childline or similar organizations, where they can seek additional help if needed.			Encourage open communication and provide information about available support options to help children and young people feel supported and secure.

Research Element	Checklist	Yes	No	Top Tips
Training Opportunities	Are the researchers/facilitators confident in collaborating with children and young people in research activities? If no, it is important to avail of any training opportunities that are available to you.			There are several different groups in Ireland offering support or training for collaborating with patients or members of the public, including the PPI Ignite Network and others which **can be found here**. The PPI Shared Learning Group on Children and Young People which is hosted 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 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. Research or facilitation teams may include researchers or volunteers who are gaining experience through a "learning by doing" approach. This is a commendable approach when the process is led and supervised by an experienced, qualified practitioner. Such leadership ensures that less experienced team members receive proper guidance and support, helping to prevent errors and fostering their professional growth.
	Are the researchers or facilitators trained in working with children and young people?			

Phase 1: PPI in Preparation Phase

Research Element	Checklist	Yes	No	Top Tips
Training Opportunities *(continued)*	Have children and young people been offered training and support to help them understand PPI and their collaboration?			
	Have you completed an introductory session for any children and young people to explain what their collaboration means?			An introductory session for children and young should create a welcoming, supportive environment where they understand the purpose of their collaboration. 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.

Phase 2: PPI in Action Phase

After the planning stage, the "PPI in Action" phase marks the beginning of research collaborations. During this phase, researchers actively work alongside children and young people, ensuring their voices are heard and prioritized throughout the research process.

Undertaking / Management

Analysing and Interpreting

Phase 2
PPI in Action Phase

Phase 2: PPI in Action Phase

Research Element	Checklist	Yes	No	Top Tips
Agree terms and commitments	Have you got an agreement document in place? **Agreement documents should include** **Scope of Involvement** - Defines the extent and nature of participation. **Roles and Responsibilities** - Outlines the duties of both researchers and collaborating children and young people. **Confidentiality** - Specifies how the identity of children and young people will be protected. **Feedback** - Describes how participants can provide input and receive updates. **Compensation and Reimbursement** - Details any payment or reimbursement for participation-related expenses. **Right to withdraw -** participation is voluntary and that they can withdraw from the study at any time without any negative consequences. **Safeguarding practices -** Physical and emotional safety practices/procedures and staff involved. **List of researchers, institutions and funding bodies involved** **Duration of activities -** Timeframe for participation **Acknowledgement of contributions -** How the contributions from children and young people' will be acknowledged (will their contributions be publicly recognised, such as in publications or presentations). **Reviewing and Reporting** - if any data will be collected or reported on the effectiveness of PPI collaboration. If so, how this data will be stored and managed is required. **Termination of contract** – any reasons why the agreement may be ended. **Expectations** – What is realistically expected to be achieved in timeframe of involvement.			

Phase 2: PPI in Action Phase

Research Element	Checklist	Yes	No	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?

Research Element	Checklist	Yes	No	Top Tips
Child Safety/ Safe-guarding	For in-person activities, have you checked that the physical space is safe and secure, free from hazards, and appropriate for activities involving children and young people?			Always prioritize the physical and emotional safety of all children and young people.
	Have you checked the child/young person-to-adult ratios for support and supervision to ensure you have the necessary supports in place for any activity involving children and young people throughout? In Ireland, these ratios vary depending on the type of setting.			
	Have you all necessary safety protocols and distress reporting procedures in place?			Familiarise 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.
	After any consultation, confirm that children and young people have access to suitable support systems. This includes: • Identifying an appropriate adult they feel comfortable talking to (e.g., a parent, guardian, teacher, or trusted mentor). • Ensuring they are aware of external support resources, such as Childline or similar organizations, where they can seek additional help if needed.			Encourage open communication and provide information about available support options to help children and young people feel supported and secure. You could pair each child or young person with an adult mentor or guide who can offer support, ensure their well-being, and provide a trusted person for them to talk to about their experiences throughout the research process.

