IMPERIAL MedTechONE

# PATIENT & PUBLIC INVOLVEMENT & ENGAGEMENT

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# PATIENT & PUBLIC INVOLVEMENT & ENGAGEMENT (PPIE)

## AT IMPERIAL

Patient & Public Involvement (PPI), also known as Patient & Public Involvement and Engagement (PPIE), is the practice of involving members of a given community in the design, execution, and dissemination of research relating to that community.

PPIE enables clinicians and researchers to direct their knowledge and resources towards the most valuable innovations and knowledge-acquisition for the condition or community in question. This is also known as “identifying a clinical need”.

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# WHAT IS PUBLIC INVOLVEMENT?

Public Involvement itself is a type of research – It's when research is being carried out "with" or "by" patients, carers and members of the public rather than "to", "for" or "about" them. There are various ways you can include members of the public in your project:

## Classic PPIE

Representatives are recruited from the relevant community, and are part of regular meetings or focus groups, particularly at the start of the design phase of the project. They support the basis of the project, aid in the drafting of the project documents (including the SOP, Participant Information Sheet and Consent Forms, amongst others), and help disseminate the work within their community.

## Public Engagement

Information being shared with the public such as talks and events, sharing research findings, media communication, community outreach etc.

Note that this is different to public involvement, public engagement is about raising awareness of / sharing and disseminating the work.

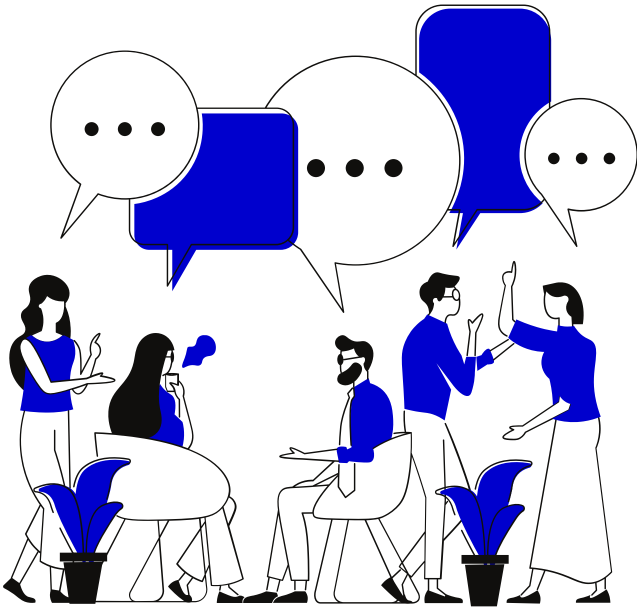
## Public Participation

Actual research participation, where the research is being done "to, for or about" a group/member of the public. For qualitative research, this can blur the lines between involvement and participation, as a qualitative project may ask questions that have more broad answers/where the answers describe other members of the community, not just that one participant e.g. an answer along the lines of "I've heard it said by others that…" or "Lots of people feel/experience that…" etc.

