CBVCT Services

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Current obstacles and opportunities

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Disclaimer

The content of this report represents the views of the author and it is his/her sole responsibility; it can in no way be taken to reflect the views of others.

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Acronyms

AAE	AIDS Action Europe
AIDS	acquired immune deficiency syndrome
CBO	community based organization
CBVCT	community-based voluntary counselling and testing
CEEISCAT	Centre d'Estudis Epidemiològics sobre les ITS i Sida de Catalunya
CHW	community health worker
EATG	European AIDS Treatment Group
ECDC	European Centre for Disease Control and Prevention
ECUO	East Europe & Central Asia Union of PLHIV
EECA	Eastern Europe and Central ASIA
EFTA	European Free Trade Association
EU	European Union
HAV	hepatitis A virus
HBV	hepatitis B virus
HCV	hepatitis C virus
HTS	HIV testing services
HIV	human immunodeficiency virus
INMI	Istituto Nazionale Malattie Infettive / National Institute of Infectious Diseases
M&E	Monitoring & Evaluation
MoH	Ministry of Health
MSM	men who have sex with men
NGO	non-governmental organization
PLHIV	people living with HIV
PrEP	Pre Exposure Prophylaxis
RRI	Responsible Research and Innovation
STI	sexually transmitted infections
USA	United States of America
WHO	World Health Organization

1. Introduction

This work represents a contribution to AIDS Action Europe's (AAE) advocacy work aimed at the sustainability of Community Based Voluntary Counselling and Testing (CBVCT) services, precious low threshold contexts within community based settings that have proven to be one of the best ways to reach key affected groups and test them for HIV, hepatitis and/or STIs.

It is acknowledged that the challenge of the 90-90-90 targets will be won only by testing and diagnosing early as many as possible of the people living with HIV (PLHIV) who are currently unaware of their status. The most relevant international agencies have recognized the irreplaceable role of community sites in contacting and establishing relationships with those who do not access healthcare services due to a number of reasons, but mostly to the persistence of stigma and discrimination, that prevent them from receiving support, prevention, treatment and care[1].

NGOs, CBOs and other community organizations and networks have developed great competence and expertise in the offer of CBVCT services and in some cases have achieved amazing results in terms of number of clients tested, number of reactive tests, number of acute infections detected, percentage of new HIV cases on the total number of cases in their countries, support in linking clients to care. They have welcomed people at risk who had never been tested before as they were not allowed to access the regular healthcare system. Such positive achievements came along not only thanks to the brightness, capacity and smart work of CBVCT management and staff, but also, in a few cases, thanks to the support and recognition granted by institutional stakeholders and other relevant actors.

After more than ten years of pilot programs and demonstration projects, the opening of checkpoints and steady services, the expansion of these activities and the positive results, we still need to look into the obstacles and opportunities in the collaboration of partners in the field of CBVCT services at national and European level from different perspectives… Why? Because many barriers still must be removed to expand and improve community services, and a lot still needs to be done to improve and increase collaboration between stakeholders, in order to reach key affected populations and to benefit from more accurate monitoring at Public Health level.

[1] http://www.aidsmap.com/What-are-the-barriers-to-HIV-testing-and-treatment-access-and-how-do-we-overcome-them/page/3170458/?utm_source=NAM-Email-Promotion&utm_medium=euro-bulletin&utm_campaign=3172192

This study assembles the opinions and ideas of different stakeholders who provided very diverse points of view on the subject as they play different roles at the national and European levels and come from different countries. Their opinions and ideas, together with some extracts of the many documents produced on the subject of CBVCT services, were used as the basis to develop recommendations which serve as an advocacy tool for improving the actual situation both at the national and European level.

2. Methodological considerations

The acronym "*CBVCT*" was widely adopted in the European HIV context thanks to the HIV-COBATEST project[2], co-funded by the European Commission under the Public Health Programme 2008-2013. A study definition of "*CBVCT*" was proposed through one of the project's surveys, conducted in all EU/EFTA countries.

Consensus was reached around the following definition:

"CBVCT is any program or service that offers HIV counselling and testing on a voluntary basis outside the formal health facilities and that has been designed to target specific groups of the population most at risk and is clearly adapted for and accessible to those communities. Moreover, these services should ensure the active participation of the community with the involvement of community representatives either in planning or implementing HIV testing interventions and strategies."

No restrictions were set concerning the physical location, staff characteristics, funding source or whether testing services were provided for free or at a cost[3].

The COBATEST project represented the first European effort to put together and systematize the many experiences developed mostly through the initiatives of local/national NGOs and CSOs around the offer of community based testing services. It came to conclusion in 2012 and was soon followed by the Euro HIV EDAT project, which involved many of the partners and CBVCT services engaged in the

[2] https://eurohivedat.eu/ (Search for "COBATEST" in the list at the left)
[3] COBATEST team (July 2012). HIV-COBATEST Project: Cross-National Survey on the Implementation of CBVCT Programmes - Quantitative Report

previous project. Other important projects and studies (the OptTEST[4] project among the many and the ongoing Integrate project[5]) have been completed in the last ten years and paved the way for the development of policies, guidelines and documentation in support of community centres.

The methodology adopted for the preparation of this report consisted of some desk research around recent CBVCT policies and documents, but predominantly of the analysis of seven qualitative interviews with three representatives of CBVCT facilities, two representatives of academia as well as two CBVCT facility users.

The three representatives from NGOs were selected because of their very different and relevant experience in the field of CBVCT services:

- Michael Meulbroek of the BCN checkpoint in Barcelona was contacted because of the relevance and impressive results achieved by the checkpoint
- Richard Stranz and Grégory Braz of AIDES were contacted because of the great advocacy efforts and consequent results reached by AIDES, which secured adequate institutional funding of their testing services in France
- Loreta Stoniene was contacted because of the difficulties recently experienced by the checkpoint managed by DEMETRA, a Lithuanian NGO, as a result of the barriers posed by the health institutions that limited the offer of community testing services.

The two representatives from the academia, Jordi Casabona Barbarà of CEEISCAT, Catalonia and Enrico Girardi of INMI Spallanzani, Italy, were contacted because both of them coordinated the implementation of projects for the organization and development of CBVCT services, at European and national levels respectively. Jordi Casabona's interview should be given special attention, since he gave a very detailed and comprehensive overview of the present scenario and ongoing initiatives – obviously, from his point of view.

Lastly, the two clients who accepted to be interviewed were contacted while they were taking rapid tests in the Athens checkpoint and in LILA Milano premises.

[4] http://www.opttest.eu/
[5] http://integrateja.eu/integrate/

Some information were also derived from a recent presentation made by one of the representatives of the ECUO network in October 2016, since it offers a picture of the situation in the EECA region on the same topic of this study, i.e. CBVCT practices, challenges and opportunities for advocacy[6].

It is important to note that some of the considerations that were included do not find a specific reference in this report, since they are rather the result of the many discussions, reflections, meetings, workshops which took place in the last years during the most important meetings of the European community (the HIV/AIDS Civil Society Forum, the AIDS Action Europe Steering Committee meetings and Members and Partners 'Meetings, the European AIDS Treatment Group meetings, plus obviously many international conferences and gatherings). Lastly, LILA - the Italian League for Fighting AIDS – the organization that assumed the task to write this report, runs CBVCT services and provided some insights to the work.

[6] Madoyan, H. (September 2016). Community based HTC in EECA region: practice, challenges and opportunities for advocacy. EQUO East Europe and Central Asia Union of PLHIV

3. Main findings

First of all, it is important to highlight that all the existing literature concerning CBVCT services agree with the fact that CBVCT are key in combating the HIV epidemic as well as viral hepatitis and other sexual transmitted infections (STI).

The 2015 *Consolidated Guidelines on HIV Testing Services* from the WHO recommend that lay providers who are trained can, using rapid diagnostic tests, independently conduct safe and effective testing services. Expanding HIV testing services (HTS) to trained lay providers working in the community may help to increase access to these services and their acceptability to people from key populations and other priority groups. These groups might be reluctant or unable to use HTS in health facilities[7].

The ECDC Evidence Brief on HIV Testing in Europe, published in the same year, among the key options for action includes the expansion of community-based and outreach testing services that increase availability, accessibility and uptake of HIV testing for those who are most at risk and are most likely to have undiagnosed infection[8].

Before the age of the Continuum of care – the conceptual framework enabling countries to monitor the effectiveness of key areas of HIV response - and the "90-90-90" targets, CBVCT were already regarded as one of the most effective ways to reach key populations; presently they are acknowledged as being the key actors in the achievement of the first "90" goal – 90% of all PLHIV diagnosed and aware of their HIV status – and as playing a strategic role in linking the diagnosed people to care and in supporting them with treatment adherence and retention in care.

At the same time, among the different stakeholders and experts in the field of HIV, viral hepatitis and STIs, there is widespread awareness that community based testing services are still far from being in the best conditions to ensure the stability and continuity of their activities. In almost all of the countries of the WHO Europe Region they lack adequate funding, have to rely on the support of volunteer staff and donations from the pharma industry, private foundations and individuals (which

[7] World Health Organization (July 2015). Consolidated Guidelines on HIV Testing Services. 5Cs: Consent, Confidentiality, Counselling, Current Results and Connections

[8] ECDC European Center for Disease Control and Prevention (September 2015). ECDC Evidence Brief – HIV Testing in Europe

are harder and harder to get due to the persisting economic crisis), and are not included in national testing strategies: the data they produce are not incorporated in country reporting and surveillance systems. Needless to say, this state of things penalizes key affected groups in their access to testing, treatment and care services, as well as those community-based organizations that struggle to maintain their initiatives. Civil society representatives feel their contribution is not recognized nor valued, both at national and European levels, and the encouraging words written in the international documents are surely not enough to motivate them and help improving the situation.

Before entering in the analysis of the different aspects that need attention, it is interesting to reflect on the comment captured during one of the interviews, made by Michael Meulbroek:

"I think that the topics of this interview are outdated. We, the community, keep on repeating and providing the same information to many different parties, in meetings and conferences; it has been 12 years of work and results now. We provided case studies that have been incorporated in the reports of WHO Europe[9], ECDC, UNAIDS and are included as best practices in testing. We keep on giving the same advice but our voice is not heard in the sense that things do not change, we do not receive the attention we deserve and our big contribution maybe recognized but is certainly not rewarded. Nor has the knowledge ever been translated in new policy implementation.

Also, in my opinion the acronym CBVCT is obsolete. Counselling and testing services are always voluntary in community centres; why should we still underline the fact that people come to community services voluntarily? We should come up with a new definition because this is an outdated terminology. In fact, we did, we call them now community centres!" (See Appendix 3.)

Michael Meulbroek's voice is one among the many voices of civil society experts in the field, but it surely encompasses the opinion of a lot of other civil society representatives, even if different points of view also need to be taken into due consideration – and will be given consideration in the course of this report. It must be added that his opinion is respected and influential, since he is one of the managers of the BCN Checkpoint in Barcelona, i.e. the community centre that has achieved the most relevant results in Europe in terms of variety of services offered, number of clients attended, clients diagnosed and acute infections detected. His comments help describing the predominant "mood" of many other community health workers (CHW) engaged in CBVCT activities.

