Community engagement for Lassa Fever research data collection: A researcher's perspective

By Rashid Bundu Kpaka

My name is Rashid Bundu Kpaka and I led community entry for a Lassa fever study in Kenema District, Sierra Leone. In this note, I give a personal account of what we did, in the order we did it, so other researchers can follow the same path.

Background

Our study investigated how Community Engagement and Involvement (CEI) transforms health system governance for Lassa fever control in Eastern Sierra Leone, where case fatality rates reach 38.8% despite decades of clinical investment. We employed a realist evaluation paradigm with mixed-methods explanatory design, bridging implementation science (how to embed CEI institutionally) and evaluation science (why and under what conditions CEI generates change) using Bruton's community engagement theory and realist evaluation to uncover mechanism-based explanations for policy-relevant institutional reform.

Step 1: Laying the groundwork

Before we could even think about entering the communities, we had to sit down and plan properly. This wasn't something to rush; because in Sierra Leone, especially in the Eastern Province, communities remember researchers who came unprepared, made promises they couldn't keep, or disappeared after taking what they needed. We were determined not to be one of them. We started at the District Medical Officer's (DMO) office in Kenema town.

What we did:

- Met with the DMO, who also runs the Lassa fever unit at Kenema Government Hospital and thus understood both the hospital side and the district health side.
- We presented our research plan: what we wanted to study, why it mattered for Lassa fever response, and how long we would be around.
- His dual role as DMO and Lassa clinician was critical in aligning the research with ongoing response structures and ensuring that the study was not perceived as an external or extractive activity.
- Most importantly, he connected us; and introduced me personally to the District Health Management Team DHMT surveillance officer who would become our daily collaborator. He wrote letters of support that we would carry to chiefs and explained to his staff that we were not competitors or auditors but we were part of the same effort to reduce Lassa fever deaths. He then ensured that the DHMT, the surveillance team, Tulane research staff, and the Lassa Unit at KGH all knew about us and agreed we weren't duplicating or interfering with their work.

Identifying where we needed to go

The first task we undertook was deciding which communities to work with; this wasn't random selection as we needed places where Lassa fever was a real, ongoing problem and where communities had experienced cases recently and would benefit from better engagement with the health system.
I worked with the DHMT surveillance team and Tulane's field staff to identify the hotspots. We looked at case data from the past two years, tracing where infections had clustered. We settled on three specific areas: *Lambayama in Nongowa Chiefdom, Bayama in Small Bo Chiefdom, and Panguma in Lower Bambara Chiefdom.* These were places where Lassa fever kept recurring, where the health system had presence but community trust was shaky, and where we could realistically maintain regular contact given our resources.

An important next step was to ask the surveillance officers: "Which of these places will actually let us in? Which ones are fed up with researchers?" Their answers

shaped our final list. Panguma, for example, was added specifically because a Tulane researcher had built good relationships there years before, and that goodwill might still remain.

Understanding the risks

Next, we conducted a proper risk assessment for myself, the team and the communities we would work with. In contrast to Ebola, Lassa fever doesn't spread through casual contact, but it is dangerous, and fear of it can cause harm even when the virus doesn't.

I visited Kenema Government Hospital's Lassa unit and spoke with the nurse clinicians there. I wanted to understand: What were the actual transmission risks in a village setting? How did people typically get infected? What were the signs that a case was becoming severe? I also assessed the health infrastructure we would be working alongside; which peripheral health units were functional? Which ones had staff who could actually diagnose and refer suspected cases? Where were the gaps between what the system promised and what it delivered? This mattered because I didn't want to raise community expectations about treatment that the hospital couldn't provide.

The risk assessment had a social dimension too. I spoke with colleagues who had worked in these areas during Ebola. What had gone wrong then? Where was the lingering anger? One colleague told me about a village in Lower Bambara where the quarantine had been enforced harshly, where houses were marked and families stigmatized for years after. I made notes. We would need to enter that place with extra care, if we entered it at all.

