

ACCISS STUDY **FOCUS GROUPS:** CROSS-COUNTRY SYNTHESIS



OVERVIEW

Between 2024 and 2026, four linked qualitative and mixed-methods studies examined the lived experience of people living with type 1 diabetes across Kyrgyzstan (lead by Health Policy Analysis Center (HPAC)), Tanzania (led by Tanzania NCD Alliance (TANCDAA)), Mali (led by Santé Diabète), and Peru (lead by CRONICAS). As part of the Addressing the Challenge and Constraints of Insulin Sources and Supply (ACCISS) Study, these studies aimed to better understand the systemic challenges and support needs of people living with type 1 diabetes. In doing so, we can co-create feasible, community-endorsed solutions in partnership with affected individuals, caregivers, healthcare providers, and key stakeholders.

This initiative builds on evidence previously gathered by country partners to improve access to insulin, supplies and care.

Since 2018, ACCISS partners have created an evidence-base of nationally-specific data and interventions that aim to improve access to insulin and care across the supply chain.

To carry out these focus groups, partners used various participatory methods that were determined to be most appropriate in their contexts, including group discussions, in-depth interviews, and stakeholder or co-creation workshops. These methodologies were designed based on lessons learned from previous experience of a focus group project to develop a Target Product Profile for self-monitoring blood glucose devices in low- and middle-income countries (LMICs), carried out by ACCISS Study and FIND.¹

These focus groups included people with type 1 diabetes, caregivers and healthcare workers.

¹ Safary, E., Lepeska, M., Beran, D., Ewen, M., et al. 'Development of a target product profile for new glucose self-monitoring technologies for use in low- and middle-income countries', PLOS ONE (2024), 19(8), e0309062. Available at: <https://doi.org/10.1371/journal.pone.0309062>

SUMMARY OF METHODS AND FINDINGS BY COUNTRY

Kyrgyzstan

Focus group discussions were held in December 2025 in Bishkek and in Osh, with a total of 46 participants across four groups consisting of: young people living with type 1 diabetes (18 – 29 years old); people living with diabetes over 29 years old; pregnant women; and parents/caregivers. At each focus group, participants worked through three topics: social media, pregnancy, and nutrition using a problem-tree method to move from discussion around barriers and issues to ranking and developing solutions related to the topics. Each session was audio recorded.



46 participants across four groups:

- young people living with type 1 diabetes (18 – 29 years old)
- people living with diabetes over 29 years old
- pregnant women
- parents/caregivers.

Across all three topics, the most consistent barrier was unreliable and contradictory information, particularly on social media. Another issue identified within social media was a limited amount of Kyrgyz-language material available, and in particular material that had been professionally vetted.

On the topic of nutrition, unreliable information created barriers around calculating carbohydrate units and insulin-to-carb ratios. Participants felt they were receiving standardised insulin regimens rather tailored individual regimes based on lifestyle or dietary choice, or they felt that meal or nutrition education was focused on people living with type 2 diabetes.

In the pregnancy focus groups, participants pointed to poor technical competences of family doctors in managing and planning of pregnancy in women with type 1 diabetes. This was exacerbated by a structural gap in which care is concentrated with endocrinologists rather than family doctors, thereby limiting the latter's competence development. Another issue found was stigma and fear around heritability of the disease, which is also a concern in young males who do not know where to seek care.

After carrying out problem tree and screening interventions for relevance, two key interventions were identified:

1. Development and approval by Ministry of Health (MoH) of a Guideline on Patient Education of Type 1 Diabetes and, based on this, a series of educational videos on nutrition and physical activity. Co-developed with clinicians, nutritionists, bloggers, and patient communities and disseminated through the MOH and social media in Kyrgyz and Russian languages.
2. A policy dialogue, comprising a policy brief and a roundtable with the MOH, healthcare organisations, and patient representatives, to promote the recommendations from the focus groups to be used within national decision making.

