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How participation in deliberative engagement affects awareness of, and attitudes towards, genomics research and data sharing: evidence from rural Ghana

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Abstract

Background Deliberative engagement offers an opportunity for communities to provide informed opinions on complex ethical, legal, and social issues in genomic research and biobanking. However, its use is limited, particularly in resource-constrained settings like Ghana. This study examines the influence of deliberative engagement on participants' awareness of genomic research and attitudes towards data sharing.

Methods This research forms part of a larger mixed-methods study exploring deliberative methods for community engagement in genomics research in Ghana. Using a quasi-experimental one-group pretest-posttest design, 66 participants completed a baseline survey assessing awareness of genomic research and attitudes toward data sharing. Following this, a deliberative workshop was conducted with facilitated discussions. Post-engagement surveys measured changes in awareness and attitudes, and Fisher's exact test was used to assess statistical significance.

Results Respondents (aged 47–67 years; mean 57, SD 4.2) were predominantly male (65%), with 18% having no formal education. Significant improvements were observed in participants' awareness of genomic research (51–90%, $p = 0.001$) and confidence in consent processes ensuring privacy and confidentiality. Other variables, including willingness to share samples and trust in data governance, showed no significant change.

Conclusions This study demonstrates that deliberative engagement could enhance awareness of genomic research and offers a promising approach to informing, educating, and fostering dialogue on complex ethical issues in genomic research and biobanking, particularly in resource-limited settings.

Clinical trial number Not applicable.

Keywords Deliberative engagement, Genomic research, Biobanking, Data sharing, Ghana

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Background

There has been a significant growth in genomic research and biobanking globally, with the potential to improve disease prevention and treatment [1]. However, as the number of genomic research projects conducted in African countries increases [2, 3], it becomes imperative to address persistent ethical challenges that remain unresolved in these settings. These concerns extend beyond traditional healthcare research and include unique ethical, legal, and social issues [4, 5]. Key among these are: adequacy of consent models for data and samples [6–8], process for withdrawing consent [9, 10], ownership rights over biological samples and data [10, 11], privacy and confidentiality concerns [9, 12], and equitable benefit-sharing [13, 14].

These challenges are compounded by trust issues [15], unbalanced power dynamics in research collaborations [16, 17], a legacy of historical exploitation of local populations, and the heightened vulnerability of participants due to socioeconomic disparities [18]. Additionally, low literacy rates and the lack of appropriate terminology in native African languages create unique barriers to informed participation in genomic research [19].

Given these complexities, we argue that conventional community engagement (CE) approaches are insufficient for fostering genuine participant understanding and trust. While traditional CE methods offer some value, they often fail to facilitate meaningful two-way dialogue (instead focusing on one-way information dissemination, which does not empower communities in the decision-making processes, and account for cultural and socioeconomic diversity within communities [20–22].

This gap underscores the need for more participatory approaches such as deliberative engagement which prioritizes structured dialogue, education and inclusive decision-making [23, 24]. Despite its potential, the utilisation of deliberative engagement remains limited, with most deliberative engagement studies conducted in high-income countries, such as Canada, the USA, Australia, and New Zealand [22, 25–27], leaving critical questions about its applicability and effectiveness in African settings unanswered. Furthermore, while prior research has explored deliberative methods in theory [29–32], there is striking limited empirical evidence on how deliberative engagement influences awareness and attitudes in genomic research, key factors that determine its success or failure, and its feasibility in low-resource, culturally diverse African contexts [32–34].

This study sought to examine the influence of deliberative engagement on awareness of genomic research and attitudes toward data sharing in Ghana. Our work not only contributes empirical data to an understudied area but also provides actionable insights for improving ethical genomic research practices in Africa.

Methods

Study design

This paper was part of a larger study that examined the procedural and contextual factors influencing the implementation of deliberative engagement in genomic research and biobanking among research participants involved in a genomic study of body composition and cardiometabolic disease in Ghana [35]. This quantitative component of the study employed a quasi-experimental one-group pre- and post-test design to assess whether or not participation in a deliberative engagement session would affect awareness of and attitudes towards data sharing in genomic research and biobanking.

