Meeting summary
04 March 2021, 10:00-12:30 CET

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1. Introduction

The EU Civil Society Forum (hereafter CSF) started with a preliminary debrief from the members’ survey on expectation and motivation to engage. Members who have not yet replied, were encouraged to do so by 15 March 2021.

Motivations/expectations:

- Sharing of on the ground experiences and be informed of best practices in Europe
- Members want to be part of this work for joint advocacy efforts
- Sharing expertise on EU funding

Challenges:

- Lack of workplan in the beginning
- Online format also a challenge – not seeing each other
- Too little advance planning of meetings
- Missing: more space getting to know other organizations

2. UNAIDS Strategy Development and follow-up action

Ferenc Bagyinszky from AIDS Action Europe (observer at UNAIDS Programme Coordinating Board) reported on the UNAIDS 2021-2026 strategy to be adopted on 25 March. See ppt here.

The draft strategy places greater emphasis on inequalities. The 2025 targets are more ambitious than the 2020 targets and now finally go beyond treatment. Overall, the NGO delegation welcomes a progressive strategy. Broad sign up by member states will be useful at national level for advocacy. After the strategy is adopted focus will need to be on funding for national programmes, including civil society.
It will also be important for civil society to be involved in the preparation of the UNGA high level meeting on HIV/AIDS on 8-10 June 2021. A UNAIDS call for a civil society platform was launched. Civil society to be involved in preparation for meeting and in the wording of political declaration document.

The CSF then discussed the trend to shrink the space for civil society everywhere. The UNAIDS PCB was set up in 1994-1995, and is now being questioned by member states. There is a push to remove civil society seats. The PCB has traditionally worked on consensus.

If the Strategy approved in March, UNAIDS will have to set up a monitoring system and attach a budget to the strategy.

It was noted that communication between the Global Fund and UNAIDS appears to have improved. Continuous pre-negotiations and discussions between the Global Fund and UNAIDS civil society delegations seemed to be effective in supporting cooperation between the two institutions.

The discussion then moved to COVID-19 and a context where funds are going towards COVID-19 vaccine key players. It was noted that the greater emphasis on inequalities and a human rights approach to health in the UNAIDS strategy came from the COVID-19 crisis and the ensuing inequalities and rights violations. Member states who argue that HIV rights are not human rights were unhappy with the UNAIDS COVID-19 report, which underlined human rights aspects in how the pandemic unfolded.

In the run of the meeting where the strategy (24-25 March) is to be adopted, CSF members were encouraged to press their governments (development or health ministries) to highlight civil society support for progressive strategies. Civil society representatives on the UNAIDS PCB are deeply engaged in this direction. For instance, the Civil Society and Key Populations communities from Central, Eastern European and Central Asia region to support Global AIDS Strategy zero draft was a response to opposition https://eecaplatform.org/en/ceeca-letter-to-unaidsl.

3. Stigma and discrimination within the Dublin reporting

Teymur Noori, from ECDC presented on a planned survey on stigma and discrimination as part of the Dublin Monitoring survey. He noted that while data about HIV testing/treatment targets and incidence, and prevention enable a better understanding and measuring of the gaps to be addressed. However, the stigma gap remains unaddressed. ECDC already started discussion with the Dublin Advisory Group how to measure and monitor stigma and discrimination in healthcare settings. The Global AIDS Monitoring includes standardized stigma indicators: a) Discriminatory attitudes towards people living with HIV; 2) avoidance of health care among key populations because of stigma and discrimination and 3) Experience of HIV-related discrimination in health-care settings. However, most countries do not have data on these indicators. The 2021 Dublin Declaration Questionnaire was just sent out. Community-based organization could support national focal points in reporting. The 2021 questionnaire is shorter and now includes specific questions on laws and policies & stigma and discrimination.

The principles behind the survey are:

- Simple (5-10 questions)
- Either PLHIV, communities at risk for HIV/NGOs
- Manageable: driven by community
- Dedicated resources from members of CSF needed
- Cheryl Gowar will be providing a brief on stigma
- Meaningful to advance our understanding of stigma and discrimination
- Replicable (e.g. 2021, 2025, 2030) to show progress over the next 10 years
CSF members of the Dublin advisory group added some questions for discussion:

- Focus on HIV care or healthcare settings?
- Decide on indicators to track
- Important to make this replicable to compare over time
- Resources – network support needed at regional level
- Translation support would be needed. This should be feasible if the survey is brief
- Taking advantage of networks is crucial for dissemination of survey.

The meeting participants overwhelmingly advised to address people living with HIV rather than organisations. It was noted that a methodological tool other than a survey will be needed to reach some communities.

The stigma indicators and how to define them were discussed. It was suggested to a quick literature review on the subject (rather than a long one). The Stigma Index carried in several European countries, the UK Positive Voices questionnaire and UNAIDS examples of stigma indicators in South America could provide a good starting point.