[9] http://apps.who.int/iris/bitstream/10665/180212/1/WHO_HIV_2015.22_eng.pdf?ua=1

With his words in the background, let's try and focalize on the two main issues to be addressed.

1. **Community based testing services are not given the deserved recognition and reward for the work they perform; they are not considered as equal actors, at the same level as the other stakeholders in decision making processes. They are not adequately funded**

   This is not only the statement and the opinion of many of the representatives from the community, but was partly echoed by both the representatives of the academia and it is often touched during national and European gatherings, so it should be considered as a relevant issue and be devoted the necessary attention.

   The point of view of academia representatives

   More into detail, for the purpose of this study academia representatives said that in their opinion community centres rightly feel they are not part of a common effort to promote access to HIV testing at the European level. They suggested that organizations running CBVCT services be involved together with other stakeholders by health institutions in the development of national and local plans to improve access to HIV testing, based on the analysis of local epidemiology; clear rules on how to organize CBVCTs and how to receive economic support from the institutions also need to be developed.

   Expanding more on this subject, academia representatives feel that during the last years CBVCT services gained a very important role and visibility and the concept of CBVCT has today very good recognition, but huge heterogeneity still characterizes the organizations running CBVCT services. Important platforms like AAE and the CSF play an important role at European level, but some NGOs do not access these platforms and complain about it, especially in Southern European countries where, within the EU, they lack support. Furthermore, public health administrations should consider community based services and the information they generate as important as public health services, and their data as part of the overall health system. The lack of CBVCT data determines a big gap for national administrations and a formalization of these services is needed. At the national/regional level, academia representatives feel that some NGOs would like to be more involved but there are barriers, for instance language and economic barriers, to participate at the European level; English is still a problem in many cases. There is awareness that, for NGOs eager to play a more relevant role, it is not only a matter of participating in the research, but of discussing at the same level, both academia and NGOs, as key actors. Collaborations should be discussed from the beginning and analysed case by case: the importance and visibility of the partners should be addressed together with the respective roles. At the moment, instead,

decisions are taken by academia and the institutions; also in the collaboration on projects and research studies, the lead roles around CBVCT are attributed to academia, together with the relevant budgets. (See Appendix 5 and 6.)

The points of view of NGO representatives

NGOs representatives' opinions do not differ much in substance, but there are different levels of awareness, involvement and response to the various difficulties. In countries where community centres have a long history, a good stability and good results to bring at national and European level, the reflections are surely more mature as a consequence of an in-depth knowledge and awareness of the mechanisms, situations, rules and contexts.

Spain, which is a country with a long tradition in CBVCTs, has many different examples of these initiatives and national networks in place for a long time. Michael Meulbroek's views are critical, given the fact that, from his viewpoint, the impressive results achieved did not bring to any substantial changes in terms of increased recognition of the role played by community centres. The checkpoint in Barcelona was opened with the goal to lower the HIV incidence in the community and to end HIV, and today the intention is to progress in this objective as a community, which implies the need to be a part of society, an actor that receives recognition. According to Michael, community centres are giving a very important contribution to the achievement of the global targets but their financial resources are the lowest of all Europe. And recognition of the work done should foresee that there is a considerable and proportional budget line created and destined for community centres at local, national and European level.

Data collected during testing activities do not seem to make a difference in policy and financial allocations both at national and at European level, since the relevance of the data collected did not translate into any changes.

CBVCT services should be addressed part of the European funds, which presently are mostly accessible by European institutions, because they have proven to be effective and, moreover, to be cost effective and should be adequately supported; this remark has been addressed many times in the past in different occasions and surely not only by the BCN Checkpoint representatives, but it did not produce the desired improvements.

It appears that in the countries where the main barriers have been removed and community testing sites benefit of continued support from the institutions (e.g. Denmark, France, Germany, the Netherlands to name a few), collaboration among the different stakeholders has reached a balance and there are no major claims from community representatives, even if there is obviously

room for improvement. The interview with the representative of AIDES in fact does not touch on the issue of scarce recognition and little reward, since community testing sites are presently adequately funded by the national health system and maintain a productive relationship with institutional stakeholders and other actors. It must be underlined that such achievements are the consequence of strong advocacy actions carried out by AIDES and the French civil society, which led to a change in legislation in November 2010, still considered as a landmark and a political win by French activists. French activists are presently more focused on technical details (e.g. availability of tests for different STIs) rather than on the issue of reward. (See Appendix 2.)

In the EECA countries, the situation is quite different due to the lack of financial support, widespread criminalization of behaviours and legal/regulatory barriers. Community health workers struggle for the survival and continuity of their services: the reduction of international financial assistance to the region calls for urgent measures aimed at the improvement in cost-effectiveness of HIV testing; in order to survive, in the EECA countries community centres need to be recognized by the institutions and to become a part of the diagnostic algorithm[10].

The experience of Demetra, the Lithuanian NGO that implemented rapid HIV testing in the country through a network of partners consisting of more than 20 institutions in 16 cities, offers an example of how governments and institutions can threaten NGOs' freedom of action and their prevention and testing activities. In fact, as recently as in 2017, on the basis of charges concerning "illegal activities" filed by the National Centre of Communicable Diseases and AIDS, and due to the ambiguity in national legislation and regulations not complying with international practice and recommendations, rapid HIV testing was prohibited in non-medical settings. After 60 international organizations and networks expressed concerns that the ban blocked access to services for the most vulnerable and would be detrimental to the control of the HIV epidemic, and signed an open letter to the Ministry of Health, an interim victory was won. The MoH signed amendments to the legal acts which, since September 2017, allow HIV testing to be offered as before, through the cooperation with medical facilities.

Demetra, as many other European NGOs, brought to its country the benefits of being part of the COBATEST network, i.e. introduced the standardized data collection tool, translated into Lithuanian, in their testing activities and since 2014 have periodically submitted HIV testing and

[10] Madoyan, H. (September 2016). Community based HTC in EECA region: practice, challenges and opportunities for advocacy. EQUO East Europe and Central Asia Union of PLHIV

linkage to care data to CEEISCAT. Guidelines prepared by the network's partners are among other advantages of being part of COBATEST, as well as the possibility to participate in several conferences; being part of the network, though, does not provide any financial support for CBVCT activities. This is why Demetra, as many others community centres not funded by national institutions, relies on funding from pharma companies or other private foundations. In 2010 Demetra joined the AIDS Healthcare Foundation (AHF) network as a partner of AHF project "Test millions", receiving financial support for rapid HIV tests, condoms and staff costs, as well as full methodological support, data collection tools, advocacy tools. To be part of COBATEST is important because it gives visibility in the EU as a CBVCT service and allows to be part of an international network, but this is possible only thanks to the financial support offered by AHF and pharma companies. (See Appendix 4.)

The same situation is experienced in other Southern European countries, like Italy. LILA has been part of the COBATEST network since 2012 and the partnership allowed to systematize data collection, to introduce and implement correct operational guidelines, to benefit of an efficient database and upgrade CBVCT activities, bringing them up to European standards. All of these advantages were highly appreciated and valued in a country where the institutions do not support NGOs working on HIV, viral hepatitis and other STIs. However, the lack of institutional funding and the growing difficulties in accessing funding from private donors, threaten the continuity and stability of services, as in the case of the other Italian NGOs engaged in this field.

2. **In some countries, community based testing activities are still medicalized, preventing the expansion of services**

Medicalization of community testing represents a huge barrier, since it obliges NGOs to have healthcare staff in the team and this obviously implies additional costs and challenges. Testing services, for instance, cannot be offered at all times, whenever clients establish contact with such request; a doctor or at least a nurse needs to be present in the premises and therefore activities need to be planned in advance and calendarized; many opportunities of giving people the chance to know their status in the moment they need to access such information are lost. As it has been mentioned already, the most relevant international agencies recommend that trained lay providers independently manage community centres.

As one of the surveys carried out during the HIV-COBATEST project indicated, at the European level there is large heterogeneity, since in some countries screening with rapid tests are still required to be done by medical staff.

In France, in addition to medical staff, trained non-medical staff are allowed to perform HIV or HCV rapid tests. Reactive results must be confirmed by a doctor or a laboratory. The type of tests available in CBVCT services are limited to HIV and HCV.

In Lithuania, only medical staff who work in medical institutions can perform rapid HIV tests (not tests for hepatitis B and C) in non-medical facilities - for example, in the premises of Demetra, which recently made very detailed agreements with medical facilities in order to be allowed to perform rapid tests.

In Spain it is not compulsory to have medical staff in CBVCTs. Even if Spanish regulations are very strict on assigning to health professionals the duty to perform diagnostic procedures, back in 2006, with the introduction of rapid testing, civil society and academia succeeded in having this type of tests considered only as screening devices; therefore, there is no need of having them performed by medical staff. Trained lay staff, peers and people from the community can offer rapid tests, as far as they comply sanitary requirements, particularly dealing with blood testing.

There is a tendency of a few community centres to become more medicalized and use high technology; in general, the others do not. They offer educational interventions, support and social services. The situation in Spain is anyway not easy to explain. The majority of autonomous governments only allow to perform rapid tests on saliva, but tests on blood samples are still medicalized. The Barcelona Checkpoint and Catalonia represent an exception: in the checkpoint there is no need for doctors but, on the other hand, medical staff belonging to the community, as well as nurses, pharmacists, etc. have been incorporated. The model is that of a community centre totally managed by people from the community – professionals, peers, volunteers. Doctors and nurses are needed when some STI tests are performed; furthermore, in case of a positive result it is of ultimate importance to prescribe treatment and cure the infections and hence break/stop the transmission chain within the community.

Self-testing is about to be introduced in Spain and rapid tests will be sold in pharmacies. However, according to community representatives it seems unrealistic that testing is still medicalized in CBVCT services, while people can buy freely the kits and take their tests at home without any support.

This is exactly the situation that Italy has been facing since December 2016, when self-testing was introduced and the HIV rapid test kits started to be sold in pharmacies. People can now test in their homes with very little competence and knowledge about HIV, the window period and

testing procedures, but at the same time community centres are still medicalized and healthcare staff need to be present during testing activities, even for the collection of saliva samples. Italian NGOs have brought their difficulties and complaints many times to the attention of the institutions, but so far advocacy efforts have not given positive results.

Community centres' clients are in all cases very satisfied with the service they receive in these more welcoming and informal settings. The two interviews collected from clients in Athens and Milan cannot of course be taken as the average opinion of the thousands of clients accessing community testing centres throughout Europe, but all CHWs would likely agree that they reflect the general feelings of the people they meet. Both respondents highly valued the ease of access, the friendly and non-clinical environment, the more intimate and relaxed, informal atmosphere, the expert advice, the competence and professionalism of staff. (See Appendix 7 and 8.)

