

**Vaccine  
Acceptance  
& Demand**

 SABIN VACCINE INSTITUTE

**STRUCTURAL  
INEQUITIES  
IN VACCINE  
ACCEPTANCE,  
DEMAND,  
DELIVERY, &  
DECISION-MAKING**

**INITIAL FINDINGS FROM THE 2021-2022 SOCIAL  
AND BEHAVIORAL RESEARCH GRANTS PROGRAM**

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# A PRIMER FOR DECISION-MAKERS AND IMPLEMENTERS

The COVID-19 pandemic has laid bare significant social, economic, and health inequities both at the global level, as exemplified by the COVID-19 vaccination rollout, and at national and sub-national levels. Existing inequities within societies have been thrown in stark relief during the response to this global health emergency, and often these are deeply rooted and structural in nature.

Structural inequity is the systemic disadvantage of one social group compared to another group with whom they coexist and can exist within policy, law, governance, and culture<sup>1</sup>. Historical events including war, institutionalized social exclusion, and collective trauma experiences can lead to structural inequities affecting certain segments of the population. As structural inequities are produced on the basis of social identity (e.g., race, gender, and/or sexual orientation, etc.) and lived experiences<sup>1</sup>, such entrenched and systemic disadvantage for certain groups can drive inequities in access to health and other social services, including vaccination.

Investigating the nuanced barriers and enablers of COVID-19 vaccine uptake amongst marginalized communities contributes to overall understanding of historical marginalization and its impact on existing structural inequities within societies, including the creation of key challenges and opportunities for vaccination acceptance, demand, delivery, and decision-making at all levels. Learnings from the COVID-19 pandemic and its vaccination rollout may also serve for future pandemic preparedness or as an indicator for the expected challenges in or strategies required for the uptake of other existing or future life-course vaccinations amongst specific social groups.

Launched in 2019, Sabin's [Social and Behavioral Research Grants Program](#) supports a global network of interdisciplinary and multisectoral researchers to investigate the social and behavioral drivers behind vaccination acceptance, demand, delivery, and decision-making. The program supports the design, piloting, and testing of community-informed interventions in low- and middle-income countries (LMICs) in order to elevate locally contextualized evidence that can be used to reduce barriers and identify opportunities that ultimately increase vaccination uptake.

This case study report includes three of the projects from Sabin's Grants Program, which have investigated the uptake of COVID-19 vaccines within the context of communities who have experienced – and continue to experience – marginalization in their country context. Preliminary findings are presented and synthesized to continue to inform action and investment around the globe that seek to build more vaccine confident communities.

## Approaches for Generating Localized Evidence for Global Solutions

All three studies aimed to understand more about the structural inequities affecting COVID-19 vaccination acceptance, demand, and uptake amongst various marginalized communities: people living with HIV (PLHIV), men who have sex with men (MSM), transgender, people living

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1. Communities in Action: Pathways to Health Equity. Washington (DC): National Academies Press (US); 2017 Jan 11. 3, The Root Causes of Health Inequity. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK425845/>

with disabilities, and indigenous peoples. In designing these projects as mixed methods or qualitative studies, research teams could investigate their research aims comprehensively, seeking out differing perspectives and understanding the detail and nuance of these perspectives and vaccination behaviors through qualitative methods.

- [Universidad del Valle de Guatemala](#): *COVID-19 vaccination and people living with HIV in Thailand*;
- [Sangath](#): *Structural inequities in COVID-19 vaccine access and uptake among transgender and disability communities in India: A qualitative study through intersectionality lens*; and
- [Adam's Love Global \(ALGO\) Foundation](#): *Building a pathway for a pertinent vaccination transdisciplinary dialogue in Sololá, Guatemala: Combining local demands, national public health priorities, and research efforts from a mixed methods approach*.



## Emerging Insights for Community Action

Broad insights can be synthesized from across all three case studies and center around addressing issues of vaccine inequities and practical barriers to accessing vaccination for marginalized communities. Specific insights are to:

- Acknowledge and address historical barriers and inequities within communities in vaccination decision-making and prioritize marginalized communities (e.g., PLHIV, transgender, disability) and their specific needs;
- Invest in multistakeholder advisory groups, which include stakeholders from marginalized communities, and incorporate members from these groups into vaccination program service design and delivery;
- Engage with communities directly through trusted community leaders and/or community-based organizations;
- Consider specific barriers to vaccination registration experienced by marginalized groups in the design of vaccination delivery systems (e.g., stigma, identity cards, inaccessible websites);
- Create and expand options to improve accessibility and safety of vaccination registration and delivery systems and include broad definitions of accessibility into the monitoring and evaluation of these delivery systems;
- Integrate chronic disease providers and regular care (e.g., HIV) with vaccination service delivery and develop protocols for adverse post-vaccination events specific to the two communities;
- Integrate community participatory approaches in research design;
- Sensitize care providers/vaccination staff to specific needs of marginalized groups and train vaccination staff in structural determinants of stigmatized and marginalized populations in their communities; and
- Create and disseminate messages and communications strategies that are accessible to all.

Commonalities in study approach emerged across the three case studies which surface insights around Community and Stakeholder Engagement and overall Research Design (Table 1).

Table 1. Emerging Insights from Projects' Stakeholder Engagement and Approach

Key Insight	Examples
<b>Community and stakeholder engagement</b>	
<p>Working with – or within - organizations well known to and trusted by the community helps develop buy-in and sustainable engagement</p>	<ul style="list-style-type: none"> <li>• ALGO<sup>a</sup>– well known in the community; history of working with MSM<sup>a</sup></li> <li>• Sangath – been around for 25+ years, well-known</li> <li>• UVG<sup>a</sup> – history and experience of working in Solalá</li> </ul>
<p>Bringing in community members as part of the research team enables co-production of knowledge that can inform sustainable, community-led solutions</p>	<ul style="list-style-type: none"> <li>• Drawing on community members as researchers/research leads</li> <li>• Training/skills transfer to local community members</li> </ul>
<p>Engagement of community members in data analysis facilitates ownership of research findings that stay in the community, as well as ensures quality interpretation of results</p>	<ul style="list-style-type: none"> <li>• Pluri-epistemic data analysis incorporates different perspectives and ways of knowing into the data analysis process</li> </ul>
<b>Overall research design</b>	
<p>Community-based participatory methodologies involve community in all aspects of knowledge generation, recognizing and elevating local knowledge and experience as essential evidence for transformational change</p> <p>Reflexivity / self-reflection built into the research design.</p>	<ul style="list-style-type: none"> <li>• Photovoice Stories – uses the medium of photographs as a way to discuss, reflect, capture, and share their lived experiences to advocate for change</li> <li>• Transdisciplinary approach - uses social equality in participation throughout the project stages, fostering a co-creation process and pertinent knowledge translation with local key stakeholders to solve societal challenges</li> <li>• Ethnographic diary amongst research assistants, who are also community members</li> </ul>
<p>Exploratory methods utilized for under-researched areas and 'hidden' populations</p> <p>Pandemic-era data collection strategies (WhatsApp, Zoom, video) for 'virtual interviews' were successful</p>	<ul style="list-style-type: none"> <li>• Sequential Exploratory Design - qualitative strand precedes the quantitative strand, enabling further exploration of the quantitative results in more detail</li> <li>• Qualitative Methods – interviews with community members and key informants</li> </ul>

<sup>a</sup>Adam's Love Global Foundation, ALGO; men who have sex with men, MSM; Universidad del Valle de Guatemala, UVG.

