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**Description and improvement of different approaches of
linkage to care for HIV among MSM in Europe**

Data report

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1 ABBREVIATIONS & DEFINITIONS

CBVCT	Community-based voluntary counselling and testing service
ECDC	European centre for disease prevention and control
EDAT	Early diagnosis and treatment
EEA	European Economic Area
EU	European Union
GIPA	Greater Involvement of People living with HIV
GP	General practitioner
HIV	Human immunodeficiency virus
HIV-COBATEST	HIV community-based testing practices in Europe
MSM	Men who have sex with men
NGO	Non-governmental organisation
OptTEST	Optimising testing and linkage to care for HIV across Europe
STI	Sexual transmitted infections
WP	Work package

Definitions

Linkage to care

There is a wide range of definitions of linkage to care in use (see chapter 5, Literature Study). In our work with WP6 all of the interviewed CBVCT managers have in practice used the definition used in the HIV-COBATEST Network (14) (besides that we today would prefer to use the terminology ‘a reactive HIV test’ at a CBVCT, as most tests taken at a CBVCT have to be confirmed) stating that:

Linkage to health care is defined as entry into health care or follow-up by an HIV specialist or in an HIV unit after HIV diagnosis at CBVCT facility and the linkage was facilitated by the CBVCT facility.

This is also in line with the definition used in the OptTEST WP4 project. Here linkage to care is defined as:

A patient was considered linked to care if seen for specialist HIV care after diagnosis, measured as the time between the HIV diagnosis date and first clinic attendance date/CD4 count date/viral load date/HIV treatment start date, depending on data availability.

Very few CBVCTs receive information on CD4 count date, viral load date or HIV treatment start date, but quite many get information on first clinic attendance date – although this is often either informal information or information from the client.

It should be emphasized that when this report refer to ‘people with a confirmatory HIV test who are linked to care’, this covers different situations. In most cases the CBVCT have this information either from the client himself or through information from the HIV-unit. Only one CBCVT (BCN Checkpoint, Spain) does confirmatory testing.

This study recommends the following definition for future use:

Linkage to health care is defined as entry into health care or follow-up by an HIV specialist or in an HIV- unit after a reactive or confirmatory HIV-test at a CBVCT facility.

A reactive HIV-test

This terminology is used when the HIV-test used in the CBVCT is an Elisa-test. As there is a risk that the Elisa-test gives a false positive result this kind of test result has to be confirmed either by a PCR-test or a Western Blot test.

A positive HIV-test

This terminology is used when the reactive HIV-test has been confirmed by either a PCR-test or a Western Blot test.

CBVCT

Literature and evidence show that the definition of community-based voluntary counselling and testing differs enormously from one national European context to the other. For this reason, the HIV-COBATEST project had proposed the following definition (13) and this is also how we will use the concept of CBVCT in this report:

CBVCT is any program or service that offers HIV counselling and testing on a voluntary basis outside formal health facilities. It has been designed to target specific groups within the most-at-risk populations and is clearly adapted 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.

2 EXECUTIVE SUMMARY

This study (Work package 6) is part of project 'Operational knowledge to improve HIV early diagnosis and treatment among vulnerable groups in Europe' with the acronym Euro HIV EDAT.

The aim of WP6 has been to describe and improve approaches of linkage to care for MSM with a reactive HIV-test in a CBVCT.

This report provides an insight of the results of the study.

Initially, an overview of the literature on definitions and barriers to being linked to care was necessary and WP4 in the OPTtest project kindly shared their literature review with this project and the Study Protocol for this study was developed.

A questionnaire has been sent to 40 CBVCTs in Europe with the purpose of getting an overview of number of people getting tested and linked to care in the different CBVCTs, to collect information on cooperation with health facilities monitoring and treating people living with HIV and to know what kind of support the different CBVCTs were offering people who test positive for HIV. 16 questionnaires were filled in and returned.

To get a more in-depth insight of the cooperation between the CBVCTs and the health care system, to capture difficulties and challenges but also to capture successes and the context for these, CBVCT managers and health care professionals in seven countries were interviewed.

To capture the voice of MSM with experience of having a reactive HIV-test in a CBVCT and later linked to care also a questionnaire to this group was developed and translated into seven different languages and made available via links on the internet. A total of 53 filled in questionnaires were accepted for analysis.

Finally, interviews were conducted with eight MSM about their experiences of having a reactive HIV-test in a CBVCT and later being linked to care.

Key findings

- The procedures in CBVCTs of testing and linking to confirmatory testing and care are very different between the CBVCTs.
- When the CBVCTs have knowledge of a confirmatory HIV-test, a very high number of people tested in a CBVCT are linked to care.
- The knowledge of linkage to care is less impressive when the CBVCT do not have knowledge of a confirmatory HIV-test following the reactive test in CBVCT.
- Getting reliable information on success or failure of linkage to care is a problem in most countries because of confidentiality issues. A little more than half of the CBVCTs receive information about the result of the confirmatory test although this information is often *informal*.
- It seems evident that having a close coordination between the CBVCT and the health care system is important for a successful linkage to care.
- Both health care professionals and the CBVCT managers, with a very few exceptions, assess the cooperation between CBVCTs and the health care system as very good.
- Most clients with a reactive HIV test are helped with a specific appointment at the HIV-unit and linkage to care was arranged quickly. More than nine out of ten had an appointment with the

health care system within two weeks and clients assess the referral practice between CBVCTs and the health care system as very good.

- All CBVCTs are offering different kind of support to people who are newly diagnosed with HIV, which is typically peer-to-peer support, psychological, social or medical support.
- None of the CBVCTS mention in the questionnaire any specific problems in linking MSM to care from CBVCTs and the same apply for the CBVCT managers and health care professionals being interviewed.
- A number of more general barriers to linkage to care that are not specifically related to the MSM group have been seen. These are e.g. lack of access to a HIV-unit where the client is living; HIV-units refuse to accept HIV-positive patients because the hospital department are overcrowded or underage young people who cannot have access to HIV-test or HIV-treatment without their parents' knowledge and accept.

3 STUDY CONTEXT

In a previous project funded by the European Commission (the HIV-COBATEST project), a network of CBVCT services targeting the most affected population (MSM, migrants and people who inject drugs) has been implemented across Europe. The HIV-COBATEST project identified key indicators allowing the monitoring of these CBVCT services' activity, helped by a standardized instrument of data collection.

This study, WP6 (Work Package 6), is part of the project **Operational knowledge to improve HIV early diagnosis and treatment among vulnerable groups in Europe** with the acronym Euro HIV EDAT (Early Diagnosis And Treatment) (Grant Agreement 2013 11 01) co-founded by the Consumers, Health and Food Executive Agency (CHAFEA).

The overall purpose of the Euro HIV EDAT project is to generate operational knowledge to better understand the role and impact of community based voluntary counselling and testing services (CBVCTs), to explore the use of innovative strategies based on new technologies and to increase early HIV/STI diagnosis and treatment in Europe among the most affected groups.

The project is aimed at generating harmonized monitoring and evaluation data from CBVCTs across Europe using the Indicators and Data Collections Instruments developed by the COBATEST Project and to explore the acceptability, feasibility and effectiveness of innovative strategies, HIV self-testing and web based outreach and counselling approaches.

The expected outcomes of the Euro HIV EDAT project will contribute to decrease HIV/STI transmission, improve clinical outcomes, promote equity across Europe, contribute to the improvement of CBVCT services and will inform policy makers to better contextualize these interventions within their national HIV Prevention Programs.

The following six specific objectives have been defined in the Euro HIV EDAT project:

- 1) To monitor and evaluate CBVCT services in Europe
- 2) To identify determinants for HIV test seeking behaviour and sexual risk behaviour among MSM in Europe
- 3) To describe and improve approaches of linkage to health services for HIV among MSM in Europe
- 4) To improve the implementation of CBVCT services specifically addressed to MSM in Europe
- 5) To describe HIV testing patterns and identify barriers to testing and care among migrant populations in Europe
- 6) To assess acceptability and feasibility of innovative strategies and interventions aimed at increasing HIV counselling and testing.

The aim of the current project (WP6) is to examine and describe objective no 3:

To describe and improve approaches of linkage to health services for HIV among MSM in Europe.

Overall, the project outcomes will provide operational data and implementation manuals and guidelines to improve the effectiveness and scale up of testing and linkage to care programs, as well as new tools to increase access to them.

Background

At the end of 2015, it was estimated that around 810.000 people were living with HIV in the EU/EEA countries.¹ The epidemic overall has remained relatively stable with HIV prevalence having changed little since 2004 (23).

In 2015, 29.747 HIV diagnoses were reported by EU/EEA countries giving a new diagnosis rate of 6.3 per 100.000 population. The highest rates were observed in Estonia, Latvia and Malta. The lowest rates were reported by Slovakia, Slovenia and Czech Republic (8).

HIV infection has had a large impact on MSM in Europe, as sex between men is the predominant mode of HIV transmission, accounting for 42% of HIV diagnoses in 2015. HIV cases among MSM have increased considerably over the past decade in all but four EU/EEA countries, and significant increases were seen in countries with overall low rates of HIV such as Croatia, Cyprus, the Czech Republic, Hungary, Malta, Romania and Slovakia.

Reported prevalence among MSM is high, ranging from 0.5 to 17.7 %. In 2012, France (17.7 %), Spain (13.1 %), Greece (12.7 %) and Germany (11.5 %) were the countries with the highest prevalence among MSM (21), with no newer estimates available.²

For these reasons, the European Commission considers MSM to be the highest priority group for interventions to combat HIV infection in the EU and neighbouring countries (9) (19).

The ECDC recommends that given “the persistent increase in cases diagnosed in MSM over the last decade, it would appear that current prevention and control interventions need to be scaled up and strengthened and should remain the priority cornerstone of the HIV response.”

In 2002, the first community-based facility was established in Amsterdam in an effort to promote rapid HIV testing. Since then, a large number of CBVCTs all over Europe have been introduced.

Easily accessible CBVCT services are designed to reach key populations (typically MSM and/or sex workers) who might otherwise not seek HIV testing because of risk of prejudice and stigma. CBVCT are simply tailored to increase accessibility, affordability and acceptability for these priority groups with a higher risk of HIV-infection. CBVCT services are established in most European countries, generally targeting key populations (e.g. Spain, Denmark, and Switzerland) and other not specifically targeting these groups but the general population (e.g. Poland).

It is beyond discussion that the CBVCT services reach more MSM than the formal health facilities (19, 24, 26, 28) – among other things because gay men are less likely to be satisfied with the health care they receive in the formal health facilities, in particular with respect to sexual health issues, and often do not disclose their sexual orientation to their providers (26).

With a very few exceptions the CBVCT services do not offer medication (ART) to clients or other services related or unrelated to infectious diseases. For this reason, referrals to other institutions are necessary.

¹ EU countries: Austria, Belgium, Bulgaria, Croatia, Republic of Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, Netherlands, Poland, Portugal, Romania, Slovakia, Slovenia, Spain, Sweden and the UK. EEA countries not in EU: Iceland, Liechtenstein and Norway.

² However, it is also worth noticing that the lowest proportions of those diagnosed late were observed in MSM (37%) (7).

This transfer between two or even more institutions is time-consuming and requires patients to disclose intimate information repeatedly to new providers. Hence, the risk of insufficient linkage to care is high.

It should though be mentioned that the estimated expected time from HIV infection to diagnosis decreased from 4.2 years on average in 2011 to 3.8 years in 2015 (23) and this might be a reflection of increased or more targeted testing.

4 METHODOLOGY

The study consisted of

- a literature review,
- a questionnaire to a total of 40 CBVCTs in Europe,
- qualitative semi-structured interviews done by phone with CBVCT managers from the associated partners and health care professionals working with the CBVCTs,
- a questionnaire to MSM living with HIV, having been tested in a CBVCT and linked to care
- interviews with MSM living with HIV, having been tested in a CBVCT and linked to care.

