Research Square

Preprints are preliminary reports that have not undergone peer review.
They should not be considered conclusive, used to inform clinical practice,
or referenced by the media as validated information.

Retaining Participants in a Prospective Epidemiological Study Involving Blood Draws Through Sustained Engagement: Lessons from Enable 1.0 Incidence Study on Lassa Fever Infection in Abakaliki, Southeast Nigeria

Cosmas Kenan Onah

onahcosyo@gmail.com

Alex Ekwueme Federal University, Ndufu-Alike

Onyinyechukwu Uzoamaka Oka

Alex Ekwueme Federal University, Ndufu-Alike

Chijioke Vitalus Iloke

Alex Ekwueme Federal University, Ndufu-Alike

Nkechi Violet Nwachukwu

Alex Ekwueme Federal University Teaching Hospital

Marycynthia Nnenna Otta

Alex Ekwueme Federal University Teaching Hospital

Olaedo Nnachi

Alex Ekwueme Federal University Teaching Hospital

Christian Obasi Akpa

Alex Ekwueme Federal University Teaching Hospital

Victoria Chioma Azuogu

Alex Ekwueme Federal University Teaching Hospital

Robinson Chukwudi Onoh

Alex Ekwueme Federal University, Ndufu-Alike

Emeka Ogah Onwe

Alex Ekwueme Federal University, Ndufu-Alike

Suzanne Penfold

P95 Clinical and Epidemiology Services

Henshaw Mandi

Coalition for Epidemic Preparedness Innovations

Benedict Ndubueze Azuogu

Alex Ekwueme Federal University, Ndufu-Alike

Research Article

Keywords: Blood draw, community engagement, epidemiological study, Lassa fever, Nigeria, participant retention

Posted Date: November 10th, 2026

DOI: https://doi.org/10.21203/rs.3.rs-11064897/v1

License: This work is licensed under a Creative Commons Attribution 4.0 International License.
Read Full License

Additional Declarations: No competing interests reported.

Abstract

Background

Participant retention is critical in longitudinal studies involving blood draws. Enable 1.0 Incidence Study on Lassa Fever was conducted to estimate Lassa virus infection and disease to inform outbreak preparedness and vaccine research. This nested analysis aimed to explore community engagement strategies employed to retain participants.

Methods

Enable 1.0 was a multi-site, multi-country, prospective cohort study (December 2020–December 2023) aiming to estimate the incidence of Lassa virus infection and symptomatic Lassa fever disease. In Abakaliki Nigeria, the study tracked Lassa virus seroconversion among 1,000 healthy participants across 10 communities in three Local Government Areas. Community Liaison Officers, village guides, and field workers sustained engagement through fortnightly visits and sensitization meetings. Fieldworkers completed a semi-structured Google Forms questionnaire documenting their experiences and observations across 713 participants, including participant reception, retention threats, and their engagement strategies. The data were analyzed descriptively using IBM-SPSS Statistics Version-25.

Results

Overall, the study achieved a 90.5% participant retention rate over the 24-month follow-up period across the full cohort of 1,000 participants. Based on fieldworker reports covering 713 participants, 91.4% (652/713) completed the study, while 8.6% (61/713) did not. Reported retention threats (102/713; 14.3%) included inadequate compensation (52/713; 7.3%), family pressure (48/713; 6.7%), and fear of blood rituals (37/713; 5.2%). Reasons for non-completion were relocation (23/713; 3.2%), refusal (15/713; 2.1%), family opposition (6/713; 0.8%), and death (6/713; 0.8%). Key retention strategies included engaging village guides (439/713; 61.6%), incentives (293/713; 41.1%), family support (152/713; 21.3%), and involvement of traditional leaders (151/713; 21.2%). Despite rumours related to blood rituals, sustained community engagement and unscheduled home visits supported by reassurance from the study technical team helped dispel misinformation, with 88.2% (629/713) of participants remaining warmly receptive to fieldworkers throughout the study.

Conclusion

The Enable 1.0 study demonstrated that high participant retention is achievable in resource-limited high-risk settings when structured community engagement and rapid response mechanisms are integrated

into study implementation. Future studies should embed engagement structures, institutionalize rapid responses to rumours, and prioritize transparent communication to strengthen retention and public trust.

BACKGROUND

Participant retention is pivotal in longitudinal epidemiological research: without sustained follow-up, findings become vulnerable to attrition bias, loss of statistical power, and inaccurate incidence estimates – all of which jeopardize its utility for guiding public health interventions [1, 2]. In the context of Lassa fever (LF), a disease with highly variable clinical presentation and episodic outbreaks, achieving reliable incidence and seroconversion data depends critically on maintaining cohort integrity through repeated blood draws over time [3].

Lassa fever is an acute viral haemorrhagic illness caused by Lassa virus (LASV) of the *Arenaviridae* family, transmitted through exposure to rodent excreta (*Mastomys natalensis*) and via human-to-human spread, particularly in health-care settings with poor infection control[4, 5]. It is endemic in West Africa, with Nigeria, Sierra Leone, Liberia, and Guinea bearing the brunt of disease burden. The African CDC estimates that West Africa sees 100,000–300,000 LF infections and approximately 5,000 deaths annually, though these are rough estimates due to diagnostic limitations and extrapolation from historical data [6, 7]. In Nigeria, repeated yearly outbreaks—especially in states like Ebonyi, Edo, and Ondo—underscore the unpredictability and evolving epidemiology of Lassa fever [8–10].

Given these challenges, community-based prospective cohort studies with repeated sampling are essential to capture accurate seroconversion rates and infection incidence, which are fundamental to disease modelling, risk stratification, and intervention design [3]. Such data also inform vaccine efficacy trials, where understanding the baseline incidence and force of infection is vital to estimating sample size and assessing vaccine impact [3]. However, these designs critically depend on participant retention – particularly when frequent blood draws may elicit discomfort, cultural suspicions, or avoidance [11].

In response to these needs, the Coalition for Epidemic Preparedness Innovations (CEPI) launched the Enable Lassa Research programme in 2019, representing the largest-ever Lassa fever research initiative in West Africa [12]. In the first study, now referred to *Enable 1.0*, over 23,000 participants were enrolled across five countries – Benin, Guinea, Liberia, Nigeria, and Sierra Leone – to generate epidemiological and clinical insights to inform LASV vaccine development and trial, and outbreak preparedness [13, 14]. Central to Enable's success are strong retention rates that ensure valid seroconversion and symptomatic incidence measures through time [3].

