

Soil-Transmitted Helminths Surveillance in Benin:
A Mixed-Methods Analysis of Factors influencing Participation in
Longitudinal STH Surveillance Activities

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Abstract

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Background: Ongoing research aims to determine the feasibility of interrupting transmission of soil-transmitted helminths (STH) via intensive approaches to deworming, including community-wide mass drug administration (MDA). Transitioning from a policy of STH control to transmission interruption will require rethinking existing STH surveillance protocols. Surveillance will be crucial for identifying priority areas for community-wide MDA, monitoring implementation, and verifying elimination. Although broad participation in surveillance activities is necessary to accurately estimate STH prevalence, minimal research has been conducted to investigate drivers of participation in stool-based surveillance.

Methods: This mixed-methods exploratory sequential study took place in Comé, Benin in association with the DeWorm3 Project. Six focus group discussions (FGD) were conducted with a sample of individuals who were invited to participate in annual stool surveillance as part of DeWorm3 activities. Quota sampling was used to ensure respondents included both people who provided a stool sample at baseline and people who did not. Respondents were asked about reasons they chose to participate in STH surveillance. Thematic analysis was used to identify drivers of participation and inform the quantitative analysis. Backwards stepwise model building was used to identify correlates of participation in baseline stool sampling. The influence of twelve variables

on participation were considered based on existing literature and a hypothesis-driven conceptual framework developed from qualitative findings. A mixed-effects logistic regression model was built, with study cluster included as a random effect. Odds ratios and corresponding 95% confidence intervals are reported. Qualitative and quantitative findings were merged for interpretation.

Results: Among the 7,039 individuals invited to participate in baseline stool surveillance, the refusal rate was 8.14%. Cluster-level refusal rates ranged from 0.6% to 20%. Qualitative themes indicate that drivers of participation include: community members weighing community-level benefits against individual-level risks, circulating rumors about misuse of stool samples, interpersonal communication with field agents, and cultural norms around handling adult feces. Recommendations to improve surveillance activities focused on communication and community engagement strategies. The quantitative analysis showed school-aged children were significantly more likely to provide a stool sample than adults (OR:1.44, CI:1.13 – 1.83), a finding that converged with the qualitative results. Individuals from areas in the highest quartile of population density were less likely to participate (OR: 0.58, CI: 0.40-0.86), which aligned with qualitative findings about circulating rumors. Several variables linked to community-affinity aligned with qualitative results; residing mainly in the community (OR: 2.76, CI:1.51 – 5.03) and having lived in the community for more than 10 years (OR: 1.31, CI: 0.87-1.85) increased likelihood of participation.

Conclusion: This study found that certain individuals are more likely to participate in STH surveillance activities than others, including children, individuals in rural areas, long-term residents in the community, and those perceiving their families to be at risk for STH. If STH surveillance is intensified for the purposes of transmission-elimination programming, programs

will need to reimagine how STH surveillance is conducted to address community concerns and ensure that no subpopulations are inadvertently excluded from surveillance data. Otherwise, programs could misidentify priority areas for MDA implementation or bias transmission verification data.

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Introduction

Globally, the World Health Organization (WHO) estimates more than 1.5 billion people, or 24% of the world's population, are infected with soil-transmitted helminths (STH).^(1,2) Individuals with moderate-to-heavy intensity infections experience adverse health outcomes including diarrhea, abdominal pain, anemia, and impaired cognitive and physical development in children.^(3,4) These infections occur primarily in low- and middle-income countries across tropical and subtropical regions, and disproportionately affect low-income communities.^(1,2) According to the Institute of Health Metrics and Evaluation, in 2019, STH infections were responsible for 25.5 disability adjusted life years (DALY) per 100,000 persons globally.⁽⁵⁾ The WHO's current STH policy is control of STH through mass drug administration (MDA) of albendazole or mebendazole to school-age children and adults in certain high-risk groups (e.g. adolescent girls and pregnant individuals).^(1,6-8) While targeted MDA is successful at controlling morbidity in school-aged children, community transmission continues to occur in many areas with adults serving as reservoirs of infection, particularly of hookworm infections.⁽⁹⁻¹¹⁾ Several studies are underway to determine the feasibility of interrupting transmission of STH via more intensive approaches to deworming, including community-wide MDA (cMDA), which treats all age groups as opposed to just children and specific targeted high risk populations.⁽¹²⁻¹⁴⁾

Transitioning from a policy of STH control to transmission interruption, and the associated expansions in treatment programs, will require rethinking existing STH surveillance protocols. Community-based surveillance will be necessary for identifying areas with low baseline transmission, where cMDA efforts may have a high probability of interrupting transmission. New surveillance measures will also be necessary for verifying transmission interruption at the level of the implementation unit. Current diagnostics used for STH surveillance require collecting stool samples for microscopy-based assessment of infection, usually via the Kato-Katz technique, and novel approaches including qPCR are also increasingly available.⁽¹⁵⁾ Both methods require collecting fecal samples.

Although broad consent and participation in surveillance activities will be necessary for gaining accurate estimates of STH prevalence, minimal research has been conducted to investigate the acceptability

of stool-based surveillance and opportunities to optimize participation in surveillance activities. One study in Kenya evaluating factors influencing decisions to participate in treatment and research programs targeting STH and schistosomiasis found associations between socioeconomic status, history of disease, receipt of treatment through the program, and an understanding of the importance of the research with an individual's willingness to provide samples (urine, blood, and stool) for research purposes.⁽¹⁶⁾ A Ugandan study evaluating the acceptability of sampling procedures (self-collected vaginal swabs, blood draws and stool sample collection) related to the study of HPV vaccine efficacy in the presence of malaria and STH co-infections found that participants had positive views of providing a stool sample but were wary of vaginal swabs and blood sampling due to fears of how the samples might be misused.⁽¹⁷⁾ Evidence from clinical settings in higher income countries indicate that providing stool samples is driven by perceived benefits, clear information about the process, and protocols that assuage fears around hygiene and discretion.⁽¹⁸⁾ Studies of other NTD surveillance activities, including those for onchocerciasis and trachoma, indicate that less invasive sampling procedures are preferable and decisions are similarly driven by perceived benefits, and trust and understanding of the program.^(19,20) However the specific factors influencing participation in STH stool-based surveillance activities are unknown.

Low participation in STH surveillance activities among some communities may act as a barrier to accurate detection, diagnosis, and elimination of STH. Understanding drivers of participation in STH surveillance activities is essential to identify strategies needed to improve participation in stool sampling. If certain types of individuals are underrepresented amongst participants, estimations of prevalence for certain communities may be biased. This in turn has implications for identifying geographic areas that are ready for elimination programming, for monitoring program implementation, and for ascertaining elimination status. The purpose of this mixed-methods study is to generate evidence regarding the demographic, sociocultural, and financial factors influencing participation in STH surveillance activities in Comé, Benin. Findings from this study may have implications for best practices in redesigning STH surveillance, should a global policy for STH transmission interruption move forward.

Methods

This analysis used an exploratory sequential mixed methods design (QUAL → QUANT) to identify factors influencing participation in STH surveillance activities, for the purposes of improving design of future STH surveillance activities. Findings from qualitative data collection were used to develop quantitative data analysis procedures (model building), and findings were merged for interpretation.

The DeWorm3 Project

This study was nested within the DeWorm3 Project, a cluster randomized control trial based in India, Malawi, and Benin that is testing the feasibility of interrupting transmission of STH.⁽²¹⁾ In Benin, the DeWorm3 trial is conducted in the district of Comé, which is located in the Mono Department and has a population size of 94,969 persons, per baseline study estimates. The trial site is divided into forty clusters, randomized to receive either annual MDA of albendazole to school-aged children (standard of care) or biannual cMDA of albendazole to all eligible age groups. Treatment was provided for three years (June 2018-December 2021) followed by two years of surveillance to monitor for recrudescence (2022-2023). More information about the DeWorm3 study design can be found elsewhere.⁽¹²⁾

DeWorm3 uses two methods to monitor changes in STH prevalence and infection intensity over time. Cluster-level STH prevalence is determined by collecting and testing stool samples from a random cross-sectional sample of cluster residents at baseline, 6 months post the final round of MDA, and endline. Additionally, 150 individuals from each cluster were invited to participate in a longitudinal monitoring cohort (LMC). LMC participants were randomly selected at baseline from an age-stratified census (30 pre-school-age children, 30 school-age children, 90 adults) of current cluster residents. LMC participants provided annual stool samples throughout the study period to assess changes in STH prevalence and rates of reinfection. Participants in control clusters (who are not routinely offered treatment via the DeWorm3 Project) who were found to be infected via Kato-Katz were followed-up with and offered deworming treatment. This analysis uses data from the baseline LMC in Benin, with consenting procedures and sampling occurring March-May 2018.

Qualitative Methods

Six focus group discussion (FGDs) were conducted with individuals invited to participate in the first LMC to understand factors influencing their decisions to participate in stool collection for surveillance in December 2019. Purposive sampling was used to sample individuals from DeWorm3 clusters with high refusal rates (>7.5% refusal) and low refusal rates (<4.5% refusal). Three FGDs were conducted in each setting (high refusal and low refusal clusters). Both adults invited to participate in the LMC and adult parents or guardians of children invited to participate in the LMC were sampled. For each FGD, quota sampling was used to ensure participants included a balance of both people who provided a stool sample during the LMC and people who did not. FGD respondents in high refusal clusters were sampled from five different study clusters. FGD respondents in low refusal clusters were sampled from sixteen clusters, in order to identify enough people who refused to provide a stool sample in these settings.

