

ZIAUDDIN UNIVERSITY



PATIENT & PUBLIC INVOLVEMENT AND ENGAGEMENT GROUP (PPIE)

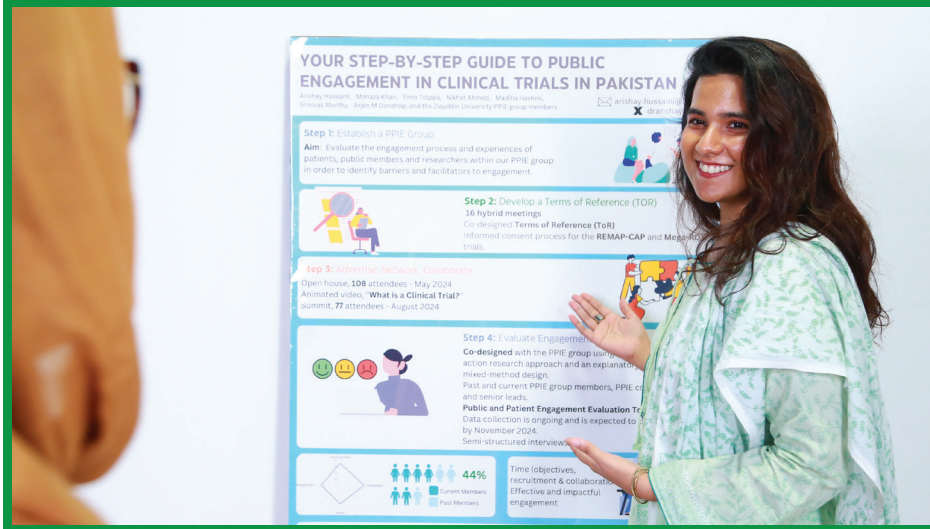
THIRD
EDITION



NEWSLETTER

NEWS

WELCOME TO THE PPIE NEWSLETTER CELEBRATING A SUCCESSFUL 2024!



Our coordinators and public members have been very busy since the last newsletter one year ago. In this special edition, we celebrate the accomplishments of the PPIE initiative in 2024. Read on to find out about two public events in Karachi, our first academic publication and an educational video we co-produced on clinical trials in Urdu, Sindhi and Pashto. Our PPIE group member has written a beautiful reflection about their most significant experience in 2024 at the end of the newsletter - Be sure to check it out.

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Timo Tolppa

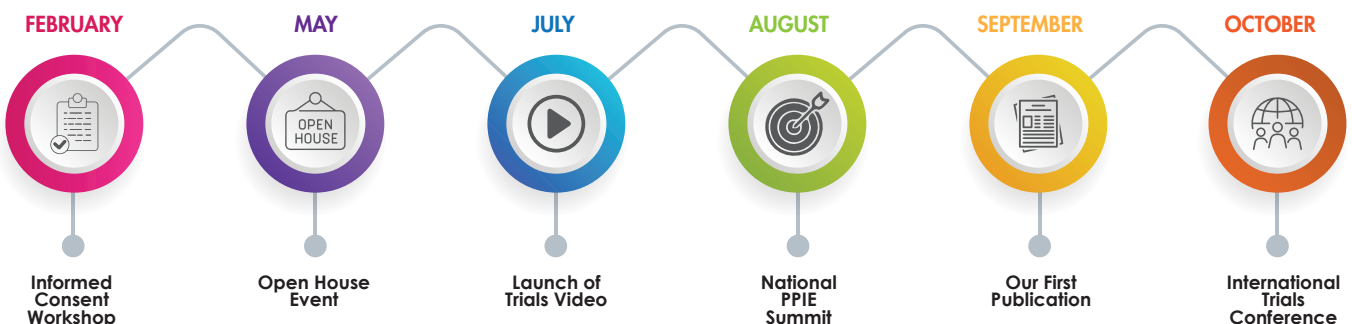
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OUR JOURNEY: 2024



OPEN HOUSE EVENT

On 20 May, the doors of our Clinical Trials Unit were opened to the public to celebrate International Clinical Trials Day. Members of the local community had a chance to hear about current trials, patient safety in research as well as the role of public engagement. Over 100 members of the community attended the event, of whom 80% had never heard about trials. Attendees expressed huge enthusiasm for learning more, supporting local trials and spreading the word to their fellow community members.



NEWS

NATIONAL PPIE SUMMIT

On 17 August, the first ever National PPIE Summit was held at Ziauddin University to promote awareness of patient engagement. The event featured presentations on various aspects of PPIE and concluded with a Q&A with an exciting panel comprising of Prof Saeed Hamid (Director CTU, Aga Khan University Hospital), Dr Zulfiqar (Director ORIC, Ziauddin University), Mr Adnan (PPIE member, Ziauddin University), and Dr Rakhshi Memon (PhD Bioethics, Pakistan Institute of Living



and Learning). The Summit attracted online and in-person attendees from four continents, and national news coverage.




OUR FIRST PUBLICATION

Our story of establishing the first ever PPIE group for clinical trials in Pakistan was published in the international 'Research Involvement and Engagement' journal. The article is free to access and includes a lay summary as well as a Urdu video summarising the key points.