Some community centres conduct surveys to assess the quality of their services and the results are reported as positive and encouraging; studies have also been conducted to better focus on clients' desires and needs. According to the respondents of an online survey[11] conducted and presented in 2014 by PLUS Onlus - the patient organization that opened the first Italian Checkpoint in Bologna - the ideal HIV test should be: reliable (86%), with no medical prescription (75%), free (63%), rapid (55%), with no personal information collected (45%), with the opportunity to speak with a peer-counsellor (36%). The study concluded that home-testing and community-based testing seem to be among the best ways to offer new opportunities though they may require a change in the legal, social and cultural context to be implemented; the ideal picture identified by respondents calls for demedicalization and the required legal changes need to be made in such direction.

As already mentioned, the situation in the rest of the European countries is very different but it surely needs to be addressed. Demedicalization would translate in simplification, cost saving and a higher number of tests performed in community based services.

[11] http://www.plus-onlus.it/ricerca-plus-test-hiv-come-vuoi-tu/#english

4. Suggestions for an advocacy toolkit to support community testing services

The interviews collected for this study clearly indicate that there are different positions and critical views concerning the present role of community centres in the European context and in the different countries where they are situated and offer their services.

Such a role needs to be recognized and attributed the right importance it deserves and, in order to achieve this goal, community health workers will have to advocate at various levels, otherwise they risk to experience growing difficulties due to the tough overall economic framework and to the diminished attention devoted to health issues in general and, going into detail, to HIV and the other STIs.

The position of one of the community representatives interviewed is that of limiting the collaboration with national stakeholders (academia and institutions) and of maintaining a critical relationship with European institutions, given the fact that CHWs are not considered as equal actors in the decision making process and that available funding is going almost entirely to institutions and academia. NGOs and CBVCT services are left with very little support and, in those countries where they do not receive funding from the national and regional authorities, they risk to shut down.

Academia representatives, on the other hand, seem to understand the problems experienced by community centres and agree on the fact that they should be incorporated in the health system and be granted more importance, recognition, as well as funding, tasks and the deriving responsibilities. They differentiate between their own role of academia officials and the role of public health institutional representatives, but perceive that sometimes NGOs think of them as being the same people covering same positions. In some countries, academia are part of the health departments and work in the same institutions which are supposed to fund the projects. Their responsibility is not financial though, and in countries where health is not adequately funded, these aspects often interfere with the implementation of projects.

The hope is that academia and community centres come to term with each other in order to advocate together in support of the same instances, both at national and European levels, involving other stakeholders. The role of civil society and NGOs has historically been that of taking very critical positions to bring about the needed changes, which do not come if not strongly requested. They need to take difficult positions and to keep them, in order to make their point. As the French community

representative noted during his interview, NGOs offer the chance to prove that different strategies work in changing contexts and therefore could be applied elsewhere, and they also offer the chance of bringing together a community driven voice calling for change, despite being complex to define. The other stakeholders should support their campaigns, battles and advocacy efforts since the entire society will then benefit of the improvements - even by giving up some of the advantages and privileges. As indicated in one of the interviews, a consensus process on these services should be developed at European level, addressing their role, organizational standards and financing strategies.

With this proposition in mind, what are the tools that today should be part of an advocacy toolkit in support of community centres offering testing services? The following are those suggested during the interviews of this study:

1. The recommendations of the most important international agencies which, as already mentioned, have collected evidence about the fact that lay providers – today we like to define them as community health workers - can run efficient community centres for testing key affected groups.
2. Quality data of the services offered, to give evidence of the number of tests performed, number of reactive tests detected and acute infections detected, number of clients linked to care. In some countries with well-established CBVCT facilities, CHWs identify more or less 15-20% of the total of HIV reported cases, mostly those cases that would not be identified or would be late(r) identified by the public health systems - a very relevant contribution that cannot be ignored by health institutions. The information collected through the different projects has proven to be strategic in increasing the evidence on the need for strengthening community-based service delivery models as an integral part of the HIV strategic investments.
3. Studies on the cost-effectiveness of community based testing services: Some research was already made to this extent in previous projects to inform policy changes in some countries. In addition, some checkpoints of the COBATEST network performed an economical evaluation showing the different factors that can influence the cost of each HIV diagnosis. More is needed to better assess the cost-effectiveness of CBVCTs, including outreach strategies, in the mid and long term, but these data are key to convince decision makers in making changes to health policies and budgets.
4. Special focus of the unique position and role played by NGOs with strong links with different key populations to access people at risk in the early phase of the infection, as well as to ensure their linkage to care.

5. The key role played (or to be soon played) by CHWs in the delivery and uptake of PrEP. Community centres are in fact precious sites not only for the offer of HIV testing services, but also for increasing testing frequencies in key populations, implementing newer technologies to detect infections in earlier phases, offering testing for other STIs and vaccination for hepatitis A and B. If adequately supported, they can provide faster linkage to care and treatments in case of positive results, and PrEP to those clients who receive a negative result to HIV and could benefit from it.
6. The integration in multi sectorial Public Health frameworks and, in some countries where it is needed, the willingness of more developed community centres to facilitate the integration of small ones with limited logistical capacities, to increase effectiveness and efficiency of their programs, and to offer continuous capacity building and training with new strategies and technologies, harmonization of indicators and data collection and systematic evaluation.
7. The possibility to increase outreach testing activities, which have proven to be extremely effective in reaching those people who not only do not access public healthcare services, but do not even access community services in the NGO premises; the CBVCT concept can evolve according to the epidemiological scenarios and evidence on new strategies and technologies.

Lastly, community centres have greatly evolved and changed since they opened their services several years ago and they differ a lot among themselves, due to the different contexts in which they operate. They all would like to improve some aspects of their activities and it is worth listing some of the desires expressed during the interview, since they give the evidence of the strong ideal impulse to move forward and to progress, which moves all CHWs despite the difficult situations and the barriers encountered along the way:

- to offer tests for all STIs, not only for HIV and viral hepatitis
- to deliver PrEP
- to be able to welcome and give support to all the people accessing the services, which is presently not possible due to insufficient funding
- to offer comprehensive sexual health education and related services
- to offer counselling of chemsex
- to have guidelines on demedicalised rapid testing – as well as training, legal recognition, authorization and different tests covered, in order to overcome legal barriers and facilitate access across Europe
- to use same data collection tools and criteria in all of Europe

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6. Appendixes

Appendix 1 – Table with information of the interviewed community testing sites

	AIDES, France	BCN Checkpoint, Catalonia	Demetra, Lithuania	LILA Milano, Italy
Is your organization a member of the COBATEST network?	*Yes*	*No*	*Yes*	*Yes*
Is your organization a member of other CBVCT networks?	*No*	*Yes*	*Yes*	*No*
Which network?		*"Network of Checkpoints", an informal one.*	*AIDS Healthcare foundation network*	
Are community centers medicalized?	*No*	*No*	*Yes*	*Yes*
Who is allowed to perform rapid tests?	*Medical staff and trained non-medical people (lay providers)*	*Most autonomous governments only demedicalized tests on saliva; tests on blood samples are still medicalized. BCN Checkpoint and Catalonia are an exception: no need for doctors, but presence of doctors belonging to the community, as well as nurses, pharmacists, etc.*	*Only medical staff (doctors, nurses) working in medical institutions. Only medical staff can perform rapid HIV tests (only HIV, excluding hepatitis C and B) in non-medical facilities*	*Medical staff only*
To whom do you report data relative to your CBVCT services (number and type of tests performed, number of reactive results, number of clients confirmed and linked to care…)?	*Local/regional public health services and/or institutions*	*Catalonia Health Department*	*Local/regional public health services and/or institutions*	*In some cases, to local/regional public health services and/or institutions*
Which are the stakeholders you keep in contact with in relation to your CBVCT activities?	☒ *Hospitals/clinics* ☒ *Local/regional public health services and/or institutions* ☐ *Pharmacies* ☐ GPs ☒ *Other NGOs* ☒ *Regional/national surveillance institutions*	☒ *Hospitals/clinics* ☒ *Local/regional public health services and/or institutions* ☒ *Pharmacies* ☒ *GPs* ☒ *Other NGOs* ☒ *Regional/national surveillance institutions*	*Institutional authorities only*	☒ *Hospitals/clinics* ☒ *Local/regional public health services and/or institutions* ☐ *Pharmacies* ☐ GPs ☒ *Other NGOs* ☒ *Regional/national surveillance institutions*

How are your CBVCT services funded?	*By the state and other institutions.*	*The Barcelona checkpoint is funded for 1/3 by the Catalan govt. and for the other 2/3 by foundations, pharmas, private donors and clients*	*AIDS Healthcare Foundation and pharmaceutical companies*	*In Italy there is no public funding for CBVCTs, we need to look for funds and some succeed to get funds from private donors and pharmas*
Did your organization experience any interruption in the delivery of services?	*No*	*No*	*Yes*	*No*

Appendix 2 – AIDES, France -Interview to Grégory Braz

Community Based Voluntary Counselling and Testing Services

Present obstacles and Opportunities

Your organization: *AIDES*

Your name: *Grégory Braz*

The country where you live and work: *France*

Structure of your CBVCT services

- ☑ My organization's main activity is to offer CBVCT services
- ☐ My organization has a broader mission and periodically runs CBVCT services as part of its activities
  - o Once a week
  - o More than once a week
  - o Once a month
  - o More than once a month
  - o A few times during the year
- ☐ My organization is defined as a checkpoint

CBVCT networks - Europe

Is your organization a member of the COBATEST network? ☑ Yes ☐ No

If yes, what is your experience as a member of the network?

We wrote the guide on improving screening practices, updating it with a table for auto-evaluation. In addition, we created a questionnaire to evaluate how members of the network had disseminated the guide.

If no, why haven't you joined the network?

Is your organization a member of other CBVCT networks? ☐ Yes ☑ No

If yes, how did you come to know about the network/s and why did you join?

What benefits did the membership in the COBATEST and/or other CBVCT networks bring to your organization?

The guide on improving practices was disseminated internally and externally; however, the guide was not used very much internally. We had no feedback from the COBATEST network on the guide…

Which tools do you utilize in your CBVCT work that were introduced thanks to the membership in your CBVCT network(s)? Please indicate precisely:

Are there any negative aspects/shortfalls in being part of your CBVCT network(s)? Please explain so that your opinion can be taken into account to lead to a constructive improvement:

Do you find it easier to connect to other CBVCT services at European level or at local/national level?

At European level, there is always the question of which language to use and the differences in legal set-ups which can hamper connections. However, we have participated in several meetings (e.g.: Ljubljana).
At national level, we work with other NGOs also doing testing but there are few networks really (see below).

CBVCT networks – National/local level

What is your experience of networking for CBVCT services at local/national level?

AIDES is the main French organization offering CBVCT services. Between 2012 and 2015, 211.900 HIV rapid tests have been made by NGOs, 70% of them were made by AIDES.
In 2016 we had a partnership with another French organization named ENIPSE: it resulted in 402 outreach actions and 376 screenings.

Are CBVCT services in your country medicalized? ☐ Yes ☑ No

Who is allowed to perform rapid tests in your country?

As well as medical staff, trained non-medical people are allowed to perform HIV or HCV rapid tests. A positive result must be confirmed by a doctor or a laboratory. An accompaniment can be proposed to facilitate confirmation and linkage to care.

To whom do you report data relative to your CBVCT services (number and type of tests performed, number of reactive results, number of clients confirmed and linked to care…)?