Study setting and population

The study was carried out in the two districts of Kassena and Nankana, located in Ghana's Upper East region. The population of Ghana is estimated to be approximately 31,071,609 (GSS, 2022), and the Kassena-Nankana district has a population of 99,895, made up of 48,895 males and 51,237 females. According to the Population and Housing Census (GSS, 2022), the Kassena Nankana district's employment rate in agriculture is 64.9%. The district is primarily rural, with agriculture serving as the primary source of income for most of the population. According to the 2021 Population and Housing Census by the Ghana Statistical Service, approximately 50.2% of the individuals aged 11 years and above are literate in this district, with male literacy at 58.1% and female literacy at 42.8%. Additionally, about 48.5% of the literate population can read and write English, with 56.2% for males and 41.3% for females.

The district forms the coverage area of the Navrongo Health and Demographic Surveillance System (NHDSS) of the Navrongo Health Research Centre (NHRC), an INDEPTH Network member site [36]. The NHDSS conducts routine surveillance on approximately 165,000 individuals, of whom 52.3% are females, across 32,000 households [37]. The Centre has carried out numerous community-based studies over the years, one of which is the cardiometabolic disease genomic study from which participants were drawn for this study. The genetic research project was part of a larger international collaboration called Africa Wits-INDEPTH Partnership for Genomic Research (AWI-Gen), which focused on studying the genetic and environmental factors contributing to heart-related diseases in African populations. This collaboration, funded by the National Institutes of Health, was part of the H3Africa Consortium [13, 14]. The AWI-Gen study participants were aged 40–60 from both rural and urban areas in Ghana and other African countries. It aimed to understand how physical characteristics, living conditions, and genetics influence body weight, body fat distribution, and the risk of heart-related diseases [35].

Participants in our study were 47–67 years of age since they were drawn from the AWI-Gen project one of the few genetic studies conducted in Ghana, approximately 7 years before our study initiation.

To ensure broader representation and inclusivity, these individuals who are often marginalized economically, socially, and politically were included. Given their limited access to technology, transportation, and basic services, these communities are frequently excluded from policy development. AWI-Gen participants were particularly suitable for this study, as their biological samples and data, stored in a South African biobank, give them a direct stake in policies and decisions related to genomic research and biobanking [23, 24].

Sample size and sampling technique

The sample size was determined through a complete census of the eligible population [38]. The initial pool of potential participants comprised 2,005 individuals enrolled in the AWIGEN study. Applying inclusion criteria, specifically, participants with at least a primary level of education who were available and consented to participate, resulted in a reduced pool of 91 eligible individuals. Given the small pool of eligible participants, it was feasible to contact all 91 of them using a census approach. However, the final sample consisted of 66 participants who consented to participate. The remaining 25 individuals were either unavailable or declined to participate. Figure 1 below illustrates the process of arriving at the sample size.

Data collection

Participants in this study were recruited in person from their homes using a household list derived from the NHDSS data and the AWIGEN study population data. Data collection was conducted entirely at the Navrongo Health Research Centre, beginning with informed consent, followed by a structured questionnaire administered face-to-face to the participants. This questionnaire was administered by trained research assistants at both the beginning (baseline) and end (endline) of their participation in a deliberative engagement forum. The questionnaire comprised 13 items, each requiring a response on a 3-point scale. Four demographic questions (age, sex, education, and religion) were asked only at baseline, while the remaining nine items, focused on awareness and attitudes, were administered at both pre- and post-engagement phases to allow for comparison. The pre- and post-assessment questionnaires were developed specifically for this study, drawing on existing literature [39–43], and the English version has been uploaded as a supplementary file. The questionnaires were developed by the lead researcher in collaboration with the primary supervisor, who has significant expertise in community

