

Exploring Patterns of Non-Participation Across Multiple Health Campaigns: An Exploratory Study Using Qualitative Methods in Ghana and Indonesia

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Key Messages

- Reasons for non-participation are similar across public health campaigns (childhood immunization, mass drug administration, bed nets, COVID-19 vaccine) and occur across four domains: health system, personal, commodity-related, and biological factors.
- Gender plays a significant role in health care decision-making at the household level, which in turn, affects participation in health campaigns.
- Knowledge of the benefit of the intervention may not lead to actual experience and participation; other factors have stronger influence such as social norms, health care access, quality of health care, health literacy, and self-efficacy.
- Poor quality of care from health care personnel can negatively influence community members' trust and participation in public health campaigns.
- Rumors play an important role in the decision to participate in health campaigns.
- Health literacy among respondents who did not participate in health campaigns is low and is demonstrated by low understanding of the risks and benefits of the campaign-delivered intervention, and by limited access to health information for decision-making.

Abstract

Globally, there is an increased call for action to address people who may be “left behind” by public health campaigns. Called the “never treated” in neglected tropical diseases or the “zero dose” child in immunizations, these individuals represent populations that have missed campaign-delivered commodities either for intentional or unintentional reasons. One of the key challenges in this area relates to the identification and programmatic response to find those individuals who have missed most, or all, health campaign visits. Our research team hypothesized that households that have never taken preventive chemotherapy offered during any round of mass drug administration of preventive chemotherapy for neglected tropical diseases may also be missing childhood immunizations, insecticide-treated bed net delivery, and/or health information related to other health campaigns (e.g., COVID-19, water and sanitation). We sought to explore reasons for non-participation and to identify if there were any patterns of acceptability, availability, awareness, and hesitancy among community members across multiple public health campaigns. To do this, we used participatory qualitative methods including: mapping with health volunteers, transect walk, in-depth interviews with household members and health care workers, and focus group discussions with men and women aged 20-49 years.

Results showed that reasons for non-participation are similar across campaigns and fall across four domain areas: health systems, commodity-related, personal, and biological. At the individual level, while one household may not participate across multiple campaigns, the reasons for non-participation for each campaign differ. This reflects the complexity of decision-making and levels of low health literacy amongst respondents who did not participate in health campaigns. Low health literacy was reflected in poor understanding of the risks and benefits of the campaign-delivered intervention, and limited access to health information for decision-making. Gender plays an important role in health care decision-making at the household level and can be assessed across the four domain areas outlined in the *Jhpiego Gender Analysis Toolkit for Health Systems*: beliefs and perceptions; access to and control over assets; roles and responsibilities; and laws, policies, and institutions. Rumors influenced the decision to participate in campaigns, although this appeared to be less important in insecticide-treated bed net delivery programs. Quality of health care was also related to non-participation as reflected in poor adverse events management, rude or shaming behavior toward community members, and lack of communication. Hesitancy for the COVID-19 vaccine was high in all sites, reflecting the challenges of uptake.

Introduction and Background

Public health campaigns deliver a specific commodity to entire communities at a specific point in time throughout the year. These commodities can include preventive chemotherapy, immunizations, insecticide-treated bed nets, and nutritional supplements. Due to their singular focus, public health campaigns can be characterized as “vertical” or “siloed,” operating as independent entities outside of routine health care delivery [1]. Increasingly there have been calls for integration across public health campaigns to maximize efficiencies and to improve coverage following the disruptions due to COVID-19 [2].

Globally there have been significant losses to public health gains due to the COVID-19 pandemic as public health campaigns were delayed or cancelled. This has renewed a sense of urgency to implement campaigns in the pandemic era as quickly and effectively as possible [3]. Not all health campaigns are equal in terms of the impact of the disruptions on activities and the time to restart these activities. Neglected tropical disease–related activities, immunizations, and malaria interventions experienced significant disruptions, second only to activities related to mental health and neurological disorders [4]. Disruptions were due to supply chain delays, reorientation of health personnel toward COVID-19 activities, population fears to access health services, and COVID-19 mitigation measures [4,5]. Mass drug administration (MDA) for lymphatic filariasis, for example, experienced a 10.3% drop in coverage between 2019 and 2020 in Indonesia, diphtheria-pertussis-tetanus first-dose (DPT1) vaccine coverage dropped by 7% and 2.52% in Indonesia and Ghana, respectively, and the modeled percentage of the population with access to insecticide-treated nets declined by 22.4% from 2019 to 2020 in Ghana [6,7,8]. The global community witnessed the stark disparities and inequities that the pandemic highlighted – including disproportionate impacts on women and racial and ethnic minorities, as well as disproportionate access to health care, personal protection, and vaccines [9,10]. As public health campaigns regain losses due to the pandemic, ensuring that there is sufficient coverage of the delivery of commodities will also result in reaching people previously been left behind.

One of the key challenges faced by multiple public health campaigns is the identification and programmatic response to individuals who have missed most or all health campaign visits or who have never taken up the intervention (preventive chemotherapy, bed net, vaccine). Called the “never treated” in neglected tropical diseases or the “zero dose” child in immunizations, these individuals represent populations that have been left behind by campaigns either for intentional or unintentional reasons. By definition, “zero-dose” children refers to children missed by both campaigns and routine services, whereas “never treated” refers to individuals who self-report that they have never taken preventive chemotherapy during any MDA round [11, 12]. There is a risk that significant numbers of “never treated” or “zero dose” individuals may impede elimination and control goals, in addition to increasing personal risk of infection. Recently, the World Health Organization (WHO) and United Nations Children’s Fund (UNICEF) estimated that the number of zero dose children increased from 13 to 18 million from 2019-2021 [13]. Within MDA for lymphatic filariasis, studies have shown that 19.2% in Guyana, 38% in Indonesia, and more than 40% of over-18-year-olds self-reported having never taken treatment for lymphatic filariasis in areas where MDA was conducted [14-16]. The reasons identified for never treatment range across the spectrum of intentional to unintentional. Individuals may intentionally refuse to participate in the MDA for a variety of reasons (e.g., adverse effects, fear, rumors, feeling healthy, religious/cultural beliefs and seeing no need for treatment). Individuals may also miss treatment unintentionally because they were out of their community at the time of MDA delivery, or the community volunteer never visited their home or village. In these studies, never treatment appears to be a household phenomenon whereby whole households may not participate in the lymphatic filariasis MDA. If true, then this could indicate a potential predictor for never treatment (e.g., if one individual is never treated, there may be others with a similar profile within the household). This may reflect a gap in health care access or access to information, or the presence of similar beliefs or experiences.