Key Insight	Examples
Conceptual frameworks that are interdisciplinary, community-centric, and systems-level can help uncover structural inequities	<ul style="list-style-type: none"> <li>• Transdisciplinary approach</li> <li>• Youth Participatory Action Research (YPAR) - an innovative approach to positive youth and community development in which young people are trained to conduct systematic research to improve their lives, their communities, and the institutions intended to serve them<sup>2</sup></li> <li>• Intersectionality lens - a concept that enables recognition that membership in a particular group can make people vulnerable to various forms of oppression<sup>3</sup></li> <li>• Social Ecological Model - considers the complex interplay between individual, relationship, community, and societal factors<sup>4</sup></li> </ul>

## Informing & Investing in Vaccine Confident Communities to Drive Vaccine Demand & Uptake

The goals of sharing these initial results are to:



Provide researchers and program implementers in LMICs with blueprints of successful research methodologies and approaches for piloting and evaluating strategies to increase vaccine confidence and acceptance in their communities.



Demonstrate the value of including these types of approaches and perspectives to sub-national, national, and global funders and policy and program decision-makers.

Considered together, these three projects have brought forth actionable insights for vaccination policy, programs, and practice. While individual, contextually-relevant recommendations are outlined in detail in each country’s case study, broad insights have been synthesized from across all three case studies, as outlined.

These case studies demonstrate the value of community-centric approaches for generating localized solutions, which is an essential strategy for addressing the complex social and structural factors of vaccine acceptance. These early learnings aim to inspire and inform similar methodologies that can and should be used to continue generating critical knowledge and solutions to strengthen vaccine acceptance and demand in LMICs. One size does not fit all, and

2. UC Berkeley. Why YPAR? <https://yparhub.berkeley.edu/why-ypar>

3. VAWnet. Applying an Intersectional Lens. <https://vawnet.org/sc/how-faithreligion-can-best-meet-needs-abuse-survivors-those-who-cause-harm/applying>

4. Centers for Disease Control and Prevention. The Social-Ecological Model: A Framework for Prevention. <https://www.cdc.gov/violenceprevention/about/social-ecologicalmodel.html>

resources should focus on understanding effective approaches to design context-appropriate messaging and policy. These strategies should be embraced universally to drive vaccine uptake amongst historically marginalized social groups.

CASE STUDY FROM SOLOLÁ, GUATEMALA

# **BUILDING A PATHWAY FOR A PERTINENT VACCINATION TRANSDISCIPLINARY DIALOGUE IN SOLOLÁ, GUATEMALA**

Combining local demands, national public health priorities, and research efforts from a mixed methods approach



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The pilot project was conducted in Guatemala's Sololá department between January and December 2022. It was implemented by the Universidad del Valle de Guatemala, with funding from the Sabin Vaccine Institute. The project received ethics approval from the Universidad del Valle Institutional Review Board. Investigators: Dr. Monica Berger, Daniella Da Costa, and Daniela Ochaita.



## KEY TAKEAWAYS

- Historical, contextual, and cultural factors have weight in the relationship between communities and the healthcare system;
- Participatory approaches that enable community co-creation can confront the power matrix of colonialism;
- Transdisciplinary team building methods can reconsider boundaries of the status quo to advance towards democratic, decolonial, and participatory practices; and
- Civil society members and researchers should be integrated as a team to address informational gaps.

## HISTORICAL CONTEXT

Guatemala experienced a Civil war between 1960 and 1996, due to political and economic inequalities. In the 1970s, the Maya began participating in protests, demanding greater equality and inclusion of the Mayan language and culture to be recognized by the government. The Guatemalan army reciprocated with military violence against the Mayan population under the premise of ending insurgent guerilla warfare. In February 1999, the United Nations concluded genocide was committed against four specific groups: the Ixil Mayas; the Q'anjob'al and Chuj Mayas; the K'iche' Mayas of Joyabaj, Zacualpa and Chiché; and the Achi Mayas<sup>1</sup>.

Even today, the Maya still require equality and inclusion. While national healthcare programs have worked to overcome geographical and economic barriers, cultural barriers, and contextual aspects requiring attention to reach and support indigenous populations, they remain largely ignored.

## APPROACH

Through a transdisciplinary approach to address vaccination hesitancy in Sololá, Guatemala, where 96.4% of the population self-identifies as indigenous Mayan<sup>2</sup>, a mixed-method, cross-sectional study (June-August 2022) was conducted to achieve the following objectives:

- Transfer research skills to local community members,
- Estimate the prevalence of COVID-19 vaccination hesitancy amongst adults of indigenous communities,
- Identify COVID-19 vaccination hesitancy determinants that deepen the understanding and shaping of local beliefs, and
- Create a road-map of inter-sectional dialogues that documents the transformation process of evidence into actions.

1. <https://hnh.org/library/research/genocide-in-guatemala-guide/>

2. Estadística INd. XII Censo Nacional de Población y VII de Vivienda. In: Guatemala CdG, editor. Instituto Nacional de Estadística Guatemala, INE: Instituto Nacional de Estadística Guatemala INE; 2018.

## What is transdisciplinary team building?

Transdisciplinary (TD) team building uses social equality in participation throughout the project stages, fostering a co-creation process and pertinent knowledge translation with local key stakeholders to solve societal challenges. It allows the conditions for co-creation of solutions using knowledge from the community (e.g., a bottom-up approach). The TD team building reflects on different perspectives of a participatory model, taking communities as the subjects of their own experiences.

Following the Youth Participatory Action Research (YPAR) framework, a TD team of social and health scientists and six youth leaders trained as “community researchers” was created. The TD team divided into ethnolinguistic groups (Tz’utujil, Kaqchikel, and K’iche’) to implement community household surveys and semi-structured interviews with individuals from both the health sector and civil society to access the determinants of vaccine hesitancy in five municipalities of the Sololá region (Santiago

Atitlan from the Tz’utujil region, Sololá and Concepción from the Kaqchikel region, Santa Clara and Guineales from the K’iche’ region). These municipalities were purposely selected together with the Ministry of Health (MoH) given they had less than 40% COVID-19 vaccination coverage by May 2022.

Pluri-epistemic data analysis was conducted amongst the TD team around three types of data: 1) Historical aspects, 2) Cultural-linguistic aspects, and 3) Contextual aspects of the Covid-19 pandemic and related vaccination strategies.

## What is pluri-epistemic data analysis?

This type of data analysis highlights a researcher’s own experiences and perspectives, accounting for their impact throughout the research process. It allows for a deeper understanding of the data obtained through a group-oriented, data interpretation process.

The six-steps of data analysis included:

- An exchange of field notes and collective reflection of the data collection phase,
- Separate analysis of data and reporting-out per ethnolinguistic group, followed by a synthesis process presenting research findings to all during a TD team workshop,
- A collective analysis of key research findings around historical, cultural-linguistic, and contextual determinants,
- Creation of a joint narrative using “storytelling” for linking findings and shared results with a culturally pertinent overview,
- Co-creation of data presentation between scientists and community researchers with the aim of sharing information with key stakeholders in local languages, and
- Standardized sharing of research findings with governmental health authorities, primary healthcare workers, and community leaders.

3. Liebenberg L, Jamal A, Ikeda J. Extending youth voices in a participatory thematic analysis approach. *International Journal of Qualitative Methods*. 2020;19:1609406920934614.

The TD team distilled the main findings and presented them in local languages. Results were discussed with both audiences, in separate meetings. To create a more culturally pertinent approach for strengthening health delivery systems, an inter-sectorial dialogue table with four working groups was created with representatives from the MoH, local leaders, non-government organizations, research institutions, and Mayan authorities from the Sololá department.

This process is exemplary for how to implement quality data collection and analysis activities within communities which have a historical hesitancy to receive assistance from and collaborate with local healthcare workers and researchers.



## IMPLEMENTATION STAGES

### 1. Transfer of Skills to Community Members

Community researcher training was focused on developing ethical and quality research competencies to promote knowledge transfer and team engagement. Key learning modules were:

- Capacity building of technical research skills;
- Collective reflection and team integration;
- Self-reflection through an ethnographic diary to document their thoughts, observations, and lessons learned throughout the data collection process; and
- Participatory activities, including power mapping and rumor tracking group exercises.