The study was conducted from May 2015 to January 2017.

Literature review

The WP4 in the OPTtest project very kindly shared their literature review with us and we only did some random search for extra literature. This extra literature is mainly from US.

Questionnaire

The questionnaire was sent to 40 CBVCTs in Europe, seven of them from the HIV-COBATEST network and the rest not part of this network. The main purpose of the questionnaire to the CBVCTs was to get an overview of number of people getting tested and linked to care in the different CBVCTs, to collect information on cooperation with health facilities monitoring and treating people living with HIV and to know what kind of support the different CBVCTs were offering people who test positive for HIV. The questionnaire was distributed in June 2015 asking about testing and linkage experiences in the year 2014.

The questionnaire was in English, contained 33 questions and is attached in appendix 1.

The questionnaire to the CBVCTs was answered by 16 CBVCTs from 12 countries: Poland, Ukraine, France, Greece, Portugal, Spain, Italy, Denmark, Latvia, Austria, Slovenia and Germany. This gives a response rate of 30 %.

Qualitative semi-structured interviews with CBVCT managers and health care professionals

The purpose of the qualitative semi-structured interviews with CBVCT managers and health care professional was to get a more in-depth and qualitative insight of the cooperation between the CBVCTs and the health care system, to capture difficulties and challenges but also to capture successes and the context for these. Interview guides were developed and pilot-tested with the Danish CBVCT manager and one health care professional from Denmark.

The interview guides are attached in appendix 2 and 3.

The qualitative semi-structured interviews were conducted by the field coordinator from Denmark with CBVCT managers and health care professionals working together with the CBVCTs (and chosen by the CBVCT managers) in Spain, France, Portugal, Germany, Slovenia, Denmark and Greece.

It was the original plan, according to the Study Protocol, that the qualitative semi-structured interviews with CBVCT staff among the associated partners and the health care professionals should have been carried

out by the local CBVCT managers guided by an interview guide, have been recorded, transcribed and translated into English.

It was assessed however that it would improve the quality of the interviews if these all were done by the same person, namely the field coordinator from Denmark. Both the CBVCT managers and the health care professionals were prepared for the interviews with the questions from the interview guide.

All interviews, except the interviews with the interviewees in Greece, were done by phone. The interviews in Greece were done face-to-face.

A list of the interviewees is shown in table 12. The interviews lasted between 22 and 71 minutes. Ten of the interviews lasted less than 40 minutes and five interviews lasted more than 40 minutes.

All the interviews were recorded. The interviews were not transcribed in full but comprehensive notes were taken after the interview when listening to the recording.

Questionnaire to MSM living with HIV, having been tested in a CBVCT and linked to care

After having received the completed questionnaires from the 16 CBVCTs and interviewed managers from CBVCTs and health care providers it was important to also hear the voices of people with real life experience – the people that have had a HIV reactive test in a CBVCT (that was later confirmed) and having been linked to care after 1 January 2012. A questionnaire was developed for this purpose, translated into seven different languages and made available via links on the internet.

The associated partners were asked to distribute information on the survey to as many as possible of relevant people and preferably not less than 3-5 persons from each country. A total of 53 questionnaires were accepted for analysis (see table 13).

It is not possible to calculate the response rate, as we do not know how many MSM, linked to care and tested in a CBVCT that have been contacted with an invitation to fill in the online questionnaire. In some countries the CBVCT had contact information on relevant clients, in some countries the HIV-unit helped with contact and in other countries local HIV-organisations helped to distribute the link to the questionnaire.

The questionnaire is attached (in English) in appendix 4.

Interviews with MSM living with HIV, having been tested in a CBVCT and linked to care

In the questionnaire the respondents were asked if they would accept to participate in a face-to-face or telephone interview about their experience of being tested in a CBVCT and linked to care, and if they agree on this they were asked to write contact information (email or telephone number).

24 people accepted to participate in a face-to-face or telephone interview and eight MSM were interviewed by the local CBVCT (two from France, two from Portugal and four from Denmark). These interviews were not recorded but a written summary of the interviews were made and sent to the field coordinator.

Approval from the Danish Data Protection Agency

Approval from the Danish Data Protection Agency to conduct the survey was received before starting the distribution of the questionnaire.

5 LITERATURE STUDY

Existing knowledge on linkage to care

In a meeting report from ECDC from September 2015 a summary of the results from a review of the literature on linkage to care was presented (7). The review included studies published up to the end of June 2015 and focused on definitions and measurements of linkage to care, as well as barriers to being linked to care after diagnosis in the WHO European Region.

Key finding of the review was:

There is limited published data on linkage to care in Europe; most studies are from the USA and Canada.

There is a wide range of definitions of linkage to care in use (e.g. CD4 count measurement within 28 days, 1 month, and/or 3 months of diagnosis; CD4 cell count or viral load measurement after HIV diagnosis within 3 months; first HIV consultation within 4 weeks, 1 month of diagnosis and/or within 6 months; attendance at a specialist HIV appointment within 72 hours of a positive rapid test result; HIV unit referral within 4 weeks (≤ 28 days); registration/enrolment at an HIV clinic within 1 month of diagnosis).

The majority of studies defined linkage to care using laboratory data, which despite being relatively reliable, may not always accurately reflect the date when a patient is integrated into HIV specialist care.

The variety of settings, time periods, populations and definitions utilised make it difficult to compare measurements between countries and studies.

There is limited research focussing on barriers to patients being linked to care following diagnosis, with the vast majority being single-site studies from the UK. These are not necessarily generalizable to other European countries, as barriers are often a product of a country's cultural, political and social environment.

The WP4 in the OPTtest project very kindly shared their literature review with us and we only did some random search for extra literature. This extra literature is mainly from US. By examination of the existing literature (regarding both Europe and US), it is clear that only few studies have been looking into linkage to care – and even fewer when talking about linkage to care from CBVCT services and the subgroup of MSM;

Reports on linkage to care from community testing projects are few (24);

Linkage to care after HIV diagnosis remains under-investigated in Europe. Data from European countries are very limited (1);

To date, however, little work has focused on identifying factors associated with intentions to adopt linkage-to-care interventions (22);

However, little population-based information is available on linkage to care (12);

Additional research on best practices to link and retain HIV-infected individuals in care is needed (11);

However, of the three [testing, linkage to care and treatment], linkage to care is by far the least well described in the HIV literature (5);

... few studies have examined reasons why patients fail to seek care after a diagnosis of HIV infection (17);

The lack of research on the best strategies to link and retain MSM in care is concerning (4).

A population-based study from 2013 on linkage to care in high-income countries (including France, Italy and Spain) concludes that overall, the majority of people diagnosed with HIV (not only MSM) were linked to care within 3 months of diagnosis (more than 70 %)³ – but also that data vary by country and population subgroups (12).

In a 'loss to follow-up study' from the international multicenter observational cohort study EuroSIDA it was found that between May 1994 and December 2006 14.282 patients were diagnosed with HIV and of these 22 % were lost to follow-up (not only MSM). It is stressed that there is a considerable variation in lost to follow-up among the different countries – but when being linked to care, patients are more likely to be from Central and Northern Europe and less likely to be from Eastern Europe (20).

In an analysis from selected European countries using data from 2010 to 2012 to determine disparities in the HIV treatment cascade among all people tested positive for HIV (not only MSM) the conclusion is that the percentage of people linked to care are as follow: Denmark 81 %, United Kingdom 79 %, France 74 % and the Netherlands 73 %. In Georgia, the percentage is as low as 44 %. (25).

Data from the UK CHIC Study (The United Kingdom Collaborative HIV Cohort Study Group), regarding the period 1996 to 2009, shows that black and minority ethnic MSM were more likely to fail to engage in care after diagnosis and it mentions that this finding is consistent with findings from several cohorts in North America and Europe (31).

Other studies have shown that lower or limited education, injecting drug use and higher baseline CD4 cell counts can be predictors for loss to follow-up (28). In an article also dealing with problems of linkage to care in US it is mentioned that along with poverty, unemployment, underemployment, and limited health literacy, domestic violence must be included as a factor that can negatively affect HIV care (3) – and it is here worth noticing that intimate partner violence is more prevalent among gay male couples than among heterosexual couples (30).

A study on barriers for women living with HIV in US mention the following reasons as key barriers for entry into care: Lack of transportation, child care issues, economic factors, symptoms of clinical depression, history of drug or alcohol abuse or physical or sexual abuse, non-white race, private insurance or lack of insurance, not receiving specialist care, inability to take time off work, and being too sick (2).

³ Definitions of linkage to care vary from study to study. Some studies of patients initiating HIV care use "one visit with a provider" as a marker of linkage, and these visits can range from receipt of confirmatory results after a rapid test to a comprehensive HIV clinic intake to a visit with the patient's assigned primary care provider. Other studies use CD4 cell count and viral load measurements within 3 or 6 months of HIV diagnosis as markers of linkage. This literature review has not gone into a discussion of different definitions of linkage to care - but has just accepted the definition that the different studies have chosen.

A recent analysis from the 'The People Living with HIV Stigma Index Project'⁴ also showed substantial variation among European countries in terms of time relapse before accessing care after HIV reactive test, with a range of 31 % (Moldova) to 90% (Turkey) of patients registering within the first 6 months after HIV diagnosis. In Poland 23 % of respondents are not in contact with HIV-units within in the first two years after receiving the HIV positive diagnosis and in Estonia the figure is 14 %. In Moldova and Ukraine close to 25 % of people tested positive for HIV do not access care within the first two years after diagnosis (these figures are not specifically connected to CBVCT services or MSM but are demonstrating huge problems of linkage to care after a HIV positive diagnosis) (27).

A few studies have shown high success in linking HIV positive testing MSM from CBVCT services to care. Among these is a study from Barcelona (Spain) where 90.5 % (448 of 495) MSM were linked to an HIV-unit (2007-2012) (19) and a study from Copenhagen (Denmark) where 97 % (36 of 37) MSM were linked to care (2008-2012) (24).

Other studies show much less success in linking to care from CBVCT services. In Poland only 58 % of newly HIV diagnosed people at CBVCT services were linked to care (1). Although the Polish CBVCTs are not specifically targeting MSM (or other most-at-risk populations) 71 % if the people testing positive were MSM.

A more recent publication on linkage to care from CBVCTs in Poland show that 62 % of people testing HIV-positive in CBVCTs in the period 2010-2013 were linked to care, but despite these low figures on linkage to care it is worth mentioning that persons linked to care were more likely to be MSM (83.3% vs. 62.5%) (15).

In another recent published study, data from 24 CBVCTs from the COBATEST network are analysed. Out of 9.266 HIV screening test 1.6 % were reactive and of the reactive tests 51.1 % had a confirmatory positive test. It is finally mentioned that 84.1 % were successfully linked to care which – as they write – is high compared to other studies. They do make the reservation that data may be not comparable, because of differing definitions of linkage to care (10).

The limited knowledge on problems with linkage to care highlight the need for well-defined mechanisms for linkage and it is obvious that the collaborating CBVCT services should collect all possible information to improve linkage to care in the future and agree on a common understanding of the definition of linkage to care.

In the sparse literature on the issue of linkage to care, some attempts of explanations of the failure to linkage have been made.

The study from the CBVCT service in Barcelona, Spain emphasizes that “peer support is fundamental in helping HIV-infected persons to deal with the emotional impact of receiving such a diagnosis, as well as in helping them to seek medical care and adhere to treatment” (19).

The issue of supporting people to deal with the emotional impact of having an HIV-positive test (or a reactive rapid HIV-test) is also evident in a study from US on linking people living with HIV from Emergency Departments to specialized care:

“... it is likely that the fact that patients are linked into care immediately following their HIV diagnosis contributes to their likelihood of attending their first clinic

⁴ A Pan-European retrospective patient questionnaire study, including data from Estonia, Moldova, Poland, Turkey and Ukraine.

appointment and remaining in care. We believe that this instant access to HIV clinic services is extremely important to patients.”

