

# Comparing the Information and Support Needs of Different Population Groups in Preparation for 2014 Government Approval for HIV Self-testing in France



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## Introduction

HIV self-tests are due to be approved in France in 2014 with the aim of facilitating screening both for the general population and for high risk populations.

As in most western European countries, HIV prevalence in France is still high in several population groups including men who have sex with men (MSM), drug users, transgender people and immigrant communities from Sub-Saharan Africa.

**Objectives:** In the context of a study aiming to identify the information and support needs of the general population and the different higher risk groups concerning the use of HIV self-tests, the current presentation places a particular focus on the needs of MSM and substance users with regard to these tests.



Source: Pr François Simon, Saint Louis, Paris  
Hundreds of HIV self-tests, many of doubtful quality, are currently available on the Internet.

## Methods

- Experts working in eight parallel groups participated in a three-round Delphi process, conducted on the Internet. Each group developed recommendations for a specific population:
  - Six high HIV prevalence populations: MSM, transgender people, drug users, migrants from sub-Saharan Africa, French West Indies, Guyana;
  - Two low prevalence populations: people under 25, the general population.
- Each group included:
  - Expertise from four areas: policy-making, research, community groups, screening and care.
  - A broad geographical representation: the Greater Paris Area (*Région Ile-de-France*) / the other provinces (apart from the two expert groups specifically addressing the two overseas French departments).

A three-round Delphi process was conducted with each group of experts:

**Round 1:** Experts were asked to propose ten or so statements which in their opinion constituted "good practice for responding to the information and support needs of HIV self-test users". For each factor proposed, experts were asked to explain briefly why they considered this to be important.

The final lists of factors for each expert group were then analyzed by two researchers using the following method:

- Factors that were identical or that used different words to describe the same phenomenon were grouped into one factor.
- Factors that covered more than one issue were divided into distinct entities.

The researchers took pains to respect each expert's nuances in describing his or her different recommendations, using as far as possible the terms and expressions chosen by the experts to formulate final versions of each recommendation. After the within-group analysis for each of the eight groups of experts, the same process was used to identify factors that were common to more than one expert group and to harmonize the terminology used across different groups.

**Round 2:** The complete list of factors identified by all the experts within each group were sent back to all the members of that group. Experts were asked to score each factor on a scale from 1 (not at all relevant) to 9 (highly relevant), with regard to the degree of importance they attributed to that factor for informing and supporting self-test users when the self-test comes onto the market in France. The mean score for each factor was then calculated as the group score for that factor for the group in question.

**Round 3:** Experts were invited to reconsider their scores, if they wished, in the light of the mean group score for each factor. A final list of factors with the highest mean scores was thus established for each of the eight population groups, with mean  $\geq 7$  as cut-off point.

## Results

Table 1. Number of experts and number of recommendations for each expert group

Expert group	N° experts	N° recommendations
General population	10	57
Young people	11	77
MSM	10	90
Sub-Saharan African migrants	10	66
Drug users	11	60
Transgender people	9	48
French West Indies	6	55
Guyana	5	43

From February to May 2014, a total of 72 experts participated to the study (Table 1).

The MSM expert group produced the highest number of recommendations, showing their interest and concern for the HIV self-test.

Using qualitative analysis methods as described above, a final total of 263 recommendations were aggregated into eight themes (Table 2). The number of recommendations reveals the diversity of propositions within each theme.

