DAKSHAMA HEALTH – CONSOLIDATED THREE-YEAR IMPACT REPORT (2022–2025)

Strengthening Patient Voice, Equity & Integrated Care in India

1. Executive Summary

Over the last three years, DakshamA Health has accelerated its role as a national leader in patient engagement, health systems strengthening and multi-stakeholder collaboration. This report captures major achievements from 2022–2025.

Strengthening Patient Voice, Equity & Integrated Care in India**

1. Executive Summary

Over the last three years, DakshamA Health has accelerated its role as a national leader in patient engagement, health systems strengthening and multi-stakeholder collaboration. Through its programs in **stroke**, **psoriasis**, **rare diseases**, **cancer advocacy**, **patient safety**, oncology, NCDs and **integrated NCD–communicable care**, the organisation has expanded its footprint across India and deepened its role in representing patient voices at national and global platforms.

This consolidated report captures DakshamA's major achievements from 2022–2025, drawing from its flagship initiatives, research collaborations, community engagement efforts, and policy contributions. These years have marked:

- Stronger **patient-led networks** across disease areas
- Expansion of **evidence-based advocacy**
- Integration of the **patient voice** into policy, research and implementation
- Growth in **national and international presence**
- Launch of new platforms like the **International Patient Summit** and **STEP-UP Fellowship**
- Multi-sector partnerships to advance equity, safety and universal access

Together, these efforts reflect DakshamA's mission: strengthening patient knowledge, capacity and voice to build a more inclusive, equitable and people-centred health system.

2. About DakshamA Health

Dakshayani & Amaravati Health and Education (DakshamA Health) is a registered nonprofit dedicated to improving access, safety and quality of care. Established in 2012, it aims to integrate the lived experiences of patients and caregivers into national health agendas, policy frameworks, research, and clinical care pathways.

Vision:
A world where people live healthy and disease-free lives through informed choices, in an environment of equity and access.

Mission:
To empower patients and caregivers with knowledge, tools, networks and platforms that enable them to meaningfully engage in health decisions and advocate for systemic change.

Core Pillars of Work:

- **Information:** Accessible, structured resources on disease management, innovation and safe care
- **Capacity:** Competency-building for patient leaders, communities, and stakeholders
- **Research:** Needs assessments, gap analyses, evidence generation
- **Partnerships:** Cross-sector collaborations with medical societies, policymakers, academia, NGOs
- **Advocacy:** National and regional advocacy rooted in lived experience

3. Three-Year Strategic Themes & Focus Areas

Across 2022–2025, DakshamA's work advanced five strategic themes:

1. Building Patient Leadership Ecosystems

Strengthening patient advocates through multi-disease networks: stroke survivors, psoriasis patients, rare disease communities, cancer patients, caregivers and youth fellows.

2. Expanding Influence in Policy

Active participation in:

- National Rare Disease Policy deliberations
- WHO NCD Labs Steering Committee
- Global Rare Disease Networks (CGN4D)
- WHO Patient Safety networks

- National patient safety expert groups
- National TB–HIV–NCD integration dialogues

3. Enhancing Research and Evidence Generation

Robust needs assessments for:

- Atopic Dermatitis
- Psoriasis (PRPD)
- Stroke awareness and access gaps
- Integration of HIV/TB/NCD programs
- Patient-reported experiences and pathways
- Publications in peer reviewed journals

4. Strengthening Engagement Across Disease Areas

Programmatic growth in:

- Stroke Support Alliance
- Community of Psoriasis Supporters (COPS)
- ATTR-CM patient support
- Cancer patient education
- Rare disease roundtables and capacity building
- NCD programs

5. Mainstreaming Patient Safety & Integrated Care

Leading dialogues on:

- WHO Global Patient Safety Action Plan
- Patient & Family engagement in safety
- Integrated care models across HIV, TB & NCDs
- Community-led monitoring

4. Key Programmatic Impact (2022–2025)

A. Stroke Support Alliance (National Programme)

- 20+ webinars, 16 survivor stories, short films and educational podcasts
- Multi-lingual IEC materials including 15 pamphlets and a national stroke booklet
- National and regional roundtables leading to updated Stroke Guidelines 2019 revision inputs
- Advocacy for inclusion of neurology packages in Ayushman Bharat
- Digital assets: website, WhatsApp groups, social media channels
- Scholarships for stroke survivors supporting skills and livelihood enhancement

B. Psoriasis & Rare Psoriatic Disorders (COPS – 2022)

- Formation of PRPD patient group; 5 patient advocates trained
- 50+ patients in WhatsApp communities; 232+ on Facebook
- 7 webinars, 9 patient stories, dietary and mental health sessions
- Needs assessment of dermatologists across India
- Development of IEC materials, videos and annual newsletter
- Advocacy with IADVL, policymakers, COEs, and 250+ specialists
- Articles in Express Healthcare and ET HealthWorld
- Engagement with international networks: IFPA, GlobalSkin, APARDO

