Working around stigma

Sensitization Training for Health, Community, and Outreach Workers

Healthcare workers, community and outreach workers should be provided with sensitisation training in order to understand and empathise with the intersectional oppressions faced by marginalised communities as well as provide a safe space for them. This can foster vaccination, COVID treatment, and other health-service uptake.

Information, Education, and Communication (IEC) and Information, Technology, and Communication (ICT):

IEC and ICT modules should be utilised to help marginalised communities acquire essential knowledge about sanitation measures, HIV related healthcare, COVID-19, general health, mental health, the interaction of vaccines with ART medication, and other needs.

ICT modules can be used to seek knowledge online, through social media use and/or seek healthcare by contacting providers online or via phone.

a. Information needs to be designed using simple and discrete language and images and distributed as flyers, posts, posters and pamphlets at locations where marginalised community members often visit or pass by, including online.

Information should also be provided through word of mouth, such as during in-person meetings (e.g., Self Help Groups (SHG)).

b. Communication tools should be customised to marginalised communities specifically.

For instance, to address vaccine hesitancy, a special section in the vaccine awareness communications should be included regarding the safety of vaccines for the specific marginalised community population.

The communication channels, as well the content in them, is often not optimised for the special needs of communities like marginalised community population.

Hence an inclusive communication and Knowledge transfer strategy needs to be adopted that caters to their needs.

c. There should also be the availability of onsite or telemedical counsellors to speak about specific concerns marginalised community population might have about the vaccine.
Working around stigma

Access to Healthcare, Medicines, and Vaccines

- Equitable healthcare access, including general health services, SRH services, HIV treatment and medicines, COVID-19 vaccine, and mental health care should be ensured for marginalised communities through outreach programs.

  a. COVID-Protection kits should be provided, either for pick up in vaccination camps, health centres, or NGO and CBO offices. They should contain masks (with information on how to wear them properly and safely dispose of them); surface and hand-sanitisers (with information on how to use them properly); antigen self-tests (with instructions on how to use, read them and dispose of them). The kits should also contain additional sanitisers for surfaces, masks and self-tests due to them being at a higher risk of infection, and condoms.

  b. Vaccination camps should be set up in marginalised communities. Vaccination camps should be used as an opportunity for taking regular health checkups targeted at monitoring the well-being of marginalised communities. Post-vaccination, members of the community should be encouraged to have regular medical check-ups to discuss their health habits and overall well-being. This can also be an opportunity to educate them on the proper care they should be taking as well as new medicines and forms of treatment.

  c. There should be medical care access to follow up post-vaccination to address concerns about any side effects of the vaccine. Side effects can be a major source of panic and stress, especially for the members of the marginalised community. Hence post-vaccination medical follow-ups, as well as medical counselling via Tele-Healthcare, should be introduced focusing on the issues faced by the community especially after getting their vaccine doses.

d. Sensitization training, telecare, telemedicine, and mobile clinics, should be used to address different concerns in access to healthcare such as stigma and discrimination, distance, time, and cost of travel.

Transportation Support

- Members of the marginalised communities often face long distances to health care facilities, cost of travel, time of travel, fear of going with strangers, risk of infection with COVID, fear of stigmatisation, fear of discrimination, fear of violence, and other challenges in their reaching healthcare facilities, which leads to a non-regular adherence of HIV medicines and other health requirements falling short. Therefore, marginalised communities should be supported with transportation support to and from the health care and vaccination centres, both in rural and urban areas.