Retaining participants in such settings, however, is not straightforward. Blood-sampling studies in rural West Africa often face rumours and misconceptions, ranging from suspicions of blood "selling" to associations with ritual or spiritual harm; these sociocultural barriers can deter participation or lead to dropout, thereby impairing the study's ability to yield reliable longitudinal data [15–17]. Documented cases

across African research environments emphasize how uninformed or culturally insensitive approaches can undermine trust, even in scientifically critical studies [17, 18].

Consequently, community engagement frameworks become indispensable retention tools. Global guidelines like the UNAIDS/AVAC Good Participatory Practice (GPP) and regional guidance such as H3Africa Community Engagement articulate principles for sustained stakeholder involvement, transparent communication, and culturally attuned feedback – all contributing to sustained participation in long-term biomedical research [19–21]. These strategies serve dual purposes: they minimize attrition, preserving data integrity, and they foster community trust, which is foundational to accepting future interventions such as vaccines [21, 22].

In Lassa fever endemic zones – where repeated sero-surveying is critical – effective retention strategies not only enable scientifically valid incidence and immune-response data but also lay the groundwork for successful vaccine trial preparedness and eventual uptake [3, 23]. Against this backdrop, as part of the Enable 1.0 Lassa Fever Incidence Study at Alex Ekwueme Federal University Teaching Hospital Abakaliki AEFUTHA, we evaluated fieldworker experiences with aim to understand the challenges and facilitators of continuing participant engagement in a prospective epidemiology study involving blood collection in LF-endemic communities in Nigeria.

METHODS

Overview of Enable 1.0

The Enable 1.0 LF study, funded by the CEPI was a multi-site prospective cohort study conducted from December 2020 to December 2023 in LF-endemic areas across multiple West African countries, including Nigeria, with two primary components: the LF Disease Cohort, which enrolled individuals presenting with suspected LF to estimate the incidence and clinical outcomes of symptomatic disease, and the LASV Infection Cohort, which followed healthy community participants to estimate the incidence of LASV infection through longitudinal seroconversion analysis. While some sites implemented both study components, the AEFUTHA site in southeast Nigeria conducted only the LASV Infection Cohort. This cohort study enabled the generation of epidemiological data essential for understanding LASV transmission dynamics in the local context, contributing to the broader multi-site study. Detailed study design and procedures, including recruitment, follow-up schedules, and laboratory methods, are described in the full protocol [3].

The study population comprised healthy males and females aged two years and above who had resided in the study area for at least six months prior to recruitment and were anticipated to remain within the area throughout the study period, lasting for 24 months. At the AEFUTHA site, a total of 1,000 participants were recruited into the study. These were from 10 communities (identified as clusters) within three Local Government Areas (LGAs): Abakaliki, Ebonyi, and Izzi. The communities included

Abofia, Amagu Unuhu/Azuiyiokwu, Ishieke, Kpirikpiri, Ndiawala, Nsugbe/New Layout/Timber Shade, Okpoitumo, Hausa Quarters, Ugwuachara, and Unagboke.

Prior to the commencement of the study, the study team, led by the Site Principal Investigator (PI), conducted targeted advocacy and sensitization in the State, LGA, and community levels to secure stakeholder support. At the state level, key actors within the Ministry of Health – including the Commissioner for Health, the Director of Public Health, and the State Epidemiologist – were engaged, alongside parliamentarians such as the Speaker of the Ebonyi State House of Assembly and the Chairman of the House Committee on Health. These advocacy visits aligned the study objectives with state health priorities and stimulated political goodwill.

At the LGA level, advocacy visits were made to Chairpersons of the LGAs. Local health authorities, particularly the Disease Surveillance and Notification Officers (DSNOs), were sensitized, leveraging their familiarity with local communities. At the community level, traditional rulers, village heads, religious leaders, women's groups, and youth representatives were sensitized to ensure broad-based acceptance.

Field activities for the study were implemented by 10 field teams, each assigned to a specific cluster. Every field team consisted of two data collectors (DCs), one phlebotomist, two community liaison officers (CLOs), and one Village Guide. The DCs and Phlebotomists were trained healthcare providers from AEFUTHA. The CLOs and Village Guides were trusted members of the participating communities, who were nominated by key stakeholders with strong influence in the communities, including village heads, traditional leaders and political office holders. They were deliberately co-opted into the study to strengthen community entry, build trust, and enhance cooperation. The CLO cadre included the three DSNOs of the participating LGAs, whose established roles in public health surveillance gave additional legitimacy to the study

All field workers were trained on the study's purpose, objectives, and procedures before being delegated to their specific tasks. The field workers successfully recruited and followed up with the 1,000 participants over a 24-month period, from December 2020 to January 2023, with baseline and six-monthly 5ml blood draws for serological testing to detect LASV-specific IgG antibodies and for potential future assessments – amounting to five blood draws per participant. Between these visits, CLOs maintained regular contact with the participants through fortnightly household visits or phone calls to monitor their well-being and remind them of follow-up schedules.

During follow-up, the field and study technical teams worked proactively and reactively to address emerging concerns that threatened participant retention such as rumours or misinformation. Field workers managed most issues directly; however, in extreme situations where challenges could not be resolved at the field level, the Site PI and technical team intervened directly to help clarify study procedures, reassure participants, and restore trust by rapidly conducting unscheduled stakeholder or household visits to clarify concerns. Depending on the issue, they re-engaged and re-sensitized the community, demonstrated that only 5 mL of blood was collected, or provided counselling to address fears related to infertility, venipuncture discomfort, repeated questioning, or non-return of serological

results – serology test results were returned to participants as part of the study's commitment to ongoing engagement. However, results from the baseline blood draw were returned to participants at the 18-month follow-up visit. Results from the 6-month and 12-month blood draws were provided at the 18-month and 24-month follow-up visits, respectively, resulting in delays of approximately 12–18 months between sample collection and result feedback. These delays prompted some participants to seek clarification about their results and, in some cases, expressed dissatisfaction and explicit threats to withdraw from the study.

Data for the primary study was collected by the field workers using standardized questionnaires designed in REDCap [24]. These questionnaires captured relevant epidemiological information, including demographic data, household composition, history of Lassa fever exposure, and socioeconomic variables. The primary incidence and epidemiological surveillance data of LASV infection were not the focus of this paper; instead, emphasis was placed on fieldworker experiences at the AEFUTHA site.

