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

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# HIV self-test

- 2 steps performed by the users
  - Taking the sample
  - Analyzing the result
- 2012: oral self-test approved and onto the market in the US
- 2014: self-test no longer prohibited in the UK
- 2014 (Dec.): self-test expected to be approved for sale in France



Diapositive : François SIMON

Source: Pr François Simon, Hôpital Saint-Louis, Paris

# Growing literature on HIV self-tests

- Studies in industrialized and developing countries with oral/blood tests
- (+) Fast, convenient, anonymous
- (+) Promote user empowerment
- (-) Access to counselling and care
- (-) Test used coercively
- Lack of research on
  - Reasons for different populations to use HIV self-tests
  - Needs, perceptions, preferences and priorities with regard to HIV self-testing

Krause et al. BMC Public Health 2013, Pant Pai et al. Plos One 2013; Greensides et al. Public Health Rep. 2003; Carballo-Diéguez et al. AIDS and Behav 2012; Greacen et al. AIDS care 2012; Greacen et al. Sex Transm Infect 2012

# Objectives

- To identify the information and support needs concerning the use of HIV self-tests for
  - the general population
  - the different higher risk groups
- A particular focus on the needs, with regard to self-testing, of
  - MSM (men who have sex with men)
  - Drug users

## The selection of the experts

- A three-round Delphi process conducted on the Internet with each group of experts
- One group of experts by specific population
  - 6 high HIV prevalence populations: MSM; drug users; transgender people; migrants from sub-Saharan Africa; French West Indies; Guyana
  - 2 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 / the other provinces

# The Delphi Process

- Round 1: the question
  - “Propose ten or so statements which in your opinion constituted good practice for responding to the information and support needs of HIV self-test users from [population]. Explain briefly why you considered this to be important.”
- Qualitative analysis of the final lists of factors by two researchers
- Round 2: scoring
  - Each expert gives a score for all the recommendations produced by his/her group
  - A scale from 1 to 9 (not at all relevant - highly relevant)
- Round 3: confirmation of scoring
  - Experts reconsider their scores in the light of the mean group score

## The experts

- From February to May 2014, a total of 72 experts participated to the study

<b>Expert group</b>	<b>N° experts</b>	<b>N° recommen- dations</b>
General population	10	57
Young people	11	77
MSM	10	90
Sub-Saharan African community	10	66
Drug users	11	60
Transgender people	9	48
French West Indies	6	55
Guyana	5	43

## 263 recommendations in 8 themes

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

# 1. Communicating at national, community and population-specific levels concerning the self-test

Recommendations	N° grps	m (SD)	m MSM	m DU
→ 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	
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

m (SD) = mean score (standard deviation)  
 m ≥ 7 means relevant (min-max=1-9)

## 2. Providing users with reliable, user-friendly and population-specific information on using the self-test

Recommendations	N° grps	m (SD)	m MSM	m DU
→ 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
→ The instructions on how to use the self-test and how to interpret test results need to be clear and understandable for all users.	8	8.6 (0.3)	8.9	8.2
→ The instructions should include information on how to access 24h/7 free-of-charge telephone support on using the self-test	5	8.4 (0.6)	8.8	7.7
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
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
The instructions should use pictograms.	7	8.1 (0.6)	7.9	7.4

### 3. Providing quality support to users purchasing and using the test, and accessing to care in the case of a positive result

Recommendations	N° grps	m (SD)	m MSM	m DU
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	
→ Create a telephone hotline providing support on how to use the test, accessible 24h/7.	8	7.8 (0.9)	8.9	6.8
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)		

#### 4. Making self-tests available to different population groups in terms of accessibility and cost

Recommendations	N° grps	m (SD)	m MSM	m DU
A moderate and accessible price for all.	7	8.2 (0.6)	8.6	8.8
→ 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
Self-tests should be widely accessible, not just in drugstores.	5	7.2 (0.8)		7.2
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	

- Significant disagreements within and/or between groups
  - Open access to self-tests for minors
  - Self-tests free-of-charge

## 5. Preparing community healthcare and existing screening support and information systems before the self-test comes onto the market

Recommendations	N° grps	m (SD)	m MSM	m DU
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
Situate self-tests as a complementary strategy with regard to existing screening options.	6	7.7 (0.5)	7.9	
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

## 6. Commercializing only high quality self-tests

Recommendations	N° grps	m (SD)	m MSM	m DU
A test that is easy to handle	4	8.2 (0.6)	7.5	

- Significant between-group disagreement about the nature of the test
  - MSM experts explicitly favored self-testing using blood (m=7.3)
  - The young people's experts favored oral testing (m=7.0)

## 7. Defending self-test users' legal rights

Recommendations	N° grps	m (SD)	m MSM	m DU
Publish a specific legislative text underlining people's rights and duties with regard to HIV self-testing	3	6.7 (1.3)	6.6	8.1

## 8. Evaluating self-test use

Recommendations	N° grps	m (SD)	m MSM	m DU
Evaluate HIV self-test use	4	8.1 (0.6)	7.8	

## Recommendations specific to the MSM expert group

Recommendations scored highly relevant (mean score $\geq 8$ )	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 manufacturing company	8.1	1.3
Inform users concerning early HIV acute infection symptoms and the greater risk of transmitting the virus during this phase.	8.0	1.1

## Recommendations specific to the drug user expert group

Recommendations scored highly relevant (mean score $\geq 8$ )	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

# Conclusions

- High interest of experts for HIV self-testing
    - Many recommendations on informing, communicating and the contents of the instructions
  - High overall agreement
    - Casual disagreements on availability of self-tests
  - Certain recommendations specific to specific expert groups
    - Needs and preferences of specific population groups
    - Providing adapted access, information and support will contribute to facilitating screening
- Significant contribution to policy decisions concerning the 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

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## 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, the HIV prevalence in France is still high in several groups including 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 high-risk groups concerning the use of HIV self-tests, the current presentation poses a particular focus on the needs of MSM and substance users with regard to these tests.