Things to remember when we design, disseminate and redesign Information Education and Knowledge (IEC) products catering to the community

In order to tackle dangerous misinformation that has led marginalised groups, such as the TGNB and PLHIV community, to put themselves at risk of infection; it is essential to continuously design, disseminate, evaluate, remove, redesign and disseminate knowledge and information products with up-to-date and verified facts. However, this material needs to be packaged appropriately and target the particular questions and myths pervasive in the community:

- Information should come through sources trusted within the community, videos and posters should include trusted people from within the community speaking about vaccinations.
- Should address the common fears regarding stigma and discrimination.
- Should address questions around reactions with hormone replacement therapy, de-addiction medication, HIV medications etc.
- Posters should be installed at locations that the target group often visit or pass by.
- Involve community leaders to ensure that information reaches many “hard-to-reach members through their networks and by word of mouth” (Reza-Paul et al., 2020, p. 105).
People living with HIV (PLHIV) are one of the most marginalised communities in India and represent over 2.1 million people (Parikh et al., 2021). The COVID-19 pandemic poses a significant threat to PLHIV’s well-being, healthcare and livelihoods. Although PLHIV has increased sanitary practices and ART (Antiretroviral Treatment) adherence, the nature of the pandemic poses greater risk to their wellbeing.

PLHIV would benefit from income and employment support and nutrient-rich food programs to alleviate financial drain and risk-taking. Mobile Vaccination Camps and including nutrient rich food distribution for PLHIV in vaccination camps have proved to be useful.

PLHIV face an identity crisis due to a lack of recognition and respect as to who they are in the community. PLHIV are deeply affected by the stigma and judgement that surrounds them in society. Therefore, it is necessary to reach out to PLHIV and offer psycho-social support. Telecare should be utilised to provide support to as many PLHIV as possible without putting them at risk and adding the burden of reaching healthcare centres. This approach should especially be utilised with hard to reach communities such as rural PLHIV. To be of maximum benefit, telecare should be free of cost, available 24/7, and advertised in target communities. Additionally, psycho-social support in the form of counselling should be offered at vaccination camps and mobile clinics. Moreover, psycho-social support should also be made available and accessible to PLHIV to address the stress, anxiety and confusion related to the vaccine.
Access to medications should also be ensured in order to prevent a break-in PLHIV’s treatment and/or having to find alternate (non-traditional) methods to procure medicines (Parikh et al., 2021). Medicine delivery should be made available for PLHIV, either at home or at meeting/collection points. But for some PLHIV, at-home delivery has posed problems due to privacy concerns but PLHIV has been enabled to take home three months’ worth of Antiretroviral Therapy (ART), which has been of great support to them during periods of strict lockdowns.

Key aspects to be addressed in the COVID-19 response for PLHIV should include food security and livelihoods. It is important to protect this marginalised group from engaging in risky and dangerous behaviour to create livelihoods, such as prioritising work over healthcare. Therefore, support in the form of grocery and basic necessity distribution for marginalised PLHIV should be provided to support their safety, well-being, regular medication uptake and healthcare-seeking behaviour. Moreover, PLHIV would benefit from income and employment support to alleviate financial drain and risk-taking and promote health. Moreover, as many among the PLHIV work in the informal sector, resources regarding and information about exploitation should also be provided. The Vaccination Camp is a good place to initiate this conversation.

The incidence and severity of HIV infection and opportunistic infections (illnesses that occur more frequently and severely in PLHIV) such as tuberculosis, pneumonia, and Wasting Syndrome are significantly determined by nutritional status and in turn, have severe nutritional consequences. Good nutrition improves the quality of life, supports antiretroviral therapy, and assists to maintain lean body mass. PLHIV should be enabled to have and maintain healthy diets to ensure adequate energy, micronutrient, and macronutrient intake. PLHIV often require additional vitamins and minerals (such as Vit A, B, C, E, Zinc) to support and strengthen the functioning of the immune system, which should be ensured through a well-balanced diet fortified with nutritional supplements.
COVID-19 Vaccination for Transgender and Non-Binary People

To reduce vaccine and COVID treatment hesitancy, it is important to ensure that the vaccination sites and quarantine centres are welcoming and safe for the TGNB community. It is advised to have healthcare workers there that have undergone sensitisation training on how to provide adequate care to the marginalised TGNB community. They should also be trained to provide care for the additional health needs the TGNB community may have when they come to the sites and centres (e.g., gender-affirming care).