- ☐ Hospitals/clinics
- ☑ Local/regional public health services and/or institutions
- ☐ Regional/national surveillance institutions
- ☐ Other
- ☐ None of the above

Are you requested to meet specific reporting requirements?

One report for every Region is to be transmitted to the ARS (the Regional health authority) and CPAM (the social security agency) and one global/national report needs to be sent to the DGS (the Health Ministry).
We collect data relative to number of TROD performed, gender, key populations, rapid tests made in premises versus outreach, positive results and confirmatory tests.

Which are the stakeholders you keep in contact with in relation to your CBVCT activities?

- ☑ Hospitals/clinics
- ☑ Local/regional public health services and/or institutions
- ☐ Pharmacies
- ☐ GPs
- ☑ Other NGOs

☑ Regional/national surveillance institutions
☐ Other
☐ None of the above

How are your CBVCT services funded?

The General Direction of Health (DGS Health Ministry) with the help of CNAMTS (Caisse Nationale de l'Assurance Maladie des Travaileurs Salaries) organize a national call for projects every three years. CBVCT services receive 32€ per each person who benefits of the service, i.e. for a single HIV test, or a single HCV test, or for both of them. This amount includes the purchase of rapid tests and the costs relative to CBVCT activities (training, treatment of sharps'& medical waste disposal, monitoring, etc.)

Did your organization experience any interruption in the delivery of CBVCT services?

Never since 2012 and the beginning of CBCVT services.

What was the reason causing the interruption?

The way forward – Obstacles and opportunities in the development of CBVCT services

In your opinion, which are the obstacles still present that prevent a fruitful collaboration among partners and stakeholders in the field of CBVCT services at European level?

The lack of a common outlook on who can perform tests and on which tests can be offered in CBVCT services. Guidelines on non-medicalized rapid testing would be helpful –training, legal recognition and authorization, and tests covered. This could help to overcome legal barriers and facilitate access across Europe. There is also the issue of funding, of course. And also, common data collection tools and criteria are needed.

In your opinion, which are the obstacles still present that prevent a fruitful collaboration among partners and stakeholders in the field of CBVCT services at national level?

Nationally, in France, the type of tests available in CBVCT services are limited to HIV and HCV…

In your opinion, which are the opportunities that the collaboration among partners and stakeholders in the field of CBVCT services offers today at European level?

They offer the chance to prove that different strategies work in other places and therefore could be applied elsewhere. They also offer the chance of bringing together a community driven voice calling for change, despite being complex to define.

In your opinion, which are the opportunities that the collaboration among partners and stakeholders in the field of CBVCT services offers today at the national/local level?

Same as above (common voice and demands). We need to get a wider panel of tests available and better coordination within the health systems.

If you were given the chance to improve one only aspect of your CBVCT services, what would such aspect be?

To better target key populations, especially MSM and migrants, and to improve repeat screening among MSM (in 2015, 30% of those who tested in our services had taken an HIV test in the last 6 month).

If you had to launch an advocacy campaign for the improvement of CBVCT services, what would be your key messages and requests? What tools would you use - or would like to have in your hands - to be more effective in your advocacy efforts?

From the above answers: European guidelines on greater CBVCT testing.

Are there any additional comments/suggestions that you would like to make on the topic of CBVCT services?

Thank you very much for your time!

Appendix 3 – BCN Checkpoint, Catalonia -Interview to Michael Meulbroek

Community Based Voluntary Counselling and Testing Services

Present obstacles and Opportunities

Your organization: *BCN Checkpoint, Barcelona*

Your name: *Michael Meulbroek*

The country where you live and work: *Catalonia*

Structure of your CBVCT services

- ☐ My organization's main/only activity is to offer CBVCT services
- ☐ My organization has a broader mission and periodically runs CBVCT services as part of its activities
  - o Once a week
  - o More than once a week
  - o Once a month
  - o More than once a month
  - o A few times during the year
- ☒ My organization is defined as a checkpoint

Initial remarks

I think that the topics of this interview are outdated. We, the community, keep on repeating and providing the same information to many different parties, in meetings and conferences; it has been 12 years of work and results now. We provided case studies that have been incorporated in the reports of WHO Europe, ECDC, UNAIDS and are included as best practices in testing. We keep on giving the same advice but our voice is not heard in the sense that things do not change, we do not receive the attention we deserve and our big contribution maybe recognized but is certainly not rewarded. Nor has the knowledge ever been translated into new policy implementation.

Also, in my opinion the acronym CBVCT is obsolete. Counselling and testing services are always voluntary in community centers; why should we still underline the fact that people come to community services voluntarily? We should come up with a new definition because this is an outdated terminology. In fact, we did, we call it now community centers!

CBVCT networks - Europe

Is your organization a member of the COBATEST network? ☐ Yes ☒ No

If yes, what is your experience as a member of the network? ---

If no, why haven't you joined the network?

We did not join the network because it was not clear to us what the objective of the network was and who would be making decisions in the network. Nor do we encounter clear information on the financial compensation for the network members for all the work done. We are talking of a network of community based testing services which is not lead by the community and where the community representatives are not involved in the decision-making process. It should be us making decisions for the community centers, not only the institutions or academia. These are the reasons why we did not join the network.

Is your organization a member of other CBVCT networks? ☒ Yes ☐ No

If yes, how did you come to know about the network/s and why did you join?

We are part of the "Network of Checkpoints", which is an informal one. It grew in a natural way. Twelve years ago everything was new, we created something totally new and it was successful; we obtained good results and others followed our path. This informal network started around 2006, with the Portuguese colleagues, and then others followed, mostly from Southern European countries: France, Greece, Italy… There are advantages of being an informal network, which mainly have to do with no specific structures to fulfil: we are connected to each other and communicate when there is a need to do so, when we believe in an interesting common project and when we have the time to do so.

What benefits did the membership in the COBATEST and/or other CBVCT networks bring to your organization? Again, we are not a member of the Cobatest network.

In case of the Checkpoint Network, the fact that the BCN Checkpoint is the pioneer has allowed us to share our expertise with the new partners. However, even if you are the one who started, you always have opportunities to learn from the others. We learn from what the other partners do and introduce in their countries; we all share our experiences and every partner is free to "copy and paste" some ideas they get from the other checkpoints, if we need to; we surely all benefit from the mutual exchange.

Which tools do you utilize in your CBVCT work that were introduced thanks to the membership in your CBVCT network(s)? Please indicate precisely:

We did not adopt any specific tool, but we rather meet and share our work, encourage new partners to start the same process.

Are there any negative aspects/shortfalls in being part of your CBVCT network(s)? Please explain so that your opinion can be taken into account to lead to a constructive improvement:

We started our community center with the goal to lower the HIV incidence in our community and to end HIV. We want to progress in this objective as a community and to do so we need to be a part of society, an actor that receives recognition. Community centers are giving a very important contribution to the achievement of the global targets, but our financial resources are the lowest of all Europe. And recognition of our work means that there is a serious and proportional budget line created and destined at local, national and European level.

It would be important to see that the data we collect during our testing activities are used for something, but it does not seem that our data make a difference both at national and at European level. The relevance of the data we collect did not bring the EC to introduce substantial changes. What we are doing is important, we succeed in keeping the epidemic under control but this does not seem to translate into increased recognition for the role that community centers play.

We should be able to use part of the European funds which as of now are only accessible by European institutions. Our services have proven to be effective and, moreover, to be cost effective and should be supported adequately; we have said so many times in the past.

Do you find it easier to connect to other CBVCT services at European level or at local/national level?

For us, both the national and the European levels are easy to connect with. As I previously said, we know each other within Europe and for a newcomer it is easy to connect with any of us and we are all delighted to help and support where needed. For example, a new checkpoint just opened last week in Seville and other checkpoints will be opened in Madrid and other cities. We keep in contact also within Spain with these other checkpoints, there is an easy collaboration.

CBVCT networks – National/local level

What is your experience of networking for CBVCT services at local/national level?

As I mentioned already, we collaborate with other checkpoints but the collaboration goes back in time. In 2010 we organized a symposium on CBVCT services here in Spain and many HIV organizations afterwards began to offer testing services in their premises. That was the beginning of a good collaboration among the different NGOs.

Are CBVCT services in your country medicalized? ☒ Yes ☐ No

Who is allowed to perform rapid tests in your country?

The situation in Spain is not easy to explain. The majority of autonomous governments only allow to perform rapid tests on saliva, but tests on blood samples are still medicalized. Our Barcelona Checkpoint and Catalonia are an exception, we do not need doctors but, on the other hand, we have incorporated doctors belonging to the community, as well as nurses, pharmacists, etc. We are a community center totally managed by people from the community – professionals, peers, volunteers. For example, we need also doctors and nurses when we offer some STIs tests; in case of a positive result, it is of ultimate importance to prescribe treatment and cure the infection and hence the transmission chain within the community.

Self-testing is about to be introduced in Spain and rapid tests will be sold in pharmacies. However, it seems to be surrealistic that testing is still medicalized in CBVCT services in Spain, while people can buy freely the kits and take their tests at home with no support.

To whom do you report data relative to your CBVCT services (number and type of tests performed, number of reactive results, number of clients confirmed and linked to care…)?

- ☐ Hospitals/clinics
- ☒ Local/regional public health services and/or institutions *(We report our data at the end of each year at the Catalonia Health Department)*
- ☐ Regional/national surveillance institutions
- ☐ Other
- ☐ None of the above

Are you requested to meet specific reporting requirements?

We report on the basic data (number of tests performed for the different infections, number of positive results, clients linked to care…) but we also report on data which we find extremely important, like for example the number of clients receiving the HIV diagnosis within 3 months after acquiring the infection. We all know how important it is to detect new infections during the acute phase and to give treatment to people immediately after; in our checkpoint we are very efficient in this and provide all the data. We also report data related to the surveillance of STIs for MSM, which was non-existent, and to vaccination of hepatitis A and B.

Which are the stakeholders you keep in contact with in relation to your CBVCT activities?

- ☒ Hospitals/clinics
- ☒ Local/regional public health services and/or institutions
- ☒ Pharmacies

☒ GPs
☒ Other NGOs
☒ Regional/national surveillance institutions
☐ Other
☐ None of the above

How are your CBVCT services funded?

The Barcelona checkpoint is funded for 1/3 by the Catalan government and for the other 2/3 by foundations, pharmas, private donors and clients.

Did your organization experience any interruption in the delivery of CBVCT services?

No.

What was the reason causing the interruption?

The way forward – Obstacles and opportunities in the development of CBVCT services

In your opinion, which are the obstacles still present that prevent a fruitful collaboration among partners and stakeholders in the field of CBVCT services at European level?

As already said, the big obstacle is that we are not equal partners with the other stakeholders: we are allowed to sit at the same table but we are not part of the decision-making process, both at European and national levels. And this is illogical because we are the ones that help controlling the epidemic today. In Europe the Checkpoints detect 20% of all cases in their countries , but this is not given the necessary attention and value. We should all be taken more seriously, since without our work and commitment the HIV epidemic and STIs epidemics would rise again, but we are not adequately supported. On the other hand, the assessment and evaluation should be translated in an adaptation of current policies.