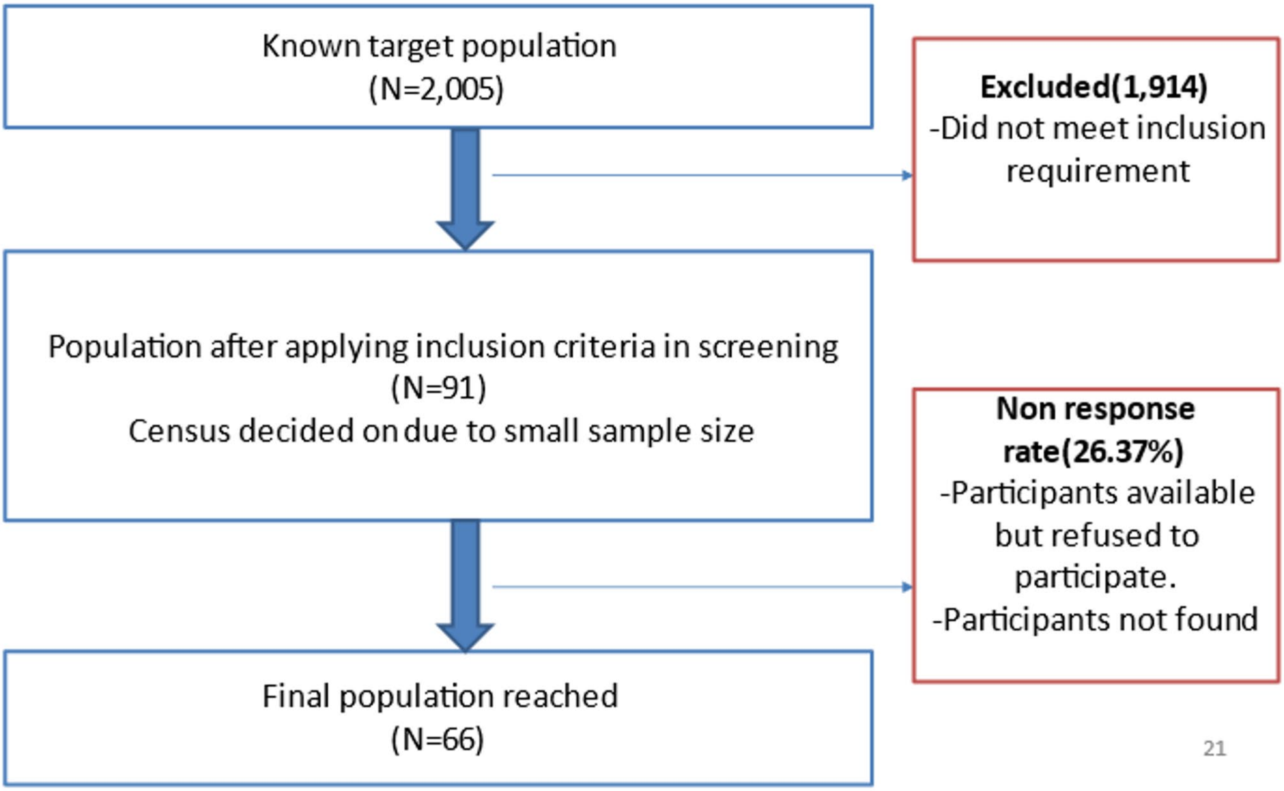

Fig. 1 Sampling and sample size

engagement and the ethical, legal, and social implications (ELSIs) of genomic research and biobanking in sub-Saharan Africa.

In addition to demographics, the surveys assessed participants' general views on data sharing, including attitudes toward sharing data with pharmaceutical companies and beliefs about compensation for data sharing. Participants were presented with a hypothetical scenario in which biobank data contributed to commercial drug development and profit. They rated their willingness to share genomic data with commercial entities and their expectations of potential benefits on a three-point scale. The survey also assessed their understanding of genomic research, knowledge about data protection regulations, trust in researchers and consent processes to safeguard privacy and confidentiality. All assessments used the same three-point scale. All study activities, including the pre- and post-surveys, were conducted in person at the Navrongo Health Research Centre.

The questionnaire was originally designed in English but was administered in English and local languages (Twi, Kassem, and/or Nankam). For respondents who were not proficient in English, the questions were translated into the Kassem and Nankam languages. Trained data collectors fluent in English, Kassem, Twi, and Nankam administered the questionnaire to such respondents. The questionnaire was administered to all participants before participating in the deliberative engagement session and immediately after participation. All two-point assessment surveys included the same questions on measures of attitude and awareness.

The deliberative engagement process

The information delivery session

Figure 2 outlines the deliberative engagement process implemented for this study, adapted from Carman et al.'s model [44] with modifications to the delivery method and reporting phase. Given participants' limited access to technology, a face-to-face format was used instead of virtual engagement. Rather than seeking consensus, a full transcript capturing diverse perspectives on genomic research, biobanking, and data sharing was produced. The engagement comprised two main parts: an information session and small group discussions. During the information session, participants received an overview of the study and the purpose of the engagement. A day-long session format was followed [40, 45]. Before the sessions, participants were re-consented to upon arrival. Recruitment had taken place a week earlier, where participants had verbally consented and contact information had been collected. On the day of engagement, consent for photography and audio recording was obtained. Informed consent was administered in English or translated into the local language by a research team member when needed. Participants were encouraged to ask questions throughout to ensure clarity and understanding.

