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LESSONS FROM THE PANDEMIC ON ACCESS TO HEALTH IN SOUTH ASIA: ANALYSES FROM A FEMINIST INTERSECTIONAL PERSPECTIVE

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FEMINISTS
FOR A PEOPLE'S
VACCINE

ACRONYMS

AAAQ	Availability, Accessibility, Acceptability and Quality
ACT	Access to COVID-19 Tools
AIDS	Acquired Immunodeficiency Syndrome
ART	Anti-retroviral treatment
ARV	Anti-retroviral
ASP	National AIDS/STD Program
EDI	Equality Diversity Inclusivity
FGD	Focus Group Discussion
HIV	Human Immunodefiency Virus
INB	Intergovernmental Negotiating Body
LGBTIQ	Lesbian, Gay, Bisexual, Transgender, Intersex, Queer
LMIC	Low and Middle Income Countries
NACO	National AIDS
NGO	Non-government organisation
OST	Opioid Substitution Therapy
PLHIV	People Living with HIV
PPE	Personal Protection Equipment
PWID	People Who Inject Drugs
PWUD	People Who Use Drug**s**
SAARC	South Asian Association for Regional Cooperation
SPRP	Strategic COVID-19 Preparedness and Response Plan
SRHR	Sexual and Reproductive Health and Rights
STI	Sexually Transmitted Infections

CONTENTS

INTRODUCTION

The COVID-19 pandemic highlighted the existing weaknesses and inequities in the health care system and the divide between high and low and middle income countries (LMICs). In LMICs where health systems are already weak, systems were stretched and, in some instances, came close to collapsing. Given the limited resources and in-built inequities of health systems, women, the poor and other communities living at the margins of society were most affected.

It is well recognised that the health system is gendered in favour of males which is further exacerbated by social status, race, disabilities, etc. (Heise et al., 2019). During the COVID-19 pandemic these structural differences were exacerbated (Gilson, 2021). The structural and social factors that affect the health system negatively are particularly enhanced in the case of women, the poor and especially those who face discrimination from both poverty and their social identity such as sex workers, the lesbian, gay, bisexual, transgender, intersex, queer (LGBTIQ) community, people who use/inject drugs (PWUD/PWID) and people living with HIV (PLHIV) (Sehgal and Patni, 2023, Banerjee and Nair, 2020, Callander et al., 2021, Chakrapani et al., 2022, Vasylyeva et al., 2020). Globally, despite several calls being made to warn countries on how these communities may be excluded from the pandemic response (Vasylyeva et al., 2020, Platt et al., 2020) their special needs were nonetheless overlooked.

The design of the pandemic response was led mainly by males (Van Daalen et al., 2020) so that a gender lens was missing (Rahman and Dang, 2023) from the measures that were undertaken. Women's experience of the pandemic was a reflection of their perceived gendered roles so that more women than men faced employment loss while their unrecognised domestic and care providing workload increased (Kabeer et al., 2021, Tomsick et al., 2022, Flor et al., 2022). Women comprise 70% of the global health and social workforce so that loss of employment and exposure to risky working conditions during the pandemic affected them disproportionately (Beyrer et al., 2024, Kabeer et al., 2021). At the same time, stay-at-home orders increased gender based violence including domestic and intimate partner violence (Ravindran and Shah, 2023, Sultan et al., 2022, Ghoshal, 2020, Hamadani et al., 2020). Women and girls were also adversely affected as several essential reproductive and sexual health services were disrupted (Gadsden et al., 2024, Arsenault et al., 2022) thus jeopardising attainment of the Sustainable Development Goals in these countries.

Major financial setbacks were experienced in the countries of the South Asian Association for Regional Cooperation (SAARC) which covers Afghanistan, Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, and Sri Lanka. A review of these countries showed some were at the highest risk for an economic shock during the COVID-19 pandemic with decreasing current account balance and GDP growth (Irfan et al., 2023). Many countries had to take loans and are now facing a severe debt crisis. The conditionalities of debts from IMF bring austerity measures, that have serious implications for sovereign states in their capacity to deliver on social protection measures, especially sectors like health, education, water, sanitation among others that determine the right to health. (Tamale, 2021). As a result, health care systems emerging from the pandemic now face additional stress of reduced budgets.

The COVID-19 pandemic highlighted the divide between countries that were the producers of technical products including personal protection equipment (PPE), test kits, medicines and vaccines and poorer countries which had to pay exorbitant prices for such products (Gostin et al., 2023). The weak health systems were stretched and the Access to COVID-19 Tools (ACT) Accelerator system was also hamstrung by the powerful nations and conglomerates (The Lancet, 2021). There was inadequate supply of PPE, standard masks, and hand gloves for health service providers, which was a major constraint in providing treatment. Moreover, test kits were limited especially in the early days of the pandemic when only RT-PCR was available and as this requires special equipment and trained personnel, resource poor countries were especially affected. As a result testing was extremely low in most of the South Asian countries (Sarkar et al., 2020, Islam et al., 2020).

The pandemic also saw inequitable access to vaccines despite a few South Asian countries ability to manufacture vaccines (Altindis, 2022, Ramachandran et al., 2021, Beyrer et al., 2024) as patents especially of the mRNA vaccines were held by the multinational pharmaceutical companies which were unwilling to share the technology (Gostin et al., 2023). This is reflected in the finding that by July 2023, 31% and 90% of people in low- versus high-income countries respectively had received at least one dose of the COVID-19 vaccine (Beyrer et al., 2024) despite vaccine acceptance being fairly high in South Asia (Hawlader et al., 2022).

This divide between high-income countries and LMICs and gender was also evidenced in research. The importance of taking gender into consideration for any

research cannot be overstated as many aspects of human health are influenced by gender (Haupt et al., 2024). Prioritisation of research topics for COVID-19 was also largely determined by the high-income countries which have a stronghold over research funding (George et al., 2023). The World Health Organisation (WHO) set global priorities for COVID-19 research and regional WHO offices also explored regional priorities which were aimed to target regional research topics relevant to their Member States (Azim et al., 2022) but funding remained a concern. This led to a delayed understanding of the needs of LMICs, of women and of people in the margins of society.

