

ZIAUDDIN UNIVERSITY



SECOND
EDITION

**PATIENT & PUBLIC INVOLVEMENT
AND ENGAGEMENT GROUP (PPIE)**

NEWSLETTER

NEWS

WELCOME TO THE PPIE NEWSLETTER!



Our coordinators and public members have been very busy in the first part of 2024. We are excited to share our progress with you in this second quarterly newsletter. Read on to find out more about our current work and upcoming public events, and make sure to read the inspirational message from one of our public members at the end.



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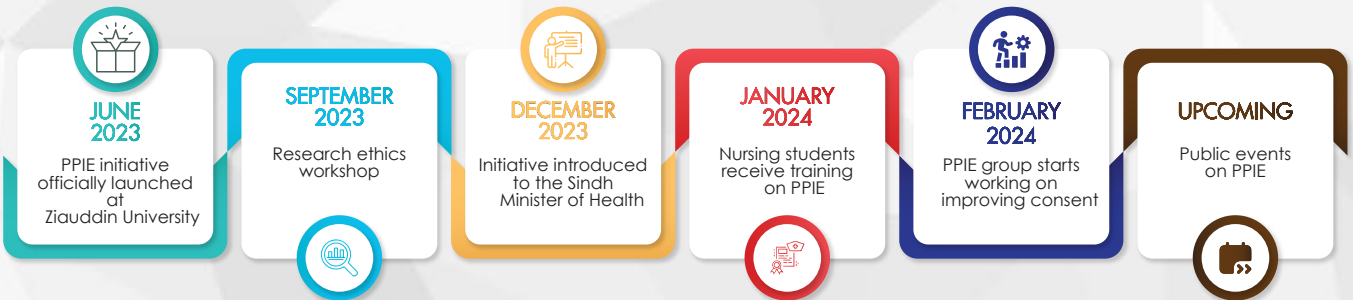
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OUR JOURNEY



OUR INITIATIVE

Our PPIE initiative is the first collaboration in Pakistan, aiming to make clinical trials more relevant and beneficial to the community in Karachi. We have learned many valuable lessons throughout our experiences of setting up this new initiative and want to share them with others to help them start their own involvement and engagement initiatives. Watch the recording of one of our coordinators, Arishay Hussaini, presenting key lessons learned from the first six months of our work on the PPIE website: <https://zu.edu.pk/ppie/>



NEWS

OUR PRIORITIES

The current priority of our PPIE group is to improve the informed consent process for the REMAP-CAP trial. This international trial is active in several intensive care units in Pakistan and is trying to find the best treatments for chest infections due to COVID-19. Our PPIE group is in the process of making recommendations on how to make the informed consent form for REMAP-CAP more relevant and easily understandable for patients in Dr. Ziauddin Hospital.



OUR RECENT EVENTS & ACTIVITIES

1. Ethics Workshop at CBEC-SIUT

Our PPIE group benefited from the expertise of the Centre of Biomedical Ethics and Culture (CBEC) at SIUT during a research ethics workshop



2. Presentations Across The World

We shared our story in India, Nepal and at international meetings to inspire others to start their patient engagement activities



3. Video Explaining PPIE

Have you seen our video explaining PPIE in Urdu? Check it out on our website!



OTHER EVENTS

9th November 2023:

Presentation to students at the Ziauddin Faculty of Nursing & Midwifery about PPIE.

10th December 2023:

The PPIE initiative was presented to the Minister of Health for Sindh.

19th January 2024:

Ten nursing students received PPIE training from our coordinator.

24th February 2024:

Informed consent training workshop for PPIE group members.



OUR NEXT STEPS

We have plans to arrange public events to meet as many community members as possible and exchange ideas about the best ways to involve patients in research. What kind of events would you like to attend? Do you have any ideas or suggestions for activities or presentation topics? Email us at ppie@zu.edu.pk



OPEN HOUSE EVENT

Join us on
May 20th, 2024 at 12 pm OR 6 pm

for an open house event at Ziauddin University's Clinical Trials Unit, celebrating International Clinical Trials Day! Discover the world of Clinical Trials, learn the vital role you can play and get a glimpse into what it really means to join a clinical trial.

See you there!

20TH JULY, 2024 MARK THE DATE!

Another thrilling event on patient and public engagement is coming soon! Join us to uncover our journey and the progress we've made together.

MESSAGE FROM OUR PPIE GROUP

Our PPIE group is composed of several inspirational individuals working hard to improve research at Ziauddin for the benefit of patients and their families. We want to highlight their messages, stories and experiences in our newsletter. For our first PPIE group member message, Zahyd Shuja shares his reasons for joining our PPIE group.

"Participating in Patient and Public Participation and Engagement (PPIE) is more than just joining a group or committee. It is about actively contributing to the design of health services and policies that directly impact individuals and communities. There are several compelling reasons why I wanted to join the PPIE effort. I believe in the power of inclusivity and collaboration in healthcare decision-making. PPIE provides patients, caregivers, and community members a platform to share diverse perspectives, lived experiences, and unique needs. Actively involving these stakeholders in the healthcare delivery process can ensure that services are more responsive, accessible, and patient-centred. I am personally passionate about equitable access and outcomes in health care. PPIE's work plays a critical role in closing disparities and promoting health equity by amplifying the voices of marginalised and underrepresented populations. By actively engaging with these communities, we can identify barriers to health care, advocate for policy change, and work towards building an inclusive health system. Additionally, by joining PPIE, you can contribute to meaningful change and innovation in healthcare. By collaborating with health professionals, researchers, and policymakers, we can provide valuable insights and feedback that influence decision-making, improve service delivery, and drive quality improvement initiatives. As part of PPIE, you can have a measurable impact on health practices and outcomes, including participating in focus groups, co-designing interventions, and evaluating health programmes. Finally, I would like to state that my main motivation for participating in PPIE is because it aligns with my values, passions, and aspirations. I can help shape a more just, inclusive, and patient-centered healthcare system while fostering personal growth and development. My view:

PPIE is more than just a promise. This is an opportunity to make a meaningful difference in the lives of individuals and communities, and I am excited to be a part of this important work."