# WHAT IS PUBLIC INVOLVEMENT?

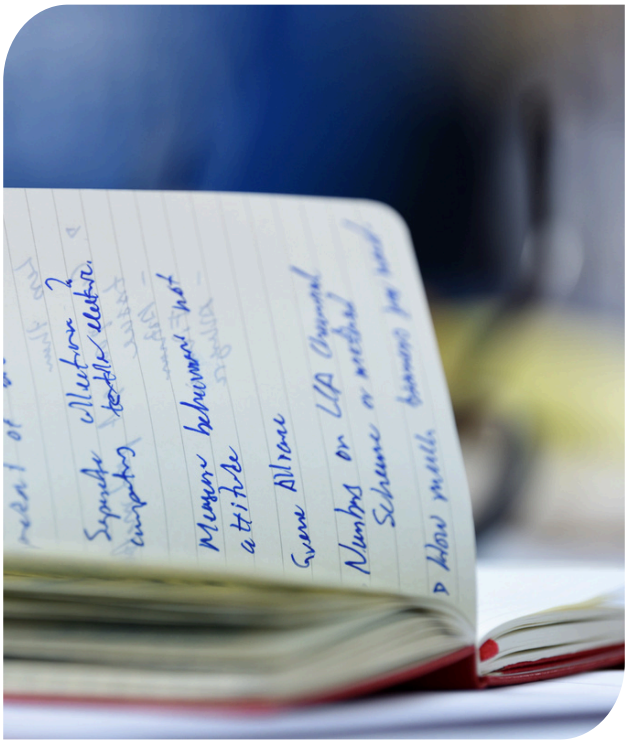
## Co-Production

A process that's difficult to achieve as it's about sharing power with the patient representatives, for example, the PR have just as much decision-making power as the research team, and may even be involved in the execution of the project. This is the most time-consuming form of PPIE. It takes time to build trust and can be expensive as it may require reimbursing representatives for their time in a more significant way than other PPIE (particularly if they are supporting the execution of the project).



# WHY IT'S IMPORTANT: PPIE BASICS

PPIE can be one of the most valuable tools at a research teams' disposal when it comes to tailoring their projects to both patient and clinical needs, and when making sure the project would not cause harm. It is commonly noted among researchers that, due to the specific nature of topics being studied, such as the efficacy of a novel technology, there can be a "cannot see the forest for the trees" effect where the team need an outside view of the project or aims to help inform the value and direction of said project.



## PPIE & GOOD RESEARCH

**PPIE protects the rights and interests of affected communities, and adds value to a research project. PPIE can be an indicator of integrity and quality in research.**

Perhaps most importantly, PPIE also protects the rights of affected communities – People who are affected by the outcomes of the research have a right to have a say in how the research is conducted, and what the aims should be.

**PPIE serves the following purposes**, to:

- **Improve the quality of the research** design.
- **Provide an external viewpoint** from the affected community, to inform the design and process of the project.
- **Protect the democratic rights of the affected community.**

# WHY IT'S IMPORTANT: PPIE BASICS

- **Prevent the exclusion of people from the most vulnerable aspects of the community** e.g. individuals who would be affected by the outcomes of the research but may have a high barrier to entry to the research such as those with communication disabilities.
- **Identify the clinical need**, improve the relevance of the research, and identify any missed opportunities.
- **Reduce harm**, particularly in vulnerable communities.

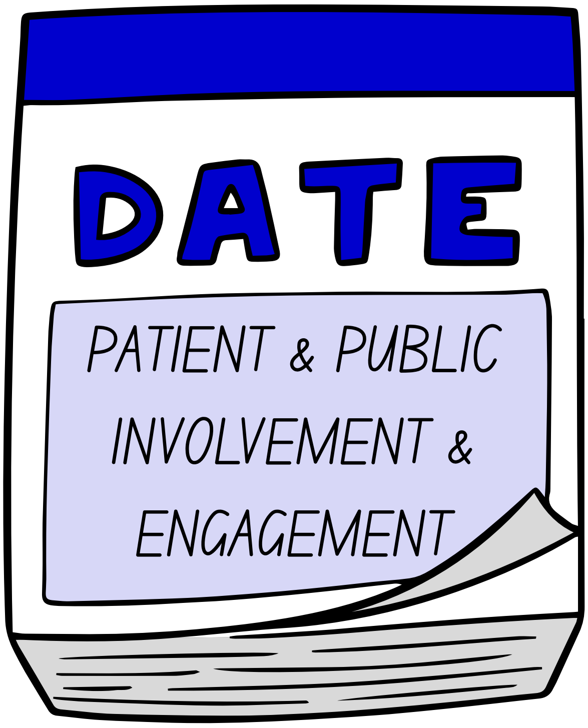
UNDERSTANDING PPIE

**Carefully consider who will be participating in your research, and create opportunities to listen to their perspectives.**

- **Improve the quality and value** of research outcomes.
- **Direct the project dissemination** towards the communities where it will be most valuable.
- **Ensures research is grounded in real experiences** and which requires involving the people it aims to benefit for the research to be relevant and impactful.
- **Makes research more accessible and inclusive.**
- **Provides practical insight** and innovative solutions that researchers may not have considered.
- **Fosters transparency, trust, acceptability and support** for research and research outcomes.