They further stress the importance of having highly trained social workers who are available to immediately address the stress and anxiety that patients can feel when they are newly diagnosed HIV-positive (16).

Another study from US (18) highlights the importance of the first visit with an HIV care provider, stating that:

“... almost all participants reported having some fears or anxiety about initiating HIV care. Although the psychological impact of HIV was not the focus of this study, it was clear that the shock and devastation of diagnosis with advanced HIV had implications for connection to HIV specialty care with respect to deciding when and where to seek care.”

And it is further mentioned that:

“... stigma was often at the forefront of patient’s minds after diagnosis when considering attending an HIV clinic. Patients were worried about being judged by healthcare professionals and being recognized in the clinic.”

Other studies, also from US, have shown that stigma, homophobia, lack of support, fear of disclosure, mental health status, shame and language barriers can be predictors for loss to follow-up (3).

The pan-European survey from ‘Stigma Index’ notes that the most common reason for delaying engagement with medical care was that the respondents was not ready to address their HIV infection and that concerns about mistreatment, lack of confidentiality by health care workers and fear that one will be recognized at the HIV-unit can influence in not seeking care (27).

Several studies have convincingly demonstrated that engagement in HIV care begins at the testing site (3). How closely the HIV counselling, testing, and referral experience correlates with subsequent linkage to care appears to be related to the tone and expectation for future engagement in care established during counselling and testing. It is further mentioned that:

“Dissatisfaction with the counselling, testing and referral experience was a pervasive theme. Some of the factors reported were lack of empathy, insufficient counselling, and incorrect information.”

In the earlier mentioned study on barriers for women living in US (2) it is mentioned that the study highlights how poor counselling can affect a person’s care-seeking behaviour and motivation to seek care. Lack of trust in health care providers and the medical community may contribute to decreased use of health care services. In addition, maybe more importantly it is mentioned that “a recent study examining hospitalized HIV-infected patients found that patients who were not being “helped into care” after an initial diagnosis of HIV infection were less likely to engage in subsequent HIV care” and that providing actual appointments rather than general referral information may be useful.

Another study from US revealed that healthcare providers generally underestimate the impact of emotional rather than circumstantial barriers that prevent people from seeking testing, care, and treatment for HIV infection. Healthcare providers were more likely to view structural barriers (finances, transportation, family care) (58%) and substance abuse (49%) as important barriers to patients seeking care, while emotional barriers such as fear of HIV medication side effects (82%), fear of people knowing

(58%), and stigma (55%) were the most commonly reported reasons for not seeking care by HIV-infected patients (17).

Although some of the studies are from US and most of them are not specifically related to MSM it is most likely that the experiences already drawn can be used when looking into the problems of linkage to care of MSM from CBVCT services.

It seems evident that the testing situation and the method of referral has an effect on linkage to care. Passive referral in form of a card, brochure, or verbal direction is probably often perceived as constituting little or no help. Clients receiving passive referrals are probably less likely to go to a treatment location.

On the other hand, active referrals in which the counsellor makes an appointment with the HIV-unit (or accompany the client to the HIV-unit) are probably associated with a feeling of support – and a higher likelihood of entry into care. A clear and established pathway for onward referral for patients with a reactive rapid HIV test is essential to achieve good rates of integration into HIV care services for timely ART initiation and attaining viral suppression.

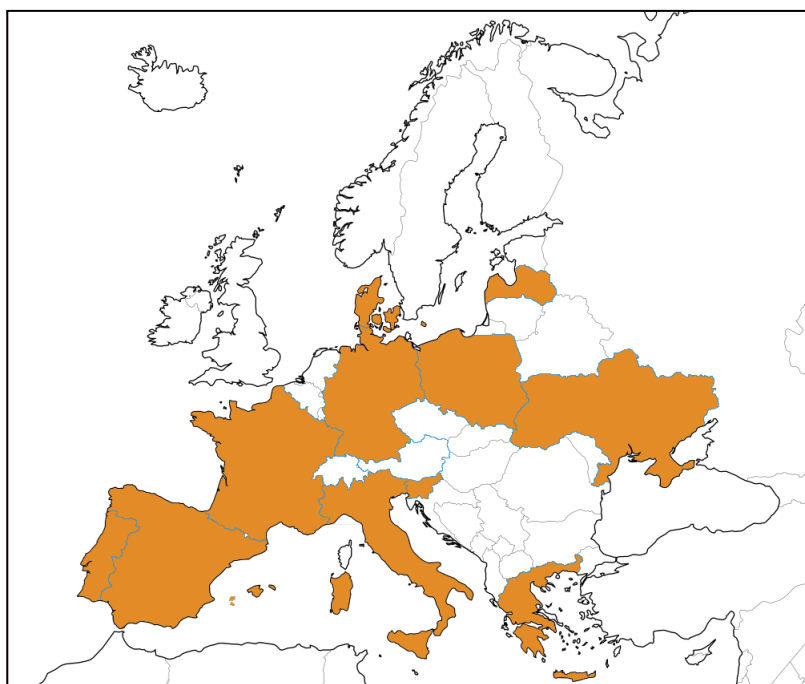
6 QUESTIONNAIRES TO CBVCTs

In June 2015 AIDS-Fondet distributed a questionnaire to a large number of CBVCTs regarding methods for linkage to care or confirmatory testing in the health care system from the different CBVCTs. The questionnaire is attached in appendix 1.

Sixteen CBVCTs answered the questionnaire, see table 1.

Table 1
CBVCTs participating in the survey
1. Poland – 30 Voluntary Counselling and Testing Centres
2. Poland – Foundation for Social Education
3. Ukraine – Community Centre for gays and bisexuals
4. France – Checkpoint, Paris
5. France – AIDES (79 CBVCTs in French territory – Mainland, Antilles, French Guiana)
6. Greece – Athens Checkpoint
7. Portugal – CheckpointLX / GAT
8. Spain – BCN Checkpoint
9. Spain – Associació Ciutadana Antisida De Catalunya
10. Italy – Fondazione LILA Milano ONLUS
11. Denmark – Checkpoint Copenhagen
12. Latvia – Checkpoint for MSM (NGO “Baltic HIV Association”)
13. Austria – AIDS-Hilfe Wien
14. Germany – Stadt Essen
15. Germany – AIDS-Hilfe Hagen e.V.
16. Slovenia – Association Legebitra

The CBVCTs were asked to give information about data from 2014 and as the Community Centre for gays and bisexuals in Ukraine started doing testing in 2015 there is only general information (e.g. possibility of getting an anonymous test, what contact data are collected from the client, etc.) from Ukraine.



Map of countries where CBVCTs have completed the questionnaire

Information from the questionnaires

The CBVCTs are of very different size

AIDES (France) covers 79 sites, both in the French mainland, the Antilles and French Guiana. Total number of HIV tests performed in 2014 at these 79 sites are 43.414.

The National AIDS Centre in Poland covers 30 CBVCTs from across the country – these CBVCTs are not specifically targeting MSM. All the Polish CBVCTs are supervised by the National AIDS Centre. Total number of HIV tests performed in 2014 at these 30 sites are 31.047.

The two 'single' CBVCTs with most tests are Athens Checkpoint (6.324) and AIDS-Hilfe, Wien (6.254).

The two CBVCT with the least number of HIV tests are Checkpoint for MSM (NGO "Baltic HIV Association") in Latvia (115) and AIDS-Hilfe Hagen e.V. (Germany) (300).

In table 2 below some of the key issues from the questionnaires are shown.

Table 2 Overview of the answers from the questionnaires distributed among CBVCTs								
	1 Poland	2 Poland	3 Ukraine	4 France	5 France	6 Greece	7 Portugal	8 Spain
	30 Volun- tary Counsel- ling and Testing Centres	Founda- tion for Social Edu- cation	Commu- nity Centre for gays and bi- sexuals)	Check- point Paris	AIDES 79 CBVCTs Main- land, Antilles, French Guiana	Athens Check- point	Check- pointLX / GAT	BCN Check- point
How many test were performed in CBVCTs in 2014	31.047	5.036	N/A	2.950	43.414	6.324	3.146	4.768
How many % was MSM	?	40 %	N/A	84 %	30 %	70 %	80 %	100 %
How many people received a reactive HIV-test result in CBVCT	469	100	N/A	51	322	123	102	162
What was the % of MSM in the total number of reactive HIV-tests	?	50 %	N/A	96 %	62 %	95 %	100 %	100 %
How many reactive HIV-tests were confirmed	378	70	N/A	51	187	122	102	142
What was the % of MSM in the total number of confirmed reactive HIV-tests	69 %	66 %	N/A	96 %	N/A	100 %	100 %	100 %
How many % of people with confirmatory test were linked to care	N/A	62 %	N/A	96 %	91 %	90 %	83 %	91 %
What was the % of MSM in the total number of people linked to care	N/A	80 %	N/A	95 %	N/A	90 %	100 %	91 %
*) The Ukrainian CBVCT opened for HIV testing in June 2015.								

Table 2 - continued Overview of the answers from the questionnaires distributed among CBVCTs								
	9 Spain Asso- ciació Ciuta- dana Antisida De Cata- lunya	10 Italy Fon- dazione LILA Milano ONLUS	11 Den- mark Check- point Copen- hagen	12 Latvia Check- point for MSM	13 Austria AIDS- Hilfe Wien	14 Ger- many Stadt Essen	15 Ger- many AIDS- Hilfe Hagen e.V.	16 Slovenia Asso- ciation Lege- bitra
How many test were performed in CBVCTs in 2014	1.036	622	2.067	115	6.254	2.152	300	480
How many % was MSM	17 %	45 %	63 %	100 %	26 %	25 %	N/A	100 %
How many people received a reactive HIV-test result in CBVCT	14	11	21	3	29	19	N/A	6
What was the % of MSM in the total number of reactive HIV-tests	57 %	82 %	90 %	100 %	69 %	47 %	70 %	100 %
How many reactive HIV-tests were confirmed	3	7	20	No info	25	19	3	6
What was the % of MSM in the total number of confirmed reactive HIV-tests	67 %	71 %	90 %	N/A	88 %	90 %	N/A	100 %
How many % of people with confirmatory test were linked to care	67 %	100 %	100 %	N/A	N/A	100 %	100 %	100 %
What was the % of MSM in the total number of people linked to care	100 %	71 %	90 %	N/A	N/A	90 %	N/A	100 %

It must again be emphasized that when this report refer to ‘people with a confirmatory HIV test who are linked to care’, this covers different situations. In most cases the CBVCT have this information either from the client himself or through information from the HIV-unit. Only one CBCVT (BCN Checkpoint, Spain) does confirmatory testing.

It should here be stressed that some of the CBVCTs in the questionnaire has noted that some of the people with a reactive test were foreign nationals who left for their home country for care and other people were 'self-linked' to care and could consequently not be confirmed as linked to care. It should also be mentioned that the information of linkage to care given by the CBVCTs are 'what they know' as one CBVCT mentioned in the questionnaire, 'the number can be higher' as they wrote. This should be remembered when reading all the tables in this chapter.

As it is shown, quite a high number of people testing positive through a CBVCT are linked to care.

Although CBVCTs in general target selected key populations (typical MSM), there are huge differences in the respective number of MSM tested in the different CBVCTs.

It spans from the lowest numbers (25 % and 26 %) in Germany (Stadt Essen) and Aids-Hilfe Wien, Austria to 100 % MSM in BCN-Checkpoint in Barcelona (Spain) and in Latvia Checkpoint.

The two sites that tested the highest number of people with a reactive HIV test were AIDES in France and Poland covering respectively 79 and 30 sites. The prevalence is relatively low though (0.7 % and 1.5 %).