These interventions are being carried out in 2026.

Tanzania

A participatory study was conducted in Dar es Salaam in 2025, comprising six focus group discussions that, overall, included 18 people living with type 1 diabetes, 36 caregivers, 11 healthcare providers. These focus groups were facilitated in Kiswahili using a socio-ecological model.

Findings from these focus groups were further validated and refined into actionable, time-bound recommendations with clearly assigned responsibilities during a one-day national multi-stakeholder workshop attended by civil society organisations, healthcare providers and people living with diabetes.



The dominant concerns, ranked by the share of workshop participants who raised them included:

- Widespread myths and inadequate diabetes education (85%).
- Inconsistent availability of insulin and monitoring supplies (75%).
- Limited health insurance coverage and catastrophic out-of-pocket expenditure (60%).
- Household financial hardship and structural poverty (55%).
- Shortages of trained diabetes specialists alongside poor inter-facility coordination (50%).

From the focus groups, stigma, caregiver mental health burden, and the absence of school or workplace accommodation cut across all five of the key barriers identified. Participants and stakeholders jointly scored and ranked five priority interventions corresponding with the five barriers:

- Guarantee uninterrupted, free availability of insulin and essential monitoring supplies in all public health facilities.
- Scale up culturally appropriate diabetes education targeting communities, schools, and faith leaders; expand National Health Insurance Fund (NHIF) coverage and establish dedicated subsidies for type 1 diabetes supplies.
- Establish peer support networks and integrate mental health screening into diabetes clinics.
- Strengthen the training, deployment, and retention of diabetes-specialised healthcare workers.

Interventions with time bound indicators were created as an action plan up to 2030, led by TANCDA and partners.

Mali

In 2024, a two-stage qualitative study was carried out in Bamako, led by Santé Diabète and hospital teams, focused specifically on stigma and discrimination among children and young adults with type 1 diabetes. The exploratory phase, combined a review of prior literature with in-depth interviews of doctors, interns, and nurses from the paediatric diabetes unit (plus one type 2 diabetologist) and seven focus groups using projective techniques, including an image bank that evoked diabetes experiences and feelings.

The second phase included interviews of 36 people with type 1 diabetes and 18 caregivers, and closed with two validation focus groups to confirm and prioritise the findings.



Stage 1

In-depth interviews of doctors, interns and nurses from the paediatric diabetes unit, and seven focus group discussions.

Stage 2

54 participants across two focus groups:

- people living with type 1 diabetes
- caregivers/parents

The findings in Mali centred on information and its psychosocial consequences:

- Knowledge about type 1 diabetes remains insufficient for the general public, families, and even people with diabetes themselves, which sustains stigma and self-stigma.
- The mental burden of self-management (restrictive diet, insulin regimen) is heavier for many than the condition itself.
- Family support is protective but fragile, and shaped by the person with diabetes' age and gender.
- Self-stigma outweighs proven external discrimination as a source of distress.

Recommendations for interventions as a result of these focus groups centred heavily on combating stigma and self-stigma within education and care regimes. These included:

- Differentiated public awareness campaigns for the general public, families, and people with diabetes respectively.
- Age- and gender-tailored therapeutic education, with distinct objectives and teaching methods for children, adolescents, and adults entering work or marriage.
- Stronger, in some cases mandatory, family involvement in education sessions.

- Improved access to simplified insulin regimens, paired with training for healthcare workers to reduce stigma in clinical care.

Peru

CRONICAS is coordinating a three-phase participatory co-creation process (a prioritisation workshop, one co-design workshop, and a validation workshop) with people living with diabetes, caregivers, healthcare workers, and decision-makers.



Focus Group 1

Prioritisation workshop with 34 participants

Focus Group 2

Co-design workshop with 21 participants

Focus Group 3

Validation workshop with 16 participants

The prioritisation workshop was carried out in early 2026 with 34 participants (13 people living with diabetes, 10 caregivers and 11 healthcare workers). Four main problem areas were discussed: access to insulin and supplies; self-management education; health system responsiveness; and citizen participation in decision-making.