Based on our previous experience, our research team hypothesized that households with never-treated individuals for neglected tropical disease treatment may also be missing immunizations, insecticide-treated bed net delivery, and/or health information related to other health campaigns. With

this in mind, we wanted to explore the rationale for non-participation and never treatment across the different health campaigns and to ascertain how similar or different these factors are in order to inform a programmatic response.

Objectives

1. Identify patterns of acceptability, availability, awareness, and hesitancy among community members across multiple public health campaigns (neglected tropical diseases, malaria, childhood immunizations, and COVID-19 measures including vaccines).
2. Explore reasons for non-participation across multiple public health campaigns (as above).
3. Provide insights to ministries of health and regional health bodies to inform programmatic action to address never treatment / zero dose, including the identification of individuals missed through routine immunization services and MDA programs.

Research Questions

1. In areas with low coverage of MDA or a history of never treatment, low coverage for Expanded Programme on Immunization (EPI) vaccines, and/or high malaria prevalence in Ambon City and in Volta Region, Ghana, is never treatment/zero dose a household phenomenon that spans more than one health domain (e.g., neglected tropical diseases, vaccines, insecticide-treated bed net use)?
2. What are the features/traits of households or individuals who miss more than one public health intervention?
3. Does never treatment / zero dose / non-participation vary between public health interventions?

Study Areas

Ghana

The study site was the South Dayi District in the Volta Region of Ghana. South Dayi District is one of 18 districts in Volta Region, and Kpeve is its capital town. It has a total area of 1,000 km² with the Volta Lake, the largest artificial lake in the world, representing 20% of the total area. The total population is 57,526 people.

The district was purposively selected from the 18 districts in the region based on the availability of information related to the public health campaigns of interest, allowing the research team to select appropriate communities for the study. The district is reported to have significant challenges in public health campaigns resulting in missed doses of childhood immunization, and low coverage of malaria and COVID-19 immunizations.

Three rural communities, Kpeve, Abui, and Dzemeni, were selected from the South Dayi District of the Volta Region for the study. The selected communities were based on prevalence of schistosomiasis and onchocerciasis, low coverage of malaria immunization, missed doses in child immunization (such as

measles), and low coverage of COVID-19 immunizations. The communities were identified in consultation with the District Health Management Team.

The Ghana study team is based in the Volta Region, at the University of Health and Allied Sciences.

Indonesia

The study was conducted in three urban areas of Ambon: Air Besar, Latuhalat, and Waiheru. These areas were selected in consultation with the City Health Office of Ambon and are known for high levels of never treatment during the MDA program for lymphatic filariasis, poor childhood immunization coverage, and low coverage of COVID-19 vaccines. Ambon City is the capital of Maluku Province, located in Ambon Island, in the eastern part of Indonesia.

The Indonesia study team is based at the Faculty of Medicine, Universitas Pattimura, Ambon.

Methods

This study used a combination of community-based participatory, qualitative methods to understand patterns of non-participation across public health campaigns. The research design used an exploratory framework with findings triangulated in the analysis. Qualitative methods were determined to be the most appropriate for these research questions as they allowed for an exploration of ideas so that the range of factors associated with the phenomena in question could be determined.

Mapping

Consultations at the beginning of the study took place with health volunteers based in the communities. Each community identified volunteers to work for the various health campaigns that occur at the community level – including childhood immunizations, child health, MDA for neglected tropical diseases, and providing general health information. These volunteers are a part of the Community-based Health and Planning Services in Ghana and the Posyandu program in Indonesia. Community volunteers often participate across multiple public health campaigns and so are aware of areas where there have been coverage challenges across campaigns and/or where individuals have refused to participate [17].

The research team identified volunteers who work in the selected communities for this consultation. In each community, at least two volunteers were invited to draw a community map together from their understanding of the context, local landmarks, and the research questions. By allowing them to draw the map from a blank page (rather than from a formal map), the exercise allowed participants to note what elements are most important to them and not to be dictated by other maps (Figure 1). In this process, participants were also asked to outline those areas where people have not participated or where people who have never treated were living. In Indonesia these were marked by red dots to indicate “red zones” on the map.



Figure 1. Indonesian map with "red zones" demarcated.

Transect Walk

A transect walk with community leaders, health care workers, and/or volunteers was carried out by taking the longest route through the community (Figure 2). During the walk, facilitators probed for pockets of households where there have been coverage challenges across any of the health campaign platforms in addition to noting landmarks, neighborhoods, geographic, and other defining features of the community. The findings of the transect walk complemented the community mapping and provided an opportunity for the research team to validate the maps and probe for more understanding from a different group of stakeholders



Figure 2. Indonesian team mapping with community health workers.

In-Depth Interviews With Health Care Personnel

Key informant interviews with health care personnel followed the transect walk to build on the understanding gleaned from the mapping and transect walks. In each community, at least one in-depth interview (IDI) was carried out with a health care professional, purposely identified by their knowledge of coverage across public health campaigns (Table 1).

