

Assessment of HIV knowledge and its association to HIV status in the population attending Non-Governmental Organizations to perform the rapid HIV test in Catalonia

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<u>Abstract</u>

Background: Human Immunodeficiency Virus continues to be a pandemic. Spain is one of

the European countries with the highest incidence of HIV. Within Catalonia, Spain many

projects have been implemented with the intention of improving HIV knowledge and

lowering the incidence. HIV knowledge is also known to have a positive effect on lowering

stigma and discrimination of the people living with HIV. However, few studies study the

distribution of HIV knowledge and its association to HIV status, age, sex, geographical

zone of origin and level of education within the same study.

Objectives: To identify if HIV knowledge is associated with HIV status, age, sex,

geographical zone of origin and level of education.

Method: Quantitative, cross-sectional, centre-based study comprising of people receiving

an HIV test in Catalonia, Spain. Data will be collected from the 11 HIV Non-Governmental

Organisations in Catalonia, Spain. The Brief HIV Knowledge Scale will be used to assess

HIV knowledge; information from the HIV test session will be used to assess HIV status,

age, sex, geographic zone of origin and level of education. The association between HIV

knowledge and the afore mentioned variables will then be calculated.

Key words

HIV knowledge, HIV status, education, age, sex, geographic zone, level of education,

Catalonia, HIV-Non Governmental Organizations

<u>Abbreviations</u>

**AIDS**: Acquired Immune Deficiency Syndrome

CEECISCat: Centre d'Estudis Epidemiològics sobre les ITS/HIV/SIDA de Catalunya

HIV: Human Immunodeficiency Virus

**HIV-NGO**: Human Immunodeficiency Virus Non-Governmental Organisation

**STI**: Sexually-transmitted infection

**UNAIDS:** Joint United Nations Program on HIV/AIDS

**UNGASS:** United Nations General Assembly Special Session on HIV/AIDS

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## 1. Introduction

The Human Immunodeficiency Virus (HIV) epidemic has had a profound impact on a global level. Since 1981, an estimated 65 million people worldwide have been infected and 25 million people have died as a result of Acquired Immune Deficiency Syndrome (AIDS) [1]. HIV continues to be an international pandemic and efforts to slow the incidence of HIV infections continue [2]. Despite substantial reductions in HIV related morbidity and mortality since the beginning of highly active antiretroviral treatment, HIV is still a major public health problem in Europe [3]. However, the experience of and the response to the pandemic differs across countries.

The Council of European Union Health Ministers approved a Plan of Action for the period 1991-1993, through the program 'Europe against AIDS' which called for "the evaluation of the knowledge, attitudes and behaviour of the general society and specific groups in regards to HIV" [4]. In more recent years, the Joint United Nations Program on HIV/AIDS (UNAIDS) have referred to this commission in order to demonstrate the need to perform more research in the correlation between HIV and knowledge in all European countries, including Spain [5,6].

UNAIDS [5] show that the majority of countries in Europe do not have data on the knowledge of the population in regards to HIV/AIDS, Spain included. This demonstrates the need to continue collecting data in order to know if this lack of knowledge is contributing to the HIV/AIDS epidemic. It is not sufficient to only collect data but also ensure that the data collected is of a consistent high quality. This can be achieved through rigorous, systematic research.

A barrier that continues to exist in field of HIV research throughout the world is the inconsistency of epidemiological data and difficulties with data collection. This limits the conclusions that can be drawn from the HIV and AIDS epidemic. Missing information makes it difficult to directly measure the incidence of HIV. However, existing estimates from 2010 show that in Catalonia, 34,957 people are currently living with HIV and in the same year there were 1,600 AIDS-related deaths [7]. These are amongst the highest figures in Western Europe. However, it is important to note that HIV incidence in Catalonia has been falling steadily since 2008 [8]. While this is a positive step, research into why and how should be investigated in order to maintain this decrease. Current research into HIV incidence and potential correlations are essential in order to know whether there are

demographic or structural factors which predispose people to HIV. Correlations are also important to know in which areas more effort is needed in order to slow the growth of HIV. Country specific HIV knowledge is an important part of epidemiological vigilance in order to know if lack of information in relation to HIV is a factor in the incidence.

Epidemiological vigilance is universally considered to be central in the monitoring of HIV and the assessment of interventions which in turn intend to lower the incidence of HIV within a country. HIV testing and diagnosis have been monitored in Catalonia since 1992 [9]. The Centre d'estudis epidemiològics sobre les ITS/VIH/SIDA de Catalunya (CEEISCat) acts as a reference for the epidemiological vigilance of HIV/AIDS in Catalonia and is in charge of all surveillance activities on STIs/HIV/AIDS in Catalonia [9]. This includes the designing, implementing, analysing and distributing of the necessary information systems for the monitoring of the HIV epidemic in Catalonia.

Within the community, Catalonia controls the incidence of HIV in two main ways, through the Primary Attention Centres and also through the HIV Non-Governmental Organizations (HIV-NGOs). The HIV test performed in the Primary Attention Centres is the Western Blot. The 'Western Blot' is an antibody detection system that separates the viral proteins and then the binding of specific HIV proteins is visualised [10]. It is currently accepted as the 'gold standard' of HIV diagnosis. There are 366 Primary Attention Centres in Catalonia [11] and in 2008, approximately 180,000 Western Blot test were performed in them. 0.9% of these tests were positive [12]. Of the 4,500 tests performed in the HIV-NGOs, in the same year, 2.8 % were positive [12]. While significantly fewer tests were performed within HIV-NGOs, the percentage of positive test results is higher in comparison to the Primary Attention Centres. This suggests that the population attending the HIV-NGOs is distinct from that attending the primary health centres. The comparatively high rate also suggests the need for investigation into this population.

The 'Western Blot' is also the test that is used to confirm the rapid HIV test that is performed in the HIV-NGOs. While the person receiving the test has to wait a week for the result, there is no possibility of a false positive outcome. The rapid HIV test performed in the HIV-NGOs of Catalonia is the HIV-1/2 test and is the Determine HIV-1/2 test manufactured by Inverness Medical. The sensitivity of the test is 100.0% and the specificity is 99.6 % [13]. It is an in vitro visual, qualitative immunoassay for use with human serum, plasma or whole blood. For whole blood, 50 µL is required followed by

chase buffer [14]. If antibodies are present, a line appears letting the technician know that HIV antibodies are present in the test. Every HIV test that the HIV-NGOs perform is recorded on a sheet provided by CEEISCat [ANNEX 1] that collects demographic, behavioural and HIV status information about the person who comes to perform a rapid HIV test. Persons receiving a positive test result are referred to Hospital Clinic, Barcelona or Hospital Universitari Germans Trias I Pujol, Barcelona for counselling and a confirmatory test as the specificity of the Determine test means that there is potential for false positives. In 2010, there were 4 false positives in Catalonia [15].

Another route of HIV diagnosis that will not be discussed within this study is the hospital. Most people who are diagnosed in hospital already have symptoms and are nearly always classified as a late diagnosis [16]. This is defined as accessing medical treatment or presentation after clinical or immunological disease progression that will reliably identify an individual at high risk of mortality over the first three months of diagnosis [17]. In recent years, the incidence of late diagnosis of HIV has been increasing within Catalonia. Early diagnosis and the prevention of late diagnosis is a priority in which the Primary Care Centres and the HIV NGOs play an important role.

HIV testing is free both by the primary healthcare provider and through the NGOs. The HIV-NGOs are managed by non-governmental organisations and receive financial subsidies from the Health Department of Catalonia. In the HIV-NGOs, testing is voluntary and anonymous in comparison with the alternative of hospital laboratories and primary care laboratories where it is voluntary and confidential. In the HIV-NGOs the name of the patient is not requested. The anonymity of the people that come to perform the test is essential in order for it not to be a factor discouraging people from performing the HIV test.