Moreover, it was suggested to ask the European Commission for $ a Eurobarometer survey on knowledge, attitudes towards people living with HIV. It was also noted that HIV stigma cannot be resolved without addressing homophobia which strong in a number of countries. Such Eurobarometer survey would not capture that. It was suggested to ask the EU Fundamental Rights Agency to look at intersecting discrimination.

AIDS Action Europe reported that the HIV Legal Forum is working on legal report, with case studies on discrimination against people living with HIV in healthcare in 11 countries. It will be ready around the end of November 2021. It could be presented at a future CSF.

**Next steps**

The CSF Working group on Dublin declaration will take the discussion forward and provide ECDC additional feedback. It was suggested to consider casting wide net and have two sets of questions (for instance, five questions addressed to persons living with HIV and five addressed other communities at risk.

4. **Impact of the COVID-19 pandemic on the diagnosis of HIV, viral hepatitis and STI and TB in Europe**

Daniel Simões reported on the results on the assessment on the impact of the COVID-19 pandemic on the diagnosis of HIV, viral hepatitis and STI and TB on behalf of EuroTEST. The initiative was supported by a consortium of partners around Europe and was addressed to laboratories, secondary care clinics, primary health care units, community testing sites, national public health level. The survey was conducted in October-November 2020. There has been a significant decrease in testing with 50% less tests done from March to May. There was a in June-August but not as drastic as the one in Spring. It appears that community organizations were most affected compared to secondary care providers and national sites in the first three months (80% community respondents were doing 50% less tests). The
reasons reported for the observed declines in testing volume included sites closed because of lockdown, staff being re-allocated, fewer appointments, triaging of patients, move to remote services options.

In response to the disruption various measures were introduced: remote counselling in community and secondary care, remote counselling, HIV self-testing options, triage of patients and on appointment services, testing campaigns at community level. Guidance or support considered important to reduce impact. Survey respondents considered additional human resources, increased financial support and regulatory changes important.

Responses to the survey highlighted some linkage to care issues (34% of community testing sites indicating issues in linkage to care). This were due to to delays in scheduling consultations, contacting specialist care units, no referrals possible, specialist care closed, etc.

Secondary care sites did not report changes in majority of situations regarding time to results and treatment initiation. However, mentioned increased time lapse and other reduced time delay in terms of testing, treatment, and monitoring of patients

Magdalena Ankiersztejn-Bartczak reported on the self-testing programme started by Foundation for Social Education (FES) in Poland during the first wave of COVID-19 restrictions from March to May 2020. The organization opened a testing helpline, through which free self-testing could be ordered. The organization used Simplitude test. FES is looking into how to maintain this programme as the initial funding is ending. She stressed the importance of including pre and post counselling though noting the latter as an issue to be follow up. There were 1062 orders (57.5% men; 42.5% women). Overall, COVID-19 has a huge impact for HIV and STI testing in Poland. She emphasized the need continue reminding that HIV, viral hepatitis and STI prevention, testing, care and support services are essential and must continue to be supported; especially during times of crisis

Halvor Frihagen from HIV Norge (Norway) reported on the situation in Norway. In 2020, Norway has not that the strict lockdown as experienced in other countries. There are about 4000 persons living with HIV in Norway, mostly in Oslo where half of the population lives. Norway is seeking to achieve the 95-95-95 targets. There has been drop in incidence amongst MSM. During the first COVID-19 wave, testing has remained available, by appointment only. Helseutvalget working on drop-in basis a bit still. NGOs had very limited number of positive test results. They cautiously starting self-testing as there are concerns around follow up and linkage to care. The relatively good system for electronic prescriptions has been helpful for ARVs prescribing.

5. Access to COVID-19 vaccines for different vulnerable groups

The session started with a presentation from Alyna Smith, Platform for the International Cooperation on Undocumented Migrants (PICUM) on the explicit inclusion and exclusion of undocumented migrants in/ in vaccination programmes. PICUM is monitoring national vaccination policies at national level via media and information reported by its members.

There are variations in access policies. In Belgium, France, Ireland, Italy, The Netherlands, Portugal, Spain, UK, undocumented migrants are explicitly included in vaccination plans. There are variations in access policies and some concerns about the practice. In Ireland, a person coming forth to access vaccine will not be reported to immigrant authorities. The French government announced no distinction
based on citizenship regarding access to vaccine and a person can be vaccinated even with health insurance card present documentation. The Belgian policy at national includes undocumented migrants but at regional level only Brussels has done so. The Dutch situation is similar. In Italy, access without distinction was announced but the practice is unclear. In Spain, there is explicit inclusion but there are discrepancies among regions. In Poland only third-country nationals with right to reside in country are included.

