

UMA, Every Pregnant Woman's Friend: A Case study in Researching and Designing for the Indian Maternal Health

ABSTRACT

In the rural and semi-rural regions of India, maternal deaths from preventable pregnancy complications are still widely recorded. These stem from a lack of accessible information, pregnancy practices that are at odds with modern medicine, and a lack of infrastructure. UMA is a pregnancy service that considers the socio-demographic context of the various pregnancy stakeholders and then engages with them through organic accessible touchpoints. For the pregnant woman and her support system, the service leverages household resources, and practices to inculcate medical adherence, proactive decision-making, and build help-seeking behaviours. For medical personnel, UMA lessens the burden of care and smoothens doctor-patient interactions for increased productivity. This paper covers our enquiry into the maternal care landscape, shares the research, and explains the design intervention.

Keywords: Maternal healthcare, pregnancy, service design, systems, agency, decision-making.

INTRODUCTION

The World Health Organisation defines maternal health as the health of the person through the course of their pregnancy, during childbirth, and the postpartum period [16], while antenatal care, delivery care, and postnatal care are the services that constitute maternal healthcare [16]. It is a sad fact that every year pregnant people lose their lives to preventable pregnancy complications [2] that existing healthcare services can mitigate. A 2021 study of Indian maternal mortality trends places the country's maternal mortality rate at 99/1,00,000 live births – an objective that was outlined in the 2015 millennium development goal [9]. Further, an estimated 1.3 million people have died from maternal causes in the last twenty years, mostly in the country's rural areas [9]. While healthcare innovation and reach of technology have reduced maternal deaths, many people cannot access healthcare facilities or do not know the importance of utilizing available services.

RESEARCH

Our objective was to understand the current maternal landscape and context of the lower-income category (define here people with an income of \$2.01 - \$10 a day) in the rural and peri-urban settings. The research included contributors from 8 different states, who are

engaged in different professions (mostly in the unorganised labour sector) and are at various stages in their pregnancy journey and/or child-rearing.

We began our primary research with pregnant persons and women with children (aged 20-55 years) and their ancillary support systems and a few employers. In the context of this paper, 'ancillary support system' refers to the person's partner and immediate family who inhabit the same space as them and so are affected by the pregnancy. We also engaged with medical professionals and government-appointed community healthcare workers - ASHA and Anganwadi Workers. For more information, see [3,4,7 and 14].

We leveraged a mix of research methods like storytelling, semi-structured interviews, subjective assessments, in-depth interviews, and observational techniques like shadowing and fly-on-the-wall to understand and map the existing ecosystem of care around a pregnant woman. Our key research areas included:

- The cultural beliefs and traditions that impact pregnancy and influences the actions and decisions of pregnant persons and their ancillary system
- The form and structure of different ancillary systems and how this impacts pregnancy and maternal health
- The prevalence and depth of pregnancy-related medical information in different communities as well as management methods they follow
- The daily routines and practices that are dictated by pregnancy
- Nutritional changes and challenges that come with pregnancy
- The barriers in accessing and utilizing maternal healthcare services
- The quality of care and current medical practices

We concluded our research stage with 79 interviews, identified 4 user types, and clocked 120+ interview hours.

FINDINGS*

Our research methods and design tools uncovered a dynamic complex ecosystem that is strongly influenced by information, culture, and infrastructure. While this paper does not cover all the research findings in detail, the more relevant findings are elaborated on below:

The Scarcity of Information

Our primary research showed that pregnancy, as an experience, is not openly discussed by pregnant people and their ancillary ecosystem. This means that the circulation of pregnancy-based information within the community is low. Mothers and grandmothers pass on their experiences and customs to their daughters only when the latter become pregnant. There is little to no planning or birth preparedness that comes before onset of pregnancy.

During pregnancy, the women come to rely on an 'older trusted female relative' who guides them on daily practices, nutrition, and physically helps them with household chores and daily activities. The pieces of advice they receive mostly concern the child's conformity to cultural notions of perfection, i.e., strength for boys or petiteness for girls (based on prevalent binary ideas of gender) and fairness. The socio-economic class of this group limits their ability to purchase and consume a variety of healthy foods [11]. They usually make do with their region's staple grain and dairy-based supplements. Even with the food that they can access, cultural notions dictate the consumption – they are often scared to eat too much or are afraid of how certain foods will affect the child. They are often given homemade pregnancy preparations made from local ingredients and instructed to consume them; they are rarely given a reason and are often scared into consuming the preparations.