The adult FGDs were divided by gender to create a more comfortable atmosphere for participants to discuss their experiences with stool sampling. FGDs with parents/guardians were not divided by gender as the topic of discussion was not their participation in STH surveillance but that of their children, which was perceived as a less sensitive topic. Each FGD ultimately consisted of 5-8 participants. Table 1 presents a summary of the sample and sampling frame.

Table 1: Sampling Frame

Cluster Type	Focus Group Population	# of Clusters Sampled	# of Sampled Individuals	Sampling Frame	Number of FGD participants
Low refusal to participate in STH surveillance	Adults (male)	16	20	Invited to participate in LMC	8
	Adults (female)		20	Invited to participate in LMC	5
	Parents/guardians		20	Child invited to participate in LMC	5
High refusal to participate in STH surveillance	Adults (male)	5	20	Invited to participate in LMC	6
	Adults (female)		20	Invited to participate in LMC	5
	Parents/guardians		20	Child invited to participate in LMC	7

FGDs were conducted using a semi-structured question guide informed by the Theory of Planned Behavior (TPB), which has been used previously for similar research questions.^(18,22) Figure 1 presents the

TPB as applied to this study. The question guide (Appendix 1) was piloted by the research team outside of the selected study areas and adapted thereafter. All FGDs were led by trained members of the Benin research team and conducted in the local language (Pédah, Mina, or French). All the FGDs were audio-recorded following written consent from participants. Audio data from the FGDs were transcribed into French and underwent quality control checks by the Benin research team. The French transcripts were then translated into English by a research team member outside Benin. Afterwards, a final round of quality control checks on the French-to-English translation were conducted.

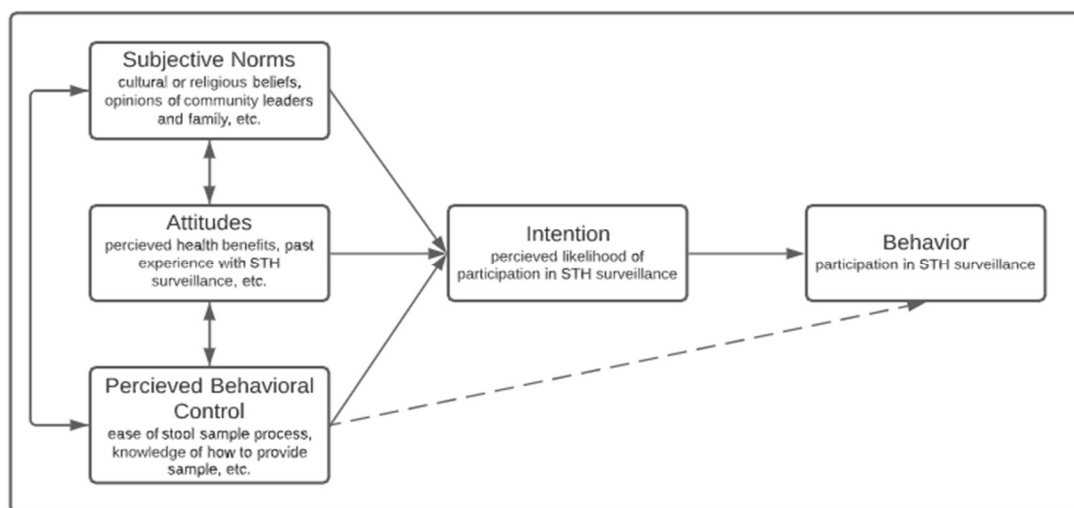


Figure 1: Theory of Planned Behavior Conceptual Framework applied to STH surveillance participation

English transcripts were coded using the qualitative analysis software ATLAS.ti 9. A preliminary codebook was developed in advance, informed by the TPB and the FGD discussion guide. A mixture of deductive and inductive coding techniques was used to allow for iterative adaptations to the codebook throughout the coding process. See Appendix 2 for codebook. Each transcript was coded initially by a primary coder (EM) and validated by a secondary coder (ICT) who reviewed all coding decisions, added new codes, or removed codes. A standardized validation tracker was used to record instances of disagreement and a third researcher (ARM) served as a tiebreaker as necessary. Thematic saturation in coding was reached when no new emerging codes or themes were identified across coders. Once all FGD

transcripts were coded, case memos were developed jointly by the two coders for each setting (high and low refusal clusters) to identify salient themes.

Quantitative Methods

This analysis included 7039 individuals invited to participate in the baseline LMC survey in Benin. These 7039 individuals represented 5821 households as multiple individuals could be sampled from the same household. Demographic information was ascertained for a range of variables during a baseline census of all households in the study catchment area and/or via a baseline survey administered during the first LMC survey. Individuals that consented to participate in the LMC were asked to provide a fecal sample at the time of the baseline survey.

We conducted an exploratory analysis to identify the prevalence and correlates of participation in the baseline LMC in Benin. The primary outcome of interest was a binary participation variable (1= participation, 0=non-participation) that indicates if the individual either: a) did not consent to provide a stool sample, or b) consented but did not provide a sample at the time of collection. We present descriptive statistics (proportions, means, and standard deviations) of participants who do and do not participate, separately by age, sex, SES, religion, language, education, household toilet type, time in current residence, place of main residence, population density, village population size, and baseline cluster STH prevalence. Either a Pearson's Chi-squared test or a Welch Two Sample t-test was used to test the associations between dependent and independent variables.

We conducted backwards stepwise model building to identify correlates of participation in baseline stool sampling. The choice of independent variables considered for inclusion in the analysis were based on available data, existing literature, and a hypothesis-driven conceptual framework driven by the qualitative thematic analysis (Appendix 3). We then developed a mixed-effects logistic regression model using all non-collinear variables of interest. The full model was then simplified using backward stepwise elimination. We compared the AIC of the full model to the AIC of models in which each variable, separately, was dropped. The model was adjusted for Cluster ID during each step. The reduced model with the lowest AIC was kept

and the process was repeated until AIC was no longer further reduced in the adjusted model. Adjustments for multiple comparisons were made by controlling the false discovery rate.⁽²³⁾ We present results from the fully adjusted model: odds ratios, 95% confidence intervals and the p-value based on which significance is determined. All statistical analyses were conducted using R and RStudio software (version 4.1.2).

Results

Among the 7,039 individuals invited to participate in the baseline LMC in Benin, the overall refusal rate for baseline stool sampling was 8.14% (573 individuals). Of these, 231 individuals did not consent to the stool sampling and 342 refused to provide a sample at the time of collection despite consenting. Overall cluster-level refusal rates ranged from 0.6% to 20% (Figure 2).

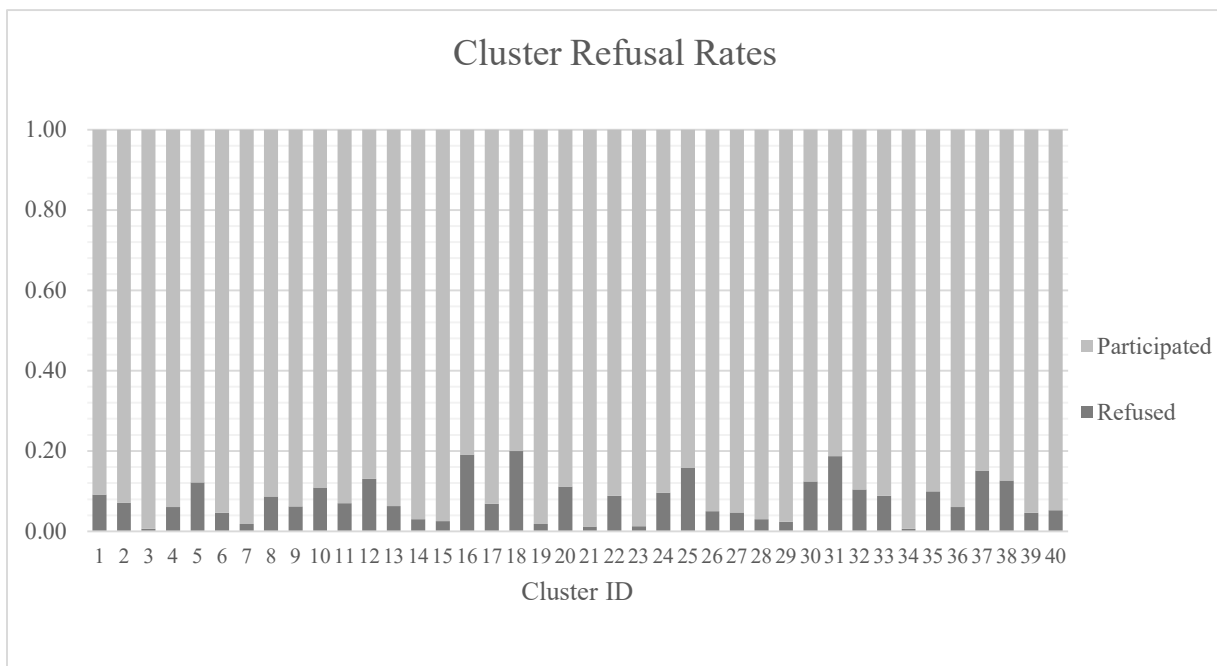


Figure 2: Cluster-level refusal rates

Qualitative Results

During six FGDs with 36 total participants, community members reported several factors that influence their decision to participate in stool surveillance for STH. Main themes in their responses included: weighing of community-level benefits against individual-level risks of STH surveillance,

circulating rumors about misuse of stool samples, interpersonal communication with field agents, and cultural norms around handling feces, particularly among adults. In general, FGD respondents from clusters with low refusal rates reported fewer negative perceptions of stool surveillance.

