

Narrative Review Article

HSI Journal (2026) Volume 9 (Issue 1):1603-1616. <https://doi.org/10.46829/hsijournal.2026.7.9.1.1603-1616>



Open  
Access

# Understanding and addressing sample collection hesitancy in biomedical research in Ghana: A narrative review

Elvis S LOMOTEY<sup>2</sup>, Daniel A ODUMANG<sup>2</sup>, Christopher DORCOO<sup>2</sup>, Abdul G MOHAMMED<sup>3</sup>, Irene O DONKOR<sup>1\*</sup>

<sup>1</sup> Department of Epidemiology, Noguchi Memorial Institute for Medical Research, University of Ghana, Legon, Accra, Ghana; <sup>2</sup> Department of Parasitology, Noguchi Memorial Institute for Medical Research, University of Ghana, Legon, Accra, Ghana; <sup>3</sup> School of Public Health, University of Ghana, Legon, Accra, Ghana

Received January 2026; Revised March 2026; Accepted May 2026

## Abstract

**Background:** Human biological specimens are essential for biomedical research, driving advancements in disease understanding, biomarker discovery, and the development of diagnostics, vaccines, and therapies. In Ghana, reports and experiential accounts from researchers indicate increasing hesitancy toward providing biological samples, leading to high refusal rates and participant attrition that threaten the validity and representativeness of scientific studies.

**Objective:** This study aims to identify and analyze the drivers of biological sample hesitancy in Ghana and West Africa, and to develop an evidence-based operational checklist for researchers to improve participant recruitment, retention, and community trust in biomedical research.

**Methods:** We conducted a narrative review of peer-reviewed and grey literature on biological sample hesitancy in Ghana and West Africa. We searched PubMed, Google Scholar, and African Journals Online (AJOL) between October and November 2024 for publications from 2000 to 2024 using terms including biospecimen, sample refusal, research participation, hesitancy, informed consent, Ghana, and Africa. Of 127 records initially identified, 89 were screened, and 46 studies (38 peer-reviewed articles and 8 grey literature reports) met inclusion criteria. Studies were appraised using adapted CASP and Newcastle-Ottawa criteria.

**Results:** Hesitancy is influenced by deep-rooted mistrust stemming from historical unethical research, ethical concerns, cultural and religious beliefs, language barriers, limited research literacy, and tribal influences. Sample type and research context significantly affect acceptability, with blood samples evoking the greatest concern. Consequences extend beyond individual refusal, contributing to selection bias, underrepresentation of populations, delayed innovation, and compromised public health interventions.

**Conclusion:** Addressing hesitancy requires multifaceted approaches, including trust-building initiatives, culturally sensitive education, transparent communication, community engagement, and operationalized benefit-sharing mechanisms. We provide an evidence-based operational checklist to guide researchers in implementing sustainable strategies that prioritize participant rights and foster long-term community partnerships.

**Keywords:** Hesitancy, biomedical research, participation, Ghana

Cite the publication as Lomotey ES, Odumang DA, Dorcoo C, Mohammed AG, Donkor IO (2026) Understanding and addressing sample collection hesitancy in biomedical research in Ghana: A narrative review. HSI Journal 9 (1):1603-1616. <https://doi.org/10.46829/hsijournal.2026.7.9.1.1603-1616>

## INTRODUCTION

The use of biological human samples remains an irreplaceable gold standard in advancing

biomedical research. They have proven to be precise correlates for understanding disease mechanisms, identifying biomarkers, developing diagnostic tools, vaccines and therapies [1]. Despite increased efforts in biomedical research in Africa, hesitancy to provide biological samples, whether for observational studies or those requiring follow-up, has been accompanied by reports of changing participation rates [2]. In Ghana, reports and

\* Corresponding author

Email: [iowusu@noguchi.ug.edu.gh](mailto:iowusu@noguchi.ug.edu.gh)

survey-based evidence suggest that a growing proportion of participants are hesitant to provide biological samples, such as blood, saliva, urine, stool, or tissue, due to historical mistrust, ethical concerns, and a lack of transparent communication. Fear of sample misuse, along with cultural and religious beliefs, further exacerbates this reluctance [3].

For this review, we define hesitancy as reluctance, delay, or uncertainty in accepting or providing biological samples despite the availability of sampling opportunities, whereas refusal refers to an outright, definitive decline to participate in biological sample collection. Attrition refers to participant dropout during the follow-up phases of longitudinal studies. These distinctions are important as they represent different stages and intensities of non-participation, each requiring tailored intervention strategies. We opted for a narrative rather than a systematic review approach for several reasons. First, the literature on biological specimen hesitancy in Ghana is highly heterogeneous, comprising diverse study designs (qualitative interviews, cross-sectional surveys, cohort studies), sample types, and research contexts that resist standardization and meta-analysis. Second, our primary goal was to synthesize conceptual frameworks and generate practical, context-specific recommendations rather than estimate pooled effect sizes. Third, we aimed to integrate grey literature, experiential accounts from researchers, and local policy documents that are typically excluded from systematic reviews but provide critical contextual insights for implementation. While this approach introduces potential selection bias, it allows for a comprehensive exploration of the multifaceted nature of hesitancy in the Ghanaian context.

The consequences of this hesitancy affect the quality and representativeness of scientific research, extending beyond individual participation. For instance, when certain populations opt out of studies, findings may become skewed, limiting diagnosis and the development of effective treatments and interventions across diverse populations. It is important to note that attrition rates help to contextualize this decline. Rates below 5% are generally acceptable; rates between 5% and 20% may be acceptable but may introduce bias; rates exceeding 20% suggest a potential compromise in research quality [4,5]. This review examines quantitative surveys, qualitative studies, mixed-methods research, and grey literature addressing biological specimen collection in Ghana and West Africa. We included studies involving any biological sample type (blood, saliva, urine, stool, tissue) across diverse research contexts, including clinical trials, epidemiological studies, surveillance programs, and biobanking initiatives. Our study is expected to benefit biomedical researchers planning studies in Ghana or similar contexts, institutional review boards evaluating research proposals, community advisory boards engaging with researchers, public health practitioners implementing surveillance programs, and policymakers developing research governance frameworks. Our aim is to provide evidence-based, actionable guidance

that can be immediately implemented to improve research participation and strengthen community-researcher partnerships.

## MATERIALS AND METHODS

### Search strategy and databases

We conducted a narrative review of peer-reviewed and grey literature on biological sample hesitancy in Ghana and West Africa. Literature searches were conducted between October 15 and November 30, 2024, focusing on publications from 2000 to 2024.

