

Patient Academy for Innovation and Research

ANNUAL REPORT 2023













www.pairacademy.org

About Us

The Patient Academy for Innovation and Research (PAIR) is an organization committed to advancing patient-centric healthcare globally by focusing on developing and sustaining the capabilities of patients worldwide and empowering them to actively participate in their healthcare journey. Our mission is to enhance their ability to engage strategically with health systems, and through evidence-based expertise, PAIR equips individuals to not only manage their health effectively but also share invaluable insights with others facing similar conditions.

Embracing innovation and research, PAIR envisions a future where patients play a pivotal role in shaping a more informed and collaborative healthcare landscape.

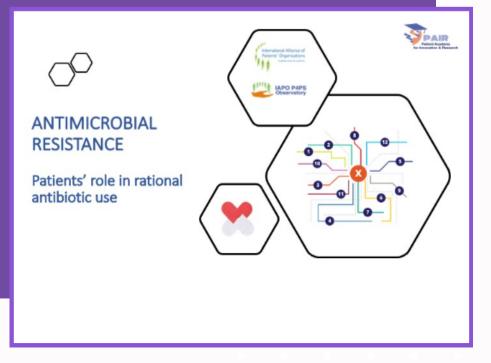
Our Mission

In the emerging digital world, patients with chronic conditions increasingly want to be empowered into becoming expertpatients in order to participate in and understand how to navigate their healthcare system as equal partners. However, many are not knowledgeable and skilled enough to do so right now. To add to that, the rise and speed of the use of innovative clinical and therapeutic approaches and medical technologies has made the healthcare industry a very complex entity.

Our mission is to empower the patients so that they can impact sustainability of healthcare systems and improve the safety, quality, accessibility, acceptability, affordability and equity within their healthcare systems.



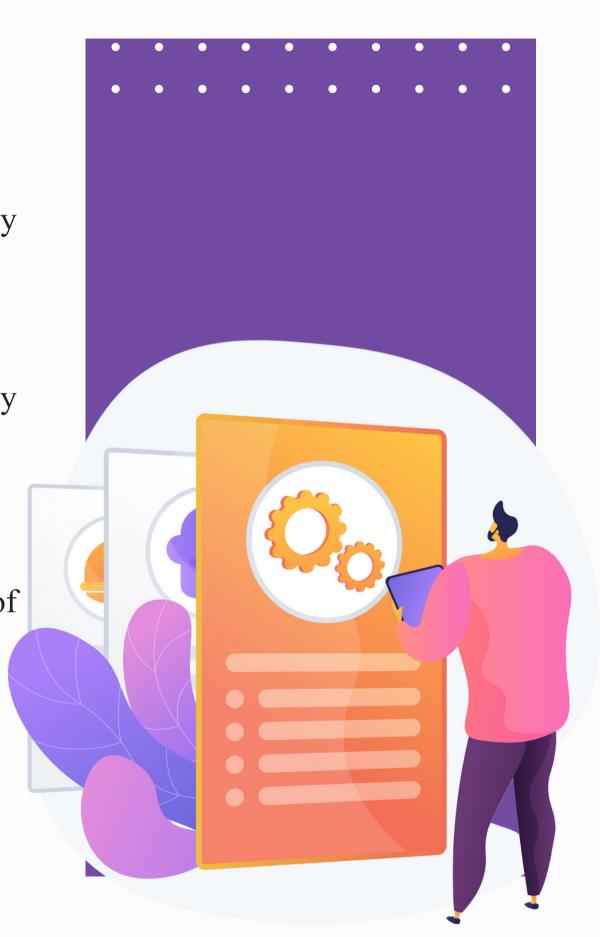




Our Principles

Conceptually, PAIR Academy is based on six adult learning principles, that largely support the learning process and improve knowledge uptake:

- Participants' autonomy and self-direction are valuable contributors to the quality of the learning experience.
- Participants' perspectives play an important role in the learning process.
- Participants' accumulated life experiences and knowledge are inseparable part of the learning journey.
- Participants join the process as goal-oriented and practical.
- Participants' relevancy-oriented attitude adds value to the learning curve.
- Participants' diversity requires tailor-made approach to learning.



Message from the Director

Dear esteemed stakeholders,

It is with great pleasure that I share with you our 2023 Annual Report, a testament to the continued growth and impact of PAIR Academy in advancing our mission of embedding patient voice for quality healthcare.

Over the past year, our dedicated team at PAIR has once again demonstrated unwavering commitment, working tirelessly to bring forth innovative and effective solutions for patients and caregivers. The positive impact we've achieved reaffirms our dedication to improving healthcare outcomes. In alignment with our commitment to social responsibility, we have persistently worked towards raising awareness and ensuring equitable access to healthcare, particularly for marginalized communities.