Based on the key barriers and solutions identified, a second workshop was held in March 2026 with 21 participants (seven people living with diabetes, seven caregivers and seven healthcare workers), including returning participants from the first workshop. The objective of this session was to co-design the components, content, and delivery modalities for an intervention.

Discussions focused on educational pathways tailored to different groups, including patients/caregivers, clinical healthcare workers, and health system actors (e.g., managers and pharmacy staff).

A final validation workshop was subsequently conducted with 16 participants (eight people living with diabetes, four caregivers, and four healthcare workers). This session aimed to review and validate the proposed intervention components and materials developed through the previous workshops, and to gather final feedback to refine them before implementation.

The following educational routes were discussed:

- **Route 1** (patients and caregivers) is a hybrid course of educational modules on insulin, carbohydrate counting, mental health, school, and work, delivered through short videos, infographics, and periodic in-person practical sessions, run by a multidisciplinary team with peer participation.
- **Route 2** (clinicians) is a hybrid course on advanced counting, insulin adjustment, technology, and supply management, combining virtual modules with interactive case discussion and accreditation.
- **Route 3** (health managers) is an asynchronous course on service organisation, supply management, and use of data for decision-making. Peru has moved from design to a fully specified, ready-to-test intervention, but implementation is still pending.

CROSS-CUTTING LESSONS LEARNED

The four studies were not designed as a single comparative research program; they were instead created to address specific needs within the country context. Although methods and subject matters differed, the findings converge closely enough to support genuine cross-country learning. This section draws out that learning theme by theme, linking to the specific country evidence behind it.

1. Gaps in diabetes information are a key issue

In every completed study, participants identified unreliable, absent, or contradictory information as key barrier to self-management, not a secondary complaint. In Kyrgyzstan, this took the form of unregulated social media content and its ability to spread misinformation, compounded by the lack of Kyrgyz-language material vetted by professionals. In Mali, the same gap operated at a societal level: people with diabetes and their families, and even the general public, lacked accurate information about type 1 diabetes, which encouraged myths, misunderstandings and stigma. In Tanzania, inadequate diabetes education was the single most frequently cited barrier. Peru's workshops found that gaps in education were apparent across the system, and the need to combat misinformation or gaps at every level, from people with diabetes to healthcare providers.

2. The psychosocial and mental health burden is under-addressed

Across the studies, the emotional and cognitive load of daily self-management (dosing decisions, dietary vigilance, fear of complications) emerged as comparable to, or greater than, the physical burden of the condition itself. For example, Mali's focus groups found that self-stigma can often be a bigger problem than externally imposed discrimination. Focus groups in Tanzania found that the caregiver mental health burden and stigma were key issues that touched all other barriers impacting access to care.

3. Barriers to accessing affordable insulin, supplies and blood glucose self-monitoring technologies remain

Access to treatment for type 1 diabetes remained a foundational issue mentioned across focus groups. In Tanzania, inconsistent availability of insulin and monitoring supplies ranked as the second most common concern, with catastrophic

out-of-pocket expenditure and limited insurance coverage close behind. Mali's participants raised concerns and stress about what will happen to them when they phase out of donation-supported treatment programs and the impact it will have on treatment adherence. In Kyrgyzstan, participants raised parallel concerns about the cost and availability of self-monitoring products in pharmacies. Addressing the issues around access to insulin and technologies in Peru was a key area of discussion during their focus groups.

4. Family and caregiver support is central but structurally fragile

Caregivers, most often parents, are consistently identified as central to whether patients manage type 1 diabetes well, yet are consistently under-supported in that role. Tanzania outcomes found caregivers carrying a distinct, significant mental health burden of their own. Mali found that family support conditions a person living with diabetes' acceptance of diabetes and adherence to treatment, but that often this support can be variable and dependent on cultural and social contexts. Kyrgyzstan's findings pointed to specific psychological difficulties between adolescents and parents, in particular around dietary restrictions.