Research Element	Checklist	Yes	No	Top Tips
Creating a safe and empowering space for children and young people	Have you created a safe and supportive environment where children and young people feel secure expressing their views?			Prioritize the physical and emotional safety of all participants. Informal spaces may work best. 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. Be sensitive to their individual needs and experiences. Be aware of and respect cultural differences that may influence perspectives. Encourage children and young people to express their opinions and ideas openly and ensure they feel that their contributions are heard and valuable. Be open minded, flexible in approach and do not pass any judgment. If anyone says something showing prejudice or that is discriminatory (whether intentionally or unintentionally), you need to challenge this in an appropriate way, to make it clear that it is not acceptable and is not condoned.
	Have you an additional safe space available should any issues or challenges arise?			Ensure there is a designated room or space where a child or young person can go if they feel upset or if any issues arise. This space should offer a calm and supportive environment where they can receive assistance and talk about their concerns.
	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**. Children or young people may have different preferences for icebreaker activities or may prefer to talk instead so it is important to involve them in this process.

Phase 2: PPI in Action Phase

Research Element	Checklist	Yes	No	Top Tips
Creating a safe and empowering space for children and young people *(continued)*	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?			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. Be open and flexible in your approach. Ensure that all children and young people feel confident to share their perspectives and that their opinions are listened to. Establish mechanisms for ongoing feedback. If possible, involve children and young people in decision-making processes at every stage (e.g., co-develop project aims, methods, and outputs).
	For any activities, have you considered involving only facilitators who are trained or experienced in working with children and young people, ensuring they can foster a welcoming and age-appropriate environment?			

Research Element	Checklist	Yes	No	Top Tips
Creating a safe and empowering space for children and young people *(continued)*	For any activities, have you scheduled appropriate breaks or downtime for children and young people to rest, play, or relax?			Ensuring children and young people have regular breaks is essential for their well-being, focus, and overall productivity. Breaks allow them to recharge, process information, and maintain a positive attitude toward activities. Consider their age and energy levels when planning break times and ensure the environment during breaks is safe and conducive to relaxation or play. Regularly reviewing this practice will help create a balanced and supportive atmosphere.
	For any activities, are you providing drinks and snacks?			Access to drinks and snacks is vital to keeping children and young people energized, hydrated, and focused. Ensure that water or other suitable beverages are readily available, and plan snack times to align with their energy needs. When providing snacks, check for preferences and dietary requirements with children, young people and parents or guardians as needed.
	Maintain communication with both children and young people and their parents/guardians about the involvement process, schedule and any outcomes.			

Research Element	Checklist	Yes	No	Top Tips
Creating a safe and empowering space for children and young people (*continued*)	Have children and young people been informed about the outcomes of any 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 young people, considering transport, access and safety.			
	Have you made any activities child or young people 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)			Children or young people at different development stages may have different preferences for activities or may prefer to talk instead so it is important to involve them in deciding ways in which they wish to engage.

Research Element	Checklist	Yes	No	Top Tips
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.			There are additional resources for budgeting and remuneration **available here**.
	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 before the collaboration 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.			This may be a barrier for participation for some groups and should be considered and relayed thoughtfully.