In recent years, the amount of studies focused on the HIV-ONGs has increased due to the realization that they have an important role in HIV prevention [18-20]. Although the attendance to HIV-NGO has increased greatly during the last 7 years, there is still very little research on this population. The author intends to use this population in order to gain information that is unable be found in other health care situations, for example, in primary healthcare centres or hospitals. It can be assumed that the people attending HIV-NGOs have had a risk experience or they are not sure. The population in attendance of HIV-NGOs also differs from the population accessing the Primary Healthcare Centres because

in the HIV-NGOs the HIV test is anonymous whereas in the Primary Healthcare Centres, the test is confidential but it goes on the patient record. People may prefer to take the HIV test in an anonymous environment for fear of stigma [21].

An additional advantage to using the population from the HIV-NGOs is that they do not require a National Health card as is required in the Primary Attention Centres. This allows illegal immigrants to know their HIV status. Early detection of HIV within the immigrant community is more important now than ever as Catalonia is experiencing a high incidence of immigrants with HIV [22,23]. For this reason, it is important to know if lack knowledge is a factor in the high HIV incidence.

The population attending the HIV-ONGs is varied. Many other studies on populations at risk of HIV solely focus on one group at a time and they collect data from settings where groups of these people are likely to be. This includes collecting data about young people from secondary schools [24]. The danger of only collecting data from various groups and labelling them as 'at risk' and is not only dangerous in that it can create stigma and discrimination but also because it can cause other groups to become neglected from HIV prevention interventions. This study intends to collect data from the socio-demographically varied population of the HIV-ONGs.

It has been said that HIV-NGOs have led the initiative against HIV, increased knowledge and aid communication between the most vulnerable sectors of the population and the health services [18,19]. Since the introduction of the Rapid antibody tests in 2006 in Spain, more people have been tested than in any previous historical period [15,19]. Although the results of this test have to be confirmed with a 'Western Blot' test, the high reliability, the 15 minute wait for the results and the ease of administration mean that it is widely used in clinics that offer HIV testing in Barcelona. All HIV-NGOs in Barcelona use finger-stick tests due to high sensitivity and specificity and ease of use.

It has become clear that various differences exist between Primary Attention Centres and HIV-NGOs [18]. The benefit that HIV-NGOs have in a study to determine level of knowledge and its associates is that they have a relatively high number of positive HIV tests, they are anonymous, the population is socio-demographically varied and the person receives an immediate result. From a health promotion point of view, they also provide a supportive environment which in turn encourages an increase in knowledge and promotes

community action [25]. The promotion of community action involves the participation of groups which are similar to the group in which you are trying to increase the knowledge. Evidence shows that people are more responsive and the intervention more effective when the participant identifies with the person giving the knowledge e. g a young person giving HIV knowledge to another young person.

As mentioned previously, the person can receive their results at the time they are at the HIV-NGO. This acts as an incentive for people discover their HIV status and provides an opportunity for increasing HIV knowledge. A common problem, before the implementation of the rapid HIV test, was that people would not return for their test results. This would mean that the person would remain unaware of their HIV status and the anonymous nature of the test meant that the HIV-NGO had no way of contacting the person. In Catalonia, since the implementation of the rapid HIV test in 2007, the demand for HIV tests in the HIV-NGOs has multiplied by 102.9% [15,19,26]. It is important not to forget the sensitive nature of HIV. Although much work has been done to reduce the stigma and discrimination associated with the disease, the fact remains that unfortunately it is still a disease that generates a lot of fear and shame and any measure to increase the attendance in these clinics is essential in order to reduce these barriers to treatment [26-28].

Level of HIV knowledge and its associations are essential in order to be able to know the educational needs of various populations and implement and assess high quality interventions. The HIV-NGOs of Catalonia are an ideal setting to discover the level of knowledge due to the varied population and the anonymous nature of the HIV test.

## 2. Literature Review

To perform the literature review, a combination of public health, social science and nursing research was used. Medline, Google Scholar, PubMed, SciELO and Springer were searched for articles published since 2002 until the present day. The main search terms were "human immunodeficiency disease", "HIV", "VIH", "HIV knowledge", "conocimientos de VIH", "HIV status", "level of education", "nivel de educación", "HIV knowledge correlate/association/effect", "HIV prevention", "HIV knowledge intervention", "HIV gender", "VIH género", "HIV immigrants", VIH inmigrantes", "Rapid point-of-care testing", "HIV Non-governmental organisations", "VIH Cataluña" and "HIV Catalonia".

The subject of HIV knowledge is not a new topic and since the beginning of the HIV/AIDS epidemic a good knowledge base has been considered a central concept in encouraging behavioural change [29]. A good understanding of how HIV is transmitted and prevented is necessary for disease control. Lack of knowledge can contribute to people not recognising their risk behaviours. It has been claimed that one of the barriers to HIV testing is the low-risk perception [30]. Under the title lack of knowledge is also contained misconceptions. These can prevent individuals from making correct decisions and taking preventative strategies to protect themselves against HIV [31].

A systematic review by Lyles et al. [32] found that in high quality interventions aimed at reducing HIV risk behaviour, none of them depend solely on information to achieve this change. However, while high levels of HIV knowledge are not proven to reduce risk behaviour [33], they are considered to be the necessary first step for risk reduction to take place [29]. This highlights the importance of HIV knowledge when planning HIV preventative activities. Many studies promote HIV knowledge as a measure of reducing risk behaviour [34,35] and assessing the effectiveness of the interventions [19].

According to UNAIDS [5], there is no official data for HIV knowledge in Spain and many other European countries. In Great Britain in February 2011, the National AIDS Trust performed an HIV knowledge survey [36] and found that one in 5 adults did not know the transmission routes of HIV. Similarly worrying, research performed in other Western European countries also demonstrates a decline in HIV knowledge [37]. It is essential to assess levels of HIV knowledge in various areas to know the needs of the population. Once the level of knowledge has been assessed, it is also important to know if a greater knowledge of HIV reduces the possibility of getting HIV. It is not only important to assess the relevance of HIV knowledge levels for the benefits of the individual but also in order to assess if the financial and time investments are achieving the desired results from a public health perspective [5].

The subject of HIV knowledge is sensitive within the HIV prevention community as many interventions focus on the increase of knowledge as the central tool in HIV prevention. If a high level of knowledge is found in the participants with an HIV positive status, it suggests that other variables such as motivation or behavioural skills [38] are essential and lacking in the HIV interventions that the population is exposed to. A study performed by Parker & Rüütel [33] found that higher knowledge scores were not associated with lower rates of

HIV infection. The study by Parker & Rüütel establishes the association within their setting, they do not draw conclusions as to what this association means. These finding are complex to interpret as it would suggest that while the populations at risk of HIV are receiving the HIV information it is not enough to make them take up HIV risk prevention behaviour. In an interpretation of the results of the study by Parker & Rüütel, higher knowledge is probably associated with higher rates of HIV infection due to the fact that HIV interventions are directed at groups with high risk behaviours and it is these high-risk behaviours that cause transmission of HIV.

The opposing view is that we need to increase HIV knowledge and that it is enough to change behaviour. Other demographics in which the level of HIV knowledge will be examined include age, sex, geographical zone of origin and level of education. The possibility exists that these demographic variables are associated HIV knowledge, HIV risk behaviour and consequently, HIV status. However, no matter the effect of HIV knowledge on HIV status, it is important to emphasize that HIV knowledge is a vital factor in HIV prevention activities.

While the Centre for Disease Control and Prevention in the United States [39] have a long history of the promotion of the central role of HIV/AIDS knowledge because of its influence on risk behaviour, studies that investigate the relationship between HIV knowledge and HIV status are still rare. From a public health perspective, it is essential to continue gathering information on the level of knowledge and its associates within the population in order to design appropriate interventions directed at the correct demographic groups [28]. It is vital that this body of research is developed not only in reference to high quality interventions but also to assess if groups of people with low levels of HIV knowledge still remain. In the selection of various demographic groups, this investigation will discover if there is a lack in HIV knowledge in certain areas. A lack of knowledge is dangerous for the individual and communities as it can lead to increased HIV risk behaviour and late diagnosis of HIV [40]. It is indisputably an important part of HIV prevention.

