PATIENT & PUBLIC INVOLVEMENT AND ENGAGEMENT GROUP
PPIE
ZIAUDDIN UNIVERSITY

Toolkit

TO ESTABLISH A PPIE INITIATIVE

by Timo Tolppa, Arishay Hussaini, Nikhat Ahmed & Madiha Hashmi

Patient & Public Involvement and Engagement Toolkit

by the Critical Care Research Group at Ziauddin University

This toolkit is intended as a resource to support the establishment of Patient & Public Involvement and Engagement (PPIE) initiatives within health research teams and projects. While focused on South Asia and experiences from the Critical Care Research Group (CCRG) of Ziauddin University in Pakistan, the toolkit provides useful resources and guidance for anyone seeking to involve patients, their families and members of the public in health research.

The toolkit is divided into an introduction, 10 chapters, conclusion and 16 appendices. The introduction defines PPIE and describes a national PPIE network for which the toolkit was originally created. The first chapter gives an overview of establishing a PPIE initiative with subsequent chapters offering guidance for every step in the process.

The advice provided in this toolkit is based on the experiences of our group in establishing the first-ever PPIE group in Pakistan to support trials, supporting the formation of PPIE groups at other institutions across Pakistan and South Asia, and learning from global engagement initiatives. Any suggestions for improvements are welcome. Feel free to amend and adapt all aspects of this toolkit for your own purposes in any way you wish, however, make sure to appropriately credit the creators as per the license below. Do not hesitate to get in touch with us a ppie@zu.edu.pk.

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Introduction

Patient and Public Involvement and Engagement (PPIE) in research is defined as research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. It recognises that patients, families, and communities bring valuable lived experiences that can make research more meaningful, ethical, and relevant to real-world needs. Involving patients and the public strengthens the quality, acceptability, and impact of health research. It ensures that research questions reflect community priorities, study designs are culturally appropriate, and findings are shared in ways that people can understand and use.

According to the National Institute for Health and Care Research, PPIE can be understood across three levels: *participation, engagement,* & *involvement*, with each representing a higher level of public contribution and influence.

1. *Participation* is the foundational level of PPIE, where patients or members of the public are study participants. This has historically been the most common form of interaction between researchers and the public.
2. *Engagement* refers to the sharing of information about research with the public. It is often a *one-way* process, where researchers communicate what they are doing and what they have found. Examples include using infographics or videos to share study results, or holding community meetings to discuss findings.
3. *Involvement* represents the highest level of PPIE, where patients and community members work *in partnership* with researchers throughout the research process, from setting priorities and designing studies to analysing results and sharing outcomes. Involvement fosters collaboration, ownership, and trust.

1	**Participation**	People recruited to a clinical trial or other research study
2	**Engagement**	Information and knowledge about research is provided and disseminated
3	**Involvement**	Active partnership between patients and the public that influences & shapes research

Benefits of PPIE

- Enhanced Research Quality: Patients and the public offer valuable insights into what matters most to them, improving the *relevance, feasibility* and *acceptability* of a study.
- Improved Recruitment and Retention: Patients and the public are best placed to identify the most effective and acceptable recruitment strategies and ensure study materials are *clear and accessible*. They can also provide advice on how to keep participants motivated to remain in a study.
- Ethical Research Conduct: Involving patients and the public aligns with the principle of "nothing about us without us" and helps ensure adherence to ethical standards. Patient input also helps with gaining ethical approvals.
- Increased Awareness & Impact: Engaging with patients and the public raises awareness and acceptance of the research, supporting *participant feedback* and helps translate findings into practice.
- Success with Funding Applications: Funding agencies are increasingly requiring the involvement of patients and the public in study design and conduct due to the multiple benefits of PPIE on research quality and efficiency. Studies that incorporate the patient voice in design are more likely to succeed in gaining funding.

Types of Involvement

Members of the community and experienced PPIE coordinators can support all aspects of study design, conduct and dissemination. Maximal benefit is achieved when patient and public partners are included early in the process. A key way to enable effective involvement is to establish and maintain a PPIE group of members and coordinators that can:

- Advise on research priorities to help identify the most relevant health topics, populations & interventions to study from the perspectives of patients and the public.
- Advise on the design of study protocols to make it more feasible, acceptable and relevant to the patients and the public. This can include advice on participant selection, intervention protocols and outcome measures.
- Contribute to the ethical review of studies to ensure that the proposed research is acceptable to patients and the public before formal institutional ethics review.
- Safeguard patient and participant rights to ensure no harm is done during research.
- Support the development of study materials such as participant information sheets, informed consent forms and recruitment leaflets, posters and social media content.
- Support the conduct and implementation of studies by improving the recruitment strategy, informed consent processes, administration of interventions, data collection and follow-up.
- Participate in data analysis to ensure the patient perspective is incorporated in the interpretation of the results of the study.
- Support the dissemination of results to the public by providing advice and feedback on dissemination strategies and materials (e.g. posters, infographics, video, articles, presentations, workshops, public events).

National PPIE Network

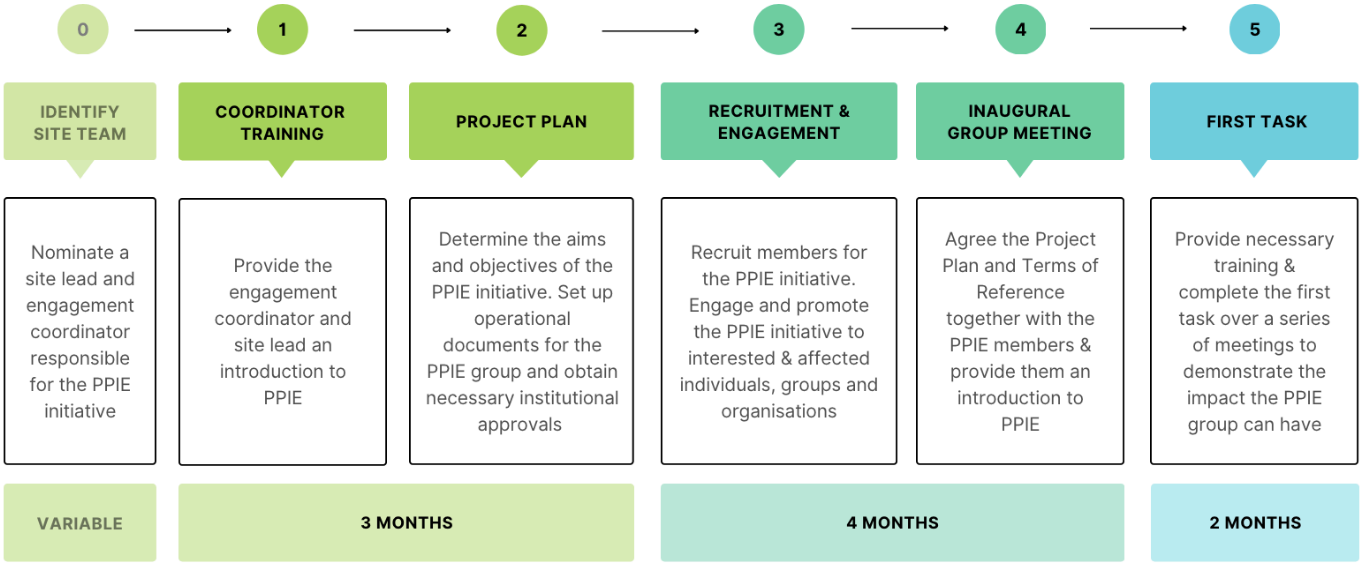
The National PPIE Network brings together PPIE groups from across Pakistan with an aim to strengthen the culture of meaningful involvement in health research. One key function of the network is to support the development of new PPIE initiatives. Support is offered in multiple ways, with this toolkit being one of them. It is a starting point and source of guidance for individuals and institutions interested in starting their PPIE initiative or group. However, the network also offers additional support, mentoring and opportunities for professional development:

- **Annual National PPIE Summit** that brings together partners from across the country for in-person collaboration, knowledge exchange, and shared learning.
- **Regular webinars, workshops, and training sessions** to build capacity in patient and public engagement.
- **Online platform** to enable collaboration, access to a resource repository, and exchange of best practices.
- **Guidance** on evaluation of PPIE initiatives to ensure continuous improvement and accountability.
- **Advice** from experienced PPIE practitioners to assist with all aspects of engagement work.
- **Advocacy** by drafting policy and creating governance frameworks to promote a high standard of practice.
- **Translation** of educational and dissemination materials to enhance reach to all communities in Pakistan.
- **Dissemination** of research findings through public events, media engagement, and community partnerships.

Our dream is to build a connected and sustainable PPIE network across Pakistan that supports meaningful collaboration between researchers and the communities they serve.

Chapter 1: Overview

Establishment of a successful PPIE initiative takes careful planning and execution. Figure 1 provides an overview of the process our team followed to establish a PPIE group and the list below highlights the importance of each step in the overall success of an initiative. The remainder of this toolkit gives detailed guidance for each step.



Nominate a site lead and engagement coordinator responsible for the PPIE initiative

Provide the engagement coordinator and site lead an introduction to PPIE

Determine the aims and objectives of the PPIE initiative. Set up operational documents for the PPIE group and obtain necessary institutional approvals

Recruit members for the PPIE initiative. Engage and promote the PPIE initiative to interested & affected individuals, groups and organisations

Agree the Project Plan and Terms of Reference together with the PPIE members & provide them an introduction to PPIE

Provide necessary training & complete the first task over a series of meetings to demonstrate the impact the PPIE group can have

Figure 1. Process for the establishment of a PPIE initiative

0. *Identify Site Team:* Having a person dedicated to PPIE is crucial in order to progress and coordinate the initiative, while a senior lead is needed to navigate institutional processes and gain buy-in from leadership.
1. *Coordinator Training*: The dedicated people have to be equipped with the knowledge and skills to effectively lead a PPIE initiative, including an understanding of international standards on public engagement, ethics of working with vulnerable individuals as well as skills in communication and group facilitation.
2. *Project Plan*: Clear aims and objectives serve as a guiding light for the initiative, enabling the team to plan the work, communicate with potential members and partners, and evaluate progress as well as impact.
3. *Recruitment & Engagement*: Generating awareness and gaining support for the initiative from a broad range of partners not only helps with recruitment, but also encourages collaboration and promotes impact in the long-term. Effective onboarding of PPIE members sets the tone for a collaborative working relationship.
4. *Inaugural Group Meeting*: Co-creation of a Terms of Reference with PPIE members promotes ownership and engagement with the PPIE initiative, and sets the ground rules for the group moving forward.
5. *First Task*: Completing a task that is 'low-hanging fruit' early provides evidence of potential impact of the initiative and is important for motivation and retention of both PPIE coordinators and members.

Chapter 2: Team & Training

Patient and public involvement and engagement is not a simple add-on to usual research practice. Rather, it requires staff equipped with content expertise and the right set of skills. At a minimum, we recommend that the initiative has a dedicated PPIE coordinator and a senior lead. The senior lead is needed for oversight, support with navigating institutional approvals and funding requirements, and convincing senior leadership and doctors to support PPIE. The coordinator should allocate approximately 50% of their working week to PPIE activities, particularly at the start of the initiative where significant time is spent on creating a project plan, establishing processes, recruiting members and engaging with various partners. An example job description for a PPIE coordinator can be found in Appendix A.

Ideally, your PPIE initiative is managed by a diverse team with different backgrounds and responsibilities. As an example, our PPIE initiative at Ziauddin University started with three coordinators and a senior lead, with a fourth marketing coordinator joining 18 months later (Table 1). Having a team of individuals working towards a common goal was key to our success, as we were able to motivate and support each other and benefit from our distinct expertise and ideas. However, one of the coordinators was working on the initiative voluntarily without pay for the first 18 months and another could only dedicate 10 hours per month to the project. Our team was able to grow and provide adequate compensation to all coordinators due to the success of the initiative, which took time and effort. This may not be feasible in all situations. The national PPIE network led by Ziauddin University is able to support new PPIE initiatives with advice, templates and training, which should lessen the burden on individual teams.

Role	Background	Responsibilities
Engagement coordinator	Research manager	Recruitment of members. Coordination of PPIE meetings and activities. Key liaison for patient and public members.
Public coordinator	Retired neuroscientist	Build strategic relationships with local leaders and institutions.
Marketing coordinator	Medical graduate	Manage the website, social media, newsletter & event adverts.
Scientific coordinator	Foreign researcher	Lead evaluation & reporting. Key liaison for global partners.
Senior lead	Head of department	Oversight. Obtain funding and institutional approvals.

Table 1. PPIE coordinator roles, background and responsibilities at Ziauddin University

Once the team has been identified, an important next step is training. We strongly recommend that all individuals involved in the PPIE initiative complete the free online course 'An Introduction and Practical Guide to Community Engagement and Involvement in Global Health Research' created by the National Institute for Health and Care Research (NIHR) and the Mesh Community Engagement Network. A key skill to develop for PPIE is small group facilitation. Further training and reading can be found on the Mesh website and in Appendix B.

In addition to training and reading, we also suggest that individuals involved in PPIE join a community of practice dedicated to engagement. Our team members have found it very helpful to be a part of a group of peers that are passionate about PPIE. Such a community offers motivation, advice and peer-to-peer support as well as opportunities for professional development, including webinars and events. One such community of practice is the national PPIE network led by Ziauddin University for those based in Pakistan. The Mesh Community Engagement Network is available to all globally: https://mesh.tghn.org/

Chapter 3: Project Plan

The success of any research initiative lies in having clear aims and objectives along with a detailed method and feasible timeline documented in a protocol or project plan. A PPIE initiative is no different. Careful planning and creation of a PPIE project plan sets your team up for success. The plan can also be used to apply for funding and approvals, explain the initiative to potential collaborators, and as a basis for a budget, manuscript and evaluation. A worksheet to come up with a Project Plan, with examples, can be found in Appendix C as an example.

Essential components of a project plan include:

- Title: A clear and succinct title outlining the focus of the initiative.
- Aim: An overarching purpose of the project outlining the action and desired outcome.
- Objectives: The specific, measurable, achievable, relevant and time-bound steps needed to achieve the aim.
- Team: The individuals contributing to the project and their responsibilities.
- Planned work: Detailed methods and planned activities to accomplish each objective.
- Expected outcomes: Outcomes and tangible outputs if the aim and objectives are achieved.
- Timeline: Important milestones and timeframe in which tasks are completed.

Top tips

- *Tokenism*: Avoiding tokenism, the symbolic inclusion of patients, is essential to avoid wasting the time and effort of patients. A key way to avoid tokenism is to plan for PPIE input where changes are realistic. Asking a PPIE group to review documents that will never be used or to provide feedback on a research project with a finalised protocol is pointless. The objectives and activities should focus on where your team has influence. For example, you will be able to change the consent form for a study led by your senior lead, whereas it is less likely you'll be able to change the consent form template of the national ethics board.

- *Solutions*: Another way to avoid tokenism and ensure effective engagement is to identify problems that could be solved by PPIE. Our group chose to focus on improving the consent processes for trials because of feedback from study coordinators and families that the trial information was not clear or communicated in a patient-centred manner. Input from a PPIE group was a clear solution to this problem.

- *Low-hanging fruit*: Early achievements are important to demonstrate value to PPIE members, leadership and collaborators, and will serve as motivation for coordinators. Thus, the first activity should be a straightforward task with a clear output. For example, reviewing and improving a patient-facing information sheet.