The first session focused on delivering key information to participants. It began with a welcome address, followed by a general overview of the study presented in English by the principal investigator (PI), with local language interpretation provided by one of the experts. The research team, including experts and facilitators, were then introduced. Three local experts, including a social scientist, a bioethicist, and a qualitative research specialist familiar with the study communities, led the remainder of the session. These experts, who had direct

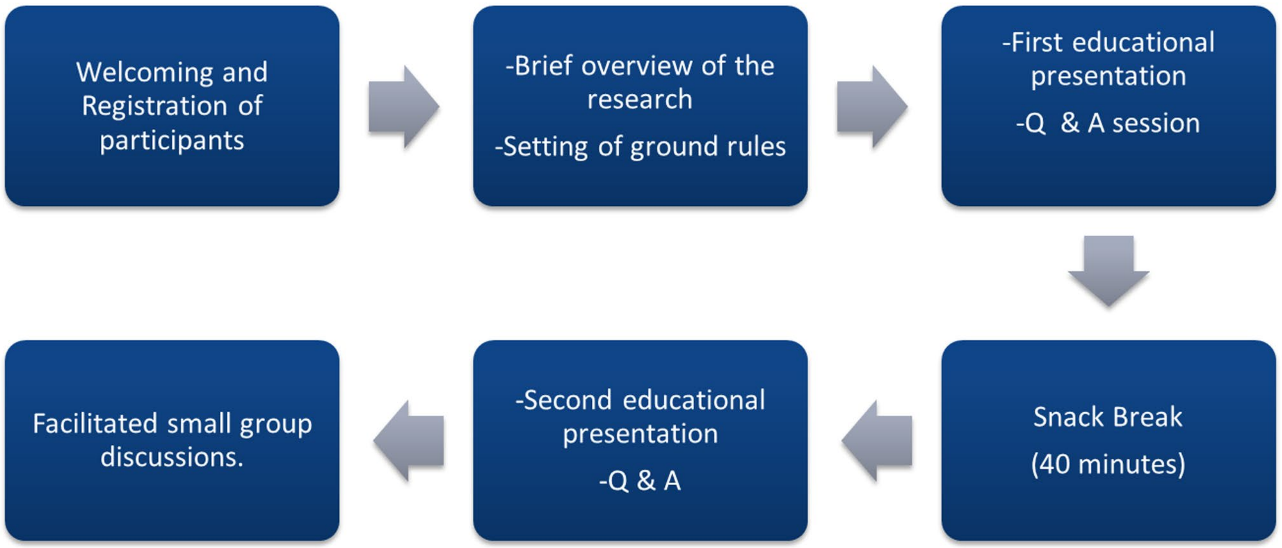

Fig. 2 Implemented Deliberative Engagement Forum

experience with the AWI-Gen project and expertise in the ethical aspects of genomic research and biobanking, facilitated discussions, addressed participants' questions, and summarized key points. To minimize potential bias, the PI stepped back after the initial presentation and observed the discussions without direct involvement [43]. As is standard in deliberative engagement processes [42, 43, 46, 47], participants were provided with educational resources to familiarize them with the study topic. The video materials used were developed by the H3Africa Community Engagement in Biobanking and Genomics (CEBioGen) project through a collaborative effort involving genetic researchers, qualitative experts, bioethicists, and communication specialists. These resources underwent pilot testing and were refined based on feedback from external experts.

Initially, we planned to distribute animation handouts and video documentaries electronically before the sessions. However, due to participants' limited access to email, smartphones, and compatible devices, pre-session distribution was impractical, away from methods used in previous studies [42, 44, 46–48]. To address this, key information was integrated into the information delivery sessions, as outlined in Fig. 2.

Participants were introduced to core concepts through two 15-minute educational videos delivered in local languages. The first video, *Basic Genetics*, explained genes, inheritance, and the importance of genomic research. The second, *The Journey of My Sample*, detailed the sample collection process and highlighted ethical considerations around privacy and confidentiality. These videos were shown multiple times to reinforce understanding.

Additionally, narrated PowerPoint presentations were delivered and interpreted by social scientists and bioethicists affiliated with both the CEBioGen and AWI-Gen projects. The presentations, based on the *What is a Gene* storyline from Ralefala et al. [48], explored ethical issues in data sharing, highlighting both potential benefits and risks. Content was carefully structured to guide participants through the deliberative process step-by-step, ensuring clarity and active engagement.

The small group deliberation sessions

After the information delivery sessions, participants were divided into nine small groups, averaging seven people each. Groups were formed based on language preference: English (3 groups), Nankam (3 groups), Kasem (3 groups), and Twi (1 group).