In your opinion, which are the obstacles still present that prevent a fruitful collaboration among partners and stakeholders in the field of CBVCT services at national level?

Same as above.

In your opinion, which are the opportunities that the collaboration among partners and stakeholders in the field of CBVCT services offers today at European level?

Today there are lots of great opportunities. Let's think for instance about PrEP. Community centers should be taken more seriously and engaged much more in the game now, because we are key players in this process and we definitely play or will play a key role in the delivery and uptake of PrEP. Community centers should be organized not only for performing HIV testing services, but also for what follows next: increase testing frequencies in key populations, implement newer technologies to detect in earlier phases, offer testing for other STIs and vaccination for hepatitis A and B. Therefore, we should be put in the condition to provide faster linkage to care and treatments in case of positive results, and to provide PrEP to those clients who receive a negative result to HIV and could benefit from PrEP. To do this, obviously more and adequate resources would be needed.

In your opinion, which are the opportunities that the collaboration among partners and stakeholders in the field of CBVCT services offers today at the national/local level?

Same as above.

If you were given the chance to improve one only aspect of your CBVCT services, what would such aspect be?

I can think of many. First, I would like to have enough, reasonable and accessible resources to be able to attend more people; Unfortunately, the Checkpoint cannot meet the needs of all the people who come to us, which means a loss of opportunities. Secondly, I would like to offer a complete check-up for STIs to all clients. Then, I would like to offer counselling and services on chemsex, on sexuality issues – people come to us with many different needs, so this will make the Checkpoint a real reference point on sexual health.

If you had to launch an advocacy campaign for the improvement of CBVCT services, what would be your key messages and requests? What tools would you use - or would like to have in your hands - to be more effective in your advocacy efforts?

We have the results and the evidence we produce and this evidence should put us right in the middle of the decision-making process; in our hands we have the capacity to evaluate what we are doing, to valorize the cost effectiveness and benefits of our work and to cut on what does not produce the desired results. These tools should be attributed great value.

Are there any additional comments/suggestions that you would like to make on the topic of CBVCT services?

Thank you very much for your time!

Appendix 4 – Demetra, Lithuania -Interview to Loreta Stoniene

Community Based Voluntary Counselling and Testing Services

Present obstacles and Opportunities

Your organization: *Association of HIV affected women and their families "Demetra"*

Your name: *Loreta Stoniene*

The country where you live and work: *Lithuania*

Structure of your CBVCT services

☒ My organization's main/only activity is to offer CBVCT services

☐ My organization has a broader mission and periodically runs CBVCT services as part of its activities

- o Once a week
- o More than once a week
- o Once a month
- o More than once a month
- o A few times during the year

☒ My organization is defined as a checkpoint *(In our structure there is a checkpoint)*

CBVCT networks - Europe

Is your organization a member of the COBATEST network? ☒ Yes ☐ No

If yes, what is your experience as a member of the network?

We joined the network in 2013,we benefited from the standardized data collection tool which was translated into Lithuanian and also connected with the network. We submitted HIV testing and linkage to care data periodically since 2014. When HIV testing was interrupted in 2017 due to gaps in the national legislation, we informed the network about it.
Also, we benefited from the guidelines prepared by partners. One scientific article was published where our data was included. http://www.tandfonline.com/doi/full/10.1080/09540121.2016.1146218.
We do not receive any support with HIV tests, but we have had the possibility to participate in several conferences.

If no, why haven't you joined the network?

Is your organization a member of other CBVCT networks? ☒ Yes ☐ No

If yes, how did you come to know about the network/s and why did you join?

In 2010 we joined the AIDS Healthcare foundation (AHF) network as a part of AHF project "Test millions". This project is based on support with rapid HIV tests, condoms and staff. Also, we are receiving full methodological support, data collection tools, advocacy tools on access to rapid testing, treatment and support, etc. Demetra is part of the AHF international network which this year celebrated its 30 years anniversary. AHF is a main donor for rapid HIV testing in the country.

What benefits did the membership in the COBATEST and/or other CBVCT networks bring to your organization?

To be a part of COBATEST was important for the reason that we are known in the EU as a CBVCT and as a partner of the international network. But we are there as a partner because of AHF support with rapid HIV tests, etc. Otherwise we would not be able to participate in COBATEST at all.
From AHF we benefit from all financial and methodological support needed for rapid HIV testing and linkage to healthcare.

Which tools do you utilize in your CBVCT work that were introduced thanks to the membership in your CBVCT network(s)? Please indicate precisely:

During our daily work we use AHF tools and collect data about every anonymous tested person – age (full years), gender, testing reason, testing time and last test result, current test result. If the HIV test result is positive, we link our clients to the healthcare system – we have the HIV test result confirmed, organize the visits to ART therapists and help with prescriptions for blood tests including CD4 count. Linkage to care in our project means that people are registered in the healthcare system and received their CD4 cell test result.
For COBATEST, we are submitting the requested data periodically. The requested information differs a little bit from that requested by AHF. For this reason, only the data related to the Checkpoint is submitted.

Are there any negative aspects/shortfalls in being part of your CBVCT network(s)? Please explain so that your opinion can be taken into account to lead to a constructive improvement:

No.

Do you find it easier to connect to other CBVCT services at European level or at local/national level?

Of course, it is easier to connect at EU level.

CBVCT networks – National/local level

What is your experience of networking for CBVCT services at local/national level?

Demetra as a main institution implementing rapid HIV testing in the country has partners in Lithuania– our own Demetra network. The network consists of more than 20 institutions in 16 cities. They are mostly medical institutions, some NSPs. Collaboration is driven by a cooperation agreement which clarifies responsibilities from Demetra side (free HIV tests, condoms and methodological support) and partner's side (performing HIV tests for most at risk populations, condom distribution and monthly reports).

Are CBVCT services in your country medicalized? ☒ Yes ☐ No

Who is allowed to perform rapid tests in your country?

Only medical staff (doctors, nurses) who are working in medical institutions can perform rapid HIV tests (excluding hepatitis C and B) in non-medical facilities - for example, "Demetra" (New Guidelines 2017). This non-medical facility has taken very detailed agreements with medical facilities about all testing episodes.

To whom do you report data relative to your CBVCT services (number and type of tests performed, number of reactive results, number of clients confirmed and linked to care…)?

- ☐ Hospitals/clinics
- ☒ Local/regional public health services and/or institutions *(explanation below)*
- ☐ Regional/national surveillance institutions
- ☐ Other
- ☐ None of the above

Medical personnel who are working in medical facilities and performing HIV testing in Demetra (non-medical facility) premises have had responsibility to report to public health institutions every month using standardized reporting forms 65 and 67.

Are you requested to meet specific reporting requirements?

Reporting about number of performed rapid HIV tests based on standardized forms no 65 and 67. A non-medical facility does not report, but medical personnel from medical institutions, who perform HIV

tests in Demetra ,do report. These reporting requirements are strictly regulated in agreement between Demetra and the medical facility.

Which are the stakeholders you keep in contact with in relation to your CBVCT activities?

- ☐ Hospitals/clinics
- ☐ Local/regional public health services and/or institutions
- ☐ Pharmacies
- ☐ GPs
- ☐ Other NGOs
- ☐ Regional/national surveillance institutions
- ☐ Other
- ☒ None of the above

We are in contact with the Ministry of Health of the Republic of Lithuania and the Advisor of the Prime minister (a young open minded man who finished course in Hungary).
The second level authority - the director of the National Surveillance institution under the MoH, is the main opposition who sends complaints to the Accreditation Institution for medical services that Demetra activities (HIV testing) are illegal. This institution decided to stop rapid HIV testing till the new amendments of legal acts will be signed.

How are your CBVCT services funded?

AIDS Healthcare Foundation and pharmaceutical companies GSK and AbbVie.

Did your organization experience any interruption in the delivery of CBVCT services?

Yes. Since 2011 we tested for HIV about 73,000 people anonymously and for free. We knew that legal acts were in a "grey" zone as in many countries, but that situation was known to the MoH and they gave us permission to do it. Official letters were received. But when the vice Minister who had supported us for several years stepped down due to new elections, the Director of the National Center of Communicable Diseases and AIDS started to act institutional violence against Demetra and others NSPs.
The situation was terrible because of the weak will of decision makers to counter the Director of the National Center of Communicable Diseases and AIDS; also, our complicated legislation system does not allow simple solutions.
International organizations and networks expressed concerns that the ban blocked access to services for the most vulnerable and would be detrimental to the control of the HIV epidemic. Soon, 60 national and international organizations signed an open letter to the Minister of Health of the Republic of Lithuania demanding that rapid testing be made available again. After five months of strong advocacy efforts, an interim victory was won. The Minister of Health signed amendments to the legal acts which allow HIV testing to be offered as before, through cooperation with medical facilities. In spite of all the barriers, Demetra began rapid HIV testing in community settings again on 1st September 2017.

This is just an interim achievement. The next task is to ensure that non-medical staff in Lithuania can perform rapid HIV testing, like in other EU countries.

What was the reason causing the interruption?

On the basis of complaints of "illegal activities" from the National Center of Communicable Diseases and AIDS. Due to the ambiguity within the national legislation and a regulation that is not in accordance to international practice and recommendations, rapid HIV testing has been stopped in non-medical settings.

The way forward – Obstacles and opportunities in the development of CBVCT services

In your opinion, which are the obstacles still present that prevent a fruitful collaboration among partners and stakeholders in the field of CBVCT services at European level?

In my opinion the different legislation basis, legal acts that medicalized rapid testing and skin perforating with lancets are assigned to serious medical procedure. Those who cannot perform such procedures legally (non-medical staff) cannot move forward for improvement of the services. When in other countries CBVCTs are thinking what to do more and better, we are still facing an old fashioned approach. These inequalities are the major barriers for the cooperation.

In your opinion, which are the obstacles still present that prevent a fruitful collaboration among partners and stakeholders in the field of CBVCT services at national level?

Legal acts, which are the same as octopuses: you cannot touch one leg without influencing the others. And a mentality which is not based on patients' benefit, but rather on the stability of the health system: all the attempts to change it are interpreted as a threat to the system.

In your opinion, which are the opportunities that the collaboration among partners and stakeholders in the field of CBVCT services offers today at European level?

This is a very important platform for information and experience, best practices exchange, also to advocate together both at the EU and national levels.

In your opinion, which are the opportunities that the collaboration among partners and stakeholders in the field of CBVCT services offers today at the national/local level?

"Demetra" is the strongest community organization which at the moment fits national legislation and has had the possibility to legally test for HIV. For advocacy purposes, we united forces with "Coalition I can live" and "Lithuanian patient forum". Both are pretty strong organizations in the advocacy field.

The Ministry of Health of Lithuania for many years has had a Minister who is not strong in decision making. For this reason, lower level authorities as the Director of the National AIDS center, who has been in the position for more than 20 years, are acting without any control and behaving disrespectfully towards community organizations, community leaders, etc.

If you were given the chance to improve one only aspect of your CBVCT services, what would such aspect be?

HIV testing by non-medical personnel.