To monitor and assess community researchers' competency and improvement, two surveys were conducted post-training and TD team building and at the completion of the project. All six community researchers self-reported strengthened research skillsets; while four perceived strengthening their technical skills through conducting surveys, interviews, and key actor mapping. Half of the community researchers felt they honed their communication skills through participating in the knowledge translation process, and two individuals felt an increase in their self-reflection skills.

### 2. Community Health Worker-led Ethnographic Observations

#### Household Surveys

Within each of the five municipalities, five villages were randomly selected for the conduct of at least 20 face-to-face household surveys in local languages (N=602 surveys, with a double sample from Santiago Atitlan [n=198, 32.9%]). Real-time electronic capture allowed for the

collection of sociodemographic characteristics, perception of COVID-19, beliefs in COVID-19 vaccine misinformation, trust in healthcare services, and perceptions of use of traditional medicine to treat COVID-19. Table 1 summarizes the data from the surveys.

**Table 1: Key findings from household surveys in Sololá**

Sociodemographic Characteristics, proportional majority were...	Risk Perception of COVID-19 and vaccination beliefs	Trust in healthcare system and use of traditional medicine
Women (n=353, 59%)	Rejected COVID-19 vaccination due to: Fears of side effects (n=234, 39%) <sup>b</sup>  Rumors in the community that the vaccine sterilizes men or women (n=57, 9%)	COVID-19 vaccination had been offered to them (n=550, 91%) and of those offered, 285 (52%) were vaccinated
6th grade educational level (n=108, 17%)	Believes in myths around COVID-19 vaccine causing death (n=159, 26%)	Non-vaccinated group – as compared to vaccinated group - was more likely to have lower levels of trust <sup>d</sup> in: <ul style="list-style-type: none"> <li>• Hospitals (49.8% vs. 38.5%; p-value=0.02)</li> <li>• Primary healthcare services<sup>e</sup> (48.4% vs. 32%; p-value&lt;0.0001)</li> <li>• Healthcare workers (43.9% vs. 24.1%; p-value&lt;0.0001)</li> </ul>
Household decision makers (n=442, 73%)	Believes that COVID-19 is not an illness <sup>c</sup> (n=169, 28%)	Both vaccinated and non-vaccinated groups had similar perception of use of traditional medicine in the community (n=253, 95% and n=277, 97%, respectively; p-value=0.066), especially to treat COVID-19 (n=255, 85% and n=238, 84%, respectively; p-value=0.073).  This suggests a homogenous and wide use of traditional medicine in the region.
K'iche ethno-linguistic group <sup>a</sup> (n=221, 37%)	Believes there is a difference between COVID-19 and childhood vaccines (n=134, 22%)	

<sup>a</sup>Of the respondents, 188 (31%) and 182 (30%) were of the Tz'utujil and Kaqchikel ethno-linguistic groups, respectively.

<sup>b</sup>Those who responded being moderately to very worried

<sup>c</sup>The respondents who rejected the COVID-19 vaccine due to the belief that COVID-19 was not a serious illness were more likely to have no formal education (p-value<0.001)

<sup>d</sup>Comparison of proportion of having none to low levels of trust

<sup>e</sup>Such as health posts and health centers

## Semi-structured Interviews

Seventeen semi-structured interviews were held with key actors mapped through a 'snowball' sampling methodology with representation from two sectors that influence health decisions at the community level – community leaders or authorities (N=9) and health providers (N=8) encompassing traditional healers, midwives, and healthcare workers. Community leaders and authorities refer to a supra-communal governance structure that coordinates local, village-level authorities. Some of these organizations have existed since the colonial period; others have been constituted or reconstituted after the armed conflict ended in 1996<sup>4</sup>. Traditional healers refer to local traditional health providers who currently treat patients but not necessarily exercise community leadership. Interviewees were representative of the three ethnolinguistic groups.

Key learnings from the interviews were:

- All interviewees recognized the efforts and diverse strategies employed by the formal health sector to increase vaccination uptake; however, only 73% of interviewees considered the strategies effective.
- All interviewees mentioned that the community members prioritize treatment with medicinal plants over 'chemical' (modern biomedical) treatments, as many individuals distrust vaccines.
- Traditional leaders self-reported deeper engagement with community healthcare workers in the promotion of vaccination as compared to traditional healers, and about 80% of them reported having participated formally or informally in vaccine promotion efforts.
- Only 35% of the traditional healers reported vaccination acceptance and participated in vaccination promotion with the formal health sector.
- For 71% of both traditional leaders and healers, health system mistrust was considered a key reason (N=12) for vaccination hesitancy among the general population, and 89% (N=15) did not consider the governmental vaccine distribution strategy to be linguistically and socially adequate to the indigenous context.

The TD research team noted that the Sputnik COVID-19 vaccine was the first brand available for distribution in the territory. The region is prone to have high rates of immigration to the United States. Various discussions led to the understanding that community members may not have wanted to become vaccinated over fears of subsequently not being allowed to enter the US - local media clearly communicated Sputnik was not recognized by US immigration authorities as valid vaccination. This generated greater rejection as it was perceived as a State imposition rather than a Covid-19 pandemic containment strategy.



4. Sieder R. Indigenous sovereignties in Guatemala: between criminalization and revitalization. *NACLA Report on the Americas*. 2017;49(3):370-2.

### 3. Six-step, Pluri-epistemic Data Analysis

The data was reconstituted by the TD team through integrating both quantitative and qualitative main findings with a contextualized and holistic overview. The “Knowledge translation” (KT) concept of the Canadian Institutes for Health Research was applied and undertaken with local leaders who were interviewed and primary healthcare workers of the municipalities where data was collected<sup>5</sup>. Table 2 contains the main findings by theme.

#### What is the Knowledge Translation concept of the Canadian Institutes for Health Research?

This process includes knowledge dissemination and communication in a two-way exchange between researchers and those who apply knowledge and develop guidelines or further actions<sup>6,7</sup>.

**Table 2. Summary of historical, cultural-linguistic, and contextual determinants of vaccine hesitancy in Sololá**

Historical Aspects	Cultural-Linguistic Aspects	Contextual Aspects
<p>Local mistrust in the government and health system, as a direct consequence of the 36-year Civil War<sup>a</sup>.</p> <p>Distrust increased due to:</p> <ul style="list-style-type: none"> <li>• Government being sole provider of the COVID-19 vaccine</li> <li>• Inappropriate linguistic and social vaccine information strategy at the primary healthcare level</li> <li>• Lack of health system infrastructure, medicines, human resources</li> </ul>	<p>Information is not properly transmitted (only in Spanish where the communities are mostly monolingual in one of three local indigenous languages).</p> <p>Elders and women are the main child caregivers and influence health decision-making in the household.</p>	<p>Public rejection of COVID-19 vaccine by influential religious leaders along with misinformation in social networks was pointed out by community researchers during the data analysis as important factors that determine the willingness of the population to get vaccinated against COVID-19.</p>

<sup>a</sup>Occurred during the 1980s and 1990s and was focused primarily on indigenous territories

Five knowledge dissemination meetings were held in a systematized way - two with local leaders (midwives, President, and members of the Community Councils for Urban and Rural Development [COCODE]) and three with healthcare workers (nurses, Director of the Municipality Health District, auxiliary nurses, social worker) that had been interviewed.

5. Tetroe J. Knowledge translation at the Canadian Institutes of Health Research: a primer. Focus Technical Brief. 2007;18:1-8.

6. Straus SE, Tetroe J, Graham I. Defining knowledge translation. Cmaj. 2009;181(3-4):165-8.

7. Wensing M, Grol R. Knowledge translation in health: how implementation science could contribute more. BMC medicine. 2019;17(1):1-6.

A thematic analysis was conducted from discussion notes to identify emerging main themes, which were:



#### Local leaders:

- Need for information provided to the community around the benefits of vaccination and the differences among the various available vaccine options.
- Lack of medicine and human resources in healthcare facilities, leading the community to prefer private services.