Most women make sporadic visits to their healthcare centres through the course of their pregnancy and are prescribed supplements like iron, calcium, and folic acid. Unfortunately, they do not consistently take the supplements. They sometimes experience side-effects that they do not know how to manage, hear stories of supplements affecting the foetus and then get scared, or are simply ambivalent because they do not understand why they should be taking the medicines. Their only source of medical information is from the hurried interactions with overworked medical staff or underpaid community health workers. During the limited time of the monthly appointments, the staff is barely able to brush through essential pregnancy-related information owing to the high volume of patients. We also found that for most patients, voicing their doubts or asking for clarification is a struggle; they are shy/uncertain in doing so or do not feel comfortable enough with their healthcare provider. The disconnect between doctors and patients in language and culture only adds to this communication gap. The medical pamphlets that are given out at healthcare centres are extremely text-heavy and difficult to understand. They are unable to connect to the content or ascertain its relevance to their lives. This lack of knowledge and adherence regarding supplements is one of the reasons for the high prevalence of anaemia-inflicted maternal deaths.

We also discovered that for most of the women we spoke to, going to the hospital was perceived as the last resort. In addition to financial constraints and the general notion of "waiting to get better" (more on that below), we found that neither the pregnant women nor their ecosystem is aware of danger signs. Through the pregnancy, there are certain signs that signify something is amiss. The pregnancy stakeholders need to look out for these signs and are generally required to get immediate medical help or mention it to the doctor at the next appointment. Since they are unaware of the need for vigilance or the protocol on experiencing the signs, most women delay seeking medical help and this leads to complications in the pregnancy.

There are multiple government schemes and policies like [1, 13, and 15] (these are provided by the Central Government of India, state governments have their own incentives as well) that provide subsidized and free services, and food and transport facilities, but the utilization remains low. Many women are unaware of these services while others are unable to access them due to bureaucratic barriers like ID and registration.

We have identified the low rates of literacy and prevailing poverty as major barriers in the accessibility to medically verified information, which further influences help-seeking and decision-making behaviours of the entire pregnancy ecosystem [5]. Further, it is not only the lack of accessible information that is concerning, but also the prevalent misinformation that is spread that causes fear and paranoia.

The Barriers of Culture

In the absence of medically verified and accessible information, people widely follow their cultural beliefs and traditional customs. Most of the people we interviewed belong to patriarchal communities and their pregnancy practices are influenced by the inherent power structures and religious orientation [5].

Pregnancy is viewed as the woman's domain, one where the man's involvement is minimal. The 'older trusted female relative,' usually the mother or mother-in-law, is by the pregnant woman's side to help and guide her. However, the responsibility of care is also placed on the woman, even for things out of her control. If the delivered child does not meet the family's expectations – in terms of gender, colouring, features, and ability – the woman is held accountable. These accusations tend to be based on superstition and we found that a lot of women have been conditioned to self-blame. While pregnancy is perceived as a "gift" in most cultures, many people, especially younger women, feel as though it is something that is happening *to* them. In such a situation, they feel unbalanced and powerless. While the pregnant woman gets helps with housework and taking care of the other children (if any), the presence of the 'older trusted female relative' does not necessarily mean the woman has a friend and ally for her emotional needs. Denial of mental health needs as well as oppressive gender roles has in some ways affected the way women present themselves, especially in pregnancy.

We see an extension of the gendered denomination of pregnancy in hospitals as well where men are "not allowed" inside the maternity wards and delivery rooms. In fact, we observed that even while accompanying their wives to the antenatal care appointments, most men preferred waiting outside the doctor's room. We noticed that most men knew little about pregnancy, its danger signs, delivery, or post-delivery health requirements and were minimally involved in the preparatory steps of their child's birth, as supported by [10]. The only protocol that necessitates the man's involvement is during a crisis where decisions regarding care of the mother and child need to be made.

The Dearth of Infrastructure

As mentioned above, seeking care at a hospital or health centre is often the last resort. In the socio-economic context that we are investigating, poverty plays a huge role in accessing care. Many women find that they, despite knowing the need for antenatal care and having the desire to go to the appointments, cannot take the time off from work to go to the hospital. Missed work is missed pay, which has all sorts of repercussions in their respective households. In some places, health facilities are open only during specific time periods and so patients are forced to wait, unsure if they will even get to meet their doctor. We discovered that most women in this group continue working well into their third trimester

and are often engaged in strenuous physical labour as domestic, field, construction, and daily-wage workers [11].