Across all clusters, community members weighed community-level benefits against perceptions of individual-level risks

Participant decisions to provide a stool sample were made based on the balance of perceived risks and benefits, including both individual-level and community-level risks and benefits. Generally, most of the risks cited by respondents were at the individual level while most of the perceived benefits were at the community level. The main perceived benefit of participating in stool surveillance was the belief that it would lead to a reduction in STH infections which would positively impact the community collectively. There was recognition that little individual benefit would be gained from participation in surveillance activities but that the diagnostic information would help inform the program's treatment strategy. Participants described their willingness to provide a stool sample, despite a general aversion to handling feces, for the good of their communities. These statements were connected to an awareness that their families and community suffered from intestinal worms. Parents particularly reported the belief that participating would contribute to the reduction of STH symptoms for their children.

"We agreed because intestinal worms destroy human health. It's also a good project brought in. It's to help the population. People care about us, that's why this project is being proposed to us. That's why we agreed." [Respondent 5, Parents FGD, Low Refusal Cluster]

"I told them in my turn, that it is certainly to cure a disease, because according to the explanations of the workers of the project, it is to reduce the intestinal worms that are causing enough havoc in the commune and that is why I participated by providing my stools," [Respondent 3, Women FGD, High Refusal Cluster]

In contrast, FGD respondents also reported individual-level concerns about providing a stool sample. Respondents reported fear of their stool being misused and resulting in illness or death, a belief supported by circulating rumors. Such comments were voiced particularly by men in high refusal clusters. Respondents also expressed hesitancy due to perceived stigma they expected to experience if they provided

a stool sample. Women in both settings cited a cultural belief that if an adult handled their own feces it would result in swelling of the abdomen.

"Even eating is a problem, that's why people refused to provide stool samples. Because they suspect that they will mysteriously disappear after they provide their stool samples or people will use them to do something they don't know, and many people really had this fearful idea." [Respondent 4, Women FGD, High Refusal Cluster]

"It can happen that we suffer from swelling if we defecate and take a sample of our own feces. That is why I refused to provide a sample." [Respondent 5, Women FGD, Low Refusal Cluster]

While respondents from high and low refusal clusters cited similar risks and benefits, high refusal cluster FGDs discussed the individual-level risks with greater frequency. This suggests that in high refusal clusters, perceived individual-level risks influenced decisions more strongly than perceptions of community-level benefits. Additionally, in high refusal clusters several respondents expected to receive diagnostic results from their stool tests. Respondents reported that not receiving the results sowed skepticism in the program and led to future non-participation.

"Why do adults agree to participate and provide bowel movements, but no longer do so? This is related to the fact that the record of test results is no longer being sent so that people know what they have been diagnosed with. From that point of view and after thinking about it, they no longer perform the stool donation, because they simply ask: what's the point of providing the stool if the test results are not given to them?" [Respondent 3, Women FGD, High Refusal Cluster]

Rumors of misuse of stool samples, compounded by a lack of familiarity with stool samples, were more common in high refusal clusters

When participants did not understand the rationale for collecting stool samples, they were more likely to choose not to participate in the survey. FGD participants noted many rumors circulating in the community at the time of LMC implementation. These were reported in both settings (high and low refusal clusters), however the high refusal cluster respondents commented on rumors with greater frequency than respondents in low refusal clusters, who generally described rumors as influencing others and not themselves. Similarly, statements about the "unknown purpose" of stool sampling were cited with greater frequency (approximately double) in the FGDs with high refusal cluster residents, which helped solidify belief in some of the circulating rumors. Commonly cited rumors included a belief that occult practices

would be performed with stool samples, which could lead to illness and death. A few participants said that the stool surveillance was affiliated with white foreigners with harmful intentions, such as lowering the birth rate in Africa. FGD participants reported hearing about these rumors from neighbors, community leaders, and media (social or otherwise).

“We see on the WhatsApp most of the serious events happening in the world. These events are broadcast via WhatsApp, and we see them. For example, you may see someone vomiting blood and dying moments later. All of this is what makes some people scared.” [Respondent 4, Women FGD, Low Refusal Cluster]

“All together we see that rumors can frighten us, but we must have courage to do so. We must not let ourselves be intimidated by these rumors.” [Respondent 6, Women FGD, Low Refusal Cluster]

“They are afraid, they are afraid just because the stool comes from the human being for an unknown destination, are they going to use it for our well-being or to harm us? Really, we're all scared on that level.” [Respondent 5, Parents FGD, High Refusal Cluster]

Respondents across all FGD reported little (to no) prior experience providing stool samples, especially outside a hospital setting; this compounded misunderstanding or skepticism about the purpose and use of stool samples. Participants were more comfortable with the idea of collecting stool samples for the first time at the hospital as opposed to at the household level. As a result, within high refusal clusters, participants expressed concerns that the program might be disconnected from the local health system. This disconnect gave credit to rumors of misuse.

“What's all this stuff? Is it the deworming that requires all this? But I was told that some diseases require stool samples to be taken for analysis to find out... I said I've never seen that. You see! You see! The fact that I've never seen certain things makes it difficult.” [Respondent 5, Parent FGD, Low Refusal Cluster]

“I'm afraid that the hospital is not involved.” [Respondent 2, Parents FGD, High Refusal Cluster]

Clear communication messages increased acceptability of providing a stool sample, with stool collectors' communication style strongly influencing community member willingness to participate

Field agents provided information to community members about the purpose of STH surveillance, how to take a stool sample, and key messages to directly address rumors. FGD participants reported that the communication styles and message of the field agents strongly influenced community member decisions to participate in stool surveillance. Respondents noted that they were more likely to participate when the collectors were patient in explaining the benefits of the program and willing to accommodate household

preferences for the timing of stool collection. However, not all FGD respondents reported positive interactions with the project agents, noting instances of perceived impoliteness or agents who were unable to answer questions about the stool sampling with confidence. These experiences negatively impacted willingness to provide a sample. Respondents in high refusal clusters had stronger and more polarized opinions of project agents and were more likely to describe negative experiences.

“What I liked about these agents, they don't get angry but adopt a gentle character that makes you provide the stool sample even if you don't want to. That's what I liked about them.” [Respondent 2, Men FGD, High Refusal Cluster]

“OK, first of all, agents who go into the field don't give a convincing speech that appeals to the people they're targeting.” [Respondent 6, Parent FGD, High Refusal Cluster]

“What I see, the fear we are talking about is related to the fact that we were not explained the operation sufficiently.” [Respondent 2, Women FGD, High Refusal Cluster]

There is less aversion to handling children's feces, leading to increased willingness to provide stool samples for children

Almost all participants reported a general aversion to handling feces due to sanitation concerns and its odor. Participants described having to have “courage” to provide a sample, suggesting this presented a substantial hurdle that had to be overcome through understanding of the sample's purpose and benefits. However, in all FGDs, respondents stated it would be fine (even easy) to give a child's sample. They reported being less likely to provide a sample themselves, as an adult. Female respondents directly tied this difference in willingness to handle feces to the practice of cleaning up after infants and toddlers. Respondents also cited a common belief that if an adult handles their own feces they will experience swelling of the abdomen.

“If it was even a stool sample from a child that was asked for, it would be easier to take the sample, but me at my age! No! It's not easy to take a stool sample.” [Respondent 4, Men FGD, High Refusal Cluster]

“It makes you suffer from swelling. Or that's what our grandmothers say. Or it causes something. Or... I don't remember, my grandmother used to say that. Making your own bowel movements and picking them up yourself, it's not good. Our grandmothers used to say that, and we heard it. That's what we do so that when a child defecates, he doesn't pick it up himself...don't you see that because it was like that in our mentality, it's bad to pick up your own stool? If you have to collect some for your child, it's easy. But if you have to collect your own stool, it's bad. It's a bit difficult.” [Respondent 5, Parents FGD, Low Refusal Cluster]

Participant recommendations to improve STH surveillance activities focused on communication and community engagement strategies

Most of the recommendations for improving stool surveillance across all sampled clusters involved increased communication and awareness raising strategies to explain the benefits of stool sampling and assuage people's fears. Some respondents recommended changing the stool sample kit design, such as by increasing the size of the sample receptacle and including gloves, however these recommendations were not described as essential for increasing participation. In discussing communication strategies, FGD respondents suggested using radio advertisements, town criers, community leaders, and local residents who've already provided a sample to educate community members about the benefits of the program and the need for STH surveillance. An emphasis on combatting rumors was suggested for the message content. This community engagement was highlighted as necessary for increased acceptability of and participation in STH surveillance.

“The second thing is to go and explain and inform via the radio so that people who had not provided their stool before can do so. Because if you drag a disease around and don't talk about it, it kills. So, the disease can hurt you. In my opinion, those who are stubborn and have not done so before, if we can go through the radio channel, explain to them that they are invited to give their stool, that it is for diagnostic research purposes to determine something, and not for an undisclosed use. Therefore, to come and give their stool for them who had not given it. I think that would be just as well.” [Respondent 1, Women FGD, High Refusal Cluster]

“In my opinion, if we can contact the village chiefs and town criers who will be able to pass on and re-disseminate information to the people, ringing the gong; raising their awareness; and further explaining to them how this project is important for our well-being. Because everything we eat today is a source of contamination from parasitic worms that we carry in our intestines. Basically, you have to be able to talk to them in such a way that they agree it very much by changing their intention towards the project, so that when the agents go down to the field, they are involved in the operation.” [Respondent 5, Men FGD, High Refusal Cluster]

Participants in high refusal clusters recommended working closely and more visibly with local health facilities and health workers, including community health workers, to increase the perceived legitimacy of the stool surveillance. They also suggested increasing the training for project agents, so they are better equipped to patiently address concerns of participants at the time of consent and stool collection. Lastly, participants emphasized the importance of explaining whether diagnostic results will be shared after

the stool is tested and providing a clear rationale for why results will not be shared. This explanation will assuage fears of misuse, reduce dissatisfaction, and increase acceptance of the surveillance activities.