Collection of Field Experiences

Field experiences were collected by two field workers per cluster, self-reporting information using a semi-structured questionnaire, designed in Google Form. This form collected data on key aspects of participant engagement, including the participants' reception of field workers at baseline and during each of the six-monthly blood draw, measured using a five-point Likert scale ranging from "very unfriendly" to "very warmly." It also captured threats to withdraw from the study along with the underlying reasons, participant concerns that could potentially impact retention, and the retention strategies employed by field workers and the technical team to maintain participation despite community rumours and skepticism. For this analysis, threats to withdraw were defined as explicit statements by participants or their proxies indicating an intention to discontinue study participation unless specific conditions were met, whereas concerns about continuing participation referred to expressions of dissatisfaction or apprehension without a clear intention to withdraw.

To gain deeper insights into field experiences, the Google form included an open-ended question where field workers were asked to provide a detailed account of interactions with participants that they felt had a significant impact on retention. The link to the Google Form was shared with field workers, who were responsible for completing it during follow-up visits. Out of the total of 1,000 participants enrolled in the Enable 1.0 study, 90.5% were retained until the study's conclusion. The 713 participants dataset represents the interactions for which field worker reports were available and forms the basis for the descriptive and qualitative analysis presented here.

Data Analysis

Data were exported from Google Forms into Excel and analyzed with SPSS Version 25 (IBM Corp., Armonk, NY, USA). Categorical variables such as reception of field workers, threats to withdraw, and reasons for withdrawal were summarized using frequencies and percentages. For reporting purposes,

the five-point Likert scale for reception was collapsed into three categories: *hostile, neutral*, and *warm*. Reasons for withdrawal were treated as multiple responses, with each coded as reported or not reported. Responses to the open-ended questions were reviewed and analyzed thematically to identify common patterns in participant concerns and retention strategies. Illustrative quotes from field workers were used to support the qualitative findings.

Measurement of Variables

The primary outcome variable was threat to withdraw from the study, measured as a binary categorical variable with responses categorized as “Yes” for field workers who reported that a participant (of the parent/guardian of participants under 18 years) expressed any intention to discontinue and “No” for those who did not. Among those who indicated a threat to withdraw, follow-up questions were used to capture the reasons for such decisions. This was treated as a multiple-response variable, with predefined options including inadequacy of compensation, pressure from family members or friends, fear of ritual use of blood, pain or discomfort associated with blood draw, stigmatization from peers, fear that the amount of blood collected could be detrimental to health, belief that blood draw may cause infertility in females, and other reasons. Each reason was coded as reported or not reported, and percentages were calculated based on the total number of field workers who provided reasons; hence the cumulative frequency exceeded the number of participants who threatened to withdraw. This approach is consistent with previous longitudinal studies where reasons for attrition were coded as multiple responses to capture the complex socio-cultural dynamics influencing retention [25, 26].

Reception levels of participants during field engagement were also measured and classified into three categories based on field workers’ repeated observations across follow-up visits. Field workers rated participant reception on a standardized 1–5 scale at each encounter. Because participants were followed up a varying number of times, an aggregate reception score was computed for each participant by dividing the total reception score by the number of follow-up visits. For participants seen only at enrollment, the enrollment score served as the aggregate score. Aggregate scores were then categorized as *hostile* (< 3), *neutral* (= 3), or *warm* (> 3). Participants who displayed suspicion, anger, aggression, or open resistance were categorized as *hostile*. Those who were indifferent, showing minimal engagement but without overt resistance, were categorized as *neutral*. Participants who demonstrated friendliness, cooperation, trust, and willingness to engage positively with the fieldworker were categorized as *warm*. The use of subjective fieldworker assessments of participant attitude has been documented in community-based cohort studies as a valid measure of participant – researcher interaction and predictor of retention outcomes [27].

RESULTS

A total of 18 field workers out of 20, representing two DCs from each of the nine reporting clusters, submitted experience reports (Table 1). Twelve DCs from six clusters provided complete reports for all

participants under their follow-up, while six from three clusters submitted partial reports. No reports were obtained from one cluster. The respondents comprised 8 males (44.4%) and 10 females (55.6%), with ages ranging from 24 to 47 years. Most field workers were within the 36–40-year age bracket (8/18; 44.4%), followed by those older than 40 years (7/18; 38.9%), while 16.7% (3/18) were aged 35 years or younger. Almost all the field workers (17/18; 94.4%) had attained tertiary education. In terms of professional cadre, the majority were medical doctors (83.3%), while one fieldworker each was a nurse, an environmental health officer, and a non-professional with secondary education.

Table 1
Characteristics of Reporting Field workers in the Enable 1.0 Study at the AEFUTHA Site Nigeria

Variable	**Frequency N = 18**	**Percentage (%)**
Age of respondents in years		
≤ 35	3	16.7
36–40	8	44.4
> 40	7	38.9
Age range		24–47
Sex		
Male	8	44.4
Female	10	55.6
Educational level		
Secondary	1	5.6
Tertiary	17	94.4
Professional cadre		
Medical doctor	15	
Nurse	1	
Environmental health officer	1	
Non-professional	1	

For the analysis presented in this paper, data was available from interactions with 713 participants. This subset includes participants for whom field workers completed the follow-up documentation, including interactions with participants who eventually withdrew or had incomplete follow-up. Of the 713 participants for whom field workers provided enrollment (T0) reports, 97.9% (698/713) were followed

during month 6 (T1), 96.6% (689/713) during month 12 (T2), 96.4% (687/713) during month 18 (T3), and 96.1% (685/713) during month 24 (T4). Fifty-two point five percents (374/713) of the participants were females, and the majority were aged 11–40 years (Table 2).

Table 2
Sociodemographic characteristics of the Enable 1.0 study participants at AEFUTHA site, Nigeria

VARIABLE	FREQUENCY N = 713	PERCENTAGE (%)
Age Group in years		
< 11	109	15.3
11–20	173	24.3
21–30	131	18.4
31–40	119	16.7
41–50	101	14.2
≥ 51	80	11.22
Sex		
Female	374	52.5
Male	339	47.5
Education		
No formal	59	8.3
Primary	242	33.9
Secondary	295	41.4
Tertiary	117	16.4
Employment		
Employed	284	39.8
Unemployed	429	60.2
Place of residence		
Rural	396	55.5
Urban	317	44.5

Regarding their educational status, 41.4% (295/713) had completed secondary education, 33.9% (242/713) had primary, 16.4% (117/713) had tertiary, and 8.3% (59/713) had no formal education. Only 39.8% (284/713) of the participants were employed. In terms of place of residence, 55.5% (396/713) lived in rural areas, and 44.5% (317/713) lived in urban areas.