In-Depth Interviews at the Household Level

Through the community mapping and transect walk, the research team identified at least five households in each community that reported to have missed out in one or more public health campaigns (i.e., neglected tropical diseases, malaria prevention through insecticide-treated bed net delivery and malaria vaccines [Ghana only], childhood immunization, and/or COVID-19 immunization). Further households were identified using a snowball technique whereby IDI participants were asked if they knew of others in their community who may have missed public health campaigns. At the household level, an IDI was conducted with the primary caregiver of the household who was home at the time of the visit. Interviews were done in the predominant language of the study area and were conducted in a mutually agreed upon location that maximized the comfort and confidentiality of participants. A maximum of 10 households per community was the target (Table 1).

Focus Group Discussions With Men and Women

Together with the primary health care facility team and / or community health volunteers, the research team identified 6 to 10 women of reproductive age (ages 20-49) and 6 to 10 men (ages 20-49) from the same community to participate in a focus group discussion (FGD). There was a geographical spread of respondents in the community to avoid selecting individuals from the same neighborhoods. Two FGDs were conducted in each country, one with men and one with women (Table 1).

Analysis

In Ghana, recorded IDIs and FGDs were transcribed and translated into English at the same time. In Indonesia, recorded IDIs and FGDs were transcribed in Bahasa Ambon. They were then translated into Bahasa Indonesia and then into English. The research team read through each transcript to identify themes, following which a codebook was developed collaboratively. Finally, the transcripts were coded in NVivo.

Results

Participant Description

Table 1 presents the number of male and female participants in each country. Most informants at the household level were women because men were not home at the time of the interviews.

Table 1. In-depth interviews and focus group discussions with community members and health care workers

Areas	Ghana				Indonesia			
	Abui	Dzemeni	Kpeve	Total	Air Besar	Latuhalat	Waiheru	Total
In-depth interviews at household level								
Female	9	8	10	27	8	9	8	25
Male	1	0	2	3	2	2	1	5
Total	10	8	12	30	10	11	9	30
In-depth interviews with health care workers								
Female	1	1	1	3	2	0	2	4
Male	0	0	0	0	0	2	1	3
Total	1	1	1	3	2	2	3	7
Focus group discussions								
Male	7	-	-	7	-	5	-	5
Female	-	6	-	6	-	6	-	6
Total	7	6	-	13	-	11	-	11

Reasons for Non-Participation

Table 2 illustrates a list of reasons for non-participation for each campaign in Ghana and Indonesia. This table helps to visualize similar reasons for non-participation across campaigns and those that were reported to pertain to each campaign. Although the list of reasons is not exhaustive, it demonstrates areas of potential intersection for integrated action. Reasons for non-participation occur across four domains: health system, commodity, personal, and biological. A list of quotes on reasons for non-participation is included in Appendix 1.

Table 2. Reasons for non-participation across campaigns for childhood immunizations, COVID-19 vaccine, mass drug administration, and insecticide-treated nets in Ghana and Indonesia (based on in-depth interviews and focus group discussions)

	Childhood immunization	COVID-19 vaccine	Mass drug administration	Bed nets/ malaria vaccine
Health system-related factors	Poor access	Lack of access to services points	Poor access	Poor access
	Miss one step and lose opportunities for next doses	Poor availability of vaccines		Missed registration; could not access bed nets / participated in registration; missed delivery day
	Physical space at the clinic			
	Lack of awareness about campaigns		Lack of awareness about distribution	Lack of awareness about distribution of bed nets
	Inconvenient health center location			
			No demonstration – e.g., leaders did not take it in front of us	
Commodity-related factors	Alternative methods/ beliefs offer protection (religion, traditional medicine)	Alternative methods/ beliefs offer protection (religious)		Alternate methods offer protection (use mosquito coils instead)

	Childhood immunization	COVID-19 vaccine	Mass drug administration	Bed nets/ malaria vaccine
	Adverse events (fear / experiences)	Adverse events (fear / experiences)	Adverse events (fear / experiences)	
			Large tablets	
		Lack of trust in vaccines		
	Quantity (many doses)		Quantity of pills	
Personal factors	Distance		Distance	
	Absence during campaigns		Absence during distribution	Absence during distribution
	Time (constraint, long wait times)			
	Paracetamol syrup availability for adverse event management			
	Immunization book issues (damaged, lost)			
	Parental refusal / family forbids	Parental refusal / family forbids	Family forbids	
	Personal reasons/ undisclosed	Personal reasons/ undisclosed	Personal reasons / forgot to take	
	Poor health literacy – parents unaware of what vaccines children have received	Poor health literacy	Poor health literacy – lack of awareness about how to take MDA pills	Poor health literacy – unaware about need to replace old nets
	Cultural / religious beliefs	Cultural / religious beliefs	Cultural / religious beliefs	
		No perceived need	No perceived need	
	Rumors	Rumors	Rumors	
Biological factors		Pregnancy/ breastfeeding	Pregnancy/ breastfeeding	
		Comorbidity/ sickness		

Rumors and Misperceptions

Rumors about side effects resulting from the intervention impacted all campaigns and resulted in hesitancy to participate. These rumors may have been related to an individual they knew or an experience they had heard about in their community. The rumors could also be generated from social media, radio, TV, the internet, other community members, or even health care workers themselves. Table 3 illustrates some of the rumors detected in the dataset.