Our search strategy yielded the following results: 127 records were initially identified from all databases (PubMed: 45, Google Scholar: 68, AJOL: 14). The search terms used were “biospecimen”, “sample refusal”, “research participation”, “hesitancy”, “informed consent”, “Ghana”, “Africa”, and “community engagement”. After removing 38 duplicates, 89 records were screened by title and abstract. Of these, 43 were excluded (non-human research: 12, non-health focus: 8, languages other than English: 7, outside data range: 6, insufficient detail on hesitancy: 10). Forty-six (46) full-text articles and reports were assessed, all of which met inclusion criteria and were included in the final synthesis (38 peer-reviewed articles and 8 grey literature reports). We did not exclude any studies solely on the basis of quality appraisal scores, given the exploratory nature of this narrative review.

### Quality appraisal

Quality appraisal was conducted systematically using established frameworks. For qualitative studies (n=18), we applied the Critical Appraisal Skills Program (CASP) qualitative checklist, evaluating research aims clarity, design appropriateness, sampling adequacy, data collection rigour, reflexivity, and interpretation coherence. For quantitative studies (n = 20), we used a modified Newcastle-Ottawa Scale to assess sampling strategy, sample size adequacy, measurement validity, analytic robustness, and potential biases, including nonresponse bias and confounding. Mixed-methods studies (n = 8) were appraised using both frameworks for their respective components. Based on these criteria, 12 studies (26%) were rated high quality, 28 (61%) moderate quality, and 6 (13%) low quality. Low-quality ratings primarily resulted from small convenience samples (n < 30), insufficient methodological detail, or insufficient discussion of limitations. Given the exploratory, synthesis-focused scope of this narrative review, no studies were excluded based on appraisal scores; however, quality ratings informed the weight assigned to findings during synthesis, with greater emphasis placed on high-quality studies and findings corroborated across multiple sources.

### Stakeholder engagement

This review did not involve formal stakeholder consultation during the literature search and synthesis phases. However, the interpretation of findings and the development of

Table 1: PRISMA Flow Diagram of Record Review Process

Stage	Description	Number
Identification	Records identified through database searching (PubMed= 45; Google Scholar= 68; AJOL= 14)	127
	Duplicate records removed	38
	Records after duplicates removed	89
Screening	Records screened (title and abstract)	89
	Records screened (title and abstract)	89
	Records excluded (non-human research= 12; non-health focus= 8; non-English publications= 7; outside date range (2000-2024) = 6; insufficient focus on biological sample hesitancy= 10)	43
	Full-text articles assessed for eligibility	46
Included	Studies included in narrative synthesis (peer-reviewed articles= 38; grey literature reports= 8)	46

recommendations were informed by the authors' direct research experience conducting community-based studies in Ghana and through informal discussions with community advisory board members, research participants, and field staff during previous projects. We acknowledge that formal stakeholder engagement would have strengthened the review and recommend that future updates incorporate structured input from community representatives, research participants, and ethics committee members.

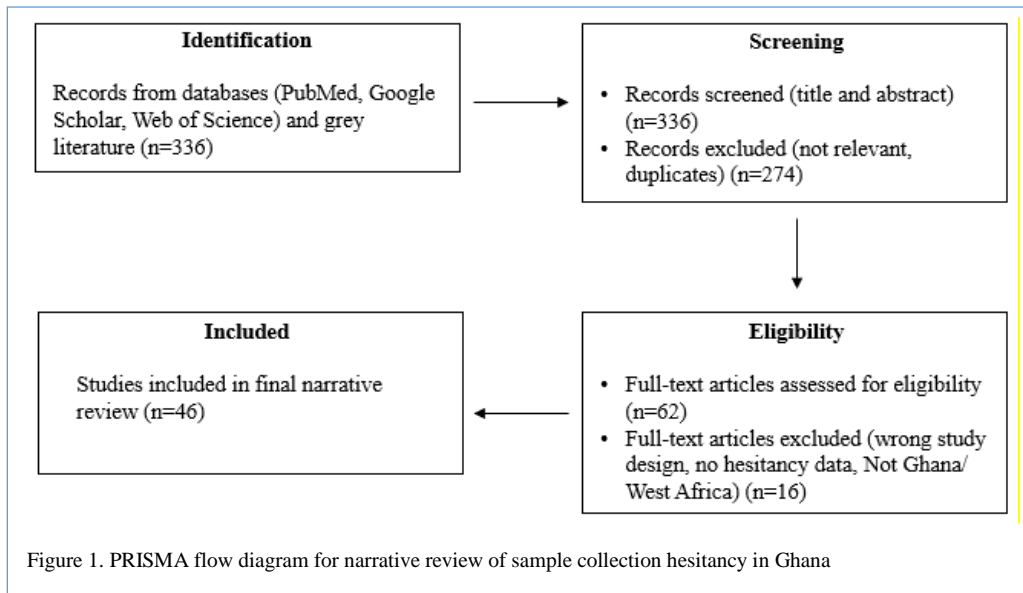
#### Limitations of review methodology

A full systematic review with meta-analysis was not feasible for several reasons. First, the included studies exhibited substantial heterogeneity in design (qualitative, quantitative, mixed-methods), outcomes measured (refusal rates, attrition, attitudes), and populations studied, making statistical pooling inappropriate. Second, hesitancy rates were inconsistently reported or not reported at all in many qualitative studies. Third, the lack of standardized measurement instruments precluded direct comparisons. Also, this review was limited to English-language publications and three databases, potentially missing relevant studies in other languages or regional journals. Findings are primarily from Ghana and Nigeria, which may limit generalizability to other African countries and the global context. These methodological limitations mean our synthesis is subject to potential selection bias and cannot provide precise pooled estimates. However, the narrative approach enabled us to capture the breadth and complexity of factors influencing hesitancy and to develop actionable, context-specific recommendations grounded in diverse evidence sources.

## RESULTS

#### Demographics of included studies

The 46 studies included in this narrative review comprised a mix of qualitative, quantitative, mixed-methods, and grey literature reports conducted between 2000 and 2024. Of these, 38 were peer-reviewed articles, and 8 were grey literature reports, including institutional reports and policy documents. Most studies were conducted in Ghana (n = 29), with the remaining studies carried out in Nigeria and other West African countries (n = 17). Study populations included community members, patients attending health facilities, clinical trial participants, research volunteers, and special population groups such as rural dwellers, urban informal settlers, and ethnic or tribal communities. Sample sizes ranged from small qualitative studies with fewer than 30 participants to large cross-sectional surveys involving over 1000 respondents. Across the included studies, adult participants (>18 years) constituted the majority of study populations. Where reported, participants were drawn from both urban and rural settings, with several studies highlighting higher levels of hesitancy in rural and peri-rural communities. Both males and females were represented across studies. Commonly described sociodemographic variables included age, sex, education, occupation, religion, and ethnicity. Lower educational attainment, strong cultural or religious beliefs, and limited research literacy were frequently associated with increased hesitancy toward biological sample provision. The included studies covered diverse research contexts, including clinical trials, community-based surveys, surveillance activities, and biobanking initiatives, with blood being the most commonly examined sample type, followed by saliva, stool, urine, and swabs.



### Quantitative overview of hesitancy patterns

Among studies reporting quantitative refusal rates ( $n = 24$ ), substantial variation was observed based on sample type, research context and setting.