On a more mercurial note, it should be acknowledged that funding and ethical approval can hinge on PPIE.

# WHEN TO CONDUCT PPIE?



You can involve people at any point in the research process, but it's especially valuable at points where research is being designed, when recruitment begins, and when results are analysed and published.

PPIE representatives may have more involvement in the execution of qualitative research, as they can support in the interview/data collection processes. For some communities, it can be valuable to have someone from the research-side of a project who is also part of that community.

# DO YOU NEED ETHICS?

The short answer is **"It depends"** – Usually you wouldn't need ethics if your PPIE involvement is exclusively for project design and similar, more administrative, tasks. However, you would need ethics approval for peer-led research and qualitative research where a member of the public will be helping in the execution of the project. Generally speaking, as long as you are not testing something on a member of the public, or if there is no chance that the public may be harmed over the course of the project, you wouldn't need ethics.

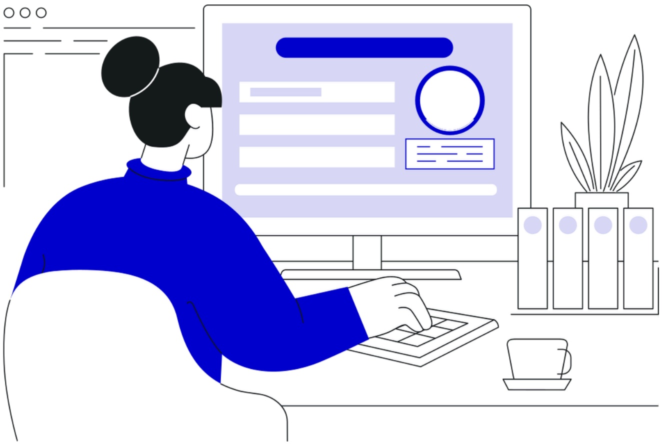
The limit / line on where you need ethics can be variable in this context. For example, for a focus group-based PPIE strategy, you wouldn't usually need ethics BUT you still need to ensure safeguarding standards such as making sure support is available where needed (like having mental health first aiders in a session where cancer survivors are talking about their experiences and making sure you check-in 24 hrs later).

## THE PURPOSE OF ETHICS

**Research Ethics Committees review the safety and potential for harm in your project.**
**PPIE is usually low-risk, but carefully consider how you plan to involve the public.**

As a researcher you have a duty of care towards your PPIE representatives and must ensure that they do not experience harm as part of their participation.

**If you are unsure if you need ethical approval for your PPIE strategy, send a query email to the Imperial College Research Ethics Committee (ICREC), or to the Research Office.**



# BUDGETING PPIE

As a standard estimate:

- £25 per hour per person (over 16yrs)
- £5 per meeting for working from home, per person
- Reimburse travel costs where needed
- Refreshments
- Venue costs
- Access costs e.g. interpreters, assistive technologies, childcare etc.
- Recruitment costs
- Dissemination costs
- Training costs where applicable
- PPIE Lead and staff salaries where applicable

All payments to PPIE representatives and participants must be made promptly and securely. You should never be keeping participants waiting on their remuneration.
If there are any issues with the payment process, keep participants updated – Be transparent!

# WHO SHOULD YOU INVOLVE? AND HOW?

## Who should you involve?

When planning your PPIE, you should consider:

- **Do the representatives need experiential knowledge** of a condition or service? Consider carers too.

- **Do they have capacity to be involved** or do their carers or other people need to be involved?

- **Do they need any specific skills**, or can they be trained/supported to better fill the role? Make sure they are able to have their voices heard.