Table 3: Rumors related to public health campaigns

Childhood vaccines	“Some people vaccinate their child and ‘bird carries them’ (convulsion).” —IDI in Abui, Volta Region, Ghana
	“I have heard that sometimes when people are injected, they die.” —IDI in Abui, Volta Region, Ghana
Mass drug administration	“Some say the drug has once killed their children, so they won’t allow their children to receive the drug.” —IDI in Abui, Volta Region, Ghana
	“Some say the medications isn’t good for their children because after they receive it they send the children to hospital for treatment where some even receive drip before they get better and that makes them spend a lot of money before they get healed and those who gave out the medication don’t bear the cost, so anytime they come with the medication they wouldn’t allow their wards to receive it.” —IDI in Kpeve, Volta Region, Ghana
COVID-19 vaccine	“People said when you take the vaccine you would be infertile.” —IDI in Dzemeni, Volta Region, Ghana
	“While on a public transportation trip, I heard that hmm, if you go vaccinated, you will become a zombie ... when I had this vaccine, my husband said to me, ‘You made me a guinea pig; look at this, this doctor on YouTube said that you cannot get vaccinated, you will become zombies.’ Well, since then, many people do not want to be vaccinated.” —FGD with women in Indonesia
	“I heard that you will die sometime after the vaccine. I actually wanted to go because breastfeeding mothers are recommended to get it. I think due to hoax people are afraid to go.” —IDI in Latuhalat, Ambon City, Indonesia

Patterns as Seen in Cases

The conceptual model by Dubé et al (2013) [18] in Figure 3 illustrates some of the factors associated with individual decision-making about vaccination. Some of these factors can be considered “intentional” (e.g., the individual is in control of their decision not to participate), whereas other factors can be considered “unintentional” (e.g., the individual may not have access to the campaign commodity due to factors outside of their control) — most of these factors lie in the category of “public health and vaccine policies” illustrated in Figure 3. We applied this model during data analysis, extending it from vaccines to

the delivery of other commodities in public health campaigns. Analysis of the transcripts revealed many of these same factors related to all four campaigns under study. As seen in the case studies in Appendix 2, an individual may cite multiple themes when explaining the rationale for non-participation or never treatment. While we were unable to detect a pattern that detects never treatment / zero dose / non-participation, we ascertained that the range of themes responsible for never treatment / zero dose / non-participation was the same, regardless of the commodity offered during a public health campaign.

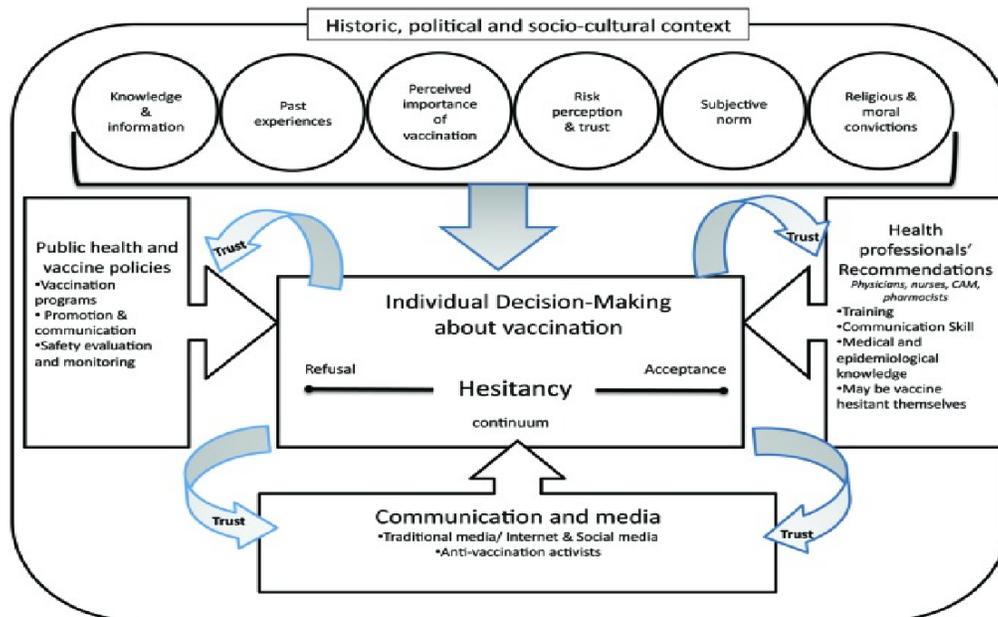


Figure 3. Conceptual Model of Vaccine Hesitancy. Source: Dubé et al (2013) [18]

Gender

Using the *Gender Analysis Toolkit for Health Systems* [19], we analyzed barriers to participation in campaigns that were related to gender roles, beliefs, access to resources, and laws and policies.

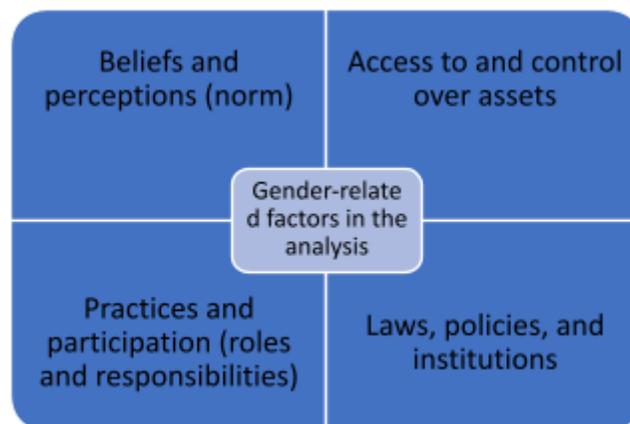


Figure 4: Gender Analysis Toolkit for Health Systems. Source: Jhpiego [19]

Roles, Practices, and Participation

This thematic area refers to factors such as the gendered division of labor, restrictions on mobility, types of activities men and women engage in, as well as different skills and capabilities. In both countries, women were identified as the household members who accompanied their children for immunizations. If they were unavailable to do so, they identified another household member to help. A woman's role in the markets (e.g., trading, selling) meant that they were sometimes unable to attend the clinic's vaccination schedule.