“What I still have to say is that the villages and regions where we want to send agents should have local people in the teams. So, it won't just be foreigners; otherwise, it will be difficult, but if there are local people in the teams, that is, if there are two people, there will be one local person to join a foreigner to lead the operation. But let's make sure it's not just foreigners who don't master the life of the area. Otherwise, it will be a bit difficult.” [Respondent 5, Parents FGD, Low Refusal Cluster]

Quantitative Results

The influence of 12 variables on stool sample participation were considered (Table 2). Four of the variables (population density, village population size, household toilet type, and cluster-level baseline STH prevalence) were considered based on qualitative findings. Population density and village population size were included because qualitative findings indicated that the degree of solidarity between community members might increase perceived community-level benefits of STH surveillance. Household toilet type and cluster-level baseline STH prevalence were included because qualitative data suggested that an individual's experience with STH or perceived risk of STH infection increased the likelihood of providing a stool sample.

An individual's age, socio-economic status, household religion, household language, consenters' education, household toilet type, time in current residence, place of main residence, population density, village population size, and baseline cluster STH prevalence were significantly different amongst individuals who participated versus those who refused to participate in STH surveillance (Table 2).

Table 2: Descriptive statistics

Characteristic	Consented and provided stool sample N = 6,466ⁱ	Refused to consent or provide stool sample N = 573ⁱ	p-valueⁱⁱ
Sex			0.384
Male	2,986 (91.5%)	276 (8.5%)	
Female	3,480 (92.1%)	297 (7.9%)	

Characteristic	Consented and provided stool sample N = 6,466ⁱ	Refused to consent or provide stool sample N = 573ⁱ	p-valueⁱⁱ
Age			0.002
PSAC ⁱⁱⁱ (1-4 yrs)	1,258 (92.7%)	99 (7.3%)	
SAC ^{iv} (5-14 yrs)	1,374 (93.7%)	93 (6.3%)	
Adult (15+ yrs)	3,834 (91.0%)	381 (9.0%)	
Socioeconomic status asset-based index (in quintiles, where 1 is lowest)			<0.001
1	1,035 (94.0%)	66 (6.0%)	
2	1,088 (92.8%)	85 (7.2%)	
3	1,251 (92.9%)	96 (7.1%)	
4	1,443 (91.6%)	132 (8.4%)	
5	1,649 (89.5%)	194 (10.5%)	
Household language			<0.001
Pédah	1,609 (96.1%)	65 (3.9%)	
Sahoué	858 (92.1%)	74 (7.9%)	
Watchi	1,860 (90.8%)	188 (9.2%)	
Mina	1,078 (91.2%)	104 (8.8%)	
Other	1,061 (88.2%)	142 (11.8%)	
Household religion			<0.001
Christianity	4,026 (90.8%)	406 (9.2%)	
Islam	135 (87.1%)	20 (12.9%)	
Voodoo	1,650 (95.3%)	81 (4.7%)	
Other traditional religion	125 (93.3%)	9 (6.7%)	
None	318 (90.3 %)	34 (9.7%)	
Other	210 (90.1%)	23 (9.9%)	

Characteristic	Consented and provided stool sample N = 6,466ⁱ	Refused to consent or provide stool sample N = 573ⁱ	p-valueⁱⁱ
Highest education achieved by consentor			<0.001
No education	2,438 (92.1%)	210 (7.9%)	
Primary	1,491 (94.0%)	96 (6.0%)	
Secondary	1,232 (91.7%)	111 (8.3%)	
Higher secondary	620 (90.1%)	68 (9.9%)	
College/Diploma/University	515 (88.3%)	68 (11.7%)	
Unknown	166 (89.2%)	20 (10.8%)	
Household toilet type			<0.001
Flush toilet	470 (88.0%)	64 (12.0%)	
Pit latrine	3,348 (90.1%)	369 (9.9%)	
No toilet facility/Bush/Field	2,141 (95.5%)	101 (4.5%)	
Other	504 (92.8%)	39 (7.2%)	
Time in current residence			<0.001
<1 year	378 (89.8%)	43 (10.2%)	
1-5 years	1,770 (90.0%)	197 (10.0%)	
6-10 years	1,418 (90.4%)	150 (9.6%)	
11-20 years	1,210 (93.7%)	82 (6.3%)	
>20 years	1,643 (94.3%)	99 (5.7%)	
Don't know	47 (95.9%)	2 (4.1%)	
Live here majority of days past 6 months			<0.001
Yes	6,411 (92.0%)	557 (8.0%)	
No	55 (77.5%)	16 (22.5%)	

Characteristic	Consented and provided stool sample N = 6,466 ⁱ	Refused to consent or provide stool sample N = 573 ⁱ	p-value ⁱⁱ
Population density w/in 1km of household (in quartiles)			<0.001
3-404.5 persons/km ²	1,653 (93.8%)	110 (6.2%)	
404.5-817 persons/km ²	1,635 (93.1%)	122 (6.9%)	
817-1,480 persons/km ²	1,603 (91.1%)	156 (8.9%)	
1,480-2,528 persons/km ²	1,575 (89.5%)	185 (10.5%)	
Village population (in quartiles)			<0.001
1,379-7,600	1,742 (94.6%)	100 (5.4%)	
7,600-11,000	1,606 (90.2%)	175 (9.8%)	
11,000-12,500	1,562 (89.7%)	179 (10.3%)	
12,500-18,657	1,556 (92.9%)	119 (7.1%)	
Baseline cluster-level STH prevalence	5.36 (7.59)*	3.70 (5.21)*	<0.001**
<i>i n (%)</i>	<i>iii PSAC: Pre-school aged children</i>	<i>* mean (SD)</i>	
<i>ii Pearson's chi-squared test</i>	<i>iv SAC: School-aged children</i>	<i>** Welch two sample t-test</i>	

The full set of variables (Table 2) were included in a mixed-effects logistic regression model, with cluster ID included as a random effect. After five rounds of backwards stepwise elimination, no further reduction in AIC was reached by removing remaining variables (Appendix 4). The final reduced model included age, household language, consenters' education, time in current residence, place of main residence, population density, and cluster-level baseline STH prevalence. Odds ratios, confidence intervals, and p-values for the reduced model are reported in Table 3. Overall, while there were statistically significant differences between participants and non-participants, the actual magnitude of difference was not that large for most variables.

Table 3: Reduced Model

Consent for and Provision of Baseline Stool Sample			
<i>Predictors</i>	<i>Odds Ratios</i>	<i>CI</i>	<i>adjusted p-valueⁱ</i>
Age			
Adult (15+yrs)	Reference		
Pre-school age children (1-4yrs)	1.26	1.00 – 1.60	0.106
School-age children (5-14yrs)	1.44	1.13 – 1.83	0.012
Household language			
Pédah	Reference		
Sahoué	0.50	0.34 – 0.76	0.005
Watchi	0.60	0.41 – 0.86	0.018
Mina	0.69	0.47 – 1.02	0.121
Other	0.51	0.35 – 0.74	0.004
Consenter education level			
None	Reference		
Primary	1.46	1.13 – 1.89	0.013
Secondary	1.12	0.87 – 1.43	0.497
Higher secondary	1.04	0.77 – 1.41	0.797
College/University	0.88	0.65 – 1.20	0.521
Unknown	0.90	0.54 – 1.48	0.699
Time in current residence			
<1yr	Reference		
1-5yr	0.92	0.64 – 1.33	0.699
6-10yr	0.89	0.61 – 1.31	0.649
11-20yr	1.22	0.80 – 1.85	0.482
>20yr	1.31	0.87 – 1.98	0.288
Don't know	2.72	0.62 – 11.95	0.288

Consent for and Provision of Baseline Stool Sample			
<i>Predictors</i>	<i>Odds Ratios</i>	<i>CI</i>	<i>adjusted p-valueⁱ</i>
Participant lives in community majority of days during past six months	2.76	1.51 – 5.03	0.005
Population density w/in 1 km of HH (in quartiles)			
1 st quartile (3-404.5 persons/km ²)	Reference		
2 nd quartile (404.5-817 persons/km ²)	0.71	0.52 – 0.98	0.096
3 rd quartile (817-1,480 persons/km ²)	0.69	0.48 – 1.00	0.103
4 th quartile (1,480-2,528 persons/km ²)	0.58	0.40 – 0.86	0.018
Baseline Cluster STH Prevalence	1.02	0.99 – 1.05	0.253
<i>i: p-values adjusted to control for the false discovery rate per Benjamini & Hochberg^(23,24); p-values that are significant at the 0.05 level are bolded</i>			

Results demonstrate that pre-school and school age children were more likely to provide a stool sample than adults (OR:1.26, 95%CI: 1.00-1.60 and OR:1.44, 95%CI:1.13-1.83, respectively). This finding aligns with qualitative findings that suggest it is more acceptable to provide a child’s stool sample than an adult’s. Individuals from households who speak a language other than Pédah, the language most commonly spoken in rural areas of Comé, were less likely to provide a stool sample than those who spoke Pédah at home (Table 3). Individuals who had lived in their place of residence for the majority of days during the 6 months preceding the LMC survey were more likely to provide a sample than others for whom their home had not been their main place of residence preceding the survey (OR:2.76, 95%CI: 1.51-5.03).