- **Be mindful of diversity** and ensure you involve under-represented groups wherever you can. Experience, characteristics, and intersectionality – **Making opportunities accessible!**

## How to find people?

- **Communities** – Build trust and rapport by speaking to people from communities you're trying to reach, and find the best way, place, and time to engage with them.
- Try a **variety** of methods, not only online – You can put up flyers, send out emails, and ask for support from community leaders. You can even ask for support from the NHS, like advertising in relevant clinic spaces.
- **Go to where people are**: This could include religious outreach, charities, community centres and events, flyers, social media, PPIE networks (e.g. PERC, or VOICE, Young Persons Advisory Network, North West London Community Champions Committee, etc) and online public involvement platforms, amongst other things.
- **Be clear** what's in it for them – Clearly state any benefits to participation, and be up front about remuneration.

# WHO SHOULD YOU INVOLVE? AND HOW?

## How to recruit a PPIE consultant?

The **NIHR has excellent resources on PPIE**, including on how to recruit contacts. In the design of your project you should be aiming to adhere to the UK Standards for Public Involvement wherever possible – Note that many grant and ethics applications will directly ask how you are involving patients and members of the public in your project, and **you must have a significant justification if you do not intend to conduct PPIE** processes.

The easiest way to recruit PPIE contacts is to **identify the community**, or communities, that will be affected by the outcomes of your project and **find out if there are any existing PPIE and research channels** you can access for volunteers. This could include:

- Charities
- Hospital clinics
- Patient Support Groups
- Dedicated PPIE recruitment groups

Ensure you **complete due diligence** for any organisation you seek to work with, check their history and research their overall aims and goals.

When recruiting volunteers, it is vital that you **make the process inclusive and consider any limitations that may be specific to the community** you're working with.

For example, for a project involving the deaf community, your working groups may need sign language interpreters with the skills to interpret specialist (such as medical) language accurately and smoothly.

If your project involves a community with a high number of wheelchair or other mobility aid users, you must ensure that all meetings are accessible both in person and online.

If your project is international or focuses on a community where English is not the primary language, you should have specialist translators for all sessions, and all materials should be available in relevant languages, including braille.

# WHO SHOULD YOU INVOLVE? AND HOW?

Just as with recruiting study participants, **it is vital that no one is excluded** from participating in PPIE due to poor accessibility.

An important topic to consider is financial reimbursement for PPIE. As mentioned in the above “Budget” section, good rule of thumb is to treat this similarly to your actual participants. You may not be able to completely pay them for their time, depending on your grant’s or financial support’s rules, but you should at minimum be reimbursing items such as travel costs and providing refreshments at long sessions or focus groups. Where possible however, you should aim to **pay your PPIE volunteers for their time** – This will usually mean setting a reasonable hourly rate. This further reduces the barrier to entry for participants from all backgrounds, and as such it is prudent to include the cost of reimbursements and payment for time within your proposed budget (check your funder’s guidelines for any relevant policies).

## How to involve people?

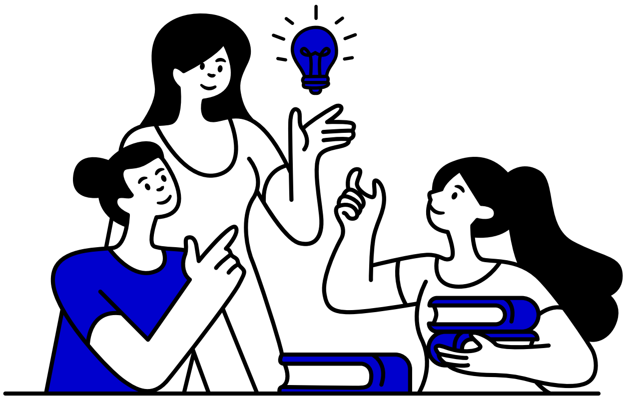
There are various ways to involve the public in your work, depending on what kind of involvement and responses you’re looking for. **Consider**:

- Surveys
- Interviews
- Focus Groups and workshops
- Arts-based approaches – Particularly useful where you’re asking people to share their experiences for emotions on a topic.
- Public Steering Group – For when you’re looking to be advised by the community your work focuses on.
- Wider Management Group – When you need a patient/public perspective within the scope of management decision-making. This approach requires that you carefully consider power dynamics within the group you set up.