"Honestly, we, the women, are the people most concerned about our children, so it is rare for the man to send the child for weighing (and immunizations)." —FGD with women in Ghana

"As the mother of the child I'm the most likely person to take the child for their vaccination. When the mother fails to send the child personally, the child may receive an injection they were not supposed to be injected or administered medicine that shouldn't have been given to them. So as a mother, when you personally send your child, you are able to monitor whatever goes on." —IDI in Dzemeni, Volta Region, Ghana

"I told my husband that (to accompany children for immunization) when I was sick because the children needed it, but he was reluctant." —FGD with women in Indonesia

In the FGD with women in Indonesia, women joked that men only know how to "produce" children; it is the mothers who do the rest of the work of childrearing. In the FGD with men in Indonesia, men said they are not able to take the children for immunizations because they are all fishermen and, therefore, leave early in the morning for the sea:

"What was said earlier is true. Fathers do not participate very often because their activities are mostly fishing. So, when we look for fish, mothers bring the children during immunization hours." —FGD with men in Indonesia

"There is almost no time for family but that does not mean we do not want to take them, but it is because of activities." —FGD with men in Indonesia

Beliefs and Perceptions

According to the *Gender Analysis Toolkit for Health Systems* [19], beliefs and perceptions refer to culturally appropriate behaviors for men and women, interpretation of new experiences or information, and who makes decisions, among others. In the FGD with women in Indonesia, a woman explained that her husband made the decision not to immunize the children even though she wanted to:

"I have two children too. He [husband] did not allow vaccines, and his decision was: 'if you want the kids to stop going to school, just stop, but do not vaccinate' ... If something goes wrong, I am the one responsible... So, I would just follow him... But if it is me, I really want the vaccine." —FGD with women in Indonesia

Some women described the reasons why their husband refused the vaccines. A woman in Ghana said it was because of rumors her husband was hearing:

“... the father says he won’t allow his children to receive the malaria vaccine... he said he heard some rumors about the vaccine, which isn’t good. So, he won’t allow his children to receive the vaccine. And he does not live here with us.” —IDI in Kpeve, Volta Region, Ghana

In an in-depth interview, a woman in Indonesia mentioned not wanting to fight her husband when he refused immunizations for their children:

“Once, we saw our friend’s child got sick after immunization. So, the father said then: ‘do not get the children immunized again’ ... I just went with the father, instead of us fighting unreasonably.” —IDI in Indonesia

Access to and Control Over Assets

This thematic area refers to the kinds of resources that men and women have access to, and what they own individually and collectively. In this study, this was related to who kept the immunization cards. In Ghana, one woman, who usually takes her children for immunization and must show her child’s immunization card, said:

“It is with my husband (who was not in the house) ... It could rain on the weighing [and immunization] cards, or the children could get them torn; that is why he hides them [immunization cards].”

Laws, Policies, and Institutions

This area relates to laws, the legal system, gendered differences in wages, and employment opportunities for men and women. In our study, men were frequently away from their homes because of the nature of their jobs. In Ghana, there were instances where men lived outside of the house or frequently traveled away from their female partners and children. This resulted in less support from men in some cases on health care decision-making in the household. Because of the different employment opportunities offered to men and women, health care decision-making was affected at the household level.

Health Care Workers Attitude and Skills

Although most participants appreciated the campaign-related efforts from health care workers, a few participants mentioned being shamed by health care workers when they missed vaccinations. Health care workers’ negative attitudes toward community members can have a detrimental effect on health care participation [20]. This is further illustrated in the following quotes:

“When the month passes and we are unable to go for weighing (immunization), some of the nurses lament a lot, others pass abusive words behind our backs.” —IDI in Dzemeni, Volta Region, Ghana

“If we skip a month, they will warn us. I will hate their tone; it humiliates me in front of everyone.” —IDI in Latuhalat, Ambon City, Indonesia

“There is a nurse (who’s) a little fussy, but there is also a kind one... I mean when they are friendly, kind, I’ll definitely like it. But if they come, they are chatty, angry, I don’t like them, I’m also annoyed with their behavior.” —IDI in Latuhalat, Ambon City, Indonesia

“When the child runs temperature, I don’t like it at all and sometimes the nurses make mistake by not injecting the children well, the child then suffers after receiving the vaccine and when it happens like that you the mother would be suffering to get the child healed.” —IDI in Dzemeni, Volta Region, Ghana

“What I am not happy about is some nurses’ hand isn’t good for children’s thigh. Like this child, when he took the vaccine on the thigh, it got swollen. That of my sister’s child too. But after complaining and when a different nurse took over, it was okay.” —IDI in Kpeve, Volta Region, Ghana

Promising Practices

The Health Campaign Effectiveness Coalition defines a promising practice as an action emerging from the study that campaign planners/implementers should consider doing and building into plans. The following are promising practices for research resulting from this exploratory research:

- **In areas where there are known challenges with poor campaign coverage, conduct a transect walk during the microplanning phase** to identify households that are missing campaigns. This information can be used to strengthen the next round of delivery.
- **Empower community health workers/volunteers to identify missed communities or households.** Community health workers/volunteers often participate in multiple health campaigns and frequently know exactly which households or individuals do not participate in health campaigns. Training, supervising, and incentivizing these individuals to identify never treated or zero dose children prior to and during campaigns could provide an important point for integration.
- **Validate answers by checking immunization cards and /or MDA household registers.** During research interviews and/or campaign distribution, recommend that teams confirm completeness to date in terms of vaccine history, MDA participation, and bed net use. This provides an opportunity to directly ask the respondent about their vaccination history. Where possible, consider an integrated form that captures participation across all public health campaigns to further integrate activities and follow-up at the household level.

Lessons Learned

The Health Campaign Effectiveness Coalition defines a lesson learned as an insight on how to adjust what is being done based on experience or learning.

- **There are similar factors related to non-participation, zero dose, or never treatment across the different public health campaigns.** However, at the individual level, a person may have

multiple reasons reflecting the complexity of health care decision-making at the household level.

