



RARE IMPACT
2025



RARE IMPACT 2025

ROLES, TIME COMMITMENTS &
COMMUNICATION



[www.dakshamahealth.org/
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**NOV 2025
TO FEB 2026**



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Introducing our **Country Leads!**

VIETNAM



HUY DO

President, Vietnamese Organization for Rare Diseases

NEPAL



DR NIRAJ PARAJULI

Founding President, Rare Skin Disease Nepal

SINGAPORE



**ELLIL MATHIYAN
LAKSHMANAN**

Co-Chair, SingHealth Patient Advocacy Network

THAILAND



EKAWAT SUWANTAROJ

Vice President, Thai Hemophilia Patient Club

INDIA



NAVINTARA KAMATH

*Co-Founder,
Niemann-Pick India*



MANOJ KUMAR SINGH

*National President,
Power In Me Foundation*



MALAYSIA



**NADIAH HANIM ABDUL
LATIF**

President, Malaysian Rare Disorders Society

PHILIPPINES



ARACELI LANORIO

*Lead Advocate,
Neurofibromatosis Friends
Philippines*



Key operational rules

(applies to all roles)

- **Attend the global opening & keynote (Day 1 start).**
Everyone joins this.
- **Country introductions:** each country attends only during its scheduled country-intro slot (see agenda).
- **Ideation / Breakout window (Day 2):** live throughout the official working hours (08:00–17:00 IST). Teams work in their country breakout room; participants may join and leave within this window according to availability.
- **Group chat:** every team will have a country WhatsApp (or locally preferred app) group for real-time coordination; organizers will create these before Phase 1.
- **Deliverable:** each team must upload a one-page concept note by the submission cutoff on Day 2.



STAKEHOLDER TYPE

Patient Advocates, PAGs, & People with Lived Experience

REQUIRED PRESENCE		
PHASE 1	DAY 1 (24th Nov, 2025)	Mandatory joining only during your country's intro slot (brief intro).
	DAY 2 (25th Nov, 2025)	Expected to be available in the country breakout room during the team's working hours, as schedule permits.
PHASE 2	DAY 1 22nd Jan, 2026)	Join the prototype presentation session for your country's team-mandatory (joining for other teams' presentations- voluntary)
	DAY 2 (23rd Jan, 2026)	*fixed 30 min slot will be provided between either 8 th or 9 th Jan to present the prototype
PHASE 3	DAY 1 (24th Feb, 2026)	2 days mandatory participation if the team is in the top 3 finalists
	DAY 2 (25th Feb, 2026)	

MODE OF COMMUNICATION

- Country WA group + Zoom breakout room (Day 2).
- Email for follow-ups and documentation.

PRIMARY FUNCTION

- Facilitate team progress, keep discussions focused on feasibility and impact, and unblock obstacles (technical, design, clinical or coordination).
- Flag patient-safety or regulatory concerns.



STAKEHOLDER TYPE

Clinician / Healthcare Expert

REQUIRED PRESENCE		
PHASE 1	DAY 1 (24th Nov, 2025)	Mandatory joining only during your country's intro slot (brief intro).
	DAY 2 (25th Nov, 2025)	Expected to be available in the country breakout room during the team's working hours, as schedule permits. Clinicians may join intermittently.
PHASE 2	DAY 1 22nd Jan, 2026)	Join the prototype presentation session for your country's team-mandatory (joining for other teams' presentations- voluntary)
	DAY 2 (23rd Jan, 2026)	*fixed 30 min slot will be provided between either 8 th or 9 th Jan to present the prototype
PHASE 3	DAY 1 (24th Feb, 2026)	2 days mandatory participation if the team is in the top 3 finalists
	DAY 2 (25th Feb, 2026)	

MODE OF COMMUNICATION

- Country WA group + Zoom breakout room (Day 2).
- Email for follow-ups and documentation.

PRIMARY FUNCTION

- Validate clinical accuracy and feasibility of problem statements and proposed solutions.
- Flag clinical workflow or regulatory concerns.
- Clinicians are expected to step in for quick validation when the team requests clinical input or when the mentor flags a clinical blocker.



STAKEHOLDER TYPE

Policy Makers

REQUIRED PRESENCE		
PHASE 1	DAY 1 (24th Nov, 2025)	Mandatory joining only during your country's intro slot (brief intro).
	DAY 2 (25th Nov, 2025)	Expected to be available in the country breakout room during the team's working hours, as schedule permits. Policy Makers may join intermittently.
PHASE 2	DAY 1 22nd Jan, 2026)	Join the prototype presentation session for your country's team- mandatory (joining for other teams' presentations- voluntary)
	DAY 2 (23rd Jan, 2026)	*fixed 30 min slot will be provided between either 8 th or 9 th Jan to present the prototype
PHASE 3	DAY 1 (24th Feb, 2026)	2 days mandatory participation if the team is in the top 3 finalists
	DAY 2 (25th Feb, 2026)	

MODE OF COMMUNICATION

- Country WA group + Zoom breakout room (Day 2).
- Email for follow-ups and documentation.

