AD HOC CONSULTATION: FOLLOW-UP ON JUNE THINK TANK/CIVIL SOCIETY FORUM MEETING

29 SEPTEMBER 2015

LUXEMBOURG

Participants: Paolo Guglielmetti and Velina Pendolovska (EC, DG SANTE), Alessandra Martini (EC, DG RTD), Marina Rota (IOM), Teymur Noori and Marieke van der Werf (ECDC), Dagmar Hedrich (ECMDDA), Cinthia Menel Lemos (CHAFEA), Henning Mikkelsen (UNAIDS), Olivia Castillo Soria (Spain), Antonio Diniz (Portugal), Johann Fontaine (Germany), Tatjana Nemeth Blazic (Croatia), Piotr Wysocki (Poland), Ina Bistritchi (Moldova), Michael Krone (AAE), Ann-Isabelle von Lingen (EATG), Isabelle Eibl (Aids Hilfe Wien)

1. Welcome, adoption of the agenda

The Commission (EC) opened the meeting and greeted the participants. EC briefly presented the purpose of the meeting, with the main objective to start the process of gathering insight on the content of a possible new action plan on HIV/AIDS, with the intention to also consider hepatitis and tuberculosis as diseases on their own right. EC clarified that there is no clear position yet on the instrument and form of the action plan but that work is on-going internally to determine the course of development. EC underlined that the working methods of the Commission have changed and are now guided by the ten priorities identified by President Juncker.

Thus, the main objective of the meeting was two-fold:

- to gather information about existing on-going initiatives in the area of HIV/AIDS across Member States, international organisations and civil society organisations in order to have an informed overview of current strategies

- to gather first ideas about the priority areas for action in the future action plan, building on the existing one and also considering the possibility to add hepatitis and tuberculosis. For this first meeting, there was very limited participation of experts on these two diseases (with the exception of Marieke van der Werf from ECDC's Tuberculosis programme and Dagmar Hedrich from EMCDDA who is also an expert on viral hepatitis) and the meeting was largely focused on HIV/AIDS, yet expanding the group in the future was also considered.

The participants were also invited to discuss and agree on *modus operandi* of the group, with the leadership of the Commission in hosting and convening future meetings.

2. Presentation of delegates

The participants presented themselves in a quick tour de table. There was a good overall balance between Member States representatives, experts from international organisations (IMO, UNAIDS) and representatives of civil society. The EC was represented by DG

SANTE and DG RTD. Representatives of ECDC, EMCDDA and CHAFEA were also participating.

3. State of play – What do the data tell us? (ECDC)

The meeting proceeded with a presentation from ECDC based on the latest available data on HIV/AIDS surveillance and response. The presentation provided indication regarding the key remaining challenges: vulnerable groups like men having sex with men (MSM) covering 42% of all cases in 2013 and migrants (32%), followed by people who inject drugs (5%) and unknown/other (20%). MSM were the only group that shows an increase in cases reported (33% since 2004). On migrants, the data shows a decline of infections (61% since 2004). It was interesting to discuss that "migrants" in this sense means any person who is diagnosed in another country, i.e. both EU nationals abroad as well as non-EU nationals. ECDC also showed data from the UK from a recent study showing that a growing proportion of migrants become infected after arrival to the UK.

The presentation also revealed that late diagnosis is still a critical issue in the EU/EEA, with 47% of all cases diagnosed late. Concerning treatment, the number of people on antiretroviral therapy (ART) has almost doubled from 174 000 in 2009 to 333 000 in 2013 in 29 countries who report data consistently. In the EU, an estimated 30% of people living with HIV are unaware of their HIV status, meaning many do not have access to life-saving treatment. ECDC also showed data on the cost of ART, ranging from over €20,000 per month in Switzerland to €187 in Kyrgyzstan and an average of about €9,000 in most EU Member States for which data is available. Finally, the presentation stressed that the HIV transmission is mostly occurring in the part of the population that is infected and undiagnosed or diagnosed but not put to treatment. ECDC stressed the need to target this undiagnosed fraction and put forth the following priorities: efforts targeting prevention (i.e. for people not infected by HIV) and testing (i.e. for people infected but not yet diagnosed), followed by linkage and retention in care and treatment (for people diagnosed), and reaching viral suppression.