- **Levels of health literacy are low.** For example, community members may not know what vaccinations their children receive, why they are asked to return to clinics, what the MDA drugs are for, how MDA drugs are supposed to be ingested, need for new insecticide-treated bed nets over time, among others. Low levels of health literacy were found to impact an individual's participation and ability to confront rumors.
- **Poor quality of care** during public health campaigns as demonstrated in reports of “shaming” mothers, not reassuring fears, insufficient information about the commodity offered during the campaign, and poor management of adverse events.
- **Awareness of MDA is suboptimal** resulting in many respondents not taking treatment.
- **There is strong resistance to COVID-19 vaccines.** Rumors about adverse events such as infertility, death, paralysis, and convulsions are prevalent. Some people do not see the need to take the vaccine or believe that COVID-19 is over.
- **Rumors affect all campaigns offering a vaccine or drug.** Sources of these rumors varied, ranging from traditional sources of information (TV/radio) to social media to community members and health care workers.
- **Experience and rumors about side effects resulting from vaccines / treatment affect participation.** These experiences may not be related to the individual, yet they have the power to sway participation.
- **Trust in health care workers varies.** Some participants reported shaming, poor information giving, and poor injection administration, whereas others appreciated health care workers' hard work and dedication.
- **Gender plays an important role in decision-making** at the household level.
- **Men are frequently away** – living elsewhere, traveling, or working. Their absence affects health care decision-making at the household level as some women cannot participate without their permission, or men hold the vaccination cards.
- **Knowledge of the benefit of the intervention** may not always be related to actual experience and participation; other factors have stronger influence such as social norms, health care access, quality of health care, health literacy, and self-efficacy.
- **Perception of personal risk** (or risk at the household level) may influence the acceptability of the intervention.

Implications for Policy, Practice, and Future Research

Research

- Explore the intersectionality of multiple vulnerabilities that families face at the household level that preclude their participation in public health campaigns.
- Given the variation in reported quality of care from health care personnel and volunteers while delivering public health campaigns, assess their resilience and mental health over time to understand the impact that multiple campaign-related activities may have on health care delivery.
- Conduct a quantitative study on patterns of non-participation across different campaigns to determine the strength of associated factors.
- Test new approaches to improve identification of missed households or individuals and improve reach.
- Explore phenomena of never treatment / zero dose / non-participation in a wider geographical area.

Policy and Practice

- Explore opportunities for campaign integration; specifically, health care worker training on professionalism, messaging, and surveillance to enhance coverage. Messaging should be specific to the context, gender norms, and local community awareness and campaign experiences.
- Test the role of enhanced and specialized training for select health care personnel and volunteers on professionalism, communication skills, compassionate care, and counseling to enhance quality of care and reach to households where never treated individuals / zero dose children reside. Potential area for integration across campaigns.
- Ensure the budget is sufficient within campaigns to sufficiently reach the community and communicate about the public health commodity under offer. Communication needs to provide avenues for response to questions and concerns. Consider community sensitization that enhances health literacy, rather than awareness only.
- Improve access to health campaigns by considering geographic barriers, time and seasonality, economic and gender-related population movements, and other gender barriers due to roles and social norms.
- Consider how learnings can be shared across public health campaigns about how never treatment / zero dose / non-participation is being measured and addressed.

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Appendix 1. Quotes on Reasons for Non-Participation

Reasons for non-participation	Campaigns	Quotes
Health system issue Health system issue (location and/or access)	Immunization	"Yes..I hate it because I have to carry my baby while standing and waiting... not to mention if it rains, and you have three children." IDI Latuhalat
	MDA	"I don't know. I have never heard of it (MDA)." IDI Waiheru
	Bed nets	"I had travelled when they came to write names, but I was around when they came to do the distribution. And there was an announcement that if you missed the counting and writing of names you can come and explain it to them. I went there a couple of times and they were not giving us any attention so I didn't go again." IDI Dzemeni
	COVID-19 vaccine	"They didn't come to our area with the vaccine" IDI Dzemeni
Missed	Immunization (Miss one step and lose opportunities for next doses)	"Mostly it is because I am not around when they come for the home visit and immunization. For example, the one at 9 months, if you miss it, the child cannot receive it again. So that is why I missed some of the schedules." IDI Abui
	Bed nets (Missed registration; could not access bed nets / participated in registration; missed delivery day)	"Also, people come with their children within the five years, but they don't even give them. It is good news that at least that, we have few nets, and it will cover us till for some time." IDI Kpeve
Physical space at the clinic	Immunization	"The trouble is there... no one got a seat, so they stood up, the children even queued, using the queue number. But it's a pity, sir; they feel hot in that condition." IDI Latuhalat
Lack of awareness about availability/distribution and usage	Immunization (lack of awareness about campaigns)	"...the house is close to the posyandu (integrated health service post), so you can go. But sometimes I do not hear the information." IDI Latuhalat
	MDA (lack of awareness about distribution)	"I guess we appreciate it because it means free medicine. But while being distributed, there was no explanation whatsoever, so the community was afraid to take it." IDI Latuhalat