C. Rare Diseases Advocacy (2021–2023)

- Roundtables on National Policy for Rare Diseases (NPRD)
- White paper submitted to government with cross-stakeholder recommendations
- National deliberations with COEs, policymakers and clinicians
- Sessions at PGIMER, Udaipur, and global platforms
- Expansion of rare disease patient leader networks

D. Cancer Advocacy & Patient Education (CAPE) and SPAN HNC

- 435 direct beneficiaries at Delhi State Cancer Institute
- 600+ patients across Delhi/Haryana and UP receiving direct support through nutrition and counselling

- 10,000 indirect support through camps and screening sessions
- Counseling, nutrition guidance, lifestyle support, emotional care
- Yoga, music therapy and information services for patients and caregivers
- Participation in major national cancer forums and summits

E. Integrated Care – HIV/TB/NCD (2022–2023)

- National roundtable: "Collective Action Towards Integrated Care"
- Comprehensive report on integration opportunities and global learnings
- Policy mapping of HIV/TB/NCD programmes
- Recommendations for integrated screening, community engagement and data systems
- Emphasis on patient-centred pathways and PHC-level integration

F. Patient Safety & International Patient Summit (2023)

- Series of national webinars on patient and family engagement
- Collaboration with WHO Patient Safety leadership
- Launch of **Patient for Patient Safety Network – India**
- International Patient Summit 2023: 40 stakeholders co-creating India's patient safety agenda

G. STEP-UP Fellowship (Young Physician Capacity Building) 2022-ongoing

- 7 fellows across 6 major hospitals
- Participation from Apollo, Manipal, Fortis, Max, Sparsh, Arcus
- Curriculum bridging clinical practice, technology and patient-centric care
- Increasing demand from national hospital chains

H. **International Patient Summit**

5. Research, Evidence & Thought Leadership

Across the three years, DakshamA produced high-impact research outputs including:

- Atopic Dermatitis Needs Assessment Study (21 moderate, 3 severe cases)- paper published
- Psoriasis Needs Assessment (Dermatologist survey; patient journeys)
- Stroke access barriers research and survivor insights- report on National Consultation
- HIV/TB/NCD Integration Report (national and global evidence review)
- Articles in Express Healthcare, ET HealthWorld, News9
- Knowledge resources: IEC materials, booklets, videos, awareness campaigns

These outputs shaped national dialogues, informed policy development, and strengthened lived-experience-based advocacy.

6. Partnerships & Networks

DakshamA's partnerships expanded significantly, including collaborations with:

National Bodies

- MoHFW
- ICMR
- DBT
- DGHS
- NHA
- AIIMS, PGIMER, JIPMER, MAMC, LHMC, Father Muller, Apollo
- DSCI, ESI, AIMS New Delhi, Kalyan Singh Super Speciality Hospital LKO, and major tertiary hospitals

International Networks

- IAPO
- WHO NCD Labs Steering Committee

- Global Rare Disease Networks (CGN4D)
- GlobalSkin, IFPA, APARDO
- UICC
- International NCD Alliance

Civil Society & Academic Partners

- Healthy India Alliance
- HRIDAY
- Rare Cancers Australia
- NGOs, patient groups, researchers across India

These partnerships strengthened program reach, credibility, and multisector collaboration.

7. Key Achievements & Multi-Year Results

Across 2022–202, DakshamA achieved:

- **1600+ patients** directly supported across disease programmes
- **5 major national roundtables** with white papers submitted
- **100+ webinars, meetings, and training events**
- **400+ patient stories, testimonies, and digital engagement outputs**
- **National presence** across 90+ patient organisations through IAPG
- **Launch of India's first unified Patient Safety Network**
- **Multi-disease patient advocacy leadership ecosystem established**
- Stronger recognition as a **trusted patient voice** in national and international policy circles
- Rare Disease Hackathon
- International Patient Summit I and II

8. Challenges & Lessons Learned

Key cross-cutting insights from three years of work:

- Patient engagement must shift from episodic consultation to **structural inclusion**
- Digital health adoption remains unequal—requiring more accessible formats
- Lack of standardised referral pathways continues to burden patients
- Multimorbidity needs integrated system responses, not disease silos
- Investing in patient leadership yields significant system-wide returns
- Multi-stakeholder coordination requires time, trust-building and sustained presence

9. The Way Forward (2026 and Beyond)

DakshamA Health will continue to scale its work through five forward-looking priorities:

1. **Institutionalising patient voice** into policy, research, reimbursement and quality standards
2. **Strengthening multi-disease patient networks**, especially for rare and chronic conditions
3. **Expanding integrated care pilots** at PHC and state levels
4. **Deepening community-led monitoring and patient-reported outcome frameworks**
5. **Scaling the International Patient Summit** into an annual flagship platform
6. **Expanding STEP-UP Fellowship** and interdisciplinary training modules
7. Creating **digital health and patient education ecosystems** that are accessible and multilingual