At enrollment (T0), majority (81.1%; 578/713) of the participants received the field workers warmly, while 15.4% (110/713) were neutral, and 3.5% (25/713) were hostile (Fig. 1). The warm reception increased slightly during the month-6 (T1) follow-up to 86.0% (600/698). During month 12 (T2) follow-up, warm reception remained consistently high at 85.3% (689/713), with 5.4% (37/713) expressing hostility. A similar trend persisted during month 18 (T3), where warm receptions were recorded at 85.6% (687/713), and hostility at 5.8% (40/687). During the final follow-up on the month 24 (T4), there was a slight decrease in warm receptions to 85.4% (585/685), while hostile receptions peaked at 6.7% (46/685), the highest observed across all visits. The aggregate reception rating shows that most (88.2% (629/713) participants maintained a warm reception towards the field workers during their engagements. Neutral and hostile receptions were considerably lower, at 6.6% (47/713) and 5.2% (37/713), respectively.

While field workers reported that the vast majority (611/713; 85.7%) of participants did not express intentions to withdraw, 14.3% (102/713) reported threats to withdraw (Table 3). The most frequently cited reasons included inadequacy of compensation (52/713; 7.3%), pressure from family members (48/713; 6.7%), and fears that collected blood was being used for rituals (37/713; 5.2%). Other notable reasons were pain and discomfort associated with blood drawing (34/713; 4.8%), stigmatization from peers (30/713; 4.2%), and concerns that the volume of blood collected could be harmful to health (24/713; 3.7%).

Table 3
Threats to Withdraw from the Study and Reasons (Rumours and Misinformation Included) Among Enable 1.0 Participants at the AEFUTHA Study Site, Nigeria

VARIABLE	FREQUENCY N = 713	PERCENTAGE %
Threat to withdraw from the study reported at any point		
No	611	85.7
Yes	102	14.3
Reasons for threat to withdraw from Enable 1.0 study*	**N = 698**	
Inadequacy of the compensation	52	7.3
Family pressure	48	6.7
Fear of blood rituals	37	5.2
Pain/discomfort of blood draw	34	4.8
Stigmatization	30	4.2
Fear of excessive blood draw	24	3.7
Pressure from friends	21	2.9
Fear of later female infertility due to blood draw	8	1.1
Parent refusal	7	1.0
Others** (< 1%)	15	2.2

*Multiple response; ** Too many questions asked by research team, relocation, sickness, husband refusal, non-provision of test result, Study lasting longer than expected, spiritual reason

Among the participants reported on, a retention rate of 91.4% was observed, with 652 completing the study and 8.6% (61/713) not completing participation (Table 4). The primary reasons for termination, derived from the main study records, not from the fieldworker experience survey described in the methods section, included participant relocation to non-participating communities (32/713; 4.9%), outright refusal to continue follow-up (15/713; 2.1%), and refusal by parents or family members (6/713; 0.8%). A small proportion (2/713; 0.3%) withdrew due to demands for increased compensation while 0.8% (6/713) were terminated due to death.

Table 4
Completion and Reasons for Non-Completion of Participation in Enable 1.0 Study at the AEFUTHA Site, Nigeria

VARIABLE	FREQUENCY N = 713	PERCENTAGE %
Study Completion status of participants		
Not completed	61	8.6
Completed	652	91.4
Reasons for non-completion of study		
Participant relocated	32	4.9
Participant refused further follow up	15	2.1
Parental and family members' refusal	6	0.8
Demand for increase in compensation	2	0.3
Termination due to death	6	0.8

Few qualitative insights from field workers' responses to the open-ended questions provide context for these figures. In one case, a female participant who was in her thirties, after initially welcoming the field team, discontinued participation following recurring nightmares in which her late husband accused her of selling their children's blood. Despite reassurance efforts, the fear of spiritual retribution led her to withdraw. A male fieldworker and a medical doctor presented it this way:

"The participant, as the household head, welcomed us during enrollment. However, after months of follow-up, she declined to continue, citing nightmares after the first blood sampling. In the dreams, her late husband accused her of selling their children's blood and threatened that she would die if she did it again. Despite persistent efforts to persuade her, she refused out of fear."

Another eight-year-old female participant who was residing with her aunt, who acted as her guardian at the time of enrolment, was withdrawn after her parents, upon discovering her involvement, accused her of being manipulated by her aunt into "selling her blood." They removed her from her place of residence, making her untraceable. The female fieldworker and a medical doctor reported:

"The participant was living with her aunt when she was enrolled in the programme. However, upon learning about her participation, her parents began accusing her of selling her blood under the influence of her aunt. As a result, they took her away from her initial residence, and she has been untraceable ever since."

In a different instance, an adolescent girl's father, who was initially unaware of her enrollment due to frequent travel, opposed her continued participation upon his return. Although the mother had previously

consented, the father's refusal, driven by familial disputes and distrust, ultimately led to the withdrawal. According to the male fieldworker and a medical doctor:

"The girl's father was firmly opposed to her participation. Initially, her mother consented and enrolled her in the programme since her father, a driver, was often away. However, when he returned months later and learned about the programme, along with other internal family issues, he refused to allow both his wife and daughter to continue participating."

Among the 713 participants, the most frequently expressed concern for continuing in the study was the desire for increased compensation (86/713; 12.1%), followed by delays in receiving test results (45/713; 6.3%) and fear of needle prick pain or injury (11/713; 1.5%) (Table 5). Other concerns, such as communication with CLOs (visits, calls, text messages), perceived health risks from repeated blood collection, demand for more study education, and expectations for provision of social amenities, were reported less frequently.

The field workers reported that the rapid response approach was used to prevent participant withdrawals. The most frequently observed retention strategies included engagement of CLOs and Village Guides (61.6%), who facilitated introductions to households, clarified study procedures, and resolved minor concerns before they escalated. Other strategies noted by the field workers included incentives (41.1%), involvement of technical team members (32.4%), engagement of trusted family members or friends (21.3%) and traditional leaders (21.2%). Political (15.6%) and religious stakeholders (15.1%) were also occasionally engaged, while re-education of participants (11.6%), provision of material support (5.0%), and efforts to address individuals who spread misinformation (1.1%) were less frequently reported.