- *Flexibility*: The project plan will likely change over time. In fact, it is important that the plan is flexible enough to be guided by the priorities of your patient members. In the beginning, your members will benefit from having clear tasks to ease them into the work. Later, your objectives should be co-created with the patient members to ensure ownership and relevance. For example, when working on improving consent for trials, members could first review existing forms and later decide the format and content of new consent materials.

- *Feedback*: Once drafted, it is worthwhile getting critical feedback from others. The group at Ziauddin University would be happy to review any PPIE project plans.

Chapter 4: Budget, Ethics & Contracts

Establishment of a PPIE initiative may require consideration of finances, ethics and contracts dependent on institutional requirements, collaborations and funding arrangements. While these are primarily guided by project and context-specific considerations, below are some key points when planning a PPIE initiative.

Budget

Effective and meaningful patient and public involvement and engagement requires finances for personnel, compensation and reimbursement of patient and public partners (Chapter 5), marketing and outreach (Chapters 6-7), meetings (Chapter 8), activities of the PPIE initiative (Chapter 9) and evaluation (Chapter 10). Ideally, each research project and grant application should have a budget for PPIE, as obtaining separate funding for PPIE is challenging - See the funding page on Mesh for potential sources. Coming up with a budget requires clarity on your project plan, proposed activities and local costs. A budget worksheet can be found in Appendix D.

Ethics

No consensus exists nationally or internationally about the necessity of obtaining ethics approval for the establishment of a PPIE group consisting of patients, their families and the public, and each jurisdiction approaches the issue differently. Some argue that the involvement of patients in any activity requires the oversight of an ethics committee, while others maintain that involvement in PPIE groups is fundamentally different to being a research subject and thus does not fall under the remit of institutional review boards. Our recommended approach is to obtain written confirmation from the committee that no ethics is required or an exemption from ethics has been granted for the establishment of the PPIE group. This practical approach ensures that your team has a document to share in case a funder, journal editor, collaborator, senior leader or any other party feels ethics approval is needed. Appendix E provides further guidance and a worksheet for an ethics exemption application for the establishment of a PPIE group.

Some PPIE activities may require ethics approval depending on the nature of the activity. It is always best to liaise with your institutional review board in case of uncertainty. The recommendation above pertains only to the establishment of a PPIE group to advise or collaborate with researchers.

Contracts

Depending on your funding arrangements and collaborations, you may need to have contracts or memorandums of understanding to facilitate your PPIE initiative. For example, our group at Ziauddin University uses a Memorandum of Understanding (MoU, Appendix F) to formalise collaborations with other institutions, who we support with their PPIE activities. In cases where our PPIE initiative provides funding to compensate patient and public partners at other institutions, for example, a Research Collaboration Agreement (RCA, Appendix G) is used. The main difference between the two documents is that an RCA usually requires the involvement of a legal and finance team while the MoU is simply signed by senior leadership.

Chapter 5: Honoraria & Expenses

A clear policy on honorariums and reimbursement of expenses for patient, family and public members has to be in place before asking them to be involved in your PPIE initiative. A written policy provides transparency and sets clear expectations for potential members. An example policy, created based on guidance from the National Institute of Health and Care Research (NIHR) and feedback from our patient and public partners, can be found in Appendix H.

Honoraria

Honorarium payments are made to acknowledge the time and contributions made by patient, family and public members to the PPIE initiative. Members' lived expertise, skills and time should be compensated, similarly to how researchers are paid for their work on a research project.

Payment can be made based on the time spent preparing and attending PPIE-related activities or based on the nature of the task or activity. The payment rate is based on your judgment, local practices and, ideally, input from your patient members as there are currently no nationally recommended payment rates in Pakistan. Our group uses a rate of 1000 PKR/hour for both online and in-person activities based on our experience and feedback from members.

Expenses

Patient, family and public members should not incur any out-of-pocket expenses in order to contribute to the PPIE initiative. Travel to PPIE activities, meals and refreshments during meetings, as well as accommodation and subsistence for out of town visits should be reimbursed. Additional expenses should also be considered depending on the circumstances of the members. For example, childcare costs should be covered for parents of young children while costs incurred by a family member for arranging a carer for an elderly relative while they attend a meeting should be reimbursed. Accessibility needs of members should also be considered.

Payments

The policy should outline how to claim expenses, when to expect honoraria and reimbursements, and how funds are received (i.e. cash, cheque, transfer). Our group advocates for making the payment process as easy as possible for members. For example, instead of requiring receipts or other proof of payment for local travel, we provide all members a flat rate that is sufficient to reasonably cover return travel in a 10km radius. Electronic bank transfers are also preferred by our members, as this avoids the need to physically go to a bank to deposit cheques.

Alternative methods of payment or recognition, such as vouchers or gift cards, are commonly used in high-income countries. Our group has decided not to use these methods due to the absence of appropriate vendors and based on advice of members, who prefer to decide for themselves how to use their honoraria (e.g. donations).

Taxation

Receipt of honoraria may have tax implications for the recipients. It is best to liaise with your institutional legal and finance teams about the appropriate tax procedures for making payments to members and advice to give to members in case they have any additional tax responsibilities.

Chapter 6: Marketing

Patient & Public Involvement & Engagement initiatives involve, by their very nature, public-facing communication. Recruitment for PPIE members is likely to include printed and digital advertising materials distributed in-person and on social media. Raising awareness of a disease, intervention or research study as part of the PPIE initiative requires determining key messages, creating educational content and driving engagement with the content using various channels. The trustworthiness of messages from the PPIE initiative will be shaped by your public image and brand. While PPIE initiatives certainly do not aim to sell a product for profit, much can be learned from the field of marketing to deliver your messages to an intended audience, recruit members and identify collaborating partners.

Our team has benefited hugely from having a marketing strategy and clarity on our brand (Appendix I). Our online and social media presence has led to new partnerships and invitations to speak at events. The visibility of our initiative has provided us with legitimacy. Our branding, including a color scheme, slogans and key sentiments, make it very easy to come up with advertising materials, graphics, events and presentations. Articulating a primary marketing goal and activities ensured we have been able to evaluate and demonstrate progress. Consistent monitoring of our marketing efforts has enabled us to report our reach and impact to funders and senior leadership.

How can a PPIE initiative develop a marketing strategy? Our group has created a worksheet (Appendix J) that can be used by anyone to think through their goals, activities and branding. Below are some key things our group thought through when we built our strategy and approach:

- Logo (Figure 2): One of the first tasks we undertook was to design a logo to use as part of our recognisable brand identity in all our public-facing materials. The design depicts our PPIE initiative as a connection between people while maintaining focus on individuals, with the colour scheme aligned with our institution.
- Website (https://zu.edu.pk/ccrg/ppie): Concurrently to creating a logo, we also ensured to have an online presence with the creation of a website. The site serves as a repository of our activities, a source for additional information and signals legitimacy as an active entity.
- Primary Goal: During the early parts of our initiative, our marketing activities were sporadic and often an afterthought. While our marketing activities achieved success, the unstructured approach made it feel resource-intense and somewhat pointless. Setting a primary goal clarified the purpose of our marketing activities, focused our efforts, reduced our workload and helped us set processes to support the activities.
- Process: Due to limited resources, we have kept our marketing activities simple and embedded in day-to-day processes. While we would like to create more interesting audiovisual content or establish presence on new platforms (e.g. Bluesky), we focus on content that is easy for us to produce (simple graphics) and platforms where our institution is active.
- Voice: Our group considered what our public voice should sound like, whether authoritative, professional, casual, knowledgeable, revolutionary or something else. Establishing our desired voice as ‘positive, excited, inquisitive and collaborative’ has meant that every time we create materials, social media posts, events and presentations, we check that we channel these desired characteristics.

Figure 2. PPIE Logo

Chapter 7: Recruitment

All PPIE initiatives require the recruitment of some patient and public members. Effective recruitment requires a clear objective and appropriate recruitment activities. See Appendix K for an example recruitment strategy.

Recruitment Objectives & Desired Members

Your recruitment objective should specify the number and characteristics of desired members, and be directly informed by your initiative's purpose. For example, if you aim to improve care for heart disease patients, you will likely recruit those directly affected, such as survivors of heart attacks and carers looking after people with heart failure. Other interested groups to recruit include those working for heart disease charities e, first responders or psychologists dealing with the emotional consequences of chronic illness. Finally, including people with existing ties to communities (e.g. community organisers) and useful skills (e.g. communication specialists) could be beneficial.

- Size: No guidance exists about the optimal size for PPIE groups. In our experience, it is good to aim for a group of 8-10 people in order to include a range of perspectives but be small enough to encourage meaningful engagement. To account for dropouts, a target of 12-14 is recommended for a group of 8-10 people.
- Balance: Including individuals with lived experience of the topics of your focus is key, but so is the inclusion of other perspectives. In our experience, it is worthwhile to have a 60:40 split in your group between those directly affected (e.g. patients, carers, staff) and others, such as community leaders and charity workers.
- Arts: We strongly recommend having someone in your group with a background in art, media or storytelling to help your initiative have wider impact and reach intended audiences through effective communication.
- Diversity: A group of 10 individuals will never be able to represent the diversity of any population. However, it is possible to purposefully maximise diversity of perspectives. For example, our group made sure we had members who supported, felt neutral and opposed research, and had diversity in language, socio-economic background, religion and geographical location. Additionally, your close public working partners are just the start - Your activities down the line can involve surveys and further engagement with a wider population.

Recruitment Activities

Activities to recruit members depend largely on your desired members (e.g. if you want school-aged children, you would engage with your local school), but below are some broad considerations:

- Build on trust: Recruit people through trusted individuals and established organisations, groups and networks, who already have established relationships with a community. For example, physicians, charities and local leaders. Getting their endorsement will enable you to reach people you couldn't otherwise.
- Engage widely: At the beginning, take all opportunities to meet people, network, hold events and engage. Most of it won't amount to anything, but collectively these efforts promote awareness.
- Snowball: Ask your team members, new connections and identified partners to assist with recruitment through their personal contacts and by posting in their alumni and professional WhatsApp groups.
- Public events: Holding a workshop or interactive public event allows people to get practically involved and learn more about your work, which may inspire some to volunteer to become PPIE members.
- Persist: Recruitment for PPIE is hard. It took us 6 months to get 10 members. But it is worth it. Persist.

Chapter 8: Selection & Onboarding

Selection Criteria

Prior to selecting individuals to your initiative, it is good to consider how you will assess their suitability for inclusion. While there is no need for strict eligibility criteria, it is useful to consider characteristics that could indicate people's ability to effectively participate in your initiative. For us, the most important attributes were motivation, confidence and ability to voice opinions. We also viewed prior experience of working with communities in some capacity as a desirable quality. However, we did not feel that prior research engagement experience, English language skills or education were qualities that our PPIE members needed to possess.

It is also important to consider factors that would indicate that an individual is not a good fit for the initiative. Primary focus on compensation, lack of curiosity about the project, and an inability to articulate a clear motivation for joining all point to someone who may not be committed to engagement. During interactions with potential members, we also noted that many listened to our pitch out of respect towards us or the person who referred them. These *'Yes Men'*, as our public partners call them, would not be able to critically contribute. Finally, any individual with disproportionate impact on group dynamics may need to be excluded. For example, our group decided not to recruit religious leaders due to concerns that other members would not feel comfortable disagreeing with them.

Selection & Onboarding Process

Our group follows a three-step process to vet & onboard members following expressions of interest. Having multiple interactions with potential members helps confirm they are appropriate for the initiative and establishes the foundations of a good collaborative relationship between the coordinator(s) and new members.

- Vetting: An informal phone discussion with one of the coordinators is used to understand motivations for joining the PPIE group, confirm that individuals can commit the time required for the initiative and establish whether they are prepared to provide honest feedback during meetings. If the potential member and coordinator jointly feel that inclusion is appropriate, a time is arranged to meet in-person.
- Confirmation: An hour-long in-person meeting is used to complete the *'My Involvement Profile'* (Appendix L) on a laptop together with two coordinators in order to facilitate a two-way exchange about expectations and needs. The profile asks about experiences, skills, interests and motivations, allowing coordinators and members to get to know each other more intimately. The exploration also helps identify the unique perspectives a member brings to the initiative and ways they may be able to contribute.
- Onboarding: Prior to attending the first meeting, the new member will be asked to review and sign the Terms of Reference for the group. The Terms of Reference outlines the aims and activities of the group, as well as the responsibilities and code of conduct of members.

Further Training & Orientation

Additional training may be needed depending on the nature of your PPIE initiative. Our approach is to teach members whatever is necessary for them to effectively engage with the task at hand. For example, explaining the core concepts of informed consent prior to reviewing consent materials for a study. We treat our members as experts in lived experience, who do not need to become experts in research, ethics or medicine in order to contribute meaningfully. A further consideration is relationship-building within a group. If someone new joins, it is worthwhile thinking about how they will integrate and what you can do to promote cohesion (e.g. organise social activities).

Chapter 9: Meetings & Activities

The First Meeting

The first meeting represents an important step in building a team from the diverse set of patient and public partners selected for the initiative. As with building any team, it is important to ensure individuals agree on a shared goal and values, determine the most effective ways of working together, and achieve clarity about roles and responsibilities. Our recommendation is to use the first meeting with your PPIE partners to collaboratively come up with a '*Terms of Reference*' (template in Appendix M) outlining the mission, aim, activities and governance of the group, ways of working, and roles and responsibilities of individuals, including a code of conduct. The key is to co-create the 'Terms of Reference', not to draft it for review by the members, as the act of deciding collaboratively promotes ownership and commitment. A suggested outline for a first meeting can be found in Appendix N). Other things to keep in mind:

- Authority: Any actual or perceived asymmetric power relations will hinder effective engagement and need to be proactively managed. In our case, our coordinators were doctors yet never used their titles with the PPIE members in order to prevent the perception of a hierarchy. The coordinators insisted on not having a right to vote as it was important that decisions were made by members. Coordinators ensured everyone was able to speak in meetings, with dominant voices moderated and quieter ones encouraged.
- Language: The primary spoken language should suit members' needs, not coordinators, and efforts should be taken to promote equal opportunity for all members to contribute regardless of language skills.
- Environment: Ideally, meetings should take place in a neutral place where all members feel comfortable, rather than where it is convenient for coordinators to meet (e.g. research office, hospital).
- Confidentiality: To promote honest and critical input, meetings should be held in private settings and it should be clear that nothing that is shared will leave the group.
- Team-building: Fostering positive social relationships is important for effective teamwork, which can be achieved by incorporating small acts, like icebreakers and joint lunch, at each meeting.

The First Task

A key lesson we have learned is that early wins are vitally important for morale, retention and sustainability. Our recommendation is to choose your first collective task to be 'low-hanging fruit' - A task that can be completed easily and quickly with tangible impact. Successful completion of a task should be emphatically celebrated. It will demonstrate value to leadership and give everyone motivation to keep going with an initiative that can often feel theoretical, intangible and aspirational. First tasks could include creating a study lay summary (written, graphic, video), reviewing a consent form or public-facing material, or sharing the findings of a study (social media, video). Of course, creating, ratifying and publishing a 'Terms of Reference' on a website is also a type of 'low-hanging fruit.'