Many countries in South Asia with their limited resources (both capital, infrastructure and skilled health care work force) were unable to cope with the high demand of the pandemic and marginalised communities were disproportionately affected by their exclusion. In most South Asian countries, some marginalised communities are criminalised (UNAIDS, 2022) so that access to the available limited resources and the special services and measures that were put in place for COVID-19 was not practicable. Moreover, marginalised communities were not included or consulted while developing the pandemic preparedness plans (UNAIDS, 2021) so their realities were overlooked.

Thus, the right to health based on availability, affordability, acceptability of services that met quality norms and ethical standards (AAAQ), was undermined during the pandemic especially for LMICs and for women and people living on the margins even in high-income countries.

This paper discusses how selected marginalised communities in the South Asia region were impacted by COVID-19 and the measures that were undertaken to overcome some of those effects either by themselves or through the government and non-government organisations (NGOs) as well as feminists and human rights activists. The impacts and responses are analysed based on a feminist perspective and an equality, diversity and inclusivity (EDI) approach.

METHODOLOGY

The analysis conducted in this paper relied on a review of secondary literature, namely published peer reviewed articles, published reports, grey literature consisting of unpublished reports and communications, and information from a couple of informal focus group discussions (FGDs).

The marginalised communities included here are female sex workers, the LGBTIQ community, PWUD/PWID and PLHIV. It is to be noted that males who have sex with males, Hijra/Khwaja Sira and transgender women have been included under the broad label of LGBTIQ. The countries finally selected are Bangladesh, India, Nepal and Pakistan. These countries were selected based on the availability of at least ten published articles in the public domain.

The literature search was conducted through search engines Google Scholar and PubMed using keywords such as COVID-19 pandemic, female sex workers, males having sex with males, LGBTIQ, transgender women, Hijra, PWUD, PWID, PLHIV, mental health, violence, resilience. Published reports were also accessed using websites of UNAIDS, WHO, UNFPA and others. In addition to the published literature, grey literature was collected from Bangladesh, Nepal and Pakistan through personal contacts in each of these countries. In Bangladesh, two FGDs were carried out with female sex workers, one each from a brothel and the streets of Dhaka.

This analysis is limited in its scope as it is restricted to a selective group of communities in only four countries from South Asia from where information was more easily available in the public domain. It therefore does not represent all of South Asia and marginalised communities in all their diversities.

FINDINGS

Pre-existing widespread inequalities were exacerbated during the COVID-19 pandemic so that people living in the margins of society suffered disproportionately and the measures undertaken by governments to contain and control spread of the pandemic increased the barriers and inequities already faced by marginalised communities. Analysis of how some of these measures affected the different communities in the selected countries of South Asia as well as the positive actions taken and coping mechanisms of communities in the face of these challenges are presented here. In addition, the weaknesses of global pandemic policies and strategies and the lack of evidence based planning are discussed.

IMPACT OF THE PANDEMIC ON MARGINALISED COMMUNITIES

Some of the major impacts of the pandemic on marginalised communities from the measures adopted by countries that are examined here are outlined in Fig. 1.

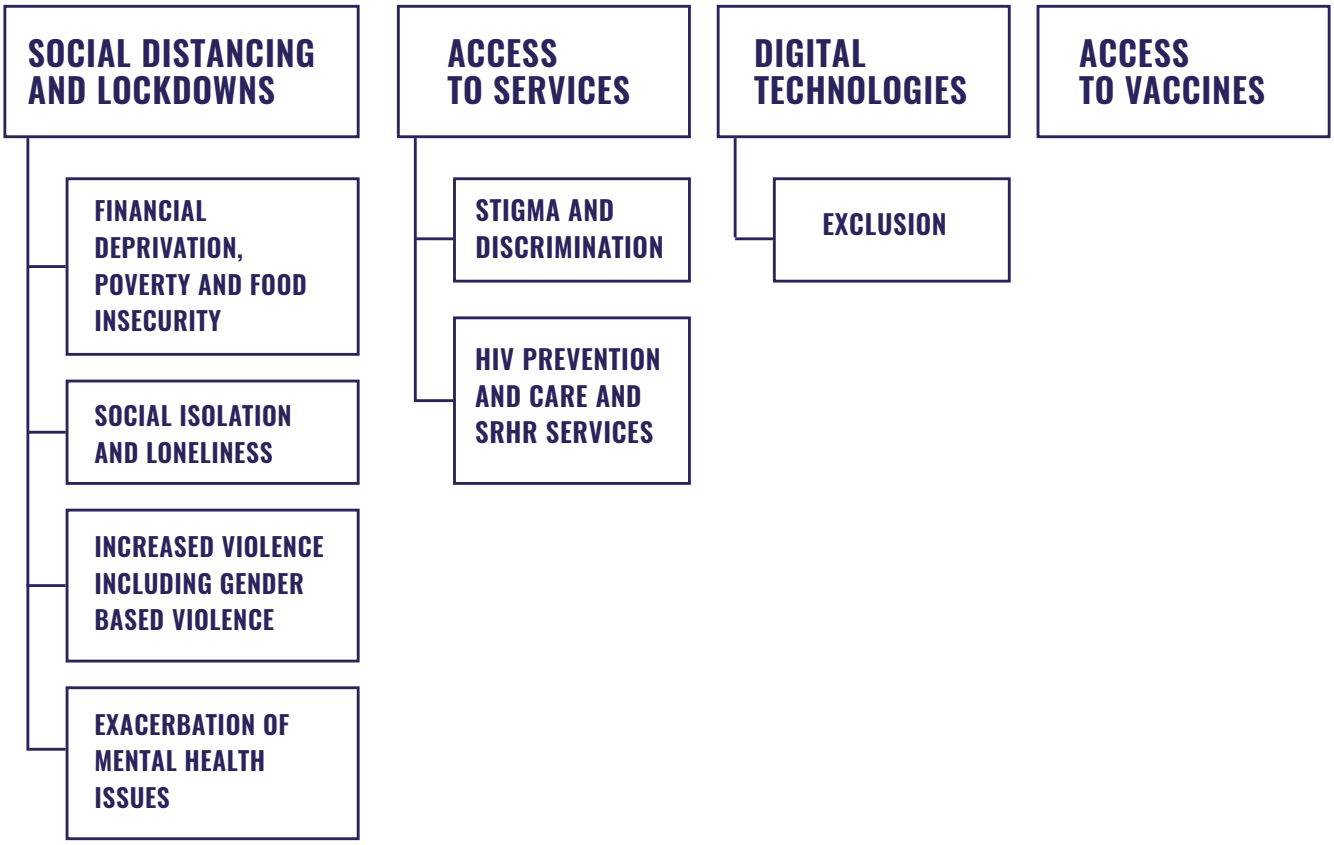


Fig. 1. Impact of Selected Pandemic Measures

SOCIAL DISTANCING AND LOCKDOWNS

Imposition of lockdown and social distancing measures during the COVID-19 pandemic impacted sex workers, PWUD/PWID, LGBTIQ and PLHIV communities in various ways (McFall et al., 2022) as outlined in Fig. 1. Each of these is discussed below:

1. FINANCIAL DEPRIVATION, POVERTY AND FOOD INSECURITY

One of the most important issues faced by these marginalised communities was loss of employment and earnings, poverty and hunger. A recurrent theme was the need for employment and nutrition rich food. Transgender persons faced severe lack of employment and poverty as reported from India (Chakrapani et al., 2022), Nepal (Rahman and Dang, 2023); Bangladesh (International Centre for Diarrhoeal Disease Research Bangladesh, 2024, Rashid et al., 2020, Bandhu, 2020, Sifat et al., 2023) and Pakistan (Kirmani, 2021, Azhar et al., 2023). For people engaged in sex work, client

numbers declined precipitously plunging them into extreme poverty as reported from Bangladesh (Lighthouse et al., 2020, Sultan et al., 2022, Save the Children, 2024, Naripokkho, 2024), India (Sehgal and Patni, 2023, Godbole, 2020, Pollard et al., 2021), Nepal (Ghimire et al., 2021) and Pakistan (Kirmani, 2021). Many in Bangladesh and India resorted to loans (UNFPA et al., 2022). In India, some sex workers and LGBTIQ borrowed money at high interest rates that pushed them further into poverty (Sehgal and Patni, 2023, Chakrapani et al., 2022). Similarly, PWUD, who are generally malnourished and impoverished, were further deprived of employment and suffered starvation (Save the Children, 2024, Nai Zindagi, 2019).

Some aid in the form of free food and cash was distributed to marginalised communities in all four countries however, many faced barriers in accessing this assistance. For instance, documents such as national identity or ration cards for accessing the aid were required but many transgender women and sex workers do not have these documents (Chakrapani et al., 2022, Rahman and Dang, 2023, Rahman et al., 2022, Godbole, 2020, Naripokkho, 2024). National identity cards require sex identification and only accepts the binary male/female options for which reason many of those belonging to this community have not registered and for those who had national identity cards, the sex identity recorded on the card was different from their gender identity (Rahman et al., 2022). Some who did receive aid, complained of discrimination while receiving it (United Nations Bangladesh, 2020). However, NGOs, private organisations, activists, feminists and individuals came forward to help as much as they could in their own capacities (Rahman et al., 2022, Naripokkho, 2024, Save the Children, 2024, Godbole, 2020, Kirmani, 2021, Nai Zindagi, 2019). For example, a few PWUD in Bangladesh and Pakistan were provided nutritional support through HIV prevention NGOs (Save the Children, 2024, Nai Zindagi, 2019) but the numbers were negligible.

2. SOCIAL ISOLATION AND LONELINESS

The social support system of sex workers, PWUD, PLHIV and LGBTIQ communities often comprise of their own peers and networks, collectives (formal and informal) that provide friendship, comraderies and sometimes become their adopted families especially as their own families may either disown them or with whom they do not share their identity. The pandemic imposed restrictions in movement and social distancing, that led to social isolation and loneliness along with depression and anxiety across the board. LGBTIQ communities (Li et al., 2023) in India (Raghuram et al., 2023) and Bangladesh (Rashid et al., 2020) felt it acutely. Female sex workers

who were in regular contact with outreach workers providing HIV prevention and care services, felt isolated and abandoned when these contacts were lost during the lockdown (Reza-Paul et al., 2022).

3. INCREASED VIOLENCE INCLUDING GENDER BASED VIOLENCE

Violence is commonly faced by all the marginalised communities addressed here even under normal circumstances which increased during the pandemic. In a study across several countries including India, female sex workers reported increase in abuse, harassment, violence and discrimination from partners, clients, the general public and police (Brooks et al., 2023). In Bangladesh and India, they often faced violence from law enforcement agencies when they attempted to go out to earn a living (Sultan et al., 2022, Chakrapani et al., 2022). Poverty drove many sex workers to take clients who paid less and with whom they had less negotiating power (Shankar et al., 2022, Chakrapani et al., 2022, UNFPA et al., 2022). In Bangladesh sex workers faced increased violence both in brothels and streets where violence increased three-fold and five-fold respectively, between March and April 2020 (United Nations Bangladesh, 2020). Violence at the hands of law enforcement and local goons also increased because of their inability to pay bribes (UNFPA et al., 2022). Similarly in India, sex workers faced violence from the brothel keepers (Godbole, 2020). Domestic violence was also reported by sex workers in India (Reza-Paul et al., 2020).

LGBTIQ communities were affected in various negative ways including having to return to their homes where they were unwelcome and further subjected to violence worsening their mental health (Sifat et al., 2023, Banerjee and Nair, 2020, Rahman and Dang, 2023, BRAC James P. Grant School of Public Health, 2021). In Pakistan and Bangladesh, some had to conceal their gender identity by dressing as men (Azhar et al., 2023, Sifat et al., 2023). In Bangladesh violence against transgender women increased substantially and they often faced violence from their gurus as they were unable to bring in money (UNFPA et al., 2022). In Nepal, shelters that are operated by community based organisations for LGBTIQ suffering domestic violence were shut during the pandemic (Rahman et al., 2022) thus leaving them without any form of support.

4. EXACERBATION OF MENTAL HEALTH ISSUES

Mental health issues were exacerbated for these communities because of fears of becoming infected, having to attend medical centres that were unfriendly, poverty, costs related to transport and treatment, hunger, etc. (Sifat et al., 2023, Raghuram et al., 2023, Chakrapani et al., 2022, Reza-Paul et al., 2022). The prevailing stigma and discrimination were exacerbated during the pandemic especially for the LGBTIQ community (Sifat, 2020) among whom some in Bangladesh were accused of being carriers of the SARS-CoV-2 (Hossain, 2022) while stigmatising posters were displayed in India accusing this community of spreading the virus (Rahman and Dang, 2023). Returning to unwelcome homes where they often experienced violence enhanced mental health issues already faced by the LGBTIQ community (Rahman et al., 2022, Raghuram et al., 2023, BRAC James P. Grant School of Public Health, 2021). In Bangladesh, existing counselling services stopped providing in-person counselling (BRAC James P. Grant School of Public Health, 2021). In Nepal, a member of the Blue Diamond Society talked about the extreme suffering that community members were undergoing during the pandemic and reported that 38 from the LGBTIQ community had committed suicide during the period (Rahman et al., 2022).