The two CBVCTs with the highest incidence are BCN-Checkpoint in Spain (3.4 %) and CheckpointLX/GAT in Portugal (3.2 %). Both of these testing sites target MSM.

Although most of the CBVCTs are targeting MSM, it is noteworthy that in five of the CBVCTs the percentage of MSM among people with a reactive HIV-test is below 70 % (see table 3). This demonstrates that the option of a quick and anonymous HIV-test is also relevant for people who do not belong to the MSM group.

Table 3	
The percentage of MSM in the total number of reactive HIV-tests	
1. Poland – 30 Voluntary Counselling and Testing Centres	69 %
2. Poland – Foundation for Social Education	66 %
3. Ukraine – Community Centre for gays and bisexuals	N/A
4. France – Checkpoint-Paris	96 %
5. France – AIDES	62 %
6. Greece – Athens Checkpoint	95 %
7. Portugal – CheckpointLX / GAT	100 %
8. Spain – BCN Checkpoint	100 %
9. Spain – Associació Ciutadana Antisida De Catalunya	57 %
10. Italy – Fondazione LILA Milano ONLUS	82 %
11. Denmark – Checkpoint Copenhagen	90 %
12. Latvia – Checkpoint for MSM (NGO "Baltic HIV Association")	100 %
13. Austria – Aids-Hilfe Wien	69 %
14. Germany – Stadt Essen	47 %
15. Germany – AIDS-Hilfe Hagen e.V.	70%
16. Slovenia – Association Legebitra	100 %

Three of the four sites where all reactive HIV tests are by MSM are all exclusively testing MSM (Spain – BCN Checkpoint, Latvia and Slovenia).

Linkage to care from CBVCTs

Three CBVCTs do not have any information on how many people are referred to care – this could be because there is no formal linkage (people are e.g. given the address of the hospital and have to make appointment by themselves). In eight of the 16 CBVCTs the percentages of clients referred to care are above 90 % (see table 4).

Table 4 What percentage of people with a confirmatory HIV test were linked to care from the CBVCT	
1. Poland – 30 Voluntary Counselling and Testing Centres	N/A
2. Poland – Foundation for Social Education	62 %
3. Ukraine – Community Centre for gays and bisexuals	N/A
4. France – Checkpoint-Paris	96 %
5. France – AIDES	91 %
6. Greece – Athens Checkpoint	90 %
7. Portugal – CheckpointLX / GAT	83 %
8. Spain – BCN Checkpoint	91 %
9. Spain – Associació Ciutadana Antisida De Catalunya	67 %
10. Italy – Fondazione LILA Milano ONLUS	64 %
11. Denmark – Checkpoint Copenhagen	100 %
12. Latvia – Checkpoint for MSM (NGO "Baltic HIV Association")	N/A
13. Austria – Aids-Hilfe Wien	N/A
14. Germany – Stadt Essen	100 %
15. Germany – AIDS-Hilfe Hagen e.V.	100 %
16. Slovenia – Association Legebitra	100 %
<i>The questionnaires were distributed in June 2015, asking about testing and linkage experiences in the year 2014. How many people are linked to care is listed as what the specific CBVCT knew at the time of filling in the questionnaire.</i>	

In the early spring 2017, data from the HIV-COBATEST project was received on the number of people who in 2015 had a reactive HIV-test in a CBVCT, had this reactive test confirmed and how many of these people that were linked to care.

These data are only available for CBVCTs being part of the COBATEST project and can therefore only be compared to seven of the CBVCTs that have been part of this study.

In table 5 all the data are presented; how many tests have been performed in the different CBVCTs, how many of these tests were reactive, how many of these reactive test were confirmed and lastly, how many people were linked to care to the knowledge of the CBVCT staff.

Table 5 Comparison of tests performed, reactive and confirmatory tests and people linked to care in 2014 and 2015								
	2014	2015	2014	2015	2014	2015	2014	2015
	Number of tests performed		Number of reactive tests		People with a confirmatory test		People linked to care	
3. Ukraine	N/A	583	N/A	33	N/A	12	N/A	12
5. France – AIDES	43.414	43.097	322	293	187	128	171	120
8. Spain – BCN CP	4.768	5.095	162	186	142	172	129	151

9. Spain – Catalunya	1.036	618	14	9	3	7	2	6
10. Italy	622	583	11	2	7 *)	2	7 *)	1
11. Denmark	2.067	1.873	21	19	20	15	20	12
13. Austria	6.254	6.490	29	59	25	36	N/A	21
*) This is numbers that they know are confirmed and linked to care, but the number can be higher.								

It should be emphasized as mentioned before that the number of people linked to care is likely to be higher than indicated in the table.

For the sake of clarity, data is presented differently in table 6. Here is shown the percent of people with a reactive test who are linked to care, compared the percent of people with a confirmatory test who are linked to care.

Table 6 Comparison in % of people with reactive tests linked to care and, people with confirmatory tests linked to care in 2014 and 2015						
	2014 Number of			2015 Number of		
	ROW 1 % of reactive tests confirmed	ROW 2 % of reactive tests linked to care	ROW 3 % of confirmed tests linked to care	ROW 4 % of reactive tests confirmed	ROW 5 % of reactive tests linked to care	ROW 6 % of confirmed tests linked to care
3. Ukraine	N/A	N/A	N/A	36 %	36 %	100 %
5. France – AIDES	58 %	53 %	91 %	44 %	41 %	94 %
8. Spain – BCN CP	88 %	80 %	91 %	92 %	81 %	88 %
9. Spain – Catalunya	21 %	14 %	67 %	78 %	67 %	86 %
10. Italy	64 %	64 %	100 %	100 %	50 %	50 %
11. Denmark	95 %	95 %	100 %	79 %	63 %	80 %
13. Austria	86 %	N/A	N/A	61 %	36 %	58 %

The success of linkage to care is much higher when the CBVCT have knowledge on the confirmatory test result. Just a very small part of the difference can be related to false positive reactive tests – the difference demonstrates most likely one of the fundamental problems for the CBVCTs; because of confidentiality issues many CBVCTs does not have access to the result of the confirmatory tests.

For comparison purposes, the same analysis that has been done with the CBVCTs being part of the HIV-COBATEST network has been done on the CBVCTs not being part of this network. This is shown in table 7 and 8.

Table 7 Comparison of tests performed, reactive and confirmatory tests and people linked to care in 2014								
	2014	2015	2014	2015	2014	2015	2014	2015
	Number of tests performed		Number of reactive tests		People with a confirmatory test		People linked to care	
1. Poland – 30 centres	31.047		469		378		N/A	
2. Poland - Foundation	5.036		100		70		43	
4. France - Checkpoint	2.950		51		51		49	

6. Greece	6.324		123		122		110	
7. Portugal	3.146		102		102		85	
12. Latvia	115		3		N/A		N/A	
14. Germany Essen	2.152		19		19		19	
15. Germany Hagen	300		N/A		3		3	
16. Slovenia	480		6		6		6	

Table 8 Comparison in % of people with a reactive tests linked to care and people with a confirmatory test linked to care in 2014						
	2014 Number of			2015 Number of		
	ROW 1 % of reactive tests confirmed	ROW 2 % of reactive tests linked to care	ROW 3 % of confirmed tests linked to care	ROW 4 % of reactive tests confirmed	ROW 5 % of reactive tests linked to care	ROW 6 % of confirmed tests linked to care
1. Poland – 30 centres	81 %	N/A	N/A			
2. Poland - Foundation	70 %	43 %	62 %			
4. France - Checkpoint	100 %	96 %	96 %			
6. Greece	99 %	89 %	90 %			
7. Portugal	100 %	83 %	83 %			
12. Latvia	N/A	N/A	N/A			
14. Germany Essen	100 %	100 %	100 %			
15. Germany Hagen	N/A	N/A	100 %			
16. Slovenia	100 %	100 %	100 %			

It is remarkable that the CBVCTs *not* being part of the HIV-COBATEST network in general seems to get more knowledge on the confirmation of reactive HIV-tests.

The reason for this lesser knowledge on linkage to care has nothing to do with being or not being part of the HIV-COBATEST network. The reason is probably that CBVCTs referring people with a reactive HIV-test to confirmatory testing at a laboratory or with a general practitioner will receive much less information on the result than if people are referred to a HIV-unit. This applies at least to most of the CBVCTs with little knowledge of linkage to care for people with a reactive HIV-test (e.g. Ukraine, France – AIDES, Spain – Catalunya, Austria and Latvia).

It is very likely though, that most of the people with a reactive test result are linked to care. However, as long as the CBVCT do not have any knowledge on this linkage, it cannot be used to demonstrate the success of the CBVCTs in linking people to care.

The CBVCTs were also asked in the questionnaire how many of the people linked to care belong to the MSM group. Five out of 16 CBVCTs do not have information on the percentage of MSM linked to care out of the total number of people linked to care.

In AIDS-Hilfe Hagen e.V. (Germany) they give no information on MSM in the total number of people being tested – but only three people are diagnosed with a confirmatory HIV test and they are all linked to care.

In AIDS-Hilfe, Wien (Austria) they do not have any information on how many people are linked to care – and thus also no information on the percentage of MSM in the total number which is 25.

In Checkpoint for MSM (Latvia) people are referred to their GP for confirmatory test and the CBVCT do not receive any feedback following that referral.

The percentages of MSM among people referred to care are high among the CBVCTs that collect this information. However, five CBVCTs do not have information on linkage to care in the MSM group.

In the 30 voluntary counselling and testing centres in Poland they do not get any information at all on linkage to care.

Table 9	
The percentage of MSM in the total number of people with a confirmatory test linked to care	
1. Poland – 30 Voluntary Counselling and Testing Centres	N/A
2. Poland – Foundation for Social Education	80 %
3. Ukraine – Community Centre for gays and bisexuals	N/A
4. France – Checkpoint-Paris	95 %
5. France – AIDES	N/A
6. Greece – Athens Checkpoint	90 %
7. Portugal – CheckpointLX / GAT	100 %
8. Spain – BCN Checkpoint	100 %
9. Spain – Associació Ciutadana Antisida De Catalunya	100 %
10. Italy – Fondazione LILA Milano ONLUS	71 %
11. Denmark – Checkpoint Copenhagen	90 %
12. Latvia – Checkpoint for MSM (NGO “Baltic HIV Association”)	N/A
13. Austria – Aids-Hilfe Wien	N/A
14. Germany – Stadt Essen	90 %
15. Germany – AIDS-Hilfe Hagen e.V.	N/A
16. Slovenia – Association Legebitra	100 %

On confirmation of a reactive test

It differs a lot where the blood sample for the confirmatory HIV-test is taken; at BCN Checkpoint in Spain the confirmatory test is performed at the CBVCT, at other sites clients are referred to a laboratory, to a general practitioner or to the HIV-unit at the hospital.

As already mentioned the likelihood of getting the result from the confirmatory HIV-test seems to decrease when this test is taken at a laboratory or with the general practitioner.

Nine of the CBVCTs receive information about the result of the confirmatory test although this information is often *informal* and is information originating from a close personal collaboration between the CBVCT and the HIV-unit.

In Portugal they do not receive this information anymore because the exchange protocol data was ended by the current medical doctor-director.

The BCN Checkpoint in Spain and the CBVCT in Italy are the only two CBVCTs that always receive feedback on CD4-count when the client is linked to care.

The CBVCTs were asked in the questionnaire whether they offer any kind of support to newly diagnosed HIV-positive clients and everybody answered 'always' – except Checkpoint Paris in France who wrote 'sometimes.'