Table 5
Concerns of Retained Participants and Retention Strategies in the Enable 1.0 Study at AEFUTHA Study Site, Nigeria

VARIABLE	FREQUENCY N = 713	PERCENTAGE %
Concerns of Retained Participants in the Enable 1.0 Study*		
Desire for increased compensation	86	12.1
Delays in receiving test results	45	6.3
Fear of needle prick pain and injury	11	1.5
CLO* communication (visits, calls, text messages)	7	1.0
Concerns about health implications of blood collection	5	.7
Need for more study education	1	0.1
Expectation for provision of social amenities	1	0.1
Retention Strategies Employed by Field Workers*		
Involvement of CLOs and Village Guides	439	61.6
Provision of incentives	293	41.1
Involvement of technical team	231	32.4
Support from trusted friends/family members	152	21.3
Engagement of traditional leader	151	21.2
Involvement of political stakeholder	111	15.6
Engagement of religious leader	108	15.1
Participant re-education	83	11.6
Provision of material support	36	5.0
Engagement of community members spreading misconceptions	8	1.1
*Multiple responses; CLO = Community Liaison Officer		

DISCUSSION

At the AEFUTHA site, a prospective cohort study involving repeated blood draws for Lassa fever infection had high overall retention. Field workers noted a minority of participants who threatened to withdraw, most often due to concerns about incentives, pressure from family and peers, discomfort associated with venipuncture, and rumours that blood was being used for ritual purposes.

Two patterns deserve emphasis – first, the content of threats was highly "social" – rooted in family and peer influence and community narratives – more than purely individual inconvenience. This aligns with long-standing ethnographic work across West Africa showing that research with blood draws are interpreted through local "economies of blood," where blood is seen as valuable, exchangeable, and potentially exploitable; in such contexts, rumours of "blood selling" or "stealing" become plausible and can erode trust if not directly addressed [28, 29].

Second, the rapid counter-measures – unscheduled stakeholder visits, community re-engagement, and practical, demonstration-based reassurance – map closely to what risk-communication and community-engagement guidance recommends for rumour control: act quickly, listen, identify influencers, and close feedback loops in the same channels where misinformation spreads [30, 31]. At the AEFUTHA site, this was operationalised through a rapid response system in which rumours or dissatisfaction reported by field workers triggered immediate unscheduled home and community visits by the Site PI and technical team. During these visits, concerns about blood collection were addressed through live demonstrations showing that only small blood volumes (5 mL) were collected, alongside clear explanations of safe phlebotomy procedures, consistent with WHO best-practice guidance for reducing anxiety and perceived harm [32]. Reassurance was further strengthened through the visible involvement of certified healthcare professionals and trusted community actors, including CLOs, Village Guides, traditional leaders, and religious figures.

Blood-related fears and fertility concerns have been widely documented across African research settings. Studies from The Gambia, Benin, Kenya, and other countries in sub-Saharan Africa have reported similar beliefs linking research blood draws to ritual practices, loss of life-force, or infertility, with documented negative effects on study participation and retention [16, 18, 33]. Consistent with this literature, our findings reinforce that *who* delivers information is as important as what is communicated, particularly in settings where trust is socially mediated [31].

Compensation adequacy emerged as the single most frequently cited reason behind threats to withdraw. The retention literature – while dominated by high-income settings – does suggest that appropriately framed incentives and practical supports can improve follow-up, especially when combined with good communication and flexible contact strategies [27, 34]. In Enable 1.0, dissatisfaction related to incentives was often mitigated through explanation, reassurance, and non-financial support delivered by CLOs and Village Guides, helping to prevent escalation into actual withdrawal.

Social pressure from family and peers is a second cluster of threats that also tracks prior work. Mixed-methods studies show that decision-making about trial participation in West African settings is often collective, with family members acting as gatekeepers or veto players [35]. The study team's practice of on-the-spot family engagement when concerns arise is well-supported by community-engagement guidance from H3Africa [20], and risk communication and community engagement toolkits, which

recommend proactive involvement of family decision-makers and iterative consent conversations rather than one-off information sessions [31].

A smaller but important set of threats involved requests for results, concerns about study length, and "parent/husband refusal." These issues intersect with evolving guidance on feedback of results and ongoing consent. While most frameworks arise from genomics, the underlying ethical principles – clarity at consent about what individual results (if any) will be returned, how, and when, and the use of community engagement to manage expectations – apply equally to observational infectious-disease cohorts. In Enable 1.0, delays in returning individual serology results generated dissatisfaction and occasional threats to withdraw, illustrating how uncertainty about result timelines can undermine trust even when overall engagement is strong. Ethical guidance from CIOMS and H3Africa, supported by evidence from African genomics studies, emphasizes transparent planning and communication around result feedback to maintain trust and prevent confusion [36–38].

In our study, although delayed return of serology results was one of the most expressed concerns (45/713; 6.3%), only a very small proportion of participants (0.1%) threatened to withdraw for this reason. This suggests that sustained communication and community engagement helped mitigate the potential negative effects of delayed result feedback, consistent with evidence that clear expectations reduce anxiety in longitudinal studies [39].

Policy and practice implications are clear. Rumour management should be a planned and well-funded part of Lassa fever research, not something done only in emergencies. Existing risk communication and community engagement (RCCE) guidance already provides practical tools. many of which were applied at the AEFUTHA site, including recording and sorting rumours, quickly engaging local influencers, and using practical demonstrations to build trust [30, 31].

Second, incentives should be periodically reviewed with community input to ensure they are perceived as fair without being coercive. Evidence from retention studies suggests that combining incentives with flexible visit scheduling, transport support, and multi-modal reminders (phone calls, text messages, or home visits) improves follow-up by reducing both financial and logistical barriers [27, 34].

Third, consent and re-consent processes should explicitly recognize the role of families in participation decisions. Short, structured family dialogues at enrolment and during follow-up blood draws – co-facilitated by a community health worker and a trusted local leader – may help prevent later withdrawals triggered by household objections, consistent with H3Africa guidance on iterative and relational consent processes [20].