#### Healthcare Workers:

- Lack of recognition of the work performed by the health sector (e.g., theater plays to portray the vaccination process, TV and radio shows).
- Recognition of community mistrust in healthcare services due to lack of resources and overburden of workload.

## 4. Creating a Road-Map for Knowledge Translation into Action

Results of the National Rapid Ethnographic Assessment of Influencing Factors in COVID-19 Vaccination, commissioned by the MoH and the Pan-American Health Organization (PAHO) were presented and discussed<sup>8</sup>. Participants were divided into the following four, inter-sectoral working groups to discuss and propose an action plan to be executed in the following 6 months:

- Accessibility barriers,
- Education and Communication,
- Research, and
- Intercultural processes.

Progress of the working groups was meant to be presented in monthly meetings chaired by the Health Commission of Sololá (CODESAL) and documented by the research team, from June 2022 onwards. Unfortunately, the MoH cancelled the TD inter-sectoral table working groups after two meetings due to lack of greater institutional commitment and misalignment of priorities amongst the stakeholders.

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8. Berger-González M, Fortín, I., Mazariegos, L., Wagner, C., Monterroso, C., Da Costa, D., Ochaita, D., González, I., Pacheco, G. and D. Solares. Evaluación Etnográfica Rápida sobre Factores que Influyen en la Vacunación contra COVID-19. Evaluación comisionada dentro del marco del Plan Nacional de Vacunación contra COVID-19 y la campaña de vacunación del Ministerio de Salud Pública y Asistencia Social de Guatemala.: Laboratorio Etnografico; 2021.

Research results were presented to the Health Area Directorate of Sololá and their healthcare team only. Following the meeting, they shared their research and information gaps regarding immunization, which focused mainly on child immunization programs. Even though the intersectoral table halted presentations to its members to prevent further criticism from local communities opposing emphasis on pushing vaccination, it contributed to strengthening the relationship between UVG, community researchers, and the Health Area Directorate of Sololá. In view of a new 'preparedness and response' program planned for 2023 in the region by PAHO (especially in view of a growing fear around avian influenza), the research team will present project results as a contribution towards the do's and don'ts for future pandemic preparedness efforts.



# INFORMING COMMUNITY ACTION

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## Policy

- Acknowledge and address the historical, cultural, and contextual factors that lead to community mistrust in the healthcare system, as they continue to have an impact on health service coverage and uptake amongst indigenous populations.
- Invest in and prioritize multisectoral stakeholder advisory groups (e.g., community leaders, healthcare workers, researchers) to address further healthcare challenges in a joint, horizontal, and egalitarian manner.

## Program

- Integrate community participatory approaches that enable epistemological co-constructions of healthcare solutions for communities, which reconsiders the boundaries of current practices and allows for the possibilities of advancement of more democratically selected and sustainable practices (e.g., the TD team building method).

## Practice

- Support the integration of civil society members and researchers to address information gaps existing in local communities caused by cultural-linguistic barriers.

# RESEARCH LEADS

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## Monica Berger González, PhD, MPH

Director, Unit of Medical Anthropology in the Center for Health Studies, Universidad del Valle de Guatemala

Mónica Berger González is a sociocultural anthropologist graduated from Universidad del Valle de Guatemala, with a PhD in Science from the ETH Zurich, Switzerland. She directs the Unit of Medical Anthropology at the Center for Health Studies in Universidad del Valle de Guatemala and is an associate researcher at the Swiss Tropical and Public Health Institute in Basel University, Switzerland. She has over 20 years experience in research for development in topics related to environmental anthropology, One Health approaches, Maya ethnomedicine and ethnobotany, intercultural transdisciplinarity for public health interventions.



## Daniela Da Costa, MBCh.B, MPH

Researcher Guest, Unit of Medical Anthropology, Universidad del Valle de Guatemala

Daniela Da Costa is a young early-career researchers from Guatemala. She has a Masters in social-epidemiology from University College London (2019-2020), with a strong background on surveillance systems and health implementation at primary healthcare. She has worked with surveillance systems for the COVID-19 response; digital health implementation; health promotion interventions with a culturally pertinent and transdisciplinary approach; behaviour health analysis through the adherence to preventive and mitigation measures of COVID-19 and COVID-19 vaccination. She also has experience in medical entomology, mainly with malaria vectors understanding the development of insecticide resistance, mosquito rearing, and freshwater entomology monitoring systems. In 2021 she collaborated in the "Rapid Ethnographic Assessment of Factors Influencing Vaccination against COVID-19", a nationwide cross-sectional survey commissioned by the Ministry of Health and the Pan-American Health Organization aimed to inform the COVID-19 vaccine promotion campaign. Daniela is currently a researcher guest of the Unit of Medical Anthropology, of the Center for Health Studies in Guatemala, and part of the Institute of Inclusive Health. Her main interest is to contribute to build the most appropriate surveillance systems for resource limited settings and transfer the necessary skills to healthcare workers to promote evidence based decisions.

# RESEARCH LEADS

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## Daniela Ochaíta

### Junior Associate Researcher, Unit of Medical Anthropology, Universidad del Valle de Guatemala

Daniela Ochaíta is a junior associate researcher at the Unit of Medical Anthropology at Universidad del Valle de Guatemala (UVG). She has studied sociocultural anthropology at UVG and Development Policies and Practices at the Graduate Institute of Development Studies in Geneva. Her work focuses on primary healthcare systems in intercultural contexts. She has worked in Guatemala, Honduras, and Costa Rica conducting qualitative research. She has been part of inter and transdisciplinary research teams addressing accessibility barriers to health with vulnerable populations, especially indigenous communities of Guatemala. Additionally, she has coordinated communication and health promotion strategies in intercultural contexts, as well as implementation, monitoring, and evaluation of public health projects, focused on vaccination against Covid-19, rabies, maternal and child health, and chronic non-communicable diseases. Her goal is to contribute to universal health coverage under pertinent and transdisciplinary approaches.

CASE STUDY FROM INDIA, SANGATH

# STRUCTURAL INEQUITIES IN COVID-19 VACCINE ACCESS AND UPTAKE AMONG TRANSGENDER AND DISABILITY COMMUNITIES IN INDIA:

A qualitative study through intersectionality lens



The pilot project was conducted in India between January and December 2022. It was implemented by Sangath, with funding from the Sabin Vaccine Institute. The project received ethics approval from the Sangath Institutional Review Board and permission obtained from the Delhi State Committee for Research on Disabilities (SCRD) as per local regulatory requirements. Investigators: Dr. Anant Bhan, Dr. Sunita Bandewar, Dr. Aqsa Sheikh, and Dr. Satendra Singh.

## KEY TAKEAWAYS

- Community-based participatory research (CBPR) methods seek to address the asymmetrical relationship between the 'researcher' and the 'researched' by centering equitable involvement of those most impacted by the research topic in the research process;
- There is a historical neglect of marginalized communities, a lack information on COVID-19 vaccines' intersection with unique healthcare needs, and infrastructural and procedural barriers in vaccine programs, which impeded access;
- Trust in vaccines plays a large role in the vaccination decision-making process amongst the transgender community and people living with disabilities; and
- The photovoice stories (PVS) point toward ongoing inequities rooted in government and health systems, which negatively impact COVID-19 vaccine access and uptake for marginalized communities.

## IN CONTEXT

Marginalized communities, such as people with disabilities and transgender individuals, face higher risk of infection with and mortality due to COVID-19 while also facing considerable challenges in accessing COVID-19 vaccines due to inaccessible health facilities, lack of affordability, and lack of availability<sup>(1-6)</sup>. In response, activists from both the disability and transgender communities in India have raised voices and courts have intervened<sup>(7-10)</sup>.