#### By sample type

Blood samples showed refusal rates ranging from 12% to 35% (median 18%,  $n = 12$  studies). Stool samples exhibited the highest hesitancy, with rates ranging from 15% to 45% (median 28%;  $n = 6$  studies). Saliva and swab samples had the lowest refusal rates, ranging from 5% to 15% (median 8%,  $n = 8$  studies). Urine samples showed intermediate rates of 10% to 22% (median 14%,  $n = 4$  studies).

#### By research context

Clinical trials, particularly vaccine and drug trials ( $n = 8$ ), demonstrated higher refusal rates, ranging from 15% to 40% (median 22%), compared to observational epidemiological studies ( $n = 11$  studies) that reported substantially lower refusal rates of 8% to 25% (median 15%). Public health surveillance programs reported intermediate refusal rates of 10% to 30% (median 18%).

#### By setting

Urban settings ( $n = 14$  studies) reported refusal rates ranging from 10% to 25% (median 15%), compared with rural settings ( $n = 10$  studies), which reported significantly higher refusal rates of 18% to 45% (median 28%). This urban-rural difference persisted across sample types and research contexts.

#### Temporal trends

Comparing studies chronologically suggests increasing hesitancy over time, though heterogeneity in methods and populations limits definitive conclusions:

2000 - 2010 ( $n = 7$  studies): Median refusal rate 14%

2011 - 2029 ( $n = 10$  studies): Median refusal rate 18%

2020 - 2024 ( $n = 7$  studies): Median refusal rate 24%

The 71% relative increase in median refusal from 2000 to 2024 (14% to 24%) may reflect multiple factors, including increased public awareness of research ethics controversies, social media amplification of mistrust narratives, and the effects of the COVID-19 pandemic on institutional trust.

#### Attrition patterns

Among longitudinal studies ( $n = 9$ ), follow-up attrition rates ranged from 12% to 38% (median 22%), representing loss-to-follow-up beyond initial recruitment refusal. Attrition was notably higher in studies requiring multiple biological specimen collections (median 26%) compared to those with single baseline sampling (median 16%). Study duration strongly predicted attrition: studies extending  $< 12$  months showed a median 15% attrition, while those  $> 24$  months exhibited 28% attrition.

#### Factors influencing hesitancy

Hesitancy towards research participation is a complex issue influenced by cultural, socioeconomic, and institutional factors, particularly in low- and middle-income countries like Ghana. Several key barriers contribute to this reluctance, including mistrust, stigma, lack of awareness, and language barriers, and they often intersect and reinforce one another.

#### Cultural and social drivers

Superstitious beliefs, some religious doctrines, cultural norms, and tribal disputes influence people's willingness and eagerness to participate in research. This hesitancy is observed to be especially pronounced in studies involving sensitive topics or rare diseases that bring about social stigma or marginalization [6]. Previous experiences with unethical research groups have left a lasting legacy of mistrust. This has led to some individuals perceiving

Table 2. Local evidence from Ghana and West Africa

Citation	Study Design	Sample Size	Setting	Year	Sample Type	Refusal Rate	Type	Research Context	Driver of Hesitancy
Brackstone 2022 (Ghana)	Cross-sectional survey	n=1245 approached, n=1021 participated	Urban, Greater Accra, Ghana	2021	Blood	18%	Initial	COVID-19 vaccine trial	Mistrust of vaccine trials; misinformation
Erves 2017 (Ghana)	Qualitative (focus groups)	n=150 approached; n=132 participated	Mixed (urban/rural). Ashanti Region, Ghana	2016	Saliva, blood	12%	Initial	Community-based health survey	Cultural beliefs about blood; spiritual concerns
Mfofo-M'Carthy 2022 (Ghana)	Cohort study (longitudinal)	n=420 enrolled; n=327 completed follow-up	Rural, Northern Region, Ghana	2019-21	Stool	22%	Attrition	Intestinal disease surveillance	Privacy concerns; embarrassment; cultural taboos
Harding 2011 (Nigeria)	Cross-sectional study	n=580 approached; n=493 participated	Rural, Rivers State, Nigeria	2010	Blood	15%	Initial	Population genetics research	Mistrust, tribal concerns about genetics research

Type: Initial= initial recruitment refusal; Attrition= dropout during follow-up

participation as a risk, fearing biological samples could be misused or that they may be subjected to inhumane experiments [7].

In areas with deep-seated tribal conflicts, individuals often align with collective decisions. If key community leaders or influencers oppose research participation, many individuals follow suit to avoid being seen as betraying their tribe. This reluctance is mostly evident when researchers are from different tribes or are associated with groups that have a historical tension with the community. Additionally, tribal hesitancy towards research is heightened when a tribe perceives research as violating cultural norms or spiritual beliefs, particularly in studies involving blood collection or genetic analysis [8]. Cultural beliefs and superstitions were identified as barriers in 22 studies (48% of included studies), with consistent findings across both urban and rural settings. Of these studies, 9 were rated high quality, 11 moderate quality, and 2 low quality, providing strong evidence for this driver.

### Historical mistrust

The legacy of colonial-era and externally driven research has contributed to persistent mistrust of research activities in many African settings. Historical experiences in which research findings were not communicated back to communities, benefits were inequitably distributed, or biological samples were exported without adequate consent have fostered skepticism toward research participation. These historical and ethical concerns continue to shape contemporary perceptions of research in Africa, including Ghana [9]. In this review, historical mistrust arising from colonial practices and unethical research conduct was identified in 18 studies, representing 39% of the included

studies. This finding underscores the enduring influence of past research experiences on community willingness to participate in research and highlights the importance of transparency, equitable benefit-sharing, and meaningful community engagement in building trust. Findings were highly consistent across contexts. Of these, 8 were high-quality, 9 moderate-quality, and 1 low-quality, indicating strong, consistent evidence for mistrust as a primary driver.

### Language and communication barriers

Linguistic diversity across Ghana and Africa presents a significant challenge to effective research communication. The existence of multiple local languages and dialects can hinder participants' understanding of research information, thereby complicating the informed consent process. Even when study materials are translated, many scientific and technical terms lack direct equivalents in local languages, which may result in misunderstandings and reduced clarity. Community volunteers and local interpreters often play a crucial role in facilitating communication between researchers and participants; however, in rural and underserved areas, translations may be inconsistent or diluted, further impeding accurate information exchange. These communication challenges can undermine participants' comprehension of research objectives, procedures, risks, and benefits, thereby reducing trust and willingness to participate in research [10]. Language and communication barriers were identified in 15 of the included studies (33%). The quality of evidence was mixed, comprising 3 high-quality, 9 moderate-quality, and 3 low-quality studies. Overall, findings demonstrated moderate consistency across studies, although the impact of these barriers was more pronounced in rural than in urban

settings. Consequently, the evidence suggests a moderate but context-dependent influence of language and communication barriers on research participation.