The method and scope of HIV preventative activities varies throughout the world. Within the field of HIV prevention, there is emphasis on the importance of performing research that is evidence based and adapted to suit the country and its epidemiological situation. There are many education programs focused on education in the prevention of HIV but few studies evaluate if HIV knowledge affects HIV status [33]. At a glance, it may seem

obvious that a high level of HIV knowledge must lead to less risk behaviour but studies have shown that high levels of HIV knowledge do not always lead to the implementation of this knowledge in practical situations [22,33].

In recent years, the majority of research produced in Spain in relation to HIV prevention focuses on the high incidence of HIV in immigrants and adolescents as they are the newest risk groups [35,41]. While research in the area of HIV in Spain has increased, knowledge gaps remain in the field of HIV prevention. In relation to HIV knowledge, the amount of evidence is increasing within various populations such as in the general population [42], in the prison population [43] and the population attending Primary healthcare centres [22]. This study will be the first to assess levels of knowledge in the population attending HIV-NGOs in Spain.

A longitudinal study by Chocarro et al. [42] shows that no significant changes in HIV related knowledge were shown between 1997-2005 in the Spanish population. While this means that the level of knowledge in the population was maintained, it did not increased. With a concentrated effort on the interventions that raise knowledge and awareness of HIV, it is unusual that the level of knowledge has not been shown to increase in this period and further study is needed to investigate this.

This study intends to fill one of the knowledge gaps that exists in relation to HIV knowledge in Spain. There are a limited number of studies that focus on HIV knowledge in the general population and its relation to HIV status. Current research focuses on immigrants [44,45], youths [24,46] and other risk groups [47,48]. Results from CEEISCAT [49] show that the group with the highest percentage of HIV positive tests, was the age range 36-40. This demonstrates the need to continue HIV education throughout the life span and not only focus on a particular ages and demographic groups.

In recent years, one of the groups that have received significant focus within Spain is the immigrant population. Since the late 1990s Spain has witnessed significant growth in the immigrant population with 16.1% of the population consisting of immigrants in 2011 [50]. This figure does not reflect the illegal immigrant population, so it can be assumed that the true figure is larger than 16.1%. Spain currently rates 4<sup>th</sup> in the European Union for the amount of immigrants and the majority of these are from countries with a higher HIV prevalence than Spain [23]. For example, the 'Reversing the Epidemic' document [51]

focuses on the low level of HIV knowledge in Eastern European countries. The fact that 8.5% of the immigrants in Catalonia are from Romania [50] may demonstrate that there is a, previously unstudied, lack of knowledge that is associated with their acquisition of HIV.

In 2011, 45% of new HIV infections were found in immigrants [6]. This highlights the need for the HIV-NGOs where this vulnerable group have free, anonymous access to their HIV status and information. Immigrants are an important group in HIV populations, not only in high income countries but also middle and low income countries [35]. It has been well researched that the stigma associated with immigrant status, loss of social and familial support, and legal and language difficulties contribute to an increase in the potential of getting HIV [2]. However, it is important to recognise that the term 'immigrant' is a broad term and it covers a range of situations. Within this study the immigrant group will be divided into geographic zones of origin in order to identify more clearly which groups have high or low levels of knowledge and its association to HIV status.

Spain has a unique situation in Europe in that the majority of the HIV cases are from people from Latin America [35]. Latin America has a similar incidence of HIV as Spain. Without the language and culture barrier, it is surprising to see this high level of HIV incidence in this population. Studies have shown that the majority of immigrants become HIV positive in their host country [52]. Whether the person became HIV positive in the host country or in their own country changes the role of HIV prevention and education depending on the situation. The level of HIV knowledge within this group may affect their behaviour and consequently their HIV status.

A recent study by Ríos et al. [22] into levels of HIV knowledge in Latin American and Moroccan immigrants concludes that there is a lack of HIV knowledge within this population. While this study provides much needed information on the level of knowledge within the immigrant community in Barcelona, there are two main weaknesses. The first weakness is the purely descriptive methodology. A correlational methodology would have strengthened the conclusions that could be drawn from the data collected. Secondly, the sample is collected solely from primary care centres, excluding illegal immigrants and people without health cards. However, the authors include this in their limitations stating that they realize that many immigrants face difficulties in accessing the Catalan health service and performing medical tests. This study will increase the knowledge base regarding HIV knowledge levels because it will use the population of the HIV-NGOs where

the 'illegal' immigrants are able to attend. While the true number of illegal immigrants is difficult to know, estimates suggest that they account for between 20-30% of the immigrant population of Catalonia [53]. To exclude this population from a study into HIV knowledge levels in immigrants, would affect the accuracy of the data collected.

Although much effort has gone into providing access and quality care to the immigrant population in Barcelona there is still evidence to show that barriers exist that prevent immigrants from accessing the health system [54]. The fact that in HIV-NGOs the HIV test is anonymous, potentially reduces the perception of a barrier that the person accessing the test may feel. HIV-NGOs often act as a place of HIV prevention information or an intermediary level of access to the health system if found HIV positive. This in turn can prevent late diagnosis and reduce morbidity and mortality from AIDS [55].

Another area that will be covered by this study is the level of education. Whilst health disparities are well known and researched in relation to HIV, the majority of current research focuses on race [56] and sex [57]. Very little research exists in relation to HIV knowledge and level of education. It is important to know if those with a lower level of education are missing vital HIV education which puts them at a disadvantage and may increase their vulnerability to HIV in comparison to a person with a higher level of education [58]. It may mean that HIV knowledge increasing interventions need to be aimed in other areas.

While interventions that target young people may succeed in increasing knowledge in young people that have a secondary or university education, the possibility exists that the people who do not have a secondary or university education are missing the HIV interventions and subsequently increasing their possibility of being exposed to HIV. This is an important variable to collect because the possibility exists that the recent focus on HIV education within risk groups means that people with a low level of education have not previously been targeted.

An additional reason why HIV knowledge is important is that studies [59] show that among adults, inadequate health literacy decreases the likelihood of engaging in preventative health behaviours. This also may contribute to HIV/AIDS related stigma by perpetuating misconceptions about how HIV is transmitted. Lack of knowledge may also play a part in increasing stigma against HIV positive people [60].

Considering that gender inequalities in relation to HIV/AIDS is a central theme in the Declaration of Commitment of the United Nations General Assembly Special Session on HIV and AIDS (UNGASS) [61], the evidence regarding gender at an international level is sparse. There are few studies in the high income countries that study the difference in HIV knowledge between men and women. Half of new HIV cases occur in women and girls [62] for a number of complex socio-economic, sociocultural and biological factors. The study by Careal et al. [62] suggests that women are often at a disadvantage when it comes to accessing HIV information and implementing it effectively. This study collects HIV knowledge data from 64 countries and describes the differences between men and women level of knowledge. In 2005, women were found to have a HIV knowledge level of 28% and men, 37%. In 2009, their findings show an improvement in the gap that existed between men and women in 2005 with 40% of men and 38% of women with accurate knowledge on HIV and how to avoid transmission. Although this shows that the gender gap is closing, these figures are still significantly below the Department of Commitments aim of ensuring that 95% of young people had HIV knowledge by 2010, a goal which has not been met [63].

At an international level, UNGASS [61] have declared it a priority to ensure sound HIV knowledge within young people. Within Catalonia, various programs and resources exist with the intention of increasing HIV/AIDS related knowledge within young people. One example of one such project is Dance4Life [64]. It is an international HIV/AIDS educational project that is directed at young people where they participate in workshops in their schools. While Dance4Life and similar interventions are essential in HIV prevention in risk populations, it is unknown how much of the population this information is reaching and what effect it has.