Our research uncovered the inadequate quality of medical infrastructure at the rural level. There seem to be insufficient medical facilities and resources (like blood banks, syringes, medical bandages etc.). The percentage of skilled staff is too low to meet the medical needs of the region and doctor-to-patient ratios are alarming. We heard accounts of abuse and poor treatment of patients by the medical staff particularly in the maternity ward, which is supported by [8]. Negative experiences like this stop women from utilizing healthcare services for their next pregnancy.

These factors contribute in to a hesitancy in utilization healthcare services, especially in rural areas [17] - even for delivery. This contributes to adverse pregnancy outcomes.

Thus, the scarcity of information, barriers of culture, and dearth of infrastructure lead to delayed responses in seeking and accessing medical care. They also contribute to a lack of agency as experience by the pregnant person. Our findings corroborate the framework laid out in the three-delay model [12]. As per our research and resources, the first delay stands out as a potential area for intervention.

ANALYSIS

Design tools helped reveal underlying patterns, map the system's interconnectedness, and identify core gaps that may lead to adverse pregnancy outcomes.

We used system maps to explore cognitive and behavioural patterns, and interdependencies, deconstructing the involvement of the ecosystem and the factors that influence their actions.

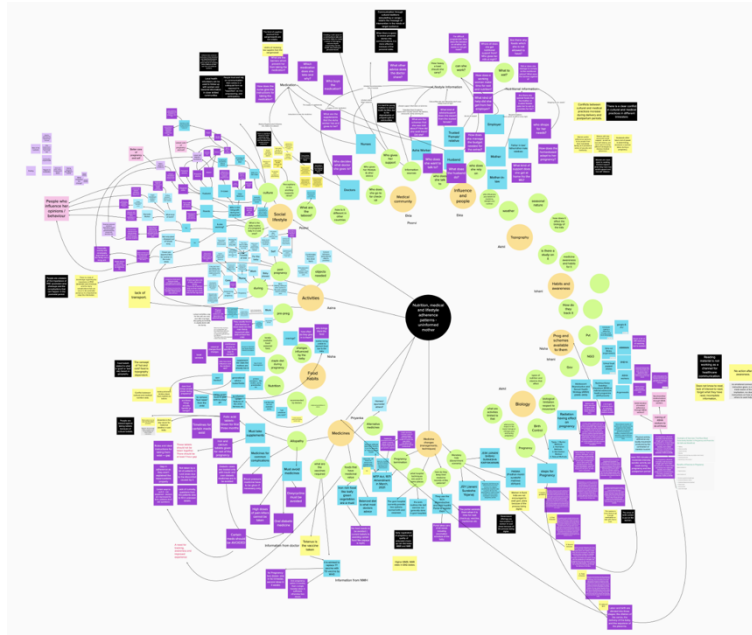


Figure 1 System Map

Through persona mapping and contextual enquiry, we unpacked their mental models about pregnancy and ascertained their goals within the complex ecosystem.

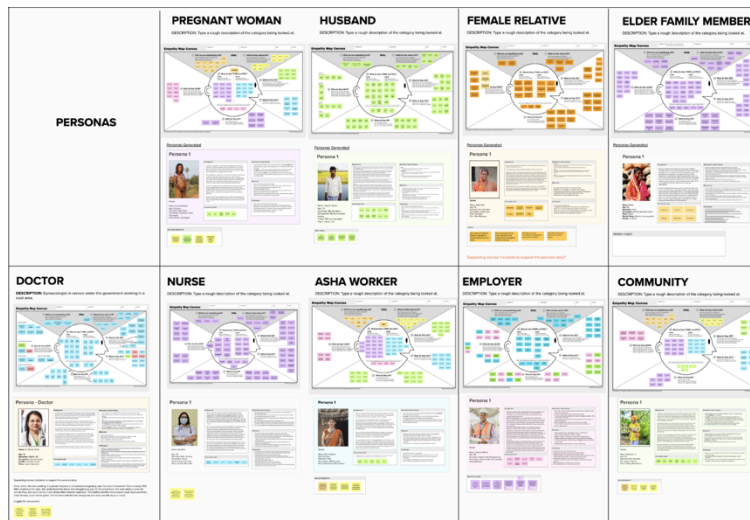


Figure 2 Persona Mapping

We created causal loops to understand the behavioural triggers of our users. For example, the decision to go to the hospital was influenced by stories heard from people in the ecosystem. Stories of successful deliveries had a positive impact, while stories of unsuccessful deliveries had a negative influence, resulting in the patient delaying the decision to go to the hospital. This in turn resulted in an unsuccessful delivery at the hospital, thereby reinforcing the loop. Similarly, stories about tablets having a 'detrimental' effect on the pregnancy discouraged users from taking the supplements.