4. Discussion

In the discussion that followed, several points were raised (shown in the order they were raised, not ranked in importance):

Prevention:

- The term "migrant" needs to be carefully considered and broken down, if possible, to better reflect the different groups that fall under this category. Migration itself does not equal HIV vulnerability or risk.
- There may be room for raising awareness of doctors and healthcare workers, in particular when dealing with vulnerable groups such as MSM.
- Further data and studies were also needed and the EU can assist countries in that direction. In particular, studies on sexual behaviour and socio-economic determinants of this behaviour would be very useful in informing targeted prevention strategies. There can be new behavioural patterns (e.g. use of mobile phone applications to seek sexual partners,

use of recreational drugs at mass parties, etc.), which need further understanding in order to identify opportunities for successful prevention.

- The specific cultural circumstances of each country need to also be considered in building knowledge on specific vulnerable groups, e.g. migrants. Programmes need to always be country specific and targeted to the circumstances and challenges of each country.
- The criminalization of transmitting an HIV infection in many EU counties is still a barrier to effective prevention and treatment.
- On MSM, more efforts need to be invested into bringing the issue of HIV/AIDS into the radar of the gay community, raising awareness of this key vulnerable group. It is also important to consider the location and setting – where is the transmission happening?
- It is also important to engage with the city level (the example of Lisbon representing 43% of all cases in Portugal was given) to develop testing and prevention strategies.
- There is a need to consider treatment as prevention, not only hard-reduction measures but also new scientific advances such as pre-exposure prophylaxis (PreP) and post-exposure prophylaxis (PEP). The cost-effectiveness and implementation models of these measures are key. Discussions with pharmaceutical companies may also be considered.
- Over the past years there have been several important scientific and technological advances in testing and treatment but the prevention strategies have not developed with the same pace. The quality of prevention needs to be strengthened and better measured.
- Regarding research, it seems important to continue research into the socio-behavioural determinants behind the spread of the diseases, which is the more short-term type of research. In the longer run, research efforts should also include bio-medical research on vaccines and new treatments, also covering hepatitis and tuberculosis. A new EU policy would serve to steer priorities in research activities.
- The need to have more information on behavioural determinants was strongly raised. Current and past projects under the Health Programme have contributed to building the knowledge base, linking it to overall sexual health of specific groups (e.g. MSM, ethnic minorities, migrants with specific backgrounds, etc.). This information is essential to inform targeted prevention in risk communities but also to support healthcare professionals.
- The need to maintain continuity was also stressed, otherwise, efforts risk to be undermined and the epidemics risk flaring up anew. The sustainability of action, even in low-level epidemics, should be maintained in order to prevent further spread and also with an ultimate view to end the epidemics.
- Primary prevention, such as education, public campaigns and awareness raising should not be forgotten as they remain important, especially since HIV is no longer so pertinent in the public view.
- The aging of people living with HIV is a new phenomenon that has not been actively addressed yet.
- Stigma and discrimination continue to be significant barriers to effective access to testing and treatment, which need to be addressed.
- The important role of the Commission in contributing to knowledge-sharing and exchanges of best practice at EU level was strongly underlined. Member States cannot

individually achieve the same level of advanced knowledge sharing. The example of Austria was given where there is a challenge in the national capacity to absorb on national level all the useful resources that exist on EU level. EC's role in creating and maintaining a network was also highly supported, including the established dialogue with civil society through the Civil Society Forum.

– The usefulness of having a systemic view – engaging with other players such as the EU Fundamental Rights Agency (FRA) or the European Agency for the Management of Operational Cooperation at the External Borders of the Member States of the European Union (Frontex). Links to Decision 1082/2013 on cross-border health threats and the Health Security Committee should also be explored.

From the Member States present, Croatia, Spain and Poland reported that they are in the process of having new national policies/action plans being adopted. Croatia also reported about a recent publication on the lessons learnt from Croatia regarding the phasing out of the Global Fund and the transition to national solutions[1].

5. Next steps

The working methods of the group were also discussed and it was agreed that for future meetings, it would be preferable to meet for two half-days instead of one full day. The involvement of experts from the hepatitis and tuberculosis community in the future is strongly recommended. Also, it can be explored if other groups such as gay and lesbian associations should be involved. The main aim of the group would be to assist the Commission in the development of the content of the future action plan, not to deal with the form or instrument. It was agreed that the next meeting should be scheduled back-to-back with the CSF/TT meeting at the end of November.

*** End of meeting ***

[1] http://www.eurasia.undp.org/content/rbec/en/home/ourwork/democratic-governance-and-peacebuilding/hiv-and-health/sustainable-financing-of-hiv-responses.html