Findings

Societal and health:
- "Second" priority, stigma, social disconnection
- Victimization from the traditional social stereotyping,
- "Third gender" based discrimination,
- Associated factors like poverty and administrative apathy,
- Increased dependency and segregation based on age (Banerjee, D., & Rao, T. S., 2020)

Based on interviews:
- High HIV prevalence
- Barriers in access to care- fear of persecution, disrespectful care, digital divide
- Institutional inequity- distrust, previous adverse experiences

Learnings:
- Most people who don't work with the community don’t think about the fact that either the IDs are not available or there is a lot of sensitivity towards “deadnaming.
- The visual and name difference between IDs was also found to be a deterrent in accessing services.
- Ensuring that individuals know that this would be a friendly place both during mobilisation and that all volunteers and health care providers are sensitised was key.

How to encourage TGNB community for vaccination?
- Explain the risk of not getting vaccinated
- Interact with the ‘gurus’ or leaders of the gharanas/ families they are part of. As once the guru is convinced, it is high chance (90%) that other members also get convinced.
- Address their concerns regarding HIV, hormone therapy, drugs and alcohol.
- Use community based organisations that have built trust capital with the community to mobilise individuals.
- Consider special camps or special timings to ensure a safe space free of stigma and positive experience.

Tool kit-
- Covid Vaccination and HIV | Trust the Facts, Let's get vaccinated by Safe Access | Kannada
- Clinician sensitisation for providing gender affirming care | Kannada
- Clinician sensitisation for providing gender affirming care | English

*Deadnaming is the use of the birth or other former name (i.e., a name that is “dead”) of a transgender or non-binary person without the person’s consent.
COVID-19 Vaccination for Transgender and Non-Binary People

Transgender and Non-binary community (TGNB)

Background and problem statement

- Transgender and Non-Binary (TGNB) community, have been exceptionally affected by the pandemic in several ways:
- **Risk** of exposure to the virus and its adverse outcomes,
- Delays in access to gender-affirming care (the processes through which a health care system cares for and supports an individual, while recognizing and acknowledging their gender identity and expression)
- **Diminished access** to social support, which is crucial to protecting against the effects of stigma and discrimination.

Source: Columbia Psychiatry, 2020

Other delivery side gaps:

- Very poor vaccine utilisation rates, ID and registration issues (ex. name and photo mismatch) CoWin app (operational inefficiencies)

How to help?

**How to gain trust**

- Respecting the names and pronouns of others
- Gharana - value gender behaviour, expressions, attitudes and emotions
- Peer and community support
- Develop tools for sensitising providers on addressing individuals, for e.g. - sensitize healthcare individuals and volunteers on how to address non-availability of IDs, visual and name differences between IDs. (Watch: How to address a transgender person respectfully)

What are the key tips to keep in mind while organizing the vaccination camp for TGNB community?

- Ensure the leaders are convinced about the vaccination and not hesitant.
- Ensure the camps are organized in a nearby location.
- Organize a camp suitable for 100-200 people, not a large camp.
- Avoid early morning camps.
- Take support from community organizations for smoother mobilization process.
- NGOs should ask to understand what % of Trans people living in the state have been vaccinated and ensuring these rates are high.
Marginalised women

Background and problem statement

- Certain groups of women and girls may be at higher risk because of poverty, poor access and lack of information and resources.
- Indian Nurses and midwives make up about 80 percent of HCW (UN)
- More susceptible to exposure owing to their presence as frontline caregivers and workers in the health and service sectors.
- “Being least organised and lacking institutional support, domestic workers are extremely vulnerable to exploitation and human rights violations, and the pandemic has aggravated the situation.” (Surnalatha et al., 2021)

Findings

Delivery side gaps:
- Poor operationalisation of Co-WIN
- ID discrepancies for migrant women
- Reliance on their partners or male relatives for phones creating logistic difficulty
- Poor digital knowledge and access to devices
- Barriers in access to care due to gender gaps and lack of decision making

Migrant women and factory workers face even more challenges such as:
- Lack of sanitation measures
- Lack of grievance mechanisms
- Poor facilities for women in the reproductive age
- Inadequate investment in women’s well-being management is more reactive than responsive
- Poor fabrication around women workers and well-being-no soap for hand wash

COVID-19 Vaccination for Marginalised Women

How to help?