If you had to launch an advocacy campaign for the improvement of CBVCT services, what would be your key messages and requests? What tools would you use - or would like to have in your hands - to be more effective in your advocacy efforts?

HIV testing by non-medical personnel, obtained through the tool of legislation changes. For that, we need a good lawyer/expert who can give us advice on what we need to do.
Also, another tool is wide publicity about the existing situation: articles in the press, online media, social media, and outdoor advertisement.

Are there any additional comments/suggestions that you would like to make on the topic of CBVCT services?

Thank you very much for your time!

Appendix 5 – CEEISCAT, Catalonia - Interview to Jordi Casabona

Community Based Voluntary Counselling and Testing Services

Present obstacles and Opportunities

Your organization: Center for Epidemiological Studis on HIV and STI of Catalonia (*CEEISCAT). Health Department of the Generalitat de Catalunya.*

Your name: *Jordi Casabona*

The country where you live and work: *Catalonia (Spain)*

Other:
Principle Investigator of the COBATEST and EUROHIVEDAT projects.
Member of the HIV in Europe Steering Committee.

Does your organization maintain a collaboration with CBVCT services at European, national or local level?

Yes. So many collaborations, both at national level, being part of the Health Department of the Generalitat de Catalunya, and at the European level through a number of European Commission funded projects.

If yes, what is the purpose of your collaboration?

At the local level, the collaborations are part of the mandate of our center since its creation back in 1995, which involve HIV/STI surveillance (including bio-behavioral surveillance), monitoring and evaluation of services and applied research to improve the response towards these infections. In Catalonia most of the CBOs/NGOs working in the HIV field are offering testing services, so our collaboration with them involves different aspects. Regarding testing, the collaboration mainly consists in monitoring and evaluating the CBVCT activities together with them, as well as assessing on the introduction of new strategies like outreach programs or new diagnostic tools like rapid saliva and blood test. Community research at the regional level in Catalonia has always been a pillar of our research agenda.
At the European level, we have coordinated two projects funded by the European Commission addressed to CBVCT services - the HIV-COBATEST and the Euro HIV EDAT projects - with a number of different objectives and work packages. These projects were inspired on our local experience and have been carried out in close collaboration with a number of NGOs from more than 15 countries and representing about 50% of the partners. With WHO, we are now involved in a pilot study on different

Point of Care technologies; we are assessing their acceptability with some NGOs participating in the COBATEST Network (currently involving 40 centers from 20 countries)- one of the outputs of the previously mentioned projects (Fernadez L et al, AIDS Care 2016).
The purpose of the COBATEST network is:
To develop and implement standardized questionnaires and procedures for monitoring and evaluation of CBVCT activity
To evaluate the potential impact of CBVCT services in the improvement of HIV early diagnosis and linkage to care
To consolidate a network of CBVCT services in which to perform operational research
To use the network for advocacy and good practices dissemination

If no, would you like to initiate a collaboration with CBVCT services? What would such collaboration be useful for?

Are there any negative aspects/shortfalls in the actual collaboration between academia/institutions and CBVCT services? Please explain:

I think it is very difficult to generalize because we have identified different gaps and some problems in a number of countries.
At the local level, apart from suffering from a weak historical culture of collaboration, there is very little collaborative research between the administration, public health academia and NGOs, and as a matter of fact the concept of "community research" was introduced quite recently. Both community and public health organizations are not as strong and consolidated as in other countries. A part from this I see that NGOs, again, especially in Southern Europe, are forced to work in a very tough economic framework and -even though the research we do is very operational and usually involves to help to develop information systems, collect and analyze programmatic data- the economical issues are always an element in these collaborations, From 2009, the economical situation in Spain has worsened not just the funding of NGOs but also of healthcare in general and of public health and research in particular. So, when establishing collaborations with NGOs, there is always a mix up between the need of funding the services and funding the research itself. This is a discussion that of course needs to involve other actors, namely the public administration and other donors.
Nevertheless, I would say that the research we have been doing during those years has been quite useful for the services involved and the acceptability has been very high, because the first consequence is the use of the results by the NGOs themselves to improve their activity and for advocacy. Of course we always have exceptions, particularly with organizations or groups that receive resources from the industry and the private sector and do not see any benefit in sharing data with administrations which they consider as not being helpful enough. It is understandable, but WHO and UNAIDS, in the strategic information document, say that the information should be both shared between the different actors and used by policy makers to improve the response.
At the European level, of course each country has a different scenario in terms of public health resources, funding and community health work, but I would say that ,in general , in the HIV field during

the last years there has been a huge consistent increase in the collaboration between NGOs and public health academia that has allowed to learn a lot from each other.

Are you aware that checkpoints and other CBVCT services feel their contribution and efforts are not recognized and valued?

Again, I think there are many different backgrounds and scenarios across Europe. In Europe as a whole the concept of "community services" and the role of non medical staff in running them has not been as developed as for instance in the USA and we are in this process; but, as I said before, I do think that during the last years it has been great progress which has been reflected in many initiatives by both the public and private sector empowering NGOs. Most of the HIV related projects funded by the European Commission –among them the ones we have coordinated - have been inclusive in all the process of design, analysis, implementation and dissemination of the research. >The evaluations of COBATEST and Euro HIV EDAT have clearly identified that they have been useful to improve community programs and many times the organizations themselves. Overall, more than half of the partners of these projects were NGOs, many have lead specific work packages, they are always part of the scientific publication process and we know that data generated by these projects are extensively used by NGOs for both advocacy and planning. This is an evolving process: in some places NGOs have undergone an intensive learning process and now they know more about public health than the official institutional officers themselves.
In general, I would say that if the different roles of each sector are recognized and both technical aspects and visibility are discussed and agreed from the beginning of the projects, empowerment and recognition should not be a problem. However, this requires a framework with a clear commitment from all actors in accepting each other role, having the common purpose of pushing the agenda for evidence based policies, as well as the capacity to properly fund community services and the vision that only working together we could improve the response.

In your opinion, is it a fact that CBVCT services are not given the right consideration, attention and reward at European level?

During the last years, CBVCT as a concept has gained a very important role and visibility in Europe and I hope the projects that I mentioned helped in such sense. As a matter of fact, an operational definition of CBVCTs was developed within the projects, being one of its purposes to make clear that community based testing cannot be done without the community members and organizations to whom these services are addressed:

> *"CBVCT is any program or service that offers HIV counselling and testing on a voluntary basis outside the formal health facilities and that has been designed to target specific groups of the population most at risk and is clearly adapted for and accessible to those communities. Moreover, these services should ensure the active participation of the community with the involvement of community representatives either in planning or implementing HIV testing interventions and estrategies."*

ECDC, WHO and other international agencies have recognized its crucial role in improving early diagnosis and treatment; most of the international and national guidelines include CBVCT as a main activity.
Another issue is the visibility of the organizations that run CBVCT services. Again, there is huge heterogeneity. There are important platforms like AAE and the CSF, which play an important role at European level, but some NGOs do not access these platforms and they complain about it. Yesterday, during a local meeting, different NGOs running CBVCT services complained about their capacity to be more involved in European meetings, the main barriers being language and the lack of economic means to travel.

In your opinion, is it a fact that CBVCT services are not given the right consideration, attention and reward at national level, in your country?

At national level, health administrations should consider community based services as a formal health provider and use the info they generate to M&E the national response. CBVCT services should be part of the overall health system and be funded and monitored as it is usually done with other health services and providers.

What would you suggest to make checkpoints and CBVCT services feel as equal partners at the European and national levels?

At European level there are already many platforms and initiatives with their lead and participation. ECDC is systematically involving NGOs in the testing guidance development and other front line issues in the field of prevention, like PrEP. Many research calls take into account the participation of NGOs and RRI. Keep going in that direction. Countries should facilitate the creation of networks and their participation in European initiatives.

As I said, at national level, to include these services and programs in the formal health systems, through whatever legal frameworks exist in the different countries for other providers; NGOs running CBVCT and other community programs and services should be included in the process of discussing and defining National Plans; data generated by them should be shared and analyzed together with public health authorities. We need a formalization of these services to insure sustainability and keep improving their effectiveness.

What in your opinion is the contribution of CBVCT services to the European efforts in reaching the global targets 90-90-90 and the end of AIDS?

CBVCTs are key in the response. In our setting currently CBVCT services identify more or less 15-20% of the total of HIV reported cases and this is a very relevant contribution. It makes sense because people at risk do not go to the health system unless they have symptoms; NGOs with strong links with different vulnerable and key groups are in a unique position to access people at risk in the early phase of the

infection as well asi in ensuring linkage to care. So, both in terms of test numbers and early diagnoses and treatment, community services surely play a key role, but there is still room for improvement. The information collected through the COBATEST network have proven to be strategic in increasing the evidence on the need to strengthen community-based service delivery models as an integral part of the HIV strategic investments, to be used as an important source of information contributing to supporting quality services along the HIV care cascade.

Are CBVCT services in your country medicalized? ☐ Yes ☒ No

If by "medicalized" we understand the presence of medical staff, no, but there is a tendency of very few of them to become more medicalized and use high technology; in general the others are not, they offer educational interventions, support and social services and are not willing to become more medicalized.
As it showed the survey done in the HIV-COBATEST project (www.eurohivedat.eu and Reyes-Ureña J et al, Int J of STI & AIDS, 2015) at the European level there is also a large heterogeneity, since in some countries medical staff is still required to perform screening with rapid test. After 7 years of this survey, we would like to repeat it shortly to assess how the "medicalization" among other characteristics of the CBVCTs have evolved. Nevertheless, what is important is to guarantee the continuum of care through the different levels of the local health systems, being the community services the starting point and to decrease as much as possible the time between the bars of the Cascade of Services. With this purpose, the need of medicalization of CBVCT is also a function of how good primary health care and specific STI services are performing in each country.

Who is allowed to perform rapid tests in CBVCT services in your country?

It is not compulsory to have medical staff in CBVCTs. Besides the Spanish regulations are very strict on the need of being a health professional who actually performs the diagnosis procedures, back in 2006, with the introduction of rapid testing, we succeeded in having this type of tests considered only as a screening procedure and therefore there is no need of having them performed by medical staff. Trained lay staff, peers and people from the community can offer rapid tests, as far as they comply sanitary requirement, particularly dealing with blood testing.

Do CBVCT services in your country report data relative to their activities to the health authorities? (number and type of tests performed, number of reactive results, number of clients confirmed and linked to care…)?

☒ Yes ☐ No

In 1994, in Catalonia we established the DEVO network, which inspired the COBATEST network, and started to systematically collect data on testing activities including some epidemiological characteristic of the users and linkage to care information. We systematically collect data since 1994 and a few years ago we introduced the COBATEST data collection tool at the local level, which is used by all of them

but one who a few years ago decided sharing only overall activity figures with the administration. In the rest of Spain, the Ministry of Health is working on an application to systematically collect data from all NGOs offering HIV testing; the variables have been harmonized with those of the DEVO and COBATEST networks and an agreement has been made to share these data at national level and with the COBATEST network. Data from CBVCT is crucial to construct some of the indicators of the Dublin Declaration and to assess the contribution of this strategy in the overall increase of early detection.