As a result, state and district initiatives in different states have created separate vaccination provisions (e.g., separate counters, awareness programs, and home vaccination initiatives for persons with disabilities in Tamil Nadu), but there has been low demand, suggesting lower vaccine confidence<sup>(11)</sup>. However, this should be viewed in the context of the historical marginalization and experiences of exclusion of these communities in the health system, which the COVID-19 pandemic has exacerbated<sup>(3,12,13)</sup>. A large segment of the existing scholarship in this field has a narrow framing of 'vaccine hesitancy' with focus at the individual level and viewing it as a behavioral and attitudinal issue, such as mistrust in the safety/reliability of the vaccine, lack of information about the impact of vaccine, accessibility to information, and

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10. Chandrababu D. Prioritise vaccination for the disabled, high court tells TN. Hindustan Times [Internet]. 2021 Apr 20 [cited 2021 Jun 29]
11. Premkumar R. Vaccine hesitancy slowing efforts to inoculate differently-abled. The Hindu [Internet]. 2021 Jun 27 [cited 2021 Jul 15]
12. Chowdhary P. Less than 4% vaccinated – Transgender Indians have been 'othered' by vaccines and forms. The Print [Internet]. 2021 May 16.
13. Pandya A, Redcay A. Access to health services: Barriers faced by the transgender population in India. J Gay Lesbian Ment Health [Internet]. 2020 Dec 14;1–26.

physical access to vaccination centers<sup>(14)</sup>. There is little scholarship looking at it structurally through the lens of equity and intersectionality, incorporating wider issues such as trust deficit in the public health system, embedded stigma, and exclusion both in practice and clinical trials, which often exclude marginalized communities<sup>(4,15)</sup>.

## APPROACH

Recognizing the significant barriers to everyday life and health access that members of the transgender and disability community face, the investigators studied how COVID-19 vaccine access and uptake is shaped by historical and entrenched structural inequities that affect both of these communities in India. The theoretical approach to this study was informed by the social-ecological model (SEM) and intersectionality. Using a community-based participatory research (CBPR) approach, the team made several key decisions to ensure the study was co-designed and co-led by members of the transgender and disability communities, such as:

- Including co-investigators from each of the two communities,
- Recruiting research assistants from both communities,
- Conducting a series of participatory workshops, and
- Establishing an advisory board which included members from both communities.

Specifically, the community workshops and advisory board provided input on various aspects of the project, including: data collection instruments (e.g.; interview guide), participant recruitment and sampling strategy, analysis and development of preliminary themes, and strategies for dissemination.

### What is a community-based participatory research approach?

CBPR seeks to address the asymmetrical relationship between the 'researcher' and the 'researched' by centering equitable involvement of those most impacted by the research topic in the research process. The main benefit of CBPR is that results both come directly from and go directly back to individuals impacted. The level of community immersion varies from collecting data directly by community members to community members being involved in the research team. This process allows for the building of partnerships and trust with communities and provides mechanisms for incorporating lived experience and knowledge of communities in the research process<sup>1</sup>.

To achieve their aims and objectives, the team conducted both in-depth interviews (IDIs) with community representatives and key informant interviews (KIIs) with stakeholders in vaccine delivery in India and collected photovoice stories (PVS) from community members.

14. Hrynck T, Ripoll S, Schmidt-Sane M. Rapid Review: Vaccine Hesitancy and Building Confidence in COVID-19 Vaccination. SSHAP [Internet]. 2020

15. Swenor BK. Including disability in all health equity efforts: an urgent call to action. *Lancet Public Heal* [Internet]. 2021 Jun 1;6(6):e359–60.

16. Israel BA, et al. *Methods in Community-Based Participatory Research for Health* [Internet]. 1st ed. Hoboken, USA: John Wiley & Sons, Incorporated; 2005.

## What are photovoice stories?

The PVS method is a participatory research method through which community members represent and advocate for their needs using the medium of photographs as a way to discuss, reflect, capture, and share their lived experiences. Using PVS in conjunction with other research methods provides a participant-driven entry point into understanding the needs of communities and attempts to reduce power differences between research and participants. PVS can be a useful tool for communicating and advocating for community demands with gatekeepers.

## IMPLEMENTATION STAGES

### Interviews

The research team conducted a total of 41 interviews: 24 IDIs with community members and 12 KIs with stakeholders in vaccine delivery in India. Five interviewees qualified as both a community representative as well as a key stakeholder in vaccine delivery and discussed both perspectives (e.g., a vaccine advocate who is a parent of a child with a disability).

Interviews were conducted using an evolving interview guide virtually over Zoom or other preferred platforms, such as WhatsApp or voice calls. Interviews were recorded, transcribed verbatim, and translated (from Indian languages such as Marathi, Telugu, Hindi to English) where required. Researchers implemented an inductive thematic analysis approach using elements of the grounded theory method for coding and analysis. Adopting this approach created space to engage with the incoming data from the start and shape the subsequent data collection using insights gathered from the completed interviews.. This helped unravel complex relationships amongst various dimensions or determinants of access to COVID-19 vaccination among the two communities.

### In-depth Interviews

IDI participants were self-identifying as transgender or as a person with disability (as per the Rights of Persons with Disabilities Act, 2016), 18 years and older, and a resident of India. Of the 24 IDIs conducted:

- 11 were representatives from the transgender community and included transmen, transwomen, genderqueer people, non-binary people, agender persons, and people from the kinnar community (an ethnocultural community in India, consisting of transgender persons with distinctive practices and kinship structures);
- 12 were among the disability community and included people with physical disabilities, sensory disabilities, intellectual disabilities, psychosocial disabilities, blood disorders, and multiple disabilities; and
- One was with a transman with disability.

## Key Informant Interviews

Key stakeholders were purposively selected to be interviewed based on stakeholder mapping and emerging data from KIIs. Participants were vaccine advocates, program managers, and providers; and media professionals. Of the 12 KIIs, five were with health system representatives, six with civil society members, and one with a journalist. These stakeholders provided insight into the vaccination roll-out and specific initiatives for the two communities.

## Key Themes from IDIs and KIIs

Interviews were conducted with representatives from 19 of the 28 states in India; and interviewees were from diverse religions (Hindu, Muslim, Parsi), marginalized castes, and other identity-based intersectionalities. The majority of the participants were vaccinated with two COVID-19 doses. Key themes from IDIs and KIIs can be found within Table 1.

**Table 1: Key themes from the IDIs and KIIs**

Theme	Explanation
<b>Neglect</b>	Historical neglect of marginalized communities emerged as a structural issue that shapes vaccine attitudes, access, and uptake. In many cases, vaccine attitudes were a response to structural and historical marginalization within health and socio-economic systems.
<b>Information on vaccines and its intersection with unique healthcare needs</b>	Participants had questions about the interaction of the vaccines with their specific healthcare needs, which caused contemplation, confusion, and fear: <ul style="list-style-type: none"><li>• For the transgender community, this was related to gender affirmative therapies such as hormone replacement therapy and anti-retroviral therapy.</li><li>• For the disability community, the unique healthcare needs were related to their disability itself, as well as other comorbidities.</li></ul> The challenge of clarifying these unique concerns was also linked to a larger structural barrier of access to information around their health needs.
<b>Infrastructural and procedural barriers in vaccine programs</b>	The design of vaccination programs impeded access to vaccines for the two communities: <ul style="list-style-type: none"><li>• For the transgender communities, this included aspects such as lack of acceptance of gender discordant identification cards and gender segregation in the binary of male and female within vaccination and quarantine centers.</li><li>• For the disability community, this emerged as lack of physical accessibility to vaccination centers (e.g., no wheelchair ramp) and difficulty in accessing the mobile application for vaccination registration, etc.</li></ul> These challenges were not limited to vaccination centers, but are present across the health system, serving as structural barriers.
<b>Trust</b>	Trust in vaccines emerged to be a central influence on participants' motivation and decision-making around and uptake of the COVID-19 vaccine. Trust in vaccines is related to trust at several levels, such as the healthcare system, the pharmaceutical industry, scientific bodies, and even the government's intentions.



## Photovoice Stories

Participants for PVS were recruited from the personal networks of the project team and extended networks across different geographies to ensure diversity and intersectionality. Participants were at least 18 years of age, self-identified as belonging to the transgender and/or disability community, and currently a resident of India.