Fourth, studies should develop a clear, site-specific policy on which individual research results will be shared (if any), aligned with the approved protocol and Ethics Committee guidance. This policy should be communicated consistently at enrolment and reinforced during follow-up visits. Where individual

results cannot be returned, community-level feedback sessions can help maintain transparency and trust [36, 38].

Finally, a clear and consistent explanation of phlebotomy safety should be institutionalized, using simple visual aids to show tube size and cumulative blood volume across visits, and aligned with WHO best-practice wording. This approach strengthens credibility, reduces anxiety, and standardizes messaging across field teams [32].

A practical way forward is to establish a context-specific “Retention and RCCE Bundle” at AEFUTHA, drawing on established risk communication, community engagement, and retention guidance. This would include systematic rumour tracking, with a named focal person responsible for responding within 48 hours of reported misconceptions or dissatisfaction. It should also include regular engagement with community influencers, while allowing the PI to intervene rapidly when rumours escalate. In addition, fair incentives should be agreed with community input, complemented by transport support where necessary. Multi-modal reminders – including phone calls, text messages, and home visits – combined with flexible scheduling should be documented in a standard retention operating procedure.

A clear plan for feedback on research results, approved by the ethics committee, should be developed and explained to participants both at enrolment and during follow-up. Finally, a simple phlebotomy communication kit – using laminated visuals showing 5 mL tubes, total blood volume across visits, and WHO-recommended safety messages – should be institutionalized. Together, these measures are feasible, affordable, and compatible with existing site workflows, while being supported by evidence from African research settings [27, 31, 32, 34, 36].

Lastly, while the immediate focus of this analysis is participant retention, effective RCCE should also be understood as a core component of Lassa fever preparedness and response. By aligning site-level practices with Nigeria Centre for Disease Control and Prevention (NCDC) and One Health RCCE training materials, AEFUTHA can strengthen collaboration with national partners and position itself for scalable implementation across states [40].

CONCLUSION

In this study, field workers reported that a minority of participants threatened to withdraw, mostly due to perceived inadequacy of compensation, social pressure from family and peers, discomfort with repeated venipuncture, and misinformation about blood use. Although these issues affected only a small proportion of participants, the findings highlight that retention is shaped not only by individual experiences but also by social and relational dynamics that shape participation in community-based research. Overall, retention in longitudinal research emerged as a social and cultural process, shaped by community narratives, interpersonal relationships, and trust in research teams, rather than solely a technical challenge of follow-up procedures. Furthermore, there is the need for proactive engagement strategies from the outset of longitudinal research and responses to the social environment surrounding

research participants. Swift and visible responses to misinformation were central to sustaining trust and continuity of participation.

For policy and practice, this underscores the need to embed community engagement structures into research design, treat misinformation management as an ethical obligation, and recognize the social embeddedness of consent and retention in African research contexts. Future cohort and vaccine-preparedness studies should institutionalize rapid response mechanisms for rumours, strengthen collaborations with local influencers, and provide clear communication strategies to address participant concerns. By adopting these approaches, longitudinal epidemiological studies in Africa can strengthen participant retention, safeguard ethical practice, and reinforce public trust in biomedical research.

Abbreviations

AEFUTHA: Alex Ekwueme Federal University Teaching Hospital, Abakaliki

CEPI: Coalition for Epidemic Preparedness Innovations

CLO: Community Liaison Officers

DSNO: Disease Surveillance and Notification officers

LASV: Lassa virus

LF: Lassa fever

LGA: Local Government Area

NCDC: Nigeria Centre for Disease Control and Prevention

RCCE: Risk Communication and Community Engagement

WHO: World Health Organization

Declarations

Ethics approval and consent to participate:
Ethical approval for the parent Enable 1.0 study was obtained from the Nigeria National Health Research Ethics Committee (NHREC/01/01/2007-23/06/2020) and the Alex Ekwueme Federal University Teaching Hospital Abakaliki Health Research Ethics Committee (AEFUTHA/REC/VOL.3/2020/056). The present analysis was nested within the approved study and focused on field workers' reports of their interactions and experiences during participant follow-up. Written informed consent was obtained from all field workers who provided these reports. All data were recorded in de-identified form, with field workers represented only by unique identifiers. Confidentiality, privacy, and participants' rights were maintained

throughout the study. All research activities were conducted in accordance with the Declaration of Helsinki.

Consent for publication

Not applicable. This manuscript does not contain any individual person's identifiable data or information requiring consent for publication.

Availability of data and materials

The datasets analysed during the current study are not publicly available due to ethical and confidentiality restrictions but are available from the corresponding author on reasonable request, subject to appropriate ethical and institutional approvals.

Competing interests

Some authors are affiliated with the study funder, the Coalition for Epidemic Preparedness Innovations (CEPI). The authors declare that these affiliations did not influence the design, conduct, analysis, interpretation, or reporting of the study.

Funding

This work was supported by the Coalition for Epidemic Preparedness Innovations (CEPI). The funding provided for the Enable 1.0 project did not include provision for the cost of publication of this manuscript.

Authors' contributions

Conceptualization: CKO, BNA; Methodology: CKO, OUO, BNA; Data collection: CKO, OUO, CVI, NVN, MNO, ON, COA, VCA, RCO, EOO, BNA; Data analysis: CKO; Writing – original draft: CKO; Writing – review & editing: CKO, OUO, CVI, NVN, MNO, ON, COA, VCA, RCO, EOO, SP, HM, BNA; Supervision: CKO, RCO, EOO, SP, HM, BNA; All authors read and approved the final manuscript.

ACKNOWLEDGEMENTS

The authors gratefully acknowledge the Coalition for Epidemic Preparedness Innovations (CEPI), the funder of the Enable 1.0 project; P95, the coordinating partner; Epicentre, for data management; MMARCRO, the contract research organization responsible for monitoring; the Bernhard Nocht Institute for Tropical Medicine (BNITM), for laboratory oversight; and the Nigeria Centre for Disease Control and Prevention (NCDC), for national coordination of the Enable study.

References

1. Nohr EA, Liew Z. How to investigate and adjust for selection bias in cohort studies. Acta Obstet Gynecol Scand. 2018;97(4):407–16.
2. Howe CJ, Cole SR, Lau B, Napravnik S Jr. Selection bias due to loss to follow up in cohort studies. Epidemiology. 2016;176(5):139–48.