It is well recognised that PWUD suffer from a multitude of mental health issues (Colledge et al., 2020) but there is a dearth of information on PWUD from this region and how they were impacted by COVID-19. A global survey of medical practitioners on substance use disorders showed that in India PWUD/PWID suffered from a myriad of comorbidities associated with substance use and COVID-19 but mental health was not addressed separately in this study (Farhoudian et al., 2021).

In Bangladesh, at the start of the epidemic female sex workers, similar to the LGBTIQ community, were considered to be carriers of the virus and all brothels in Bangladesh were shut for months leaving sex workers in a state of desolation (Nasreen and Habib, 2021). Female sex workers faced severe mental distress especially as many had to borrow money sometimes at exorbitant interest rates pushing them into a cycle of debts for repayment of loans (Shankar et al., 2022, Sehgal and Patni, 2023). A report from India showed how desperation led a female sex worker to attempt suicide (Reza-Paul et al., 2022).

ACCESS TO HEALTHCARE SERVICES

Barriers to access were imposed by lockdowns, fear of contacting COVID-19, inability to pay for transport and healthcare, diversion of routine care for patients with COVID-19, and the redeployment of health workers or hospitals to COVID-19 care and prevention (Arsenault et al., 2022, Hung et al., 2022, Pollard et al., 2021). The overarching factor that enhanced each of the above was the prevailing stigma and discrimination against these communities which prevented easy access to COVID-19 care as well as to the regular services that they were receiving such as for HIV and STI prevention (McFall et al., 2022, Rahman and Dang, 2023, Azhar et al., 2023, Sifat et al., 2023) and SRHR services (Parikh et al., 2022). Each of these issues is discussed below:

1. STIGMA AND DISCRIMINATION

Harassment and discrimination against marginalised communities prevents them from readily seeking treatment from medical centres. A global study revealed that being non-binary was significantly associated with experiencing discrimination or violence from health providers (Adamson et al., 2022). Hospital wards are designated for men or women, and the LGBTIQ community have to be admitted into either of those wards which is uncomfortable not only for them but also for other patients as well as the service providers who often have a very negative attitude towards them (Sifat, 2020). Thus a transgender woman in Bangladesh who sought testing for COVID-19 in a medical centre, was kept waiting for hours so that she left without getting a test conducted and said she was later relieved because if she needed to be admitted, it would not have been possible for her to stay in either ward (Hossain, 2022). Similarly, the transgender community in Multan, Pakistan refused to visit health centres due to the maltreatment they were subjected to because of their gender identity (Khan, 2023). It was not just the LGBTIQ community that faced discrimination, PLHIV in Pakistan reported fear of ridicule by healthcare providers based on the experience of other PLHIV while receiving treatment for COVID-19 at hospitals (Ahmed et al., 2022). Sex workers also complained of ridicule and even being turned away from health centres (Rahman and Dang, 2023).

2. HIV PREVENTION AND CARE AND SRHR SERVICES

HIV prevention services declined in many cities across the four countries and HIV care services for PLHIV were also hampered (Hung et al., 2022, Parikh et al., 2022,

SeyedAlinaghi et al., 2023). The decline in HIV prevention services for LGBTIQ communities and PWUD were recorded in several cities in India (McFall et al., 2022, Chakrapani et al., 2022) and similarly for female sex workers, LGBTIQ and PWUD in Bangladesh (International Centre for Diarrhoeal Disease Research Bangladesh, 2024, Save the Children, 2024). In Pakistan, PWID expressed concern about the decrease in harm reduction services specifically the distribution of clean needles/syringes which was severely hampered (Van Hout et al., 2022). Between March to May 2020, at least five member countries of the South East Asia Region of WHO reported significant decline in the number of monthly HIV diagnosis compared to corresponding months in 2019 and hence initiation of treatment of new cases also declined (World Health Organization, 2022). In Nepal the number of people tested for HIV declined by 63% (Arsenault et al., 2022) and in Bangladesh by 86% in the early stages of the pandemic (United Nations Bangladesh, 2020). In India, data from a survey of PLHIV across 15 integrated HIV care centres in different cities showed that 52% and 45% of PWID and males who have sex with males, respectively, faced barriers in accessing HIV treatment services (McFall et al., 2022).

In India sex workers had limited access to SRHR services during the pandemic because of the lockdowns and also in part because of budgetary constraints as services were diverted towards COVID-19 (Rahman and Dang, 2023). LGBTIQ youth in Bangladesh reported not having access to condoms, lubricants and SRH services (Rahman et al., 2022). A similar finding was reported by males who have sex with males in Chandigarh, India (Chakrapani et al., 2022).

DIGITAL TECHNOLOGIES

Digital technologies were widely used during the pandemic for different purposes – contact tracing, medical advice, registration for tests and vaccines. In many South Asian countries digital technologies are limited with lower use by women compared to men, in rural versus urban areas and by less educated versus well educated groups of people (Rahman and Dang, 2023). In the case of marginalized communities, the use varied but by and large many did not have easy access to these technologies. For example, sex workers needed help in using the app for accessing vaccines as discussed below (Naripokkho, 2024). In India, language barrier was reported as an additional issue for example not using simple language that could be understood by people with different levels of literacy (Rahman and Dang, 2023). In Bangladesh, women's rights and legal aid organisations urged state authorities

to introduce virtual courts to ensure justice including for violence against women however, it is not clear whether or how successful this was for marginalised communities (Sultan et al., 2022). Despite the shortcomings of digital technologies, it was reliance on simple technologies such as WhatsApp, hotlines and telemedicine that enabled many from marginalised communities to access services as discussed later.