How to gain trust
- Vaccination camps should have a separate section for women with screens to make them feel more comfortable adjusting their attire whilst taking the vaccine.
- Population-specific vaccination camps (for trans women, sex workers).
- Training of camp staff to sensitise them about gender issues.

How to advocate
- Engage with Self Help groups (SHGs) and CBOs to spread more awareness and also tackle certain stigmas, apprehensions and fears about the vaccine. Proper education should be provided about the effects from the vaccination.

How to mobilise
- Immunisation sites or the mobile camps to be located closer from their homes.
- Strategies of providing non-financial incentives such as ration for families (for days missed during vaccination).
- Layering NCD screening and provision of ration kits, Provide-Home quarantine kits, provide post-screening counseling about NCDs, etc., to improve access to any experience of the vaccination.

Source: World Economic Forum

How to increase uptake of vaccination?
- Address their fears regarding the side effects of vaccination since most women (mothers) are afraid to fall sick which can impact childcare and in cases where they are employed and can lose daily wages/work.
- Interact with leaders/head of religious and cultural groups and self-help groups as, they play a pivotal role in passing down the information to women members and can help convince them to get vaccinated.

What are the key tips to keep in mind while organizing the vaccination camps for marginalized women?
- Ensure that the vaccinating area has privacy, make arrangements for screens and avoid conducting vaccination camps on open stages. Be respectful.
- Guide the women who might not have the mobile phones or don’t know how to use one to check for OTP messages.
- Ensure the camp staff is trained and sensitised about gender issues.
- Ensure the camps are not too far from their homes and/or arrange for temporary creche.
COVID-19 Vaccination for People Living with Disabilities

People living with disabilities

Background and problem statement

- In many communities, individuals with disabilities are at higher risk of infection, severe illness and even death from COVID-19 due to underlying medical conditions, mostly related to their primary disability.
- Because disability is not listed as a priority risk group for vaccination, they are often left out from the eligible criteria causing a series of challenges:
  - difficulty navigating systems to prove eligibility
  - difficulty navigating systems due to limited mobility
  - limited understanding of guidelines due to disrupted access
  - inability to communicate challenges faced
- For PwD, receiving inclusive and dignified care has always been a challenge and this difficulty to access healthcare has further exacerbated during this pandemic

How to help?

- Special provisions and mechanisms to vaccinate people living with disabilities
- Track and create a list of PwDs in communities and conduct targeted vaccine drives.
- Engage civil societies and organizations working for PwDs in awareness campaigns and mobilization efforts.
- Conducting vaccine drives in locations accessible by the individuals from PwD community.
- Targeted messaging to address specific concerns around vaccine hesitancy.
- Proper communication about vaccine drives to ensure communities get enough time to plan and attend the vaccination camps.
- Specialised healthcare providers available at the centre/campsite to cater to the specific needs of individuals with various types of disabilities.

Findings

- Location of vaccination centers have been the biggest challenge for PwD, especially for individuals with locomotor disabilities.
- Registration for vaccination is a common problem for underprivileged PwDs who don’t have a phone. Unable to go and register physically, makes the process more challenging for them.
- Inaccessibility of Co-win and Arogya Sethu app is another challenge.
- Families were sometimes reluctant to take PwDs to vaccination centers, especially women members in rural locations.
- Intersectionality among PwDs - poverty, dalits, tribals, women etc. further amplifies the challenges in vaccinating these communities.
- Lack of knowledge about the when and where of vaccination as well as whether they can attend the same camps as the general population.
- Myths and misconceptions leading to vaccine hesitancy among the PwD communities.