These findings indicate that if someone has resided in their community for more than ten years, they are more likely to provide a stool sample (Table 3). For example, individuals who have resided in their community for at least 20 years were more likely to provide a sample compared to those who’ve been living in their communities for less than a year (OR:1.31, 95%CI: 0.87-1.98). Additionally, as the population density within 1km of an individuals’ household increased, they were less likely to provide a stool sample (Table 3). Lastly, participation increased with increasing baseline STH cluster prevalence (OR: 1.02,

95%CI: 0.99-1.05). While this finding is not statistically significant and not of high magnitude, it aligns with qualitative findings about the relationship between experience with STH symptoms and willingness to provide a stool sample.

Additionally, based on qualitative findings that suggested individuals' perceptions of and intentions to provide stools samples change over time, we examined longitudinal participation data (Figure 3). Longitudinal data indicates that, generally, there was decreasing participation overtime with a large drop-off after the initial baseline survey. While some of the longitudinal changes may be due to participants moving outside the study zone, some individuals who refused to provide a sample at baseline later chose to and vice versa.

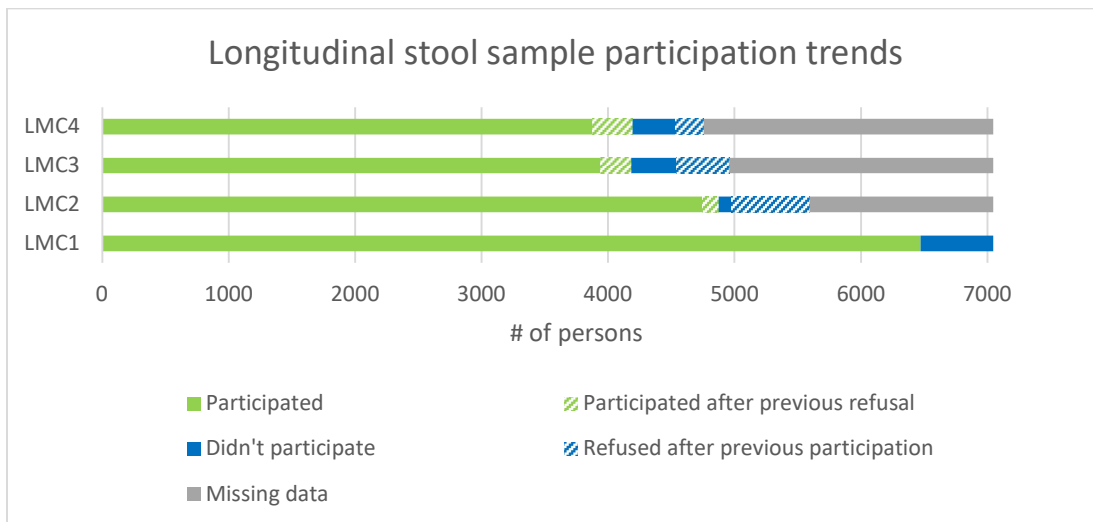


Figure 3: Longitudinal stool sampling participation trends

Discussion

High and representative participation is needed in STH surveillance programs to monitor elimination progress. However, there is a dearth of evidence about the acceptability of stool-based surveillance, and factors that influence participation. Motivated by observed refusals to consent to STH surveillance activities associated with the DeWorm3 trial in Benin, this study aimed to understand determinants of this variation. This paper presents a mixed-methods analysis of factors influencing participation in stool sample-based STH surveillance programs.

This study identified several individual-level characteristics that influenced participation in STH surveillance surveys. Both qualitative and quantitative data demonstrated an increased willingness to provide a child's stool sample in comparison to adults (Table 4). Systematic reviews examining factors affecting participation in MDA programs for schistosomiasis and lymphatic filariasis, similarly found that adults were less likely to participate, as compared to children.^(25,26) Given that adults can serve as reservoirs of infection for STH in many communities, systematic non-participation of adults in STH stool surveillance may pose a challenge to accurately estimating STH prevalence within elimination programs.

Secondly, individuals from Pédah-speaking households were more likely to provide a stool sample than other language groups. In Comé, the Pédah communities more commonly live in rural areas, in comparison to Mina and Watchi-speaking families that are concentrated in urban or peri-urban areas. Thus, language may serve as a proxy for urbanicity. This trend aligns with other quantitative findings about population density, where increased density was linked with increased refusals. Studies exploring perspectives of MDA for both STH and schistosomiasis found that perceptions of infection risk increased participation in MDA.^(25,27) In urban settings, where sanitation infrastructure tends to be more advanced and healthcare access more readily available, individuals may perceive themselves to be at lower risk of STH, and thus are less likely to participate in stool surveillance. Qualitative data from this study similarly linked experiences with STH symptoms and perception of it being a problem in the community with increased participation, supporting this hypothesis. Another explanation for why increased population density was associated with increasing refusals to provide a sample could be due to the ease with which rumors about misuse of stool samples and misinformation about the potential dangers of providing a sample can circulate in communities with high population density. These differences in participation are particularly concerning as rural-to-urban migration increases; if urban populations are less likely to participate, programs will need to address this.

Individuals who did not reside in the community for the majority of days in the six months preceding the survey were substantially less likely to participate. Perhaps because semi-migratory

individuals are less able to commit to longitudinal participation in surveillance, they did not wish to participate in the LMC. This group is of particular concern as migratory populations, including those that travel for work or split their time between communities, may also be more likely to be missed by cMDA campaigns. For example, one study found that reaching pastoralist communities in Tanzania with MDA for trachoma was particularly difficult due to seasonal migration.⁽²⁸⁾ Even when participation in stool surveillance is high, if certain groups are more likely to refuse, data used for verification of transmission interruption may be biased.

An important driver of participation in stool-based surveillance identified by this study is community cohesion. FGD respondents who provided a stool sample reported prioritizing community-level benefits (e.g. that surveillance will help inform treatment programs and reduce STH prevalence in the community) that outweighed individual aversion to handling feces. In contrast, refusal to provide a sample was largely driven by mistrust of the sample's purpose and fear about misuse or physical harm to the individual. These findings parallel findings from other settings that tie decisions to participate in STH programs, willingness to provide a stool sample for diagnostic purposes, and consent to NTD surveillance activities to an understanding of the importance of the research, fears of how the samples might be misused, and perceived benefits.^(16-18,20) Similarly, studies examining participation in MDA have found that trust in the program, rumors about harmful consequences, and perceptions of benefits drive acceptability of treatment.^(25-27,29) Of note, findings from this study align with evidence from high-income settings where patients faced barriers to providing a stool sample in a primary healthcare setting due to a lack of information and concerns about privacy.⁽¹⁸⁾ The influence of community cohesion was similarly evident within the quantitative findings. Individuals who resided in the community at least eleven years were more likely to consent to provide a sample, suggesting the importance of community identity. Interventions targeting improved community building may be important for increasing participation in activities that primarily afford community benefit. Table 4 presents a full matrix of points of convergence (and divergence) between the qualitative and quantitative findings.

Table 4: Points of convergence / divergence between qualitative and quantitative findings

Qualitative Theme	Qualitative Findings	Quantitative Findings	Convergence v. Divergence
<p>Across all clusters, community members tended to weigh community-level benefits against perceptions of individual-level risks</p> <p>When benefits of STH surveillance for the collective are appreciated, participation increases</p>	<p><i>“However, it is because we saw in this action a benefit for us and for our family that we became interested in it”</i> [Respondent 3, Men FGD, High Refusal Cluster]</p> <p><i>“People have agreed to provide stool samples so that the disease can be reduced.”</i> [Respondent 1, Women FGD, Low Refusal Cluster]</p> <p><i>“However, it is from the unpleasant that comes the pleasant, and then as we have the love of our village, we gave the stool samples.”</i> [Respondent 3, Men FGD, Low Refusal Cluster]</p>	<p>The longer someone has resided in their community, the more likely that individual was to provide sample</p> <p>Time in current residence [1-5yr] (OR: 0.92, CI: 0.64 – 1.33) Time in current residence [6-10yr] (OR: 0.89, CI:0.61 – 1.31) Time in current residence [11-20yr] (OR: 1.22, CI:0.80 – 1.85) Time in current residence [>20yr] (OR: 1.31, CI:0.87 – 1.98)</p>	Convergence
		<p>If the community is an individual’s main place of residence, the individual was more likely to provide a stool sample (OR: 2.76, CI:1.51 – 5.03)</p>	Convergence
		<p>Villages who were in the lowest quartile of population size (<7,600 persons), had the highest proportion of individuals consenting to provide a stool sample (94.6%)</p>	Convergence
<p>Experience w/STH or perception of STH being a problem in the community increases participation</p>	<p><i>“Especially that one of my children suffers from them. I can say that this is why I agreed to register them and provide their stool sample”</i> [Respondent 3, Parents FGD, High Refusal Cluster]</p>	<p>Individuals who participated were more likely to live in clusters with higher STH prevalence, than those who refused (5.36% and 3.70% respectively).</p> <p>This association between participation status and baseline cluster STH prevalence is significant (p<000.1)</p>	Convergence
<p>Rumors of misuse of stool samples were more common in high refusal clusters</p> <p>Individuals living in communities in which rumors circulated easily had increased rates of refusal</p>	<p><i>“Actually, the way I see my elders and my younger brothers react in the Commune since this stool sampling operation began is that in their mentality; according to them the Whites are carrying out actions to make us sick. Others go so far as to say that the Whites want to dissolve Africa, well! Things like taking their stools to use them clandestinely or to destroy them, why are they going to give the stools away! You know what I mean.”</i> [Respondent 1, Men FGD, High Refusal Cluster]</p>	<p>As the population density within 1km of individuals’ households increased, their likelihood of refusal also increased. The proximity of individuals to one another geographically is associated with refusal.</p> <p>Population density [1st quartile] Reference Population density [2nd quartile] (OR: 0.71, CI:0.52 – 0.98) Population density [3rd quartile] (OR: 0.69, CI:0.48 – 1.00) Population density [4th quartile] (OR: 0.58, CI:0.40 – 0.86)</p>	Convergence