3. Penfold S, Adegnika AA, Asogun D, Ayodeji O, Azuogu BN, Fischer WA, et al. A prospective, multi-site, cohort study to estimate incidence of infection and disease due to Lassa fever virus in West African countries (the Enable Lassa research programme)–Study protocol. PLoS ONE. 2023;18(3 March):1–20.
4. World Health Organization. Lassa fever [Internet]. 2024 [cited 2025 Aug 17];Available from: https://www.who.int/news-room/fact-sheets/detail/lassa-fever
5. CDC. About Lassa Fever [Internet]. 2025 [cited 2025 Aug 21];Available from: https://www.cdc.gov/lassa-fever/about/index.html
6. African CDC. Lassa Fever [Internet]. [cited 2025 Aug 25];Available from: https://africacdc.org/disease/lassa-fever/
7. Reyna RA, Littlefield KE, Shehu N, Makishima T, Maruyama J, Paessler S. The Importance of Lassa Fever and Its Disease Management in West Africa. Viruses. 2024;15:35–45.
8. NCDC. Lassa Fever Situation Report Epi week 52: 23rd -29th December 2024. 2024 [cited 2025 Aug 21];1–8. Available from: https://ncdc.gov.ng/diseases/sitreps
9. Ezenwa-Ahanene A, Salawu AT, Adebowale AS. Descriptive epidemiology of Lassa fever, its trend, seasonality, and mortality predictors in Ebonyi State, South- East, Nigeria, 2018–2022. BMC Public Health [Internet]. 2024;24(1). Available from: https://doi.org/10.1186/s12889-024-20840-y
10. Siddle KJ, Eromon P, Barnes KG, Mehta S, Oguzie JU, Odia I, et al. Genomic Analysis of Lassa Virus during an Increase in Cases in Nigeria in 2018. N Engl J Med. 2018;379(18):1745–53.
11. Abshire M, Dinglas VD, Cajita MIA, Eakin MN, Needham DM, Himmelfarb CD. Participant retention practices in longitudinal clinical research studies with high retention rates. BMC Med Res Methodol. 2017;17(1):1–10.
12. CEPI. Largest-ever Lassa fever research programme launches in West Africa [Internet]. 2020 [cited 2025 Aug 16];Available from: https://cepi.net/largest-ever-lassa-fever-research-programme-launches-west-africa
13. CEPI. Enabling science: From biological standards to preclinical models, CEPI supports enabling science activities to accelerate the development of safe and effective vaccines [Internet]. 2025 [cited 2025 Aug 21];Available from: https://cepi.net/enabling-science
14. CEPI. Enable Lassa Research Programme Mid-term Workshop [Internet]. 2022 [cited 2025 Aug 22];(October). Available from: https://media.tghn.org/medialibrary/2023/03/CEPI_Enable_2022_Abuja_Report_Final.pdf
15. Chatio S, Baiden F, Achana FS, Oduro A, Akazili J. Knowledge and perceptions about clinical trials and the use of biomedical samples: Findings from a qualitative study in rural northern Ghana. PLoS ONE. 2016;11(4):1–11.
16. Grietens KP, Ribera JM, Erhart A, Hoibak S, Ravinetto RM, Gryseels C, et al. Perspective piece: Doctors and vampires in Sub-Saharan Africa: Ethical challenges in clinical trial research. Am J Trop Med Hyg. 2014;91(2):213–5.

17. Boahen O, Owusu-Agyei S, Febir LG, Tawiah C, Tawiah T, Afari S, et al. Community perception and beliefs about blood draw for clinical research in ghana. Trans R Soc Trop Med Hyg. 2013;107(4):261–5.
18. O'Neill S, Dierickx S, Okebe J, Dabira E, Gryseels C, D'Alessandro U, et al. The importance of blood is infinite: Conceptions of blood as life force, rumours and fear of trial participation in a Fulani village in rural Gambia. PLoS ONE. 2016;11(8):1–13.
19. Kutywayo A, Yah CS, Naidoo NP, Malotana M, Dyani S, Mullick S. Implementing the Good Participatory Practice Guidelines in the Girls Achieve Power Trial in South Africa. SAGE Open 2018;8(4).
20. H3Africa. H3Africa Guidelines for Community Engagement (Version Two) [Internet]. Community Engagem. Work. Gr. H3Africa Consiortium2017 [cited 2025 Aug 24];(September):1–17. Available from: https://www.biorepository.africa/h3africa-sops-and-policies/
21. UNAIDS and AVAC. Good Participatory Practice Guidelines for Biomedical HIV Prevention Trial. Https://Partnersinresearch.Nih.Gov/Good-Participatory-Practice-Gpp-Guidelines/2011.
22. Tindana P, Yakubu A, Staunton C, Matimba A, Littler K, Madden E, et al. Engaging research ethics committees to develop an ethics and governance framework for best practices in genomic research and biobanking in Africa: The H3Africa model. BMC Med Ethics. 2019;20(1):1–7.
23. CEPI. Enable Programme: The largest-ever Lassa fever research programme in West Africa [Internet]. 2025 [cited 2025 Aug 21];Available from: https://cepi-tr.tghn.org/research-and-development/epidemiology/enable-epi-study/
24. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)-A metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform [Internet]. 2009;42(2):377–81. Available from: http://dx.doi.org/10.1016/j.jbi.2008.08.010
25. Mein G, Johal S, Grant RL, Seale C, Ashcroft R, Tinker A. Predictors of two forms of attrition in a longitudinal health study involving ageing participants: An analysis based on the Whitehall II study. BMC Med Res Methodol. 2012;12:1–7.
26. Teague S, Youssef GJ, Macdonald JA, Sciberras E, Shatte A, Fuller-Tyszkiewicz M, et al. Retention strategies in longitudinal cohort studies: A systematic review and meta-analysis. BMC Med Res Methodol. 2018;18(1):1–22.
27. Booker CL, Harding S, Benzeval M. A systematic review of the effect of retention methods in population-based cohort studies. BMC Public Health [Internet]. 2011;11(1):249. Available from: http://www.biomedcentral.com/1471-2458/11/249
28. Fairhead J, Leach M, Small M. Where techno-science meets poverty: Medical research and the economy of blood in The Gambia, West Africa. Soc Sci Med. 2006;63(4):1109–20.
29. Geissler PW, Pool R. Popular concerns about medical research projects in sub-Saharan Africa - A critical voice in debates about medical research ethics. Trop Med Int Heal. 2006;11(7):975–82.