Table 2: The eight themes summarizing the experts' recommendations and the number of recommendations per theme

Themes	n	%
Communicating at national, community and population-specific levels concerning the self-test	62	24
Providing users with reliable, user-friendly and population-specific information on using the self-test	60	23
Providing quality support to users purchasing and using the test, and accessing care in the case of a positive result	40	15
Making self-tests available to different population groups in terms of accessibility and cost	35	13
Preparing community healthcare and existing screening support and information systems before the self-test comes onto the market	28	11
Commercializing only high quality self-tests	17	6
Defending self-test users' legal rights	13	5
Evaluating self-test use	8	3
<b>Total</b>	<b>263</b>	<b>100</b>

## Disagreements

Although a high level of within-group and between-group agreement was reached for many recommendations, significant disagreement occurred both within and between different groups:

- High discord levels within and among MSM, Sub-Saharan African migrants, General population, Young people and Guyana expert groups concerning wide access to self-test and mainly providing:
  - open access to self-tests for minors, with for example one expert in the young people's group explicitly stating he was opposed to any access whatsoever to HIV self-testing for minors.
  - self-tests free-of-charge in screening centers.
- Significant between-group disagreement about the nature of the test itself :
  - MSM experts explicitly favored self-testing using blood ( $m=7.3$ ), arguing that (a) blood tests would be perceived by the general public as being more reliable, (b) oral "saliva" testing would favor the ongoing false belief that HIV is to be found in the saliva, and (c) talking about "saliva" rather than "cravicular liquid" would be a sure source of errors.
  - The young people's experts, to the contrary, favored oral testing ( $m=7.0$ ), considering it to be more acceptable for the population in question.

## Results

The mean score for each recommendation indicates the importance attributed to that recommendation by the group of experts, a score  $\geq 7$  meaning "relevant" (Table 3).

Table 3. Recommendations (mean score  $\geq 7$ ) common to at least four groups of experts and, for each recommendation, overall mean score for all groups, and means for MSM and drug user groups.

Recommendations	N° groups	Total mean score (std)	Mean score MSM	Mean score Drug Users	Themes
The instructions need to describe the steps that should be taken after a positive test result.	7	8.9 (0.1)	8.9	8.6	Informing
The instructions on how to use the self-test and how to interpret test results need to be clear and comprehensible for all users.	8	8.6 (0.3)	8.9	8.2	Informing
Support service that is able to refer the person who discovers a positive result towards well-identified support and care services	4	8.5 (0.4)	8.4		Supporting
The instructions include information on how to access 24h/7 free-of-charge telephone support on using the self-test, similar to that currently provided by Sida Info Service (AIDS Info Service, a government-funded hotline in providing information and support on HIV/AIDS in France).	5	8.4 (0.6)	8.8	7.7	Informing
The instructions should indicate how to interpret a negative result and understand the implications of testing during the seroconversion window period.	8	8.3 (0.5)	8.1	8.0	Informing
The instructions should promote benefits to be aware of one's seropositivity, and this as soon as possible. An optimistic approach of life with HIV and care	4	8.3 (0.7)		7.7	Informing
A moderate and accessible price for all.	7	8.2 (0.6)	8.6	8.8	Accessibility
A test that is easy to handle.	4	8.2 (0.6)	7.5		The test
The instructions should use pictograms.	7	8.1 (0.6)	7.9	7.4	Informing
Evaluate HIV self-test use	4	8.1 (0.6)	7.8		Evaluating
Access to self-tests at a reasonable price or free-of-charge for population groups with high HIV risk.	5	8.0 (0.8)	6.2	8.2	Accessibility
Public information concerning self-tests should be part of a general campaign promoting HIV screening and situating self-tests as one of a number of available test options, all of which have their specific advantages.	5	7.9 (0.4)	8.0		Communicating
The instructions should include information on how to access community support and appropriate healthcare should the test result prove to be positive.	5	7.8 (1.0)	6.5	7.0	Informing
Prepare and train those who sell or distribute self-tests (drugstores, community organizations...) or who provide support in using self-tests.	6	7.8 (0.6)	6.6	7.8	Preparing
The instructions should make it clear that HIV cannot be transmitted by saliva but that the diagnosis can be made using saliva	4	7.8 (0.8)		6.9	Informing
Create a telephone hotline providing support on how to use the test, accessible 24h/7.	8	7.8 (0.9)	8.9	6.8	Supporting
Only use self-tests with CE marking (i.e. with European approval)	4	7.8 (0.2)	8.1	6.8	Informing
All information and instructions should be available in all foreign languages spoken in France, including in French overseas departments	4	7.7 (1.0)		7.7	Informing
Situate self-tests as a complementary strategy with regard to existing screening options.	6	7.7 (0.5)	7.9		Preparing
The instructions should underline the importance of using condoms and sterile equipment	4	7.6 (0.8)	6.8		Informing
Communicate with health professionals and community organizations ahead of communicating with the general public. Make health professionals aware of how the self-test will contribute to individuals' prevention strategies, its position with regard to other screening options and how best to access care if test results are positive.	5	7.3 (0.7)		7.8	Preparing
At the point of sale or distribution of self-tests, direct face-to-face counselling by trained professionals should be available	4	7.2 (0.9)			Supporting
Self-tests should be widely accessible, not just in drugstores.	5	7.2 (0.8)		7.2	Accessibility
Conduct campaigns promoting the self-test that target the different high-risk population groups, taking into account their specificities.	7	7.1 (0.6)	7.1	6.5	Communicating
The instructions should include general information on HIV, HIV transmission and prevention.	5	7.0 (1.2)		5.0	Informing
Self-tests available free-of-charge in screening centers, family planning centers, community organizations, services for people with substance abuse problems.	6	7.0 (1.3)	5.0		Accessibility