Our steadfast dedication to providing the highest level of care and service to our patients and communities remains unchanged. As we move forward, we are excited about incorporating more of the patient voice and lived experiences, fostering a more inclusive and patient-centric approach in the years to come.

Thank you for your ongoing support, and I look forward to another year of shared successes and positive impact.



Dr. RATNA DEVI

Overview

PAIR deals with mainly 5 areas of focus in the healthcare sector as stated:



RESEARCH

Evidence based reports
On site investigations
Market research





03





ADVISORY

Creation of patient support groups
Policy analysis

CONVENING

Asia-Pacific network
Workshops/ webinars
Multistakeholder summits





04

05



PROJECT MANAGEMENT

Execution of customized projects as per the clients' needs

Ongoing Projects

Project 01

Patients for Patient Safety Network-Asia Pacific (PFPSN-AP)

Project 02

Hypertension Advocacy Project India (HAPI)

Project 03

Women with Wings (WwW)

Project 04

Rare-Disease Project- Together for RARE

Project 05

International Patient Summit



PATIENTS FOR

PATIENT SAFETY

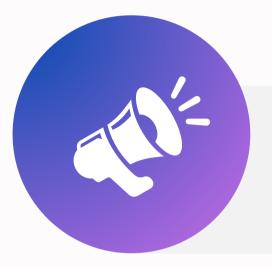
NETWORK

ASIA PACIFIC



4th Activity

Hold a poster making competition



3rd Activity

Run campaign on AMR awareness week



2nd Activity

Coorganise The 2nd Medication Safety Conference





1st Activity

Organize webinars on World Patient Safety Day 2023 theme Patients for Patient Safety Network- Asia Pacific, a network of stakeholders, including patients and patient advocates focuses on making healthcare safer in the Asia-Pacific region by supporting Strategic Objective 4: Patient and Family Engagement of the Global Patient Safety Action Plan 2021–30.

In accordance with this, a series of 3 webinars were organized a month prior to the World Patient Safety Day 2023, to raise awareness on the theme "Engaging patients for patient safety".

On 12th December, during the 1st International Patient Summit, alongside a panel discussion on Asia Pacific Patient For Patient Safety Networks- "Building A Regional Patient Network To Achieve GPSAP 2021-30", a workshop with 40 participants from across India was held. The participants grouped into 5 groups, with the support of 5 facilitators, reviewed and finalized on the proposed consensus statement drafted by PAIR to accelerating GPSAP Strategic Objective-4 (CLICK HERE FOR WORKSHOP REPORT).

















MediSAFE Conference 2023

01

16 speakers with 5 international presence

02

9 diverse topics with 10+ panels

03

Interactive Sessions including Quiz and poster presentations

04

Representations from healthcare professionals, front line workers, researchers, and patient organizations

16th September 2023 9:00am - 6:00pm Altair Boutique Hotel, Saltlake Sector 5 Kolkata This year's theme **Engaging patients for Medication Safety** MediSAFEcon



Contact Details

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medisafecon2023@gmail.com





MediSAFEcon Medication Conference

16th September 2023 | Kolkata

Registration Fee

Virtual Offline

₹ 400/- (Student) ₹ 1000/- (Student)

₹ 500/- (Working Professional) ₹ 1500/- (Working Professional)

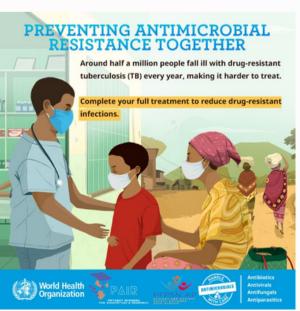
\$ 20/- (International Participants)

Anti Microbial Resistance Week

18th - 24th November 2023

Patient Academy for Innovation and Research, under its PFPSN-AP initiative, dedicated 7 days of the AMR awareness week in raising awareness on Anti-microbial resistance. Campaign materials were disseminated via social media channels on the rising concerns of AMR in linkage with the misuse or overuse of antibiotics.

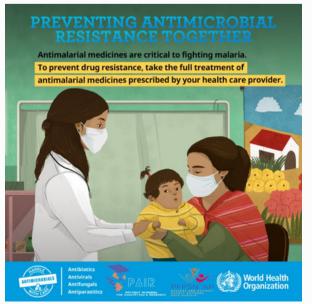














Poster Making Competition



Country - India

Country - India

Country - Thailand

PAIR organized an online poster making competition between 1st to 25th September, aimed at elevating awareness regarding patient safety.