ACCESS TO VACCINES

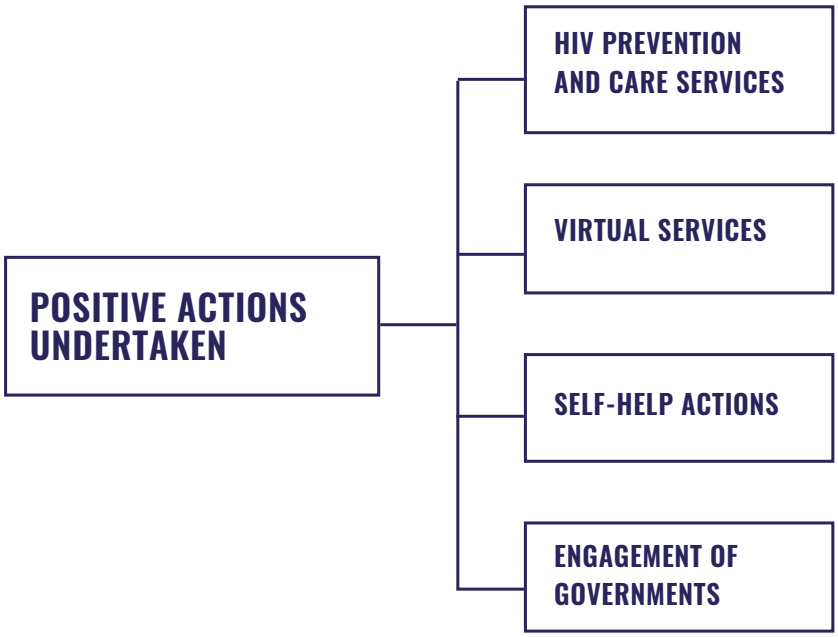
Marginalised communities faced several barriers in accessing COVID-19 vaccines. These included transport issues, lack of national documents, stigma and discrimination, as well as lack of knowledge (Rahman and Dang, 2023, D'Souza et al., 2024) and in some case, vaccine hesitancy (Save the Children, 2024). The lockdown together with the associated loss of income, made it difficult for many from these marginalised communities to reach vaccination centres (Rahman and Dang, 2023, D'Souza et al., 2024). In Bangladesh, approximately 40% of sex workers operating from different venues had national identity cards and many among them were vaccinated but several did not get vaccinated for various reasons including not wanting to disclose identity and vaccine hesitancy (Save the Children, 2024). Transgender women reported discrimination against their community as a major barrier to getting the vaccine for example in Bangladesh and Pakistan they were forced to queue with either males or females as the lines were organised based on the binary male/female sex where they faced humiliating comments (Rahman et al., 2022, Khan, 2023). Overall, information on vaccination of PLHIV is limited. A small hospital-based study in Jhelum, Pakistan, among 95 PLHIV who were admitted, found 56.8% were vaccinated (Hameed et al., 2022) and the common reasons for not getting the vaccine, among the unvaccinated, were lack of trust in the medical centres as well as in the vaccine,coupled with belief that COVID-19 is a short lived illness.

Information on vaccination of PWUD is limited (Price et al., 2024) especially from LMICs. In Bangladesh, an NGO helped nearly 3000 PWID to get vaccinated from their own centres (Save the Children, personal communication).

POSITIVE ACTIONS AND COPING MECHANISMS

Despite all the negative consequences of the pandemic there were many positive responses and organisations working with marginalised communities, feminists and human rights activists and affected communities themselves rallied to ensure continuity of services using innovative methods and strategies (Reza-Paul et al., 2022, Reza-Paul et al., 2020, UNAIDS, 2021). Fig. 2 outlines some of the positive actions undertaken for various services and by different groups of people each of which is discussed here.

Fig. 2. Positive actions undertaken for various services



HIV PREVENTION AND CARE SERVICES

In all four countries strategies were devised for ensuring regular provision of antiretrovirals (ARVs) for PLHIV and opioid substitution therapy (OST) for PWID (Shafiq et al., 2024, SPARSHA Nepal, 2020) and often by providing take home doses (Khan et al., 2021, SPARSHA Nepal, 2020, UNAIDS, 2021). Door-to-door and one on one outreach services were also enhanced to ensure services to sex workers, PWUD, LGBTIQ and PLHIV in all four countries (International Centre for Diarrhoeal Disease Research Bangladesh, 2024, Save the Children, 2024, Theresa et al., 2021).

A report from one medical hospital in Karachi early in the pandemic showed an uninterrupted supply of ARVs to 100 PLHIV between March-May 2020 (Maroof et al., 2021). In Nepal the national guidelines for ART were modified just prior to the pandemic because of the high level of resistance observed with the existing regimen. The new regimen was more stringent in the requirement of measuring laboratory parameters such as viral load which mandated a visit to the medical centre. Nonetheless, given the lockdown, the government along with NGOs adapted the process by ensuring a one-stop comprehensive service model so that clients got all the tests, medical check-up and medicines from the same site. For those who could not come to the site, staff went to their homes to collect the samples (SPARSHA Nepal, 2020).

In Bangladesh, in the early stages of the pandemic, most PLHIV were able to refill their ARV supply through medical centres and the few remaining received them through courier services (UNICEF and UNAIDS, 2020). Courier services were also used in Pakistan for delivery of ARVs (Ahmed et al., 2022). Such home delivery was however, not without complications; a sex worker from India said that when ARVs are delivered at home confidentiality can be breached which can create major problems including eviction from the home by the landlord (Pollard et al., 2021). A similar concern was expressed by a PLHIV in Pakistan who was worried about having to face increased stigma and discrimination by the society (Ahmed et al., 2020). To counteract this, discreet private sites near patients' homes were also established for ARV distribution (Hung et al., 2022, Ahmed et al., 2022). For HIV prevention among the LGBTIQ community, condom delivery was ensured in Bangladesh through need-based schedule adjustments, distributing up to a month's worth of condoms to minimize outreach visits, introducing community-based condom depots at residences of outreach staff and delivery through couriers, and encouraging virtual communication by meeting additional phone/internet bills of service providers to strengthen follow-up (International Centre for Diarrhoeal Disease Research Bangladesh, 2024). In Pakistan, the NGO, Nai Zindagi ensured continued services for PWID, both males and females, including HIV testing and visit to ART clinics of HIV positive PWID using vans following all precautionary measures (Nai Zindagi, 2020). In both Bangladesh and Pakistan, the NGOs ensured that frontline workers were provided with PPE (Nai Zindagi, 2020, International Centre for Diarrhoeal Disease Research Bangladesh, 2024).

