

The Seven Deadly Sins to Avoid When Working with the Public and Patients

By Yesmin Begum 2024

A warm welcome to my blog exploring ethical practices when working with the public and patients—specifically, The Seven Deadly Sins to Avoid in this delicate area that is fundamental to research practices. My blog sheds light on pivotal considerations for engaging Public Patient Involvement (PPI) contributors with respect, transparency, and genuine collaboration.

Assuming all PPIs think similarly

Do not assume that all PPI contributors think and share the same perspectives, needs, or preferences because they all fall into one category. Rather, acknowledge and appreciate the diversity within the PPI group, ensuring inclusivity and tailored engagement.

Remuneration on time, every time

Do not assume that all PPIs will do tasks for free because they have nothing better to do. Do not think that all PPIs like to be paid the same way, either. Also, do not assume all PPIs want payment. The best way to address this area is by asking, it is as simple as that. This way there is mutual satisfaction and transparency. And definitely, don't forget to remunerate your PPIs on time, every time, without a chase! This will build trust and a strong relationship.

Bare Minimum

Do not involve PPI contributors *only* as a formality, without genuinely integrating their insights into the research. They KNOW when it is tokenistic. Therefore, make the experience authentic and collaborate by valuing and implementing PPI contributions throughout all stages of the research process.

Delayed Engagement

Engaging PPI contributors later in the research process can mean that you are losing out on valuable and relevant content. Therefore, involve PPI contributors in the early stages of the research, and get their input on the methodology, too.

Keeping PPIs Updated

Not providing feedback or updating PPI contributors can be detrimental to your project and break the trust that is being built. To build a strong collaborative team, everyone needs to be updated throughout, and that includes the PPIs. Please, always communicate with your PPI contributors and explain to them what is happening in the project so that they feel involved and valued.

Lack of Training and Support

Do not assume that PPI contributors have the necessary skills or knowledge. Therefore, always offer adequate training or support. When you invest in your PPIs, you get a greater return on the quality of their contributions. Also, provide resources, and ongoing support to empower PPI contributors to actively participate. For example, internet costs, printing costs (if they have to print resources at home), etc.

Failure to Recognize Expertise

Do not disregard the unique expertise that PPI contributors bring as unique individuals. Acknowledge and respect the lived experiences and knowledge of PPI contributors as essential components of the research process.

Approach PPI with an open heart and a commitment to continuous improvement.