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## **EURO HIV EDAT Project**

**Optimal linkage to care among MSM:  
a practical guide for CBVCT's and Points of Care**

## Acknowledgements

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## Abbreviations

CBVCT	Community-based voluntary counselling and testing service
EDAT	Early diagnosis and treatment
GP	General practitioner
HIV	Human immunodeficiency virus
HIV-COBATEST	HIV community-based testing practices in Europe
MSM	Men who have sex with men
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. In our work with WP6 all of the interviewed CBVCT managers have in practice used the definition used in the HIV-COBATEST Network (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 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.

## Introduction

The following recommendations are made by the Danish AIDS-Foundation with support from a number of CBVCTs across Europe working on the ground with testing of MSM and national surveillance institutes from a few countries.

We are aware that there are various differences in the structure of health systems in the different countries, but nonetheless we have produced a set of recommendations that new/upcoming CBVCTs should consider in terms of optimal linkage to care.

These recommendations are the result of interviews and surveys among CBVCT managers, health care staff and MSM with a reactive HIV-test in a CBVCT and linked to care. Data are collected from seven countries (Germany, France, Spain, Portugal, Slovenia, Greece and Denmark) in the period June 2015 – February 2017 and the full report from the study is available at the HIV EDAT webpage.

The recommendations are to be included in the toolkit (WP7) that will be available online as an instrument to ensure quality and good practice in CBVCTs across Europe.

The toolkit is to be found at: [www.msm-checkpoints.eu](http://www.msm-checkpoints.eu).

## **Executive summary from the report ‘Description and improvement of different approaches of linkage to care for HIV among MSM in Europe’**

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.

## **Recommendation for an optimal linkage to care among MSM from CBVCTs**

### **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 be 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.