## Recommendations specific to the MSM and drug user expert groups

Table 4. Recommendations specific to the MSM expert group and scored highly relevant (mean score  $\geq 8$ )

MSM	Mean	SD
Prefer the most reliable tests (in terms of sensitivity and specificity).	8.9	0.3
The hotline should be managed by an independent organization with experience in delivering HIV/AIDS information	8.7	0.5
The result should be easy to read	8.7	0.5
Easy access for the general public at a price no higher than a standard EIA test	8.4	1.0
The instructions should explain how to proceed if the test result is invalid	8.4	1.0
For population groups such as MSM with high prevalence rates and multiple risk-taking, stress the importance of doing the test regularly, of repeating the test; place less focus on waiting until the end of the seroconversion window after taking a risk.	8.2	1.2
Communication and information about the HIV self-test should be government controlled and not run by the test manufacturing company	8.1	1.3
Inform users concerning early HIV acute infection symptoms and the greater risk of transmitting the HIV virus during this phase.	8.0	1.1

Some recommendations were specific to certain groups or shared with only one other group. Tables 4 and 5 present these more specific recommendations for the MSM and drug user expert groups.

MSM experts were highly sensitive to self-test reliability and the accuracy of the results.

They insisted on high quality support and information concerning the HIV self-test being provided by an independent source and not just by the manufacturer.

Table 5. Recommendations specific to the drug user expert group and scored highly relevant (mean score  $\geq 8$ )

Drug users	Mean	SD
With support from substance misuse community organizations, define and develop the tools necessary for promoting self-test use with this population group when the test comes onto the market and for providing support in using the self-test.	8.5	0.7
Train people who work with drug users to promote HIV self-test use.	8.5	0.9
Provide self-tests free-of-charge in services providing healthcare and support for people with substance misuse problems.	8.2	2.4
Accessibility throughout the country	8.4	1.6
HIV self-test should be available free-of-charge in all services working with substance users.	8.2	2.4
Adopt a community-led approach to HIV self-testing	8.2	0.8

Recommendations specific to the drug user expert group were centered around the necessary participation of community organizations and of professionals working with this marginalized population. The need for an active role for specialized structures is strongly emphasized.

## Conclusions

Results from the current study should make a significant contribution to policy decisions concerning catering for the specific access, information and support needs of different potential HIV self-test user groups when these tests become available in France at the end of 2014. Providing adapted access, information and support will contribute to facilitating screening both for people from high risk groups and for the general population, as well as potentially making an inroad into the hidden epidemic in France by bringing in vulnerable populations that have until now been reticent to use standard testing options.

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