Activities & Sustainability

Subsequent activities depend on your project plan. Similarly to research, having clear goals and methods informed by evidence are key to success. One thing to consider is whether your group will accept requests from others, in which case a procedure for handling requests may be beneficial (see Appendix O). Sustaining involvement is challenging, but can be promoted by regular communication and activities, acknowledging contributions and providing members opportunities that matter to them. However, personal circumstances and interests change over time. Loss of members is thus to be expected. Recruitment and addition of new members can, however, inject new energy and enthusiasm to your PPIE initiative, thus promoting engagement and sustainability.

Chapter 10: Evaluation

Evaluation is one way to systematically assess an initiative to establish impact and improve practice using evidence-based insights. Results from an evaluation of a PPIE initiative will assist with reporting to leadership, funders and collaborators as well as improving how activities are conducted, while evaluating the impact of PPIE activities will advance the practice and science of engagement. Both types are amenable to publication in scientific journals.

Evaluating PPIE initiatives & activities

An evaluation of your PPIE initiative should be built-in from the start in order to enable you to collect necessary information throughout your project. Planning an evaluation in the midst of your activities or at the end is cumbersome and you'll likely find you have forgotten half the things you have done. The evaluation can be informal, with a simple report on progress towards objectives, or more formal and comprehensive with multiple evaluation activities (see an example protocol). This depends on your ultimate goal, whether that is to compile a report, identify lessons learned, assess impact or conduct an evaluation study with comparable findings. Some considerations:

- Timing: Consider whether to perform an evaluation periodically, in the middle or at the end, and what an evaluation will involve at each stage. Our group has opted to evaluate our initiative annually.
- Records: Our recommendation is to keep records of activities and impact throughout the lifecycle of your project, as it is easier to capture this during rather than at the end of your project. Our group has developed a Master Log (Appendix P) where relevant activities can be recorded and data later used for evaluation, for example, the number of meetings, attendance rates, and reach of social media posts and events.
- Methods: Evaluations can employ many different methods depending on the goals of the evaluation, such as surveys, interviews, focus groups, written reflections, document analysis and quantification of outcomes.
- Participants: You may be interested in the experiences and perspectives of PPIE members or coordinators, but could also consider exploring perceptions of senior management or other collaborators whose work may have been influenced by the PPIE initiative (e.g. investigator of a study that was reviewed by the PPIE group).
- Evaluators: Ideally, the evaluation should be co-led and co-written with your patient and public partners.

Evaluating impact

The evidence on the impact of PPIE on the design, conduct and reach of research is limited, with even fewer studies attempting to measure the impact of PPIE on clinical outcomes. Part of the reason for this is that the impact of PPIE on research or clinical outcomes is indirect with multiple confounders and the desired impact of PPIE is not easily measured (e.g. more patient-centred research processes). However, often engagement practitioners fail to think about evaluation and measurement of impact. Progress can be made by: i) dedicating time to think through a theory of change for how the PPIE initiative and activities is expected to lead to specific changes; and ii) designing high-quality studies to understand the impact of PPIE initiatives. Some research ideas include:

- Study within a trial comparing participant understanding of trial-related information between consent materials and procedures created by researchers to those co-created with patient and public partners.
- Comparison of recruitment rates before and after the implementation of changes to recruitment methods and materials recommended by patient and public partners.
- A narrative case study on the evolution of a clinical trial from a research question to the recruitment of the first participant outlining changes made based on patient and public partner input.

Conclusion

Patient and Public Involvement and Engagement (PPIE) is an essential, exciting and evolving practice in health research. Pakistan is leading the way in promoting high-quality PPIE with the creation of a national network and establishment of multiple initiatives up and down the country. This toolkit has synthesised the trials, tribulations and successes of a few PPIE pioneers into a practical guide that aims to ease the journey for others taking on the noble task of meaningfully engaging and involving patients, families and communities in research. We conclude this toolkit with general advice that does not fit neatly into the specific tasks outlined in each of the chapters.

- Joy: First and foremost, remember to enjoy PPIE work! Meeting new people and building meaningful relationships is fulfilling. Running workshops is enjoyable and successful events provide a sense of success. One of our proudest moments was when our public event was featured in the national news. Creative work associated with PPIE, whether social media marketing, video creation or developing infographics, can be deeply satisfying and stimulates different parts of your brain. Finally, seeing tangible impact on patient and public partners, and amplifying their voices provides purpose and pride.
- Power: Ultimately, PPIE work comes down to power. Engagement activities aim to shift the balance of power so that research is not just the domain of researchers, but co-created and co-led with those that research intends to serve; the public. Clinicians and investigators are used to being the ‘experts’ making all the decisions. Within PPIE, lived experience is recognised as a form of expertise. Patients are experts in living with a condition, families are experts in caring for their loved ones and members of a community are experts in how life works in a specific culture or society. All these forms of expertise can improve the design and conduct of research studies, if those with power (researchers, clinicians) are willing to share the power. This is not easy nor does it happen naturally, but requires reflection and a real change in how things are done.
- Uncertainty: The novelty of PPIE is exciting but brings with it a great deal of uncertainty. Lack of established processes or practices mean that you may have to create things from scratch, even in areas that are out of your comfort zone. For example, we had to create entirely new processes for the finance and marketing departments in order to make direct electronic payments to public partners and accept subscriptions to our newsletter. Giving up control and being led by patient and public members also means that you may have to change plans unexpectedly. Amidst all this uncertainty, flexibility and adaptability is key. Be willing to change your assumptions, ways of working and plans, and accept that not everything will go to plan.
- Time & Effort: It is hard to do PPIE. Engagement in health research is relatively novel and challenges how things are usually done. Establishing meaningful relationships and building trust with patients, families and public members does not happen overnight, but requires time and persistence. Involvement and engagement activities, such as co-design, marketing and knowledge translation, all require the development of new skills and knowledge. Impact is often intangible and takes longer to achieve as you are involving more people in the process. Thus, PPIE work takes dedication, time, patience and persistence. Do not expect immediate results or be disheartened if things don’t work. The national network is always there if you need support or advice!

Our sincere hope is that the information, guidance and tools contained on these pages are helpful, and we remain available to support all those that share our vision. Do not hesitate to get in touch with us a ppie@zu.edu.pk. Our group wishes you all the success in your efforts to promote the patient voice.

Appendices

The appendices complement the chapters of the toolkit by providing concrete examples and worksheets. Any suggestions for improvements are welcome. Feel free to amend and adapt all aspects of this toolkit for your own purposes in any way you wish, however, make sure to appropriately credit the creators as per the license below. Do not hesitate to get in touch with us a ppie@zu.edu.pk. Editable versions of each Appendix are linked in the footer and available for download from this Google Drive.

Table of Contents

Appendix A: Patient & Public Group Coordinator Job Description

Overview of the role

The role contributes to the International Severe Acute Respiratory and emerging Infection Consortium (ISARIC) funded projects at Ziauddin University. The Patient & Public Coordinator will play a key role in ensuring meaningful involvement of patients, families, and communities across the research lifecycle of all ISARIC projects, from study design to dissemination. The postholder will support researchers and community partners to co-develop strategies, materials, and initiatives that enhance the quality, inclusivity, and impact of health research.

Overview of responsibilities and duties

The individual is expected to dedicate 20 hours each week to the role at Ziauddin University. Responsibilities include:

- Support the establishment of a PPIE group to guide involvement and engagement activities at Ziauddin University, including recruitment of members, initial orientation, and defining group objectives.
- Develop and maintain a plan for PPIE activities aligned with project milestones and research needs.
- Coordinate regular meetings and activities of the group, ensuring good communication and participation.
- Serve as the main point of contact between the research team and PPIE group members.
- Support the planning and facilitation of discussions, workshops, and feedback sessions.
- Help researchers incorporate the group's input into study documents, recruitment strategies, and dissemination plans.
- Draft and share meeting agendas, minutes, and follow-up action points.
- Maintain regular communication with group members through email, messaging platforms, or newsletters.
- Keep updated membership records, contact lists, and schedules.
- Support the co-development of accessible documents such as consent forms, participant information sheets, and summaries.
- Collect and document feedback from group members to inform project decisions and demonstrate impact.
- Organise meeting logistics, including scheduling, venue or online setup, and refreshments.
- Assist with processing reimbursements or honoraria for PPIE members when applicable.
- Prepare brief progress summaries or updates for funders, ethics committees, or institutional reports.
- Promote inclusion by encouraging participation from people with diverse backgrounds and experiences.
- Collaborate with communications teams to share updates and outcomes from group discussions.
- Ensure that all PPIE activities are conducted ethically, respectfully, and in line with institutional policies.

Selection Criteria

- Bachelor's degree in health sciences, social sciences, communications, or a related field.
- Demonstrated experience coordinating or supporting PPIE or community engagement in research.
- Strong interpersonal and communication skills, with the ability to work collaboratively across disciplines and cultures.
- Excellent organisational skills with ability to manage multiple priorities and deadlines.
- Experience engaging with diverse stakeholders, including patients, carers, and community representatives.
- Proficiency in Microsoft Office and online communication platforms (Teams, Zoom, etc.).

Appendix B: Training & Reading Materials

Published Articles & Reviews	
Tolppa, T., Hussaini, A., Ahmed, N. et al. (2024) *Establishment of a patient and public involvement and engagement group to support clinical trials in Pakistan: Initial lessons learned.*	Link
Hussaini, A., Ahmed, N., Ahmed, M. J., Hashmi, M., Tolppa, T. (2025). *Patient and public involvement and engagement in critical care research in low- and middle-income countries: Challenges and solutions.*	Link
Richards, T., Montori, V. M., Godlee, F., Lapsley, P., & Paul, D. (2013). *Let the patient revolution begin.*	Link
Domecq, J.P., Prutsky, G., Elraiyah, T. *et al.* (2014). *Patient engagement in research: A systematic review.*	Link
Cook, N., Siddiqi, N., Twiddy, M., & Kenyon, R. (2019). *Patient and public involvement in health research in low and middle-income countries: A systematic review.*	Link
Hoekstra, F., Mrklas, K.J., Khan, M. *et al.* (2020). *A review of reviews on principles, strategies, outcomes and impacts of research partnerships approaches: A first step in synthesising the research partnership literature.*	Link
Heckert, A., Forsythe, L. P., Carman, K. L. *et al.* (2020). *Researchers, patients, and other stakeholders' perspectives on challenges to and strategies for engagement.*	Link
Dudley, L., Gamble, C., Preston, J., Buck, D., EPIC Patient Advisory Group, Hanley, B. *et al.* (2015). *What difference does patient and public involvement make and what are its pathways to impact? Qualitative study of patients and researchers from a cohort of randomised clinical trials.*	Link
Dickert, N. W., Bernard, A. M., Brabson, J. M., Hunter, R. J., McLemore, R., Mitchell, A. R., … D. Pentz, R. (2020). *Partnering with patients to bridge gaps in consent for acute care research.*	Link
Tindana, P. O., Singh, J. A., Tracy, C. S., et al. (2007). *Grand challenges in global health: Community engagement in research in developing countries.*	Link
Frameworks, Toolkits, & Practical Guides	
Mesh Guide: *Setting Up an Advisory/Involvement Group*	Link
Ludwig Boltzmann Gesellschaft (2019). *Patient and Public Involvement and Engagement in Research: A "How to" Guide for Researchers.*	Link
MRC Clinical Trials Unit at UCL. *Patient and Public Involvement (PPI) Resources.*	Link
ACT Patient Engagement Committee. (2024, Fall). *Summary of patient engagement resources.*	Link
Public Engagement in Data Research Initiative (PEDRI). (2025). *PEDRI Good Practice Standards for Public Involvement and Engagement in Data for Research and Statistics.*	Link
PCORI. (2020). *Engagement Rubric for Applicants.*	Link
WHO. (2023). *Framework for meaningful engagement.*	Link

Educational & Training Resources	
University of Alberta, School of Public Health. (2020). *SPH 566 Special Seminars: Fundamentals of Patient-Oriented Research.*	Link
National Co-ordinating Centre for Public Engagement (2018). *What Works: Engaging the Public Through Social Media.*	Link
Global Health Network (TGHN). (2024). *Community Engagement and Involvement in Health Research: An Introduction and Practical Guide.*	Link
Global Health Social Science (2024). *Social Sciences Sessions - Session 5 [Introducing focus group discussions] and Session 8 [Using participatory methods in health research]*	Link
Reporting & Evaluation Standards	
Staniszewska, S., Brett, J., Simera, I., Seers, K., Mockford, C., Goodlad, S., et al. (2017). *GRIPP2 reporting checklists: Tools to improve reporting of patient and public involvement in research.*	Link
NIHR. (2019). *UK Standards for Public Involvement in Research.*	Link
CIOMS. (2016). *International ethical guidelines for health-related research involving humans*	Link
Principles & Reflections on Involvement	
Lefton, V., & Fleming, A. (2024). *Launching the Lived Experience in Policymaking Guide: Reflections on the principles, behaviours, and mindsets that underpin lived experience work.*	Link
Shangase, P. Z., Gachago, D., & Ivala, E. N. (Eds.). (2023). *Co-teaching and co-research in contexts of inequality: Using networked learning to connect Africa and the world*	Link

Appendix C: Project Plan Worksheet

Project Aim

Define the main purpose of your PPIE activity or project. Be clear about what change or improvement you hope to achieve through patient and public involvement. Guiding questions:

- What is the overall aim of this project?
- How will this PPIE activity make your research more inclusive, relevant, or impactful?
- What would success look like?

For example: The aim of this project is to establish a Public and Patient Involvement and Engagement (PPIE) group in a Clinical Trials Unit (CTU) at Ziauddin University in Karachi, Pakistan in order to support the patient-centred design, conduct and dissemination of clinical trials.)

[Draft your main project aim here]

Background

Explain the need for PPIE in your project or setting. Describe the research area, context, and communities you aim to engage with. Guiding questions:

- Why is PPIE important in this context?
- What gap or opportunity does this project address?
- Who are the main communities or groups affected by this research?
- What barriers might exist to participation or understanding?

For example: Patient and Public Involvement and Engagement (PPIE) groups bring together members of the public, patients and researchers to support the design, conduct and dissemination of high-quality patient-centred research. Ziauddin University has recently received accreditation for a clinical trials unit (CTU) and operationalised two large-scale international trials, Mega-ROX (Mega Randomized Registry Trial Comparing Conservative vs Liberal OXygenation Targets) and REMAP-CAP (Randomized, Embedded, Multifactorial Adaptive Platform trial for Community-Acquired Pneumonia). In view of the new CTU and current participation in international trials, this project proposes the establishment of a PPIE group within the Ziauddin University CTU to promote the patient-centred conduct of trials at our institution.

[Draft your background here]

Planned Work

Define the objectives of your work and for each objective, outline the specific methods for achieving that objective. Describe who will participate, what activities you will carry out, and how input from patient and public partners will be used. Below are example objectives and prompts to help you think through your own planned work. You can adapt, combine, or replace these objectives based on what fits your project. Your project plan is likely to change over time, especially as you receive input from patients and public partners, but it is worthwhile planning as much as possible ahead of time.

Objective 1: *Establish a PPIE group consisting of patients, family members and community representatives*

Guiding questions related to this example objective to draft the methods and planned work:

- Who will be involved (patients, families, youth, faith leaders, etc.) and how will you identify them?
- How will you invite them and support participation?
- How will diversity be ensured?
- How can participation be inclusive and accessible?

For example: We will identify and invite ICU survivors, caregivers, and representatives from local non-governmental organisations and faith communities to join the group. Recruitment will take place through posters, referrals, and social media posts. Meetings will be held quarterly to discuss trial materials and community engagement priorities. Efforts will be made to ensure diversity in gender, age, and background.