The underlying rationale for this competition was to foster interactions between patient groups and disseminate information pertaining to patient empowerment within the healthcare system. By leveraging online platforms, the competition embraced a global reach, fostering diverse participation from various backgrounds in the Asia-Pacific region.

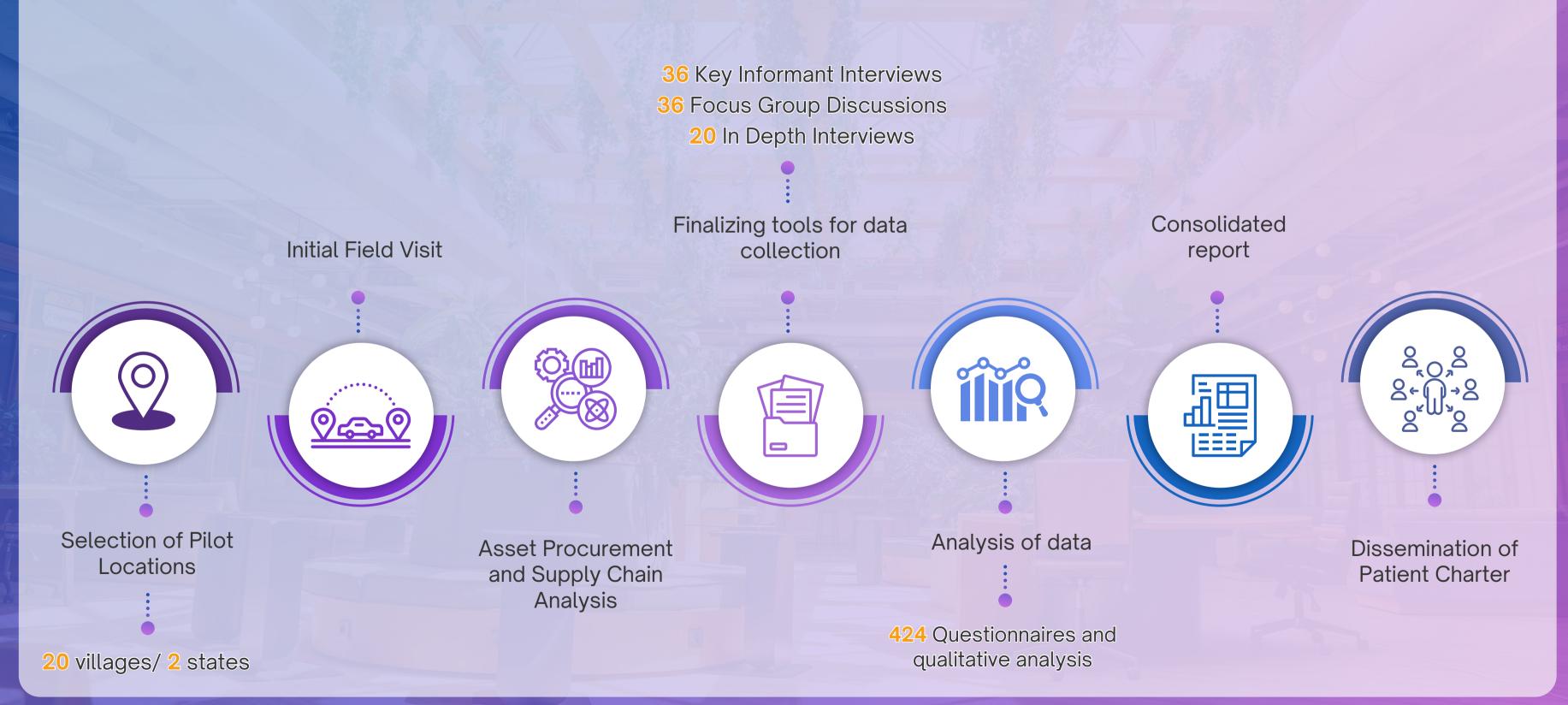
The winners of the competition were awarded with cash prizes intended to assist them in financing their own workshops to generate awareness on patient safety.

This initiative was a means to assure exponential spread of awareness amongst patients, caregivers and patient groups.



Hypertension Advocacy Project India

The project aimed at strengthening patient voices and integrating them at the policymaker level to create national networks of hypertension advocates, including individuals affected by stroke, CKD, and CVD, along with their caregivers. This project was executed between February - November 2023.



PROJECT OUTCOMES AND IMPACT

- 2 webinars with key experts and over 60 online attendees.
- 9 patient stories in text format, 3 video patient stories and 2 videos with key messages from patients.