	Bed nets (lack of awareness about distribution of bed nets)	"When we were distributing the bed nets, some were willing to take, some were not... when you ask them why they would not, they said: 'I have it already so there's no need for me taking it again'". IDI Abui
No demonstration – e.g., leaders did not take it in front of us	MDA	"You see now the world is scary, you will just be there and hear about a new medicine but when you take it, you happen to die. So you, the one coming to distribute, should first swallow the medicine in front of us before the town people can take." IDI Abui
Quantity and/or fear of injections	Immunization (Quantity (many doses); fear of injection)	"Some people don't send their children for vaccination because they complain that the doses of vaccines administered these days are a lot as compared to before when usually one dose of vaccine was administered." IDI Dzemeni
	MDA (quantity of pills)	"... he (husband) was tired of seeing so many drugs" IDI Latuhalat
	COVID-19 vaccine (fear of injection)	"I'm afraid of injections that's why." IDI Dzemeni
Adverse events (fear, experiences)	Immunization	"... The child before this one how he was handled is why (I didn't vaccinate the youngest). He was vaccinated on the thigh and the site got swollen for a long while... the time the child was supposed to walk the child didn't walk at that time. I got frightened and that's why (I didn't vaccinate the youngest)" IDI
	MDA	"For me, the way other children become very weak and sick after taking the drug, that is why I do not want my own children to even take it." IDI Abui
	COVID-19 vaccine	"I'm afraid of vaccines because I watched on television where there was one priest from the Batak tribe. He once preached and he said that in five years everyone who was vaccinated would die." IDI Latuhalat
Alternate methods	Immunization (Alternative methods/ beliefs offer protection (religion, traditional medicine))	"For those that are Christians, they pray over their children that these children should be healthy, and no evil befall them so it makes them unable to send their children for vaccination but

		those that are non-Christians send their children for the vaccination.” IDI Abui
	Bed nets (Alternate methods offer protection (use mosquito coils instead))	“No particular reason (for stopping to use bed nets) ... Now we use mosquito coil.” IDI Abui
	COVID-19 vaccine (Alternative methods/ beliefs offer protection (religious))	“In my opinion, I just believe in God above. Since I did not want to be vaccinated, I asked God to divert it from us in this neighborhood. So, we have to be strong to struggle with this because God is omniscient.” FGD Men, Indonesia
Distance	Immunization	“Some people live on the other side of the lagoon, so coming from that side, these people only bring their children to the weighing centre unless they are coming to the market.” IDI Dzemeni
Absence	Immunization	“She (sister) traveled by then and she took the child as well so she missed (doses).” IDI Kpeve
	MDA	“It was because that child didn't go to school on that particular day (that he did not get the MDA drugs).” IDI Dzemeni
	Bed nets	“My brother wasn't around so he didn't get one, but I informed them and they promised to bring one. Some other community members who weren't around did not get one, a lot of them didn't get one.” IDI Kpeve
Time (constraint, long wait times)	Immunization	“I'm just tired of waiting because this is a lot of people not one or two people. That's all.” IDI Air Besar
Paracetamol syrup availability	Immunization	“But sometimes we go and we don't even have money to buy paracetamol syrup and after immunizing the children we come home and they are so hot to touch.” IDI Abui
Immunization book issues (damaged, lost)	Immunization	“You see this book ... I placed it down and before I realized, it was wet. There was one too I left it with the grandmother, before I could go and come the same thing happened. They said the child dropped it in water. That is why because there's no book to send, I don't send them again.” IDI Abui

Parental refusal	Immunization	"But if the father wants, we certainly can; we want to bring the children. It is just that he does not want to." IDI Air Besar
	COVID-19 vaccine	"So, my two kids do not receive the COVID-19 vaccine, although they are important, right? They are going to school, but (my husband) refused. He said it is ok for them to stop going to school, as long as they are not vaccinated" IDI, Latuhalat
	Malaria vaccine	"The father says he won't allow his children to receive the malaria vaccine ... he won't allow his children to receive the vaccine. And he doesn't leave here with us" IDI Kpeve
Personal reasons/ undisclosed	Immunization	"Not basically religious but it a personal decision" IDI Abui
	COVID-19 vaccines	"They bring the COVID vaccines, they do the vaccinations there, but I have just decided not to take the vaccine... I don't know anything to say or have anything saying regarding the COVID vaccination." IDI Abui
	MDA	"We have had too much, too much work, and then we have forgotten to take the medicine" IDI Waiheru
Poor health literacy	Immunization	"She has received two on the shoulder and one on the thigh so three" IDI Abui
	MDA	"Someone told me about elephantiasis. I mean, they guessed the disease was called elephantiasis." IDI Latuhalat
	COVID-19 vaccines	"But the woman in the house heard rumors that if you take the vaccine, you will not be able to give birth." IDI Abui
No perceived need	MDA	"I have received it, but I did not take it. It was not that I was afraid to take the medicine, but in my mind, there are no elephantiasis sufferers in our area so far. The community around here has never been, even a single person. So, my mind goes there." FGD Men, Indonesia

	COVID-19 vaccine	"Personally, I do not believe the COVID-19 disease exists so I'm unwilling to take the vaccine." IDI Dzemeni
Pregnancy/breastfeeding	MDA	"I did not take medicine, doc; because I was pregnant." FGD Women, Indonesia
	COVID-19 vaccine	"At that time, at the time of the vaccine, we were still pregnant, or young pregnant, so we didn't want the vaccine." IDI Waiheru
Co-morbidity/sickness	COVID-19 vaccine	"The reason is that my mother is sick, my mother is also old, in her 60s, so she doesn't want to be vaccinated." IDI Waiheru"

Appendix 2. Sample case studies (individuals)

To understand how reasons for non-participation may manifest at the individual level, we highlight the eight case studies of case studies. These four individuals in Ghana and four in Indonesia demonstrate how complex the decision-making process is at the household level for each of the interventions.

Case study 1 (Ghana)

A female in Abui, who has missed three campaigns - childhood immunization for her children, MDA, and COVID-19 measures - mentions two reasons for missing immunization doses – lack of awareness and inability to get missed doses.

“Well, my last born is 10 months old. Some of the immunizations were done for the child but I defaulted (missed) for some... I have not really decided to stop intentionally. Sometimes when they are coming to visit us, they inform us but sometimes, they do not. So, when we do not know when they are coming, then they miss us.”

“Mostly it is because I am not around when they come for the home visit and immunization. For example, the one at 9 months, if you miss it, the child cannot receive it again. So that is why I missed some of the schedules.”

Her children missed the MDA because of she feared the side effects. Two of her children also do not go to school.

“For me, the way other children become very weak and sick after taking the drug, that is why I do not want my own children to even take it.”