Objective 2: *To improve and co-develop the consent process for clinical trials*

Guiding questions related to this example objective to draft the methods and planned work:

- What materials or processes will you review?
- What activities will you organise (e.g. meetings, workshops, feedback sessions)?
- How will feedback from the group be incorporated into your research or materials?

For example: Group members will review consent forms and participant information sheets for ongoing trials (e.g., REMAP-CAP, Mega-ROX). Feedback will be collected through discussion and short surveys, focusing on clarity and cultural appropriateness. Revised versions will be shared back with the group for approval before use in the study.

Objective 3: *To share trial results with patients and the public in Karachi*

Guiding questions related to this example objective to draft the methods and planned work:

- How will you share findings or updates with participants and the public?
- How will you share results with your own group?
- What communication channels will you use?
- How will you make materials accessible and understandable?

For example: Once trial results are available, PPIE members will help develop plain-language summaries and advise on dissemination through community forums, newsletters, and local media. Materials will be translated into Urdu and shared via social media and hospital networks to reach wider audiences.

[Draft your planned work here]

Ethics

Describe the ethical considerations of the work you intend to carry out and how you plan to prevent, mitigate or address ethical issues. Guiding questions:

- How will patient and public partners be acknowledged (e.g. authorship, presentations) and compensated (e.g. reimbursement of expenses, honorariums) for their contribution?
- What personal information will be collected from PPIE group members (if any) and how will the confidentiality and security of this information be ensured?
- Will the names, photos or contact details of members be publicly available (e.g. website), and how will consent for this be sought?
- Are the planned PPIE activities going to involve patient or public partners having to recall adverse personal experiences? If so, how will any potential emotional distress be identified and managed?
- Will patients and public partners be asked to carry out research activities themselves (e.g. interviews), and if so, how will they be trained in Good Clinical Practice to ensure study participant safety?

For example: All PPIE members will be asked during onboarding about their preferences for having their name and photo included in promotional and public-facing materials, and all personal information will be stored on a secure password-protected electronic storage space only accessible by PPIE coordinators. Members can ask for their information to be deleted or modified at any time. Manuscripts and other academic outputs from the PPIE initiative will include all members as authors, and patient and public partners will be given opportunities to attend and present at events and training courses. Reimbursement is guided by the compensation & expenses policy.

[Draft your ethics section here]

Evaluation, Consolidation & Dissemination

Describe how you will assess the success of your PPIE activities, use what you learn, and share the results with others. Guiding questions:

- How will you measure success (e.g. attendance, diversity, quality of input, impact on materials)?
- How will lessons learned be applied or sustained?
- How will you share outcomes with participants and the wider community?

For example: We will evaluate success based on meeting attendance, participant feedback, and evidence of changes made to study materials. Lessons learned will be used to draft a PPIE guide for future projects. Findings will be shared at the National PPIE Summit, through internal newsletters, and via plain-language summaries distributed to all participants.

[Draft your evaluation, consolidation and dissemination section here]

Timeline

Provide a simple overview of when major activities will occur. Use months or quarters as appropriate.

Activity	Month/Quarter	Notes
Recruit 10 PPIE members	*Jan-Feb 2025*	*Posters, physician referrals*
First group meeting	*Mar 2025*	*Orientation & introductions*
Review consent materials	*Apr-Jun 2025*	*Two meetings*
Incorporate feedback	*Jul-Aug 2025*	*Revise study documents*
Dissemination & evaluation	*Sep-Nov 2025*	*Share outcome at PPIE Summit*

[Draft your timeline here]

Team

Outline your team members and responsibilities.

[Draft your team description here]

Appendix D: Budget Worksheet

Budget Overview

Guiding questions:

- What is the total budget for your PPIE activities?
- Over how many years will funding be distributed?
- Who are the main funders or sponsors?

For example: The Patient and Public Involvement and Engagement Group at Ziauddin University is funded by the International Severe Acute Respiratory and emerging Infection Consortium (ISARIC) from September 2024 to December 2029 with a total amount of £100,000. The funding to ISARIC has been provided by the Gates Foundation, Wellcome Trust and the United Kingdom Foreign, Commonwealth & Development Office.

[Draft an overview of your budget here]

Budget Categories

Identify the main areas where funds will be used. Below are just some potential categories to keep in mind.

Category	Description	Guiding Questions	Example Items
Staff Costs	*Salaries or honoraria for staff coordinating or supporting PPIE activities.*	*Who will lead, manage, and coordinate PPIE work? Are these full- or part-time roles?*	*Salaries for a PPIE Group Coordinator and Public Coordinator*
Member Costs & Expenses	*Honoraria and expenses for patient & public members*	*How many members are there? How many meetings are there and where? What expenses will members incur?*	*Travel expenses to meetings; Honorariums for time spent preparing and attending meetings; Childcare costs*
Travel & Subsistence	*Costs for travel to meetings, conferences & events for coordinators and members*	*What events will coordinators and members attend? What travel or accommodation will be required? Do standard rates exist institutionally?*	*Travel expenses to the annual PPIE Summit; Flights & hotel for conference attendance; Travel to and from the airport; Meals*
Events & Meetings	*Costs associated with organising meetings and events*	*What is needed for a successful meeting or event?*	*Refreshments; Lunch; Venue hire; AV team and equipment; Speaker fees; Giveaways*
Training	*Costs associated with training staff or members*	*What courses or programmes would be relevant?*	*Certification course; Bespoke training session; e-learning*
Evaluation & Research Activities	*Costs associated with carrying out evaluations and/or research*	*Do you need any software or materials? What methods will you use? Will you travel?*	*Analytical software; Voice recorder; Travel; Ethics fee; Publication fee*

Software	*Costs associated with subscriptions to software*	*What software would help you with your PPIE activities? Do you need a Standard or Pro accounts for your activities*	*Zoom Pro (online meetings), MailChimp (newsletter), Canva Pro (design)*
Materials & Consumables	*Creation of physical and digital materials to support visibility and engagement.*	*What materials will you produce or print?*	*Posters; Newsletters; Animated videos; Web app development; Website*
Miscellaneous	*One-off or irregular costs that support engagement.*	*What extra resources are needed to improve accessibility and sustainability?*	*Translations; Printing; Devices*

[Draft a description of the main categories of the budget here]

Budget Details

Guiding questions:

- What are the specific items within each category?
- Why are they needed (justification)?
- What exchange rate will you use (if needed)?

Item	Justification	Year 1	Year 2	Total
Example: PPIE Group Coordinator	*To lead, coordinate, and manage all institutional PPIE activities*	*Rs 2,700,000*	*Rs 2,700,000*	*Rs 5,400,000*
Example: PPIE Group Member Honoraria	*Six in-person meetings per year at 1500 PKR/hour x 2 hours x 10 members*	*Rs 180,000*	*Rs 180,000*	*Rs 360,000*

[Draft the details of your budget here]

Monitoring & Review

It is useful to think about who will be responsible for maintaining, updating, and tracking the budget for the PPIE activities. Guiding questions:

- How often will you review the budget?
- Who is responsible for monitoring spending?
- How will you track costs (incurred, claimed, reimbursed)?

[Draft the monitoring and review section here]

Appendix E: Ethics Exemption Worksheet

Introduction

Establishing or running a PPIE group often involves working with patients, caregivers, or community members, but these activities are not research studies. They are part of developing institutional systems that make research more ethical, inclusive, and transparent.

Since the purpose of these activities is advisory and developmental, not to generate new or generalisable data, they typically fall outside the scope of ethics review for human subjects research. However, institutions and ethics committees may still request a formal exemption statement for clarity and accountability.

This worksheet therefore provides:

- A model exemption request example,
- Key points to emphasize when preparing an exemption submission, and
- A sample narrative that can be adapted for submission to an Ethics Review Committee (ERC) or Institutional Review Board (IRB).

When to Apply for Ethics Exemption

An ethics exemption is appropriate when involvement and engagement activities involve:

- Developing or running a PPIE or community advisory group, including recruiting members, co-creating terms of reference, or hosting orientation sessions.
- Training, dialogue, or consultation activities that seek input to improve research design, communication, or participant experience.
- Reviewing participant information sheets or study materials for clarity and accessibility.
- Co-developing standard operating procedures, frameworks or institutional policies for research engagement
- Evaluating internal processes for improvement, without collecting or analysing personal or health data.

In all such cases:

- No individual is recruited as a *research subject*.
- No data are collected for the purpose of drawing research conclusions.
- No clinical, behavioral, or experimental interventions are performed.
- The primary intent is institutional strengthening and partnership, not research

Ethics Exemption: Example Application Sections

Background

Explain why the PPIE group is being established and why ethics exemption is appropriate. Describe the broader research context and need for public involvement. Guiding questions:

- Why is PPIE needed in your setting or department?
- What are the key barriers or opportunities for involving patients and the public?
- How does this initiative fit within your institution's research activities?
- Is it part of broader research capacity-building efforts?

For example: Patient and Public Involvement and Engagement (PPIE) is increasingly recognized as essential for ensuring that health research is ethical, meaningful, and relevant. This initiative aims to develop a PPIE group within Ziauddin University to bring together patients, caregivers, and community representatives who will advise on study design, consent materials, and communication strategies. The activity does not involve collecting data from or about participants and therefore falls outside the scope of human subjects research.)

[Describe the background of your PPIE group here]

Rationale

Summarise why your team is applying for ethics exemption. Guiding questions:

- How does this initiative differ from a research study?
- What makes this activity advisory or developmental rather than experimental?
- Which national or international guidelines support the exemption?

For example: This is a capacity-building and systems-strengthening activity. It involves collaboration, discussion, and training to support ethical, inclusive research practices. No data will be collected for research purposes, and no interventions will be carried out. In line with Health Research Authority (HRA) and NIHR guidance, PPI activities do not require formal research ethics approval because they do not involve human subjects research.

[Describe the rationale for ethics exemption here]

Aim

Clearly define what the project intends to achieve. Guiding questions:

- What change or improvement do you hope to achieve through this initiative?
- How will it strengthen your institution's ability to engage patients and the public?

For example: This project aims to embed sustainable, meaningful PPIE practices within Ziauddin University's research ecosystem by establishing a formal PPIE group that supports ongoing clinical and public health studies.

[Describe the aim of the project here]

Objectives

Outline the main objectives of your initiative. Guiding questions:

- What are your primary goals?
- What capacity, processes, or tools will you develop?

Example Objectives:

1. *To build internal capacity through structured training on research fundamentals, ethics, and effective communication.*
2. *To strengthen operational frameworks, including updating the group's Terms of Reference and defining transparent policies on data privacy, recognition, and compensation.*
3. *To integrate PPIE into research processes by enabling meaningful contributions to the review of study documents and participant-facing materials.*

4. *To improve accessibility of research outputs by co-developing plain-language summaries and communication tools (e.g., videos) that explain research in lay terms.*
5. *To document and share learnings to support institutional knowledge around community engagement and inform future efforts.*

[Describe the objectives of the project here]

Recruitment

Guiding questions:

- Who will be eligible to join (patients, caregivers, community representatives)?
- How will recruitment occur (referrals, posters, social media)?
- What steps will ensure diversity and accessibility?
- What tool or form will you use to document interest and fit?

For example: The group will include 8–10 members representing diverse backgrounds, including patients, caregivers, and community representatives. Recruitment will occur through referrals and engagement in hospital or clinic settings. All members will participate voluntarily as advisors.

[Describe the recruitment process here]

Training

Guiding Questions:

- What orientation or training will be provided before engagement?
- How will you ensure members understand research and ethics basics?

For example: Introductory workshops on research ethics, informed consent, and participant rights will be offered in collaboration with [partner institution]. Training will be provided before members review study materials.

[Describe the training process here]

Compensation & Recognition

Guiding Questions:

- How will you compensate or reimburse members for their time and expenses?
- What institutional policy or standard will guide compensation?

For example: A transparent honorarium policy will ensure all contributors are compensated fairly for their time and travel in line with [institutional or funder] guidelines. Participation remains voluntary, but compensation ensures equitable involvement.

[Describe the compensation and recognition policy here]

Project Plan & Implementation

Guiding Questions:

- What key activities or outputs will be produced (e.g., Terms of Reference, SOPs, communication tools)?
- How will you manage logistics and documentation?

For example: The PPIE group will hold quarterly meetings. Processes will be documented for transparency, including meeting schedules, logistics, and follow-up actions. A Request for Input form will allow researchers to engage the group systematically.

[Describe the project plan and implementation here]

Ethical Considerations

Justify why the initiative qualifies for exemption. Guiding questions:

- How do you ensure ethical principles are maintained even without full ERC review?
- How will confidentiality, consent, and transparency be handled?

For example: The establishment and operation of this PPIE group fall outside the scope of ethics review because no data are collected for research. Participants are not research subjects and will not be recruited into studies through this process. Participation is voluntary, and all discussions will be documented and anonymized where appropriate. Any future evaluation involving data collection will undergo separate review.

[Describe the ethical considerations here]

Expected Outcomes & Impact

Describe what you hope to achieve and how the initiative will contribute to research culture. Guiding questions:

- What short- and long-term outcomes do you expect?
- How will this strengthen community trust and research quality?
- Will it produce materials or processes that others can use?

For example: Expected outcomes include strengthened capacity for public engagement, improved clarity of research materials, and a replicable model for embedding PPIE in other departments. In the long term, this initiative is expected to foster greater trust and relevance in research through ongoing dialogue between researchers and the public.

[Describe the expected outcomes and impact here]

References (Optional)

Include key supporting references or guidance documents used to justify exemption (e.g., HRA, NIHR, WHO, PCORI, or local ERC policy).

Appendix F: Memorandum of Understanding

between

[Institution A / Research Group Name]
&
[Institution B / Partner Organisation Name]

➤ Whereas, [*Institution A*] is a team of multidisciplinary researchers committed to advancing research, education, and public engagement in [specify field, *e.g. critical care/public health/infectious diseases*]. Through collaboration with national and international partners, it works to strengthen research capacity, promote knowledge sharing, facilitate multi-centre studies, and build sustainable networks that address pressing healthcare challenges.

➤ Whereas, [*Institution B*] is a [type of organisation, *e.g. non-profit/academic institution/healthcare network*] recognised for [specify strengths, *e.g. providing accessible healthcare, conducting applied research, supporting community health initiatives*]. It is committed to delivering quality services, fostering professional development, and engaging in research and collaborative initiatives that advance healthcare standards and strengthen capacity to address emerging health challenges.

➤ And whereas both parties have agreed to join hands to seek cooperation among health academics and scholars at [*Institution A*] and [*Institution B*] to enhance the quality of care and research in [*relevant field e.g. acute care*].

Now, therefore, it is agreed between the two parties that cooperation will be developed step by step, and in areas identified where collaboration could be initiated as soon as possible.

I. STATEMENT OF GOALS

In order to achieve the required targets, [*Institution A*] and [*Institution B*] shall collaborate:

1. To facilitate joint initiatives that advance research in areas aligned with the shared priorities of both institutions.
2. To encourage the exchange of expertise, knowledge, and resources to strengthen the capacity of both organisations in research and training.
3. To strengthen the impact of research activities through outputs, publications, and knowledge dissemination.