Twenty recruitments – 11 people from the transgender community and nine people living with disabilities - received a project orientation, including its method; and were trained in basic photography and ethics in photography like safety and consent taking. Participants were asked to reflect on vaccination and healthcare related issues that they would like to capture in this project. Post-orientation, eight participants proceeded with the project (three persons from the trans community and five from the disability community). Attrition was linked to participant time constraints and interest.

The active participants hailed from eight states in the country spread across north, central, and south India; and included the following people:

- Transmen
- Nonbinary persons
- Wheelchair users
- Amputees
- Acid Attack Survivors
- Persons with visual impairment
- Persons with intellectual disability

The researchers conducted a series of sessions virtually through Zoom, using PowerPoint, activities, and discussions. The aim of these sessions was to:

1. Orient participants to the project and PVS,
2. Encourage them to reflect on their healthcare and vaccination experiences,
3. Train them on basic smartphone photography techniques and ethical considerations in PVS, and
4. Discuss each participant's photographs and support the participants in writing their own narratives and self-descriptions to accompany the photographs and provide added context.

Consent was received for disseminating the stories for advocacy.

### Examples of Photovoice Stories:

**"After a long fight and self-advocacy, I got my booster dose of vaccination at home."**

- Abha, a wheelchair user from New Delhi

Her photos represented her experience of fighting a long battle with the local systems involved in the delivery of home vaccinations. Her experience highlighted systemic barriers of accessing healthcare in India and how persistent advocacy and demanding local authorities for home vaccinations for persons with disabilities led her to finally getting home vaccination.



“I wanted to be in the ‘Male’ section of the line outside the vaccination center, but I couldn’t do that as my documents were not updated. I was also fearful of my identity being disclosed and how people would react to that.”

- Nikunj, a transman belonging to a rural area of Central India

He reflected on his experience of systemic barriers relating to gender norms while accessing healthcare and vaccination. Free ration and quarantine centers, etc., were provided to economically weaker sections via ration cards (issued by state governments and including markers of identity and economic status), but many transgender people were not able to access free ration due to gender discordant documentation, quarantine centers, etc., which made the COVID-19 pandemic very challenging for transgender individuals. Nikunj spoke about the lack of awareness of issues faced by transgender persons in hospitals and the society at large.



### Key Themes from Photovoice Stories (PVS)

Key themes from the PVS can be found in Table 2. Overall, the PVS point toward ongoing inequities rooted in government and health systems, which negatively impact COVID-19 vaccine access and uptake for marginalized communities.

Theme	Explanation
<b>Navigating vaccine anxiety</b>	<p>COVID-19 vaccination behavior and decision-making were influenced by anxieties around, 1) being more vulnerable to the virus due to health and social disparities, or 2) potential side effects of taking the vaccine. Examples are as follows:</p> <ul style="list-style-type: none"> <li>• Individuals who acquired disabilities from lack of childhood vaccination (e.g., polio) felt the necessity to take the vaccine.</li> <li>• Participants who had some willingness to take the vaccine but also had anxiety about its impact, consulted community members, gender affirmative or disabled-friendly health professionals, and their families.</li> </ul>
<b>Inaccessible vaccination process</b>	<p>Participants portrayed inaccessibility across the vaccination process:</p> <ul style="list-style-type: none"> <li>• Vaccination scheduling portal;</li> <li>• Mandatory documentation;</li> <li>• Transportation inaccessibility and hard-to-reach centers due to long distances;</li> <li>• Lack of (wheelchair-friendly) ramps and benches and long queues created difficulty in navigating centers for persons with disabilities; and</li> <li>• Overcrowding at health centers without following social distancing guidelines, which resulted in wheelchair users, who navigate spaces at a lower altitude, being more susceptible to the infections.</li> </ul>

Theme	Explanation
<b>Challenges with vaccination providers</b>	<p>Participants narrated a range of challenges with vaccination center staff:</p> <ul style="list-style-type: none"> <li>• A transman shared that he waited long hours and made multiple visits to the facility, due to being refused vaccination on many occasions, because of his identity.</li> <li>• A person with a disability discussed the negligent conduct of a provider who hugged her and took a picture with her, putting her at a greater risk of Covid-19 infection.</li> </ul> <p>Participants echoed the need for transgender- and disability-sensitive health providers, with one woman with intellectual disability emphasizing how the presence of female doctors would be beneficial for the intersectionality of her identities.</p>
<b>Lack of prioritization of the communities in planning</b>	<p>Participants highlighted the lack of consideration for and prioritization of their unique vulnerabilities:</p> <ul style="list-style-type: none"> <li>• Lack of home vaccinations for persons with disabilities curtailed their vaccine reach due to inaccessibility of transport facilities and vaccine centers.</li> <li>• Practices like binary segregation at the center delayed vaccine-uptake, as it created a fear of being 'outed' and mistreated.</li> </ul>



# INFORMING COMMUNITY ACTION

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## Policy

- Sensitize government, health, and immunization officials to the needs of the disability and transgender communities and view them as priority populations, catering to them through an intersectional rights-based and equity-focused approach in policy, planning, and implementation.
- Make vaccination registration procedures, such as online portals, universally accessible by removing inaccessible features (e.g., timer systems and visual impairment-unfriendly screens).
- Remove mandatory requirements of identity cards for vaccination access, as many trans individuals do not have gender-concordant identity cards.

## Program

- Create affirmative practitioners through sensitizing vaccine providers and other staff members on transgender and disability issues to create awareness on community-specific needs.
- Increase professional representation from the two communities within vaccination centers to build confidence amongst the communities and drive access.
- Develop protocols for adverse post-vaccination events specific to the two communities.
- Endorse home vaccination, setting up dedicated vaccination camps near the communities and in community affirmative clinics through collaboration with communities' leaders and community-based NGOs.
- Make vaccination centers mobility-friendly, ensuring low arousal sensory environments and avoid overcrowding.

## Practice

- Create accessible public health communication through using sign language interpreters, braille, subtitles, easy-to-read text; and employing multiple media, including far-reaching media like radio, helplines, etc.
- Engage with communities directly through community leaders and community-based organizations, especially in ethnocultural communities, like the kinnar community.

# RESEARCH LEADS

## Investigators



**Dr. Anant Bhan, MBBS, PGDMLE, MHSc**

**Mentor & Investigator, Sangath Bhopal Hub**

Anant Bhan, MBBS, MHSc, is a researcher in global health, health policy, bioethics and mental health with over 22 years of experience. Trained as a medical doctor from India and in bioethics from the University of Toronto, Anant currently leads/co-leads several research projects in the areas of global mental health, health equity, participatory research and community engagement at the Bhopal Hub of Sangath, a public health research organization. In addition, Anant serves in several committees and teaches bioethics as Adjunct Professor in Yenepoya (deemed to be University). His work is focused on ethics and equity in health, mental health, digital health, public health ethics, research ethics, community engagement, ethics of innovative technologies and ethics training for professionals. Anant is also very active in engaging with news media and social media.



**Dr. Sunita Bandewar, PhD, MHSc**

**Director, Health Ethics and Law Institute, Forum for Medical Ethics and Society**

Sunita Bandewar has training in Anthropology (PhD, University of Pune) and Bioethics (MHSc, University of Toronto). Her engagement with health as a field of enquiry over these past 30 years has been primarily via empirical research in health and allied thematic; training and capacity strengthening in bioethics, human rights, and research; and legal and policy level advocacy in the broader domains of health and bioethics. Women and health, global health, public policy, medical education, and gender-based violence, community engagement, prison health, pandemics, AI (artificial intelligence) based and digital technologies in health, program monitoring and evaluation, palliative care, quality of care have been some of her thematic of engagement. Sunita is currently working with the Forum for Medical Ethics Society (FMES), Mumbai, and is one of the founding trustees of Vidhayak Trust in Pune, India.