There was no intentional gender segregation; however, the English groups consisted solely of males. This may be attributed to the historical lack of emphasis on girls' education in rural northern Ghana. Other language groups had a mix of genders, though they were still predominantly male.

Each group had a trained facilitator who sat in a circle with the participants. These facilitators all had backgrounds in qualitative and genomic research, as well as experience moderating focus group discussions. Despite differing viewpoints, the discussions remained respectful and conflict-free. This respectful environment encouraged open participation, allowing individuals to share opinions, disagree with experts, and contribute enthusiastically without fear [49]. Throughout the discussions, experts and study team members were available to answer any questions that arose.

Participant diversity was considered in the recruitment process, with efforts made to include individuals of varying demographics, including gender, age, education, religion, and ethnicity. However, participants were selected through random sampling without gender stratification. Additionally, applying the exclusion criteria, particularly participant availability, resulted in a gender imbalance, with 65% of the final sample being male. After providing participants with comprehensive information about the potential benefits, challenges, and ethical implications of genomic research, biobanking, and data sharing, facilitated discussions were conducted to encourage the exchange of ideas and viewpoints. These deliberations were transcribed for subsequent analysis.

Data management and analysis

All completed questionnaires were entered into a CSPro 7.7 database and exported into Excel for further consistency checks and data cleaning. The final dataset was subsequently exported into STATA version 13.1 MP (College Station, Texas 77845 USA), where all analyses were performed.

The analysis began with descriptive statistics to describe the key demographic characteristics of the respondents and to provide an overall summary of the data. Frequency distribution and proportions were estimated and presented in tables and charts. Furthermore, statistical differences in awareness of and attitude toward data sharing in genomics research before and after the deliberative engagement were assessed using the chi-square test and Fisher's exact test (in cases where observations for any variable were less than 5). Statistical significance was held at 95% confidence.

Results

Background characteristics of participants

Respondents were aged between 47 and 67 years, with a mean age of 57 and a standard deviation of 4.12. The majority were male, 43(65%), while 18% had reported having no formal education (see Table 1). These respondents participated in a 2014 genomic study aimed at investigating the contribution of genes, physical traits, and living conditions to body mass index (BMI), body

Table 1 Characteristics of study participants

Characteristics	Frequency (*n*)	Percent (%)
Age in years		
47–53	10	15
54–60	43	65
61–67	13	20
Total	*66*	*100*
Sex		
Male	43	65
Female	23	35
Total	*66*	*100*
Highest level of education		
None	12	18
Primary	16	24
JHS/Middle/JSS	17	26
Commercial/Vocational/Technical	5	8
SHS/Secondary	5	8
Tertiary	11	17
Total	*66*	*100*
Religion		
Christian	49	74
Traditional	13	20
Other	4	
Total	*66*	*100*

fat distribution, and potential risk factors for cardiometabolic diseases. As part of their participation, biospecimens were collected and are currently stored at the Sydney Brenner Institute for Molecular Bioscience (SBIMB) Biobank in South Africa. The AWI-GEN study was the first genomics study to involve adults between the ages of 40–60 years in Ghana [50].

The influence of deliberative engagement on awareness of and attitudes towards genomics research and data sharing

The study found a statistically significant increase in awareness following the deliberative engagement process, as shown in Table 2. The number of participants who reported being aware of the purpose of genomic research increased from 34 out of 66 participants (51.5%) before the intervention to 52 out of 58 participants (89.7%) post-intervention ($p = 0.001$).

Similarly, awareness of committees responsible for protecting privacy in data sharing increased from 41 out of 66 participants (62.1%) to 45 out of 59 participants (76.3%), though this change was not statistically significant ($p = 0.084$).

Concerning attitudes, no statistically significant changes were observed in general views towards data sharing and privacy (Tables 3a and 3b). For example, the proportion of participants who found it unacceptable to store biological samples outside Ghana decreased from 6 out of 66 (9.1%) to 2 out of 59 (3.4%), but this difference was not statistically significant ($p = 0.419$).

Confidence in researchers' ability to protect genomic data increased from 53 out of 66 (80.3%) to 53 out of 59 (89.8%), though this change was also not statistically significant ($p = 0.327$). However, confidence in the effectiveness of informed consent forms in protecting data privacy rose significantly, from 53 out of 66 participants (80.3%) pre-engagement to 56 out of 59 participants (94.9%) post-engagement ($p = 0.045$).

Additional data indicated a downward trend in participants who were unwilling to donate their samples to commercial entities (from 10 out of 66 [15.2%] to 4 out of 59 [6.8%]) and in neutral attitudes toward data sharing, but these differences were not statistically significant (Tables 3a & 3)b.