If yes, to whom they report?

- ☐ Hospitals/clinics
- ☒ Local/regional public health services and/or institutions
- ☒ Regional/national surveillance institutions
- ☐ Other
- ☐

Are they requested to meet specific reporting requirements?

At the local level, tests performed by NGOs implementing CBVCT are paid by the Health Department; although this is not mandatory by law, there is an agreement to use a common technical protocol and to share the programmatic data with CEEISCAT/Health Department. There are periodical meetings to discuss technical aspects, to analyze the data and proposed new actions within the network. No specific legal requirements, but to have the necessary training (informal) and sanitary safety conditions and if blood test are used. Before the development of the COBATEST tool, each CBVCT collected the data on paper and we digitalized at CEEISCAT. From the development of the COBATEST tool, each organization enters directly the data and has access to its own data; we help them for specific analysis they may need.

Which are the stakeholders CBVCT services keep in contact with in your country?

- ☒ Hospitals/clinics
- ☒ Local/regional public health services and/or institutions
- ☒ Pharmacies
- ☒ GPs
- ☒ Other NGOs
- ☒ Regional/national surveillance institutions *(CEEISCAT)*
- ☐ Other
- ☐ None of the above

How are CBVCT services funded in your country?

In Catalonia, NGOs in general are almost 100% funded by the Health Department, except for a few of them which have access to funds from the industry or other private donors. For the rest of Spain the

situation is not so different: some of the CBVCTs have access to resources from the pharma, but most of them are funded by the Health Ministry or regional administrations. It would be nice if all NGOs were funded by a diversity of sources, but the reality is that the majority are funded only by the public administration and due to the economic crisis they have important limitations.

Did CBVCT services experience any interruption in the delivery of services in your country?

They did not close as far as I know, but there have been ups and downs due to the instability of funding and the difficulties in midterm planning. Overall the number (and more important the effectiveness) of tests could still increase if well funded and local tailored strategies were in place.

What were the reasons causing the interruption?

As I said, financial restrictions and a lack of formal framework to consider CBVCT formal health providers.

The way forward – Obstacles and opportunities in the development of CBVCT services

In your opinion, which are the barriers that prevent a fruitful collaboration between CBVCT services and other stakeholders at European level?

At the European level, I think there is already a clear commitment of institutions like the European Commission, WHO and ECDC to include reps of the CBVCT in all meetings and processes addressed to elaborate CBVCT documents and guidelines, in collaboration with technical experts. So, I would say one of the main needs is to insure a good collaboration first at the national level and the existence of local networks and platforms which may facilitate a rotating and representative participation of its members in European initiatives and meetings.
Moreover, platforms like Civil Society Forum and AIDS Action Europe among others need to include community testing in a broad sense in their agendas and facilitate meetings with technical experts. A very good example of this is the meeting "Communities, clinics and academia. Collaboration in CBVCT: Good practices and obstacles" organized by AIDS Action Europe and the European Commission in Glasgow in 2016.
Finally, projects like COBATEST, Euro HIV EDAT and INTEGRATE among others have contributed to harmonize indicators and data collection tools, dissemination of information and therefore to establish strong collaborations across sectors. Sustainability of some of these efforts is crucial to keep these collaborations alive and improving. Private donors and in particular the pharma industry and diagnosis companies should be aware of the added value of focusing their efforts in helping to consolidate initiatives that involve both NGOs and technical experts at the European level. These initiatives in

collaboration with ECDC and other agencies would help to push local agendas at national level in a harmonized manner.
Finally, it would be difficult to establish sound, consistent and representative collaboration across Europe, if at the national level there are not the objectives and structures to establish such collaboration, this being even more important in large countries, like Spain, with a huge heterogeneity and dispersion of organizations working both in the field and in the public administration.

In your opinion, which are the barriers that prevent a fruitful collaboration between CBVCT services and other stakeholders at national level?

I think I already answered that previously, but the lack of political commitment towards evidence based policies, the lack of willingness of all actors in working together to achieve the 90-90-90 objectives, the lack of funding and a the lack of a strong public health multi sectorial framework, are in my opinion the main issues that may threaten fruitful collaborations across sectors. Strong local networks and associations, like AIDS Hilfe in Germany, are very helpful to gain efficiency in the communication with the local administrations and in participating and being represented in European initiatives.

In your opinion, which are the opportunities that a fruitful collaboration between CBVCT services and other stakeholders offers today at European level?

I think we are in an excellent momentum. The concept of CBVCT has been consolidated, disseminated and accepted, there are plenty of data showing its effectiveness in detecting undiagnosed HIV infections, as well as other STIs (which as everyone knows also help transmission of HIV), there are a number of European projects which have been working with CBVCT related issues involving both the community and experts in Public Health, in most of the countries NGOs running CBVCTs have increased and gained visibility during last years, some organizations, like EATG, are transnational, there are strong and consolidated initiatives like CSF and EAU in which the community is actively leading, and there are institutions like the European Commission and ECDC who have already shown their recognition for both CBVCT as effective preventive strategies and NGOs as necessary actors to implement them… so …
I would say that now we need to keep showing the value of CBVCT in a broad perspective and the importance of cross sectorial collaborations to improve and scale them up. Dissemination of the outputs of such collaboration is crucial to increase awareness of local administrations, and this is also an issue to be improved. I am sure there are so many more aspects than other stakeholders and organizations will identify, but I would like to mention a few particular ongoing initiatives and opportunities for the next years I am aware of:
1. Monitoring and Evaluation. *As any other service or program CBVCT needs a continuous M&E component to increase their effectiveness and to be use for advocacy purposes. It has been agreed with AAE in including some of the outputs of both COBATEST and Euro HIV EDAT projects, namely the COBATEST network, the tool for implementing CVBCT addressed to MSM (www.eurohivedat.org) and the COBA-COHORT (Lorente N et al, BMJ Open 2016), within the Operational Grant submitted by AIDS*

Action Europe. We hope that it will help not only to keep these initiatives ongoing but also to increase the participation and visibility of community organizations in them by means of establishing new collaborative governance structures. Moreover, we have been working with ECDC to include some indicators of CBVCTs in the Dublin Declaration; this should stimulate countries to better support these services.

2. Integration. *As it was shown in many countries, CBVCT initiatives have been implemented without the participation of public administrations, and on the other hand these do not know and not use the data generated by these services. Within the new European Commission funded Joint Action , the INTEGRATE project lead by CHIP in Denmark, there is a work package with one of its objectives being to assess how data from CBVCTs could be better integrated into the formal national surveillance systems; some pilot studies will be performed in several countries. We hope that these pilots will help authorities to consider these services and the data they generate an important part of their information systems, as well as to help NGOs running CBVCTs to share the data more easily.*

3. HIV in Europe and Testing Week. *The HIV in Europe initiative has been promoting the Testing Week (currently for HIV and Hepatitis) during last years and it has facilitated many organizations to start testing activities. Within the already mentioned INTEGRATE project, a work package will be especially identify how to improve the assessment of the impact of the Testing Week, as well as how to improve M&E. HIV in Europe have been very active and effective in promoting testing, particularly among health settings, together with the INTEGRATE project. This is also a good framework from which to further strengthen CBVCTs in Europe, and a working group has already been established to identify different and new strategies.*

4. Concept of "community health worker". *While in Anglo Saxon countries, particularly the USA, the concept of "community health worker (CHW)" is well established and used, in many European countries it is not. If we are trying to "normalize" CBVCTs as health providers, it would be useful to have a description and some mapping of the health promotion work and the profile of the people who are delivering it at the community level. The European Commission funded project ESTICOM (www.esticom.eu), has a work package with this aim, and currently an Internet-based survey (ECHOES - www.echoessurvey.eu) is being implemented collecting data on community health activities addressed to MSM. For the purpose of the project, a wide CHW operational definition has been set-up: "anyone who provides sexual health support to MSM in community settings, whether medically trained professionals, counsellors or lay-persons, whether the work is done on a full-time, part-time or occasional basis, and whether the work is done on a paid or voluntary basis". That could be the first piece of data on CHW at European level and the first step to further define and empower "community health work" including of course CBVCT work.*

5.Cost-effectiveness. *Within the European Commission funded OptTEST Project, lead by CHIP, one of its work packages studied the cost-effectiveness of different testing strategies with the health settings and developed an algorithm that can help consider the most cost-effective strategy for testing according to GDP and national epidemic. The work has already informed policy changes in France and local data is seen as an important tool to change HIV testing guidance*
At the CBVCT level, with some checkpoints of the COBATEST network and with funds from a competitive Gilead Grant (GoSHAPE), an economical evaluation was also implemented (Perelman J et al. AIDS Care, 2016), showing the different factors that can influence the cost of each HIV infected person detected.

Nevertheless, more studies are needed to better assess the cost-effectiveness of CBVCTs, including outreach strategies, in the mid and long term.

6.POC. *New point of care technologies are evolving very rapidly for different STIs. Many of them could be easily implemented at the community level. That would allow to also offering an STI test to users who may have been also exposed to these infections and increase the effectiveness of CBVCTs. With WHO and a number of CBVCTs from the COBATEST network, there is an ongoing study to assess the potential acceptability and viability of some of these new technologies, including dual rapid test for HIV and syphilis.*

In your opinion, which are the opportunities that a fruitful collaboration between CBVCT services and other stakeholders offers today at the national/local level?

Apart from the general issues I already mentioned, in our particular case funding for both community services and public health agencies, political support to the already existing information systems, to assure the collaboration between the different levels of the administration and to improve the collaboration between NGOs and Public Health academia.

To your knowledge, are there any countries that have already implemented a successful collaboration among the different stakeholders? If so, could you name a few? Could you indicate the outcomes / good practices deriving from such fruitful collaboration?

Mentioning specific examples is always difficult, because there are so many good case studies and you always miss some. But as examples I can think right now, I know that in Denmark, the collaboration is very good between NGOs and the health department and the surveillance unit; in Germany, they have a very good network, AIDS Hilfe, to deliver information and fund these services; in France they have had a very strong policy in implementing testing services through the country and in collaboration with large NGOs as AIDES, and the COBATEST network have shown the relevance and viability of collecting standardized data from CBVCT across Europe. But, again, there are many other examples; the Euro HIV EDAT as well as the Testing Guidelines of WHO have identified many good practices examples and ECDC is currently updating its guidance document and also has identified several good case studies.

If you were given the chance to improve some aspects of CBVCT services, what would such aspects be?