Qualitative Theme	Qualitative Findings	Quantitative Findings	Convergence v. Divergence
<p>There is less aversion to handling children’s feces, leading to increased willingness to provide stool samples for children compared to adults</p>	<p><i>“The worst thing is that it is not a child's stool sample that is required but an adult's, so I have refused to provide it.”</i> [Respondent 4, Men FGD, High Refusal Cluster]</p> <p><i>“They say that the reason why they will not give their stool is because it is still unclean to defecate and then take their own feces and give it to investigating officers. That's why friends of mine; my own brothers and sisters refused to provide it”</i> [Respondent 3, Women FGD, High Refusal Cluster]</p>	<p>Compared to adults, pre-school age children and school-age children were more likely to participate in stool surveillance (OR:1.26, CI: 1.00 – 1.60 and OR:1.44, CI:1.13 – 1.83, respectively)</p>	<p>Convergence</p>
<p>Voodoo beliefs & rumors of occult practices</p>	<p><i>“Some were afraid and thought that their stool would be used for occult purposes. So, it was fear that motivated the refusal of those people.”</i> [Respondent 4, Women FGD, High Refusal Cluster]</p>	<p>Those individuals who identified Voodoo as their household religion had higher participation in stool surveillance (95.3%) than any other religion group (p<000.1)</p>	<p>Divergence</p>
<p>Changes in participation overtime</p>	<p><i>The results no longer reached us, there is reason to be discouraged.”</i> [Respondent 4, Parents FGD, High Refusal Cluster]</p> <p><i>“But, when someone goes through the experience and is imbued with the ins and outs of the operation to collect stool without inconvenience, he will be the first to approach his brother to reassure him.”</i> [Respondent 1, Women FGD, High Refusal Cluster]</p> <p><i>“But there was counter-information. At the beginning, the parents accepted, some of them immediately, but later...when they had other information about the stool sample collection, there was a crisis of confidence, a certain atmosphere of mistrust set in.”</i> [Respondent 4, Parents FGD, Low Refusal Cluster]</p>	<p>Longitudinal data demonstrate that participation varied over time. There was decreasing participation overtime with a large drop-off after the first round of stool surveillance. Additionally, some individuals who initially refused to participate later chose to participate and vice versa. (Figure 4)</p>	<p>Convergence</p>

Limitations

This study has several limitations. First, a high rate (70%) of sampled individuals were unreachable, unwilling, or unable to participate in FGDs. This sampling frame may limit generalizability of findings, especially if individuals not included in the FGD were also more likely to refuse to participate in the study. Secondly, due to limitations in time and budget, this study was unable to conduct a member checking exercise with FGD participants. Each focus group facilitator summarized the key points of discussion at the time of the activity, requested corrections from the participants, and wrote notes in a debrief form. However, all validation of the themes emerging from this analysis was conducted by members of the research team in Benin who participated in data collection, not the FGD participants themselves. In addition, quantitative data collection tools were developed prior to the qualitative analysis; thus, there may be some drivers of participation identified in the qualitative data that were not explored quantitatively, such as previous experience providing a stool sample. This analysis drew on data only from the Comé district in Benin. Some findings, particularly those pertaining to local cultural customs or beliefs, may not be generalizable to other settings.

Conclusion

This study found that certain groups of individuals are more likely to consent to participate in STH surveillance activities than others. Our findings suggest that adults, persons who do not reside full time in the community, newly arrived members to the community, individuals who do not perceive themselves or their communities to be at risk for STH, and individuals exposed to convincing misinformation are more likely to refuse to provide a stool sample. If STH surveillance is intensified for the purposes of -elimination programming, programs will need to understand who is not participating in each setting. STH surveillance activities rely on high, representative, participation; otherwise, programs could misidentify priority areas for implementation or bias transmission verification data. This is of particular concern if groups refusing to participate in surveillance also refuse to participate in deworming campaigns.

In addition to understanding who is refusing to participate in STH surveillance, programs will need to better understand why those individuals or groups are hesitant. Investing in learning about community perspectives, priorities, and beliefs about public health surveillance will be key to ensuring the program's success. Our findings suggest a change is needed in STH surveillance to focus more on providing participants with accurate information so they can assess individual risks and benefits. This represents a shift towards understanding social drivers of participation, and the influence of these drivers on elimination programming, compared to a status quo in which surveillance refusals are largely not prioritized and resources are not allocated to investigate them. These findings suggest programs should focus on addressing misinformation and demonstrating the benefits of stool surveillance for a community, even where perceived risk of STH is low. This will have implications for community engagement strategies, training for sample collectors, and communication messages. These findings parallel other calls within the NTD – MDA space for increased efforts to engage local communities as equal partners in program planning and implementation.⁽²⁹⁾ Programs thus have an opportunity to reimagine how STH surveillance is conducted to address community concerns and ensure groups are equally represented in surveillance data.

Ethics statement and disclosures

No financial disclosures. Approval for the informed consent forms and research proposal was obtained from both the Human Subjects Division at the University of Washington (STUDY00000180) and Institut de Recherche Clinique au Bénin (IRCB) through the National Ethics Committee for Health Research (002-2017/CNERS-MS and No: 031-2019/MS/DC/SGM/DFRMT/ CNERS-Ministry of Health, Benin) from the Ministry of Health in Benin prior to this study. All participants provided informed consent after being provided an explanation of the study in local languages. All data have been de-identified. Furthermore, all researchers involved in this analysis completed human subjects research training per University of Washington requirements.

Appendix 1: FGD Question Guide

Adult (Men and Women) FGD Discussion Guide

Focus Group Discussion pour Adultes (hommes / femmes) : Guide de questions

Introduction :

- Je vous remercie d'avoir accepté de participer à cet entretien.
- Comme vous le savez peut-être, nous avons mené une étude pour déterminer si les personnes étaient infectées par un ver parasitaire, appelé vers intestinaux transmis par le sol. La manière de constater cette infection sur les gens est de leur demander un échantillon de leurs selles pour les analyses au laboratoire.
- Aujourd'hui, nous aimerions écouter vos expériences du projet deworm3. C'est pourquoi nous sommes venus dans votre communauté pour savoir ce que vous avez aimé et ce que vous n'avez pas aimé.
- Cette discussion a pour but d'enquêter sur votre expérience du projet et les facteurs susceptibles d'influencer vos décisions de participer à la fourniture d'échantillons de selles.
- La durée de cette discussion de groupe est d'environ une heure.
- Je tiens à vous assurer que la discussion sera anonyme. Nous enregistrerons la conversation. L'enregistrement sera conservé en toute sécurité dans un fichier protégé par mot de passe jusqu'à ce qu'il soit transcrit et analysé, puis nous le supprimerons.
- Ne partagez pas les commentaires des autres participants au dehors après cet entretien.
- Si vous ne souhaitez pas répondre à une question, vous n'êtes pas obligés. Il n'y a pas de bonnes ou de mauvaises réponses.
- S'il vous plaît discuter avec d'autres pendant l'entrevue. Cependant, nous voudrions demander à une seule personne de parler, et non plusieurs personnes à la fois.
- Avez-vous des questions ?
- Avant de commencer l'entretien et dans le souci de protéger votre nom et données personnelles (âge, sexe, situation matrimoniale) à vos déclarations, nous allons prendre votre nom, prénoms, sexe, âge et vous allons vous attribuer un code (ou numéro) par lequel vous serez désignés tout au long de l'entretien.

Questions d'ouverture :

Veillez prendre quelques instants pour vous rappeler le moment où les activités de surveillance des vers intestinaux transmis par le sol, appelées « cohortes de surveillance longitudinale », ont eu lieu dans votre communauté, et qu'on vous ait demandé de participer en fournissant votre échantillon de selles.

1. Quelqu'un peut-il décrire ce qui s'est passé lorsque le projet est arrivé dans votre communauté ?
 - a. Explorer : De quoi d'autres, les autres s'en souviennent à propos ?