VIRTUAL SERVICES

Messaging using WhatsApp and telephone were common in all four countries (Sehgal and Patni, 2023, Hung et al., 2022). PLHIV in India appreciated and used phone consultations with doctors and counsellors in India (Hung et al., 2022). In Nepal, online services including messaging on ART adherence, appointments for HIV testing and collection of ARVs proved to be effective during the pandemic (Bam et al., 2021) which was also reported by some PLHIV in Pakistan (Ahmed et al., 2022). Social isolation was particularly distressing for the LGBTIQ community and one of the ways to overcome this was to connect virtually with their peers through telephone and WhatsApp (Chakrapani et al., 2022). Some sex workers explored video sex and sex chats and transacted through money transfers (Reza-Paul et al., 2022) which enabled them to earn money without getting exposed to the virus. In some places sex workers opened a tele-counselling service to support their peers (Reza-Paul et al., 2022).

SELF-HELP ACTIONS

The affected communities themselves were active in mobilising their own resources to overcome some of the obstacles they faced (UNAIDS, 2021). Some examples from South Asian countries reviewed here are provided below:

- In India, female sex worker networks in several states, played a proactive role in ensuring supplies of food to sex workers(Godbole, 2020, Reza-Paul et al., 2022) as well as alternative sources of income (Reza-Paul et al., 2022). Sex worker networks mobilised themselves to also ensure HIV treatment for sex workers living with HIV (Reza-Paul et al., 2022).[1]
- In Bangladesh the PWUD network started a food distribution initiative named ‘one meal a day’ at a low scale from self-contributory money (Save the Children, 2024).

1- The Durbar Mahila Sommonoy Committee which is an organisation of thousands of sex workers in Kolkata Sonagachi brothel, organised and collected and distributed food and other essentials to the sex workers. Sex workers tried alternative sources of income in Delhi where they negotiated with some housing cooperatives and started distributing vegetables, fruits, and other essential items door-to-door in the neighbourhood. In Mysore, a sex worker organization called Ashodaya Samithi used its previously established linkages with the district hospital and a system of “community health-care navigators” within the hospital’s ART centre to form a community-led ART distribution system for sex workers during the pandemic. For setting up this system, several activities had to be undertaken including obtaining district-level authorization, securing ARV supplies, collating information on members living with HIV and receiving ART, mapping discreet distribution sites and ensuring privacy at those locations. The popularity of Ashodaya’s approach led to other sex workers outside the network seeking its services. This successful system was then adopted in other districts where Ashodaya worked.

• In Nepal, nutrition support was provided by the National Association of People Living with HIV/AIDS to PLHIV and sex workers (UNAIDS, 2021).

ENGAGEMENT OF GOVERNMENTS

Special drives were conducted for some of these marginalised communities not just by the NGOs and activist organisations, in some cases the government was also mobilised. In India, in some states and cities (Mumbai, Maharashtra, Delhi, Kolkata), NGOs and sex worker organisations successfully advocated with the government to include sex workers in the government's food aid packages (Sehgal and Patni, 2023). In Bangladesh, hubs were opened within the premises of one brothel by the government for COVID-19 testing and vaccination (Naripokkho, 2024). In India, the state governments of Delhi, Maharashtra, and West Bengal established vaccination centres for sex workers (Sehgal and Patni, 2023). In Bangladesh, the national AIDS/STD Program (ASP) circulated an official letter recognising HIV prevention services as a health emergency program aimed at district administration officials and law enforcement agencies (Save the Children, 2024). For people who use opioids, in India the National AIDS Control Organisation (NACO) made changes to its guidelines to allow PWUD to receive take home doses for OST, more fresh needles/syringes at one time as well as online helpline services for mental health issues (Parmar et al., 2020). On 14 April 2020, the Ministry of Health and Family Welfare, Government of India, issued a guideline to states for ensuring an uninterrupted supply of ART to PLHIV, through decentralized drug dispensation (Reza-Paul et al., 2022).

THE PANDEMIC RESPONSE: GLOBAL POLICIES AND EVIDENCE GENERATION

After the WHO declared the novel coronavirus to be a Public Health Emergency of International Concern on 30th January 2020, it provided interim guidelines to countries on how to control and manage the spread of the pandemic. As the situation became alarming, in May 2020 an independent Panel for Pandemic Preparedness and Response was formed at the request of the World Health Assembly to the Director General of WHO. This independent panel was tasked to review global actions undertaken for controlling the pandemic. In its report presented in 2021 the Independent Panel noted the failure of the response globally and highlighted many factors undermining the response (Singh et al., 2021, The Independent Panel for Pandemic Preparedness & Response, 2021, The Lancet, 2024). Among the many

shortcomings noted, one crucial factor was ignoring structural inequities including gender dimensions (Singh et al., 2021, Smith et al., 2022), along with a lack of community engagement and local capacity building so that the pandemic response was disconnected from local needs (Haldane et al., 2021).

The WHO developed a strategic COVID-19 Preparedness and Response Plan (SPRP 2021) (World Health Organization, 2021a) accompanied by the COVID-19 Operational Plan guideline for countries to undertake key actions and measures at national and subnational levels for a comprehensive and effective response to COVID-19 (World Health Organization, 2021b). In South Asia, a poor score was obtained using the Global Health Security Index (Babu et al., 2021) for several reasons including poor health infrastructure, inadequate financing and weak planning. However, this along with other existing frameworks have been criticised in that they address only the structural aspects of the health system (Tan et al., 2021) and ignore the many gender dimensions of the pandemic (Smith et al., 2022). The pandemic response overlooked social inequities not just between high-income countries and LMICs, but also within each country. Countries used categories of risks to allocate scarce resources however, individuals who are already subject to unfair disadvantage such as the marginalised communities reviewed here, were overlooked, despite warnings (Platt et al., 2020, Vasylyeva et al., 2020). Laws criminalising sex work, same sex relationships and drug use in many countries (UNAIDS, 2022, Beyrer et al., 2024) further marginalised these communities so that they were excluded from the pandemic response especially in the early stages of the pandemic.

Taking into cognizance the need for a more effective pandemic response an Intergovernmental Negotiating Body (INB) was established during the World Health Assembly in 2021 which was mandated to negotiate a pandemic treaty with all Member States of WHO (Gostin et al., 2024, World Health Organization, 2021). However, this body has been unable to reach a consensus and its mandate has therefore been extended till 2025 (Al Jazeera, 2024). The lack of consensus underscores the divide between high- and low and middle income countries and the power of multinational conglomerates and highlights issues of inequitable distribution of commodities and rights.