### **Educational and institutional Barriers**

Many potential participants do not fully understand the purpose of research, methodologies, and the potential benefits or risks associated with them, leading to misinformation and fear. This educational gap often leads to skepticism and reluctance to participate in studies [11]. Additionally, limited knowledge of participants' rights, such as the ability to withdraw from studies at any time and the confidentiality in place, reinforces uncertainty and reluctance [12]. Participants rarely receive information on how samples will be used, stored or shared, which also serves as a barrier to participation. Educational and institutional barriers were documented in 19 studies (42% of included studies). Evidence quality was predominantly high (11 high quality, 6 moderate quality, 2 low quality), with strong consistency across diverse settings and populations, providing strong evidence with robust generalizability.

### **Differential acceptability of sample types**

Hesitancy varies significantly depending on the type of biological specimen being used in the research studies. These nuances are important in tailoring consent processes, sampling procedures and communication strategies. Blood samples are highly sensitive and feared in most populations, including the Ghanaian population. Blood is believed to contain the person's vitality, and there are also fears associated with blood collection [3]. Stool and urine samples are mostly considered highly private and shameful. The reluctance to give out stool and urine mostly stems from embarrassment and cultural beliefs [13]. It is common for participants to provide fake samples to avoid discomfort. Saliva or a swab is usually the easiest sample type to obtain, as it is considered the least invasive in research settings. However, there are still concerns that specimens may be used for genetic manipulation and ritual purposes [6,14].

### **Differences by research context**

Hesitancy in providing biological samples also varies greatly depending on the type of research being carried out. Clinical trials are associated with fears of being used as "guinea pigs". There are also concerns about safety and proper health care. Research work, such as public health surveillance, is often met with a perceived lack of personal gain or skepticism. Participants view these as ways the government monitors or gathers data about them [15].

## **DISCUSSION**

### **Consequences for research and public health**

Hesitancy towards research slows essential public health activities, including disease surveillance, vaccine development, and studies aimed at understanding population health, and compromises both the quality and

impact of resulting findings, as well as the effectiveness of public health interventions and initiatives [7]. Participant hesitancy contributes directly to selection and attrition bias, threatening the validity and true representativeness of study samples. Even small refusal rates can substantially distort population estimates [16]. A recent publication in Ghana demonstrated that nonresponse creates systematic differences between participants and nonparticipants; when those who decline or drop out differ meaningfully in characteristics relevant to the outcomes under investigation, the resulting estimates become biased and less generalizable [17].

One major implication of research and public health is that the findings may not accurately reflect the experiences and needs of the entire population. This can lead to biased outcomes or incomplete conclusions. These findings cannot be used as generalized information for the broader public. This underrepresentation may adversely affect public health interventions, especially for vulnerable or high-risk populations, leading to ineffective or inequitable policies [18]. Public health interventions and policies rely on robust research data. Limited participation hinders the proper development of robust policies and strategies [19]. Gaps in surveillance due to hesitancy slow the understanding of public health issues such as disease transmission, pathogenesis, and outbreaks. This reluctance also delays responses to public emergencies, including the implementation of appropriate guidelines to curb or control these outbreaks [20]. It may also adversely affect vaccination campaigns and new treatment protocols, as there is already widespread mistrust or resistance to the research supporting them.

Additionally, research participation is an essential component in the development of new vaccines, medicines and diagnostic tools. Resistance can slow innovation in biomedical research. Better research coverage enables effective assessment of these vaccines, medicines, and diagnostic tools in the general population, which are key to finding lasting solutions to improve public health.

### **Contexts of successful engagement**

Not all biomedical research in Ghana encounters high hesitancy. Several studies have demonstrated high participation or retention rates (often exceeding 85%), offering valuable insights into success factors for community engagement [21,22]. These high-participation studies shared common characteristics: (1) Sustained institutional presence- research institutions with more than five years of continuous community engagement; (2) Visible community benefits- tangible outcomes from prior research, including established health clinics, scholarship programs, or infrastructure improvements; (3) Local leadership- principal investigators or senior research staff originating from the same region or ethnic group; (4) Extended consultation- pre-study community engagement lasting several months and involving repeated stakeholder meetings; and (5) Healthcare integration- research activities

embedded within existing routine healthcare services, such as antenatal care, disease surveillance, or community-based health planning services [23]. For example, maternal and child health studies in the Volta Region have reported very high uptake of study procedures and service utilization when research activities were integrated into established programs providing free antenatal care, delivery services, and postnatal follow-up, with community engagement shown to significantly improve participation and trust [21].

In such contexts, participants perceived sample donation and continued involvement as a reciprocal contribution to programs delivering tangible and immediate health benefits. Similarly, long-term infectious disease surveillance and neglected tropical disease programs in Northern Ghana have demonstrated sustained community participation and retention over multiple years, supported by strategies such as employing community members as field staff, conducting regular community feedback meetings, providing free treatment for detected infections, and supporting community-identified development priorities [22]. These success stories demonstrate that research hesitancy can be substantially mitigated through sustained relationship-building, mutual benefit, and genuine partnership, rather than transactional research encounters. They underscore that addressing hesitancy requires long-term institutional commitment that extends well beyond the timelines of individual studies.

### Structural and systemic drivers

Beyond local cultural factors, hesitancy is shaped by broader structural and systemic forces that warrant explicit consideration.

### National policy environment

Ghana's Data Protection Act (Act 843, 2012) establishes participant rights and data governance requirements, including provisions on privacy, consent, and cross-border data transfer [24]. However, implementation and enforcement remain inconsistent across institutions, particularly in the governance of biological samples and cross-border transfers [25]. Gaps in the enforcement of sample export regulations and the absence or inconsistent application of standardized Material Transfer Agreements (MTAs) create uncertainty regarding secondary use of samples and equitable benefit-sharing in international collaborations [26]. This policy-practice gap reinforces perceptions that participants lack meaningful control over their biological materials.

### Media narratives

Media coverage significantly shapes public perception of biomedical research. Studies have shown that sensational reporting of ethical controversies, such as allegations of unauthorized sample export, inequitable international collaborations, or lack of community benefit, can amplify mistrust toward research institutions [27]. Social media further accelerates the spread of misinformation, particularly during health crises [28]. Conversely, positive

media coverage highlighting research benefits, capacity building, and local scientific leadership remains comparatively underrepresented, limiting opportunities to build sustained public trust [29].

### Political dynamics

Research participation can become politicized, particularly during election cycles or periods of heightened political tension. In some contexts, biomedical research initiatives have been framed as mechanisms of government surveillance or foreign exploitation, reflecting broader mistrust in political institutions [30, 31]. Conversely, governments may promote research partnerships as symbols of national development and international prestige. These competing narratives underscore that research activities operate within inherently political environments, where trust in science is often intertwined with trust in governance [32].