Discussion

Increased awareness and trust through deliberative engagement

The present study examined the influence of deliberative engagement on participants' awareness of genomic research and attitudes toward data sharing. The results show that participation in a deliberative engagement process significantly improved participants' understanding of genomic research. This finding is consistent with previous research on biobanking conducted in Australia [51], which suggests that deliberative engagement can

Table 2 How participation in deliberative engagement affected participants' awareness about genomics research and associated regulatory bodies

Variable	Category	Pre-Intervention (%)	Post-Intervention (%)	*p*-value
Awareness about the purpose of genomic research	Not at all aware	17 (25.8)	2 (3.4)	**0.001
	Slightly Aware	15 (22.7)	4 (6.9)	
	Aware	34 (51.5)	52 (89.7)	
	Total	66 (100)	58 (100)	
Aware of committees and laws for ensuring the privacy and confidentiality of genomic data sharing	Not at all aware	13 (19.7)	4 (6.8)	0.084
	Slightly Aware	12 (18.2)	10 (16.9)	
	Aware	41 (62.1)	45 (76.3)	
	Total	66 (100)	59 (100)	

Significant level: *$p < 0.05$; **$p < 0.001$

Table 3 a: How participation in deliberative engagement affected participants' awareness about genomics research and associated regulatory bodies

Variable	Category	Pre-Intervention (%)	Post-Intervention (%)	*p*-value
Likelihood of participating in genomic research in future	Unwilling	2 (3.0)	3 (5.2)	0.348
	Not Sure	2 (3.0)	0 (0.0)	
	Willing	62 (94.0)	55 (94.8)	
	Total	66 (100)	58 (100)	
Acceptability of storing biological samples and the associated data outside Ghana	Unacceptable	6 (9.1)	2 (3.4)	0.419
	Neutral	6 (9.1)	5 (8.5)	
	Acceptable	54 (81.8)	52 (88.1)	
	Total	66 (100)	59 (100)	
Worried about privacy and confidentiality in keeping my genomic samples outside Ghana	Not at all worried	39 (59.1)	43 (72.9)	0.207
	Somewhat worried	15 (22.7)	7 (11.9)	
	Worried	12 (18.2)	9 (15.3)	
	Total	66 (100)	59 (100)	
Confident that researchers will ensure that my genomic data will be kept private and confidential	Not confident	8 (12.1)	4 (6.8)	0.327
	Neutral	5 (7.6)	2 (3.4)	
	Confident	53 (80.3)	53 (89.8)	
	Total	66 (100)	59 (100)	

Table 3 b: How participation in deliberative engagement affected participants' attitudes towards data sharing in genomics research

Variable	Category	Pre-Intervention (%)	Post-Intervention (%)	*p*-value
Confident that the informed consent I gave before participating in genomic research can ensure confidentiality and Privacy of my data	Not confident	6 (9.1)	1 (1.7)	*0.045
	Neutral	7 (10.6)	2 (3.4)	
	Confident	53 (80.3)	56 (94.9)	
	Total	66 (100)	59 (100)	
Genomic data could be donated to biobanks and sometimes given to commercial companies who use them to develop drugs and diagnostic tests for profit. Are you willing to have your data donated for such purposes?	Unwilling	10 (15.2)	4 (6.8)	0.066
	Neutral	9 (13.6)	3 (5.1)	
	Willing	47 (71.2)	52 (88.1)	
	Total	66 (100)	59 (100)	
Individuals should receive any form of benefit when their genomic data from a genomic study is shared with commercial entities like pharmaceutical companies.	Disagree	8 (12.1)	3 (5.1)	0.242
	Neutral	7 (10.6)	5 (8.5)	
	Agree	51 (77.3)	51 (86.4)	
	Total	66 (100)	59 (100)	

be a powerful tool for educating the public on complex scientific topics. According to Scheufele [52], when deliberation is done well, people become more informed and understanding. Additionally, participants in deliberative engagement forums not only learn about the technical aspects of science but also the social, ethical, and economic implications. This is important because it makes participants feel more confident in their ability to influence scientific decisions and motivates them to become more involved in the future [53]. Open and honest discussions, as observed in this current study using the deliberative approach, can create a space for debate and sharing concerns, according to existing literature. This process has also been shown to build trust between scientists and the public [54].