PRIMARY FUNCTION

- Assess how proposed ideas fit within health policy, regulations, and existing national programs.
- Flag feasibility issues, identify integration pathways with current systems, and support alignment with rare disease policy goals.



STAKEHOLDER TYPE

IT Professionals & Technical Experts

REQUIRED PRESENCE		
PHASE 1	DAY 1 (24th Nov, 2025)	Mandatory joining only during your country's intro slot (brief intro).
	DAY 2 (25th Nov, 2025)	Expected to be available in the country breakout room during the team's working hours, as schedule permits. Technical Experts may join intermittently.
PHASE 2	DAY 1 22nd Jan, 2026)	Join the prototype presentation session for your country's team-mandatory (joining for other teams' presentations- voluntary)
	DAY 2 (23rd Jan, 2026)	*fixed 30 min slot will be provided between either 8 th or 9 th Jan to present the prototype
PHASE 3	DAY 1 (24th Feb, 2026)	2 days mandatory participation if the team is in the top 3 finalists
	DAY 2 (25th Feb, 2026)	

MODE OF COMMUNICATION

- Country WA group + Zoom breakout room (Day 2).
- Email for follow-ups and documentation.

PRIMARY FUNCTION

- Translate concepts into functional or demonstrable digital solutions.
- Build mock-ups or code frameworks; advise on data flow, UX, and implementation feasibility.



STAKEHOLDER TYPE

Students

REQUIRED PRESENCE		
PHASE 1	DAY 1 (24th Nov, 2025)	Mandatory joining only during your country's intro slot (brief intro).
	DAY 2 (25th Nov, 2025)	Expected to be available in the country breakout room during the team's working hours, as schedule permits.
PHASE 2	DAY 1 22nd Jan, 2026)	Join the prototype presentation session for your country's team-mandatory (joining for other teams' presentations- voluntary)
	DAY 2 (23rd Jan, 2026)	*fixed 30 min slot will be provided between either 8 th or 9 th Jan to present the prototype
PHASE 3	DAY 1 (24th Feb, 2026)	2 days mandatory participation if the team is in the top 3 finalists
	DAY 2 (25th Feb, 2026)	

MODE OF COMMUNICATION

- Country WA group + Zoom breakout room (Day 2).
- Email for follow-ups and documentation.

PRIMARY FUNCTION

- Support research, data gathering, user mapping, and documentation.
- Provide analytical input, background research, and help compile the concept note.
- May provide technical and clinical support as per educational qualifications..



STAKEHOLDER TYPE

Mentors

REQUIRED PRESENCE		
PHASE 1	DAY 1 (24th Nov, 2025)	Must join the opening/keynotes and their country intro slot.
	DAY 2 (25th Nov, 2025)	Present in the country breakout room during the ideation window as available; mentors are not required to be continuously present – they should remain reachable and step in when the team requests help.
Between Phase 1 & 2		2–3 brief check-ins (virtual), or ad-hoc when the team requests support.
PHASE 2		Attend pitch day to support the team (as per schedule).
PHASE 3	DAY 1 (24th Feb, 2026)	2 days mandatory participation if the team is in the top 3 finalists
	DAY 2 (25th Feb, 2026)	

MODE OF COMMUNICATION

- Member of the country WA group (or local app) – primary channel for quick support.
- Email for formal feedback and resource sharing.
- Zoom for direct mentoring calls (scheduled ad-hoc).

PRIMARY FUNCTION

- Facilitate team progress and keep discussions focused on feasibility and impact
- Advise on pitch preparation
- Monitor the team group and intervene directly when requested or if the team hits a clear blocker. Additional involvement is voluntary.



STAKEHOLDER TYPE

Jury

REQUIRED PRESENCE

PHASE 1	DAY 1 (24th Nov, 2025)	Attend opening & organizer briefing (recommended).
PHASE 2	DAY 1 22nd Jan, 2026)	Attend scheduled presentation sessions for teams (live via Zoom).
	DAY 2 (23rd Jan, 2026)	
PHASE 3	DAY 1 (24th Feb, 2026)	2 days participation (as per availability)
	DAY 2 (25th Feb, 2026)	

MODE OF COMMUNICATION

- Live scoring via the secure Microsoft Forms link provided to each juror (time-stamped; no edits after submission).
- Zoom for presentations; email for any follow-up clarifications.
- Organizers will provide slide deck, concept notes and GitHub access before presentations for juror review.