II. STATEMENT OF OBJECTIVES

The arrangement for this project will be made by mutual agreement. The aim of the cooperation under this MoU is, where appropriate, to align the various cooperative initiatives between the parties, as detailed below, to benefit from synergy between them and provide a fruitful platform for new initiatives. The objectives of this academic and scientific collaboration are:

1. To promote collaborative research projects of mutual interest between both parties.
2. To strengthen academic exchange between [*Institution A*] and [*Institution B*] teams.
3. To explore opportunities for joint development of new research initiatives and expansion of existing ones.
4. To share experience and best practices to enhance the quality and impact of collaborative research.
5. [*Institution A*] and [*Institution B*] will ensure that no inconvenience is caused to research participants, employees, or the administration of either party during the conduct of research activities.
6. In case of any dispute between the two parties, mutual consultations will take place, and if not resolved, the matter will be referred to the designated focal persons from each institution for final arbitration.

III. ROLES AND RESPONSIBILITIES

A. [*Institution A*] shall:

a. Coordinate collaborative research projects, ensuring ethical and scientific rigor.
b. Develop study protocols, data collection tools, and analysis plans in consultation with [*Institution B*].
c. Facilitate ethics submissions, research governance and compliance with institutional & national standards
d. Provide training and capacity building for [*Institution B*] staff, including research methodology, data management, and community engagement practices, where applicable.
e. Ensure dissemination of study findings through publications, reports, and community feedback sessions, acknowledging joint contributions.
f. Coordinate follow-up studies and joint proposals for the implementation of projects of mutual interest.

B. [*Institution B*] shall:

a. Facilitate community engagement, including identification and recruitment of participants.
b. Support implementation of research activities within its network of clinics, ensuring minimal disruption to routine services.
c. Provide insights and feedback on study design, tools, and data collection approaches to ensure cultural and contextual relevance.
d. Offer logistical support for fieldwork, including access to facilities, staff & participants, where appropriate.
e. Participate in capacity-building and dissemination activities, including authorship, events and conferences.
f. Collaborate in identifying new areas for joint initiatives, including community-based interventions, training programs, and operational research addressing public health priorities.

Both parties shall:

a. Ensure transparent communication, shared decision-making and mutual respect in all undertakings.
b. Maintain confidentiality of shared data and respect intellectual property agreements.
c. Promote equitable recognition of contributions in all outputs.
d. Periodically review progress and identify opportunities to expand collaboration into new thematic areas such as health systems strengthening, epidemic preparedness, and community resilience.

IV. DURATION

The MoU will remain effective for [insert duration, *e.g. two (2) years*] from the date of signing. It may be terminated by either party, in which case shall [insert notice period, *e.g three (3) months*] notice in writing to the other party. This MoU may be extended by mutual consent in writing.

IV. TERMINATION

In the case of termination, both parties shall use reasonable endeavours to honour any arrangements made regarding ongoing research activities or collaborative commitments accepted under this Memorandum of Understanding if the fellow meets the terms and conditions established by the parties for the said initiative. Both organisations retain the right to engage in similar activities with other collaborators.

SIGNATURES

Date ________________________________	Date ________________________________
[Name, Designation]	[Name, Designation]
[Institution A]	[Institution B]

Appendix G: Research Collaboration Agreement

FOR THE ESTABLISHMENT OF PATIENT & PUBLIC INVOLVEMENT AND ENGAGEMENT GROUP

This Research Collaboration Agreement for the 'Establishment of a Patient & Public Involvement and Engagement Group' project is entered into on the 00th day of XXXX 20XX ("Agreement") by and between:

[Insert Institution A name and address] (Hereinafter referred to as "[Insert institution abbreviation, *Institution A*]").

(e.g. Ziauddin University, 4/B, Shahrah-e-Ghalib, Block 6, Clifton, Karachi, Pakistan 75000, through its Office of Research, Innovation & Commercialization (Hereinafter stated as "ZU").

And

[Insert Institution B name and address] (Hereinafter referred to as "[Insert institution abbreviation, *e.g. Institution B*]").

The foregoing entities are referred to each, individually as "Party" and collectively as "Parties".

Background

A. Patient and public involvement and engagement (PPIE) is an approach to research carried out 'with' or 'by' members of the public rather than 'to', 'about', or 'for' them. This methodology involves an active and meaningful partnership between patients, the public, clinicians, and researchers to identify research priorities, design studies, carry out research, and disseminate findings. This Research Collaboration Agreement (RCA) outlines the framework for collaboration between [*Institution A*] and [*Institution B*] to advance PPIE in clinical research.

B. The establishment of Patient and Public Involvement and Engagement (PPIE) groups across Pakistan is being led by [*Lead Research Group/Department Name*] at [*Institution A*] (Principal Investigator: [*Insert PI Name*]). [*Insert PI Name*] serves as [Insert Role/Position] of the [Insert Network or Organisation Name] and is working towards facilitating PPIE activities in the region.

Description of the Project

This Agreement establishes the framework for supporting [*Institution B*] in setting up its Patient & Public Involvement and Engagement Group and facilitating its effective implementation. This is a project-based initiative, rather than a formal study, with the potential to contribute to research studies in the future if deemed necessary. As part of this collaboration, [*Institution B*] will contribute to community engagement work, such as reviewing consent materials for planned studies when relevant. Collaborative activities will be mutually agreed upon by the Parties.

1.1 [Institution A] responsibilities

- [*Institution A*] *will serve as the national coordinating hub for the establishment, oversight and integration of the PPIE group into the national PPIE network as more groups develop.*
- [*Institution A*] *will a) provide training and mentorship to site teams, b) support the development of a site-specific project plan and operational documents by sharing guidance documents and templates and; c) enhance capacity building by meeting regularly to provide input on recruitment, governance, monitoring, long-term engagement strategies and offer opportunities to get certification in PPIE.*
- [*Institution A*] *will coordinate reimbursement of up to 10 PPIE group members (subject to prior approval and availability of funds): ensuring financial support for time and travel related to the group's activities, training, and public engagement initiatives.*

    - *Up to xx in-person meetings per year (maximum insert duration, e.g. two hours each)*
    - *Up to xx online meetings per year (maximum insert duration, e.g. two hour each)*
- *[Institution A] will comply with its research guidelines and hospital policies applicable to this project, which are based on ethical principles that have their origin in the Declaration of Helsinki, and are consistent with Good Clinical Practice (GCP) guidelines as well as applicable regulatory requirements.*

1.2 [*Institution B*] responsibilities:

- [*Institution B*] will establish and maintain a Patient & Public Involvement and Engagement Group in collaboration with [*Institution A*] as the national coordinating hub.
- [*Institution B*] will a) appoint a site lead and engagement coordinator to oversee local activities, b) participate in training and mentorship sessions organised by [*Institution A*] and; c) develop a site-specific project plan and operational documents, which address locally identified priorities and contribute to one or more of the following objectives:

  [*Institutions may select one or more of the objectives below to focus on in their site-specific plan*]
    - Review and improve the clinical characterisation protocol (CCP) study processes
    - Evaluate community engagement approaches and strategies
    - Sharing research outputs with patients and the public
    - Co-develop a patient outcome improvement plan for priority infectious diseases (e.g., acute brain infections, dengue, or acute respiratory illnesses)
    - Contribute to the design, conduct & dissemination of observational and interventional clinical studies
    - Co-develop and pilot a tool to measure stigma associated with emerging epidemic diseases

- [*Institution B*] will implement recruitment, governance, and monitoring strategies to ensure meaningful and sustained patient and public involvement and engagement.
- [*Institution B*] will facilitate active engagement of PPIE group members in study design, consent processes, and research dissemination.
- [*Institution B*] will collaborate with the national PPIE network, benefiting from peer support and resource sharing.
- [*Institution B*] will ensure timely documentation and reporting of PPIE activities, including tracking participation, engagement outcomes, participation in evaluation of PPIE efforts and key learnings.
- [*Institution B*] will coordinate with [*Institution A*] for reimbursement of advisory group members' time and travel, in line with the established compensation policy.

  [*Institutions may also add additional responsibilities or objectives if deemed appropriate to their context and priorities.*]

Project Leads

The scientist directing [*Institution A*] activities on the project shall be [*Insert PI Name*] ("Principal Investigator"). The [*Insert PI Name*] Investigator shall coordinate [*Institution B*] activities with *[Insert PI name]* ("Principal Investigator – [*Institution B*]"). If a designated Principal Investigator is unable to continue to serve and a successor is not found, this Agreement may be subject to termination.

Article 1. Project Monitoring

Both [Institution A] and [Institution B] shall ensure that all systems used to collect, process, store, and manage PPIE-related data, including member profiles, engagement records, study contributions, and public involvement activities, are maintained and upgraded as required to protect the integrity and security of the data. This shall be done in accordance with accepted research standards, ethical guidelines, and applicable laws on confidentiality, privacy, and governance of patient and public data.

Article 2. Financial Agreement

2.1 Prior agreed reimbursement payments to the PPIE Group members will be managed by [Institution A] on behalf of [insert name of funders, if applicable] and the Principal Investigator.
2.2 All Parties shall be responsible for their respective tax payments (if any) related to financial disbursements.
2.3 All payments shall be made to the "[name of institution A]", which will disburse funds to participating PPIE Group members.
2.4 All claims shall be sent to: name of institution A]

Article 3. Additional Collaboration Opportunities

3.1 [Institution B] will be invited to [collaborative activities, e.g. workshops, public events] organised by [Institution A], where coordinators and members can share best practices, challenges, and lessons learned.
3.2 These activities will also provide professional development opportunities, including training sessions, peer learning and and talks from PPIE experts.
3.3 Travel, accommodation, and attendance costs for [Institution B]'s coordinators and members will be covered as per prior agreed terms.

Effective Date and Term

The Agreement shall be effective from [XX/XX/20XX] and will be valid for a term of [*insert duration e.g. duration of grant*].

Article 4. Modification and Termination

4.1 The project may be terminated immediately if required by a governmental regulatory authority or if a party determines that discontinuation is necessary for health, safety or ethical reasons.
4.2 Any Party may terminate this Agreement with thirty (30) days' written notice.
4.3 If a Principal Investigator ceases participation, reasonable efforts shall be made to find a replacement. If no suitable candidate is found, the Agreement will terminate.
4.4 A Party may terminate this Agreement immediately if the other party a) commits criminal misconduct, gross negligence, or unethical behavior, b) willfully violates confidentiality, intellectual property, or contractual obligations.

Article 5. Data Protection and Confidentiality

*5.1 As used in this Agreement, the term **"PHI Data"** means all personal information (including without limitation medical data, information and other personal identifiable health information), Data means all information including de-identified medical information gathered, generated, processed for the purposes of the project shall be kept confidential and used solely for the purposes outlined in this Agreement. Under no circumstances such information shall be disclosed, shared, or used for any purpose outside the scope of the project without the prior written consent of the other party and in accordance with all applicable data protection laws.*
5.2 Data handling must comply with ethical approvals, regulatory conditions, and informed consent protocols.

Article 6. Intellectual Property.

6.1 All rights, title, methodologies and interest in and to any and all study-related materials arising out of the initiative shall be the sole and exclusive property of [Institution B] and [Institution A].
6.2 Any intellectual property (IP) or inventions developed under this Agreement shall be promptly disclosed to the relevant Parties and shall be subject to a royalty-free, non-exclusive license for internal and academic research purposes and not for commercial purposes.

Article 7. Use of a Party's Name.

7.1 Notwithstanding anything in this Agreement to the contrary and without further notice, the Parties hereto acknowledge and agree that each of the Parties may disclose the existence of this Agreement, the title of the project, identify the Parties to this Agreement, and disclose the amount of funding actually received from [Institution A] pursuant to this Agreement, including but not limited to acknowledgment in any publication or presentation relating *to the results of the study as provided herein; and that Investigator may disclose the same information in a curriculum vitae. However, no Party shall use the name of the other in any publication, news release, promotion, advertisement, or other public announcement, whether written or oral, that endorses services, organisations or products, without the prior written approval of the other Party.*

Terms of Agreement.

Nothing herein is intended to conflict with current directives and policies of each Party. If any of the terms of this Agreement is inconsistent with existing directives of the Parties hereto, those portions of this Agreement that are determined to be inconsistent shall be invalid; and the remaining terms and conditions shall remain in full force and effect.

IN WITNESS WHEREOF the Parties hereto have set their hands on the day and year first above written.

Signatures

Date __________________________________	Date __________________________________
[Name]	[Name]
[Designation]	[Designation]
[Institution A]	[Institution B]

Appendix H: Honoraria and Expenses Policy

About this policy

The 'Honoraria & Expenses Policy' details the payment of patient and public members of the Patient & Public Involvement and Engagement (PPIE) Group of the [name of site]. All members of the PPIE group and coordinators provided input and approved the final version of this policy. The policy has also been reviewed and approved by the Director of Office of Research, Innovation and Commercialization (ORIC) and Director of Finance at [name of site]. As there is no national guidance on payments for PPIE initiatives in Pakistan, this policy is based on the principles outlined in the National Institute for Health and Care Research (NIHR) payment guidance.[1] This policy will be shared with all new PPIE group members prior to onboarding.

Honoraria

Honorarium payments are made to patient and public members of the PPIE group to acknowledge their contribution to the work conducted by the group. Members will receive payment for any time spent preparing or attending PPIE-related activities, including those taking place online, at a rate of 1000 PKR/hour. If the PPIE-related activity is canceled by the organizers less than 48 hours before it is due to take place, the full honorarium amount will be given.

Rights

Members have the right to decline payment or ask for payment of a lower value at any time by informing the PPIE coordinator. The honorarium payments do not create an employment relationship between the members and [name of site], and no taxes are deducted prior to payment.

Expenses

Travel in [name of city]

Travel to regular in-person PPIE meetings and activities taking place in [name of city] will be reimbursed at a flat rate of 1500 PKR. If the amount is not sufficient to cover travel costs for a member, the amount will be increased for that member based on the average cost of their travel.

Travel & Accommodation Outside [name of city]

Travel and accommodation for in-person activities outside of [name of city] will be planned together with members and booked by [name of site]. Decisions regarding travel and accommodation will be made based on member needs and best value for money.

Meals

Refreshments provided at PPIE-related activities will be arranged and paid by [name of site]. A flat rate of 5000 PKR/day will be provided for meals at in-person activities taking place in Pakistan, accounting for 1000 PKR for breakfast, 1500 PKR for lunch and 2500 PKR for dinner. The daily amount for meals during international travel will depend on the destination of travel. Below are indicative rates for travel to the United Kingdom[2]:

- Breakfast: £10/meal
- Lunch: £15/meal
- Dinner: £30/meal

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[1] NIHR (2024): 'Payment guidance for researchers and professionals'

[2] HDR UK. 2024. Honoraria and Expenses Policy – Patient and Public Involvement and Engagement Activities version 3.0

Additional expenses

All additional expenses resulting from PPIE-related activities (e.g. childcare) will be covered. For any expenses not mentioned above, members will have to discuss the expense with the coordinator before it is incurred in order to ensure timely and appropriate reimbursement.

Payment

Members will be asked to provide their bank details (i.e. name of bank, name of account, account number, Computerised National Identity Card (CNIC) number) when they join the PPIE group. This information will be kept confidential and stored in a password-protected Google Drive. Payments to members will be made within a week of the PPIE-related activity either as an electronic bank transfer or a cheque according to preference. Patients and public members do not need to submit claims, receipts or evidence.

Review & Ratification

This policy will be reviewed and ratified annually by the PPIE group, Director of ORIC and Finance Director at [name of site], or at any time in the case of proposed amendments based on feedback from PPIE members, coordinators or staff at [name of site].