Given the heterogeneity of the European scenarios there is no single issue, but in general I would say the main issues are: funding, integration in multisectorial Public Health frameworks, in some countries facilitate the integration of small entities with limited logistical capacities to increase effectiveness and efficiency of their programs, continuous capacity building and training with new strategies and technologies, harmonization of indicators and data collection and systematic evaluation.
With this regards CBVCT services' data quality is critical in ensuring that appropriate conclusions are drawn from the information captured at the CBVCT services and to ensure that data can be integrated

into national/ regional surveillance systems in the future. Within a study commissioned by the ECDC to CEEISCAT, a data quality assessment of the data collected by the COBATEST Network was done, based on transcription validity, completeness, consistency of the data collected from 2015 to 2016. This assessment identified weaknesses in the data quality of the COBATEST network, which will need to be addressed at the country level, ensuring that staffing patterns are established to meet health information needs, providing need-based supportive supervision along with appropriate IT support, and fostering data use for evidence-based decision-making. Moreover, some outreach strategies have proven to be extremely effective in picking up unknown infections among people who otherwise would have not been tested; but within the COBATEST Network, 80% of the tests performed by CBVCTs are done in the NGO premises. Data from the network show that linkage to care is quite high, particularly among MSM, but there are low percentages in other groups from some countries. So, services should be further expanded outside the NGOs offices to reach those people who not only do not access public healthcare services, but do not even access community services in the NGO premises. I think that the CBVCT concept should be open and evolve according to the epidemiological scenarios and evidence on new strategies and technologies.

Are there any additional comments/suggestions that you would like to make on the topic of CBVCT services?

This has been a long interview. Trying to summarize, I think that CBVCT services in Europe are crucial to achieve the 90-90-90 objectives, contributing to decrease the percentage of late diagnosis and to improve linkage to care. Therefore they should be a priority component of National Prevention and Control Programs and their activities should be treated, both from the funding and evaluation perspective, as other formal health providers, according to the characteristics of the different existing local health systems. CBVCT should also be open to integrated new strategies and technologies like outreach programs, as well as to provide support to self-testing initiatives. All of that needs to be done within strong institutional Public Health frameworks to facilitate shared processes, data harmonization and evaluation, and ultimately the use of the data to design evidence based policies. Transectorial collaboration is the basis for doing so.

Thank you very much for your time!

Appendix 6 – INMI L. Spallanzani, Italy - Interview to Enrico Girardi

Community Based Voluntary Counselling and Testing Services

Present obstacles and Opportunities

Your organization: *National Institute for Infectious Disease L. Spallanzani*

Your name: *Enrico Girardi*

The country where you live and work: *Italy*

Does your organization maintain a collaboration with CBVCT services at European, national or local level?

We have worked with NGOs for 2 national demonstration projects on CBVCT and we presently collaborate with an NGO which runs a CBVCT site in Rome.

If yes, what is the purpose of your collaboration?

During the demonstration projects we provided training and support for development of common protocols and analysis of activity data. In the present phase we provide medical personnel who perform rapid tests .

If no, would you like to initiate a collaboration with CBVCT services? What would such collaboration be useful for?

Are there any negative aspects/shortfalls in the actual collaboration between academia/institutions and CBVCT services? Please explain:

CVBT run by NGO is presently seen in most parts of Italy as initiatives planned and conducted without coordination with testing offered by the national health service. In other words institutions do not consider CVBT as a part of the general strategy of offer HIV testing.

Are you aware that checkpoints and other CBVCT services feel their contribution and efforts are not recognized and valued?

I guess they feel they are not part of a common effort to promote access to HIV testing.

In your opinion, is it a fact that CBVCT services are not given the right consideration, attention and reward at European level?

I do have direct information on the situation on this issue in other European countries.

In your opinion, is it a fact that CBVCT services are not given the right consideration, attention and reward at national level, in your country?

Yes, the role of CBVCT is now recognized in the Italian national AIDS Plan. However, there is not a clear strategy on how to promote and support CBVCT al local level.

What would you suggest to make checkpoints and CBVCT services feel as equal partners at the European and national levels?

I suggest that organizations running CBVCT should be involved with other stakeholders by health institutions in developing national and local plans to improve the access to HIV testing based on analysis of local epidemiology and access to HIV testing . Clear rules on how to organize CBVCT and how to access to economic support from institutions also need to be developed.

What in your opinion is the contribution of CBVCT services to the European efforts in reaching the global targets 90-90-90 and the end of AIDS?

In my opinion, increasing access to test requires the existence of a diversified offer that includes testing in health care institutions, CBVCT and self-testing. There is a sizeable proportion of persons who may prefer being tested in a non medical setting for whom CBVCT may be an important opportunity.

Are CBVCT services in your country medicalized? ☒ Yes ☐ No

Who is allowed to perform rapid tests in CBVCT services in your country?

Only health care workers.

Do CBVCT services in your country report data relative to their activities to the health authorities? (number and type of tests performed, number of reactive results, number of clients confirmed and linked to care…)?

☒ Yes ☐No

I believe that many CBVTCT initiative do not have any obligation to report, but some, which have formal agreements with regional health services, may have.

If yes, to whom they report?

- ☐ Hospitals/clinics
- ☒ Local/regional public health services and/or institutions

- ☐ Regional/national surveillance institutions
- ☐ Other

Are they requested to meet specific reporting requirements?

There is no national standard; specific reporting requirements may exist at local level, I am not sure.

Which are the stakeholders CBVCT services keep in contact with in your country?

- ☒ Hospitals/clinics
- ☒ Local/regional public health services and/or institutions
- ☐ Pharmacies
- ☐ GPs
- ☐ Other NGOs
- ☐ Regional/national surveillance institutions
- ☐ Other
- ☐ None of the above

How are CBVCT services funded in your country?

There is no national standard. Some CVBTs may have support from local institutions in terms of locations, provision of health care workers to perform rapid tests and test kits. Counselors and persons involved management of CBVCT sites are usually unpaid volunteers. Other expenses are usually covered by NGOs on their own funds.

Did CBVCT services experience any interruption in the delivery of services in your country?

Some initiatives have difficulties in providing continuous activity.

What were the reasons causing the interruption?

For the above, mainly economic reasons.

The way forward – Obstacles and opportunities in the development of CBVCT services

In your opinion, which are the barriers that prevent a fruitful collaboration between CBVCT services and other stakeholders at European level?

The status of CBVCT is not well defined. CBVCT should be regarded as a part of a coordinated societal response to the need of providing easy access to HIV testing. Presently institutions do not see CBVCT as of the same rank of services provided directly by public health services. NGOs running CBVCT tend to see CBVCT as something that should be organized on standards that are agreed upon by all stakeholders.

In your opinion, which are the opportunities that a fruitful collaboration between CBVCT services and other stakeholders offers today at European level?

A consensus on CBVCT should be developed at European level addressing its role, organizational standards and financing strategies.

In your opinion, which are the opportunities that a fruitful collaboration between CBVCT services and other stakeholders offers today at the national/local level?

CBVCT can be seen as a model for collaboration between public institutions and other stakeholder for HIV prevention and control initiatives.

To your knowledge, are there any countries that have already implemented a successful collaboration among the different stakeholders? If so, could you name a few? Could you indicate the outcomes / good practices deriving from such fruitful collaboration?

The Barcelona Checkpoint is a notable example in this regard.

If you were given the chance to improve some aspects of CBVCT services, what would such aspects be?

The use of testing kits that are CE marked for self diagnosis could facilitate implementation of CBVCT.

Are there any additional comments/suggestions that you would like to make on the topic of CBVCT services?

Thank you very much for your time!

Appendix 7 –Ath Checkpoint, Greece - Interview to an anonymous client

Community Based Voluntary Counselling and Testing Services

Present obstacles and Opportunities

In which checkpoint did you just take an HIV test? *Ath Checkpoint*

In which city/country? *Athens, Greece*

Your gender : *Male*

How old are you? *38*

Why did you access a checkpoint to get tested? Do you prefer it if compared to healthcare settings?

I could book an appointment over the phone, there is no waiting and I think it's a nicer and friendlier environment than the hospital.

Is this your first time in the checkpoint, or are you a regular client?

I have been there 6 times for testing, over the past 2 years.

How was your experience?

I was happy with the whole experience, there was no waiting, I received expert advice and the testing was quick and painless.

Will you come back? Will you recommend this testing site to your friends and acquaintances?

I will come back and I have suggested getting tested there to friends and colleagues.

Which are in your opinion the strengths of checkpoints?

Ease of access, availability of appointments, no cost for testing, friendly and non-clinical environment.

Which are the services you did not find here and would like to receive in the future?

Free other than HIV, HBV, HCV and sometimes syphilis, STIs testing.

Are you satisfied with the competence and professionality of the staff?

Totally.

According to you, is it important to maintain and improve checkpoints and testing sites outside of healthcare settings, managed by community organizations? If yes, for which reasons?

I think community-based testing is important and very useful, because it's closer to my needs, it's more flexible and friendly. It is also free of charge, at a time when it's not free to get tested in any public hospital, which prevents people from getting tested.

Which of the differences existing between checkpoints and testing sites in healthcare settings motivate some people to choose checkpoints?

At the checkpoint someone will always answer the phone, testing is free, the testers are friendly and the environment does not feel like a hospital.

Which groups of clients are in your opinion the most interested in the expansion of this type of services?

I would like to see checkpoint for all groups of people that are sexually active.

Would you support a campaign for the expansion and improvement of testing services managed by community organizations?

I definitely would, community based testing is the future.

Do you know other activities carried out by the organization hosting the checkpoint? Are they important to you?

The organization is doing testing all over the country, constantly distributes free condoms and has a comprehensive streetwork program.

Thanks for the time you dedicated to this interview!

Appendix 8 – LILA Milano community testing service, Italy - Interview to an anonymous client

Community Based Voluntary Counselling and Testing Services

Present obstacles and Opportunities

In which facility did you just take an HIV test? *LILA Milano*

In which city/country? *Milan, Italy*

Your gender : *Male*

How old are you? *45*

Why did you access a checkpoint to get tested? Do you prefer it if compared to healthcare settings?

I liked the idea to get tested in a place that I imagined would be less formal than a hospital or a lab.

Is this your first time in the checkpoint, or are you a regular client?

Actually, today has been my first time here.

How was your experience?

It was indeed very special and positive. I really did not know what to expect, and I am happy I decided to come here.

Will you come back? Will you recommend this testing site to your friends and acquaintances?

I don't know if I will need to come back, but I would if needed. I will surely suggest this solution to some of the people I can talk about the issue of HIV and STI testing.

Which are in your opinion the strengths of checkpoints?

The staff, who was extremely professional and friendly at the same time. I also enjoyed the place, the logistics.

Which are the services you did not find here and would like to receive in the future?

I cannot think of anything for the moment, maybe because it was my first time and I do not know much about these facilities. Are there other services that I could get here?

Are you satisfied with the competence and professionality of the staff?

As I said already, I am definitely satisfied with it.

According to you, is it important to maintain and improve checkpoints and testing sites outside of healthcare settings, managed by community organizations? If yes, for which reasons?

Yes, because they contribute to disseminate a culture of prevention and sexual health, and they accept and welcome people of all kinds. I liked a lot the heterogeneity of the clients I saw here.

Which of the differences existing between checkpoints and testing sites in healthcare settings motivate some people to choose checkpoints?

I think that people like the more intimate and relaxed, informal atmosphere.

Which groups of clients are in your opinion the most interested in the expansion of this type of services?

Everybody would be interested in having access to these services.

Would you support a campaign for the expansion and improvement of testing services managed by community organizations?

Yes, surely.

Do you know other activities carried out by the organization hosting the testing service? Are they important to you?

I don't think I know them all; I know they work a lot on prevention of HIV and other STIs.

Thanks for the time you dedicated to this interview!