As seen in table 10 all CBVCTs offer different kinds of support

Table 10 What kind of support does the CBVCT offer clients with a confirmed positive test result					
	Peer-to-peer support	Prof psychological support	Prof social support	Prof medical support	Other
Poland – 30 centres		X	X		
Poland – Foundation ..	X	X	X	X	
Ukraine	X	X	X	X	
France – Checkpoint-Paris	X	X	X		
France – AIDES	X				Support groups Hosting service Physical and community support
Greece	X	X			
Portugal	X				Accompany clients to hospital
Spain – BCN Checkpoint	X				
Spain – Catalunya		X			
Italy	X	X	X		Self-help groups
Denmark	X	X	X		
Latvia	X			X	
Austria		X	X	X	
Germany – Stadt Essen	X	X	X	X	
Germany – AIDS-Hilfe Hagen e.V.	X	X	X		
Slovenia - Association Legebitra	X	X	X		

Contact person at the HIV-unit

Ten of the CBVCTs have a specific contact person within the HIV-unit who helps with linkage to care from the CBVCT. These ten are the CBVCTs in Poland (Foundation for Social Education), Ukraine, France (AIDES), Greece, Portugal, Spain (BCN Checkpoint), Italy, Denmark, Germany (AIDS-Hilfe Hagen e.V.) and Slovenia.

Six of these CBVCTs have a success rate of 90 % or above in linkage to care for people with a confirmatory HIV-test (see table 2).

What kind of problems are seen in linking MSM to confirmatory testing and care

From the questionnaires filled in by the 16 CBVCTs none mention any specific problems in linking MSM to care from the CBVCT. One CBVCT (Slovenia) mentions however that there could be a problem. To get treatment at the HIV-unit the clients need a referral from their GP and if the client either knows the GP personally or the GP is a family friend it can be a problem if the client does not want to disclose to the GP.

A few of the CBVCTs highlight problems that are not specifically related to the MSM group. This is problems like not getting information on CD4-count or viral load (Greece); hospitals that have stopped receiving people with reactive HIV-test result when the patient does not belong to the area of the hospital (Portugal); no protocol for referrals from CBVCTs to HIV-units (Latvia); or problems for people with no insurance (Germany, Stadt Essen).

Summary

A very high number of people tested in a CBVCT, and where the CBVCT has knowledge of a positive confirmatory test, are linked to care. In nine of the 16 CBVCTs the percentages of clients referred to care are above 90 %.

The knowledge of linkage to care for people with a reactive HIV-test, and where the CBVCT do *not* have knowledge of a confirmatory test, is a little less impressive. Four CBVCTs have knowledge of linkage to care above 90 % of people without knowledge of a confirmatory HIV-test.

Nine of the CBVCTs receive information about the result of the confirmatory test although this information is often *informal*.

Ten of the CBVCTs have a specific contact person within the HIV-unit who helps with linkage from the CBVCT. Six of these CBVCTs have a success rate of 90 % or above in linkage. It seems evident that having a close coordination between the CBVCT and the health care system is important for a successful linkage to care.

All CBVCTs are offering different kind of support to people who are newly diagnosed with HIV, which is typically peer-to-peer support, psychological, social or medical support.

None of the CBVCTs mention any specific problems in linking MSM to care from the CBVCT.

A few of the CBVCTs highlight problems in the questionnaire that are not specifically related to the MSM group. This is problems like not getting information on CD4-count or viral load; hospitals that have stopped receiving people with reactive HIV-test result when people do not belong to the area of the hospital ; no protocol for referrals from CBVCTs to HIV-units; or problems for people with no insurance.

7 INTERVIEWS WITH HEALTH CARE PROFESSIONALS AND CBVCT MANAGERS

Not all details and challenges can be captured in a quantitative questionnaire, so it was decided to also interview CBVCT managers and health care providers working together with the CBVCTs.

Interviews were conducted with CBVCT managers and health care providers in associated partner countries. These interviews were carried out by phone by the Danish field coordinator between January and March 2016. In September 2016 it was decided to include Greece in the qualitative interviews and during a visit in Athens CBVCT managers and health care providers in Greece were interviewed in person. For the names of the interviewed persons see table 11.

All CBVCT managers and health care providers received the interview guide in advance to prepare for the interview. These interview guides are attached as appendix 2 and 3.

The purpose of the interviews was to get a better understanding of the cooperation between the CBVCTs and the health care system and to capture difficulties, challenges and successes in linkage to care.

The following persons were interviewed:

Table 11 CBVCT managers and health care professionals interviewed		
Country	CBVCT manager	Health care professionals
Spain Barcelona Checkpoint	Michael Meulbroek	Dr. Pep Coll
France AIDES, Paris	Richard Stranz	Dr. William Tosini
Portugal CheckpointLX / GAT	João Brito and Miguel Rocha	Dr. Maria José Campos
Germany AIDS-Hilfe, Köln e.V.	Felix Laue	Dr. Matthias Straub
Slovenia Association Legebitra	Mitja Čosić ⁵	Dr. Tomaž Vovko
Denmark AIDS-Fondet, Checkpoint	Per Slaaen Kaye	Ms. Philippa Collins (nurse) Ms. Lene Pors (nurse)
Greece Athens Checkpoint	Sophocles Chano	Dr. Maria Chini Mr. Charis Daflos (nurse)

Interviews with the health care professionals

Health care staff from seven countries were interviewed and in four of the countries the health care staff were (besides working in hospitals) working in the CBVCT, either as counsellors and testers or as supervisors (Denmark, France, Portugal and Spain).

⁵ Mitca Čosić was not CBVCT manager but is working at the CBVCT and chosen for the interview because of his qualifications in speaking English.

The assessment of the coordination between CBVCT and HIV-unit is by three health care professionals rated as a 5 (maximum) and by three other as a 4 – one of the last ones included the comment; ‘there is always room for improvement.’ One health care professional did not assess the coordination between CBVCT and HIV-unit as she was not working at the HIV-unit in the hospital but as supervisor in the CBVCT.

All health care professionals are explicit declaring that they do not see any specific barriers for MSM in being linked to care.

In Denmark, France, Greece, Slovenia and Spain it is standard procedure to call the health care professionals by phone in case of a reactive HIV-test and make a specific appointment for the client, most often on the following day.

In Portugal the CBVCT send an email to the HIV-unit and the HIV-unit reply with an email after typically one week. In this email a specific appointment (date and time) is given for the first medical comprehensive evaluation. A second appointment is scheduled to receive the confirmatory result of HIV infection and other co-infections – and in case of a positive confirmatory HIV-test treatment will be offered. There is usually two to four weeks between the first and second appointment.

In Germany the health care professional who was interviewed had previously worked at a HIV-unit in a hospital, but was at the time of the interview working as a GP. From his experience the CBVCT often call the HIV-unit for an appointment in case of a reactive rapid test – but only if the client want to be referred to the HIV-unit and not a GP. The interviewee estimates Germany that 80-90 % of all people with a reactive rapid test result are referred to a GP.

Regarding the feedback to the CBVCT on the success of linkage to care – did the client show up at the HIV-unit or with the GP – the experience is quite different from country to country. In most countries there will be an informal feedback – which is probably on the boundary of the confidentiality that the clients are entitled to.

In France the interviewed health professional explicitly expresses that the HIV-unit cannot give any feedback to the CBVCT because of confidentiality. In Greece 90-95 % of clients with a reactive rapid test result are accompanied by the CBVCT staff to the first visit at the HIV-unit – and therefore the information of successful linkage to care (if this is defined as a first visit at a HIV-unit) is quite good. In Denmark the clients referred to the HIV-unit are usually asked to give permission to contact between the HIV-unit and the CBVCT.

A couple of the interviewed health professionals mentioned that clients from CBVCTs are ‘more prepared’ for the appointment with the HIV-unit – as they typically get more information on the consequences of an reactive rapid test, living with HIV and what the next steps will be – than clients coming from other testing sites. This probably applies to most of the clients referred from CBVCTs compared to clients referred from other test sites. (And as a consequence of this, the HIV-unit at the hospital are able to save staff time because the client already have a lot of the information that doctors and nurses would usually give to newly diagnosed patients).

Interviews with the CBVCT managers

The interviews with the CBVCT managers showed that the procedures in testing and linkage to care are very different between CBVCTs.

In some CBVCTs (Barcelona) they can perform a PCR-test to confirm the rapid test in 90 minutes. In other CBVCTs (Slovenia) they take a blood sample and send this blood sample to a laboratory for an ELISA-test. The client then has to show up three days later for this ELISA-test result.

In some Checkpoints (Barcelona) a client with a reactive rapid test will always immediately (= now, not tomorrow) be offered counselling with a HIV-positive staff member. The experience of this immediately peer-to-peer counselling in Barcelona is very good – the client will straightaway ‘see’ another person living with HIV and see that he is healthy and doing well. And this – it is mentioned – is in line with the GIPA principle.

None of the CBVCT managers can confirm that there are barriers in linking MSM to care. One manager clarifies that he actually does not know as they only have MSM clients – but they do not have problems in linking MSM with a reactive HIV-test to the HIV-unit.

A number of more general barriers to linkage to care that are not specifically related to the MSM group have been mentioned in the interviews. These are:

- Lack of access to a HIV-unit where the client is living
- Underage young people who cannot have access to HIV-test or HIV-treatment without their parents’ knowledge and accept
- HIV-units refuse to accept HIV-positive patients because the hospital department are overcrowded
- Undocumented migrants do not have access to HIV-treatment in some countries
- Language problems if the client do not speak the local language

Many CBVCT managers mentioned that a good collaboration with the HIV-unit is necessary if linkage to care is to be a success. In ten of the sixteen CBVCTs the CBVCT has a specific contact person at the HIV-unit (Poland – Foundation for Social Education; Ukraine; France – AIDES; Greece; Portugal; Spain – BCN Checkpoint; Italy; Denmark; Germany – AIDS-Hilfe Hagen e.V.; and Slovenia). As seen in table 2 most of these CBVCTs have a high percentage of people with a confirmatory HIV-test linked to care.

As mentioned in the paragraph on interviews with the health care professionals the referral to HIV-units differ very much between CBVCTs. The CBVCT managers confirm all the information given by the health care professionals.

As is also mentioned in the same paragraph the feedback from HIV-units is most often informal – but a few of the CBVCT managers mention that they also get feedback from clients if they show up at the CBVCT for further support.

I was suggested by one of the managers that CBVCTs can give the client (with the reactive rapid test) a form that the person brings to the HIV-unit where the person consents to allowing the HIV-unit to inform the Checkpoint about the linkage and that most people likely will accept this.

A few of the managers mention that the lack of knowledge among health professionals on sexual practices for MSM and sexualised drug use or chemsex is a problem because it makes it difficult for the health professionals to give relevant information to the patients.

The CBVCT managers in Greece and in Spain explicitly mention that clients coming from CBVCTs are much better prepared for the first visit at the HIV-unit as they know what to expect and already have been given a lot of information on HIV.

In all the interviewed CBVCTs, except in Germany, clients with a reactive rapid test result are offered to be accompanied to the first visit at the HIV-unit.

It has also been suggested that CBVCTs should prioritize to document their work in scientific articles to demonstrate the success in reaching key populations and linking people with a reactive test to confirmatory test and subsequent care.

The coordination between CBVCT and the HIV-unit is either rated as 4 or 5 (5 = very good) in most places, though it has to be mentioned that the CBVCT manager in Germany only rated the coordination as 2. This probably reflect the problems in Germany where many clients are referred to GPs and the CBVCT are not allowed to refer to specific GPs but can only give general information on names and addresses of the GPs.

Summary

Both the health care professionals and the CBVCT managers give, with a very few exceptions, high ratings on the cooperation between CBVCTs and the health care system and none of the interviewed people have experienced any special barriers for MSM being linked to care. A number of more general barriers to linkage to care that are not specifically related to the MSM group have however been mentioned in the interviews. These problems are not unique to the CBVCTs but apply to all HIV testing in the specific country whether this is done at a hospital, a clinic, a CBVCT or with a doctor.