Additionally, the increased awareness observed in this study may be attributed to several other factors. Participants' exposure to experts during the information sessions and their engagement in active discussions with peers likely allowed them to encounter a wider range of perspectives on genomic research. Wynne [55] suggests that people often form their ideas about science based on personal experience, culture, or common sense. Consequently, even those without a scientific background can contribute to discussions on scientific topics.

By engaging in these diverse viewpoints, participants may have developed a deeper understanding of the research objectives and potential benefits. As reported in an essay by Nisbet [56], social science research has shown that individuals from various backgrounds are likely to use information and make decisions about science through deliberative engagement. This enhanced understanding can empower individuals to make more informed choices regarding their participation in genomic research and data sharing. Furthermore, increased awareness can reduce fear and uncertainty surrounding this rapidly evolving field, fostering more positive public attitudes and trust in genomic research and biobanking [54].

The transformative potential of deliberative engagement extends beyond individual awareness. By promoting constructive dialogue about the ethical and societal implications of genomics, deliberative processes can enhance public discourse and support more informed decision-making regarding important scientific advancements. Overall, these findings underscore the importance of deliberative engagement as a means to enhance public understanding of complex scientific topics such as genomics. This aligns with findings from other studies indicating that effective communication and deliberative engagement can improve knowledge and understanding of complex studies like genomics, thus aiding individuals in making informed decisions [33, 52, 56, 57].

The study also observed a decrease in the number of participants who were unaware of regulatory bodies such as Research Ethics Committees (REC) following the deliberative engagement. While this change was not statistically significant, it highlights a potential trend toward improved awareness of research oversight mechanisms. This is noteworthy, as reported by Milne et al. [58], which found that people who felt reassured by laws protecting donated information were more likely to trust the data-sharing initiatives. A better understanding of existing safeguards may help reduce anxiety and fear about data privacy. When individuals are well informed about the oversight structures that govern research, they are empowered to make more informed decisions about research participation. Transparency in research processes also helps build public trust in the research enterprise [58]. Ultimately, even insignificant increases in awareness can support the development of more ethical research practices as communities become more engaged with the ethical considerations around genomic research.

Shifting attitudes towards data sharing and participation

This study observed some changes in participants' attitudes toward data sharing and privacy following the deliberative engagement. Although these shifts were not statistically significant, a general trend emerged suggesting reduced concern about storing samples and data outside Ghana. This may reflect a growing comfort with international collaboration, potentially influenced by increased awareness and trust built during the engagement sessions. Several factors likely contributed to this shift, including increased trust in researchers, improved understanding of data protection procedures, and clearer communication about the benefits and risks associated with international research collaboration [59, 60].

However, some participants continued to express reservations regarding the ability of local researchers to guarantee privacy and confidentiality. This is consistent with findings from a study in the UK, USA, Canada and Australia, where participants reported the highest levels of trust in their doctors and the lowest in individual researchers and commercial organizations [58]. People's distrust seems to be linked to concerns about how genomic data would be used, its confidentiality, and the potential for commercial exploitation [61]. While our study was conducted in a different context, these shared themes suggest the need for ongoing public education and ethical safeguards that address both global and local trust-related concerns [59, 60].

Importantly, as supported by existing literature, negative attitudes toward genomic research often stem from concerns about data handling, confidentiality, and privacy breaches, and perceived motivations of those managing the data [58, 62–68]. Building public trust in genomic research will require transparent governance, continuous community engagement, and capacity building for local researchers and institutions [15].

A particularly unexpected finding in our study was a slight increase in participants who indicated a likelihood to opt out of future genomic research following their participation in deliberative engagement. In contrast, other studies have shown that individuals with limited knowledge about genomics are often less willing to participate in studies that collect genetic information and tend to trust genetics research less [58, 62, 70–71]. However, high levels of knowledge can result in specific concerns that may not affect individuals with little or no knowledge. As reported by other studies, this may relate to individuals' concerns about the handling of their data [72]. This counterintuitive observation raises important questions regarding the factors that contribute to this shift in perspective.

Several possible explanations merit further investigation. Increased awareness of potential risks and uncertainties discussed during the deliberative engagement may have led some participants to reconsider their initial willingness to participate in genomics research. Others may have found the personal benefits unclear, even after gaining a better understanding of the research process, which could lessen their motivation to participate. Concerns about data sharing, even with an increased understanding of data protection measures, may also influence participants to opt out. This aligns with findings from other studies indicating that greater knowledge about genomics does not always correlate with positive feelings towards it. Individuals with a high level of knowledge may have specific concerns, such as apprehensions regarding how data is utilised [54]. Furthermore, unresolved questions or misunderstandings that emerge during the deliberative process could contribute to uncertainty and hesitancy regarding future participation.