A review of the literature has led to the conclusion that there is a need for high quality evidence describing the level of HIV knowledge in Catalonia. This information is necessary to know where HIV knowledge may be lacking and the correct design and implementation of HIV prevention interventions. The majority of the research performed in Spain in relation to HIV is focused on high risk groups such as immigrants [22,35] and adolescents [24,46]. This study will also discover if there is a group lacking knowledge that has not previously been discovered and targeted. Recently, many international HIV knowledge studies have focused on the difference in HIV knowledge between various

demographical groups for example, sex [65], age [24], geographical zone of origin [35] but few include all and compare them within the same study. The HIV-NGOs of Catalonia provide a good setting with a varied population allowing access to a heterogeneous population that has not previously been studied in Catalonia.

The aim of this study is to determine if an association exists between HIV knowledge and age, sex, geographic zone of origin, level of education and HIV status.

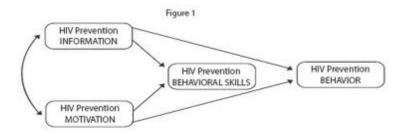
## 3. Theoretical framework

Within the HIV-NGO sites of Catalonia, the aim is to inform people of their HIV status while giving information about HIV with the intention of promoting preventative behaviours.

One of the newer models of HIV prevention through change in HIV risk behaviour is the information-motivation-behavioural model. It was developed in 1992 by Fisher and Fisher [66] with the intention of understanding HIV risk behaviour and constructing theoretical based interventions across a wide range of populations [67].

The information-motivation-behavioural skills model [66,68] asserts that HIV prevention information, HIV prevention motivation and HIV prevention behavioural skills are the fundamental determinants of HIV preventative behaviour. This model considers HIV information to have a moderator role which affects the ability to implement HIV preventative behaviour. The motivation component of the model refers to the personal motivation of the individual to practice preventative behaviours and perceptions of personal vulnerability to HIV infection. The behavioural component of the model refers to the ability of the individual to negotiate HIV testing, monogamy and other practical skills for the prevention of HIV. While this model focuses on information, motivation and behavioural skills, it is important to note that the model also specifies that prevention information and prevention motivation may exist as independent constructs and have direct effects on preventative behaviour. This suggests that some individuals may adopt preventative behaviour from only preventative information and without preventative motivation [Figure 1].

Figure 1



The figure shows that HIV prevention information can lead directly to HIV prevention behaviour although not in all cases.

The information-motivation-behavioural model identifies that specific populations may have different prevention needs. This is important in the assessment of knowledge as in some populations; knowledge may be enough to lead to HIV preventative behaviour and not in others. It highlights the importance of knowing the needs of the population in which the HIV preventative behaviour is being attempted.

Individuals often rely on HIV prevention heuristics. Heuristics are simple decision rules which allow automatic, and not always correct, choices about whether to engage in HIV preventative behaviour or not [67]. The existence of heuristics, such as, 'monogamous sex is safe sex', 'known partners are safe partners' and 'If the person doesn't look sick, they don't have HIV' interfere with preventative behaviours. This reinforces the importance of HIV knowledge as the basis of HIV prevention.

However, it is also important to highlight that HIV prevention motivation is often needed in order to promote HIV preventative behaviour in individuals. According to this model, there are three types of motivation: personal (the attitude towards performing preventative acts), social (the social perception towards performing preventative acts) and perceptions of personal vulnerability to HIV infection [69].

The information-motivation-behavioural model has received considerable empirical support because the model has often been tested in multivariate correlational research concerning informational-motivational-behavioural skills determinants of HIV preventative behaviour across populations of interest [68]. However, criticisms that exist in relation to this model are that 'information' and its effect on HIV preventative behaviour seems to be

unclear. This suggests that HIV information may not always lead to preventative behaviours.

Although a high level of HIV knowledge may not lead directly to behaviour change, it is likely a necessary precursor to the contemplation of behaviour change. Evidently HIV knowledge is important in allowing a person to make informed decisions about their life style choices and taking steps towards prevention.

## 4. Hypothesis

HIV knowledge is associated with HIV status, age, sex, geographical zone of origin and level of education.

## 5. Objectives

- 1. Identify if HIV knowledge is associated with HIV status, age, sex, country of origin and level of education.
- 2. Determine the level of knowledge in relation to HIV and AIDS.

## 6. Method

6.1 Study design

Quantitative

Descriptive

Association

Transversal

## 6.2 Variables [ANNEX 2]

**Dependent Variable** 

# Level of Knowledge

Conceptual definition: Level of knowledge is how much the participant understands about HIV transmission and effects.

Operational definition: Quantitative, continuous variable measured using the brief HIV knowledge questionnaire [70]. There are 10 dichotomous questions with the answer 'yes' or 'no'. For each correct question, the participant will receive one point. The overall mean will be calculated to determine the mean level of knowledge in the target population. The mean level of knowledge will also be calculated within each group in order to be able to

compare levels of knowledge between the groups.

## Independent variables

## Age

Operational definition: Qualitative, ordinal variable with 8 categories defined as less than 15, 15-20, 21-25, 31-35, 36-40, 41-45, 46-50 or more than 50 years old.

#### Sex

Operational definition: Qualitative, nominal variable with dichotomous categories which are male or female.

## Geographical zone of origin

Operational definition: Qualitative, nominal variable based on the birth area of the participant. There are 10 categories which are North Africa/ Middle East, sub-Saharan Africa, Latin America, North America, South Asia, Oriental Asia, Australia and New Zealand, Caribbean, Western Europe or Eastern Europe.

#### Level of education

Operational definition: Qualitative, ordinal variable with 6 categories which are primary incomplete, primary complete, secondary incomplete, secondary complete, university incomplete and university complete

#### **HIV** status

Operational definition: Qualitative, nominal variable with dichotomous categories defined as HIV positive (a reactive result) or negative (a non-reactive result).

## 6.3 Population

The population will consist of people who come to perform a rapid HIV test in one of the 11 centres in Catalonia that offer free, confidential testing [ANNEX 3]. The centres do not require that the person have neither a health card nor a national insurance.

#### 6.4 Inclusion criteria

The study sample will consist of people who take the HIV rapid test, are at least 18 years old and speak Spanish, Catalan or English. Spanish and Catalan are the two official languages of Catalonia. The decision to include English as one of the inclusion criterion

was taken because in 2010, nearly 10% of the people having the rapid HIV test in one of the Barcelona centres were from Western Europe, Northern America or sub-Saharan Africa [15]. Some of the people attending the HIV centres may not speak Spanish or Catalan. The consent form for the HIV test exists in Spanish, Catalan and English. The potential participant volume may be increased by the use of English.

## 6.5 Exclusion criteria

Participants who are already known to be HIV positive prior to the HIV test will be excluded from the study as they may have taken specific measures to increase their knowledge.

## 6.4 Sampling and Sample

A convenience sample will be used within this study. The bias often associated with this type of sampling technique will be reduced as HIV-NGOs are known for the variety of people that access them [18]. The range of demographic variables will describe the characteristics of the population, also reducing the effect of bias. The sample will be representative of the population that attend the HIV-NGO's of Catalonia. To calculate a representative sample of the population attending the HIV-NGOs, the level of confidence will be set at 95% requiring a precision of 1.00. In 2010, 7,822 rapid HIV tests were performed in the HIV NGOs of Catalonia (N=7,822) [15]. In the program Epidat, a power of 80%, the minimum sample size needed is 324. This means 162 HIV negative participants and 162 HIV positive participants. However, the population needed for this study is finite and these calculations are based on an infinite population. Once corrected and adapted to a finite population, the population needed is 159 HIV positive participants and 159 HIV negative participants (n=318).

