

Meaningful Community Engagement Principles



Guiding how we work together with people with lived experience of T1D, community-based organizations, and community representatives

Background

ALIGN-T1D is a multi-stakeholder, global initiative bringing together philanthropy, industry, technical partners, governments, and the T1D community to advance equitable access to integrated care in LMICs. The Alliance is grounded in the principle that sustainable progress requires meaningful engagement of people closest to the realities of living with and delivering care for T1D.

Community perspectives have informed ALIGN-T1D's strategy and priorities since its inception and are embedded across its governance and advisory structures. For ALIGN-T1D, "people with lived experience" includes individuals living with T1D and caregivers. Community representatives may also include healthcare providers, peer leaders, advocates, and those working within or alongside community-based organizations. These perspectives are complementary and should be represented throughout engagement processes.

ALIGN-T1D partners—including members of the Strategy Steering Group, Strategic Advisory Group, Secretariat (Breakthrough T1D), participating governments, implementing partners, and other organizations formally engaged in ALIGN-T1D processes—share responsibility for advancing these commitments.

These Principles provide practical guidance for how ALIGN-T1D and its partners can engage communities in ways that are respectful, inclusive, and actionable, while supporting country- and community-defined priorities. This document is intended as an evergreen reference across governance, country engagement, grantmaking, implementation, advocacy, and learning. It may also inform current and future funding opportunities, including Requests for Applications (RFAs) and proposal processes, while guiding broader collaboration across the ALIGN-T1D ecosystem.

When to Use This Document

This document serves as a shared reference for ALIGN-T1D partners and the Secretariat. It can be used as a practical guide during key moments of collaboration, including:

- Designing or refining country-level approaches and concept notes
- Developing or responding to Requests for Applications (RFAs)
- Embedding meaningful engagement in ALIGN-T1D-funded grants
- Convening partners and facilitating inclusive dialogue with communities
- Onboarding new alliance members or implementing partners
- Preparing for Strategy Steering Group, advisory, or learning discussions
- Reflecting on whether participation is equitable and meaningful
- Adapting partnership approaches based on feedback and learning

The Secretariat supports partners in applying these Principles through planning processes, convenings, and shared learning.

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From Values to Practice: *Why These Principles Matter*

ALIGN-T1D's mission depends on partnership practices that value lived experience, local expertise, and shared accountability. Meaningful engagement goes beyond consultation: it requires sustained community participation across governance, strategy, implementation, monitoring, and learning.

By aligning around common principles and enabling actions, ALIGN-T1D aims to:

- Elevate people with lived experience of T1D as co-designers, advisors, and decision-makers
- Strengthen collaboration across partners, sectors, and communities
- Reduce unintended burdens that limit sustained participation
- Support learning, adaptability, and long-term sustainability

Building on WHO Standards

These Principles build on the World Health Organization's *Framework for Meaningful Engagement of People Living with Noncommunicable Diseases and Mental Health and Neurological Conditions*, which calls for lived experience to inform policies, programs, services, governance, implementation, monitoring, and evaluation (WHO, 2023).

ALIGN-T1D adapts this global guidance for a multi-stakeholder partnership involving governments, funders, implementers, technical partners, and community actors. The Principles focus on practical application across grantmaking, proposal development, coordination, and country-level planning. They also address common barriers to meaningful engagement, including financial and logistical constraints, limited engagement capacity, unequal power dynamics, and weak pathways for community input to influence decisions. In doing so, ALIGN-T1D seeks to support nationally defined priorities, strengthen government-led processes, and avoid creating parallel structures.

Evidence Base and Development Approach

These Principles draw on global normative guidance and implementation experience in community engagement and philanthropic partnership. They are also informed by a broader body of evidence demonstrating that sustainable and effective health initiatives center the agency, knowledge, and leadership of local actors (Global Alliance for Community Philanthropy, 2015). Research and practice in community participation and development consistently show that strengthening local ownership is both an ethical imperative and a driver of long-term impact.

The approach was initially developed within philanthropic efforts focused on T1D, where engagement practices were co-designed with people living with T1D, community-based organizations, and global health experts. For ALIGN-T1D, this approach has been adapted to a multi-stakeholder alliance model to ensure relevance across partners, governance structures, and country contexts.

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The development process integrates three complementary sources of insight:

- **Research:** Published literature on community participation and power-sharing, including foundational frameworks such as Arnstein's Ladder of Citizen Participation
- **Lived Experience and Expert Input:** Structured feedback from people with lived experience, community leaders, and practitioners
- **Field Practice:** Lessons from implementation across philanthropic and global health partnerships in diverse settings

Together, this ensures the Principles are evidence-informed, grounded in lived experience, and applicable in real-world contexts.

Meaningful engagement is an ongoing process rather than a fixed standard. These Principles are intended to evolve alongside learning within ALIGN-T1D and its partner ecosystem.

Six Guiding Principles

The following Principles reflect ALIGN-T1D's commitment to meaningful engagement with individuals and communities in ways that are inclusive, collaborative, and grounded in shared accountability to country-defined priorities.