The generation and use of evidence for planning and implementation are essential for an effective pandemic response. The Independent Panel noted that the surveillance system could not keep pace with the spread of the virus (The Independent Panel for Pandemic Preparedness & Response, 2021). Moreover,

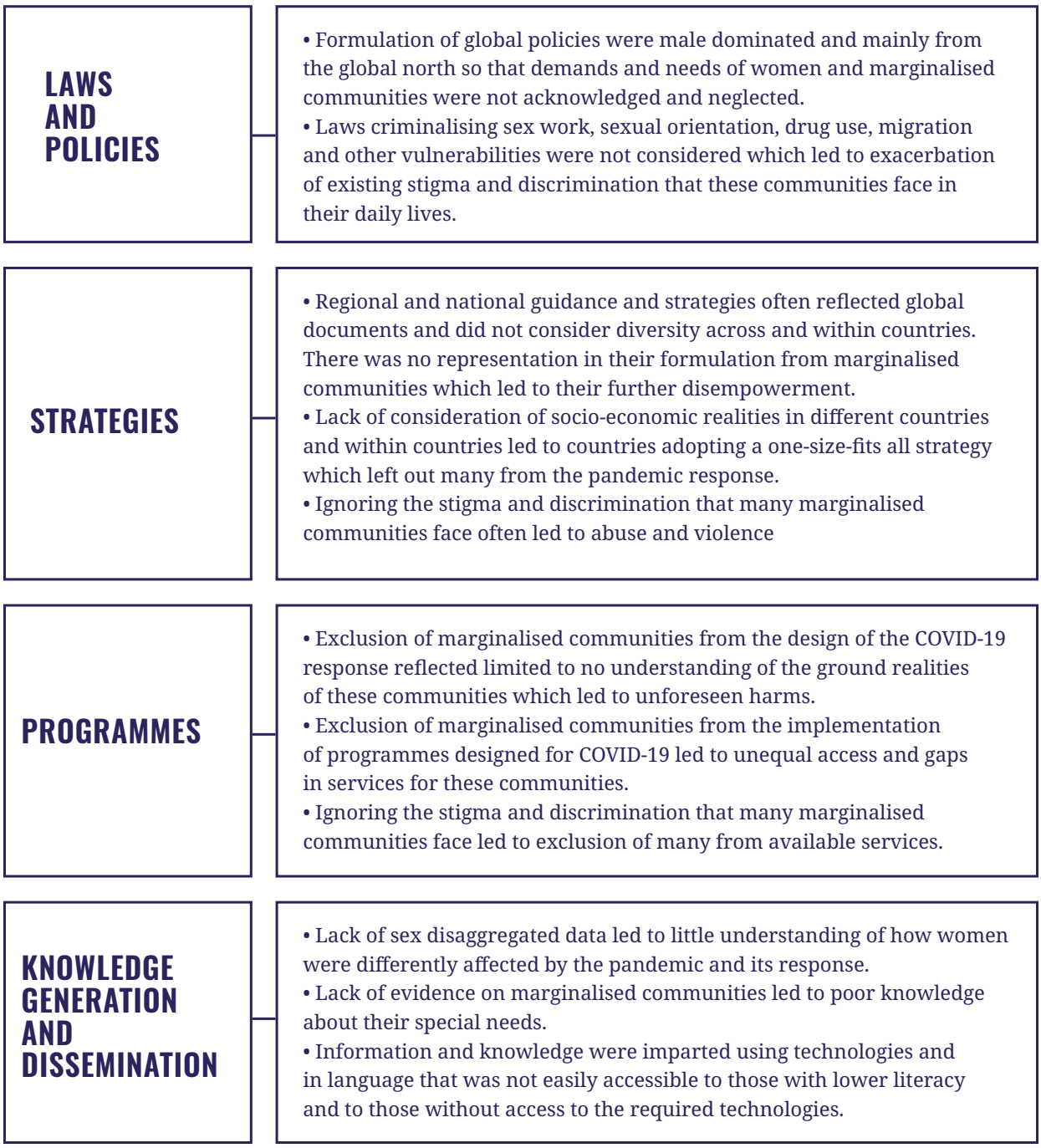
evidence was lacking on many fronts and where it was available, it was often ignored.

The lack of consideration of gender in the collection, synthesis and analysis of data hamstrung gender-responsive policy and action (Hawkes et al., 2022, Gilson, 2021). Analysis of WHO COVID-19 publications, which played a key role in guiding countries on how to manage the pandemic, showed that over half do not discuss women or gender and those that do are restricted to biological sex and ignore gender diversity (Tomsick et al., 2022). In South Asia the systems for gathering and reporting information on diseases are generally insufficient and inefficient which was reflected in the weak surveillance system for COVID-19 (Sarkar et al., 2020). Availability of evidence on marginalised communities was uneven as evidenced from all four countries presented here where the maximum number of publications were available from India followed by Bangladesh. In general transgender communities were well represented in the publications from all four countries. The information presented here were in many cases obtained through informal sources using personal networks. As examples, gaps in information were observed for PWUD/PWID (Price et al., 2024), female sex workers in some countries especially Pakistan and Nepal, violence against women, and gender diverse people (Sultan et al., 2022) among others. In most cases, countries responded to the special needs of marginalised communities as an afterthought and after much activism on the part of civil society including feminists and most importantly by the affected communities themselves.

LESSONS LEARNT

Globally, a hallmark of the COVID-19 pandemic was deepened inequities, disproportionately impacting those most vulnerable. The pandemic response reflected deep rooted underlying issues based on social and gender norms which reinforce the existing patriarchal system which in turn is bolstered by laws and policies that are generally determined by men, mainly from the global north. Knowledge power dynamics are similarly determined by the same social structures that exclude women and marginalised communities resulting in overlooked needs of people in all their diversity. Thus, social and gender norms guided laws and policies, strategies, programmes and knowledge generation and dissemination that determined the pandemic response as summarised in Fig. 3.

Fig. 3. Social and Gender Norms Determining the COVID-19 Response



At the same time experience of this pandemic from South Asian countries showed that communities can come forth, can become empowered in the face of adversity to take action for themselves and create allies in the process as we have seen with the activation of civil society organisations, activists and feminists and even governments. These mitigating actions, although fruitful, were not adequate but nonetheless remarkable in many instances from which lessons can be learnt for

the future. Analysis of the pandemic experience of the four countries in this region shows similar challenges faced by the marginalised communities in each country and the underlying causes were also the same. However, mitigating actions from some countries were stronger than others be it from self-help groups or others. As an example, the sex workers movement in India is very strong and sex worker associations in different parts of India were more effective in mobilising themselves as well as others. In Nepal the LGBTIQ group was able to mobilise support for their community while in Bangladesh, it was activists, feminists and NGOs who mobilised assistance.