Questions principales :

2. Pensez-vous que de nombreux hommes / femmes ont eu à participer en fournissant l'échantillon de selles ?
 - a. Explorer : Pourquoi pensez-vous que beaucoup d'hommes / femmes ont choisi de participer?
 - b. Explorer : Pourquoi pensez-vous que beaucoup d'hommes / femmes n'ont pas choisi de participer ?
3. [Pour ceux qui ont participé] Quelles sont les raisons pour que les hommes / femmes participent à une telle enquête et fournissent un échantillon de selles ?
4. [Pour ceux qui n'ont pas participé] Quelles sont les raisons pour lesquelles les hommes / femmes ne fournissent pas d'échantillons de selles ?
5. Pourquoi pensez-vous que certains hommes/femmes n'aiment pas donner l'échantillon de selles?
6. Qu'avez-vous aimé dans la manière dont l'enquête a été menée ?
 - a. Explorer : Pourquoi avez-vous aimé ça ?
7. Qu'est-ce qui vous a déplu dans la façon dont l'enquête a été menée ?
 - a. Explorer : Pourquoi n'aimiez-vous pas cela ?
8. Quoi d'autres auraient pu améliorer l'adhésion à participer ?
 - a. Explorer : Pensez-vous que les hommes / femmes participeraient davantage s'il y avait une incitation autre que d'obtenir le résultat du test ?
 - b. Explorer : Si ce n'est pas des échantillons de selles, par exemple, du sang ou de l'urine, pensez-vous que plus de gens vont participer ?
9. Qui vous influence pour participer à des enquêtes telles que celle qui porte sur les selles ? Y a-t-il quelqu'un dont l'opinion influence le plus vos décisions ?
10. Que pensaient vos proches (vos amis, votre famille) de votre participation à cette enquête basée sur la collecte de selles ?
 - a. Explorer : Pourquoi pensez-vous que vos amis ont ressenti cela ?
 - b. Explorer : Pourquoi pensez-vous que votre famille a ressenti cela ?
11. Pensez-vous que leurs réponses pourraient encourager ou décourager les hommes / femmes à participer à la fourniture d'un échantillon de selles ? Pourquoi ?
12. Qu'est-ce qui pourrait rendre difficile l'obtention d'un échantillon de selles par les adultes ?
13. Selon vous, quelles sont les raisons pour lesquelles des adultes ont cessé de participer alors même qu'ils voulaient participer au début ?

14. [Pour ceux qui ont participé] Avez-vous eu de la difficulté à obtenir un échantillon de selles avec le kit fourni ?
 - a. Explorer : Qu'est-ce qui faciliterait l'obtention d'un échantillon de selles ?
15. [Pour ceux qui n'ont pas participé] Pensez-vous que vous pourriez avoir du mal à obtenir un échantillon de selles avec ce kit ?
 - a. Explorer : Qu'est-ce qui faciliterait l'obtention d'un échantillon de selles ?
16. Si vous deviez choisir un facteur qui vous influence le plus, lequel choisiriez-vous ? Pourquoi?
17. Si vos amis ou votre famille vous interroge sur ce programme de surveillance, que leur diriez-vous ?
18. Si vous étiez en charge de ce projet, que feriez-vous pour l'améliorer ?

Questions finales :

19. De toutes les choses dont nous avons discuté aujourd'hui, quel est le plus important pour vous?
20. Y a-t-il d'autres réflexions sur ce sujet que vous voudriez partager ?

Conclusion : Je vous remercie d'avoir participé à cet entretien. Il a été très fructueux.

Parent FGD Discussion Guide

Focus Group Discussion pour les Parents: Guide de questions

NB : Le premier contact doit être établi la veille pour les explications en guise de l'obtention du consentement éclairé le jour de l'interview.

Introduction:

- Je vous remercie d'avoir accepté de participer à cet entretien.
- Comme vous le savez peut-être, nous avons mené une étude pour déterminer si les personnes étaient infectées par un ver parasitaire, appelé vers intestinaux transmis par le sol. La manière de constater cette infection sur les gens est de demander un échantillon de selles.
- Aujourd'hui, nous aimerions écouter vos expériences du projet depuis que nous sommes venus dans votre communauté et savoir ce que vous avez aimé et ce que vous n'avez pas aimé.

- Cette discussion de groupe a pour but d'enquêter sur votre expérience du projet et sur les facteurs susceptibles d'influencer la décision des parents / tuteurs d'autoriser leur enfant à participer à la collecte des échantillons de selles.
- La durée de cette discussion de groupe est d'environ une heure.
- Je tiens à vous assurer que la discussion sera anonyme. Nous enregistrerons la conversation. L'enregistrement sera conservé en toute sécurité dans un fichier protégé par mot de passe jusqu'à ce qu'il soit transcrit et analysé, puis nous le supprimerons.
- Ne partagez pas les commentaires des autres participants en dehors du cadre de cet entretien.
- Si vous ne souhaitez pas répondre à une question, vous n'êtes pas obligé de le faire. Il n'y a pas de bonnes ou de mauvaises réponses.
- S'il vous plaît discuter avec d'autres pendant l'entrevue. Cependant, nous voudrions demander à une seule personne de parler et non plusieurs à la fois.
- Avez-vous des questions?
- Avant de commencer l'entretien et dans le souci de protéger votre nom et données personnelles (âge, sexe, situation matrimoniale) à vos déclarations, nous allons prendre votre nom, prénoms, sexe, âge et vous allons vous attribuer un code (ou numero) par lequel vous serez désignés tout au long de l'entretien.

Questions d'ouverture :

Veillez prendre quelques instants pour rappeler le moment où les activités de surveillance des helminthes transmis par le sol, appelées « cohortes de surveillance longitudinale », ont eu lieu dans votre communauté, vous demandant de consentir à ce que vos enfants y participent en fournissant d'échantillon de selles.

1. Quelqu'un peut-il décrire ce qui s'est passé lorsque le projet est arrivé dans votre communauté ?
 - a. Explorer : De quoi d'autres les autres s'en souviennent à propos ?

Questions principales :

2. Pensez-vous que de nombreux hommes / femmes ont choisi de participer en fournissant un échantillon de selles ?
 - a. Explorer : Pourquoi pensez-vous que beaucoup d'hommes / femmes ont choisi de participer ?
 - b. Explorer : Pourquoi pensez-vous que beaucoup d'hommes / femmes ont n'choisit pas de participer ?

3. [Pour ceux qui ont participé] Quelles sont les raisons pour que les hommes / femmes participent à une telle enquête et fournissent un échantillon de selles ?
4. [Pour ceux qui n'ont pas participé] Quelles sont les raisons pour lesquelles les hommes / femmes ne fournissent pas d'échantillons de selles ?
5. Pourquoi pensez-vous que certains hommes / femmes n'aiment pas donner un échantillon de selles ?
6. Qu'avez-vous aimé dans la manière dont l'enquête a été menée ?
 - a. Explorer : Pourquoi avez-vous aimé ça ?
7. Qu'est-ce qui vous a déplu dans la façon dont l'enquête a été menée ?
 - a. Explorer : Pourquoi n'aimiez-vous pas cela ?
8. Quoi d'autres auraient pu améliorer l'adhésion de la participation ?
 - a. Explorer : Pensez-vous que les hommes / femmes participeraient davantage s'il y avait une incitation autre que d'obtenir le résultat du test ?
 - b. Explorer : Si ce n'est pas des échantillons de selles, par exemple, du sang ou de l'urine, pensez-vous que plus de gens vont participer ?
9. Qui vous influence pour participer à des enquêtes comme celle qui porte sur les selles ? Y a-t-il quelqu'un dont l'opinion influence le plus vos décisions ?
10. Que pensaient vos proches (vos amis, votre famille) de la participation de vos enfants cette enquête basée sur la collecte de selles ?
 - a. Explorer : Pourquoi pensez-vous que vos amis ont ressenti cela ?
 - b. Explorer : Pourquoi pensez-vous que votre famille a ressenti cela ?
11. Pensez-vous que si leurs réponses pourraient encourager ou décourager les hommes / femmes à participer à la fourniture d'un échantillon de selles ? Pourquoi ?
12. Qu'est-ce qui pourrait rendre difficile l'obtention d'un échantillon de selles par les adultes ?
13. Selon vous, quelles sont les raisons pour lesquelles des adultes ont cessé de participer alors même qu'ils voulaient participer au début ?
14. [Pour ceux qui ont participé] Avez-vous eu de la difficulté à obtenir un échantillon de selles avec le kit fourni ?
 - a. Explorer : Qu'est-ce qui faciliterait l'obtention d'un échantillon de selles ?
15. [Pour ceux qui n'ont pas participé] Pensez-vous que vous pourriez avoir du mal à obtenir un échantillon de selles avec ce kit ?
 - a. Explorer : Qu'est-ce qui faciliterait l'obtention d'un échantillon de selles ?
16. Si vous deviez choisir un facteur qui vous influence le plus, lequel choisiriez-vous? Pourquoi?

17. Si vos amis ou votre famille vous interroge sur ce programme de surveillance, que leur diriez-vous?
18. Si vous étiez en charge de ce projet, que feriez-vous pour l'améliorer ?

Questions finales :

19. De toutes les choses dont nous avons discuté aujourd'hui, quel est le plus important pour vous?
20. Y a-t-il d'autres réflexions sur ce sujet que vous voudriez partager ?

Conclusion : Je vous remercie d'avoir participé à cet entretien. Il a été très fructueux.