1. Commit to Long-Term Partnerships

ALIGN-T1D approaches engagement as an ongoing relationship rather than a one-time or transactional activity. Partners are encouraged to:

- Engage people with lived experience *early* in strategy development, country processes, and the development of implementation plans
- Build continuity in relationships beyond individual projects or funding cycles
- Align activities with national health priorities and long-term sustainability goals
- Adapt plans based on local context and lived experience input

Illustrative practices may include:

- ✓ Including community representatives in early-stage country scoping or needs assessments, before program priorities are finalized
- ✓ Retaining the same community advisors across multiple funding cycles or phases of work to ensure continuity and trust
- ✓ Aligning community engagement structures with existing national platforms (e.g., NCD committees, diabetes associations) rather than creating parallel groups
- ✓ Adjusting program delivery approaches based on feedback from people living with T1D (e.g., changing clinic schedules, education formats, or outreach strategies)

2. Offer Responsive and Strategic Funding

Participation in ALIGN-T1D activities should not create financial or logistical barriers. Partners are encouraged to budget for and provide support that enables equitable participation, including:

- Stipends or honoraria for people contributing lived experience or community expertise
- Travel, lodging, meals, travel insurance, and related costs when in-person participation is required
- Translation, interpretation, accessibility, childcare, or connectivity support, as needed
- Dedicated resources for advocates, peer leaders, community-based organizations, or others contributing local expertise
- Flexible support that can respond to emerging needs and country context

Illustrative practices may include:

- ✓ Including participation-related costs in proposal budgets from the outset
- ✓ Providing honoraria through accessible payment mechanisms that account for local banking or documentation barriers
- ✓ Covering caregiver, childcare, accessibility, or connectivity costs that affect participation
- ✓ Allowing community-based organizations flexible funds to support outreach, coordination, or peer leader participation

3. Communicate with Clarity and Consistency

Transparent communication strengthens trust across the alliance. Partners, particularly those convening meetings or managing reporting processes, should:

- Clearly communicate expectations, roles, timelines, and decision-making processes
- Provide timely updates and feedback during country engagement and planning
- Set realistic timelines that account for partner and community capacity
- Proactively acknowledge actual or perceived conflicts of interest
- Create opportunities for shared learning and problem-solving, not only reporting on project outcomes
- Close the loop by sharing how community input influenced decisions, or explaining when changes were not possible

Illustrative practices may include:

- ✓ Sharing clear agendas, roles, and decision points in advance of meetings
- ✓ Providing brief written summaries or action points after convenings
- ✓ Using simple, consistent communication channels to keep partners informed
- ✓ Clearly documenting decision-making processes and points of input during country planning or governance discussions

4. Support Capacity Strengthening and Inclusive Participation

Meaningful participation requires preparation, access to information, and opportunities to build confidence and skills. ALIGN-T1D places particular emphasis on resourcing participation and creating conditions for equitable contribution. Partners are encouraged to:

- Provide onboarding, technical assistance, or contextual briefings
- Offer simplified tools, materials, and processes accessible to diverse participants
- Facilitate peer learning and networking across countries and organizations
- Prepare participants before convenings so they can contribute effectively
- Use structured facilitation approaches that support equitable contribution and respectful dialogue (e.g., nominal group technique, Delphi processes, small-group breakouts, etc.)
- Be attentive to power dynamics that may limit participation or influence

Illustrative practices may include:

- ✓ Sharing plain-language agendas and background materials in advance
- ✓ Offering pre-meeting briefings for community representatives
- ✓ Using structured methods such as nominal group technique, Delphi processes, small-group breakouts, or round-robin discussion
- ✓ Pairing newer community representatives with experienced peer mentors

5. Co-Create Goals, Metrics, and Reporting Frameworks

ALIGN-T1D promotes collaborative approaches to defining success and measuring progress. Where appropriate, partners should clarify how community input informs advisory, consent, or decision-making processes. Partners are encouraged to:

- Engage people with lived experience early in defining priorities, indicators, and questions
- Ensure engagement spans strategy design, implementation, monitoring, and evaluation
- Align monitoring and learning approaches with partner capacity and local context
- Tailor reporting processes to reduce unnecessary administrative burden
- Document how community participation shaped decisions, implementation, and learning
- Celebrate achievements while learning openly from challenges

Illustrative practices may include:

- ✓ Documented roles and contributions of people with lived experience in country-level strategy design, implementation, monitoring, and evaluation
- ✓ Evidence of community participation in ALIGN-T1D global strategy and governance processes, including SAG and SSG engagement
- ✓ Examples of how community input influenced priorities, program adaptations, or decision-making

6. Actively Seek and Respond to Feedback

Continuous feedback helps ensure ALIGN-T1D remains responsive, accountable, and grounded in lived experience. Partners can foster meaningful feedback by:

- Creating safe, accessible channels for input, including anonymous options where appropriate
- Being mindful of power dynamics that may limit openness
- Establishing clear processes for raising and addressing concerns, including safeguarding-related concerns, consistent with partner policies and applicable requirements
- Routinely seeking feedback on how engagement processes are working, not only on program outputs or outcomes
- Closing the feedback loop by sharing how input influenced decisions, or explaining transparently when changes were not possible

Illustrative practices may include:

- ✓ Using short, structured feedback tools after convenings, such as anonymous surveys, SMS/WhatsApp check-ins, or quick debrief sessions
- ✓ Holding periodic reflection sessions with community representatives to review what is working and what needs to change
- ✓ Sharing summaries of feedback received and actions taken
- ✓ Designating a focal point within partners or the Secretariat to collect, synthesize, and respond to feedback

References

Global Alliance for Community Philanthropy. (2015). *The value of community philanthropy: Results of a consultation*. Aga Khan Foundation U.S.A., Charles Stewart Mott Foundation, Global Fund for Community Foundations, Rockefeller Brothers Fund, and WINGS. <https://www.mott.org/news/publications/value-community-philanthropy-results-consultation/>

World Health Organization. *WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions*. Geneva: WHO; 2023. <https://www.who.int/groups/gcm/meaningful-engagement-of-people-with-lived-experience>