Appendix I: Social Media & Marketing Strategy

Patient & Public Involvement and Engagement (PPIE) Group at Ziauddin University

This document outlines the 2025-26 social media and marketing strategy for the Patient & Public Involvement and Engagement (PPIE) group at the Critical Care Research Group (CCRG) of Ziauddin University in Karachi, Pakistan.

Primary Goal & Audience

Our main goal is to maintain a timely and complete record of our engagement initiative, activities and outputs in order to communicate the scope and impact of our work to potential and existing collaborators, clinical staff, institutions and official bodies, as well as ensure accessibility of our resources and templates to assist others in establishing their public engagement initiatives. Secondary goals are to reach a larger audience of affected and interested parties related to critical care and infectious diseases, and disseminate useful engagement and educational resources to this audience. Success of this strategy will be determined based on our ability to maintain contemporaneous and complete documentation of our initiative, the number of views and downloads of our materials, and members of the public reaching out to our group to ask questions or provide input.

Key audiences include medical students and staff at Dr Ziauddin Group of Hospitals, the Drug Regulatory Authority of Pakistan, the National Bioethics Committee, researchers and academic institutions engaged in trials and infectious disease research (e.g. Aga Khan University, Indus Hospital & Health Network, Shaukat Khanum Memorial Cancer Hospital and Research Centre), organisations related to ethics and public engagement (e.g. Center of Bioethics & Culture, Pakistan Institute of Living and Learning), international partners (e.g. International Severe Acute Respiratory & emerging Infections Consortium, REMAP-CAP), and most importantly, patients with lived experience of critical care or infectious diseases as well as their families and other affected and interested parties.

Team & Resources

A designated marketing coordinator (Wardah Khalid) is responsible for the social media and marketing activities of the PPIE group. The individual will spend a maximum of one hour a day on this work and has a responsibility to:

- Coordinate the creation, editing and dissemination of social media and marketing content
- Maintain the 'Website & Socials-Master Log' and monitor the impact of social media and marketing activities
- Update other coordinators on social media and marketing activities during the weekly coordinator meeting
- Act as the primary contact person for queries from the Marketing team at Ziauddin University
- Revise the social media and marketing strategy as required

The marketing coordinator will work together with other coordinators, PPIE group members, the Marketing team and collaborators to create social media and marketing content. Broadly, the individuals involved in a specific activity will be responsible for providing key messages and photos for social media and marketing posts, while the Marketing team will create graphics and illustrations.

Resources

The Marketing team at Ziauddin University provides in-kind support to our social media and marketing activities by creating graphics, logos and illustrations, generating the newsletter, posting social media content, maintaining the PPIE website, taking professional photos and recording and editing videos free of charge. Funding from the International Severe Acute Respiratory and emerging Infection Consortium (ISARIC) is available to support the printing of leaflets, newsletters and posters, creation of animated videos and webapps as well as annual subscriptions to software such as LucidChart, Canva Pro and MailChimp [see software license details in the Appendix]. In view of the focus of our social media and marketing strategy, no resources are allocated to market research and listening tools.

Platforms, Activities & Content

The main platform used for social media and marketing is the PPIE group website (https://zu.edu.pk/ppie) where a timely and complete record of our engagement initiative, activities and outputs will be maintained, including a quarterly newsletter to summarise key points. Visibility will be promoted by posting the website and newsletter content, with minor modifications, through Ziauddin University's Facebook, Instagram and LinkedIn accounts. Social media accounts do not exist for the PPIE initiative in view of the primary goal of maintaining a simple record of activities. Instead, coordinators will use their private social media accounts to reshare posts. The newsletter will be sent to subscribers via email and shared with Pakistani researchers through a dedicated public WhatsApp group called 'Clinical Trials Pakistan.' Copies of the newsletter will be printed and distributed at networking and academic events as well as in-person meetings with new and existing collaborators. Videos created for the PPIE initiative will be uploaded to the website and hosted on the Ziauddin University YouTube account.

All marketing material will direct individuals to visit the website for a complete record of our activities and outputs. Other ways in which each intended audience is reached is outlined below:

■ Medical students (Ziauddin)	Facebook & Instagram
■ Clinical Staff (Ziauddin)	Newsletter (subscription list)
■ Drug Regulatory Authority of Pakistan	WhatsApp Group & LinkedIn
■ National Bioethics Committee	LinkedIn
■ Researchers and academic institutions	Newsletter (subscription list) & LinkedIn
■ Ethics Groups (e.g. CBEC & PILL)	Newsletter (subscription list)
■ Partners (e.g. ISARIC, REMAP-CAP)	Newsletter (sent individually) & Tag in posts

To maximise reach to the different audiences, coordinators will ensure to add collaborators, institutions and key contacts on LinkedIn to their personal accounts as well as ask permission to include them in the newsletter email subscription list. The marketing coordinator will compile and periodically update a list of relevant LinkedIn accounts, which also includes a list of partners with contact email addresses and relevant social media handles.

Website & Social Media

The goal is to post all of our activities, events and output on our website (https://zu.edu.pk/ppie/) and social media accounts of Ziauddin University (Facebook, Instagram and LinkedIn). The website and social media updates are the main ways for us to achieve our primary goal of keeping a timely and complete record of our engagement initiative.

Content

The content is a short written summary of an activity, event or output related to our engagement initiative, accompanied by photos or videos as well as relevant hashtags and mentions. The person responsible for the activity, event or output should provide the marketing coordinator, at a minimum, key points for the post and one image. Ideally, the responsible person should give a full draft of the content with multiple images. Examples of posts include descriptions of oral and poster presentations, webinars, panel discussions, PPIE group meetings, publications, blog posts, newsletters, public events, videos, new PPIE group members or coordinators and collaborations with various external institutions. Visual material accompanying a post can include event photos, headshots, logos of external collaborators, screenshots of publications, videos and recordings.

Steps

All coordinators are responsible for updating the 'Master Log' in a timely manner with activities, events and outputs, such that they can be identified for the website and social media posts. Once identified, these steps are followed:

- ☐ Create written content and add to the Website & Social Media document under the 'Events & Activities' tab for posts on the website and the 'Social Media' tab for social media posts.
- ☐ Upload relevant audiovisual materials related to the post in the Photos & Logos folder.
- ☐ Content reviewed by PPIE coordinators who did not draft the content and changed as per feedback.
- ☐ Content shared with MH for approval and finalised based on feedback.
- ☐ Content and audiovisual materials shared with the Marketing team (Focal person: Rahimullah, marketing@zu.edu.pk).
- ☐ For Social Media posts, PPIE coordinator drafting the post is responsible for providing relevant hashtags (Instagram/LinkedIn) and mentions (e.g. international partners such as REMAP-CAP, ISARIC).

Once the social media posts have been published:

- ☐ Ask coordinators to share, like and comment on the published posts.
- ☐ Check 'Reach' once only for each post; Part of a weekly check (e.g. Fridays) to check posts put out the week before (i.e. posts have had 7-10 days to be viewed)

Newsletter

The goal is to publish a quarterly newsletter outlining activities, achievements and stories from the PPIE initiative. The newsletter supports the aims of the marketing strategy by providing a visually appealing summary record of our activities to be shared as physical printed copies, electronically via social media and the website, and most importantly, through our subscription email list.

Content

The majority of the content is a summary of social media and website posts from the past quarter about our events, outputs and activities. Three types of additional content have previously been added: i) announcements of upcoming activities, events or priorities; ii) graphics to illustrate timelines and concepts (e.g. map of ISARIC hubs); and iii) longer written contributions by PPIE group members or coordinators. Below is an indicative outline of a typical newsletter:

- Welcome message: Key message or announcement of this quarter and a one-sentence summary of the content of the newsletter. 500-750 words.
- Core sections: Two to four descriptions of activities, updates or outputs from the PPIE group with relevant images or graphics. 250-500 words.
- Upcoming: One section describing 'Our priorities' or 'Upcoming events.' 250-500 words.
- Our recent events & activities: Highlight three events/outputs from the past quarter with a short description and one image each. 75-150 words. The three highlighted events can be followed by a list of other events.
- Message from: A longer written contribution from a PPIE group member, coordinator or collaborator. No word limit. Examples include: i) Reasons why PPIE is important; ii) Reflections from an event; iii) Introduction from a new member or coordinator.

Graphics will be created by the marketing team, who will need guidance on the content and desired format. Development of graphics usually takes two to three rounds of feedback. The 'Message from' section requires asking someone else to write a reflection on a specific topic. Images and text for most other sections can be lifted from the website and social media posts. The cover image is usually a photo from one of our events or a photoshoot arranged with marketing using various CCRG team members as models.

Steps

A newsletter will be produced four times a year, approximately in January, April, July and October.

- ☐ Create a folder in the Newsletters section. Within the folder, create a Google Docs for the content and upload all images to a subfolder, including a cover image.
- ☐ Create an outline and draft the content, including instructions for the Marketing team for any desired graphic. Ask the relevant person to provide the text and images for the 'Message from' section.
- ☐ Share the draft with other coordinators for review; 3-5 days.
- ☐ Share the reviewed version with Madiha for approval; 1-3 days.
- ☐ Share the approved version with Marketing along with images. Ensure it is clear which section each image is supposed to be placed (e.g. title images with the section name). Follow up the email with a call/conversation and ask about timelines for receiving a draft.
- ☐ Dissemination
    - ☐ Ask Marketing to upload the finalised newsletter to the website.
    - ☐ Create social media posts announcing the newsletter.
    - ☐ Print 300 copies to keep in the office.
    - ☐ Send a PDF copy to the newsletter email subscription list using the template.
    - ☐ Post in the 'Clinical Trials Pakistan' WhatsApp group
    - ☐ Share directly with partners mentioned in the newsletter (e.g. ISARIC, MORU)

Other

Specific activities, such as public events, the summit, dissemination of research findings and recruitment of new members, may require different marketing activities, including institutional or local radio interviews, podcasts, press releases, Facebook groups, posters and blog posts. These will be planned and executed separately from this strategy.

Branding

Our initiative is collaborative and innovative, working to partner with patients, families and members of the public to promote the novel practice of public engagement in research both nationally as well as internationally. As such, our voice is positive, excited, inquisitive and collaborative. Our key messages reflect this sentiment:

- Making a difference together
- Pioneering Patient & Public Involvement and Engagement group in Pakistan

Colour Scheme & Logo

The colour scheme of the PPIE initiative is determined by the colours of Ziauddin University, which are green and gray, both present in the PPIE logo, depicting our brand of collaboration and connection.

- Green: RGB (67,146,76), HEX (#43924c)
- Primary Gray: RGB (128, 130, 133), HEX (#808285)
- Lighter Gray: RGB (166, 168, 171), HEX (#a6a8ab)
- Darker Gray: RGB (58, 57, 59), HEX (#3a393

Monitoring & Evaluating Progress

Overall success is defined as having a complete record of all of our activities, events and outputs on the website and social media when assessed a year after our baseline (i.e. the date of this social media and marketing strategy). Additional measures of success include a 25% increase in monthly visits to our website, views of our videos in YouTube, downloads of our newsletter and signups to our newsletter email subscription list as compared to our baseline as well as a patient or public member contacting us through social media or email.

The main way of documenting and monitoring progress is through the Master Log, where website, social media post and newsletter creation, publishing and reach is recorded. Weekly PPIE coordinator meetings will be used to get an update from the marketing coordinator about progress and ensure all recent activities, events and outputs are added to the 'Website & Socials' list such that marketing content is created. The weekly meetings also serve as an opportunity for the marketing coordinator to highlight any challenges in content creation, posting, teamwork, processes or timing. Quarterly meetings with the senior lead of the PPIE initiative will be used to formally highlight any successes or challenges of implementing the marketing strategy.

The reach of social media posts will be recorded once for each post on the Friday of the week after posting. The number of email addresses reached by each newsletter will be documented at the time of sending, while the number of downloads will be documented once at the time of publishing the subsequent newsletter. Engagement with the website and socials will be reviewed in depth annually, when this strategy is updated and amended.

Indicator	Marketing Output	Monitoring
Existence of a post for each activity, event and output	Website & Socials	Weekly: Coordinator meetings
Total number of likes, reposts and comments	Socials	Annually: Strategy review
Total number of visits to the 'Events & Activities' tab	Website	Annually: Strategy review
Total number of subscribed email addresses	Newsletter	Quarterly: Newsletter publication
Total number of downloads	Newsletter	Quarterly: Newsletter publication
Total number of views of videos on Youtube	Videos	Quarterly

Appendix J: Social Media & Marketing Worksheet

Primary Goal

Identify the main goal of your social media and marketing efforts. Specifically, define your target population and desired outcome. Your primary goal will be the basis of your entire strategy. Guiding questions:

- Who do you want to reach?
    - Be as specific as possible. It is not sufficient to say ‘academic community’ or ‘researchers’ - Do you want to reach those based in a specific country, the South Asian region or the entire world? Do you want to reach social scientists, health researchers, community- or hospital-based clinical researchers?
- What do you want to accomplish?
    - Dissemination: Communicate research findings
    - Recruitment: Find collaborators, members or participants
    - Visibility: Promote work and raise your profile
    - Career development: Attract the attention of employers
    - Documentation: Maintain a timeline and record of your activities
- What does success look like?

[Draft the primary goal here]

Team & Resources

Identify the team members that will work on social media and marketing activities, and define their roles and responsibilities. Outline the resources and materials available to the team to carry out activities. The availability of people and resources determines what is possible to achieve with your social media and marketing activities - e.g. if there is only one person spending an hour a week on social media, it would not be wise to try to be on three different social media platforms and trying to put out various types of posts (infographics, text, images, video).

Guiding questions:

- Who is responsible for creating and updating this strategy?
- Who is involved in content creation?
- Who is responsible for posting content?
- How much time can be allocated to social media and marketing activities by different team members?
- What resources are available for content creation and posting content?
    - Financial: Research or other funding to pay content creators or subscriptions (e.g. X Pro)
    - Institutional: Photographers, video studio, marketing department
    - Graphics & Design: Canva Pro, Piktochart, Easel, GoDaddy Studio, Adobe Photoshop
    - Social Media Growth Tools: Tweet Hunter, Hypefury [to help grow your audience]
    - Social Media Listening Tools: Brandwatch, Hootsuite [to help with market research]
    - Other: Grammarly, Mailchimp, Cameras, Recorders, Analytics Tools

[Draft a description of your team and resources here]

Social Media Platform(s)

Select the social media platform(s) you will use. This should be informed by your audience, goals and resources, as well as the type of content you are planning to create. Starting with a single platform is preferable to using several at once. Content can rarely be simply copy pasted from one platform to another, as each platform has different styles, limitations (e.g. word count, video duration, preferred image size) and audiences. Expansion to other platforms can occur once your team has experience of managing social media and marketing. Remember that you do not necessarily have to create and maintain a profile on each platform - e.g. the institutional LinkedIn account can post on your behalf.

Potential platforms:

- Blogs: Great for storytelling and longer articles describing research in detail. Not good for networking.
- LinkedIn: Enables professional networking and sharing of resources as well as visibility for an individual and institutions. Not widely used by health researchers or clinicians.
- Facebook: Groups are an effective way to reach people and communities. Users are primarily older.
- TikTok & Instagram: Primarily visual platforms focused on entertainment. Younger audiences.
- Twitter: Used to be the main platform for academics. Posts with links are now deprioritised.
- Bluesky: New excellent alternative to Twitter, no adverts or monetization. Currently, limited reach.
- YouTube: Brilliant for storytelling and longer videos, and hosting a record of activities.
- Research Gate: Focused on science and researchers. Great for sharing publications.