Defining what we actually wanted to achieve

With locations identified and risks understood, I developed our research objectives. I sought to ensure that these were clear to lay people, and wrote them in English first, then translated them into Krio and Mende to test if they made sense:

- **Objective 1:** Understand why people delay going to the hospital when they have Lassa fever symptoms, even when they know about the disease.
- **Objective 2:** Identify who communities actually trust for health advice, and how those trusted people could help get patients to care earlier.
- **Objective 3:** Figure out how to make the health system and communities work together better, so that surveillance improves without creating fear.

These weren't abstract academic goals but practical questions that emerged from what clinicians and community health workers had told me: people were dying because they stayed home too long, and pressurising them to go to hospital wasn't working.

Planning how to engage

Finally, we developed our community engagement strategy. This was the roadmap for everything that would follow. I wrote it knowing that paper plans always change in the field, but that having a clear starting point mattered.

I took this plan to the DMO, we sat in his office and went through it page by page and he made some changes. He pointed out where our timeline was unrealistic, where we were overlapping with another Tulane activity, where we needed stronger safety protocols.

At this stage, the research objectives and proposed community engagement strategy were discussed and refined in collaboration with the District Health Management Team (DHMT), surveillance officers, Tulane research partners, and PARES programme staff. This early alignment positioned the study as an extension of existing response efforts rather than a standalone project, which facilitated institutional acceptance and operational support. That meeting, and the planning that led up to it, took three weeks.

Why this mattered: In Sierra Leone, communities will ask "Who sent you?" If you don't have proper backing from the health system, doors won't open. We made sure our study looked like an extension of ongoing work, not a new foreign project.

That preparation made the difference between being a researcher who extracts information and being one who builds something useful with the community. The next steps: stakeholder mapping, traditional entry, community meetings, would test that preparation in ways I couldn't fully anticipate. But the foundation was solid.

What we got: Letters of introduction from the DHMT and a contact list of key health staff who would vouch for us later.

Step 2: Map who actually matters in the community

We didn't just look at organizational charts. We needed to know who really makes things happen in the villages.

How we did this:
We sat down with people who knew the area well; DHMT surveillance staff, Tulane field workers, anyone who had worked in these communities before. We asked them to name names across two groups:

Formal health actors:

- DHMT surveillance officers
- KGH clinicians and lab staff
- Peripheral health unit in-charges
- Community health workers (CHWs)

Community-level actors:

- Paramount chiefs, section chiefs, town chiefs (the traditional hierarchy)
- Religious leaders such as imams and pastors
- Women's group leaders and youth leaders
- Traditional healers
- Ward development committee members
- Lassa fever survivors (we specifically sought them out)

We then validated this list by visiting: the 3 identified Nongowa, Lower Bambara, and Small Bo chiefdoms; we didn't assume the names on paper were correct. In one village, the man with the official title was not the man people actually listened

to. We found the real decision-makers by asking villagers directly: "If something important needs to happen in this community, who do you go to?"

What we learned: Power in Eastern Sierra Leone doesn't always follow official lines. Sometimes the most influential person has no title and is not part of the health system governance structure. We adjusted our list based on what we found on the ground.

Step 3: Entry through the proper traditional channels

We did not drive directly to villages and start asking questions. That would have failed.

The entry protocol we followed was as follows:

1. **Started with the leaders:** We first visited the paramount chiefs of each chiefdom. We brought kola nuts as a sign of respect; this is essential in Mende culture.
2. **Explained ourselves properly:** We told them who sent us (showing the DHMT letters), what we wanted to do, and why their community specifically mattered for understanding Lassa fever.
3. **Waited for permission:** The paramount chief would then direct us to section chiefs, who directed us to town chiefs. We moved down the hierarchy, never skipping levels with the same signs of respect.
4. **Used the right language:** All these meetings were in Krio and Mende. Even though some chiefs understand English, using local languages shows respect and ensures everyone understands.