### Economic pressures

Economic conditions substantially influence research participation decisions. Financial incentives, while ethically permissible when proportionate, may assume heightened importance during periods of economic hardship, raising concerns about undue inducement [33]. At the same time, structural poverty and informal employment create real opportunity costs such as lost wages and transportation expenses that serve as barriers to participation [34]. Thus, modest compensation may function less as an inducement and more as reimbursement for genuine economic constraints.

### Global health events

The COVID-19 pandemic profoundly reshaped research attitudes globally and locally. Initial phases saw heightened willingness to participate in research due to perceived health risks; however, subsequent waves were marked by vaccine hesitancy, misinformation, and conspiracy theories surrounding sample collection and genetic surveillance [35, 36]. These dynamics contributed to the erosion of institutional trust and produced spillover effects affecting non-COVID research activities, demonstrating how global health crises can transform local research landscapes and trust ecosystems [37].

Addressing hesitancy, therefore, requires not only improved research practices at the individual study level but also systemic reforms in governance enforcement, transparent media engagement strategies, equitable international collaboration frameworks, economic support mechanisms, and proactive navigation of broader social and political dynamics.

### Strategies to address hesitancy

Addressing hesitancy to research participation is very important for the continual growth of scientific studies in Ghana and Africa as a whole. Building trust, improving understanding and fostering awareness at all levels are essential steps in overcoming reluctance to participate in research.

### **Equity, power dynamics and decolonizing research**

Research in Ghana is influenced by historical inequities, power imbalances and colonial legacies. These structural determinants shape research participation and the willingness of participants to provide biological specimens [6]. Decolonizing research practices aim to redistribute power and enhance local ownership. Principal Investigators (PIs) from Ghana should lead the study design, implementation, and dissemination, ensuring that the research aligns with local priorities. There should be training of local researchers, laboratory personnel, and ethics committee members to enhance institutional autonomy and sustainability [6]. Communities should gain tangible benefits, such as health interventions, capacity-building programs, or access to study findings. Regular consultations with communities, advisory boards, and civil society groups ensure research remains responsive to local concerns [8]. These approaches promote ethical research but also mitigate hesitancy by demonstrating respect, fairness and shared values.

### **Governance, Policy and Institutional Responsibilities**

Effective governance and policies are vital in addressing biological specimen hesitancy. There are national policies that provide a framework for ethical human research, biological sample collection and storage. The proper implementation of these policies builds public confidence. Proper implementation of formal agreements on the purpose and protection of participants from exploitation is also a key strategy to ensure better research participation.

There should be strict compliance with the Ghana Data Protection Act, which ensures participants' confidentiality and strengthens participants' willingness to participate. Researchers, ethics review committees (ERCs), and ministries must monitor the quality of consent, communication practices, and community engagement. Ghana's Data Protection Act and the Ghana Health Service Ethics Review Committee (GHS-ERC) provide a regulatory framework for ethical data management. However, implementation barriers persist with limited resources, a lack of standardized Material Transfer Agreements (MTAs), and insufficient mechanisms for benefit sharing. Practical policy tools such as tiered consent models, template MTAs, and community consultation protocols can operationalize ethical governance. Institutional training for RECs and data custodians remains essential. Regular audits and feedback loops can improve governance and participant trust. Implementing governance measures in tandem with equity and transparency strategies creates a framework that addresses structural hesitancy.

### **Communication and translation best practices**

Hesitancy to research can also be addressed by building trust through transparency. Participants need clear, detailed information about their roles in the study, including easy-to-understand consent forms and information sheets that address common concerns [38]. Clear, culturally sensitive communication is essential. Strategies such as forward-

back translation ensure consent forms accurately reflect the intended meaning in the local dialects. Testing participants' understanding of study information and consent forms was essential before research rollout. Trusted intermediaries must be engaged in research studies to enhance credibility and comprehension, especially in linguistically diverse regions. Effective communication reduces misunderstanding, counters misinformation and increases participants' confidence in research [10].

### **Evidence-based interventions**

Several interventions have been shown to improve biological sampling and research participation. Community engagement is one of the effective ways to increase research participation. In Ghana, durbars and consultations with religious and opinion leaders before the inception of research are known to increase participation by 20 - 25% [7]. Another effective way to drive participation in research is to return participants' results or study findings to the communities. Studies in West Africa show that communities are more receptive and cooperative when they receive meaningful feedback [19]. Training local research teams is another effective way to improve research participation. Capacity building for field staff in the community, along with cultural competence and ethical practices, ensures respectful and consistent engagement. Integrating these evidence-based inventions with governance, policies and proper research practices by researchers can reduce hesitancy in biological sample collection. It improves inclusion, coverage and generation of high-quality data [15].

### **Limitations**

This review has several important limitations that warrant acknowledgement. First, our search strategy, while comprehensive within its defined scope, was limited to three databases and English-language publications. This likely excluded relevant studies and published in French, Portuguese, or in regional journals not indexed in major databases. Grey literature coverage, though attempted, was incomplete. Publication bias likely affects findings, as studies reporting successful recruitment strategies are more likely to be published than those with high refusal rates, potentially overestimating the severity of hesitancy in the published literature. Second, we relied heavily on small-scale qualitative studies. Of the 46 included studies, 18 were qualitative with a median sample size of 24 participants. While these studies provide rich contextual insights, their findings may not generalize broadly. Only 6 quantitative studies exceeded 1000 participants, limiting confidence in prevalence estimates for different hesitancy drivers. Third, geographic representation was skewed. Most evidence originated from Ghana (61%) and Nigeria (24%), with limited representation from other West African countries and virtually none from Central, East, or Southern Africa.

Given substantial differences in colonial histories, ethnic compositions, health system structures, and research

governance frameworks across African regions, findings may not generalize beyond West Africa. Fourth, temporal changes in hesitancy remain unclear. While we noted suggestively increasing refusal rates comparing 2000 through to 2024 periods, differences in study methods, populations, and contexts preclude definitive conclusions about trends. Longitudinal studies tracking hesitancy over time within consistent populations were absent. In addition, our quality appraisal identified 13% of included studies as low quality due to methodological limitations, including inadequate sampling, lack of methodological transparency, or insufficient discussion of limitations. While we retained these studies, given our exploratory scope, their inclusion may have introduced imprecision in our synthesis.

Lastly, as a narrative review, our synthesis reflects the authors' interpretation and judgment in selecting, weighing, and synthesizing the evidence. Despite efforts toward transparency and rigour, there is potential for selection bias and subjective interpretation to influence conclusions. A systematic review with meta-analysis, while not feasible given the literature's heterogeneity, would provide a more objective synthesis of the evidence. Despite these limitations, this review provides a valuable synthesis of existing evidence and actionable recommendations for researchers, institutions, and policymakers seeking to address biological specimen hesitancy in Ghana and comparable contexts.

### Recommendations

To mitigate this hesitancy and ensure the long-term success of biomedical research, it is important to implement strategies that build trust and foster community engagement. Researchers must prioritize transparent communication to ensure that participants understand their roles, rights, and the significance of their contributions. Community involvement, through durbars and trusted leaders, can bridge the gap between researchers and participants, making the research process more relatable and acceptable. Additionally, research materials should be translated into local languages using culturally appropriate terminologies to enhance comprehension.