## 6.5 Setting

#### Catalonia

Catalonia is an autonomous Spanish community with a population of 7,535,251 inhabitants [71]. In 2010 [15], 7,822 people attended an HIV-NGO and performed a rapid HIV test in Catalonia. There are 11 HIV-NGOs in Catalonia where people can perform a rapid HIV test [ANNEX 3]. The distribution of the HIV-NGOs of Catalonia:

## Barcelona

Ambit prevenciò/Ambit Dona

Asociación Ciutadana Anti-SIDA de Cataluña

Gais Positius

Jove d'Anticoncepció i Sexualitat

Projecte dels noms-Hispanosida (PDN) Checkpoint

Servicio de atencion y prevención sociosanitario Creu Roja (SAPS Creu Roja)

**StopSIDA** 

Girona

Associació comunitária anti-SIDA de Girona

Lleida

Asociación Anti-SIDA de Lleida

Tarragona

Actua Valles

Creu Roja Tarragona

The choice to use HIV-NGOs is deliberate. HIV-NGOs often receive a more varied population. As mentioned earlier, within Catalonia problems that immigrants face in regards to access to treatment are well documented [54] and the fear they may feel at approaching conventional health centres. Whilst anyone can request an HIV test in the emergency room, people without a National Health card are unable to request an HIV test in a centre of primary health in Catalonia. This may discourage people who do not have a health card from requesting an HIV test in a conventional health setting. There is also the possibility of people who would rather perform an HIV test in an anonymous setting that is not associated with their family doctor [18,19].

## 5.6 Instruments

Three instruments will be used in the collection of data.

'Monitoring diagnosis of HIV in Catalonia' Sheet

This is a form from CEEISCat [ANNEX 1]. Every person that comes to perform an HIV test is asked to answer a series of questions referring to their demographic details and behavior. The answers are then transferred onto this sheet with a code attached to maintain the anonymity of the person. While the answering of these questions is encouraged, it is not obligatory. However, 100% of people choose to answer the questions [15]. The form covers a range of questions in regards to the person receiving the HIV test. This data is taken by the technician who performs the test. One of the sheets goes to

CEEISCat and the other remains in the HIV-NGO. For this study, the copy that remains in the HIV-NGO will be used to retrieve data on the age, sex, zone of geographical origin and HIV status of the participants.

#### Level of education

Level of education is the only socio-demographic variable that is not measured on the CEEISCat form. This qualitative variable will be collected on the same sheet that will be used for the brief HIV knowledge questionnaire [ANNEX 4] with the permission of the HIV-NGO involved. The participant will complete the level of education form. The professional performing the test will be asked to give the code that relates to the CEEISCat form to the participant.

## HIV-Knowledge Scale

Participants will complete the self-administered Spanish version of the brief HIV/AIDS knowledge scale by Espada et al. [70] [ANNEX 4]. It is a 10 item self-administered questionnaire with 'True' or 'False' questions. The 10 items are distributed across 3 major factors. To calculate the total rate for each participant, one point will be added when the answer is 'True' in items 5 and 8, and 1 point will be added when the answer is 'False' for items 1,2,3,4,6,7,9 and 10. The mean score will be calculated for the each participant, each demographic groups and in total. The three major factors are HIV oral transmission, HIV effects and other HIV transmission methods. The brief HIV-Knowledge Scale is invariant across sex and age and shows good validity and internal reliability. HIV-Knowledge Scale is a capable and useful scale self-report scale for assessing main aspects of HIV/AIDS related knowledge. Cronbach's coefficient is high at 0.70 [70]. The HIV-Knowledge Scale is brief which makes it easy and quick to assess the participants' level of knowledge while not lengthening the session or taking the focus off the primary function of the session which is to let the technician perform the rapid HIV test and educate the participant. The knowledge studies in the Spanish population that currently exist, usually use non-standardized questionnaires [22]. While they generate useful information about the level of knowledge, they have unknown psychometric guarantees [70].

The scale measures the independent variable which is the level of HIV knowledge. Permission will be asked of the authors before using the scale in this study.

## 6.7 Data collection

The lead investigator will go to each HIV-NGO involved in the study and explain to the coordinator the aims and duration of the study. The information sheet and informed consent forms [ANNEX 5] will be given. If they agree to participate, the lead investigator will hold a meeting with each of the technicians that perform rapid HIV tests in the HIV-NGOs. During this meeting, the aims, duration and what would be expected of them would be explained. They would be given the information sheet to clarify and the informed consent to sign [ANNEX 6].

The participant will be given the information sheet and informed consent sheet [ANEXO 7] by the person who will perform the rapid HIV test or the receptionist (depending on the HIV-NGO that they are in). Once the participant agrees, they will be asked to complete the HIV knowledge scale and their level of education [ANEXO 4]. Once they complete this, they will be asked write a code on the informed consent form, the knowledge and education sheet and put both of these into an envelope and then put the envelope into a locked box that will be provided for the HIV-NGOs. The contents of the locked box will not be available to anyone except the lead investigator.

It is vital that the HIV knowledge questionnaire is complete before the HIV counselling and testing session begins as HIV knowledge acquired during the session would bias the results of this study. Also, it would not be appropriate to ask participants who have just learnt of their HIV status to fill out a questionnaire.

The technician performing the test will be asked to give the code to the participant so that they can write it on the level of education and the HIV knowledge sheet. This is so the researchers can identify the participant while their HIV session remains anonymous to the technician and the HIV-NGO performing the test. The code that the technician gives to the participant will correspond to the code from the demographic sheet from CEEISCat [ANEXO 1]. Currently, CEEISCat sheet includes a carbon copy. One sheet goes to the CEEISCat and the other stays in the NGO. With the permission of the HIV-NGO involved, the lead investigator would go to each centre involved in the study and collect the age, gender and country of origin of each participant, using their code.

The lead investigator will collect the contents of the locked box once a week and at the same time collect the information from the CEEISCat sheet about the age, gender, country of origin and HIV status of the participant. In the CEEISCat form there is a part requesting the details of the confirmation of the HIV test. Only once this part is completed will the participant be considered HIV positive.

# 6.8 Statistical analysis

The data that is obtained will be entered into the statistical program SPSS 18.0. Descriptive analysis will be used to discover the data distribution. For qualitative data, frequencies and percentages will be calculated and for the quantitative data, the mean and standard deviation will be calculated. The ANOVA test will be used to assess the association between the level of HIV knowledge as the dependent variable and age, gender, country of origin and level of education. This calculation will demonstrate if there is a significance between HIV knowledge and the afore mentioned variables. Statistical difference will be set at p < 0.05.

Once the data has been collected lineal mixed model will be applied.

## 7. Ethical Considerations

The project will be sent to the Spanish Board of Ethics for approval. Participants will be recruited when they come to perform a rapid HIV test in one of the centres in Catalonia that offer free, confidential testing. An informative document with the details of the study will be taken to each institution and then if they agree to participate an informed consent will be signed [ANEXO 5]. The technicians performing the rapid HIV test will also be asked to read and sign an information sheet and informed consent form [ANEXO 6]. Each participant will be given the information sheet and informed consent [ANEXO 7] if the participant signs, they will be given a the HIV-KS to complete and place in an envelope. This ensures that the technician does not have identifying details of the participants and the HIV test remains anonymous. One copy of the informed consent will be kept by the researchers and another will be retained by the participant, the technician or the HIV NGO.

One of the advantages to going to an HIV-NGO is that it is anonymous. Within this study, the anonymity of the participant should be maintained in order to ensure that the disclosure of their identity is not a deterrent to performing the HIV test or participating in

this investigation.

Participants will be asked by the person performing the HIV test if they would mind participating in a study related to their level of HIV knowledge. They will fill out the form before the HIV session begins in order to get an accurate knowledge level and ensure that the knowledge that the person has, has not been gained from the HIV session with the professional that has performed the test.

Participants receiving a positive test result are offered counselling and referred to either Hospital Clinic, Barcelona or Hospital Universitari Germans Trias I Pujol, Barcelona for a confirmatory test.

The locked box in the room where the HIV test is preformed will ensure that the name of the person is not available to the people performing the HIV test, this is essential in maintaining the anonymity of the participant in regards to their HIV counselling and test session.

## 8. Limitations

The person may receive HIV information in the 15 minutes while they are waiting for their HIV test. This may mean that they have a higher level of knowledge before they entered the HIV-NGO.

