

IC2A Think Tank 2025

"Empowering Amputees Globally: Building Digital Communities Without Borders"

*How can we support amputees in countries without formal organizations,
using digital platforms and peer networks to strengthen IC2A's global impact?*

**17th June 2025, ISPO Congress, Stockholm, 10.00 AM.
Stockolmsmassen, Room K23 and Online by Zoom**

1- Introduction:

The session was opened by the chairman, Nils Odd, who thanked all the participants for their attendance and their commitment to support IC2A. As moderator, he presented the areas for reflection and gave the working instructions.

The questionnaire was structured as follows:

1. What are the main barriers to establishing formal amputee associations in low-resource or politically restricted countries, and how can we work around them digitally?
2. How might we create informal yet effective digital communities that still empower amputees and give them a collective voice?
3. In what ways can IC2A support local leaders or peer mentors to act as digital "hubs" in their regions without forming formal organizations?
4. What lessons can we learn from platforms like the Amputee Coalition in the US or even from peer-reviewed platforms like Airbnb or Uber in building trust and engagement online?
5. How can we ensure safety, inclusivity, and accessibility (e.g. language, tech access) in a global digital amputee community?

The session gathered 30 attendees split up into 5 groups (4 groups in person and 1 online) to reflect on questions and choose a reporter per group to share the outcomes of the group discussions.

2- Outcomes of group work:

Group 1: (Online)

- 1- The barriers and the ways to overcome them:
 - Support education

- Peer support
- Social media is a good way to go around strict law registration, get the word out to the amputee community and to meet and find each other.

2- The digital platform

IC2A, needs to know which local platforms are being used the most used in different countries and engage with other organisations that are present in different areas also.

- 3- Creating regional working groups, this discussion groups and understanding the level of need in that particular area or country and what their needs are.
- 4- Funding that is one of the crucial parts of course. There is a lot to learn from Amputee Coalition in the US. It experience can help to build these digital platforms and connecting.
- 5- We need to engage multiple **partners** and work with multiple organisations like the Red Cross and several other organisations that are globally active on these different topics.

Group 2:

The main barriers are governance/ ownership; fundings that may be mobilized from digital giants like Google, Apple, Global 50, Government, industries or tech; digital access and literacy for communities in global south; infrastructure/data protection.

The group proposed the creation of Platform 2.0 to establish a global scalable digital network. This platform will be a volunteer network, training hub, and resource standards. Every volunteer will be given a digital package (phone, internet) that will be used to share information within the communities.

Users/Patients will get resources, education, training, helpline, peer support, social/psychological support/mental health.

Success factors: Easy to use, simple, familiar

The platform will need the voice of global ambassadors from around the country together to build the purpose for this platform.

The platform can be scaled into communities via volunteer and healthcare systems.

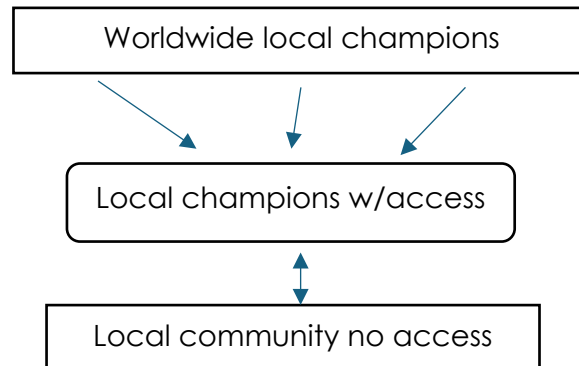
Mainstream platform: Facebook, Zoom

The group shared the models of relevant organizations like Amputee Coalition in USA and cancer peer support networks globally: their actions and their digital access management and pulling that together as a an assessment or report of

what's already working for other patient populations and bringing that into this mix.

Group 3:

- 1- Barriers: lack of access to technology, lack of awareness, lack of existing community, lack of champion in community
Suggestion: hybrid solution with community champions
- 2- Hub+Spoke model with minimal barriers to entry with roots in community networks
- 3- Feed the feeders, support champions to continue serving as "Hubs".
- 4- The lessons: Empowerment at ground level-checks + balances to prevent the dynamic of outside leaders overpowering community champions, sustainable solutions to lack of access to technology
- 5- The diagram here below is proposed by the group



Group 4:

The group started reminding the mission of IC2A is to empower as many amputees as possible and the role is to act as a framework provider, setting standards and guiding organisations.