Sustainable incentives, such as transportation support, health screenings, or community-driven benefits, can further encourage participation while ensuring ethical considerations are upheld. Finally, ongoing feedback and engagement with participants, providing updates on research outcomes and demonstrating real-world impacts will foster long-term trust and collaboration. To address hesitancy, a collaborative effort from researchers, policymakers, and community stakeholders is required. Embracing transparency, education, and culturally sensitive approaches to biomedical research in Ghana and across Africa can advance and lead to impactful discoveries that benefit diverse populations.

### Operational checklist for researchers

We strongly recommend that researchers pilot test the operational checklist below (Table 3) in at least one study

setting before full-scale implementation. The pilot phase should: (1) test feasibility and acceptability of checklist items with a small sample ( $n = 50$  participants) representing the target population; (2) gather systematic feedback from community advisory boards, field staff, and participants on practical challenges, cultural appropriateness, and resource requirements; (3) measure baseline metrics (e.g., comprehension scores through teach-back methods, consent quality through audio recording reviews, participation rates) before and after implementing checklist interventions; (4) document actual time, personnel, and financial resources required for each checklist item; (5) identify unanticipated barriers and necessary adaptations; and (6) revise the checklist based on lessons learned before full study rollout.

Pilot results should be documented and shared through institutional repositories, conference presentations, or publications to build the evidence base for these interventions and enable iterative refinement. We encourage funding agencies to allocate specific resources for pilot testing community engagement and consent procedures as integral components of research methodology.

### Operationalizing benefit-sharing mechanisms

Benefit-sharing should move beyond abstract principles to concrete, operationalized mechanisms formalized through written agreements developed in consultation with community representatives.

#### Types of benefits

##### Direct individual benefits

Free health screenings relevant to the study focus, treatment for conditions identified during research, transportation reimbursement exceeding actual costs, referrals to healthcare services, and results disclosure with clinical interpretation.

##### Community-level benefits

Health infrastructure improvements (water points, clinic renovations, medical equipment donations); employment of community members as research staff with fair compensation and skills training; support for community health worker programmes that extend beyond the study duration.

##### Capacity-building

Training for community health workers with certification, research assistantships for local youth with mentorship, scholarships linked to community research participation, and laboratory skills training for local personnel.

##### Knowledge-sharing

Community feedback sessions presenting study results in accessible language and format; health education workshops addressing community-identified priorities; written research summaries in local languages with visual aids; co-authorship opportunities for community researchers.

Table 3. Operational checklist for researchers

Priority	Action	Implementation Steps	Responsible Party	Resources Required	Success Metric	Measurement Method	Target
Essential	Established Community Advisory Board (CAB)	<ol style="list-style-type: none"> <li>1. Identify community stakeholders (chiefs, religious leaders, health workers, youth representatives, women groups)</li> <li>2. Conduct 2-3 preliminary meetings to explain CAB purpose and solicit nominations</li> <li>3. Formally establish CAB with 8-12 members representing diverse community segments</li> <li>4. Develop terms of reference, meeting schedule, compensation policy</li> <li>5. Hold quarterly meetings with documented minutes</li> </ol>	Primary: Principal Investigator Supporting: Community Liaison Officer, Ethics Committee	Time: 2-3 months setup; quarterly ongoing Personnel: Liaison Officer Budget: GHC8000/year (stipends, refreshments, transport)	Percentage of studies with active Community Advisory Board (CAB) meeting quarterly with documented minutes	Review study documents; verify meeting minutes (dates, attendance, topics)	100%
Essential	Translate and validate consent materials	<ol style="list-style-type: none"> <li>1. Perform forward-backward translation by independent bilingual translators</li> <li>2. Pilot test with 10-15 community members matching study population</li> <li>3. Assess comprehension using teach-back method</li> <li>4. Revise based on feedback</li> <li>5. Document translation process and validation results</li> </ol>	Primary: Study Coordinator Supporting: Professional translators, Community Liaison	Time: 4-6 weeks Personnel: 2 translators, 1 coordinator Budget: GHC6000-8000 (translation fees, pilot testing)	Participant comprehension score on key study elements	Structured quiz or teach-back assessment with random sample (n≥30)	≥80%
Highly recommended	Develop benefit sharing agreement	<ol style="list-style-type: none"> <li>1. Consult CAB to identify community priorities</li> <li>2. Draft written agreement specifying direct, community, capacity, knowledge, and economic benefits</li> <li>3. Obtain CAB approval and signatures</li> <li>4. Submit to ethics committee for review</li> <li>5. Implement quarterly monitoring with documented progress reports</li> </ol>	Primary: Principal Investigator Supporting: CAB, Ethics Committee, Legal Advisor	Time: 1-2 months development; ongoing monitoring Personnel: PI, legal consultant Budget: Variable based on benefits; GHC5000-20,000 (legal review)	Number of Material Transfer Agreements (MTAs) with benefit clauses	Review study protocols; verify signed agreement in ethics files	100%

Table 3. Cont.

Priority	Action	Implementation Steps	Responsible Party	Resources Required	Success Metric	Measurement Method	Target
Essential	Execute Material Transfer Agreement (MTA) for sample export	<ol style="list-style-type: none"> <li>1. Identify all receiving institutions for samples</li> <li>2. Use institutional template MTA specifying permitted uses, ownership, benefit-sharing, data access, destruction timeline, audit rights</li> <li>3. Negotiate terms with legal review</li> <li>4. Obtain institutional and partner signatures before sample export</li> <li>5. Monitor compliance through annual reports</li> </ol>	Primary: Institutional Legal Office Supporting: PI, Ethics Committee	Time: 2-4 weeks negotiation; ongoing monitoring Personnel: Legal officer, PI Budget: GHC3000-6000 legal review	Percentage of studies exporting samples with executed MTAs containing benefit-sharing clauses	Review export documentation; verify executed MTA with required clauses	100%
Highly recommended	Train research team in cultural competence and ethical consent	<ol style="list-style-type: none"> <li>1. Develop training curriculum covering: cultural beliefs about samples, respectful communication, consent best practices, addressing hesitancy</li> <li>2. Conduct 1-day interactive training workshop</li> <li>3. Include role-playing exercises for challenging scenarios</li> <li>4. Assess competence through observed practice</li> <li>5. Provide refresher training every 6 months</li> </ol>	Primary: Study Coordinator Supporting: Community Liaison, Ethics officer	Time: 1 day initial; half day semi-annual refreshers Personnel: All field staff Budget: GHC4000-6000 per session (venue, materials, trainer fees)	Percentage of field staff completing training with competency certification	Training attendance records; post-training assessment scores; supervisor observation checklist	100%
Context dependent	Disseminate results to community	<ol style="list-style-type: none"> <li>1. Prepare plain-language summary in local language(s) with visual aids</li> <li>2. Present results at community meeting/durbar within 3 months of study completion</li> <li>3. Provide printed summaries for distribution</li> <li>4. Facilitate Q&amp;A session</li> <li>5. Submit summary to community health facilities for display</li> </ol>	Primary: Principal Investigator Supporting: Community Liaison, CAB	Time: 2-3 weeks preparation; half day presentation Personnel: PI, translator, liaison Budget: GHC3000-5000 (translation, printing, venue, refreshments)	Percentage of completed studies with documented community dissemination within 3 months	Meeting attendance records; photos; signed summary distribution logs	≥80%

### Economic benefits

Preferential hiring policies for community members; support for local businesses during fieldwork (accommodation, catering, transportation services); revenue-sharing agreements for commercialized products developed from samples, with specific percentage allocations determined prospectively.