## Dr. Aqsa Shaikh, MBBS, MD

Dr. Aqsa Shaikh (She/Her) is Associate Professor of Community Medicine, Hamdard Institute of Medical Sciences and Research, Jamia Hamdard, Delhi and an out and proud trans woman. Beyond an academican she is also a health activist working on inclusion and equity for the transgender community, persons with disability and persons with mental illness. She is India's only Transgender Nodal Officer of a Covid-19 Vaccination Centre and is one of India's First Transgender Doctors. She is also Founder Director of Human Solidarity Foundation. Aqsa successfully petitioned Delhi Commission for protection of child rights to pass orders on banning unnecessary sex normalizing surgeries on intersex children. Dr. Shaikh also serves as Section Editor of PLOS Global Public Health.



## Dr. Satendra Singh, MBBS, MD

A Professor of Physiology at University College of Medical Sciences, Delhi, and a prominent disability rights activist, Satendra Singh brings extensive experience in disability research. He successfully advocated the National Medical Commission to incorporate seven hours of disability rights as disability competencies in the new medical curriculum and persuaded MCI to pass a directive to all medical colleges in India to be disabled-friendly. He is part of important think tanks like Core Group on disability at National Human Rights Commission, advisor to Delhi state commissioner for PwDs, and Delhi State Committee of Research on Disability.

# RESEARCH LEADS

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## Investigators



### Bhakti Ghatole, BA, MA

Bhakti is a psychologist with a Master's from Tata Institute of Social Sciences, Mumbai. She brings 3 years of experience in counselling and research and is a person with visual impairment.



### Deepak Tugnawat, BPT, PGDPHM, MSW

Deepak's academic training is in social work, Public Health Management (IIPH), and Physiotherapy. He has worked in a clinical setting and public health domain for last 10 years with a focus on the management of stroke patients and children with neurodevelopmental disorders, digital training interventions, and implementation research. Deepak brings the experience of leading many clinical trials and working with the health system.

# RESEARCH LEADS

## Investigators



### **Gaurav Prateek, BA, MA**

Gaurav Prateek is an independent researcher passionate about working with the LGBTQIA+ community, creating awareness, and sensitizing people towards issues related to gender and sexuality. He completed his M.A. in Mass Communication (2019-22) from AJK Mass Communication and Research Center from Jamia Millia Islamia, New Delhi, specializing in Film Studies & Production. His research interests revolve around film, photography and cultural studies, queer narratives, gender and sexuality studies, and studies of diaspora.



### **Dr. Harikeerthan Raghuram, MBBS, PGDFM, MSc.**

Harikeerthan is a medical graduate from Christian Medical College Vellore with a Master's in Health and International Development from London School of Economics and Political Science and a Wellcome Trust Masters Scholar. Having worked on the intersections of clinical medicine, public health, and mental health with a focus on health equity, he brings six years of experience in conducting research, advocacy, and implementation projects.



### **Neeharika Venuturupalli, pursuing BA**

Neeharika Venuturupalli is a third-year student at the University of Chicago studying Comparative Human Development and Data Science. She worked with the Sangath iHEAR team in Bhopal over the summer of 2022 and aided in projects including VaccinEquity and Queer Ambassadors.



### **Sharin D'souza, BA, MA**

Sharin (They/She) is a psychologist trained at the University of Delhi, North Campus. They bring more than two years of experience in research, writing, and implementation projects. They are a non-binary person interested in research at the intersection of marginalization and health equity in the Indian context.



### **Shreyus Sukhija, BA**

Shreyus (They/Them) has graduated with a bachelor's in Psychology from University of Delhi. They have been working with IHEAR since July 2022 and are interested in capacity building and working with the LGBTQIA+ community.



### **Sushil Kumar, BA**

Sushil is a filmmaker, also an active member of Ektara Collective. He has worked across fiction and non-fiction genres and further across formats – feature and short film, video documentation, and documentary. His engagement with activism played a profound role in shaping the understanding of socio-political realities and has nurtured sensitivity towards the issues posed by them.

CASE STUDY FROM THAILAND

# COVID-19 VACCINATION AND PEOPLE LIVING WITH HIV IN THAILAND



This project was conducted between November 2021 and December 2022 with participants recruited from diverse locations across Thailand. It was implemented by Adam's Love Global Foundation for MSM and Transgender Health (ALGO), with funding from the Sabin Vaccine Institute. The project received ethics approval from the Institutional Review Board (IRB) of the Central Research Ethics Committee (CREC)'s Social and Behavioral Research Panel, Thailand. Investigators: Chattiya Nitpolprasert and Tarandeep Anand.



## KEY TAKEAWAYS

- COVID-19 vaccination should be integrated with HIV care services to increase uptake among people living with HIV (PLHIV);
- Prioritize PLHIV in national COVID-19 vaccination programs; and
- Ensure stigma-free vaccination service delivery to protect PLHIV from inadvertent HIV disclosure.

## HISTORICAL CONTEXT

Since the first case of HIV was detected in Thailand in 1985, the country has made strides in addressing the epidemic and caring for those affected. In 2006, Thailand integrated HIV services including antiretroviral therapy (ART) into its universal health coverage schemes. In 2014, ART became freely available for all diagnosed with HIV, regardless of CD4 count thresholds<sup>1</sup>. Yet despite this, the HIV epidemic in Thailand remains particularly acute in key populations. In 2018, Thailand reported adult HIV prevalence at 1.1%, among the highest in the region, with prevalence rates of 11.9% for men who have sex with men and 11% for transgender people<sup>2</sup>. Even though as HIV testing and treatment are free for all Thai citizens, there remains low uptake of HIV testing and treatment among MSM and transgender women largely due to stigma and discrimination<sup>3</sup>. There is evidence to suggest that integrating HIV treatment and care with other services may decrease stigmatization.

In communities with PLHIV, especially groups that are high-risk for contracting COVID-19 and stigmatized, including MSM and transgender women (TGW), have been left out in the design of COVID-19 vaccination rollout in Thailand and globally, leading to multiple challenges related to vaccine information, availability, access, and linkage to care for these communities. This study aimed to unpack these challenges and fill an urgent need for research and data to inform public policy and the prioritization of PLHIV for COVID-19 vaccine access in Thailand.

## APPROACH

The team at Adam's Love Global Foundation for Men who have Sex with Men (MSM) and Transgender Health (ALGO) sought to fill a gap in understanding around COVID-19 vaccination among particularly marginalized people living with HIV (PLHIV) in Thailand: MSM and transgender persons. Using a sequential exploratory research design, the team investigated the following amongst this population:

- What are the COVID-19-related vaccine informational needs?
- What are the COVID-19 vaccine seeking patterns and decision-making?
- What are the challenges and barriers - including psychosocial and related determinants - of COVID-19 vaccine uptake?

1. [https://www.unaids.org/en/resources/presscentre/featurestories/2020/january/20200117\\_thailand](https://www.unaids.org/en/resources/presscentre/featurestories/2020/january/20200117_thailand)

2. [https://www.unaids.org/sites/default/files/media\\_asset/2019-UNAIDS-data\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/2019-UNAIDS-data_en.pdf)

3. <https://blogs.worldbank.org/eastasiapacific/how-increase-hiv-testing-and-treatment-bangkok-high-risk-groups>

## What is a sequential exploratory research design?

Mixed methods studies involve both qualitative and quantitative methods, and there are multiple, different research designs that incorporate both methodological approaches. One of these designs is an exploratory sequential research design wherein qualitative data is collected and analyzed, such as from in-depth interviews or focus group discussions, and then those data are used to inform the development of quantitative data collection instruments, such as surveys. This design is useful for exploring a phenomenon by utilizing the quantitative data to help interpret the qualitative findings.<sup>1</sup>

The qualitative phase of the study involved two data collection methods:

- In-depth interviews (IDIs) with 42 MSM living with HIV across the country, covering the “red zone” provinces with the highest COVID-19 infection rates; and
- Focus group discussions (FGDs) with healthcare providers and HIV care providers.