She did not follow COVID-19 protective measures stating religious reasons.

“... because we know there is an Almighty God that fights for us and so He will fight that battle too for us. So even if we observe all the above measures and God’s protection is not on us, we will still contract the disease. So, we all decided to resort to the prayers and fasting for his protection. We cannot fight in flesh. Even the COVID-19 vaccine, me and my household has not taken it. We did not, for the same reason I mentioned above, God.”

Case study 2 (Ghana)

A female in Dzemeni indicated that she missed immunization doses because of her busy schedule and side effects:

“I was supposed to send him this past Wednesday but my work schedule on market days makes me very busy. When I send him to get vaccinated, he will experience some inconveniences (adverse effects), so I didn’t send him. I am supposed to send him for the immunization but since I’m busy I couldn’t.”

For MDA drugs she said she had not been well advised about the taking of the medicines:

“The reason was that our teachers did not advise us to eat well before taking the medicine. So, school children who took the medicine on empty stomachs were inconvenienced a lot. That is why it inconvenienced a lot of school children in the school, and this made me skeptical about the medicine. So, when it is being shared, I'm unwilling to participate.”

She hasn't received the COVID-19 vaccine because she doesn't believe the disease exists:

“Personally, I do not believe the COVID-19 disease exists so I'm unwilling to take the vaccine.”

Case study 3 (Ghana)

A female in Kpeve mentioned that she doesn't believe in vaccines and drugs and, therefore, is not participating in any immunization or MDA campaigns.

“We haven't heard of that disease here before, but I think LF [lymphatic filariasis] is in the town but in my house none (it's not there).”

“If you believe in falling sick or you don't have any dependable thing to save you, that's where you would run to those things.”

“I have not vaccinated before from childhood, even taking drugs I don't do and am 40 years and above... I don't believe in those kinds of things, that's how I was brought up. You have to live the way you were brought up. I don't use it at all, you can see my children.”

Case study 4 (Ghana)

A woman in Dzemeni was not able to take her child for some of the immunization visits because of lack of access.

“We cross the river at Kpando before going for immunization sessions and the boat only crosses on market days so when the immunization days doesn't fall on a market day then it difficult to still go for the vaccines.”

She also does not allow her kids to take MDA drugs because of her experiences with side effects.

“I always tell them not to give my child the medication... because of what I experienced in school. I don't want him to also experience same.”

She mentioned not taking the COVID-19 vaccine because her mom told her so. She did not know why her mom refused.

Case study 5 (Indonesia)

A woman in Latuhalat mentions only vaccinating her two children until 9 months for two reasons: she was not aware she should continue after 9 months and the health centre is far from her house.

In this region of Indonesia, many respondents reported how geographically challenging their location was from the health center.

"Because the distance is far from the beach, sometimes...there is no information, so I do not go..."

"The distance from the beach goes up ... sometimes as a human being, right when you are tired, when you are working, sometimes when you want to go up you are tired, so you don't go."

Her husband did not take all MDA pills because of the quantity of pills.

"I said: you have to drink medicine until it runs out... but my husband said... "If you take too much medicine, your ears will go deaf"... so you don't want to drink..."

She did not get the COVID-19 vaccine due to sickness. Her husband is refusing the vaccine because of rumors:

"My husband, he said "Even if you kill me, whether you want to shoot me so that I die, I still won't want to be vaccinated". I asked him why he said that; he replied "I've read a lot on my cellphone that there are people whose vaccinated end up dying" so that's it... Finally, my children are also not allowed to vaccinate, even though it is very important, right? Because they go to school. But he still doesn't want to. My two children can stop going to school... it's okay as long as they don't get vaccinated."

Case study 6 (Indonesia)

In this interview, a woman in Waiheru explains that all her 3 children have never been vaccinated because her husband doesn't allow it. She understands the benefits of immunizations but does not want to fight with her husband.

She says that the whole family has not taken the MDA drugs because they forget to take them:

"We have forgotten the medicine, maybe we have received it but did not take it."

Fear of COVID-19 vaccines was mentioned as a reason for not being vaccinated.

"I'm just scared because I'm not used to injections... I mean, I've never been vaccinated at all since I was little."

Case study 7 (Indonesia)

A mother of 3 children explains that she is not able to carry all children to the clinic for immunizations, especially during rainy seasons.

"I can only bring one child if it rains... it's hard to bring three of them."

When asked about MDA, she mentioned not taking the drugs because she was pregnant. Her husband said:

"I guess we appreciate it because it means free medicine. But while being distributed, there was no explanation whatsoever, so the community was afraid to take it."

She has not gone for COVID-19 immunization because she is breastfeeding. In the household, a couple of people have also not opted to get the vaccine either because of their comorbidity or because of rumors they have heard.

Case study 8 (Indonesia)

A grandmother says that her one year old and 6 months old child has only received the tetanus vaccine and not other vaccines because they keep forgetting:

"We go to the market looking for a new sale and we eat and drink. . . If we do not sell, we cannot eat... Finally, because of those activities we forgot again, oh my God, I was going to be immunized. Oh, we forgot again."

When asked if she or her daughter would take the child for vaccination if they remembered, she explained:

"Let's see how things are first... If the other children are all healthy, it means I will go. Ah, that is because I have been traumatized."

She has never taken MDA drugs because she wasn't aware of the distribution.

"No. Never. Never got, never heard."

She also mentions travelling frequently to see other family members but cannot say if she missed because of that. If asked if she would take the drugs if they were given to her, she said:

"We do not have that kind of disease. You can give it to the people who are affected there... If they give it, it means that I will give it to people who have the disease."

She mentioned that few of the family members haven't taken the COVID-19 vaccine because their work requires them to. She, herself, is not vaccinated because she does not see the need to get the vaccine:

"This corona disease no longer exists, what is the purpose of getting a vaccine?"