[Draft a description of the platform you will use and the rationale for using it]

Marketing Activities

Consider other types of marketing activities aside from social media. Use of these will likely vary over time and with different projects, but if they are used, it is good to plan resources and consider how they will be used.

- Printed materials: Posters, advertising leaflets, standees, physical signs
- Newsletters: Physical, email or online on a website, frequency, type of content
- Website: Subpage within your institutional website, standalone website
- Legacy media: Institutional or local radio, newspapers, media, press releases, contacts within media

[Draft a description of the activities that will be used and how]

Branding

Branding is absolutely key to ensure that you or your group is easily findable and recognisable. Effective branding helps with content creation, engagement with audiences, networking and visibility. When establishing your brand, it would be useful to conduct some market research to see what types of individuals or brands already exist in your field to ensure your brand offers something new or additional, what tone of voice or content your intended audience responds to and what previous strategies have or haven't been successful?

- What is the name and account names you will use?
    - Make yourself easily findable: Short, simple, unique and professional. Shorter names are easier to tag and work better on platforms with word limits. Do not use things like Timo1991.
    - Ensure the name reflects your brand: @NeuroNayeem for Ahmed Nayeem interested in neurology
- How would you like others to describe you? How would you like to come across? What is the tone of your voice? [Some examples below]
    - Funny: Engaging and entertaining, putting out fun memes and videos, attracting a wider audience
    - Authoritative: Leading voice in a specific topic, professional, sharing articles, attracting specialists
    - Critical: Challenging and critiquing publications and views, attracting debate and engagement
    - Inquisitive: Curious, asking lots of questions, posting polls, engaging with a wide variety of material
    - Encouraging: Commenting on lots of post, congratulating the work of others
    - Positive & Exciting: Use lots of emojis, share lots of new material.
- What are your key messages, slogans and terms?
    - Consider a few key messages or terms that you keep repeating in your materials
    - For example, 'the first-ever public engagement group in Pakistan' is a recognisable slogan that can be used together with key terms such as 'collaboration', 'patient-centered' and 'novel'
- Do you have a logo? What is the colour scheme you will follow?
    - If your logo has the colors black, white and red, all your marketing materials should adhere to this colour scheme including infographics, posters, presentations and adverts
    - Its a good idea to define the RGB & HEX codes for your brand colors to help with content creation.

[Draft a description of your brand, including the tone of your voice and your public image as well as key messages, slogans and brand colours]

Content

Content creation and posting can be time-consuming. Planning content ahead of time and scheduling posts ahead of time will save the team a lot of trouble. All social media posts are a form of publication and leave a permanent record. Therefore, you do not want to make mistakes or publish something you may regret later. Remember that ideally only 20% of your content should directly promote your brand. The other 80% should be dedicated to audience interests and involve things like commenting and resharing the content of others. Market research will also help here to find out what your target audience engages with, what hashtags and terms to use, etc.

- What type of content will you post? e.g. memes, pictures, text, video, infographics, publications, blogs
- What do you already have? e.g. headshots of team members, event pictures
- How often and when will you post?
    - This should be guided by your platform and audience. If you are targeting South Asian researchers on Twitter, it is best to post weekday mornings or lunchtime.
- Will you use a scheduling tool or post manually each time?

[Draft a description of the type of content you will create and the practicalities of creating and posting the content]

Monitoring & Evaluating Progress

To ensure you are progressing towards your stated goals and your marketing strategy is working, it is important to determine the way in which you will be monitoring and evaluating progress.

- How will you measure success or failure?
    - Increased traffic to your website & downloads of your publication or newsletter
    - Number of new members, participants, colleagues or collaborative projects
    - Increased number of citations for your paper or mention of your group on social media
    - Followers and likes - These are often called vanity metrics as they do not reflect actual engagement
- How often will you evaluate progress and how will you evaluate?
    - Successes & challenges: Identifying what has and hasn't worked with content creation, posting, teamwork, processes and timing.
    - Engagement: Reviewing the types of content people have most engaged with.
    - Timing: Quarterly, 6-monthly or annually. Consider doing a smaller review more frequently and a deep dive into your social media strategy annually.

[Draft a description of your monitoring and evaluation plan for the marketing strategy]

Further Resources

The following blogs and resources may be helpful when considering your social media and marketing strategy

- Starter Guide: www.lib.sfu.ca/help/publish/scholarly-publishing/radical-access/twitterforacademics
- Twitter for Academics: onlineacademic.wordpress.com/social-media-for-academics/twitter-for-academics/
- Social Media for Research: https://researchimpact.ca/webinar/social-media-strategies-for-research/

Appendix K: Member Recruitment & Selection Strategy

Patient & Public Involvement and Engagement (PPIE) Group at Ziauddin University

This document outlines the recruitment strategy for the Patient & Public Involvement and Engagement (PPIE) group at the Critical Care Research Group (CCRG) of Ziauddin University in Karachi, Pakistan. The strategy focuses on the process of identifying, engaging and selecting individuals for the PPIE group, with the current priority being on recruiting those with lived experience of infectious diseases or participation in critical care and infectious disease research.

Background & Current Members

Established in 2023, the PPIE group was formed to integrate patient and public perspectives into the design and conduct of clinical trials, especially in critical care. However, since August 2024, we have broadened our scope to include all types of infectious disease and critical care research. Current members include caregivers and community advocates, including:

- Male, caregiver to a chronically ill patient.
- Female, school physician.
- Female, working on social impact & bioethics.
- Female, social scientist & midwife.
- Female, community health worker.
- Male, caregiver to a critically ill patient.
- Female, engagement specialist working persons with disabilities.

Recruitment Objective (as of June 2025)

To engage individuals with lived experience of infectious diseases (e.g., dengue, acute encephalitis), past or current research participants, caregivers of critically ill patients and community members with experience in public health.

Recruitment Methods

1. Collaboration with Study Coordinators
    - Aim: Identify potential PPIE members with the help of coordinators of ongoing studies (i.e. dengue and acute respiratory infection surveillance studies, the GenOMICC study, the Mega-ROX & REMAP-CAP trial).
    - Process:
        - A training session will be conducted with study coordinators about the PPIE group and the types of individuals suitable for PPIE involvement (i.e. interested in research, critical, inquisitive).
        - If the study coordinators identify an individual that is potentially suitable for PPIE, they are asked to: i) introduce PPIE and give a recruitment flyer to them; or ii) notify the PPIE team about a potential recruit.
        - The PPIE coordinators responsible for recruitment will check in daily with site study coordinators.

2. Direct Engagement with Trial Participants & Their Caregivers
    - Aim: Identify potential members by advertising in the Clinical Trials Unit (CTU) and directly approaching trial participants and their caregivers during their visits to the CTU.
    - Process:
        - Informational flyers and a standee have been placed in the CTU waiting area.
        - The PPIE coordinators responsible for recruitment will visit the CTU at least three times per week for 20–30 minutes to speak with trial participants and caregivers. Permission for this has been given by CTU leaders.
        - If an individual expresses interest, a follow-up will be conducted within 48 hours. Contact details (phone number and email) will be collected for continued engagement and newsletter updates.

3. Collaboration with Clinicians
- Aim: Identify potential members with the help of clinicians.
- Process:
    - Departmental educational events and regular faculty meetings will be attended by the PPIE team twice a year to discuss PPIE, share examples of its impact and encourage referrals of eligible patients or caregivers.
    - All clinicians are invited to the annual PPIE summit where referrals of potential members are encouraged.
    - Individual clinicians and department heads will be periodically approached to ask for help with recruitment.
    - PPIE standees are displayed in the outpatient waiting area to ensure visibility for clinicians and patients.

Recruitment Materials

- Flyers outlining the PPIE group's role and how to get involved have been distributed to outpatient clinics and CTU.
- Two advertising standees have been created and placed in the outpatient department and main hospital lobby.
- All PPIE coordinators have personalised business cards to hand out to potential members.

Assessment & Selection Process

Selection Criteria

No strict eligibility criteria exist for the PPIE group. Instead, coordinators assess potential members subjectively based on their experience, discuss the matter with other coordinators and existing PPIE members, and ultimately make a decision with the potential member about inclusion. In our collective experience, the following attributes indicate that a person has the ability to effectively participate in the PPIE group:

1. Interest in community health or research
2. Commitment and availability
3. Confidence to express opinions
4. Collaborative mindset
5. Desire to work towards betterment of the community
6. Prior engagement experience (Desirable)

The following attributes indicate an individual that is likely not a good fit for our PPIE group:

1. Inability to commit time
2. Reluctance to engage
3. Conflict of interest
4. Health or personal constraints

Selection Process

Once an individual has been identified as a potential new member for PPIE and initial contact has been made with an explanation of the PPIE initiative, role of members and broad expectations, contact details (phone, email) will be solicited and the process below is followed until the individuals disengages or a final decision is made about inclusion or exclusion:

- Follow-Up: Individuals who provide their contact details for recruitment or are referred by study coordinators, clinicians or other partners will be sent a WhatsApp link to the "What is PPIE?" video. A follow-up message will be sent after 48 hours and 1 week to gauge interest and answer any questions, and set up a phone call, if appropriate.
- Vetting: An informal phone discussion with one of the coordinators is used to understand motivations for joining the PPIE group, confirm that the individual can commit the time required for the initiative and establish whether they are a good fit for the initiative. If the potential member and coordinator jointly feel that inclusion is appropriate, a time is arranged to meet in-person.

- Confirmation: An hour-long in-person meeting is used to complete the *‘My Involvement Profile’* on a laptop together with two coordinators in order to facilitate a two-way exchange about expectations and needs.
- Onboarding: Prior to attending the first meeting, the new member will be asked to review and sign the Terms of Reference for the group to ensure transparency and alignment.

Monitoring of Recruitment

- A recruitment log will be maintained on the Master Log to track outreach efforts, responses, and outcomes.
- Progress will be assessed as part of the regular Quarterly Meetings of PPIE leads and coordinators. Challenges will be addressed, and recruitment strategies refined as needed.
- Feedback from new PPIE members will be sought as part of our annual evaluation to improve the recruitment and onboarding process.

Inclusivity & Diversity

The strategy aims to recruit members from diverse backgrounds, including a range of age groups, genders, socioeconomic statuses, and linguistic communities. Measures will also be taken to accommodate individuals with disabilities or other specific needs, ensuring inclusive and equitable participation.

Appendix L: My Involvement Profile Template

Patient & Public Involvement and Engagement (PPIE) Group at [Name of Site]

Thank you for your involvement in Pakistan's first-ever PPIE group! The primary purpose of this group is to make research conducted at [name of site] more relevant and meaningful for the people in Pakistan. We will review ongoing research and discuss how they can be improved.

The aim of completing this document together with us, the coordinators, is so that we can better understand your background and experience, your preferences, your requirements for support as well as your expectations of the project. This allows us to better understand members of the PPIE group and determine how we can align our objectives to reach our desired outcomes. This exercise will help us facilitate group discussions efficiently and ensure equal participation.

All information provided will be kept confidential and will not be shared with other members of the group. It will be stored in a password-protected folder that can only be accessed by the coordinators of the PPIE project and the document will be permanently deleted one year after you leave the group (or earlier upon your request).

Part 1 - Personal Information

1. Contact details

Name:

Address:

Telephone number:

Email:

Social media:
- Instagram:
- X/Bluesky:
- LinkedIn:

Year I was born:

Sex: Male / Female / Intersex / I prefer not to answer

My highest level of educational attainment:

- Below Primary
- Primary (Class 1-5 & Age 6-10)
- Middle (Class 6-8 & Age 11-13)
- Matric (Class 9-10 & Age 14-15)
- Intermediate
- Graduate
- Masters & Above
- Diploma / Certificate
- Other (please specify):
- I prefer not to answer

My current work status:
- Working (including full and part-time work, self-employment, unpaid family helpers)
- Seeking work
- Student (including part and full-time student)
- House Keeping
- Other (please specify - e.g. retired, volunteer, on parental or short-term leave, receiving benefits):
- Prefer not to answer

My mother tongue:

- Urdu
- Punjabi
- Sindhi
- Pushto
- Balochi
- Kashmiri
- Saraiki
- Hindko
- Brahvi
- Other (please specify):
- I prefer not to answer

Name of emergency contact:

Relationship of emergency contact:

Telephone number of emergency contact:

2. Preferred communication method

- WhatsApp, SMS, email, voice notes, phone calls

3. Required format of information

- Google Document (requires a Gmail account)
- Word Document (requires Microsoft)
- PDF

4. Preferred language

Spoken: English / Urdu / Other
Written: English / Urdu / Other

5. Why I want to take part in this involvement activity or PPIE group

6. Other involvement and research activities I have done

a) Involvement

I have taken part in involvement activities for the following organisations:

The area of involvement is/was:

The types of involvement activities I have done include:

b) Research studies and clinical trials

I or my family member have been part of research studies and clinical trials: Yes / No

My general attitude towards research and clinical trials is:

7. My relevant skills

Skills

-

As a result of these skills, I think I can contribute to the PPIE project in the following ways:

8. My paid and unpaid work experience

Current work

-

Experience

-

I have worked for pay in a healthcare profession: Yes / No

9. Education, training and other interests

Degrees, Diplomas & Certificates

-

Interests (personal and professional)

-

10. Social media and marketing

All social media posts and marketing materials (e.g. website, leaflets) containing any information about you will always be shared with you for review prior to publishing. Saying ‘Yes’ to any of these questions does not mean that we will publish anything publicly without your permission.

Generally, I am comfortable with the use of my name as part of social media posts and marketing materials (e.g. website, leaflets)

- Yes / No

Generally, I am comfortable with my social media accounts being tagged in social media posts

- Yes / No

Generally, I am comfortable with the use of pictures and videos of me as part of social media posts and marketing materials (e.g. website, leaflets)

- Yes / No

Part 2 - Access and Support Requirements

This section explains my access and support requirements.

1. Format of papers and documents

I need the following formats:	Large font / Small font
I need materials in advance:	Yes / No
If Yes, how many days in advance:	
Please send documents to me in the following way:	Hard copies / Soft copies on email/WhatsApp
If this is a remote activity I prefer to use:	Platform/Tool: Zoom / Teams / Skype / WhatsApp Device: Phone / Laptop

2. I need these access arrangements

For in-person events:

- Mobility
- Breaks (e.g. prayer, smoking, rest)
- WiFi

For remote events:

- Devices

3. I will be bringing support with me

Yes / No
If Yes, the name of my assistant is:

4. I need support to be provided on the day

Yes / No
If Yes, please specify:

5. I am available at these times and days

Weekdays / Weekends
Mornings / Afternoons / Evenings

6. I or the person attending with me have some dietary requirements

Yes / No
If Yes, please specify:

7. I am clear on the amount, process and reasons for reimbursement as part of this PPIE project

Yes / No

Part 3 - Expectations

This section is about my expectations regarding the PPIE group

1. Role

Member of the public / Patient / Patient’s attendant

2. My impression of PPIE is:

3. My expectations from this PPIE group are:

4. In my opinion, patients and the public can be involved in research:

Yes / No
If Yes, how and where can patients and the public be involved:

5. I have concerns about the involvement of patients/public in research:

Yes / No
If Yes, please specify:

6. I have concerns about my involvement in the PPIE group:

Yes / No
If Yes, please specify:

This template has been adapted from the Document Template created by Shaping Our Lives.