Phase 2: PPI in Action Phase

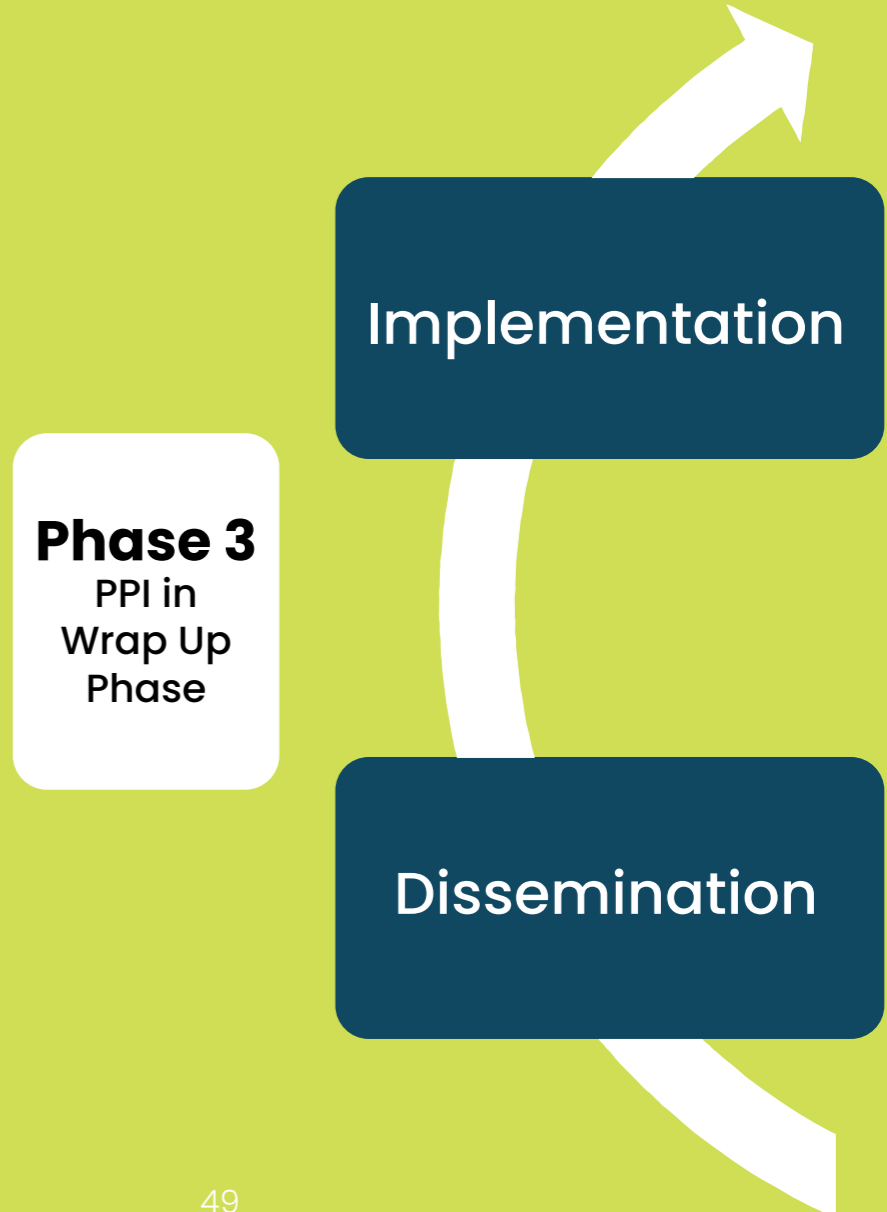| Research Element	Checklist	Yes	No	Top Tips
Confidentiality and Privacy *(continued)*	Have you considered if you require confidentiality agreements for all collaborating individuals? If confidentiality agreements are required, have you developed confidentiality agreements for all children and young people or researchers involved in the collaboration? If confidentiality agreements are required, have all researchers involved in the collaboration activities signed confidentiality agreements to protect children and young people's information? If confidentiality agreements are required have all collaborating children and young people signed confidentiality agreements?			Confidentiality agreements should always align with local laws, ethical guidelines, and safeguarding policies to ensure the rights and safety of children and young people are prioritised. Everyone involved should understand their responsibilities regarding confidentiality of children and young people. Confidentiality agreements for collaborating with 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. It can help to develop this agreement alongside children and young people. Ensure the agreement is child/young person-friendly, uses appropriate language and is transparent. If collaborating children and young people wish to have their names included in the authorship of research outputs, has this been agreed?

