



## Perspective

# Missed opportunities in using lessons from HIV response to combat COVID-19 - looking back while preparing for the next pandemic

Global response to the HIV pandemic over the last few decades taught the public health world numerous lessons. Multi-sectoral response, community and civil society engagement, rights-based approaches, innovative financing and extensive use of disaggregated local data were amongst the most significant. Few of them were even transformative for the health sector. This article describes how some of these key transformative lessons were not used to deal with the COVID-19 pandemic. It would be useful to look back, assess gaps and suggest how the world could be better prepared for the next pandemic that is inevitable while the global preparedness process is underway<sup>1,2</sup>.

### HIV epidemic and the lessons learnt

Four decades back, the world was confronted with a new pandemic of HIV, a disease poorly understood in its presentation, ways of control, diagnosis and treatment at that time. It eventually killed 40 million people since its recognition in the early 80s and infected 80 million people<sup>1</sup>. In contrast to the older methods of epidemic disease control by a top-down approach with forced mass testing, contact tracing, coercive quarantines and isolation, HIV response embraced a novel and humane approach to infection control with affected populations at the centre of response with the protection of their rights<sup>1</sup>. Further, rational methods of surveillance of HIV using sentinel sites, often in anonymous ways, helped localization of the epidemic in specific population groups and geographic areas, which were successfully used in the allocation of resources by targeting interventions appropriately<sup>3</sup>. The epidemic also made a paradigm shift in disease response through multi-sectoral intervention approach often led or endorsed by heads of state and extraordinary success in mobilizing resources from almost nothing in 1981 to 548 to an estimated 21 billion USD annually by 2025 in low- and middle-income countries<sup>4,6</sup>. Diagnostic

tests and treatment regimens were developed at unprecedented speed and treatment standards often became similar for people in both the global north and south. In all, seven major factors made HIV response unique. These were: (i) multi-sectoral response; (ii) high level of political commitment; (iii) unprecedented resource mobilization; (iv) investment in research and development of products and making them available and affordable; (v) collection and use of local data; (vi) communities and civil society engagement; and (vii) ensuring the rights of the affected and infected people with the provision of access to diagnostic, preventive and treatment services.

### What was missing during COVID-19 response

During the COVID-19 pandemic, while a few lessons learnt from HIV were used, some key ones were missed worldwide. First notified in January 2020, around 750 million cases and seven million deaths due to COVID-19 were reported in three years to date. The estimated cumulated deaths until the end of 2021 are around 15 million, pending estimation for 2022<sup>7</sup>.

The world swiftly adopted a few of the lessons learnt for tackling COVID-19 also. For example, there was a multi-sectoral response, often led by the Heads of the States. There was also extraordinary financing provided for prevention, research and treatment, and new products were developed at speed. In many ways, these moved faster than what was witnessed during HIV, within two years compared to what was achieved in 10 years.

However, three critical elements of HIV response were missing during COVID-19 response; (i) conducting local easy-to-perform surveillance and using results of such surveillance to focus on geographic areas and population groups; (ii) a response informed and led by the community; and (iii) ensuring

the rights of the affected and infected people with the provision of access to diagnostic, preventive and treatment services. Despite early awareness of the epidemic since January 2020, these three powerful elements of disease control were poorly practised and funded by governments and multilateral agencies, and these were also minimally highlighted in international peer-reviewed publications, journals or technical guidelines<sup>1,8-11</sup>.

### **Easy-to-collect data through surveillance: Missed opportunity to localize responses**

One central pillar of HIV success that was forgotten was the need to localize data at the beginning of transmission of the COVID-19 epidemic. In the case of HIV, a disease without visible symptoms that people were reluctant to report due to stigma, sentinel surveillance was conducted with specimens of blood already collected in antenatal clinics. This could be analyzed for disease burden estimation, incidence and mortality projection. Such surveillance based on already collected blood provided information on trends of HIV prevalence and informed the priority of interventions in low- and middle-income countries, whereas higher-income countries continued to use case reporting<sup>12</sup>. Thus, nationwide HIV interventions could be targeted in a few locations with higher HIV prevalence among ante-natal clinic attending women. Resource-intensive testing and case-finding methods were avoided and services were provided to those who needed them most<sup>12</sup>.