5. Interventions must be differentiated by age, gender, life stage and cultural context

In general, findings from the focus group show that a one-size-fits-all curriculum or message is not sufficient in supporting people living with type 1 diabetes. For example, Kyrgyzstan found key gaps pregnancy and family planning and separately noted that often times there was a lack of distinction in education between type 2 diabetes and type 1 diabetes. Mali's recommendations are explicit on this point, proposing different objectives, motivational levers, and teaching methods for across gender, life stage and age. In particular highlighting the need for specific topics added depending on context (e.g., family planning in woman-specific education).

Peru's design operationalises a related but distinct axis of differentiation, also recognising the importance of addressing clinician's knowledge gaps as unique from patient's self-care education.

DISCUSSION

Type 1 diabetes remains a chronically under-prioritised condition within global health, and the lived experiences of people managing it, particularly in LMICs, is rarely captured in a way that can directly inform policy. These four studies in Kyrgyzstan, Tanzania, Mali, and Peru, were designed to close that gap by grounding intervention design in the day-to-day realities described by people living with diabetes, caregivers, and healthcare workers themselves. By using participatory and qualitative methods rather than top-down needs assessments, each country was able to bring to light issues that might otherwise be overlooked in standard health system reviews.

Despite differences in context and methodology, similar barriers were identified. Access to affordable insulin, supplies, and self-monitoring technologies persisted as a foundational barrier across all four settings. Participants all cited gaps in information and education as a key barrier to care. The psychosocial and mental health burden of daily self-management was also seen as a strong barrier and something that did not just impact people living with diabetes but also their caregivers. To address these issues, there was an underscored need for interventions to not follow a one-size-fits all model.

Critically, the co-creation approach used in each country, moving from problem identification through to prioritised, community-endorsed interventions, ensured that the resulting recommendations were not only evidence-based but locally owned and feasible within each health system's constraints. This process to create context-specific, participant-validated solutions is an example of how meaningful engagement of people living with diabetes can positively impact policy and programmes going forward.

SUMMARY TABLE

Country	Study scale & method	Key barriers identified	Priority intervention(s)
Kyrgyzstan	46 pts, Bishkek & Osh focus group discussions (FGDs) (patients, pregnant women, caregivers)	Unreliable social media info; no vetted Kyrgyz-language materials; carb/insulin dosing confusion; weak pregnancy-T1D care pathway	Educational video series (nutrition, physical activity) + policy brief & MoH roundtable
Tanzania	65 pts, six FGDs + 47-stakeholder national workshop, Dar es Salaam	Diabetes myths/education gaps (85%); insulin & supply stock-outs (75%); low insurance coverage (60%); workforce shortages (50%)	Guarantee free insulin/supplies; scale culturally-tailored education; expand NHIF coverage; peer/mental-health support; workforce strengthening
Mali	Nine FGDs, 54 patient/relative interviews, eight healthcare worker interviews, Bamako	Information gaps sustain stigma & self-stigma; self-management mental burden; fragile family support; self-stigma > external discrimination	Differentiated public/family/patient awareness campaigns; age/gender-tailored education; simplified insulin access; healthcare worker anti-stigma training
Peru	Three workshops (prioritisation, co-creation and validation), 34 participants (people living with diabetes, caregivers and health care works)	Co-creation validated same core gaps: education, psychosocial burden, provider capacity, system organisation	Multilevel virtual program aimed at three groups (patients, clinicians, managers) focus in different aspects education + clinician capacity-building + manager systems training

For more information:

Molly Lepeska

Manager, NCDs and Access to Medicines, HAI

molly@haiweb.org



Publisher

Health Action International (HAI)

info@haiweb.org



HAIWEB.ORG

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