Appendix 2: Codebook

Code	TPB Construct	Definition	Inclusion/Exclusion Criteria	Notes
religious beliefs	Subjective Norm	Individual's perception of the religious acceptability of stool samples	Inclusion: Statements surrounding religious beliefs about the correctness or safety of providing stool samples. Include references to voodoo beliefs.	
social pressure	Subjective Norm	Individual's perception of the social expectations of individuals (family members) or communities (leaders, neighbors, etc.) to engage in stool sampling	Inclusion: Statements regarding social pressure to engage or not engage in stool sampling activities, from either family members, neighbors, or community leaders. Include references to rumors that circulate generally in the community. Include phrases that suggest the provision of a stool sample is not acceptable in the local culture (e.g. "It's not allowed").	Certain phrases may be double coded with autonomy if it concerns other members of the family pressuring someone (not) to provide a stool sample.
stigma	Subjective Norm	Individual's perception of societal stigma associated with providing a stool sample	Inclusion: Statements about perceived stigma that may be associated with providing a stool sample. Include phrases where the participants mention their appreciation that the stool sample kit is non-descriptive and that project agents maintain a level of subtlety when collecting the sample.	
media	Subjective Norm	Individual's experience with social media posts/messages pushing for (non) participation in stool sample	Inclusion: Comments about social media, WhatsApp, news reports, radio etc. messaging that influences decision to (not) participate in stool sampling. Include references to fear, rumors, etc. about stool samples that were generally circulating in country. Exclusion: Exclude comments concerning social pressure or rumors that aren't linked to media or social media but are just passed/communicated orally. Code those statements at "social pressure."	

general attitudes	Attitudes	General attitudes that individuals have, or suggest others have, about stool samples	Inclusion: Comments that describe general perceptions that an individual has concerning stool samples.	This code aims at capturing phrases that describing a general attitude individuals have about stool samples that are not explained. If the individual respondent explains why they hold a particular attitude, that comment should be coded accordingly.
perceived benefits	Attitudes	Individual's perception of the benefits to their health or wellbeing of providing a stool sample	Inclusion: Statements about individual's perceptions of the perceived health benefits of participation influencing their decision to provide a stool sample. Examples include (non)receipt of diagnostic results, support of a program which provides deworming medicines, etc. Exclusion: Exclude phrases that discuss that discuss perceived advantages of taking the deworming medication, unless the respondent specifically links those advantages with providing a stool sample.	
perceived dangers/risks	Attitudes	Individual's perception of the dangers to their health or wellbeing of providing a stool sample	Inclusion: Statements about individual's perceptions of the dangers to their health or wellbeing of providing a stool sample influencing their decision to provide a stool sample. Exclusion: Do not code phrases that mention the perceived risks of new diagnostics (urine sample, blood sample, etc.). Code those statements to " new diagnostics.	Certain statements might be double coded with religious beliefs.
fear	Attitudes	Feelings of fear expressed by respondents when considering providing a stool sample	Inclusion: Phrases that refer to fear, fright, or being scared Exclusion: Do not code comments in which participants mention perceived dangers of providing a sample if fear is not explicitly mentioned.	Certain statements might be double coded with perceived risks

unknown purpose	Attitudes	Comments that state an individual, or people in their communities, did not understand the purpose of the stool sample (e.g. why it was being collected and what would be done with the sample) and that this misunderstanding influenced their decision making.	<p>Inclusion: Comments in which respondents say they, or others in the community, did not understand the purpose of the stool sample collection.</p> <p>Exclusion: Comment discussing the communication strategies to clarify the stool sample collection's purpose or recommendations to that end.</p>	
past experience	Attitudes	Individual's past experience with stool samples, STH symptoms, or deworming campaigns	<p>Inclusion: Statement about individual's past experiences with stool sampling activities, STH symptoms, deworming programs, etc. that influence their decision to (or not to) participate</p> <p>Exclusion: Exclude phrases about experiences individuals have with taking the deworming medications provided by DeWorm3. Code those statements as "deworming medication."</p>	
foreign	Attitudes	Individual's perceptions that the program is associated with the "West" and thus should (not) be accepted	Inclusion: Statements about how an individual might view the program as being associated with the West/White people/colonizers, etc. and how this might influence their decision to (not) participate	Statements about rumors circulating on social media that include commentary about the West should be double coded with "media"
sanitation	Attitudes	Individual's perception of the (un)sanitary nature of providing a stool sample, or individual's aversion to handling feces	Inclusion: Statements about individual perceptions of the (un)sanitariness of providing a stool sample. Statements about individual aversion to handling feces. Examples include concerns about hygiene, smell, etc.	
results	Attitudes	Comments that establish a link between receiving the results of the STH diagnostic and the intention to provide a stool sample	Inclusion: Include phrases where respondents mention that their expectation to receive the results of the STH diagnostic test conducted with their stools ample influences their decision to provide a sample. Include phrases where respondents discuss that not receiving the results discourages them to provide another sample.	

autonomy	Perceived behavioral control	Individual's perceptions about their own autonomy (or the autonomy of others) to decide about participation in the stool sampling activities	<p>Inclusion: Statements about who in a household has the power to decide whether someone provides a stool sample. Include statements where an individual mentions that not the entire family chose to provide a stool sample. Include descriptions of cases where one person in a family chooses to participate (or not) in contrast to the rest of the family. Also include comments that describe one family member decides for everyone whether they will or won't provide a sample. Include comments about consent.</p> <p>Exclusion: Exclude statements simply stating that someone might disapprove of the choice; code as "social pressure". Only include statements about the power to choose.</p>	
"how-to" knowledge	Perceived behavioral control	Individual's knowledge of how to provide a stool sample	<p>Inclusion: Statements about whether an individual understands how to provide a stool sample. Examples include statements suggesting they do not understand the process, statements suggesting the process was unclear, etc.</p>	
ease of stool sample	Perceived behavioral control	Individual's perception of the ease of providing a stool sample	<p>Inclusion: Statements about the ease/difficulty of providing a stool sample. Examples include the ease/difficulty of using the stool sample kit, ease/difficulty of producing a sample in time window, etc. Include both experiences and perceptions.</p> <p>Exclusion: Statements about an individual's dislike of handling their feces should be coded as "sanitation"</p>	
age	Cross-cutting	Individual's perception of age being a facilitating or inhibiting factor in relation to providing a stool sample	<p>Inclusion: Statements about the age of an individual influencing their decision to (or not to) provide a stool sample. Examples include it being more acceptable for children to provide stool samples, it being physically difficult for elderly folk to provide a stool sample, etc.</p>	

gender	Cross-cutting	Individual's perception of gender being a facilitating or inhibiting factor in relation to providing a stool sample	Inclusion: Statements about the gender of an individual influencing their decision to (or not to) provide a stool sample. Include both statements where participants refer to themselves and where they are speaking about the community in general.	
communication	Cross-cutting	Individual's experience with communications of DeWorm3 program in relation to prevalence surveys	Inclusion: Statements regarding communication from program staff to community/individuals about prevalence surveys. Examples include radio, community meetings, etc. Include statements about communication styles of the collection teams when explaining the purpose of the sample, consent, etc. Exclusion: Exclude statements suggesting improvements to communication strategies; code as "program recommendations". Exclude phrases where respondents suggest that they did not understand the purpose of the stool sample collection without reference to the communication strategy (or lack thereof); code as "unknown purpose"	Certain statements might be double coded with "knowledge of how to" if it pertains to information pamphlets/instructions
intention	Cross-cutting	Comments about an individual's intention to participate or not participate	Inclusion: Statements in which a participant discusses intending to provide a fecal sample or intending not to. Include statements in which participants discuss the intentions of community members.	
project agents	Cross-cutting	Comments about the DeWorm3 agents who administered consent or collected the samples and how their behavior influenced an individual's willingness to participate	Inclusion: Phrases in which a respondent discusses the projects field agents and how their behavior increased or decreased the probability that an individual would provide a stool sample.	Certain statements might be double coded with "communication"

kit recommendations	NA	Feedback on how the stool sample kit can be improved	<p>Inclusion: Statements regarding recommendations for improvement of stool sample kit. Examples include inclusion of gloves, size of container, etc.</p> <p>Exclusion: Statements regarding programmatic aspects of the fecal sampling activities should be coded as “program recommendations”</p>	
program recommendations	NA	Feedback on how the fecal sampling activities can be improved	<p>Inclusion: Statements regarding recommendations for improvement of fecal sampling processes and procedures. Examples include amount of time allowed for generation of sample, communication activities, etc.</p> <p>Exclusion: Statements regarding the design of the stool sample kit should be coded as “kit recommendations”</p>	
new diagnostics	NA	Reactions to the idea that future STH surveillance could require a urine or blood sample	<p>Inclusion: Phrases concerning experiences with, attitudes toward, and beliefs about urine and blood samples</p>	
deworming medication	NA	Comments concerning experiences and attitudes towards deworming medication provided by the DeWorm3 study	<p>Inclusion: Include phrases concerning experiences with, attitudes towards, and beliefs about the deworming medication distributed by DeWorm3</p>	Note, these quotes will not be analyzed for this analysis because they are outside the research question. However, we are coding them in case of future analyses.

Appendix 4: AIC Selection Steps

Full Model AIC: 3807.746

Variable Removed from Tested Model	AIC of Tested Model					
	Round 1	Round 2	Round 3	Round 4	Round 5	Round 6
Cluster baseline STH prevalence	3806.329	3799.063	3795.221	3793.648	3793.287	3792.702
Village population size	3805.482	3798.184	3794.134			
Population density w/in 1KM	3807.061	3799.9	3795.522	3793.267	3795.052	3794.621
Live here majority of days past 6 months	3814.756	3807.46	3803.686	3801.432	3800.419	3799.973
Time in current residence	3808.146	3801.013	3797.953	3795.686	3795.657	3794.917
Household toilet type	3805.962	3799.128	3795.44	3793.17		
Education level of consentor	3810.102	3803	3798.947	3796.541	3796.128	3796.077
Household language	3813.95	3806.707	3803.157	3802.148	3801.979	3801.642
Household religion	3803.645	3796.436				
SES quintile	3800.457					
Sex	3807.233	3799.949	3795.954	3793.672	3792.618	
Age	3815.554	3808.156	3803.539	3801.322	3800.529	3799.486

Reduced Model AIC: 3792.618

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