

ZIAUDDIN UNIVERSITY



PATIENT & PUBLIC INVOLVEMENT AND ENGAGEMENT GROUP (PPIE)



EDITORIAL BOARD

EDITOR IN CHIEF

Timo Tolppa

EDITORS

Madiha Hashmi
Nikhat Ahmed Siddiqui
Arishay Hussaini
Wardah Khalid

GRAPHIC DESIGNER

Muhammad Ashir Umer

NEWSLETTER

SIXTH EDITION

NEWS

MESSAGE FROM EDITOR

This quarter has been a turning point in our journey. Our team organised a gathering that felt like the beginning of a movement. Participants from across Pakistan arrived with ideas and the shared belief that research should reflect the voices of the communities it aims to serve. We are delighted to take you through the story of that day.

WELCOME TO THE PPIE NEWSLETTER

CELEBRATING OUR SUMMIT'S SUCCESS!

In this edition, we are proud to highlight our 2nd National PPIE Summit 2025 – Awaz se Aaghaz, held on 1st November at Avari Towers, Karachi. The success of the Summit led to the formation of an Interim Council that will guide the development of the Terms of Reference for the National PPIE network of Pakistan. Read on to explore the key moments, national participation, and exciting next steps.



PARTICIPATING INSTITUTIONS

OUTSIDE KARACHI



National University of
Medical Sciences, Rawalpindi



Pakistan Kidney and Liver
Institute and Research
Centre, Lahore



Shaukat Khanum Memorial
Cancer Hospital and Research
Centre, Lahore



Northwest General Hospital
and Research Centre,
Peshawar



Chughtai Institute of
Pathology, Lahore



Shaikh Khalifa Bin
Zayed Al-Nahyan Medical and
Dental College, Lahore



Shalamar Institute of
Health Sciences, Lahore



Drug Regulatory Authority
of Pakistan, Islamabad

KARACHI



Aga Khan
University Hospital



Indus Hospital and
Health Network



Sindh Infectious Diseases
Hospital and Research Centre
(Dow University of Health Sciences)



Sindh Institute of Advanced
Endoscopy and
Gastroenterology

NEWS

MEET OUR KEYNOTE SPEAKER



Dr Baber Saeed Khan, Director of the Clinical Trials Unit (CTU) at the National University of Medical Sciences (NUMS) and Founder of the ACRP Ambassadors Club Pakistan.

Dr Baber spoke about the importance of PPIE in shaping research in Pakistan. He reminded us that involvement is not a formality but the key to ensuring that research truly reflects the lives and cultural realities of our people - nothing about us, without us.

"Building a systematic culture of involvement is not merely a procedural step; it is the very foundation for ensuring transparency, fostering trust, and achieving outcomes that accurately reflect the real-world needs and cultural context of our people."

MEET OUR INTERNATIONAL GUESTS



PROFESSOR PHAIK YEONG CHEAH

The head of the Bioethics and Engagement team at the Mahidol Oxford Tropical Medicine Research Unit (MORU) in Thailand. She is a Professor of Global Health and Bioethics at the University of Oxford.



MR RICHARD STEPHENS

Co-Editor-in-Chief of the Journal of Research Involvement and Engagement and CONCORD-Lancet Global Commissioner on Cancer, he is also a two-time cancer survivor and a strong advocate for meaningful patient involvement in research and policy.

NEWS

OUR TEAM'S RADIO DEBUT

In the week leading up to the Summit, our highly motivated PPIE Coordinators went above and beyond to spread our message, even reaching out to radio platforms. Dr Arishay Hussaini and Dr Wardah Khalid introduced our PPIE work to the general public, sharing our motto, and the purpose behind this Summit. Their energy set the tone for what was to come.

Listen to the full conversation of the ZU FM 98.2 show on our website here



MORNING WORKSHOP: THE HEART OF THE SUMMIT

The Summit morning began with 39 enthusiastic participants from across Pakistan and the following institutions presented their ongoing PPIE work:



Shaukat Khanum Memorial Cancer Hospital and Research Centre, Lahore (SKMCH&RC)



Pakistan Kidney and Liver Institute and Research Centre, Lahore (PKLI&RC)



Northwest General Hospital & Research Centre, Peshawar (NWGH&RC)

Participants were divided into smaller groups to imagine the future of PPIE in Pakistan! Through guided discussions, the groups explored the Mission, Activities, and Governance for a potential PPIE Network. Junior or senior, everyone spoke openly, shared challenges, and debated what meaningful involvement should look like in our context. By the end, each group elected a representative to join an Interim Council.

NEWS

MEET OUR INTERIM COUNCIL

Our Interim Council has been entrusted with developing the Terms of Reference for the upcoming National PPIE Network as it moves closer to becoming a reality.



- Prof. Ayesha Humayun (Shaikh Khalifa Bin Zayed Al-Nahyan Medical and Dental College, Lahore)
- Dr. Saniya Rehman (Sindh Institute of Advanced Endoscopy and Gastroenterology, Karachi)
- Dr. Saima Faisal (Shaukat Khanum Memorial Cancer Hospital and Research Centre, Lahore)
- Dr. Saadia Birjees (Aga Khan University Hospital, Karachi)
- Ms. Sadia Hassan (Pakistan Kidney and Liver Institute and Research Center, Lahore)
- Dr. Tahira Islam (Shaukat Khanum Memorial Cancer Hospital and Research Centre, Lahore)

AFTERNOON PUBLIC EVENT

This hybrid event was joined by over 20 international guests online and many more in-person. Collaborating institutions were invited to submit PPIE proposals prior to the Summit and the strongest four were selected to present based on feasibility, quality of proposed engagement activities and potential for impact.



Chughtai Institute of Pathology, Lahore



Shalamar Institute of Health Sciences, Lahore



Shaikh Zayed Postgraduate Medical Institute, Lahore



Sindh Institute of Advanced Endoscopy and Gastroenterology, Karachi

NEWS

MEET OUR PANELISTS

The final segment of the event was a panel discussion, where six experts engaged in a meaningful dialogue, addressing the challenges institutions face in involving patients in research in Pakistan and exploring possible solutions.



Mr. Zahyd Shuja (ZU PPIE team member), Dr. Farah Asif, Dr. Baber Saeed Khan, Mr. Richard Stephens, Mr. Hanif Ullah, Prof. Phaikh Yeong, Dr. Arishay Hussaini.

The full panel discussion is available on our website. Scan the QR code below to tune in and enjoy the insightful conversation!

MAIN HIGHLIGHTS:

OUR VOICE REACHED NATIONAL BODIES!

Through this Summit, we opened meaningful channels of communication with the National Institute of Health (NIH), Drug Regulatory Authority of Pakistan (DRAP) and National Bioethics Committee (NBC). Moving forward, we hope to inspire stronger collaboration and advance patient-centred research in Pakistan.



**SCAN FOR
WEBSITE**

To stay updated and learn more about all the exciting work our team is doing, visit our website and explore our latest initiatives. <https://zu.edu.pk/ccrg/ppie/>