In the case of COVID-19, the epidemic was mainly mapped based on case notifications in higher- and lower-income countries. Passive sentinel surveillance of hospital and health-care centre attendees to identify the presence of COVID-19 or its markers, followed by ring-fencing by preventive measures, was either neglected or not used. Non-stigmatizing testing of unlinked anonymous sampling for trend and disease burden estimation was ignored even when protocols were available. Instead, mandatory testing and compulsory isolation were resorted to<sup>13,14</sup>.

Unlike the targeted approach in HIV response, the lack of localized data in the case of COVID-19 resulted in nationwide lockdowns, with severe economic and human consequences. By April 2020, nearly 3.9 billion people were under lockdown globally, including 1.3 billion in India, where the epidemic had hardly started<sup>15</sup>. This was despite the fact that, even at the height of the

COVID-19 Delta variant epidemic in mid-2021, most of the cases in India were from a limited number of the districts and States<sup>16</sup>.

According to The United Nations Educational, Scientific and Cultural Organization (UNESCO), 47 per cent of the global student population was under lockdown in 63 countries<sup>14,15</sup>. Passive surveillance of COVID-19 was recommended by several institutions such as ICMR but was never fully implemented, even in India<sup>16</sup>.

### **Neglect of community-led response as a core element**

Before the advent of HIV, never in the history of epidemics, affected community played a key role in preventing the transmission of infection and scaling up interventions. Even before HIV testing was available, MSM communities in the United States of America started behaviour change through collectivization and peer pressure, awareness raising and the use of condoms, resulting in declining cases of HIV. Large-scale early detection of cases through community-based testing and counselling was seen in Africa. Nationwide behaviour change, even within the marginalized group of sex workers, was possible when organizations of sex workers were funded and empowered for awareness generation, distribution of condoms and creation of demand for treatment of sexually transmitted infection at community level. In the HIV response, quarantine was replaced by community-led patient-empowered testing and voluntary uptake of prevention methods instead of forceful isolation. Such a participatory method of control was forgotten during the COVID-19 response.

Before the first indigenous cases of COVID-19 were detected in India, non-coercive methods of active searching and tracking cases through household visits with voluntary isolation and quarantine with the help of local civil society organizations, non-governmental organizations and community workers in community settings, such as schools or even in homes where possible, were suggested<sup>17,18</sup>.

### **Ensuring the rights of the affected and infected people with the provision of access to diagnostic, preventive & treatment services**

COVID-19 diagnostics and vaccines were made available much faster than HIV (against which a vaccine is yet to be discovered), but access was delayed due to commercial interests and regulatory barriers that

resulted in many avoidable deaths and illnesses. Such barriers were faced during HIV response in the context of anti-retroviral therapy, but no lessons were learnt when the world faced a new pandemic. Regulatory and licencing flexibilities were not used, and the pharmaceutical industry continued its usual practices of restricting access to technologies and products often supported by governments.

### Response to future epidemics

The crucial lessons from HIV response, unless utilized in future pandemics, will keep society vulnerable. It is high time that strategies and financing plans for pandemic preparedness consider these lessons.

In the case of HIV response, financed through the largest public funding mechanism of the Global Fund, however, community ownership was insufficient. This led the Joint United Nations Programme on HIV/AIDS (UNAIDS) to shift its strategy from a mere community friendly to a community-led intervention strategy endorsed by the heads of state in the UN high-level meeting<sup>19</sup>. Even then, no lessons were learnt, and the response to subsequent epidemics, such as severe acute respiratory syndrome, middle-east respiratory syndrome and Ebola, witnessed increasingly host-centred control, and the role of the community was consistently neglected. We are likely to face more pandemics, with some researchers suggesting that the time between consecutive pandemics is shortening. The early detection of epidemics is most important in responding to a pandemic. There has been significant emphasis on genomic surveillance, while failure to operationalize easy-to-use surveillance mechanism at the local levels is underemphasized.

HIV and COVID-19 differ in many ways. Nevertheless, many of the lessons from HIV response could have been helpful also in the COVID-19 response. While there is some recognition of the importance of leveraging lessons from HIV in future pandemic preparedness, the role of community-led interventions and local surveillance need emphasis in requests for Pandemic Preparedness Fund<sup>20</sup>. It is high time that governments, academics, UN agencies and development partners ensure that the lessons from HIV response are institutionalized in development of strategies and new funding opportunities for pandemic preparedness<sup>1,20</sup>.

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