In most countries it is a problem to get reliable information on success or failure of linkage to care – because of confidentiality issues. Many CBVCTs has some kind of informal contact with the HIV-unit to get this information though. It is worth mentioning that this might be on the boundary of the confidentiality that the clients are entitled to.

It has been suggested that CBVCTs can give the client (with the reactive rapid test) a form that the person brings to the HIV-unit where the person consents to allowing the HIV-unit to inform the Checkpoint about the linkage.

Close cooperation with health staff at the HIV-unit, and preferably personal cooperation, appears to be recommendable, not only from the interviews but also from the questionnaires filled in by the CBVCTs.

Most CBVCT are arranging specific appointments for the clients for the first visit at the HIV-unit and most of the CBVCTs also offer to accompany clients at their first visit.

It is also mentioned, both by health care professionals and by CBVCT managers, that clients coming from CBVCTs are 'more prepared' for the appointment with the HIV-unit – as they typically get more information on the consequences of being HIV-positive and what the next steps will be compared to clients coming from other testing sites.

8 SURVEY AND INTERVIEWS WITH MSM LIVING WITH HIV TESTED IN CBVCTs

A survey was conducted in late 2016 with questionnaires distributed among MSM that have had a HIV reactive test (that was later confirmed) after 1 January 2012 in a CBVCT and having been linked to care. The questionnaire was distributed in Spain, Portugal, France, Slovenia, Germany and Denmark and translated into relevant languages.

The questionnaire was to be answered online through six different links – one for each language.

The questionnaire is attached (in English) in annex 4.

The contact with MSM who have tested HIV-positive in the CBVCT varies greatly from country to country and from CBVCT to CBVCT. The same can be said about the contact with the HIV-unit where people go for treatment and/or confirmatory testing. Besides this, in e.g. Germany, many HIV-positive are consulting their general practitioner for monitoring/treatment which made it difficult to get in contact with relevant possible respondents.

In spite of these difficulties, all of the involved CBVCTs managed to collect an acceptable number of questionnaires (see table 12). As seen 53 questionnaires were accepted for analysis. From Germany 17 questionnaires were received and only three accepted for analysis. 14 of the respondents were either not tested in a CBVCT or were tested before 1 January 2012. All questionnaires from the other countries were accepted for analysis.

Some questionnaires were not included as they were either not tested HIV-positive in a CBVCT or they had only answered a few of the questions.

Table 12 Number of questionnaires received from MSM living with HIV and tested HIV-positive in a CBVCT	
Country and CBVCT	Number of questionnaires accepted for analysis
Denmark, AIDS-Fondet Checkpoint, Copenhagen	12
France, Association AIDES, Paris	18
Germany, Checkpoint, AIDS-Hilfe, Köln e.V.	3
Portugal, CheckpointLX /GAT, Lisbon	6
Slovenia, Association Legebitra, Ljubljana	3
Spain, BCN Checkpoint, Barcelona	11
Total	53

It is generally accepted that ‘helping people into care’ after an initial diagnosis of HIV infection are of great importance for people to engage in subsequent HIV care and that providing actual appointments rather than general referral information may be useful (2).

One of the important issues was therefore to clarify to what extent MSM who have received an HIV reactive test result in a CBVCT were supported to getting in contact with the health system for monitoring and/or treatment – or to be more precise: How did they *perceive* the help they get or not get at the CBVCT?

Of the 53 respondents, 42 confirm (79 %) that the CBVCT had helped them with getting a specific appointment with the hospital for monitoring or treatment – and just 11 respondents said ‘no’ to this question (see table 13).

Looking into the comments to this question, more respondents were actually offered help in getting an appointment. Three people who answered ‘no’ elaborates that they in fact were offered this help but for different reasons declined and five other people who wrote ‘no’ indicated that they were helped in other ways with being connected to the hospital.

This leaves just three people (5.6 %) who did not get any help in being connected to the hospital / doctor for monitoring / treatment; two from Germany and one from France.

Table 13 Did the CBVCT help the client to make a specific appointment at the HIV-unit							
	Denmark	France	Germany	Portugal	Slovenia	Spain	Total
Yes	11	11		6	3	11	42
No	1 *)	7 **)	3 ***)				11
*) This person commented: No need. **) Two of these persons commented: 1) But it was proposed to me; 2) I was offered but I refused. In addition, four other men indicated that they were helped in other ways with being connected to the hospital. ***) One of these men was helped in other ways with being connected to the hospital.							

Of the 53 respondents, 53 % had an appointment with the hospital/doctor for monitoring/treatment within three days, 77 % had an appointment within one week and 92 % had an appointment within two weeks. Just four people (8 %) had to wait longer for an appointment (see table 14).

Table 14 How long waiting time for the first appointment at HIV-unit/with GP							
Time	Denmark	France	Germany	Portugal	Slovenia	Spain	Total
Within three days	11	6	2	1	2	6	28
Up to one week	1	7		1		4	13
Up to two weeks		3	1	2	1	1	8
One month		1		2			3
Three months		1 *)					1
*) This person did not get help with getting a specific appointment at the hospital, but were helped in other ways to be connected to the hospital.							

Portugal has unique problems with the time it takes before the client has a confirmed appointment at the HIV-unit. When a client has a reactive HIV-test in a CBVCT an email is sent to the hospital and the hospital subsequently send an email to both the CheckpointLX referral manager and the client with a time and date for an appointment for the confirmatory test. According to the interview with the CBVCT managers it normally takes up to six weeks to get this first appointment.

In most of the other participating countries, it is possible to get an appointment with the hospital only a few days after having a reactive HIV test at a CBVCT.

The questionnaire also included questions on whether the referral process was viewed to slow or too fast.

Most respondents who commented on these questions were satisfied with the time involved in the referral process. Two people found that it took too long time to get an appointment with the hospital/doctor and seven people found that the process was too fast.

One of the people who found the process to be too slow had an appointment after five days and the other one had an appointment after one month. This is one of the people from Portugal where being linked to care normally takes quite a long time.

What might be more interesting is that seven respondents found that the referral were too fast. Most CBVCT staff probably think that referral should be as quick as possible – and this is probably true for most clients. But for some people it might take some time to digest the new, often shocking message of having a reactive HIV-test.

In France three people found that the referral process was too fast. One had an appointment after one day, another after four days and the last one after three months. It is not possible from the other answers in the questionnaire to reveal why this last person found the referral too fast.

In Spain three persons found that the referral process was too fast. Two of these had an appointment after three days and the last one after one week.

No one made any supplementary comments to the questions on whether the referral process was too slow or too fast.

The participants were also asked how they would assess the referral practice between the CBVCT and doctor/hospital for monitoring/treatment in general on a scale from one to ten (one = bad; ten = very good).

37 people (69 %) gave the maximum evaluation of 10 and the total average was 9.2. There were only three persons assessing the referral practice below six, one from Denmark and two from Germany (see table 16).

The person from Denmark made a comment; he wrote 'better staff at Checkpoint', but none of the two German people made any comments to their assessment.

The reason for the low assessment in Germany might be because of the German health care system where people with a reactive test result are referred either to a general practitioner or to a hospital. The staff at the CBVCT are not allowed to recommend specific general practitioners – they can only give the client the addresses and telephone numbers to the specific general practitioners who are authorized to have HIV-positive people as patients.

In the interview with the Köln e.V. AIDS-Hilfe Checkpoint it was estimated that 80-90 % of clients choose to go to the doctor rather than the hospital. And because of confidentiality issues, the Köln e.V. AIDS-Hilfe CBVCT cannot get any feedback from general practitioners or hospital which means that the staff in CBVCT only know about the success or failure of referral if they at random meet the client.

Table 15 Client assessments of referral practice between the CBVCT and doctor / hospital on a scale form one (= bad) to 10 (= very good)							
Assessment	Denmark	France	Germany	Portugal	Slovenia	Spain	Total
10	9	10		4	3	11	37
9	1	2		2			5
8		4					4
7	1						1
6		2					2
5	1		1				2
4							-
3			1				1
2							-
1							-
No answer			1				1

The comments that the respondents made to complement their assessment are almost all very positive. From Denmark a respondent wrote ‘it worked perfectly’ and another wrote ‘everything is excellent’. From France a service user states ‘I was very well taken care of’ and ‘for me everything went well’ and in Spain one of the respondents wrote ‘the truth that it has been a hard time for me to receive this news. It is a moment when I think you cannot even think, and Barcelona Checkpoint has been a great help’ and another wrote ‘some extraordinary people [at Checkpoint].’

And these quotes are only excerpts of the many positive comments.

It was mentioned in one of the French comments, that if the CBVCT could make the confirmatory HIV-test ‘it would be top.’

In the questionnaire the respondents were also asked ‘what could, in your opinion and from your experience, be improved in the referral practice’ – and close to two out of three had comments on this.

Almost all of the comments were praising the existing system and the staff at CBVCTs – it is hard to imagine that the CBVCTs could get a better evaluation. See the examples below (table 16) of some of the praise given to the different CBVCTs (there were no comments from the German respondents).

Table 16 Extracts of positive quotations from the questionnaires to the question: What could, in your opinion and from your experience, be improved in the referral practice?	
Denmark	<i>Nothing. It worked perfectly</i>
France	<i>I see nothing to add</i>
Portugal	<i>I do not have points to add, in my case it was perfect and I recommend it. Nothing to point at, quite the opposite.</i>
Slovenia	<i>I get all the necessary information. It is really recommendable</i>

Spain	<i>I think the referral process is very correct and that they are very professional and competent people who have attended me at Checkpoint</i>
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Only five people have non-approving comments of the existing system and they are all cited below in table 17:

Table 17 Non-approving comments from the questionnaires on the question: What could, in your opinion and from your experience, be improved in the referral practice?	
Denmark	<i>Better staff at Checkpoint</i>
France	<i>Reassure the patient and be able to give him a number from a hospital to make an appointment right away</i>
France	<i>If we could make the confirmation at AIDES it would be top!</i>
France	<i>I think that this can only be done at a very early stage, for instance by communicating and sharing openly about the lives of PLHIV. It seems to me that this is the major issue (the linkage from AIDES to follow-up and care is a more simple and pragmatic issue, at least for those who have the chance to have a legal status in the country. By focusing on people's imagination linkage to care will get easier.</i>
Portugal	<i>Confirmation and initiation of treatment are faster</i>
Spain	<i>More centers in Barcelona downtown. Currently there is only Hospital Clinic and Badalona [city next to Barcelona]. I am in Badalona because the doctor who follow up me (I do not know exactly how to say) premature detection of the virus (less than a month).</i>

Interviews with MSM linked to care after a reactive and later confirmed test in a CBVCT

In the online-survey the participants were asked if they would accept to participate in a face-to-face or telephone interview about their experience with being tested in a CBVCT and linked to care. 24 people accepted to participate in an interview and eight interviews were conducted by staff from the local CBVCT (two from France, two from Portugal and four from Denmark).

These interviews confirm the positive impression that most people testing for HIV in a CBVCT have.

It should be mentioned though, that the problems in Portugal mentioned earlier (Chapter 6 and 7) are reflected in the interviews from Portugal. This is about the fact that hospitals have stopped receiving people with reactive HIV-test result when people do not belong to the area of the hospital, and that it might take very long time to get the confirmatory answer – but it is unlikely that the CBVCT staff in Portugal can alter these problems.

In one of the interviews it was suggested that the confirmatory test should be taken at the CBVCT. In another interview it was suggested that people with a reactive HIV-test should be given some written materials on HIV as this might be a help, both for the person with the reactive HIV-test and when and if he wants to talk with friends or relatives about this new situation.