# WHO SHOULD YOU INVOLVE? AND HOW?

- Peer Researchers – Under the Co-Production umbrella, this approach is especially valuable for when you are interacting with, or completing research on a community that may be less trusting of researchers. Having people from that community operating on the research-side of a project, can make their peers more comfortable in participating.
- Co-applicant – Also under the Co-Production umbrella, this approach is when a member of the public will be a formal member of the research team.

The best practiced, and most common, methods of PPIE are public steering groups and focus groups/committees of relevant members of the public.



When preparing for PPIE, you should be considering:

- **The type of research you're conducting** and tailoring your PPIE processes accordingly.
- **How can you appoint people?**
- The approach depends on the role the representative will have, but it may be useful to **post a short application form asking about demographics and motivations**. You may need a quick phone call or interview to shortlist/finalise applicants. However, **carefully consider the intended recipients** e.g. for communities with English as a second language, a written form may be intimidating.
- **What will they gain from participating?** This isn't just about remuneration, you can also leverage the social interactions people will have and the sense of community they may gain from participating.

# WHO SHOULD YOU INVOLVE? AND HOW?

- **Transparent shortlisting processes** e.g. did people meet the criteria? You should also give feedback to those not appointed.
- **Keep participants involved and updated.**

# HOW TO ENSURE A GOOD EXPERIENCE?

- **Make representatives feel valued**, ensure you thank people for their time.
- **Build rapport** and get to know people.
- Create a safe space, **a welcoming environment** – Encourage people to chat and get to know each other in group settings before you start the session.
- **Share power** where possible, e.g. operate on a first name basis, share decision-making etc.
- Co-design/co-facilitate meetings with members of the public – It's a good idea to **get information from some representatives before setting up a larger session**. They may be able to provide you with important information on how best to interact with the community, how to ensure accessibility, and how best to facilitate a productive rapport.
- **Share both the session and the project outcomes** – Your PPIE representatives can even help disseminate the outcomes amongst the community.

## Support & Safeguarding

PPIE must be conducted ethically, even if you don't need ethical approval, and participant safety and dignity are the highest priority.

- When discussing sensitive topics, **ensure you have an appropriate support scheme.**
- Warn participants of what the session entails beforehand and **tell people what to expect** from each session.
- Allow people to bring friends or support persons.
- Make sure to have a mental health first aider present, and **allow time to decompress after**, plus make sure to **check-in after 24hrs** to support your representatives.
- **Be clear that participants can take a break or withdraw** whenever they need and ensure any participants who choose to withdraw are supported in the same ways as other participants e.g. access to mental health first aid, and check-ins 24hrs later.

# HOW TO ENSURE A GOOD EXPERIENCE?

- **Signpost to relevant support** and wellbeing resources that can be accessed outside of the session. Try to **focus on free or easily accessed resources**.
- Co-develop principles (perhaps in writing) and the running plans with the participants at the first meeting – **Have a "Session 0"** to set out some house rules for how sessions will be run, and check if there are any topics that should be avoided entirely.
- **Ensure confidentiality** and follow the UK GDPR.
- **Don't question people's lived experience** – Commit to active listening.
- Ensure people have space to talk and don't talk over each other.
- Understand the individual needs of people and **support access needs**.
- Appropriately **train participants who are supporting** the execution of the sessions or overall project.
- **Pay people** properly and promptly.
- **Provide refreshments** – This can have the added benefit of supporting rapport between participants.
- Allow a buffer period at the start and end of the session where people can get refreshments, allow for stragglers, allow people to socialise and relax around the heavier topics that might be discussed. Ice breakers can be helpful to get people comfortable and to keep the mood of the session as light as possible.

## SUPPORTING YOUR VOLUNTEERS

**Good support and safeguarding strategies are vital to a productive PPIE session. You can even get advise from a smaller group before the full session on things you might need to prepare.**

# CAPTURING IMPACT

## Recording Impact

Capturing Impact is all about "conversations" – How can you capture what's said by the participants whilst remembering that different people even in the same group will give different results? It is usually beneficial to **incorporate a mixed methods approach**, utilising both qualitative and quantitative methods.