### Monitoring and accountability mechanisms

Community advisory boards should review benefit-sharing plans quarterly during study conduct, with meeting minutes documented and accessible to community members. Annual reports should itemize benefits delivered (financial value, number of beneficiaries, specific activities) and solicit structured feedback through surveys and focus groups. Benefit-sharing agreements should specify dispute

resolution procedures through institutional ethics committees with mandatory community representation. Independent audits of benefit delivery should occur at study completion, with the findings made public in accessible formats (e.g., community meetings, local-language reports). Non-compliance with benefit-sharing agreements should trigger defined consequences, including funding holds, protocol modifications, or study suspension.

### Template benefit-sharing agreements

These agreements should be developed collaboratively by research institutions, ethics committees, community advisory boards, and legal experts, then made freely available through institutional repositories. These templates should be adaptable to specific contexts while ensuring core principles of equity, transparency, sustainability, and community voice.

**Operationalizing material transfer agreements**

All biological samples exported from Ghana must be governed by comprehensive Material Transfer Agreements (MTAs) executed before sample shipment. MTAs should specify:

**Permitted uses**

Detailed description of all approved analyses, including specific assays, technologies, and research questions. Explicit prohibitions on unapproved secondary uses, commercialization without amendment, or transfer to third parties without written consent. Requirements for protocol amendment and re-consent for any analyses not specified in the original MTA.

**Sample ownership**

Clear statement that samples remain the property of Ghana/originating institution/source community, with receiving institutions acting as custodians rather than owners. The specification that ownership does not transfer even if samples are permanently consumed through analysis.

**Benefit-sharing clauses**

Specific percentage (e.g., 20-30%) of revenue from patents, licenses, or commercial products derived from samples allocated to the originating institution and/or community development fund. Co-authorship requirements for publications, with Ghanaian researchers as senior authors when appropriate, based on intellectual contribution. Technology transfer commitments, including training, equipment sharing, or establishment of in-country laboratory capacity.

**Data access rights**

Requirements for the deposition of raw data in internationally accessible repositories with appropriate access controls should be clearly defined. Ghanaian researchers should retain the right to access, analyze, and publish findings derived from data generated from collected samples. Timelines for data availability should also be specified, with data generally becoming accessible immediately upon publication of the primary research findings.

**Sample destruction timeline**

Mandatory destruction of samples after a specified period (typically 10 years, or longer if justified) unless explicit re-consent is obtained from participants and approved by the originating ethics committee. Specification of destruction methods and documentation requirements.

**Audit and monitoring rights**

Ghanaian institutions retain the right to audit the use and storage conditions of samples on reasonable notice. Requirement for annual reports documenting: samples used/remaining, analyses performed, publications generated, commercial developments, benefit-sharing distributions. Consequences of non-compliance include return/destruction of samples, termination of collaboration, and financial penalties.

**Acknowledgment and attribution**

Requirements for acknowledging sample source in all publications, conference presentations, and patent applications—specification of preferred attribution language.

**Implementation framework**

Template MTAs embodying these principles should be developed by the Ghana Health Service Ethics Review Committee in consultation with legal experts, research institutions, and community representatives. Templates should be made freely available through online repositories and actively promoted through ethics review processes. Compliance with MTA requirements should be verified during initial ethics review, with sample export contingent on executed MTAs. Post-approval monitoring should include annual verification that MTAs remain in force and terms are being honoured. Violations should be reported to ethics committees with enforcement mechanisms, including suspension of approvals for non-compliant institutions. Regional harmonization efforts should establish common MTA standards across West African countries to prevent ethics shopping, where researchers seek jurisdictions with weaker sample governance.

**Conclusion**

Hesitancy towards research participation, particularly regarding sample provision, poses a significant challenge to biomedical research in Ghana and across Africa. Rooted in cultural, educational, and institutional barriers, this reluctance impacts the quality, inclusivity, and effectiveness of scientific research. Mistrust due to unethical practices, limited local translation, and limited understanding of scientific terminology contribute to this growing challenge. Meaningful interventions are needed to prevent skewed research findings and improve the development and effectiveness of diagnostics, treatments, and public health policies. However, these interventions must be context-centred, accounting for cultural and demographic dynamics to ensure equitable and accurate health outcomes.

**DECLARATIONS****Ethical consideration**

This narrative review was drafted using existing literature and does not involve the collection of new data from human participants; therefore, ethics approval was not required.

**Consent to publish**

All authors agreed on the content of the final paper.

**Funding**

None

**Competing Interest**

The authors declare no conflict of interest

**Author contribution**

ESL, DAO, and CD conceptualized the study. ESL conducted the data analysis with support from AGM. ESL, DAO, CD, and AGM drafted the manuscript. IOD reviewed the draft manuscript. All authors contributed to and approved the final version of the manuscript.

**Acknowledgement**

The authors are grateful to all members of the Infectious Diseases Epidemiology Research Laboratory (iDEL), with special acknowledgement to Elizabeth Obeng-Aboagye for contributing to the literature search.