As befits the sequential exploratory design, the qualitative analysis was used to develop a preliminary framework for the quantitative survey, which was deployed amongst 240 MSM in the subsequent study phase.

## IMPLEMENTATION STAGES

### Qualitative Phase

A semi-structured interview guide for the IDIs was developed to cover topics related to COVID-19 vaccination including acceptance, hesitancy, decision-making, and determinants. Participants were identified and recruited through the ALGO team’s online networks, and the IDIs were conducted either via telephone or in-person at HIV clinics affiliated with ALGO.

In collaboration with provincial level hospitals and tertiary hospitals for HIV care, the research team visited affiliated centers including ART referral hospitals, antiretroviral (ARV) clinics, acute respiratory infection (ARI) clinics, and local/municipal COVID-19 vaccine inoculation centers to conduct IDIs and FGDs with 50 care providers and community groups across 15 of these sites.

All IDIs and FGDs were audio-recorded with participants’ permission. Following transcription and translation from Thai to English, the team created codes and patterns to organize and manage interview conversations and FGDs. Data analysis focused on the examination of the interpretative patterns identified through participants’ willingness to receive and experiences in accessing the COVID-19 vaccine. The team further refined and completed the quantitative survey tool using the patterns, categories, and quotes derived from the qualitative findings.

4. Clark VL. *The mixed methods reader*. Sage; 2008.

## Quantitative Phase

With the quantitative survey questionnaire informed by the preliminary qualitative data analysis and finalized, the team worked with the healthcare and HIV providers - who participated in the IDIs and FGDs at the affiliated centers - to recruit PLHIV for the survey. Recruitment occurred during regular clinic visits for PLHIV, which helped to ensure trust and confidence among participants in the study. Of 324 potential participants contacted, 240 agreed to participate.

The survey was administered through both offline and online channels (60% vs 40%, respectively), based on participant preference. The offline survey was administered at specified hours and days, based on the ART dispensing schedule in each province. Ten to 15 survey slots were organized per study team visit to the HIV clinic, with surveys administered by study staff on a one-on-one basis in a separate room/open space to ensure participant privacy.

Due to the complexity of the research and syndemics of COVID-19 and HIV, study coordinators and co-Principal Investigators often had to explain the survey questions on a one-on-one basis to the participants and guide them through completion of the questionnaire to ensure data quality. Qualtrics was used for a self-administered, online questionnaire for those choosing to complete the online survey. These data were merged into one dataset, with chi-squared tests performed to identify associations between the acceptance and hesitancy variables and gender, age, socioeconomic status, and HIV clinical level.

## Preliminary Thematic Findings from Qualitative and Quantitative Work

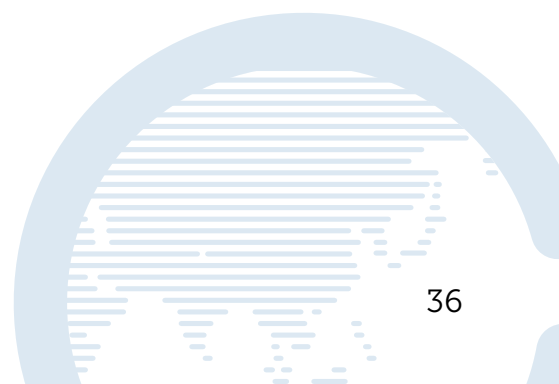
Following data analysis, the ALGO team uncovered important results related to motivations, hesitancy, and other factors influencing COVID-19 vaccine uptake among PLHIV in Thailand. Quantitative survey data confirmed findings from the qualitative phase, as indicated by each theme's corresponding mean. These preliminary findings are presented in Table 1.

**Table 1: Preliminary Themes**

Theme	Quantitative Survey Response on a 5-point scale Mean (standard deviation)
<b>Motivation to accept COVID-19 vaccine</b>	
Participants expressed a desire to prevent themselves and family from contracting COVID-19 as a reason for COVID-19 vaccine uptake.	4.23 (0.80)
HIV care providers are broadly trusted by participants and play a large role in the decision-making process around uptake of COVID-19 vaccine.	4.01 (0.92)
<b>Hesitancy leading to delayed uptake or refusal of COVID-19 vaccine</b>	

Theme	Quantitative Survey Response on a 5-point scale Mean (standard deviation)
Participants considered themselves as immunocompromised and felt it better to receive the vaccine to protect their health.	3.99 (0.99)
<b>Factors influencing COVID-19 vaccination uptake and in the context of living with HIV</b>	
Some participants felt peer pressure from work colleagues and supervisors. Some also reported workplace mandates.	3.00 (1.43)
Participants had concerns around the interaction of COVID-19 vaccine with their HIV antiretroviral (ARV) medicine. This led many participants to consult with their HIV care providers prior to booking their vaccination appointment.	3.55 (1.11)
<b>Perceived stigma and discrimination in COVID-19 vaccine uptake</b>	
Some participants expressed fear of HIV stigma and HIV status disclosure at COVID-19 vaccination centers <sup>a</sup> .	3.23 (1.38)

<sup>a</sup> Note: Few participants feared HIV status disclosure as a result of experiencing side effects or adverse events from the COVID-19 vaccine



# INFORMING COMMUNITY ACTION

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## Policy

- Prioritize PLHIV in national COVID-19 vaccination programs.
- Design strategies and interventions with public health messaging targeting PLHIV.
- Offer anonymous booking to vaccination services through use of technology, such as a QR code.

## Program

- Integrate clinic settings for COVID-19 vaccination and HIV-related services to reduce stigma and fear of disclosing HIV status.
- Increase access to vaccination through setting up COVID-19 vaccination centers that are similar to 'election booths' to ensure privacy and locate them in sub-districts, districts, and provinces.

## Practice

- Train public health staff to be cognizant of and sensitive to HIV stigmatization.
- Ensure stigma-free vaccination service delivery to ensure protection against HIV disclosure and reduce instances of PLHIV experiencing HIV-related stigma.

# RESEARCH LEADS

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## Chattiya Nitpolprasert

### Adam's Love Global Foundation for MSM and Transgender Health (ALGO)

Chattiya Nitpolprasert is a social and behavioral researcher at Adam's Love Global Foundation for MSM (men who have sex with men) and Transgender Health (ALGO), leading in implementing technology-based interventions and conducting behavioral research in HIV prevention and care. Since 2010, Nitpolprasert has successfully harnessed communications technology in engaging hard-to-reach, discreet and closeted MSM and transgender (TG) individuals into early HIV testing and treatment in Southeast and East Asia. She has extensive experience in designing innovative and culturally sensitive strategies to address HIV care, support and counseling needs of key populations living with HIV. She is currently a PhD candidate at the Amsterdam Institute for Global Health and Development (AIGHD), Department of Global Health, Amsterdam University Medical Centers, University of Amsterdam, the Netherlands.



## Tarandeep Anand

### CEO of Adam's Love Global Foundation for MSM and Transgender Health (ALGO)

Tarandeep Anand is the CEO of Adam's Love Global Foundation for MSM and Transgender Health (ALGO). Since 2008, Tarandeep has been a driving force in Asia for implementing technology-based HIV outreach projects and conducting technology-focused HIV prevention, health and behavioral research among key populations in Indonesia, Japan, Malaysia, South Korea, Thailand and Taiwan. Tarandeep's works are widely published in high-impact journals and he has been invited as a plenary speaker to showcase innovative service delivery models at several international platforms, including the International Congress on Drug Therapy in HIV Infection (HIV Glasgow 2016, UK), the European AIDS Conference (EACS 2019 in Basel, Switzerland), the International AIDS Conference (AIDS 2016 in Durban, South Africa), and the Bangkok International Symposium on HIV Medicine.

# ABOUT SABIN



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For more information, visit [sabin.org](https://sabin.org) and follow us on Twitter, [@SabinVaccine](https://twitter.com/SabinVaccine).

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