What happened in practice: In Small Bo, the speaker for the paramount chief asked us to come back the next day so he could consult with his elders; we waited. When we returned the next day, he had questions about how we would protect his people's dignity; we answered honestly. Only then did he give his blessing and directed us to the section chief.

Step 4: Hold community sensitization meetings

Once chiefs gave permission, we gathered community members in central places like community centres, mosque grounds, or open spaces under trees.

How we ran these meetings:

- **Made them conversational, not lectures.** We explained the study, then opened the floor for questions.
- **Spoke about the past.** We acknowledged Ebola and previous Lassa fever outbreaks, the often-difficult legacy.
- **Listened to fears.** People talked about isolation wards, about families being taken away, about researchers who came and never returned; we gave space to have this conversation and acknowledged the issues raised.
- **Used local health volunteers.** We brought along CHWs and Lassa fever outreach team members who already knew the community. They translated for us in more ways than just language; they explained our intentions.

A key moment: In one community, an elderly woman stood up and said, "*Usually they come and tell us. You are asking us what we think.*" That difference, being asked rather than told became the foundation of our work there.

Step 5: Negotiate roles with community members

We didn't assign jobs to people. We asked them how they wanted to be involved.

How this worked:

With traditional healers: Instead of telling them to stop treating patients, we asked how they identified serious fever. We developed a simple checklist together: fever plus bleeding gums plus contact with rats means send to hospital immediately. They became our early warning system.
With CHWs: We moved them from "message carriers" to "dialogue facilitators." Their job became listening to community concerns and bringing them back to us, not just repeating health messages.

With Lassa fever survivors: We asked if they would share their stories. Some agreed. Their testimony about surviving treatment at KGH became more powerful than any leaflet we could distribute.
With chiefs and religious leaders: They helped us schedule activities, provided meeting spaces, and lent their authority to our presence.

Important: These roles changed over time. We revisited agreements every few months and adjusted based on what was working.

Step 6: Set up three types of regular meetings

We created a structure for ongoing engagement that had three separate streams:

Why three streams: Community members won't speak freely if doctors are listening. Health workers won't admit mistakes if community members are listening. The joint forums worked because both sides had already spoken separately.

Stream 1: Implementer-only meetings

- Who attended: DHMT staff, Tulane researchers, PARES staff-our team
- Purpose: Solve operational problems, share frustrations, align our work with the health system
- How often: Every two weeks
- Where: Usually in Kenema town

Stream 2: Community-focused meetings

- Who attended: Chiefs, women's groups, youth leaders, healers, CHWs, survivors—no government officials at first
- Purpose: Let community members speak freely about what they were experiencing, fearing, and needing
- Language: Krio and Mende only
- How we ran them: Open discussion, no fixed agenda, explicit permission to criticize the health system

Stream 3: Joint forums

- Who attended: Mix of health actors(Chiefs, women's groups, youth leaders, healers, CHWs, survivors) and community representatives (Chiefs, women's groups, youth leaders, healers, CHWs, survivors)
- Purpose: Solve problems together, make shared decisions, hold each other accountable
- How we ran them: Co-chaired by chiefs and our facilitators. We presented community feedback to health staff in front of the community, and vice versa.

Step 7: Handle ethics and safety properly

Informed consent in practice:
Community forums and sensitization meetings operated differently as these were not research activities requiring individual consent; they were engagement processes to explain the study and negotiate access; here we used **oral community consent** through established customary protocols. We presented the study purpose to chiefs and assembled community members, answered questions openly, and sought the community's collective agreement to proceed. Chiefs recorded their permission, but the substantive consent was verbal, public, and deliberative—conducted in Krio and Mende so everyone could participate. We did not distribute forms in these large gatherings; instead, we created space for dissent, questions, and conditional approval, adjusting our plans based on what we heard.

- We made sure people knew they could refuse or withdraw without punishment.

Confidentiality:

- We promised never to share individual information with authorities for enforcement.
- We explained that in a village, everyone knows who is sick, our job was to control how information was used, not to pretend we could hide it completely.