30. WHO. UNICEF, IFRC. Risk Communication and Community Engagement (RCCE) Coordination in Public Health Emergencies, Including Covid-19 Interim Guidance, October 2022 [Internet]. READY Initiat.2022 [cited 2025 Aug 23];(October):1–34. Available from: https://www.who.int/publications/i/item/risk-communication-and-community-engagement-(rcce)-action-plan-guidance
31. Save the Children. Communicating With Communities in Epidemics and Pandemics [Internet]. READY Initiat.2022 [cited 2025 Aug 23];1–50. Available from: http://www.ready-initiative.org
32. World Health Organization. WHO guidelines on drawing blood: best practices in phlebotomy. World Heal Organ [Internet] 2010 [cited 2025 Aug 23];1–105. Available from: https://www.who.int/publications/i/item/9789241599221
33. Compaoré A, Dierickx S, Jaiteh F, Nahum A, Bohissou TFE, Tinto H et al. Fear and rumours regarding placental biopsies in a malaria-in-pregnancy trial in Benin. Malar J [Internet]. 2018;17(1):1–8. Available from: https://doi.org/10.1186/s12936-018-2578-9
34. Brueton VC, Tierney JF, Stenning S, Meredith S, Harding S, Nazareth I et al. Strategies to improve retention in randomised trials: A Cochrane systematic review and meta-analysis. BMJ Open 2014;4(2).
35. Kelly AH, Ameh D, Majambere S, Lindsay S, Pinder M. Like sugar and honey: The embedded ethics of a larval control project in The Gambia. Soc Sci Med [Internet] 2010;70(12):1912–9. Available from: http://dx.doi.org/10.1016/j.socscimed.2010.02.012
36. CIOMS, WHO. International Ethical Guidelines for Health-related Research Involving Humans [Internet]. Fourth. Geneva: 2016. Available from: https://cioms.ch/publications/product/international-ethical-guidelines-for-health-related-research-involving-humans/#
37. Ochieng J, Kwagala B, Barugahare J, Mwaka E, Ekusai-Sebatta D, Ali J et al. Perspectives and ethical considerations for return of genetics and genomics research results: a qualitative study of genomics researchers in Uganda. BMC Med Ethics [Internet]. 2021;22(1):1–9. Available from: https://doi.org/10.1186/s12910-021-00724-1
38. Botkin JR, Mancher M, Busta ER, Downey AS. Returning Individual Research Results to Participants: Guidance for a New Research Paradigm [Internet]. Washington DC: The National Academies Press; 2018. Available from: https://www.ncbi.nlm.nih.gov/books/NBK525079
39. Kent DA, Villegas-downs M, Rios M, Del, Freedman M, Krishnan JA, Menchaca MG, et al. Returning individual research results to participants: Values, preferences, and expectations. J Clin Transl Sci. 2024;8(e126):1–8.
40. NCDC. Facilitator's Mannual: One Health Risk Communication & Community Engagement Training for Public Health and Media Practitioners. 2023.

Figures

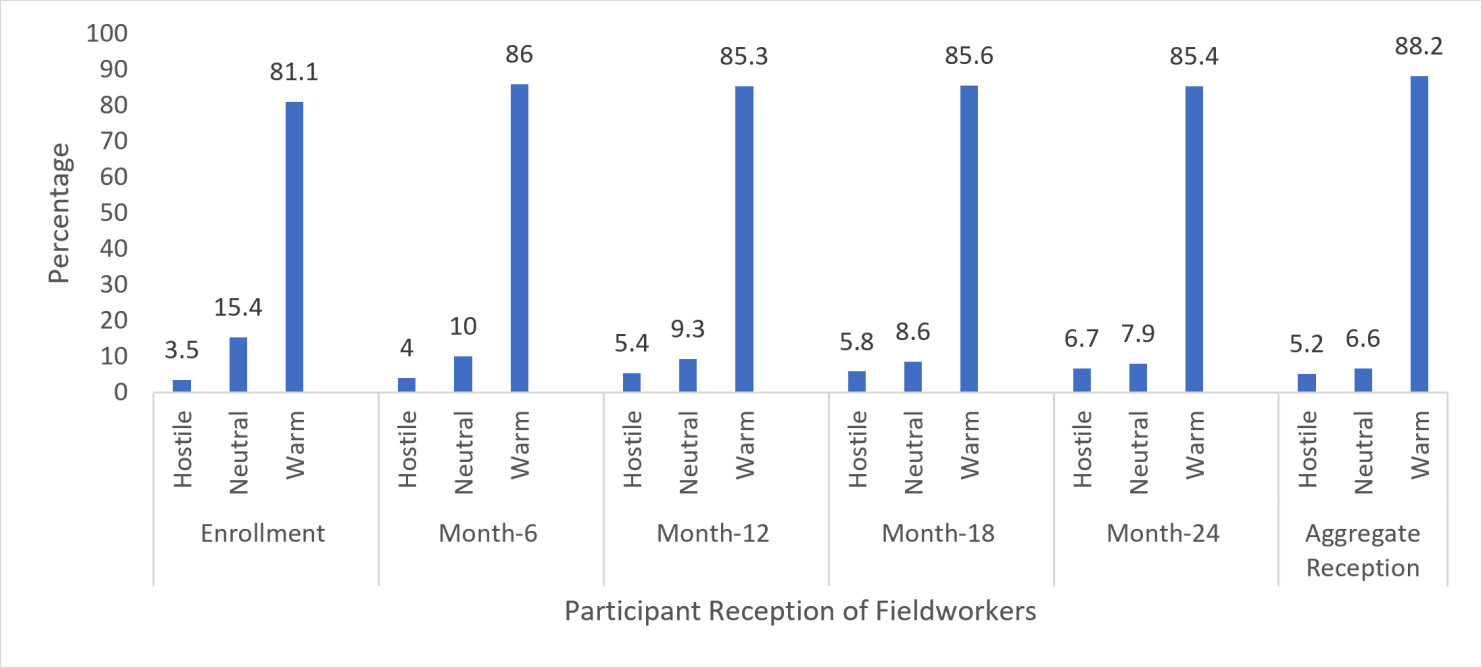


Figure 1

Level of Reception of Field workers Across Study Visits by Enable 1.0 Study Participants at the AEFUTHA Site, Nigeria (N=713 of 1000 Enrolled)