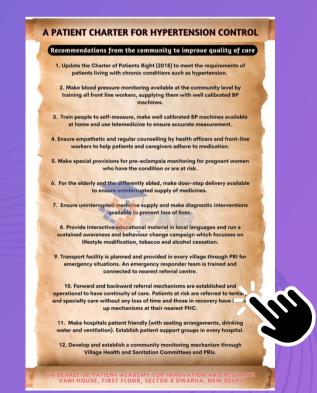
12 May 2023

04:00 PM - 05:00 PM



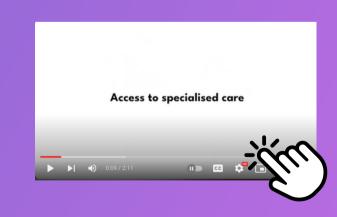
- Round table discussion with Members of Parliament
- Launch and dissemination of The Patient Charter























WOMEN WITH W WINGS

Women with Wings is an initiative of The Patient Academy for Innovation and Research dedicated to women's health by providing a safe and supportive space for women to come together to share their stories, discuss their experiences, and find help and understanding. In 2023, we focused on helping people suffering from Endometriosis, PCOS and Infertility



Goals and Objectives

- To create an **Endometriosis Patients Support Group** and platform to:
 - Raise awareness and draw attention to patient experiences & needs
 - Reduce stigma and change policy for access to early diagnosis and treatment
- To raise awareness on PCOS and Infertility with the help of expert sessions and roundtable discussions



6 "Endoruns" were organized in 5 different states to raise awareness regarding endometriosis

















r6 Focus group discussions, both online and in-person were held to empower women and share patient stories





An "Ask the expert session" on the Challenges of diagnosis and treatment of Endometriosis in India was organized to equip the women with the right knowledge regarding their health and the hurdles faced when struggling with endometriosis

ENDORUN INDIA 2023

DELHI I PUNE I HYDERABAD I KOLKATA I MUMBAI

NEWS & MEDIA











সরওমা নাভেশন গায়োজন Viman Na Phoenix Cit

Viman Nagar
Phoenix City Lane 1 was buzzing with energy and







PAIR Academy, Bayer launch EndoRun endometriosis awareness campaign Patient Academy for Innovation and Research (PAIR Academy) and Bayer launched the first phase of endometriosis awareness campaign EndoRun in Del...

Pune: EndoRun Raises Awareness About Endometriosis

Winan Nagar, 27th March 2023: Phoenix City Lane 1 witnessed a walk that aimed to
alse awareness about endometriosis, a medical condition that affects women's
eproductive health. Led by Mushboo Sharma, Project Lead of Women's Health at

Phoenics News (Mr. 2018)



Patient Academy for Innovation and Research with support from BAYER collaborates with local partners. Patient Academy for Innovation and Research with support from BAYER collaborates with local patients in said mass sements or Indooratiosis, through the Taroflux 42 million season in India are burdened with Indooratiosis Campaign... Bit Indoory May 14.



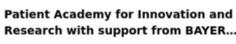




Patient Academy For Innovation And Research...

12th March 2023, Delhi : In...

menafn.com



42 million women in India are burdened with Endometriosis Campaign kicks •APN NEWS



Patient Academy for Innovation and Research with Support from.

Patient Academy for Innovation and...
2vodoindia.com



PATIENT ACADEMY FOR INNOVATION AND RESEARCH

educratsweb.com



Ms.Chetna Patnayak

I believe family support is crucial for anyone with any illness, I have been fortunate enough to have supportive family, although they lacked the knowledge of endometriosis, and it's not their fault, they heard, periods pain and heavy bleeding is normal.

I encourage all the young girls, women noticing painful periods and heavy bleeding to go for consultation and take a step towards breaking the stigma of normalizing periods pain.

The Endoruns garnered the presence of over 1300 people from across India, marking a significant milestone as the country's 1st Endorun Campaign.

A commendable 1 Million people reached through #EndoRun to raise awareness on endometriosis via Social Media, Print Media, Web News & Awareness Sessions

RARE DISEASE PROJECT- Together for RARE

An F 2 F Campaign for PSU/Corporate CSRs (Health Talk – Together for Rare) with the following objectives:

- Awareness about Rare Diseases and unmet needs of patients.
- Sensitizing Institutional donors to garner their support and aid RD patients by contributing to the crowdfunding platform and other mechanisms defined in the National Policy for Rare Diseases (NPRD).

Approach PSUs, Corporate CSR Organizations, (Institutional donors –IDs) to organize the health talk

Organise and lead the Health talk session

3

4

Sensitization meeting with the IDs to support the RD cause in line with National Policy for Rare Diseases (NPRD 2021)

Advocacy meetings with MOH, and other relevant ministries to seek their guidance and support

2023



at a glance

1st International Patient Summit

The inaugural 1st International Patient Summit (IPS) was convened on 11th – 12th December 2023, in New Delhi, India at The Radisson Blu Hotel.