## 9. Chronograph

		Months																													
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Write proposal and forms																														П	
Defend and revise proposal																														П	
Review board approval																														П	
Equiptment gathering and notification of clinics																															
Establish potential subject notification at the clinics																														П	
Data collection																														$\Box$	
Analyse data																														П	
Interpret results																														П	
Communicate findings																															
Write-up																														П	
Final defense																														$\Box$	

## 10. Implications for practice

 If significant differences are found between groups, implicates the need for increase in knowledge in various groups and vigilance of inequalities in HIV

#### education

- Change in the perception of risk groups or who is targeted in interventions to increase HIV knowledge
- Potential recognition of HIV knowledge levels as central part of HIV surveillance systems
- Potential emphasis on motivation in addition to only information
- Potential focus on HIV education rather than HIV knowledge. If it is discovered that
  there are high level of knowledge in the people with a positive result, it is possible
  to emphasis life skills within the HIV-NGOs

## What is currently known

- HIV Knowledge is an essential part of HIV prevention
- HIV Knowledge varies between demographic groups
- Whilst HIV knowledge is important, it is not always enough to promote behavioural change.
- The population attending HIV-NGOs is increasing in Catalonia

## What this study would add

- If the population receiving an HIV positive status, have higher or lower levels of HIV knowledge than the population receiving an HIV negative status.
- The HIV educational needs of the populations receiving HIV tests in the HIV-NGOs of Catalonia.

## Further study

A study that would discover and analyse the level of HIV knowledge in all newly diagnosed people with HIV would provide much needed information about which areas of knowledge are lacking in this population. This may affect future prevention interventions and the care of HIV individuals.

Although the source of HIV knowledge is not a subject that will be covered in this research, evidence shows that knowledge derived from family members and friends is more significant that HIV intervention programs [31]. This information may be applied when designing HIV prevention interventions in the future.

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# **ANNEX 1: CEEISCat Monitoring of HIV infections in Catalonia**

Generalitat de Catalunya Departament de Salut Direcció General de Salut Pública	Centre d'Estudis Epidemiològ sobre les Infleccions de Trans Sexual i Sida de Catalunya		Full número:# 0377  Centre:  Data d'emplenament del ful
Monitoratge del diagnòstic d'infecció pel virus de la immunodeficiència humana ( Formulari de petició de la detecció voluntària dels anticossos anti-VIH. Recollida d'inform		les instruccions al dors	dia mes any
. Dades del sol·licitant:		-1	
nicials cognoms : Data de naixement:		Sexe:	lome ☐ Dona ☐ transsexual/travesti
1r. 2n. dia mes any			
Si no na nascut a Espanya)		- A	ny d'arribada a Espanya:
. Motiu per sol·licitar el test:			
Percepció d'exposició de risc al VIH ( <u>duran</u> t els darrers 3 mesos) Quina: Percepció d'exposició de risc al VIH ( <u>anterior</u> als darrers 3 mesos) Quina Estava en el "periode de finestra" en el meu test anterior Manifestacions cliniques/indicació mèdica Només per conèixer el meu estat de salut		☐ Abans de l'en ☐ Cribratge pre	ella em demana la prova nbarás/preconcepció inatal: abans del part nar el preservatiu com a mètode de barrera
. Realització del test VIH anteriorment:			
S'ha fet el test alguna altra vegada? Si Duantes vegades? Data de l'últir No No ho sap / No respon	ma prova:   _  _  mes	any	Resultat de l'última prova: □ Positiu □ Negatiu □ No ho sap / No respon
En quin tipus de centre s'ha realitzat l'última prova ?			
□ En altre centre alternatiu (ONG) □ En xarxa pública (CAP,	Hosp.,etc)	centre privat	n altres
i. Informació epidemiològica sobre el sol·licitant:			
Prientació i conducta sexual:	☐ Bisexual	□ No procedeix	(nens,)
	No respon		
	de parelles (amb penetració)		
Is de preservatiu a la darrera relació sexual amb penetració?		□ No	□ No ho sap / No respon
Ha tingut relacions sexuals amb persones del seu mateix sexe		□ No	□ No ho sap / No respon □ No ho sap / No respon
Ha mantingut relacions amb la finalitat d'obtenir diners o drogues (prostitució al darrer : Ha estat internat en un centre penitenciari <u>alguna vegada</u> ?:	Si	□ No	☐ No ho sap / No respon ☐ No ho sap / No respon
Ha rebut tractaments amb sang/hemoderivats: En quin any i país?:		□ No	□ No ho sap / No respon
i. Informació epidemiològica sobre les parelles del sol·licitant:			
la tingut relacions sexuals <u>amb penetració</u> amb alguna(es) de les següents perso	nes en el darrer any?		
Persones bisexuals: Persones que tenen contactes sexuals múltiples:		□ No	☐ No ho sap / No respon ☐ No ho sap / No respon
Persones que exerceixen la prostitució:		□ No □ No	☐ No ho sap / No respon
Persones usuaries de drogues per via intravenosa:  Persones infectades pel VIH:		□ No	□ No ho sap / No respon □ No ho sap / No respon
. Ús de drogues per via parenteral:			
dguna vegada ha consumit drogues injectades per via parenteral?			
Si Data última vegada:               No mes any	Al darrer consum, va co	mpartir material d'inj	ecció (xeringues, agulles, culleres, etc.)
No ho sap / No respon	□ Si	□ No	□ No ho sap / No respon
. Infecció pel virus de l'hepatitis B (VHB) i virus de l'hepatitis C (VHC)	-		
"ha vacunat contra la VHB amb tres dosis com a mínim:	🗆 Si	□ No	□ No ho sap / No respon
stà o ha estat infectat amb el virus de l' Hepatitis B :	🗆 Sí	□ No □ No	□ No ho sap / No respon □ No ho sap / No respon
Diagnòstic actual d'infecció pel VIH:			
	esultat prova confirmatòri. Positiu □ Negatiu □ des		persona ha tornat a recollir el resultat?
□ Estàndard □	Positiu		□ Sí □ No
. Cribratge d'infecció per la sífilis:			
Data de l'obtenció de la mostra: Test ràpid:	reactiu		netge l'ha confirmat com a:
	NO reactiu	sífilis primària	a 🛘 sífilis secundària

# **ANNEX 2: Study Variables**

ANNEX 2: Sti		I	
Variable	Type of variable	Instrument of measurement	Groups
Age	Qualitative, ordinal	CEEISCat demographics form	1. <15 2. 15-20 3. 21-25 4. 31-35 5. 36-40 6. 41-45 7. 46-50 8. >50
Sex	Qualitative, nominal	CEEISCat demographics form	1. Male 2. Female
Geographic zone of origin	Qualitative, nominal	CEEISCat demographics form	<ol> <li>North Africa/Middle East</li> <li>Sub-Saharan Africa</li> <li>Latin America</li> <li>North America</li> <li>South Asia</li> <li>Oriental Asia</li> <li>Australia and New Zealand</li> <li>Caribbean</li> <li>Western Europe</li> <li>Eastern Europe</li> </ol>
Level of education	Qualitative, ordinal	Level of education sheet	1. Primary incomplete 2. Primary complete 3. Secondary incomplete 4. Secondary complete 5. University incomplete 6. University complete
HIV Status	Qualitative, nominal	Determine HIV- 1/2 test	Reactive (Positive) Non-reactive (Negative)
HIV Knowledge	Quantitative, continuous	Brief HIV Knowledge Scale	N/a

# **ANNEX 3: HIV-NGOs in Catalonia**

# <u>Barcelona</u>

Actua Valles:

Passeig de Gaudí, 31,

08203, Sabadell

Ambit prevenciò/ Ambit Dona:

Calle St. Rafael, 16 local,

08001, Barcelona

Asociación Ciutadana Anti-SIDA de Cataluña:

Calle la Lluna, 11 local,

08001, Barcelona

Gais Positius:

Calle Violant d'Hongaria, 156 bajos,

08014, Barcelona

Centre Jove d'Anticoncepció i Sexualitat:

Calle la Granja, 19-24,

08024, Barcelona

Projecte dels noms-Hispanosida (PDN) Checkpoint

Calle Compte Borrel, 164-166,

08015, Barcelona

Servicio de atencion y prevención sociosanitario Creu Roja (SAPS Creu Roja)

Avenida Drassanes, 13-15,

08001, Barcelona

**StopSIDA** 

Calle Muntaner 121, entresuelo 1ª

08036, Barcelona

## Girona

Associació comunitária anti-SIDA de Girona (ACAS)

Plaça San Ponç 9, 4º2a,

17007, Girona

### <u>Lleida</u>

Asociación Anti-SIDA de Lleida Calle Iluis Besa 17, bajos, 25002, Lleida

### <u>Tarragona</u>

Creu Roja Tarragona Avenida Andorra 61, local 43002, Tarragona

## ANNEX 4: Brief HIV knowledge questionnaire and level of education for the participants



Cuestionario del estudio "Evaluación de los conocimientos del VIH y su asociación con el estatus del VIH en la población que acude las ONG para realizarse la prueba rápida del VIH"

Dirigido por: Stephanie Ejegi-Memeh Universidad Internacional de Cataluña

Código del cuestionario:	
--------------------------	--

Código del cuestionario : .....

Fecha de cumplimento: .....

Apreciado/a Sr./ Sra.

El motivo del presente es comunicarle el interés de su colaboración en un estudio de asociación cuyo objetivo principal es conocer el nivel de conocimientos en la población que acude a las ONG para realizarse la prueba rápida del VIH en Cataluña.

El diseño de dicho estudio tiene un tamaño muestral de 318 individuos que acuden a las organizaciones non-gubernamentales de Cataluña a realizarse dicha prueba. Se complementará un documento que tiene 10 preguntas sobre su nivel de conocimiento de VIH y su nivel de educación. Una vez haya cumplimentado dicho documento, deberá introducirlo en un sobre junto al consentimiento informado. El técnico encargado de realizar la prueba proporcionará un código que el participante escribirá en un sobre y seguidamente lo depositará en una caja cerrada bajo llave ubicada en la sala donde se realizará la aprueba.

Los datos relativos a su edad, sexo, país de origen y resultados de la prueba serán recogidos en una hoja de registro obligatorio que el técnico encargado de realizar la prueba deberá cumplimentar. Al final de la sesión, el técnico encargado de realizar la prueba archivará la hoja con sus datos garantizando su anonimato.

El estudio es confidencial y voluntario tanto para los participantes como para las organizaciones non-gubernamentales .

Sra. Stephanie Ejegi-Memeh Investigadora principal Universidad Internacional de Cataluña Apreciado/a Sr./Sra. le solicito que se marque con un cruce en la caja de la respuesta correcta.

### Conocimientos del VIH (V O F)

	<u>Verdad</u>	<u>Falso</u>
1. Bebiendo de un vaso que ha sido utilizado de	e $\Box$	
una persona con VIH representa un riesgo		
2. Es peligro compartir comida o bebida de una	l	
persona con VIH.		
3. Dar un beso mojado a una persona con VIH		
es un riesgo de la transmisión del VIH.		
4. El periodo de ventana dura una semana.		
5. El periodo de ventana es el periodo		
necesario por el cuerpo se produce		
anticuerpos después de la transmisión del		
VIH.		
6. La gente que se ha sido infectado por el VIH		
pasan un tiempo asintomática de 6 meses.		
7. El VIH se transmite a través del aire.		
8. El VIH se transmite a través de secreciones		
vaginales, semen y sangre.	П	П
9. Es aconsejable dejar de visitar une persona	_	_
que tiene el VIH para prevenir la transmisión		
del VIH.	П	П
10. Lavando la ropa con ellas de una persona	_	
con el VIH o SIDA implicar un riesgo de		
contraer la enfermedad.	П	П

<u>Nivel de educación</u>	
Primaria incompleta	
Primaria completa	
Secundaria incompleta	
Secundaria completa	
Universitarios incompletos	
Universitarios titulación grado, medio o superior	

# ANNEX 5: Information sheet and informed consent. HIV-NGO Documento informativo y solicitud de consentimiento informado para las instituciones

Sr/a	
Responsable de la entidad "	,,
Asunto: Solicitud de autorización para real	lizar un estudio transversal.

Evaluación de los conocimientos del VIH y su asociación con el estatus del VIH en la población que acude a las ONGs para realizarse la prueba rápida del VIH en Cataluña

#### **Descripción**

La Universidad Internacional de Cataluña quiere llevar a cabo un estudio de investigación que va dirigido a personas que acuden a las ONGs para realizarse la prueba rápida del VIH en una de las 11 organizaciones nogubernamentales de Cataluña.

#### Objetivos

El estudio va a describir el nivel de conocimientos sobre el VIH entre la población que acude a las ONG para realizarse la prueba rápida del VIH. Quiere descubrir los factores asociados con el nivel de conocimiento del VIH. Otros factores incluidos son edad, sexo, zona geográfica de origen, nivel de educación y estatus del VIH.

#### Recogida de datos

Hay tres recogidas de datos en este estudio. El primero será la breve escala de conocimientos sobre el VIH que el participante rellenará en un cuestionario. El segundo será el nivel de educación que el participante también pondrá en el cuestionario. El tercero y último serán datos sobre la edad, el género, la zona de origen y el estatus del VIH. Estos datos serán recogidos por un miembro del equipo de investigación de la hoja de CEEISCat. Para rellenar el cuestionario y tomar nota del nivel de los estudios de la participante necesitará aproximadamente 5 minutos. El participante tiene que poner el consentimiento informado, la escala de conocimientos y el nivel de educación en un sobre que se introducirá en una caja cerrada con llave, proporcionada por el equipo de investigación.

#### Participación

La participación es completamente voluntaria y se puede rehusar una vez iniciado el estudio. Esta última decisión y la no participación en el estudio no afectará a su institución.

#### Riesaos

Este estudio no contiene ningún riesgo asociado.

#### **Reneficios**

Este estudio no contiene directamente ningún beneficio por su participación, pero sí que servirá como base de otros estudios que podrán ayudar a identificar

el nivel de conocimientos en la población que viene hacerse la prueba.

#### Confidencialidad

Los datos que se pueden obtener serán manejados confidencialmente, es decir, la identidad del participante no será revelada en ningún informe según la Ley 27/2.000 del 20 diciembre de la Generalitat de Catalunya. La prueba sigue siendo anónima porque la institución y los técnicos no tiene acceso al nombre del participante.

Si le interesa, la investigadora Stephanie Ejegi-Memeh le enviará un informe final del estudio y le contestará cualquier duda que tenga. Si desea más información sobre el estudio puede ponerse en contacto con la investigadora en el siguiente número de teléfono 638133276.

Sra. Stephanie Ejegi-Memeh Investigadora principal de la UIC

#### **Consentimiento Informado**

Mi

firma

en

este

He leído el documento informativo sobre el estudio titulado *Evaluación de los* conocimientos del VIH y su asociación con el estatus del VIH en la población que acude a las ONGs para realizarse la prueba rápida del VIH en Cataluña, y la institución ha decidido participar en el estudio de forma voluntaria.

He entendido que la institución tiene derecho a abstenerse de participar o retirarse del estudio en cualquier momento, sin perjuicio alguno para la institución. La institución tiene el derecho a recibir una copia de esta documentación.

Si la institución tiene alguna pregunta puede comunicarse con la investigadora principal, Stephanie Ejegi-Memeh en el siguiente número 638133276.

documento

significa

que

discutido y entendid del estudio.	ha decidido participar d lo la información presentada en e	lespués de haber leído, el documento informativo
Fecha	Nombre del representante de la institución	Firma
 Fecha	Nombre de la investigadora	 Firma

la institución

## ANNEX 6: Information sheet and informed consent: Technicians Documento informativo y solicitud de consentimiento informado para los técnicos que hacen la prueba rápida

Evaluación de los conocimientos del VIH y su asociación con el estatus del VIH en la población que acude las ONG para realizarse la prueba rápida del VIH en Cataluña

#### Descripción

La Universidad Internacional de Cataluña quiere llevar a cabo un estudio de investigación que va dirigido a personas que acuden a las ONGs para realizarse la prueba rápida del VIH en una de las 11 organizaciones no-qubernamentales de Cataluña.