Establishment of a patient and public involvement and engagement group to support clinical trials in Pakistan: Initial lessons learned

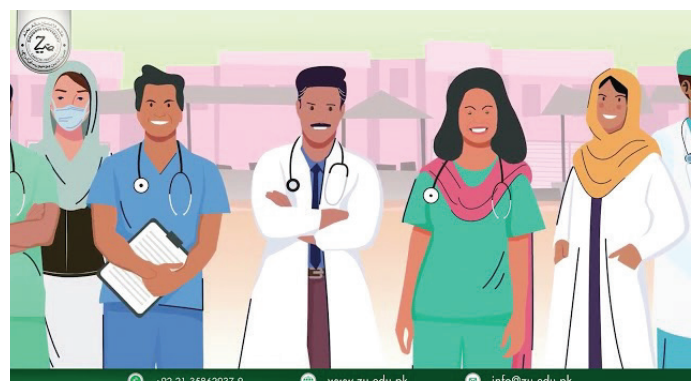
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Research Involvement and Engagement 10, Article number: 98 (2024) | [Cite this article](#)

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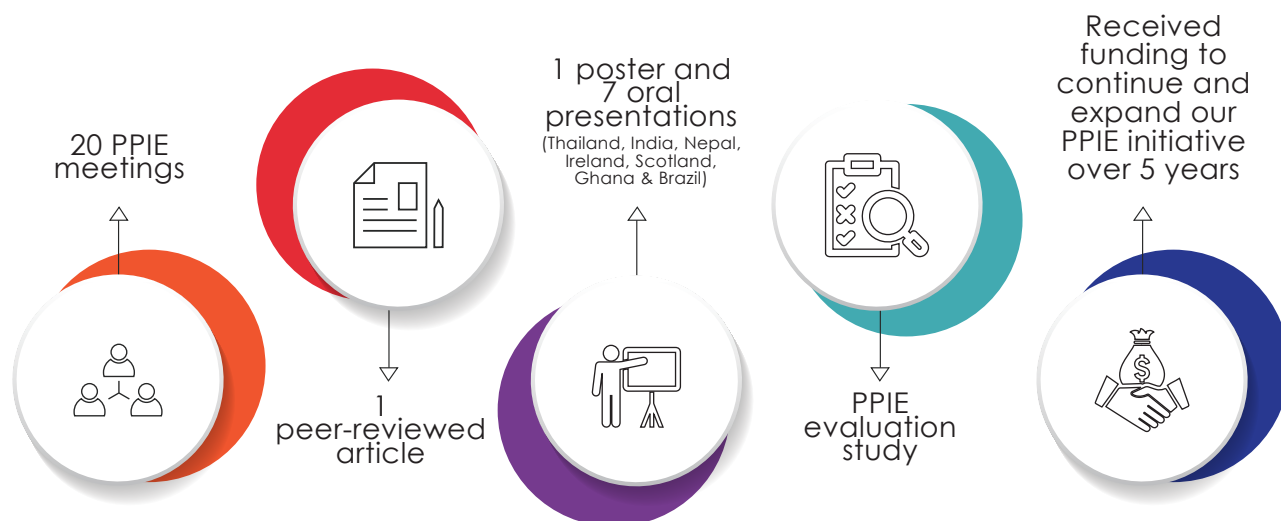
VIDEO: WHAT IS A CLINICAL TRIAL?

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NEWS

CELEBRATING THE ACCOMPLISHMENTS OF THE PPIE INITIATIVE IN 2024



PPIE MEMBER HIGHLIGHT: 2024

Our PPIE group members are an inspirational group of people working hard to improve research at Ziauddin for the benefit of patients and their families. Here we highlight their messages, stories and experiences. In this edition, Saima Saleem eloquently shares her experience and reflections after meeting PPIE collaborators in Australia.

"A crisp morning greeted me as I settled into my favorite people-watching spot, Flinders Street Station. The aroma of freshly brewed coffee from the small stall was the only comforting scent in the chilly air.

Flinders Street Station, a bustling hub of activity, embodied the vibrant diversity of Melbourne. From the elderly Chinese woman in her wheelchair, accompanied by her attentive grandson, to the Bengali immigrant holding his newborn baby and seeking directions to Alfred Hospital, life unfolded in all its forms and shapes. This diverse tapestry underscored the need for intentional and culturally sensitive healthcare decisions. A one-size-fits-all approach is simply ineffective, both in my homeland of Pakistan and everywhere else in the world.

My visit to the Monash University Public Health and Preventive Medicine Center was a pivotal moment, where I encountered the pioneering spirit of patient advocacy and the challenges of bridging cultural divides in healthcare.

My meeting with Jane Parker, Project Manager of REMAP-CAP, and Anne McKenzie, a renowned patient advocate, was a highlight of my visit. Their insights into patient rights, informed consent, and the importance of clear communication resonated deeply. Anne's unwavering commitment to empowering patients was truly inspiring. Tony

Trapani who is the research manager, also discussed in detail about the challenges they face in communicating research objective to participants. During a subsequent visit, I had the privilege of meeting Associate Professor Aidan Burrell, Intensivist at Alfred Hospital, Australia. His expertise in intensive care and research further enriched my understanding of the complexities of healthcare.



The creation of a culturally sensitive animation is a valuable tool for helping patients and caregivers understand healthcare decisions and choices. It was motivating to know that the work of the PPIE group in Pakistan in this regard was considered commendable. By visually communicating complex information in a culturally relevant manner, we can empower individuals to make informed decisions about their health. The fact that the animation was further translated into local languages is highly appreciated.

My journey to Melbourne underscored the importance of cultural sensitivity, patient advocacy, and innovative communication strategies in healthcare for which I am really grateful to Dr. Arishay Hussaini, and Timo Tolppa the lead in PPIE Pakistan to make it all possible. The lessons learned from this experience will undoubtedly guide my future endeavors as I strive to create a more inclusive and equitable healthcare system."