The summit garnered a distinguished assembly of over 200 global participants, including government dignitaries, representatives from the World Health Organization, patient advocacy groups, and a diverse array of stakeholders, hailing from more than 10 countries worldwide both online and in person, to discuss the Summit theme 'Equitable healthcare: co-planning, co-designing and co-delivery' with the inclusion of patient voice and lived experiences.

Co-hosted by The Patient Academy for Innovation and Research (PAIR), DakshamA Health, The Heart to Heart Foundation, and The Philippine Alliance of Patient Organizations (PAPO), the summit featured a robust agenda comprising over 50 speaker sessions, interactive Q&A segments, and an immersive hands-on workshop, all designed to foster collaborative learning and knowledge exchange.







World Patient Safety Day 2023

The Director of PAIR Academy received an invitation from WHO Geneva to participate in the WHO Global Conference held on September 12 - 13, themed "Engaging Patients for Patient Safety." This event acknowledged the vital roles played by patients, families, and caregivers in ensuring healthcare safety.

CLICK HERE FOR DR.
RATNA'S SPEECH

CLICK HERE FOR DR. RATNA'S PRESENTATION

CLICK HERE TO ACCESS
FULL SESSION

Unite Annual Summit 2023

Dr. Ratna Devi engaged in a conversation with Mr. Neil Johnson, the Executive Director of Global Heart Hub, during the 3rd Annual Summit held in Barcelona, Spain. This gathering aimed to foster unity and collaboration among participants and served as a platform for the development of the first patient-led global Manifesto, orchestrated by the community, advocating for action on early detection and timely diagnosis of cardiovascular diseases. As a speaker at the summit, Dr. Ratna delivered insights on the topic "Getting the Basics Right Across CVD" and focused on the social determinants of health and environmental factors influencing cardiovascular diseases.



Our Publication

Journal of Healthcare Leadership

Dovepress

open access to scientific and medical resear-

Open Access Full Text Arti

REVIEW

Bridging the "Know-Do" Gaps in Five Non-Communicable Diseases Using a Common Framework Driven by Implementation Science

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Abstract: According to the United Nations High-Level Meeting 2018, five non-communicable diseases (NCDs) including cardiovascular diseases, chronic respiratory diseases, diabetes mellitus, cancer, and mental health conditions accounted for two-thirds of global deaths. These five NCDs share five common risk factors including tobacco use, unhealthy diets, physical inactivity, alcohol use, and air pollution. Low- and middle-income countries (LMICs) face larger burden of NCDs than high-income countries (HICs), due to differences in ecological, technological, socioeconomic and health system development. Based on high-level evidence albeit mainly from HICs, the burden caused by NCDs can be reduced by affordable medicines and best practices. However, "know-do" gaps, ie, gaps between what we know in science and what we do in practice, has limited the impact of these strategies, especially in LMICs. Implementation science advocates the use of robust methodologies to evaluate sustainable solutions in health, education and social care aimed at informing practice and policies. In this article, physician researchers with expertise in NCDs reviewed the common challenges shared by these five NCDs with different clinical courses. They explained the principles of implementation science and advocated the use of an evidence-based framework to implement solutions focusing on early detection, prevention and empowerment, supplemented by best practices in HICs and LMICs. These successful stories can be used to motivate policymakers, payors, providers, patients and public to co-design frameworks and implement context-relevant, multi-component, evidence-based practices. In pursuit of this goal, we propose partnership, leadership, and access to continuing care as the three pillars in developing roadmaps for addressing the multiple needs during the journey of a person with or at risk of these five NCDs. By transforming the ecosystem, raising awareness and aligning context-relevant practices and policies with ongoing evaluation, it is possible to make healthcare accessible, affordable and sustainable to reduce the burden of these five NCDs. Keywords: non-communicable diseases, know-do gaps, implementation science, evidence-based practices, healthcare policies

Introduction

The healthcare burden of five non-communicable diseases (NCDs) including atherosclerotic-cardiovascular diseases (ASCVD; eg ischemic heart disease [IHD], stroke, peripheral vascular disease), chronic respiratory diseases (CRDs; eg, chronic obstructive pulmonary disease [COPD] and asthma), diabetes mellitus, cancer, and mental health conditions is rising exponentially, especially in low- and middle-income countries (LMICs).^{1,2} In 2018, the

CLICK HERE



Journal of Healthcare Leadership 2023:15 103-119