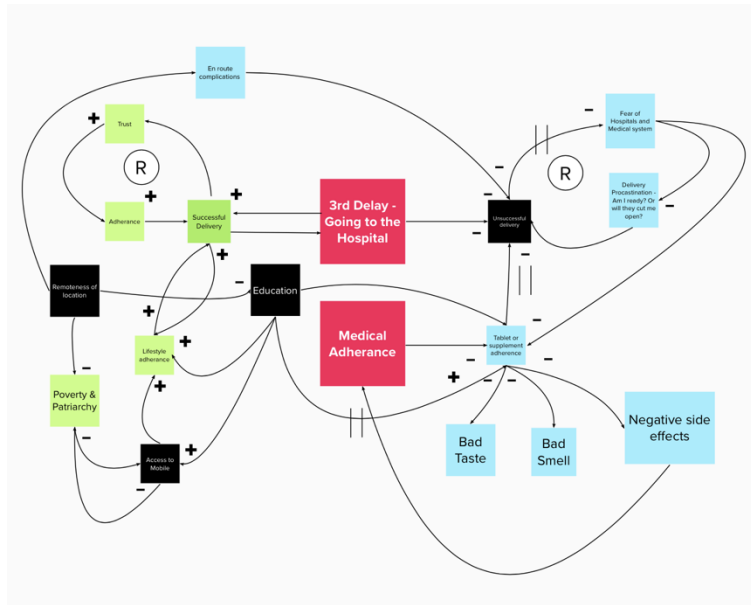


Figure 3 Causal Map with Feedback Loop

We did a causal layered analysis of the maternal landscape to examine its social, medical, and cultural paradigms. We particularly delved into the decision-making abilities of the pregnant woman, sexism within maternal care, and medical adherence to identify opportunities for intervention.