From this setting, they proposed a platform providing the following key elements:

- Knowledge Transfer
- Templates and guides for building organisations
- Sharing best practices and existing resources
- Reaching remote areas with accessible information

The digital Platform will be:

- Central hub for knowledge, reporting, and learning.
- Step-by-step guidance for grassroots initiatives.
- Low-tech and offline access options via ambassadors.

One of the main purposes of the platform will be the reporting and Exchange:

- Reporting for learning, not control.
- Peer-to-peer and organisation-to-IC2A exchange.

Outreach via Social Media:

- Targeted campaigns by region
- Use of local platforms (e.g., Facebook, WeChat)
- Adapted content for accessibility

To be sustainable, this platform should be:

- Bottom-up, community-led initiatives.
- Empowered individuals drive long-term impact.

Group 5:

The group made a proposal of a Global Peer Support Framework for Prosthetic Users with the following specificities:

1. Centralised Standards & Training:
 - Develop a culturally adaptable, internationally recognised peer support framework
 - Train-the-trainer models using grassroots organisations
 - Create an IC2A-style accreditation system for peer support groups
2. International Matching System:
 - Build a platform to connect peer supporters and trainers globally
 - Inspired by Limitless Association's 1-to-1 matching but adapted for low-resource settings.
3. Bridging Clinical & Peer Communication
 - Align language and communication between clinicians and patients
 - Train both groups to understand each other better and co-create guidance
4. Long-Term Device Support
 - Provide ongoing education and troubleshooting for prosthetic users
 - Use digital and offline tools to teach device care and basic repairs
5. Mapping & Signposting Resources
 - Map global organisations, resources, and needs.
 - Translate and disseminate materials via accessible platforms (e.g., Facebook, WeChat).

- IC2A to lead coordination with support from international bodies.

Few take aways from free discussions:

1- Expand Global Reach Through Language Diversity

Form Language-Specific Groups: Establish regional groups that operate in French, Spanish, Portuguese, etc., to better serve communities in West Africa, Latin America, and beyond.

Multilingual Communication Strategy: Translate key materials, websites, and outreach content to ensure accessibility for non-English-speaking users and ministries.

Empower Local Leaders: Support native speakers to lead initiatives and represent IC2A in their regions, fostering trust and cultural relevance.

2- Strengthen National-Level Awareness

Engage Ministries Directly: Ministries of Health and Social Affairs should be informed about IC2A so they can refer new amputees before discharge.

Early Intervention: Ensure patients receive information about IC2A immediately after amputation, especially before returning to rural areas.

3- Foster Collaboration Across Sectors

Industry + Users = Partners: Companies and users must collaborate, not operate in silos. Mutual respect and shared goals are key.

Cross-Company Unity: Even competitors should work together to improve outcomes for users.

4- Embrace the Identity of “Users”

Inclusive Terminology: Use “users” to reflect autonomy and diversity, while acknowledging that many have been patients.

Respect All Journeys: Include those who avoid prosthetics and those who pursue extreme activities—everyone’s path matters.

5- Elevate Peer Support as Core Value

Peer Support Is the Product: Volunteer organizations offer emotional and experiential support—that’s their unique contribution.

Collaborators Are Essential: Suppliers and sponsors are vital to sustaining peer-led initiatives.

6- Learn from Norway’s Model

Diverse Participation: Events like the one in Norway—with 90 users and 40 collaborators—show the power of inclusive gatherings.

Leadership from Within: Volunteers like **Petter** taking on sponsorship roles demonstrate how users can lead and shape the future.

7- Reinforce Shared Purpose

We Need Each Other: The old divide between industry, professionals, and users doesn't work. Unity is the way forward.

Gratitude and Acknowledgment: Recognizing everyone's contribution builds trust and strengthens the amputee's movement.

Conclusion:

The moderator, Nils-Odd closed the session appreciating the group's discipline and thoughtful engagement throughout the session and highlighting few upcoming actions:

- Proposal for a Task Force: Suggestion to form a small team to develop unified peer support training guidelines, especially for underserved areas.
- Digital Outreach Strategy: Emphasis on using digital tools to expand reach, with a locally adapted approach rather than a one-size-fits-all model.
- Funding Considerations: Recognition that sustainable, localized funding will be essential to support these initiatives.