THE WAY FORWARD: AN ETHICAL FRAMEWORK AND RECOMMENDATIONS

The COVID-19 pandemic has shown us that existing health systems are not responsive to women, gender diverse communities and other marginalised communities. Feminists have long argued that structural, social and gender norms have to be addressed to ensure equitable access to health (Heise et al., 2019, Rahman and Dang, 2023, Gilson, 2021). For this it is crucial to recognise the heterogeneity within a society and the power structure that determines how people in all their diversity may be affected by policies, strategies and programmes. Evidence from this region shows that strong self-help movements can be effective in bringing about change. Therefore, states have a responsibility in harnessing these strengths and further enabling communities so that their voices can be raised and heard. The slogan “nothing about us without us” needs to be materialised in action. Bringing these lessons together may benefit the entire region and establishing links to learn from and work with each other will allow a united front to take forward the lessons learnt.

AN ETHICAL FRAMEWORK BASED ON EQUALITY, DIVERSITY AND INCLUSIVITY (EDI)

It is essential to employ an ethical framework in overcoming inequities and discrepancies by mitigating unfair disadvantage (Gilson, 2021, Beyrer et al., 2021) and ensuring that marginalised communities receive special attention so as to prevent further harm. For this, an equality, diversity and inclusivity (EDI) framework may be considered for all future pandemics. Under this framework strategies can be undertaken and designed to meet the differing needs of each of these communities and to build on their resilience. Most importantly, engagement

of affected communities so that they are able to voice their needs and demands, participate in the programme design and delivery as well as in monitoring and evaluation of the programme will be essential for combating and managing future pandemics to ensure the right to health for all. Table 1 outlines the essential components of this framework.

Table 1. The EDI Framework for Future Pandemic Responses

	LAWS, POLICIES AND STRATEGIES	PROGRAMMES	KNOWLEDGE GENERATION AND DISSEMINATION
EQUALITY	Adopt "Health for All' as the guiding mantra so that needs and demands of marginalised communities are acknowledged and addressed in all policy and strategy documents. Challenge laws impinging on human rights and develop policies to overcome discriminatory laws.	Design and implement programmes to ensure all people, irrespective of their identity receive health services that are available, affordable, acceptable and of good quality following the AAAQ standards.	Collect information and knowledge regarding health needs and gaps of all people, irrespective of their identity.
DIVERSITY	Recognise diversity addressing differences in gender and social constructs as well as geography, literacy, ability, etc. along with their diverse needs.	Design and implement programmes such that they do not follow the one-size-fits all approach but address needs and demands of marginalised communities in all their diversity.	Gather knowledge and evidence by taking into consideration diversity and ensure that evidence is collected from different marginalised communities such that it is beneficial to all segments of society.
INCLUSIVITY	Include marginalised communities in the formulation of policies and strategies so that their voices, demands and needs are accurately articulated.	Include and actively engage marginalised communities in programme design and delivery of health care services, as well as in monitoring and evaluation to ensure that needs of diverse communities are addressed.	Include and actively engage marginalised communities in defining study objectives and methodologies, and in collecting evidence and disseminating the findings to ensure that evidence can be used to address them in all their diversity.

RECOMMENDATIONS

Going forward, using the lessons learnt and based on the EDI framework (Table 1), several approaches and actions are recommended for policy makers, planners, researchers as well as community groups, which are categorised under five broad headings:

1. CAPACITY BUILDING:

a. Build capacities of communities at the margins of society so that they are empowered to voice their needs and demands, to face crises themselves and to influence policy makers to ensure their inclusion at all levels. Cross regional linking and learning is an essential part of this process as a united front is more powerful than lone voices.

b. Enhance local capacity (national and sub-national) to enable a quick and suitable response and action. This needs to include all the necessary tools and approaches including adequately trained personnel, suitable communication methods, availability of necessary equipment, etc. along with the necessary funding.

2. PLANNING AND IMPLEMENTATION:

a. Engage women and communities at the margins of society at the outset in the planning and preparedness for a pandemic globally and nationally as they know best what they need and how the response can be adapted to their needs. Planners and policy makers have to recognise that excluding large segments of society will lead to unforeseen and often dire consequences.

b. Engage frontline workers at the outset in the planning and preparedness for a pandemic as they are the ones working in the field with marginalised communities who can provide information on how best to reach people and effectively provide services. They are also in need of protection themselves and to avoid burn-out so that addressing their needs is essential.

c. Ensure implementation of public health measures with participation of community members.

d. Devise technologies based on the needs of different communities – this cannot be a one-size-fits-all approach. The heterogeneity within societies, gender, socio-economic status, legal status, physical and mental abilities, geographies, etc. and intersectionality has to be acknowledged and taken into account.

e. Ensure adequate resources in ways that employ existing structures to the maximum and at the same time improve and bolster those systems. Some systems such as community outreach and health workers already exist and work well in many settings, it is important to engage and empower them.

3. MONITORING AND EVALUATION:

a. Monitor and evaluate public health measures undertaken in partnership with communities.

b. Ensure monitoring is real time so that corrective action can be taken early.

4. EVIDENCE GATHERING AND RESEARCH:

a. Gather and analyse data on the various communities and their needs and possible impacts. This should be done using a participatory approach so that communities are engaged in collecting data.

b. Design research to be inclusive of gender diversity and marginalised communities. This includes surveillance design; trials for pharmacological measures such as medicines, vaccines; stigma and discrimination; violence; access to services; etc.

c. Ensure that researchers from LMICs define research priorities themselves and synthesise evidence in partnership with local and global researchers.

d. Disseminate research evidence widely in language that is accessible to different audiences.

e. Ensure use of evidence for advocacy and action.

5. STRUCTURAL BARRIERS:

a. Remove structural barriers to address stigma and discrimination including laws that criminalize activities that many in these marginalised communities are engaged in by involving human rights groups and law makers.

b. Ensure human rights and health for all by applying the AAAQ approach for all services using the EDI framework by advocating and engaging with communities and policy makers.

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