#### **Objetivos**

El estudio va a describir el nivel de conocimientos sobre el VIH entre la población que acude las ONG para realizarse la prueba rápida del VIH. Quiere descubrir los factores asociados con el nivel de conocimiento sobre el VIH. Otros factores incluido son edad, sexo, zona geográfica de origen, nivel de educación y estatus del VIH.

#### Recogida de datos

Hay tres recogidas de datos en este estudio. El primero será la breve escala de conocimientos sobre el VIH que el participante rellenará en un cuestionario. El segundo será el nivel de educación que el participante también pondrá en el cuestionario. El tercero y último serán datos sobre la edad, el género, la zona de origen y el estatus del VIH. Estos datos serán recogidos por un miembro del equipo de investigación de la hoja de CEEISCat. Rellenar el cuestionario y tomar nota del nivel de educación de la persona necesitará aproximadamente 5 minutos. Una vez el participante decida que quiere participar, usted tiene que darle el código que corresponde con la hoja del CEEISCat.

#### **Participación**

Su rol será el de proporcionar el documento informativo, el consentimiento informado, el código de la la hoja de CEEISCat y el cuestionario al participante. Su participación es completamente voluntaria y puede rehusar continuar una vez iniciado el estudio. Esta última decisión y la no participación en el estudio no afectará a sus derechos.

#### Riesgos

Este estudio no contiene ningún riesgo asociado.

#### **Beneficios**

Este estudio no contiene directamente ningún beneficio por su participación, pero sí que servirá como base de otros estudios que podrán ayudar a identificar el nivel de conocimientos en la población que viene hacerse la prueba.

#### Confidencialidad

Los datos que se pueden obtener serán manejados confidencialmente, es decir, la identidad del participante no será relevada en ningún informe según la Ley 27/2.000 del 20 diciembre de la Generalitat de Catalunya.

Si le interesa, la investigadora Stephanie Ejegi-Memeh le enviará un informe final del estudio y le contestará cualquier duda que tenga. Si desea más información sobre el estudio puede ponerse en contacto con la investigadora en el siguiente número de teléfono 638133276.

Sra. Stephanie Ejegi-Memeh Investigadora principal de la UIC

#### **Consentimiento Informado**

He leído el documento informativo sobre el estudio titulado *Evaluación de los* conocimientos del VIH y su asociación con el estatus del VIH en la población que acude las ONG para realizarse la prueba rápida del VIH en Cataluña, y decido participar en el estudio de forma voluntaria.

Entiendo que tengo el derecho a abstenerse de participar o retirarme del estudio en cualquier momento, sin perjuicio alguno para mi persona. Así mismo tengo derecho a recibir una copia de esta documentación.

Si tengo alguna pregunta puedo ponerme en contacto con la investigadora principal, Stephanie Ejegi-Memeh al siguiente número 638133276.

Mi firma en este documento significa que he decidido participar después de haber leído, discutido y entendido la información presentada en el documento informativo del estudio.

Fecha	Nombre del técnico	Firma
Fecha	Nombre del investigadora	Firma

## ANNEX 7: Information sheet and informed consent. Participant Documento informativo y solicitud de consentimiento informado para los participantes

Código:
---------

Documento informativo y solicitud de consentimiento informado para la gente que acude a hacerse la prueba rápida del VIH

Evaluación de los conocimientos del VIH y su asociación con el estatus del VIH en la población que acude las ONG para realizarse la prueba rápida del VIH

#### **Descripción**

La Universidad Internacional de Cataluña quiere llevar a cabo un estudio de investigación que va dirigido a personas que acuden a las ONGs para realizarse la prueba rápida del VIH en una de las 11 organizaciones nogubernamentales de Cataluña.

#### Objetivos

El estudio va a describir el nivel de conocimientos sobre el VIH entre la población que acude a las ONG para realizarse la prueba rápida del VIH. Quiere descubrir los factores asociados con el nivel de conocimiento del VIH. Otros factores incluidos son edad, sexo, zona geográfica de origen, nivel de educación y estatus del VIH.

#### Recogida de datos

Hay tres recogidas de datos en este estudio. La primera será una evaluación sobre conocimientos del VIH, que contiene 10 preguntas sobre el VIH y que usted deberá rellenar en un cuestionario. La segunda serán datos sobre su educación que usted pondrá en el mismo cuestionario. El tercero y último serán datos sobre la edad, el sexo, la zona de origen y el estatus del VIH. Estos datos serán recogidos por un miembro del equipo de investigación de la hoja de CEEISCat, la misma persona que le realizará la prueba. Rellenar el cuestionario y poner los datos del nivel de educación necesitará aproximadamente 5 minutos. Usted deberá poner el consentimiento informado, la escala de conocimientos y el nivel de educación en un sobre y poner éste en una caja cerrada con llave.

#### Participación

La participación es completamente voluntaria y se puede rehusar una vez iniciado el estudio. Esta última decisión y la no participación en el estudio no afectará a la asistencia que recibe.

#### Riesgos

Este estudio no contiene ningún riesgo asociado.

#### **Beneficios**

Este estudio no contiene directamente ningún beneficio por su participación, pero sí que servirá como base de otros estudios que podrán ayudar a identificar el nivel de conocimientos en la población que viene hacerse la prueba.

#### Confidencialidad

El técnico y la institución que realizará la prueba no van a tener acceso a sus datos personales. Los datos obtenidos serán manejados confidencialmente, es decir, su identidad no será revelada en ningún informe según la Ley 27/2.000 del 20 de diciembre de la Generalitat de Catalunya.

Si le interesa, la investigadora Stephanie Ejegi-Memeh le enviará un informe final del estudio y le contestará cualquier duda que tenga. Si desea más información sobre el estudio puede ponerse en contacto con la investigadora en el siguiente número de teléfono 638133276.

Sra. Stephanie Ejegi-Memeh Investigadora principal de la UIC

#### **Consentimiento Informado**

He leído el documento informativo sobre el estudio titulado *Evaluación de conocimientos del VIH y su relación en la población asistir a las organizaciones non-gubernamental para hacerse la prueba rápida en Cataluña*, y decido participar en el estudio de forma voluntaria.

Entiendo que tengo el derecho a abstenerse de participar o retirarme del estudio en cualquier momento, sin perjuicio alguno para mi persona. Así mismo tengo derecho a recibir una copia de esta documentación.

Si tengo alguna pregunta puedo ponerme en contacto con la investigadora principal, Stephanie Ejegi-Memeh al siguiente número 638133276.

Mi firma en este documento significa que he decidido participar después de haber leído, discutido y entendido la información presentada en el documento informativo del estudio.

Fecha	Nombre de la participante	Firma
Fecha	Nombre de la investigadora	Firma

#### <u>Acknowledgments</u>

This research project would not have been possible without the support of many people. Firstly, I wish to express my gratitude to my supervisor, Dr. Albert Gallart Fenández Puebla who has continuously offered invaluable assistance, support and guidance in a wonderfully professional manner. My deepest gratitude is also due to many other members of the International University of Catalonia without whose knowledge, experience, time and assistance I would have been lost.

Special thanks also to all my Masters colleagues for sharing literature, assistance and the experience with me. Not forgetting my friends outside of the university who have helped me get through this project in a more indirect, but just as valuable, way.

I also wish to express my love and gratitude to my beloved family; for their understanding & endless love throughout the duration of my studies and life.

I would like to end by thanking the many people living with HIV who share their experiences with me allowing me to keep discovering new areas of research in order to improve HIV prevention and care.

Thank-you.