If you have any further questions, please contact us via:
Email: hello@shapingourlives.org.uk
Telephone: 0345 241 0383

Shaping Our Lives National User Network Community Interest Company
Company limited by guarantee registered in England and Wales
Company No. 04382606
Registered office: 30 St Giles' Oxford OX1 3LE

Appendix M: Terms of Reference Template

1. Background

Patient and public involvement and engagement (PPIE) is research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. This approach involves an active and meaningful partnership between patients, the public, doctors and researchers to identify research priorities, design studies, carry out research and disseminate study findings. Involvement and engagement promotes research that is more relevant and useful to the public. The PPIE group was established in XXXX by the core team of [names of individuals] to [aim of the group].

2. Mission Statement & Philosophy

To advocate for our community and ensure its voice is heard in healthcare practices. To advise on and support the undertaking of high-quality patient-centered research at [name of site].

We are committed to ensuring meaningful dialogue between researchers and the community in order to facilitate transparency in research practice and to impact decision-making. Together we are determined to foster a research culture that values diverse opinions and caters to cultural sensitivities. Our work adheres to the National Institute for Health and Care Research Standards for Public Involvement.

3. Aims & Activities

The broad aims and activities of the PPIE group are:

1. To advise on research priorities
2. To advise on the design of research protocols
3. To contribute to the ethical review of research studies
4. To support the development of study materials
5. To support the conduct and implementation of research studies
6. To participate in data analysis
7. To support the dissemination of results to the public
8. To advocate for post-study access to approved and effective therapeutics as well as diagnostics

4. Governance, Structure & Roles

The PPIE group is part of the [name of department and site] and is funded by [name of funder].

4.1. Senior Lead

The head of the [department], [name], is the senior lead of the PPIE Group. [Name] is responsible for the overall ethical, administrative, regulatory and legal aspects of the PPIE group, including managing the funding, contracts and approvals on behalf of [name of organisation]. All public-facing materials, including social media posts, website content, newsletters, marketing products and academic outputs, require approval from the senior lead prior to publication. The senior lead will meet with the coordinators every 3 months to review the “Project Roadmap” and agree the objectives for the subsequent 3 months.

4.2. Coordinators

The PPIE group has up to three coordinators that attend PPIE group meetings as non-voting members. All coordinators are responsible for arranging development opportunities for patient & public members. Coordinators will meet on a weekly basis and maintain the “Meeting & Action Log” shared with the senior lead.

1. Engagement Coordinator: Responsible for recruitment of new members, correspondence, payments and logistical arrangements for all meetings and PPIE group activities. Acts as the key liaison for patient and public members.
2. Public Coordinator: Responsible for building strategic relationships with local leaders and institutions. Provides advice on outreach and marketing.
3. Scientific Coordinator: Responsible for leading project development and evaluation as well as assisting the senior lead in reporting to ethics, funding and regulatory bodies. Acts as the key liaison for international partners.

4.3. Patient & Public Members

The PPIE group consists of up to ten patients, their family members and members of the public. Members will be compensated for their time spent preparing and attending meetings and events, as well as their travel to in-person meetings and activities.

1. The group will have no designated leader and will function on the basis of equal participation.
2. Members are free to leave the group at any time and will be replaced by new members. New members will be recruited and vetted by the Engagement Coordinator based on the following criteria:
    a. Must be able to contribute to the group critically
    b. Must be willing to give time
    c. Should ideally have experience in community engagement, research or social work
3. New members joining the group will undergo an onboarding process, involving training and a review of these Terms of Reference with the Engagement Coordinator.

5. Meetings of the Group

1. Meetings are to be held every 2 weeks or more frequently as deemed necessary by the PPIE group.
2. Meetings are to be alternated between in-person and online sessions. Members can opt for online participation during in-person meetings as well.
3. Members must inform the Engagement Coordinator if they are unable to attend a meeting.
4. Meeting dates will be scheduled at least 10 days in advance.
5. In-person meetings will be 2 hours long maximum. Online meetings will last 1 hour.
6. Any materials for review will be sent to members based on their language and format preferences as indicated in the ‘My Involvement Profile’ completed before they started their involvement in the group.
7. Urdu will be the main language of communication during PPIE meetings to facilitate participation from all members.
8. Meeting minutes will be captured by a different group member volunteering each time.
9. Decisions will be made by a majority vote, as long as a minimum of 75% of members are in attendance.
10. Content discussed during meetings is confidential and should never be shared outside of the group.
11. Guest speakers can be invited to meetings as advisors or trainers as deemed necessary by the PPIE group.
12. Refreshments will be organized by the Engagement Coordinator and provided to members during in-person meetings.

6. Code of Conduct

All members will adhere to the following values and principles during all interactions.

1. Honesty
2. Trust
3. Confidentiality
4. Respect
5. Tolerance
6. No judgment
7. Punctuality
8. Accountability

7. Ratification & Review of this Terms of Reference

This ‘Terms of Reference' document has been reviewed, ratified and signed by all members of the PPIE group as well as the senior lead and coordinators. The Terms of Reference will be reviewed annually, or more frequently as deemed necessary by the PPIE group. All new members of the PPIE group will be asked to review and sign the Terms of Reference upon joining the group.

Appendix N: First Meeting Agenda

Date:	16th September 2023
Time:	10:00 a.m.
Location:	Conference Room, Faculty of Law, Politics & Governance 7th Floor, Ziauddin University Building

Meeting Aim: To introduce the role of PPIE in clinical trials and to decide together how the group will work and what it aims to achieve

Overview

10:00 a.m. to 11:00 a.m.	Welcome & Introductions
11:00 a.m. to 11:15 a.m.	**Break**
11:15 a.m. to 12:30 p.m.	Clinical Trials & PPIE: Importance, impact and what do we want to do
12:30 p.m. to 12:45 p.m.	**Break**
12:45 p.m. to 2:00 p.m.	Terms of Reference: Decide the group's mission & code of conduct together
Lunch	

Welcome & Introduction

All attendees (coordinators and members) are asked to introduce themselves by giving their name, story of why they decided to join this PPIE group and any experiences relevant to engagement. The coordinators should point out any commonalities in motivations and interests to encourage relationship building and connection.

Clinical Trials & PPIE

Coordinators will provide a two-slide presentation to explain clinical trials and the research process. The first slide includes pictures of Drug A and Drug B, and the coordinator will explain that at their core, all trials are a systematic and robust way to determine which drug or treatment is safer and more effective. The second slide outlines a five-stage process diagram with the titles: i) what; ii) how; iii) do; iv) results and v) share. The coordinator will explain that research usually follows a five-stage process and that patients and members of the public can be involved in every stage.

- What: Deciding what disease, drug, treatment or population to study.
- How: Writing a protocol to describe how to study the disease, drug, treatment or population.
- Do: Conducting the study, including recruitment, treatment and follow-up.
- Results: Analysing data and coming up with the findings.
- Share: Informing doctors, patients, decision-makers and the public about the results.

The coordinators will facilitate a short discussion after introducing each step in the research process, asking members if and how they think patients, families and members of the public can be involved in that research step, what impact they think it can have and whether our group should contribute to that step of the research process. Coordinators will offer some examples of successful PPIE throughout the discussion to support the points raised by members. The discussion will form the basis of the list of activities to be included in the first draft of the Terms of Reference.

Terms of Reference

All members will be divided into pairs and given three blank A1 sheets and markers. All pairs will consider three topics, each with a set of guiding questions, to draft the Terms of Reference:

- Governance & Structure
    - Should the group have a leader?
    - What should be their responsibilities?
    - How should they be chosen?
    - If there is no leader, how would you like the group to operate?
- Meetings of the Group
    - How often should the group meet, how should the meeting times and agenda be decided?
    - What would the group like to talk about in these meetings?
    - How far in advance should the date and time of the next meeting be decided?
    - What should be the format of meetings (task-based, agenda-based, facilitated)?
    - Who should join the meetings?
    - How should decisions be made? i.e. unanimous, majority vote
    - Should meeting minutes be captured? Who should do this?
    - Should meetings be recorded?
- Roles & Responsibilities of the Members
    - What should be the group's rules and guiding values? (e.g. punctuality, respect, fairness)
    - Should there be a minimum required attendance? Should there be another option if a member cannot attend in-person (e.g. online attendance)?
    - Should everyone sign a Terms of Reference or code of conduct?

After all pairs have discussed and made notes on all three topics, the A1 sheets are collected. The sheets from each group for each topic are examined for similarities and differences, discussed and consensus agreement will be sought to all guiding questions as well as additional considerations. After the meeting, the coordinators will draft text for the Terms of Reference based on the decisions made by the group and share the first draft with members.

Conclusion

Coordinators close the meeting and explain the next steps in drafting the Terms of Reference and the next meeting.

Appendix O: Request Form & Application Information

Introduction

Patient and Public Involvement and Engagement (PPIE) is crucial in enhancing the overall quality and relevance of health research. Incorporating the unique perspectives of patients and the public not only aligns with ethical principles but also improves study design, conduct and outcomes. This document aims to guide investigators in identifying opportunities for effective PPIE within their research.

Benefits of PPIE

1. Enhanced Research Quality

Patients and the public offer valuable insights into what matters most to them, which can be used to improve the relevance and acceptability of research. Patient insights into the feasibility of a study assist in ensuring successful and efficient research conduct.

2. Improved Recruitment and Retention

Patients and the public are best placed to identify the most appropriate and successful strategies to recruit participants and keep them motivated to remain in a study. This can be achieved by ensuring the information provided to the participants is accessible and comprehensible.

3. Ethical Conduct of Health Research

Involving patients and the public aligns with the ethical principle of "nothing about us without us" and helps ensure adherence to ethical standards. Patient input also helps with gaining ethical approvals.

4. Increased Awareness & Impact

Engaging with patients and the public raises awareness of the research and results, which assists with acceptability, recruitment and implementation of results after the conclusion of the study. Effective engagement also provides a mechanism for participant feedback during and after the study.

5. Success with Funding Applications

Funding agencies are increasingly requiring the involvement of patients and the public in study design and conduct due to the multiple benefits of PPIE on study quality and efficiency. Studies that incorporate the patient voice in design are more likely to succeed in gaining funding.

Support offered by the PPIE group

Our PPIE group at the [your site or affiliation] is able to support all aspects of study design, conduct and dissemination, and welcomes requests from all. Our recommendation is to involve the PPIE group as early as possible in order to maximize benefits.

The PPIE group can:

- Advise on research priorities to help identify the most relevant health topics, populations & interventions to study from the perspectives of patients and the public.
- Advise on the design of study protocols to help improve study design by making it more feasible, acceptable and relevant to the patients and the public. This can include advice on participant selection, intervention protocols and outcome measures.

- Contribute to the ethical review of studies to ensure that the proposed research is acceptable to patients and the public prior to formal institutional ethics review.
- Safeguard patient and participant rights to ensure no harm is done during research.
- Support the development of study materials such as participant information sheets, informed consent forms and recruitment leaflets, posters and social media content.
- Support the conduct and implementation of studies by improving the recruitment strategy, informed consent processes, administration of interventions, data collection and follow-up.
- Participate in data analysis to ensure the patient perspective is incorporated in the interpretation of the results of the study.
- Support the dissemination of results to the public by providing advice and feedback on dissemination strategies and materials (e.g. posters, infographics, video, articles, presentations, workshops, public events, social media content).

Please note that this list is not exhaustive and that our group is willing to provide the patient and public voice and support to any aspect of health research.

Request for Input from the PPIE Group

Complete all sections of the form below and submit it electronically via email to [email address] to request input from our PPIE group. The form will be pre-screened for quality and completeness by coordinators.

Following submission, the PPIE group will review the submission within two weeks and ask for further details as necessary. If the PPIE group thinks they can offer support (decided by a majority vote), a member of the research team will be invited to attend the next in-person PPIE group meeting to discuss the study and request. Further steps will be mutually agreed.

In the unlikely event that the PPIE group is unable to offer support, this will be confirmed in writing with a reason to the person who made the request. If applicable, the PPIE group will provide written suggestions for the study or an invitation to resubmit with suggested changes.

The advice and support provided by our PPIE group is independent and made based on the principles and values guiding our group.

Please do not hesitate to contact us at [email address] or via phone [phone number] if you have any feedback or questions about the process of requesting input from our PPIE group. All details provided to the PPIE group will remain confidential and will not be shared outside of the PPIE group.

We look forward to receiving your request and collaborating on high-quality patient-centered research together!

Request Form: PPIE Input in Research

Study Information

Study Title

Principal Investigator/Lead Clinician

Study Team Contact Information

Research focus
The discipline or field (e.g. health services research, public health, critical care, mental health, oncology, etc)

Lay Summary of the Study
Provide a summary of <250 words

Purpose & Scope PPIE Engagement

Identify what support you are requesting from the PPIE group by selecting all the categories that apply (see section titled 'Support offered by the PPIE group' above)

Advice on research priorities	
Advice on the design of the study protocol	
Contribution to the ethical review of the study	
Support in the development of study materials	
Support in the conduct and implementation of the study	

Participation in data analysis	
Support in the dissemination of results to the public	
Support in making data or therapeutics available to patients and participants	
Other (please specify):	

Detail

Provide further detail about the type of support you are requesting from the PPIE group: specific advice you are seeking, any processes or documents you want the PPIE group to review, stages of involvement of the PPIE group in the research etc.

Desired Outcome

Describe how input from the PPIE group will enhance the study. What will demonstrate success of PPIE in the study?

Population of Interest

Highlight the specific population or groups of individuals you are seeking to engage (if applicable)

Timing

Specify when input from the PPIE group will be needed, over what time period and what the expected time commitment for our PPIE group members would be. Specify if PPIE members are being asked to attend any meetings associated with the study - If yes, provide frequency, format and tentative dates and times

Compensation & Recognition

Compensation

Outline any compensation provided to PPIE members for their contribution.

Recognition

Outline any recognition provided to PPIE members for their contribution. At a minimum, we expect the PPIE group members to be acknowledged in all resulting presentations and publications.

Additional Information

Please provide any further information relevant to this request (if applicable)

By adding my name and date below electronically, I confirm that I have reviewed and completed the form accurately

Name:
Date:

Appendix P: Master Log Template

The aim of the Master Log is to enable the recording of all PPIE related activities and outputs in a standardised way. Maintaining an accurate and complete log about your PPIE initiative will help you in reporting funders, writing manuscripts, publicising your initiative and applying to future grants. Each tab in the Master Log aims to capture different types of PPIE related activities:

- Group Meetings: Record all meetings and training sessions you hold with your PPIE group
- Recruitment: List all of the individuals you have approached to be members in your PPIE group, including the outcome of discussions and contact details, which may be used later to contact individuals again
- Collaborators: Document all discussions you've had with external collaborators and partners about your PPIE initiative
- Marketing: Outline all social media and marketing efforts of your PPIE group, including what audiences have been reached
- Events: Detail all public events you have carried out, including the number and characteristics of attendees
- Academic: Tabulate all conference posters, oral presentations and publications resulting from your PPIE initiative
- Impact: Maintain a log of all the feedback and input you have sought from your PPIE group, the outcomes of the input given and when you fed back the impact to your PPIE members

A template of the Master Log (Google Sheets / Excel File) can be downloaded from here.

PATIENT & PUBLIC INVOLVEMENT AND ENGAGEMENT GROUP

PPIE

ZIAUDDIN UNIVERSITY