Phase 2: PPI in Action Phase

Research Element	Checklist	Yes	No	Top Tips
Confidentiality and Privacy *(continued)*	Have you agreed, as relevant, that personal information of any collaborators is kept confidential?			Any research staff and volunteers must receive training on confidentiality practices, data protection laws, and ethical standards. If any information is stored, it must be securely in accordance with the 2018 General Data 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 considered the confidentiality of children and young people involved, especially when sharing or reporting the research findings? (National Institute for Health Research (NIHR), 2024). If children or young people wish to be involved in research outputs, have you gotten permission to include names of children and young people in outputs from them and their parents (if child is under 16 years of age)?			Discuss authorship with children, young people and their parents. Check to see if children and young people wish to be named in research outputs. Seek consent and assent for their preferred use of names or initials when reporting on research. Authorship should be discussed with children, young people, and/or their parents at various stages. If the children and young people wish to remain anonymous, some publications may not allow submissions that include anonymous authors/collaborators.

Phase 2: PPI in Action Phase

Research Element	Checklist	Yes	No	Top Tips
Confidentiality and Privacy *(continued)*	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.

Reflections:

Phase 3: PPI in Wrap Up Phase

The wrap up phase is an important final stage in closing the loop, disseminating key messages with children and young people and acknowledging the valuable contribution made by children and young people.

Implementation

Phase 3
PPI in Wrap Up Phase

Dissemination

Phase 3: Wrap Up Phase

Research Element	Checklist	Yes	No	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 hosting any research events, have you invited any collaborating children and young people and their families?			Ensure venue is child and young person-friendly
	Have you offered children and young people the opportunity to feedback on the collaboration process and their experiences?			

Phase 3: Wrap Up Phase

Research Element	Checklist	Yes	No	Top Tips
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 peers, 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.			If children or young people wish to be involved in co-creating dissemination materials, have you gotten permission to include names of children and young people in outputs from them and their parents (if child is under 16 years of age)?
	Have you considered inviting children and young people to attend or co-present at external events where the research or collaboration findings are being shared?			When engaging in external events, such as research conferences, have you considered inviting young collaborators to co-present. While you may not have control over the child or young person-friendliness of the venue (e.g., at academic conferences), participation can still be encouraged if young people are thoroughly briefed and well-supported throughout the process. Such involvement can have a significant and positive impact, showcasing the value of their contributions and fostering meaningful engagement.

Research Element	Checklist	Yes	No	Top Tips
Closing the loop	If your collaboration is 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. 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.			
	Have you thanked the children and young people and/or their families for their time and insights?			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.
	Have you provided feedback on how their involvement has contributed to the research?			This could be in the form of a report or presentation that highlights their specific impacts and what their contributions changed.
	Have you formally recognised the efforts and contributions of collaborating children and young people in ways that are meaningful to them?			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). Ideas for how children and young people efforts could be recognised include certificates, public acknowledgment, co-publications, presentations or day trips.
	Have you checked if children and young people have any concerns or feedback about the process before finishing?			

Research Element	Checklist	Yes	No	Top Tips
Remuneration and Compensation	Have you finalised all honorariums/remunerations for the children and young people involved after all activities have been completed?			There is additional information on remuneration and compensation here.
	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?			
	If so, have you ensured that all payments have been finalised before the project end.			
Follow-up	Are you completing any follow-on research? If yes, have you considered maintaining continuity and further strengthening collaborations by keeping the same children and young people you have collaborated with? If yes, are they aware of this and happy to be contacted? If yes, have you obtained parents and children's permission to keep the children and young people's contact details on file for this purpose? If yes, have you ensured that you have made it clear that this continued participation is again voluntary?			