Table 18 Extracts from the interviews	
Denmark	<i>It was really efficient - went smoothly and I had no waiting anywhere. Everyone</i>

	<i>was supportive and empathetic. I would say it went perfectly under the circumstances.</i>
Denmark	<i>I was very satisfied – 100%. I got all the information I needed and I was really comforted. After I had been to [the hospital], I even called the Checkpoint to say thank you for the great experience I had had.</i>
France	<i>No improvements to suggest because for me everything went well.</i>
France	<i>The facilitator who announced my positive test was perfect. He immediately made an appointment with the HIV service at the hospital and the next day we went together to see the doctor. Without the support of this AIDES facilitator I may not have done all of this, certainly not so fast.</i>
Portugal	<i>Book appointment to the hospital (to confirm result) immediately after reactive result in the rapid test.</i>
Portugal	<i>To have the possibility to choose the hospital for treatment and care.</i>

Summary

45 (85 %) people with a reactive rapid HIV test were helped with a specific appointment or did not require this support. Further five (9.4 %) people were helped 'in other ways' to be connected to the hospital/doctor for monitoring/treatment – leaving just three (5.6 %) people without any help in linkage to care.

The linkage to care was, for most of the respondents, done quickly. More than half of the respondents (53 %) had an appointment with the health care system within three days and 92 % had an appointment within two weeks and most respondents were satisfied with the with the time involved in the referral process.

This indisputable success in linking people to care is supported by the assessments made by the respondents on the referral practice. 75 % give maximum rating on this practice and the overall evaluation average is 9.2 (out of possible 10) and the comments to this question are overwhelmingly positive ... both on the practice and on the staff at the CBVCTS.

The comments the respondents made on their assessment of the referral practice were almost all very positive and only very few had negative comments on their experience.

The same can be said on the comments when the respondents were asked for suggestions for improvements in the referral practice. A majority of comments were praising both the referral practice and the staff at the CBVCTS.

The high success rate in linking people to care is probably not only related to the referral practice but also to the qualified counselling, the empathy and the support given by most staff at the CBVCTS.

9 Conclusions

The procedures in CBVCTs of testing and linking to confirmatory testing and care are very different between the CBVCTs. But in spite these differences a very high number of people are linked to care when the CBVCT have knowledge of a confirmatory HIV-test.

When CBVCTs do not have knowledge of confirmatory testing, the knowledge of successful linkage to care is less. This is typically when the confirmatory testing is done at a laboratory or with the general practitioner. This does not necessarily mean that people are not linked to care – but the CBVCT will not be able to document this.

In countries where CBVCT staff are not allowed to make specific appointments because the monitoring and treatment of people living with HIV is situated with the general practitioners, it is recommended to start negotiations with the general practitioners on this problem. It is the experience that having an appointment following a HIV reactive test result contributes to the likelihood of attending the first visit in the health care system.

It is also advisable to consider finding a solution of the problem that CBVCTs do not have knowledge on linkage to care when the confirmatory test is taken at a laboratory.

It is evident that close collaboration between CBVCT and the HIV-unit improve the success of linkage to care – and advisably a collaboration maintained through personal cooperation.

85 % of MSM participating in the on-line survey, all with a reactive or positive HIV-test in a CBVCT, were helped with a specific appointment at the HIV-unit or did not require this support. Further 9.4 % were helped 'in other ways' to be connected with the health care system.

The linkage to care was also, for most of the respondents, done quickly. More than half of the respondents had an appointment with the health care system within three days and 92 % had an appointment within two weeks and most respondents were satisfied with the with the time involved in the referral process.

Most CBVCTs are arranging specific appointments for the clients for the first visit at the HIV-unit and most of the CBVCTs also offer to accompany clients to their first visit. Doing this increases the chance of a successful linkage to care.

None of the CBVCT managers or health care professionals have experienced any specific barriers in linking MSM to care. There are several general barriers though (not specifically related to the MSM group or to being linked to care from CBVCTs) and these barriers should be addressed and discussed with relevant bodies.

In most countries it is a problem to get reliable information on success or failure of linkage to care – because of confidentiality issues. Many CBVCTs have some kind of informal contact with the HIV-unit to get this information though, when the confirmatory test is done at a HIV-unit. However, this might be on the boundary of the confidentiality that the clients are entitled to.

A formalized system should be developed to solve this problem of documenting linkage to care from CBVCTs and before this is developed a simple system (e.g. having the client consent to communication between HIV-unit and CBVCT with a signature on a document) might be useful.

The cooperation between CBVCTs and HIV-units are in general assessed very good, both by the health care professionals and by the CBVCT managers. In addition, the clients being linked to care from a CBVCT are giving very good assessment of the referral practice.

There is a variety of definitions of linkage to care applied in the scientific literature and it is recommended that CBVCTs take a pragmatic approach when agreeing on a definition for future use. Because of confidentiality issues most CBVCTs do not have access to CD4-counts or viral load, but many do have knowledge on first visit at the HIV-unit.

With inspiration from the definition used in the HIV-COBATEST Network the following definition is suggested for future use:

Linkage to health care is defined as entry into health care or follow-up by an HIV specialist or in an HIV-unit after a reactive or confirmatory HIV-test at a CBVCT facility.

This is also in line with the definition developed in the OptTEST project where linkage to care can be measured as 'the time between diagnosis and first attendance to HIV specialist care.'

Limitations of the study

This study is not representative, and is not intended to be representative, for the cooperation between all CBVCTs and health care systems in Europe and all CBVCTs might not have the same success in linking people to care as the CBVCTs in this study. Likewise, only a small number of MSM having been linked to care through a CBVCT has participated in the on-line survey and in the interviews and these men are not representative of all MSM being linked to care through a CBVCT.

10 RECOMMENDATIONS TO BE INCLUDED IN THE PRACTICAL GUIDE

The test situation

The success of linkage to care starts in the test situation. The following aspects should be taken into account:

- 1) A welcoming and non-judgmental attitude of the staff is important
- 2) Knowledge on sex life and sex practices of MSM is important
- 3) Knowledge on HIV and STIs (including risk of transmission, symptoms and treatments) are important
- 4) In settings where Chemsex is a practice of some MSM, knowledge on this issue is important
- 5) Some CBVCTs have good experience with having health staff from the HIV-unit working in the CBVCTs as testers. This can contribute to ensure a good cooperation between CBVCT and HIV-unit
- 6) Some CBVCTs have good experience with having HIV-positive people working as staff at the CBVCT, so clients with a reactive test result can immediately be referred to talk with a peer

If confirmatory test is not taken at the CBVCT

If a laboratory / STI-clinic is performing the confirmatory test, close cooperation with the laboratory / STI-clinic is recommended.

- 1) This could e.g. be making a specific appointment for the client with the laboratory / STI-clinic for the confirmatory test
- 2) If the laboratory / STI-clinic refer the client to HIV-unit / doctor for treatment in case of a reactive test result, it is advisable that the laboratory / STI-clinic make a specific appointment for the client with the HIV-unit / doctor for treatment
- 3) If the laboratory / STI-clinic is informing the CBVCT (and not the client) of the result of the confirmatory test, it is advisable to make a specific appointment with the client at the time the person is referred to laboratory / STI-clinic for the confirmatory test

If a HIV-unit is performing the confirmatory test, close cooperation with the HIV-unit is recommended.

- 1) Close cooperation (and advisably personal cooperation) between the CBVCT staff and the HIV-unit(s) is strongly recommended
- 2) It is recommended that the HIV-unit has in-depth knowledge about how the CBVCT operates and the procedures in referrals to confirmatory testing
- 3) It is recommended that the CBVCT staff makes a specific appointment for the client for the first visit at the HIV-unit
- 4) Clients should be offered to be accompanied at the first visit at the HIV-unit if the assessment is that this would be beneficial for the client

If a GP is performing the confirmatory test, close cooperation with the GP(s) is recommended.

In countries where HIV-treatment is offered by GPs, the CBVCT is typically not allowed to refer to specific doctors. This makes it impossible to make specific appointments for the clients – and they are often left with the only solution of giving the client a list of the relevant doctors. It is the experience that being linked to care (following the HIV diagnosis) contributes to the likelihood of attending the first visit. It is therefore recommended that CBVCTs in this situation start negotiations with the doctors about this problem.

If confirmatory test is taken at the CBVCT

- 1) Close cooperation (and advisably personal cooperation) with the HIV-unit(s) is strongly recommended
- 2) It is recommended that the HIV-unit has in-depth knowledge about how the CBVCT operates and the procedures in referrals to care
- 3) It is recommended to make a specific appointment for the client for the first visit at the HIV-unit
- 4) Clients should be offered to be accompanied at the first visit at the HIV-unit if the assessment is that this would be beneficial for the client

Documentation of linkage to care

It is suggested to use the following definition of linkage to care in the future: “Linkage to health care is defined as entry into health care or follow-up by an HIV specialist or in an HIV- unit after a reactive or confirmatory HIV-test at a CBVCT facility.”

In many CBVCTs informal information from the HIV-unit or random knowledge from clients are the basis of data on linkage to care.

Documentation of linkage to care are crucial to monitor and evaluate the effectiveness and success of CBVCTs.

A system of unique identifiers to track patients from a CBVCT testing-site to HIV-care should be developed. There are issues of privacy and data protection though, that has to be taken into account.

Before a more formalized system is developed, a simple system (e.g. having the client consent to communication between HIV-unit and CBVCT with a signature on a document) might be useful.

When making systems to document linkage to care it is important to respect the data protection law in the respective countries.

To document the success of linkage to care from CBVCTs it is recommended to collect information and prioritise publishing scientific papers.

Barriers to linkage to care which are not specifically related to the MSM group

A number of barriers to linkage to care are not specifically related to the MSM group. This can e.g. be:

- Patients are referred to a HIV-unit far away from where they live
- Underage young people who cannot have access to HIV-test or HIV-treatment without their parents' knowledge and accept
- HIV-units refuse to accept HIV-positive patients because the hospital department are overcrowded

- Undocumented migrants do not have access to HIV-treatment in some countries
- Language problems if the client do not speak the local language

These problems are not unique to the CBVCTs but apply to all HIV testing in the specific country whether this is done at a hospital, a clinic, a CBVCT or with a doctor.

It is recommended that this kind of problems are raised with relevant bodies.

Information of the support from the CBVCT

Before the clients leave the CBVCT for further care at a HIV-unit or GP they should be informed on the support that the CBVCT is offering to people living with HIV, whether this is support groups; peer-to-peer support; counselling or psychological, social or medical support.

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WP6: Questionnaire regarding your present model for “Linkage to Care” from your CBVCT to the Health Care System.

Name of your CBVCT-unit:

Name of the contact person in the CBVCT:

Contact details of the contact person (phone no/e-mail):

Testing activity in 2014

1. How many persons were tested in your CBVCT (2014)?
 - What is the percentage of MSM in the total number?
2. How many persons did receive a reactive hiv-test result in your CBVCT (2014)?
 - What is the percentage of MSM in the total number?
3. How many persons were confirmed with a positive test result in or through your CBVCT (2014)?
 - What is the percentage of MSM in the total number?
4. How many positive persons were linked to care from your CBVCT (2014)?
 - What is the percentage of MSM in the total number?
5. Does your CBVCT have any cooperation with the local or national HIV surveillance institute about monitoring or reporting HIV data?
☐ Yes ☐ No ☐ I don't know

If yes, please describe shortly:

Description of your main procedure for linkage to care

[= What happens when a person gets a reactive HIV rapid test result in your CBVCT?]