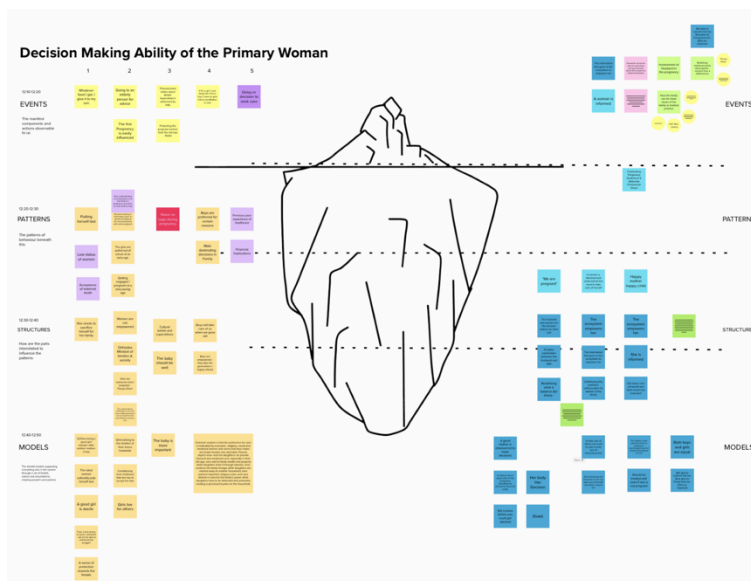


Figure 4 Layered Causal Analysis 1

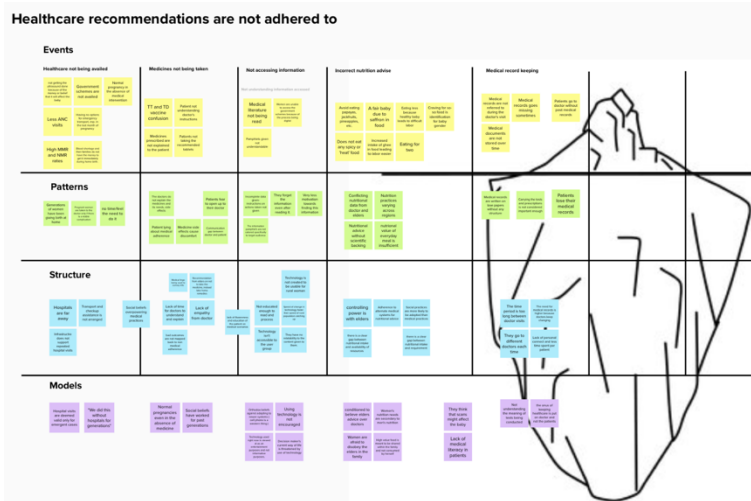


Figure 5 Layered Causal Analysis 2

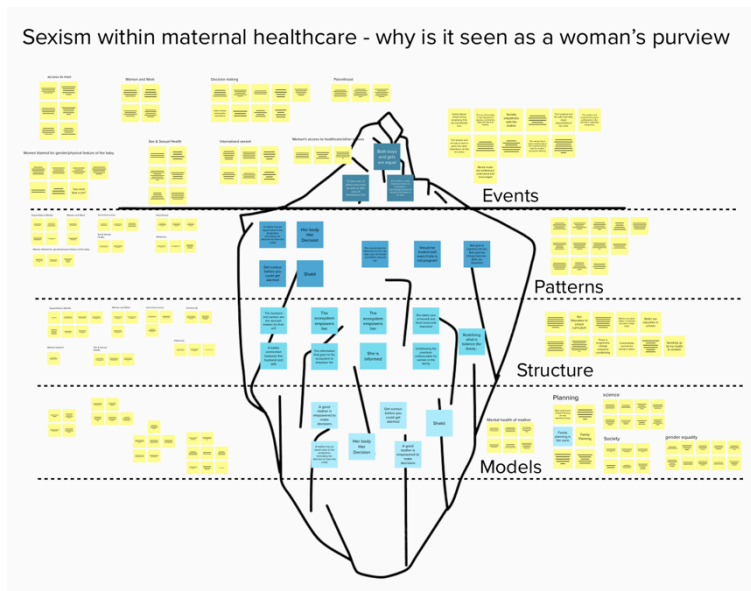


Figure 6 Layered Causal Analysis 3

These tools not only allowed us to hone in on our area of focus, but they also supported a similar deduction: there is a need for effective information dissemination and healthcare tracking methods that proactively engage all the stakeholders for overall improvement in care. Such an intervention must not alienate the users, it must fit seamlessly into their lives, considering their socio-economic context.

Content Feasibility								
Learning Curve								
Engagement (Stickiness of the product)								
Ability to test								
Ability to track success								
Error Handling								
Adoption Inertia								
Decentralisation								
Organic Fitment								
Effective Channels / Leverage Points								
Change Resiliency								
Touchpoints Availability								
Cultural Sensitivity								
Adaptability								

An exercise conducted on Mural allowed the team to assess each idea against the identified metrics and arrive at the top three ideas that met the projected requirements of our intervention based on the above metric.

Hills

Using the Enterprise Design Thinking tool of hill statements [6], we set clear goals for each member of the pregnant woman and her ecosystem

1. The pregnant woman will be able to document and communicate her symptoms to the doctors non-verbally.
2. The husband will be empowered with the right information on his wife's condition to talk about the pregnancy with her.
3. The doctor will comprehend her health through the calendar, before even talking to her.
4. The pregnant woman will gain access to accurate pregnancy-related information.
5. She will see UMA as a trusted advisor, relying on the service with the same comfort she feels with other female confidantes.

DESIGN INTERVENTION

UMA: Every Expecting Mother's Friend

A pregnancy service co-created with medical personnel

Vision: UMA aims to help pregnant persons, from the rural poor, and their support systems have a better-informed pregnancy journey and develop a proactive doctor-patient rapport.

In our service, pregnant persons receive a sticker sheet at their doctor's appointment that is relevant to their trimester. These include tablet stickers for supplements, stickers for month-specific danger signs, scannable appointment stickers, and scannable information stickers. The women put these stickers on their calendars for the days that they take their supplements or experience those symptoms. At their next appointment, the doctors scan these stickers to get insights into pregnancy pains and medical adherence, which would help the doctor devise a treatment strategy.