Resources

General Information and Resources

- The PPI Ignite Network Website: www.ppinetwork.ie
- DCU PPI Ignite Resources Page
- At the core of the PPI Ignite Network there are seven lead universities: Dublin City University, University of Galway, RCSI University of Medicine and Health Sciences, Trinity College Dublin, University College Cork, University College Dublin, and University of Limerick, that provide training, support, and guidance to help researchers engage patients and the public from the outset of a research idea. Each of the network sites have valuable supports and resources available.
- PPI Ignite Network Involving Children and Young People in shaping research
- Arthur Isacc's **Is Research Right for me:** https://issuu.com/arthurissac/docs/is_research_right_for_me_4_
- Shier, H. (2001). Pathways to participation: Openings, opportunities and obligations. Children & Society, 15(2), 107–117. Available at: https://www.harryshier.net/docs/Shier-Pathways_to_Participation.pdf
- Shier, H. (2006). Pathways to Participation revisited: Nicaragua perspective. Middle Schooling Review, 2, 14–19. https://www.harryshier.net/docs/Shier-Pathways_to_Participation_Revisited_NZ2006.pdf
- Central Statistics Office: Children and Young Persons Hub: https://www.cso.ie/en/releasesand-publications/hubs/p-cyp/childrenan-dyoungpersonshub/

- Tusla – Child and Family Agency Public and Patient Involvement
- HSE Useful Links and Resources for PPI
- Barnardo's Young Researchers: Guidance
- Shier, H. (2019). An analytical tool to help researchers develop partnerships with children and adolescents. In I. Berson, M. Berson, & C. Gray (Eds.), Participatory Methodologies to Elevate Children's Voice and Agency (pp. 295–315). Information Age Publishing. https://www.harryshier.net/docs/Shier-Analytical_tool_for_research_partnerships.pdf
- 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

Resources

Ethics and Consent

- Robinson C. 2024. Ethical considerations of children's involvement in school-based research: balancing children's provision, protection, and participation rights. https://doi.org/10.1177/17470161241272872
- PPI Ignite Network statement on research ethics committee approval
- HSE National Policy for Consent in Health and Social Care Research (V2.0, 2024). Dublin: Health Service Executive: https://www2.healthservice. hse.ie/organisation/national-pppgs/ hse-national-policy-for-consent-in-health-and-social-care-research/

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
- 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 UCC budgeting guidance: https://www.ucc.ie/en/ppi-ignite/ppiresources/budgetingforppi/
- PPI Ignite Network at UCD budgeting guidance: https://www.ucd.ie/ppi/plan/budgetingforppi/
- PPI Ignite Network at DCU Budgeting for PPI advice
- Payment guidance for researchers and professionals | NIHR
- Health Service Executive Costing and Budgeting Guide can be downloaded from this webpage: Patient and Public Involvement in Research (PPI) - HSE | Research & Development
- Draft documents from the Department of Health can be downloaded from this webpage: gov. ie - Public Consultation on a Draft Policy for Patient Voice Partners in the Irish Health and Social Care Sector

Child Safety

- Tusla - Child and Family Agency. Safeguarding Children Through Their Involvement: https://www.youtube. com/watch?v=QwWihIlqWCA
- Tusla - Child and Family Agency CFIAS Safeguarding Children Through Their Involvement https://www.tusla.ie/uploads/content/CFIAS_Safeguarding_ Children_Through_Their_ Involvement.pdf
- 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

Resources

Development

- Bernardos Child Development Information Pack
- HSE Developmental milestones - HSE. ie

Communication

- European Commission: Directorate-General for Justice and Consumers, Templeton, M. and Lundy, L., Creating child-friendly versions of written documents – A guide, Publications Office of the European Union, 2021 https://data.europa.eu/doi/10.2838/559340
- Plain English writing, structure and design tips - NALA
- Additional Icebreaker activities can be found at the following links by:
  - Session Lab
  - Ultimate Camp Resource
  - Team Building.
  - Shier, H. (2023). Circle Games for Groups. Protagonismo. https://www. harryshier.net/docs/Shier-Circle_ games.pdf]
  - The Great Wind Blows

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 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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