Several practices were highlighted, starting from having a clear reference to undocumented migrants in national and international strategies. In some cases, there are instructions from government and health authorities about how to ensure undocumented ppl get COVID care. It also critical to ensure that personal data will not be shared with immigration authorities or otherwise used for purposes not related to public health. Moreover, limiting the documentation required is needed to enable access and having information in different languages. NGOs can be involved in the definition of strategies. There must also be outreach.

Several factors are reported to impede access to vaccinations including: Administrative barriers (registration, health care, social security number/health card), lack of guarantees regarding data protection, unclear policies and procedures, lack of access to reliable information, lack of unified approaches with countries where region is responsible for implementation and the two-doses vaccines.

Siddhartha Datta, from the Vaccine-preventable Diseases & Immunization team of WHO Europe office provided an overview of WHO’s guidance around COVID-19 prioritisation. In November 2020, WHO started discussion around prioritizing groups due to discrepancy between supply, demand and urgent need of vulnerable populations. It looked at the evidence base at global and regional level. Healthcare workers and elderly people were identified as first priority group. Then came the discussion around volume of vaccine needed and access Creation of COVAX. Country access to vaccine differs and there are differences in COVID-19 incidence and health systems.

The principles for prioritization include the populations who are most infected and populations who are most vulnerable, as well as the characteristics of each vaccine differ (ie. Cold chain yes/no).

The question is then measure and monitor vaccine delivery to these groups. To do so, WHO then put together a dashboard monitoring vaccine delivery by age group. Since all countries are prioritizing healthcare workers, this is too being monitored. There is plan to disaggregate this data in the future. However, data collection is challenging for regions where electronic records are not used.

Discussion

One of the critical points is what WHO will say to governments that explicitly exclude groups? WHO laid out “values” of global solidarity and equity to underpin vaccination strategies, however the issue of national distribution remains. WHO is asking governments to develop national vaccination plan and indicate which populations will be targeted and when. It is important to check if there is any population being left out. WHO points to multi-stakeholder model to identify those left out and the service delivery model that needs to be put in place to reach them. These discussions should be happening at national and sub-national levels.

WHO Europe has developed an information note on COVID-19 vaccines and people living with HIV.
Then session went to exchange based on two country reports from Norway and Spain. Halvor Frihagen from HIV Norge (Norway) provided an overview on COVID-19 vaccines access issues in Norway. By law it is available to anyone who is physically present in Norway with no restrictions. The first prioritized groups are staff/residents in homes for the elderly, health care personnel, then elderly, those with underlying conditions (including HIV) then younger population. For the general population in the health system and with a general practitioner there should not be issue. Vaccination for asylum seekers can be made accessible via centres. Concerns are mostly for undocumented migrants who are not in the health system asylum seeker organization is optimistic of access to vaccine given location in city centre.

Ramón Espacio from CESIDA, Spain reported on the COVID-19 vaccines plan in Spain. There, HIV as risk factor for COVID-19 seems to be unclear to some. Although several clinical societies published a joint statement (BHIVA, DAIG, EACHS, GESSIDE, Polish Scientific AIDS Society and Portuguese Association for the clinical study of AIDS (APECS) on 15 January. In Spain, age and comorbidity is considered the main criteria. Then, people under 60 with risk conditions putting them at greater risk. The next group include people over 16-18yrs with high-risk conditions. The health conditions implying enhanced risk for severe COVID-19 outcomes remain to be defined. A working group (SPNS, GESIDA, SEISIDA, SEF, CESIDA) has been established to make recommendations for HIV. The national platforms of patient organizations ask for priority to be given to people with pre-existing conditions with a high-risk of exposure and risk of severe of COVID-19 next. He concluded the presentation by suggesting a CSF survey about vaccination on PLHIV and other vulnerable populations.

Discussion

During the discussion, it was noted that in Italy, HIV is not specifically included as one of the prioritized conditions. However, immune deficiency diseases are so it will likely be priority.

WHO was asked about guidance. It was noted that HIV was not considered as part of the clinical trials. Vulnerability of people living with HIV is seen as the same as general population, unless there are comorbidities or immune deficiency.

6. Other points from members

It was suggested to organize a focused discussion on sex workers at a next meeting.

WHO asked to encourage regional experts to apply to the WHO Strategic and Technical Advisory Committee on HIV, viral hepatitis and sexually transmitted infections (STAC-HHS) https://www.who.int/news-room/articles-detail/call-for-expressions-of-interest-for-2021-2023-membership.

Partners of the Learn Addiction project (www.learnaddiction.eu) are carrying out a transnational study to identify training needs among those working in the field of addictions and HIV in the EU. Please reply at https://docs.google.com/forms/d/e/1FAIpQLSe9_fn76_WDALMHVnwyPYPfe4mlAli_b-FyjX4-58X6si4sz1A/viewform

7. Next meeting

Thursday 3 June 2021.