SERVICE TOUCHPOINTS

Calendar

Calendars were discovered to be one of the most common artifacts available in every household, irrespective of geography and socio-economic statuses. Multiple calendars are available for women to track their symptoms. These calendars are also low cost, provide local cultural contexts, which have a clear influence on the households and activities, and allow the ancillary support system to be actively involved in the pregnancy journey. The

women track these signs and symptoms through trimester specific stickers that they get from their healthcare center.

Informative videos

Digital penetration has drastically increased in the rural areas since the pandemic, owing to which the usage of platforms like YouTube and Instagram has increased with developed content targeted to hyperlocal consumers. UMA leverages this increase in digital content consumption by creating engaging short videos that use local cultural contexts as vehicles to deliver information pertinent to the various stages in the pregnancy journey.

In clinic videos

The average waiting time at government healthcare centers is high. While there is some reading material like pamphlets and posters available to the pregnant women as they wait for their check-up, they have proven to have a low engagement rate. UMA allows them to better utilize this time by enabling them to access informative videos either their own phones or screens available in the healthcare center. These videos educate and encourage people to have informed pregnancy journeys.

AI-driven Insights

At the appointment, the doctor scans the patient's sticker-marked calendar from the app. The app makes use of optical character recognition (OCR) and image processing to recognize the "markers" i.e., the stickers. The size of the stickers and the dimensions allows the OCR to conduct an error-free reading. Natural Language Processing enables the app's algorithm to identify the frequency and significance of the stickers, ascertains the relative position of the stickers, and converts this data into insights. These insights make the doctor aware of the occurrence and frequency of any symptoms.

UMA, our mascot

One of the most common insights from our interviews across the states was that pregnant women have a female friend/relative that they rely upon for support, advice and often as a sounding board for the challenges and experiences of their pregnancy. These women are not only confidants but also inspire trust in the information that was shared by them. Leveraging the already existing perception of trust, we designed the Uma Didi character to tell stories that are relatable yet medically verified.

PROOF OF CONCEPT

We are piloting the Minimal Viable Product of our design in the state of Uttar Pradesh. The maternal mortality rate here is 197 (2016-2018) and has a sex ratio at birth which is lower than the national average, which is indicative of prevailing gender bias. Uttar Pradesh is also the state with the largest rural population, house around 20% of the country's total rural population.

Strategy

UMA will tap into physical and digital streams during rollout. We will leverage social media channels like Facebook and Instagram, WhatsApp, Tiktok and YouTube to put out created and curated content. We engage our users through dialogue, inter-platform sharing, and targeted ads. We will also partner local organizations and civic bodies to encourage adoption of this service.

Outcomes

- Increased agency of the pregnant woman

With access to information that is medically verified and relevant to her context, she is adherent to the doctor's recommendations and medical practices. She is vigilant and know when and how to ask for help, should she need it. She is also more in control of her body and pregnancy as she is now a decision-maker.

- Increased stakeholder activity

The calendar is usually in a visible space in the household and so by using it to track the pregnancy journey, the stakeholders are involved. Partners are more active in tracking while older relatives are more open to following medical advice. The pregnant person is now able to discuss her experiences with the other stakeholders.

- Increased productivity of ANC appointments

The wait-time for pregnancy stakeholders is led frustrating as they interact with the service in the time before their appointment. During the check-ups, doctors can glean health updates from the patient's calendar without having to ask too many questions. This results in more time for the doctor to share instructions and listen to patient concerns.

DISCUSSION

At aim at the commencement of this project – to positively impact maternal healthcare – was a broad goal. In our attempt to stimulate behavioural change, we identified the latent emotions of the pregnancy stakeholders and used those as the basis for our design decisions. For example, the trimester-specific sticker sheets illustrate the growth of the foetus as many women find the pregnancy experience to be “unreal” or external to them. By connecting the development of their child with their day-to-day lives through the calendar, we tried to manifest a connection of sorts. We found that notions of ‘care’ were as wide and varied as the people we spoke to, the spaces we analysed. While we did try to combat the lack of information and misinformation with relevant and verified medical advice, we need to be cognizant of the scope of our undertaking. Culture and fear are at the root of these gaps and so, for large-scale change and development, small interventions will

be insufficient. There is a need for education programs and pro-poor economic and healthcare policies.

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