Clients' data collection:

6. Is it possible to get tested anonymously at your CBVCT?
☐ Yes ☐ No ☐ Partly

Please explain if necessary:

7. Which contact data do you normally collect from your clients at the CBVCT?
☐ First name ☐ Last name ☐ Address ☐ E-mail ☐ Phone number ☐ Anonymous code
☐ Other - please state:

8. Do you collect information about last HIV test (date and result)?
☐ Yes, always ☐ Yes, sometimes ☐ No

Please explain if necessary:

Confirmatory Test:

9. Who delivers a reactive rapid test result in your CBVCT?
☐ The counsellor that takes the test ☐ Another staff member
☐ Somebody else – please specify:
10. Do you take an extra test in your CBVCT to “confirm” the first rapid test?
☐ Yes ☐ No ☐ Sometimes

Please explain if necessary:

11. If yes, what kind of confirmatory test?
☐ Repeat same test ☐ Another kind of rapid test ☐ A blood sample/Western Blot
☐ Another kind of confirmatory test:
12. Where is the blood sample for the confirmatory test taken?
☐ CBVCT ☐ GP ☐ Laboratory ☐ Gum clinic ☐ HIV-unit ☐ Other (which?)
13. Does your CBVCT have a formal or written procedure for confirmatory testing?
☐ Yes ☐ No ☐ I don't know

If yes, please specify:

14. Does your CBVCT have formal or written cooperation agreements with GP's, gum clinics, labs or HIV units to facilitate confirmatory testing and/or linkage to care from your CBVCT? (if yes, please specify)
☐ Yes ☐ No ☐ I don't know

If yes, please specify:

15. Does the client have to pay for a confirmatory test?
☐ Yes ☐ No ☐ Sometimes

Please explain if necessary:

16. Is it possible to get a confirmatory test anonymously?
☐ Yes, always ☐ Yes but only at our CBVCT ☐ No

Please explain if necessary:

17. Does the CBVCT receive information about the result of the confirmatory test?
☐ Yes ☐ No ☐ Sometimes (please explain)
18. If yes, how?
☐ By the client himself ☐ Because the CBVCT offers the test ☐ Through the lab
☐ Through the HIV unit ☐ Other way (please explain)
19. If not, why not?
20. How long does it normally take from rapid test result at CBVCT to confirmatory test result?
☐ Less than a day ☐ From day to day ☐ A few days ☐ A week ☐ 8-14 days ☐ More than 2 weeks.
21. Who gives the confirmatory test result?
☐ A counsellor at the CBVCT ☐ A doctor at the CBVCT ☐ The GP ☐ A doctor at the HIV unit
☐ Other (explain)

Linkage to care:

22. How is your client linked from a positive confirmatory HIV-test to HIV-care?
☐ Referral from the GP that gives confirmatory test result
☐ Referral from the lab that gives confirmatory test result
☐ Referral from the CBVCT that gives confirmatory test result
☐ Only through a recommendation from GP or CBVCT
☐ Confirmatory testing takes place in HIV-care settings
☐ Other way – please specify:
23. Does the CBVCT receive information about viral load and cd4 cell count?
☐ Yes, always ☐ Yes, sometimes ☐ No, never
- Please explain if necessary:
24. Does your CBVCT offer any kind of support to the newly diagnosed HIV-positive persons?
☐ Yes, always ☐ Yes, sometimes ☐ No, never
25. If yes, what kind of support does your CBVCT offer to newly diagnosed persons?
☐ Peer-to-peer counselling ☐ Professional psychological support ☐ Professional social support
☐ Professional medical support ☐ Other kind of support – please specify:
26. Does your CBVCT have a formal or written procedure for linkage to care?
☐ Yes ☐ No ☐ I don't know

Please explain if necessary:

27. Does your CBVCT have a specific contact person within HIV care settings who helps you with linkage to care from your CBVCT?

☐ Yes ☐ No ☐ I don't know

If yes, please specify:

28. Does someone from your CBVCT accompany the newly diagnosed HIV positive client to the HIV Care settings?

☐ Yes ☐ No ☐ Sometimes

Please explain if necessary:

29. Would you be able to interview that contact person (or somebody else inside HIV Care settings) on linkage-to-care issues? (this will be next step in WP6)

☐ Yes ☐ Maybe ☐ No

Please explain if necessary:

30. Are there any articles, annual reports or written procedures about your CBVCT's testing activities and linkage to care?

☐ Yes ☐ No ☐ I don't know

If yes, please specify:

31. Do you have any data about client satisfaction from your newly diagnosed HIV positive clients?

☐ Yes ☐ No ☐ I don't know

If yes, please specify:

32. Does your CBVCT experience any specific problems in linking MSM to HIV care in your settings?

☐ Yes ☐ No ☐ I don't know

If yes, please specify:

33. Would you be able to contact some of your MSM clients that tested HIV-positive in your CBVCT in order to ask them to answer an online survey on their experience of linkage-to-care? (this will be next step in WP6)

☐ Yes ☐ Maybe ☐ No

Please explain if necessary:

WP6

Interview guide for CBVCT managers

1. Where are clients with a reactive HIV rapid test from your CBVCT referred to for confirmation (a special HIV unit, an ordinary hospital, or a general practitioner)?
 - Are the differences depending of time of the reactive test (day / night)?
2. Has your CBVCT established procedures for referral for confirmation of a reactive rapid test?
 - If yes, which?
 - Do you have specific agreements / arrangements?
3. How do you ensure that clients with confirmatory HIV test are linked to care?
4. Do you provide 'actual appointments' with the HIV-unit or give 'general referral information' to clients testing HIV-positive?
5. Is there any kind of resistance from the client to be linked to care?
 - If yes, what kind of resistance?
 - And how often do you experience resistance?
 - Are there problems that are specific for MSM?
 - Are there problem that are specific for migrant-MSM?
 - If yes, what kind of problems?
 - And how often do you experience these problems?
6. Has stigma (e.g. being judged by healthcare professionals or being recognized in the clinic) and/or homophobia – in your opinion – an influence in failure to engage in care after HIV diagnosis?
7. Do you think that gay or bisexual men are less likely to be satisfied with the health care they receive in the formal health facilities in your country (because of their sexual orientation)?
8. Is there a lack of trust in health care providers and the 'medical community' in your country (e.g. afraid of disclosure of being MSM or drug user; poor quality of the skills of medical staff)?
 - And if yes, do you think that this influences the linkage to care?
9. What is, in your opinion, the reasons for failure (if any) to engage in care after HIV diagnosis – for MSM and for not-MSM? Are there differences between these two groups?
10. Are there any structural financial barriers that jeopardize linkage to care (e.g. not being able to choose hospital / no cooperation between CBVCT and hospital)?

11. Studies have mentioned the following as possible reasons for not being linked to care. Can you recognize any of these as having influence for HIV-positive clients in your CBVCT:

- poverty or other economic factors with the HIV positive client
- unemployment
- limited health literacy
- violence
- lack of transportation
- child care issues
- symptoms of clinical depression / psychological-psychiatric problems
- history of drug or alcohol abuse
- history of physical or sexual abuse
- insurance problems
- inability to take time off work
- being too sick
- not being ready to address the HIV-infection
- fear of stigma
- fear of being disclosed as homo- or bisexual

12. If yes to any of the above – what do you do to overcome these barriers?

13. How do you make sure that linkage to care is a success?

14. How can you in your CBVCT improve linkage to care?

15. How would you assess the coordination between the CBVCT and the HIV-unit (for linkage to care) on a scale from one to five (one = bad; five = very good)?

16. How would you assess the coordination between the CBVCT and place for confirmation of reactive rapid HIV test (if not the HIV-unit) on a scale from one to five (one = bad; five = very good)?

Anders Dahl / AIDS-Fondet, Denmark

23. December 2015

WP6

Interview guide for health professional

1. What is the 'routine procedure' when a person is referred to you with a reactive HIV rapid test from the CBVCT?
 - Do you e.g. get any information from the CBVCT that the patient will turn up at the hospital?
 - Do you give any feedback to the CBVCT that the patient has been linked with you?
 - Are HIV positive clients (sometimes) physically accompanied by CBVCT staff for the confirmatory test or for linkage to care?
2. Is the procedure the same when HIV-positive patients (or patients with a reactive HIV rapid test) are being referred to you from e.g. a GP or another hospital ward?
 - If no, what is the difference?
3. What procedure of linkage to care is the most successful – referral from CBVCT or from GP / other hospital wards?
4. How would you characterize the cooperation between you and the CBVCT?
 - Can the cooperation be improved? If yes, how?
 - What do you expect from the cooperation between you and the CBVCT?
5. Do you see any barriers in linkage to care from the CBVCT?
6. Do you see any special barriers for MSM in linkage to care from the CBVCT?
7. Are there specific problems in linkage to care from the CBVCT – compared to linkage from other test sites (GPs, other hospital wards, etc.)?
8. How can linkage to care from the CBVCT be improved?
9. How would you assess the coordination between the HIV-unit and the CBVCT (for linkage to care) on a scale from one to five (one = bad; five = very good)?

*Anders Dahl / AIDS-Fondet, Denmark
23. December 2015*

Questions to on-line survey with MSM testing HIV positive in a Checkpoint

Introduction of questionnaire:

We would like to invite you to fill in this questionnaire regarding linkage to care after testing positive for HIV.

This survey is part of a European study called EURO HIV EDAT. Our part of the study aims to improve linkage to care among men having sex with men.

To participate in this survey you must be 18 years of age or over and identify yourself as a man having sex with other men. This questionnaire is strictly confidential and anonymous and approval from the Danish Data Protection Agency to conduct the survey has been received.

Your participation is completely voluntary and you are free to choose whether or not to participate in this survey. If you decide not to participate, it will have no impact on the quality of your care. You can withdraw at any time your participation without any consequences.

It will take you around 10 minutes to fill out the questionnaire.

You can at any time go back in the questionnaire and change your answers if you want to.

This questionnaire is available in the following languages: Danish, French, German, Portuguese, Slovenian and Spanish.

Thank you for your time and your participation. Your help means a lot to us.

1. How old are you?
2. In which country were you born?
3. In which country do you live now?
4. Do you have legal residence in the country where you live?
Please comment if necessary:
5. When did you test positive for HIV (month and year)?

Intro to question 5:

When we use the term 'Checkpoint' we mean a community-based testing service where you can get a rapid HIV test. They might call themselves 'Checkpoint' or they can use another word.

6. In what Checkpoint did you test positive for HIV?

Intro to question 7:

When we use the terms 'doctor/hospital where you go for monitoring/treatment' we mean the place

where they take blood samples to check your CD4-count, viral load etc. and (maybe) give you the antiretroviral medication.

7. Where did you get the result of the confirmatory HIV test (this is the test that confirms the reactive/positive result of the rapid test)?
 - ☐ a) At the Checkpoint
 - ☐ b) At the doctor/hospital where you go for monitoring/treatment
 - ☐ c) Another place, e.g. a laboratory
8. Which organisation referred you to the doctor/hospital for monitoring/treatment?
9. Did the Checkpoint help you with getting a specific appointment with the doctor/hospital (for monitoring/treatment)?
 - ☐ Yes
 - ☐ No
 - ☐ Comments if any:
10. Did the Checkpoint help you in any other way with connecting you to the doctor/hospital (for monitoring/treatment)?
 - ☐ Yes
 - ☐ No
 - ☐ Comments if any:
11. How long did it take to get an appointment with the doctor/hospital for monitoring/treatment (from your positive HIV rapid test result in the Checkpoint)?
12. How would you in general assess the referral practice between Checkpoint and doctor/hospital for monitoring/treatment on a scale from one to ten (one = bad; ten = very good)?
 - ☐ Comments if any:
13. In your opinion, did it take too long time to get an appointment with the doctor/hospital for monitoring/treatment?
 - ☐ Yes
 - ☐ No
 - ☐ Comments if any:
14. In your opinion, was the referral to doctor/hospital for monitoring/treatment too speedy?
 - ☐ Yes
 - ☐ No
 - ☐ Comments if any:
15. What could, in your opinion and from your experience, be improved in the referral practice?

- Comments:

16. Will you accept to participate in a face-to-face or telephone interview about your experience with being tested HIV-positive in a Checkpoint?

If yes, please write your contact details (e.g. email or telephone number for sending you a text message).

If you accept, you will be contacted by a person from your local Checkpoint.

- Yes
- No
- If Yes, contact details:

WP6 / Copenhagen / Anders Dahl / 7 July 2016