Infection prevention:

- We demonstrated our safety equipment and procedures in every community.
- We invited community members to watch us work so they could see we weren't bringing Lassa fever into their villages.
- One community assigned a "safety watcher" to observe us for three days before allowing us to proceed.

Step 8: Maintain presence beyond the first visit

Our community entry did not end after the first meeting; we kept showing up for the full 18 months of our study, from January 2024 to July 2025, and our presence served purposes well beyond data collection alone. The first six months demanded intensive engagement, with weekly visits to each chiefdom to complete stakeholder mapping, navigate traditional entry protocols through paramount and section chiefs, and conduct initial sensitization meetings. We were patient during this phase; some communities required multiple courtesy visits before formal gatherings could proceed, and we honored that pace.

Once data collection began in earnest during months 8through twelve, our community contact continued through biweekly visits even when we were not actively recruiting participants. Our CEI facilitators checked in with chiefs, addressed emerging concerns promptly, and shared preliminary observations to maintain transparency. Each of the three communities had a dedicated facilitator who came to know families by name, remembered and could navigate local tensions with cultural fluency. This embedded presence meant sitting with women in clinic waiting areas, joining a chief's funeral contribution, accepting small gifts of kola or groundnuts and reciprocating appropriately; this small interactions-built trust far more than formal meetings ever could.

When problems arose, we responded quickly; for instance, a participant who felt disrespected by a research assistant saw our facilitator return within forty-eight hours to mediate and apologize. When communities asked us to shift meeting times to avoid farming schedules, we adjusted without complaint. We used our

presence to informally mentor community health workers on complementary feeding counselling, reinforcing their roles rather than competing with them. We also served as linkage facilitators, connecting community concerns to hospital administrators and advocating for improved waiting area conditions based on participant complaints, then reporting back on the responses we secured.

The final three months brought us full circle; when we returned to communities not to take more information, but to give it back; sharing aggregate findings in validation meetings where we asked whether our results matched their experience. We discussed potential programme responses with DHMT and community leaders, ensuring the research findings might actually shape local action. Throughout, we followed through on every promise: when we said we would bring information, we returned with printed summaries in Krio and Mende; when we promised to raise an issue with DHMT, we reported back on what happened, even when the answer was disappointing. This 18 months of showing up, was not merely to extract data but to build genuine partnership, transformed community entry from a procedural step into something that outlasted our study itself.

Why this mattered: Trust in Sierra Leone is built through repeated, predictable presence. A researcher who comes once and disappears is remembered as someone who took something. A researcher who returns regularly becomes part of the landscape.

What made this work: key lessons

1. **Respect the hierarchy:** Never skip the paramount chief. Present kola nuts. Wait when asked to wait.
2. **Language matters:** Use Mende and Krio for everything important. English is for documents, not for building trust.
3. **Acknowledge the past:** Ebola is not forgotten. Mention it first, don't wait for others to bring it up.
4. **Listen before measuring:** If you start with surveys and data collection, you have already failed. Start with conversation.
5. **Work with existing structures:** Don't create parallel systems. Fit into what Tulane, DHMT, and local health workers have already built.

6. **Survivors as our best resource:** People who have had Lassa fever and survived can say what no health worker can say.
7. **Be patient:** What takes one day in Freetown takes three days in Kenema District. Plan for that.

Final note

This is not a perfect blueprint for working with communities during research. Even in Eastern Sierra Leone, every community is different. Some are more suspicious of outsiders, some have stronger traditional authority and some have been adverse experiences from previous research. But these steps including: *Laying groundwork, proper stakeholder mapping, traditional entry, community sensitization, role negotiation, three-stream engagement, upholding ethics principles, and sustained presence,* formed the backbone of how we entered communities and stayed in them.

The goal was not just to collect data but to leave something useful behind; this note describes our experience of working in Kenema District, Sierra Leone and we believe many of these steps may be useful to other researchers working at community level.