PRIMARY FUNCTION

- Independently evaluate Phase 2 presentations against the judging criteria and provide concise feedback.
- Jury members are not expected to mentor or advise teams during Phase 1 ideation; their involvement is evaluative and confined to Phase 2 and the brief orientation.



AGENDA- PHASE 1 (DAY 1- TECHNICAL ONBOARDING): 24th Nov, 2025

DATE	TIME (IST)	SESSION	DESCRIPTION	DURATION (in mins)	REMARKS
24-Nov-25	9:30 - 9:45	Welcome & Opening Remarks	Opening remarks and introduction to Hackathon - Dr. Ratna	15	Joined by all participants and mentors.
24-Nov-25	10:00 - 10:15	Country Team Introductions and Technical Onboarding: 7 country introductions (5-7 min each); followed by the introduction of their respective mentors. Participants may leave and rejoin during their country's slot.	Philippines	105	12:30 - 12:45 Philippines Time
24-Nov-25	10:15 - 10:30		Singapore		12:45 - 13:00 Singapore Time
24-Nov-25	10:30 - 10:45		Malaysia		13:00 - 13:15 Malaysia Time
24-Nov-25	10:45 - 11:00		Thailand		12:15 - 12:30 Thailand Time
24-Nov-25	11:00 - 11:15		Vietnam		12:30 - 12:45 Vietnam Time
24-Nov-25	11:15 - 11:30		Nepal		11:30 - 11:45 Nepal Time
24-Nov-25	11:30 - 11:45		India		11:30 - 11:45 Indian Time

AGENDA- PHASE 1 (DAY 1- HACKATHON LAUNCH): 24th Nov, 2025

DATE	TIME (IST)	SESSION	DESCRIPTION	DURATION (in mins)	REMARKS
24-Nov-25	14:00 – 14:10	Opening- Dr. Ratna Devi (CEO, DakshamA Health)	Formal Launch of Hackathon	10	14:00 – 14:15 Indian Time
24-Nov-25	14:10 – 14:20	Alexandra Heumber Perry (CEO, RDI)	WHO resolution and its significance for regional and National action plans	10	9:45 – 10:00 Switzerland Time
24-Nov-25	14:20 – 14:30	Guest Speaker	Patient Led and Patient Delivered- How the Hackathon can be a gamechanger for Patient Led Innovation	10	9:45 – 10:00 Switzerland Time
24-Nov-25	14:30 – 14:40	Guest Speaker- Eric Mansion (Pharma GM, Sanofi SE Asia and India)	The Hackathon as a bold and Innovative strategy led by patient groups	10	17:00 – 17:15 Singapore Time
24-Nov-25	14:40 – 14:55	Keynote- Dr. B. S. Charan (ADG, DGHS, MoH, GoI)	The confluence of Digital and health- India leading by example for rare diseases	15	14:45 – 15:00 Indian Time
24-Nov-25	14:55 – 15:05	Monica Ferrie (Executive Director, APARDO)	Regional collaboration- the key to collective action	15	20:30 – 20:45 Melbourne Time
24-Nov-25	15:05 – 15:10	Closing Remarks – Day 1	Recap & next-day instructions.	5	

AGENDA- PHASE 1 (DAY 2- IDEATION SESSION): 25th Nov, 2025

DATE	TIME (IST)	SESSION	DESCRIPTION	DURATION (in mins)	REMARKS
25-Nov-25	08:00 – 08:30	Morning Briefing	Recap of Day 1 and outline of deliverables for Day 2. Unique breakout links shared.	30	Joined by all participants and mentors.
25-Nov-25	08:30 – 12:30	Team Breakout Session – Part 1	Teams work in country-wise Zoom rooms with mentors to define problem statements. Organizers/jury may visit rooms.	240	Unique link/ virtual breakout room for each team
25-Nov-25	12:30 – 13:30	Midday Check-In	Informal progress check with organizers & tech support.	60	
25-Nov-25	13:30 – 16:30	Team Breakout Session – Part 2	Teams develop solution concept & draft 1-page concept note.	180	
25-Nov-25	16:30 – 17:00	Submission & Wrap-Up	Each team must submit a 1-page concept note via shared link by 17:00 IST (using provided template) summarizing the problem statement, proposed solution, and roles of stakeholders.)	30	Official close of Phase 1.
25-Nov-25	17:00 – 20:00	Optional Collaboration Window	Breakout rooms remain open for teams wishing to continue discussion informally.	180	Voluntary participation; no facilitation after 17:00 IST.

Important Contacts



More Information



Register Now

<https://www.dakshamahealth.org/Hackathon.html#register>



Our Website

www.dakshamahealth.org/Hackathon.html



Our Email

communications@pairacademy.org