Previous research indicates that deliberative engagement can result in various changes in attitudes, including positive, negative or no change at all [73]. This underscores the complexity of the process and its differing effects on individuals' perspectives. As noted by Middleton et al., individuals' feelings about genetic and genomic research can become more complicated when it does not directly benefit their health.

To effectively address this unexpected shift and ensure the success of future initiatives, several steps are essential. Conducting follow-up interviews or surveys with those who decline participation can help identify specific concerns influencing their decisions. Tailoring communication strategies to address these concerns can enhance understanding and correct misperceptions. Providing a more tangible and personalized understanding of potential benefits may motivate individuals to overcome their initial reservations. Finally, maintaining open communication channels and fostering continuous dialogue can help build trust and address concerns as they arise.

By exploring the reasons behind this shift, researchers can refine their deliberative engagement strategies, improve communication approaches, and ultimately encourage informed and enthusiastic participation in future genomic research. This will bolster the effectiveness of deliberative engagement as a tool for enhancing public understanding and promoting responsible research practices in the field of genomics.

In summary, these findings highlight the potential of deliberative engagement as a powerful tool for enhancing public understanding of complex topics like genomic research and the regulatory frameworks that govern them. By increasing awareness and trust, deliberative engagement can contribute to informed decision-making, empower communities, and promote the development of research practices that are more aligned with public values and expectations.

Limitations

This study provides valuable insights into public understanding of genomic research within a rural Ghanaian community but has several limitations. The participant group ($n = 66$), aged 47–67 years, was predominantly male (65%) and had generally low educational attainment, with only 25% completing Junior High and 24% completing primary education. This gender imbalance, along with the overall low educational level, may have influenced the diversity of perspectives captured and limited the generalizability of the findings across different demographic groups. Additionally, most participants (74.1%) identified as Christian, which may further limit applicability to more religiously diverse or urban populations.

Translation was another challenge, as interviews conducted in local languages were translated into English for analysis. Although experienced native speakers handled the translations to minimize loss of meaning, some nuances may have been lost. Despite these limitations, the study provides important guidance for future research and community engagement initiatives, particularly in rural, resource-limited settings.

Conclusion

Genomic research presents great potential for addressing pressing health challenges in African communities. However, its ethical and social complexities, such as historical exploitation of research participants, vulnerability stemming from lower socio-economic status, mistrust, cultural dynamics and language barriers, require community engagement strategies that go beyond conventional approaches. This study explored the use of deliberative engagement as one of such approaches.While the findings suggest that it can foster increased awareness and more informed perspectives on genomic research, its influence on attitudes was complex. Some participants expressed greater trust and willingness to share data, while others became more cautious after gaining a deeper understanding of the risks involved.

These mixed outcomes underscore the need for further research. Future research should examine the contextual factors that influence the outcomes of deliberative processes, compare their impact with other engagement methods, and assess the sustainability of their effects over time. By doing so, researchers can better design ethically grounded, inclusive, and context-appropriate strategies for involving communities in genomic research and biobanking.

Authors contribution

This research stemmed from the conceptualization of the research question and overall project design by IHT. The initial draft of the manuscript was authored by IHT. It was then subjected to a collaborative review and editing process, incorporating feedback from PT, PA, and JG. All authors, including PS, contributed substantial comments to the revision of the manuscript and approved the final version for submission.

Abbreviations

CE	Community Engagement
REC	Research Ethics Committees
HDSS	Health and Demographic Surveillance System
H3Africa	Human Hereditary and Health
AWI-Gen	Africa Wits-INDEPTH partnership for Genomic studies
CEBioGen	Community Engagement in Biobanking and Genomics

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12910-025-01251-z.

Supplementary Material 1

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Author contributions

This research stemmed from the conceptualization of the research question and overall project design by IT. The initial draft of the manuscript was authored by IT. It was then subjected to a collaborative review and editing process, incorporating feedback from PT, PA, and JG. All authors including PS, contributed substantial comments to the revision of the manuscript and approved the final version for submission.

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Data availability

All relevant data are included in this paper.

Declarations

Ethics approval and consent to participate

This study was conducted following the principles of the Declaration of Helsinki. The Ghana Health Service Ethics Review Committee reviewed and approved the study protocol(number GHSERC:032/07/22). Written informed consent was obtained from all study participants, and permission to record the audio was also obtained from all participants.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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