**Availability of data**

Data is available upon request to the corresponding author

**REFERENCES**

- Bledsoe MJ, Grizzle WE (2013) Use of human specimens in research: the evolving United States regulatory, policy, and scientific landscape. *Diagn Histopathol* 19:322–330
- Drake BF, Boyd D, Carter K, Gehlert S, Thompson VS (2017) Barriers and strategies to participation in tissue research among African-American men. *J Cancer Educ* 32:51–58
- Boahen O, Owusu-Agyei S, Febir LG, Tawiah C, Tawiah T, Afari S, et al (2013) Community perception and beliefs about blood draw for clinical research in Ghana. *Trans R Soc Trop Med Hyg* 107:261–265
- Fewtrell MS, Kennedy K, Singhal A, Martin RM, Ness A, Hadders-Algra M, et al (2008) How much loss to follow-up is acceptable in long-term randomised trials and prospective studies? *Arch Dis Child* 93:458–461
- Bamer AM, McMullen K, Gibran N, Holavanahalli R, Schneider JC, Carrougher GJ, et al (2020) Factors associated with attrition of adult participants in a longitudinal database: a National Institute on Disability, Independent Living, and Rehabilitation Research burn model system study. *J Burn Care Res* 41:270–279
- Mfoafo-M'Carthy M, Grischow J (2022) Hierarchy and inequality in research: navigating the challenges of research in Ghana. *Qual Res* 22:729–742
- Brackstone K, Atengble K, Head M, Boateng L (2022) COVID-19 vaccine hesitancy trends in Ghana: a cross-sectional study exploring the roles of political allegiance, misinformation beliefs, and sociodemographic factors. *Pan Afr Med J* 43:1–12
- Harding A, Harper B, Stone D, O'Neill C, Berger P, Harris S, et al (2011) Conducting research with tribal communities: sovereignty, ethics, and data-sharing issues. *Environ Health Perspect* 120:6–10
- Tindana P, Campbell M, Marshall P, Littler K, Vincent R, Seeley J, et al (2017) Developing the science and methods of community engagement for genomic research and biobanking in Africa. *Glob Health Epidemiol Genom* 2:e13
- Glover-Meni N, Nyarko JA, Agbezorlie PK, Agyei DD (2024) Language barriers and healthcare access: a qualitative study in the Volta Region of Ghana. *J Commun Healthc* 17:301–309
- Nollett C, Eberl M, Fitzgibbon J, Joseph-Williams N, Hatch S (2024) Public involvement and engagement in scientific research and higher education: the only way is ethics? *Res Involv Engagem* 10:50
- Kyei J, Dzansi G, Acheampong AK, Adjei CA, Ohene LA, Adjorlolo S, et al (2023) Factors influencing nurses and midwives' participation in research: a qualitative study. *Nurs Midwifery Res J* 19:5–21
- Lecky DM, Hawking MK, McNulty CA (2014) Patients' perspectives on providing a stool sample to their GP: a qualitative study. *Br J Gen Pract* 64:e684–e693
- Fey JM, Bikker FJ, Hesse D (2023) Saliva collection methods among children and adolescents: a scoping review. *Mol Diagn Ther* 28:15–28
- Appeaning M, Owusu-Asante H, Kwofie S, Arhin G, Asamoah AO, Ali T, et al (2022) Improving community participation in clinical trials in Ghana: factors to consider. *Contemp Clin Trials Commun* 30:101012
- Groves RM, Peytcheva E (2008) The impact of nonresponse rates on nonresponse bias: a meta-analysis. *Public Opin Q* 72:167–189
- Dorcoo C, Gyamfi GO, Kaiser F, Lomotey ES, Sumbah JG, Fischer RJ, et al (2025) Pre-Clade IIb Mpox virus exposure in Ghana: a retrospective serological analysis. *Viruses* 17:1415
- Erves JC, Mayo-Gamble TL, Malin-Fair A, Boyer A, Joosten Y, Vaughn YC, et al (2017) Needs, priorities, and recommendations for engaging underrepresented populations in clinical research: a community perspective. *J Community Health* 42:472–480
- Crane M, Lee K, Wolfenden L, Phongsavan P, Bauman A (2024) Real-world public health interventions demonstrate how research evidence informs program scale-up. *Health Promot Int* 39:daae111
- Olivera Mesa D, Hogan AB, Watson OJ, Charles GD, Hauck K, Ghani AC, et al (2022) Modelling the impact of vaccine hesitancy in prolonging the need for non-pharmaceutical interventions to control the COVID-19 pandemic. *Commun Med* 2:14
- Alhassan RK, Nketiah-Amponsah E, Ayanore MA, Afaya A, Salia SM, Milipaak J, et al (2019) Impact of a bottom-up community engagement intervention on maternal and child health services utilization in Ghana: a cluster randomised trial. *BMC Public Health* 19:791
- Forson AO, Awuah RB, Mohammed AR, Owusu-Asenso CM, Akosah-Brempong G, Abdulai A, et al (2023) Coverage of preventive measures and surveillance for neglected tropical diseases in hard-to-reach communities in Ghana. *BMC Public Health* 23:1784
- Baatiema L (2025) Strengthening maternal healthcare in Ghana: utilizing the community-based health planning and services model as a vehicle. *Front Glob Womens Health* 6:1590452
- Data Protection Commission (2012) Data Protection Act, 2012 (Act 843). Government of Ghana, Accra
- Agyepong IA, Sewankambo N, Binagwaho A, Coll-Seck AM, Corrah T, Ezeh A, et al (2017) The path to longer and healthier lives for all Africans by 2030: the Lancet Commission on the future of health in sub-Saharan Africa. *Lancet* 390:2803–2859

26. de Vries J, Munung SN, Matimba A, McCurdy S, Ouwe Missi Oukem-Boyer O, Staunton C, et al (2017) Regulation of genomic and biobanking research in Africa: a content analysis of ethics guidelines, policies and procedures from 22 African countries. *BMC Med Ethics* 18:8
27. Andersson U (2015) Does media coverage of research misconduct impact on public trust in science? A study of news reporting and confidence in research in Sweden 2002–2013. *Observatorio (OBS\*)* 9:1–15
28. Cinelli M, Quattrociocchi W, Galeazzi A, Valensise CM, Brugnoli E, Schmidt AL, et al (2020) The COVID-19 social media infodemic. *Sci Rep* 10:16598
29. Appiah B, Gastel B, Burdine JN, Russell LH (2015) Science reporting in Accra, Ghana: sources, barriers and motivational factors. *Public Underst Sci* 24:23–37
30. Fairhead J, Leach M, Small M (2006) Public engagement with science? Local understandings of a vaccine trial in the Gambia. *J Biosoc Sci* 38:103–116
31. Wilkinson A, Leach M (2015) Briefing: Ebola—myths, realities, and structural violence. *Afr Aff* 114:136–148
32. Gilson L (2003) Trust and the development of health care as a social institution. *Soc Sci Med* 56:1453–1468
33. Council for International Organizations of Medical Sciences (2016) International ethical guidelines for health-related research involving humans. CIOMS, Geneva
34. Tindana PO, Singh JA, Tracy CS, Upshur REG, Daar AS, Singer PA, et al (2007) Grand challenges in global health: community engagement in research in developing countries. *PLoS Med* 4:e273
35. World Health Organization (2020) Managing the COVID-19 infodemic: promoting healthy behaviours and mitigating the harm from misinformation and disinformation. WHO, Geneva
36. Sallam M (2021) COVID-19 vaccine hesitancy worldwide: a concise systematic review of vaccine acceptance rates. *Vaccines* 9:160
37. Larson HJ, Clarke RM, Jarrett C, Eckersberger E, Levine Z, Schulz WS, et al (2018) Measuring trust in vaccination: a systematic review. *Hum Vaccin Immunother* 14:1599–1609
38. Tran TPT, Cormier J-C, Hopwood CA, Foster J, Scheib I, Li F, et al (2025) Building trust for community-engaged research: recommendations from a qualitative study. *J Particip Res Methods* 6:74–98