- **Capture impact from the start** including recordings of meetings (make sure you clearly notify participants if sessions will be recorded), take high quality notes, or perhaps even ask for written summaries or feedback from the session participants.

- **Consider the context** – Who, when, how people were involved? How did you approach the PPIE, did you do the PPIE well enough? How has PPIE improved your work?

- What changed from what PPIE said? **How has it impacted:**
  - **You?**
  - **The project?**
  - **The members of the public?**

Additionally, you can enact a "you said, we did" update at the start of each session if you have more than one session. This keeps the PPIE participants in the loop about the impact their work is having, and also demonstrates that you value their inputs. Take a look at the GRIPP2 Checklist – Academic Tool for more information.

# CAPTURING IMPACT

## Dissemination

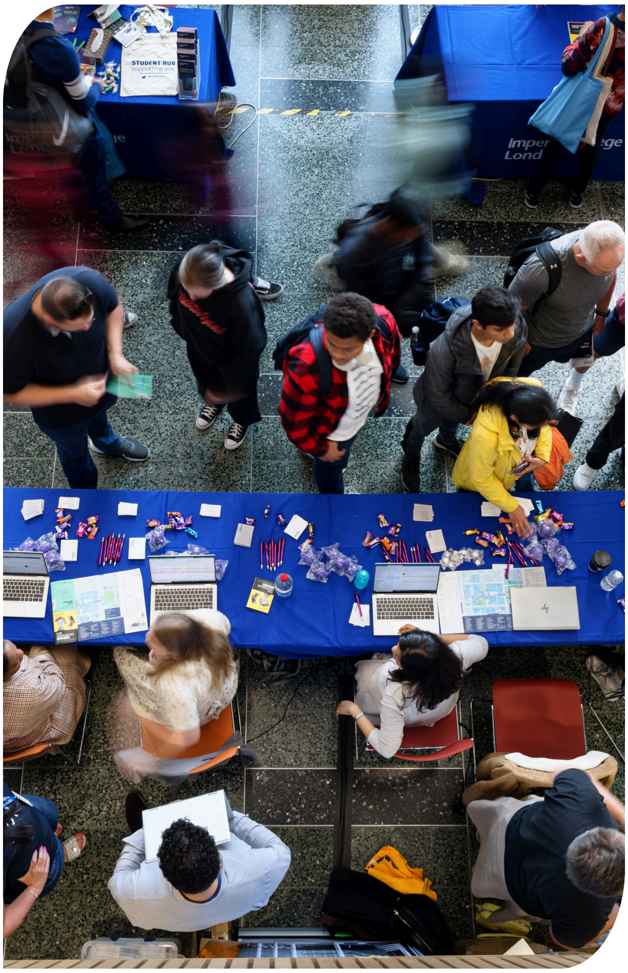
You should always **share your results with the people you involved first**, as well as within the wider community.

Use plain English language, infographics, blogs, and easily digestible information formats. Carefully **consider the accessibility requirements** of the community, including making dissemination available in appropriate languages, braille, or with specific colour schemes or formats that support conditions like colour blindness or dyslexia.

Involve your PPIE participants in coming up with ways to make your research more accessible and engaging, and, where possible (and appropriate), co-author papers / co-present at conferences.

DON’T FORGET

**Good PPIE is conducted from start to finish! Include your PPIE reps in dissemination, and credit them appropriately.**



# PPIE AT IMPERIAL

Imperial has a dedicated PPIE Resource Hub. There you can access PPIE resources and information, PPIE networks established by and for Imperial, a list of useful email contacts, and free online training courses. You can find them at: https://www.imperial.ac.uk/patient-experience-research-centre/ppi/

For colleagues and students working within the Institute for Global Health Innovation (IGHI), check out their dedicated pages and resources on PPIE here: https://www.imperial.ac.uk/global-health-innovation/what-we-do/involve/

If your project or work relates to a specific field, for example a specific field in medicine, check for specific PPIE resources both within Imperial, and externally such as with Charities, funding or regulatory bodies, or other academic or clinical institutions.

# CONTACTS

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