### 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: men who have sex with men (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:
  - Experts from four areas: policymaking, research, community groups, screening and care.
  - A broad geographical representation: the Greater Paris Area (*Région Île-de-France*) / the other provinces (apart from the two expert groups specifically addressing the two overseas French departments).

All three round Delphi processes were 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 methods:

- 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 experts' 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 was 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 who self-test 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 57 as cut-off point.

### Results

The mean score for each recommendation indicates the importance attributed to that recommendation by the group of experts; a score of 7 meaning relevant (Table 5).

**Table 2: Recommendations (mean score > 7) on methods at least four groups of experts and mean scores for each recommendation for overall expert groups, and comparing MSM and drug user expert groups.**

Recommendation	N experts	Total mean score (SD)	MSM mean score (SD)	Drug user mean score (SD)	Theme
The instructions need to describe the steps that should be taken after a positive result	7	8.3 (0.1)	8.3	8.6	Informing
The instructions on how to use the self-test and how to interpret results need to be clear and comprehensible for all users	8	8.2 (0.1)	8.3	8.2	Informing
Support centers that do not refer the person who discovers a positive result to a specialist support center	4	8.2 (0.4)	8.4	8.0	Supporting
The instructions include information on how to access self-test free-of-charge kits (e.g. via a pharmacist, similar to that currently provided by the Institut Pasteur in Paris)	5	8.4 (0.6)	8.6	7.7	Informing
The instructions should include 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 the as soon as possible an optimum approach of one's HIV care	4	8.3 (0.7)	8.3	7.7	Informing
A readable and accessible price for all	7	8.2 (0.5)	8.6	8.0	Accessibility
Attracting experts to the project	6	8.2 (0.5)	7.5	8.9	Informing
The instructions must use pictograms	7	8.1 (0.4)	7.9	7.4	Informing
Enable HIV self-tests	4	8.1 (0.4)	7.9	8.4	Informing
Access to self-tests via telephone price or free-of-charge kit for population groups with high HIV risk	5	8.0 (0.3)	8.2	8.2	Accessibility
Public information concerning self-tests should be part of a general campaign promoting HIV screening and raising self-tests as one of a number of alternative options, all of which have their specific advantages	5	7.9 (0.4)	8.0	7.8	Communicating
The instructions should include information on how to access community support appropriate to the user's specific needs prior to self-testing	5	7.8 (1.0)	6.5	7.0	Informing
Prepare and distribute self-test kits in pharmacies, drugstores, community organizations, ... or via self-test support centers	6	7.8 (0.6)	6.6	7.8	Preparing
The instructions should make it clear that HIV cannot be transmitted by saliva between diagnostic kits or by making using saliva	4	7.8 (0.3)	6.9	6.9	Informing
Conduct a survey with the main CSFs in self-care approach	3	7.8 (0.3)	8.9	6.6	Supporting
All information and instructions should be available in foreign languages	4	7.7 (0.3)	8.1	7.4	Informing
All information and instructions should be available in foreign languages	4	7.7 (0.3)	7.9	7.7	Informing
Check self-tests via computerized program with specific testing covering options	6	7.7 (0.5)	7.9	7.5	Preparing
The instructions should underline the importance of using condoms and risk equipment	4	7.6 (0.3)	6.5	8.0	Informing
Communicate with health professionals and community organizations about communicating with the general public. Health professionals are often reluctant to commit to individual prevention strategies, in particular with regard to other screening options and how to access care that reduces risk	5	7.6 (0.7)	7.8	7.6	Preparing
Self-tests should be available for people with high HIV risk	4	7.2 (0.3)	7.1	7.2	Supporting
Conduct campaigns promoting the self-test targeted to different high-risk population groups, taking into account their specificities	1	7.1 (0.5)	7.1	6.6	Communicating
The instructions should include personal information on HIV transmission and prevention	5	7.0 (1.2)	6.9	6.6	Informing
Self-tests should be available in screening centers, family planning centers, community organizations, sex shops for people with substance abuse problems	6	7.0 (1.3)	6.0	8.0	Accessibility

**Table 3: Recommendations specific to MSM and drug user expert groups**

Recommendation	Mean	SD	Theme
MSM	8.3	0.3	Some recommendations were specific to each group or shared with only one other group. Table 4 and 5 present these more specific recommendations for the MSM and drug user expert groups.
Drug users	8.7	0.5	
Some recommendations were specific to each group or shared with only one other group. Table 4 and 5 present these more specific recommendations for the MSM and drug user expert groups.	8.7	0.5	MSM experts were highly sensitive to the issue around self-test reliability and the accuracy of the test kits. They insisted on high quality support and information concerning the HIV self-test being provided by an independent source other than the manufacturer.
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**Table 4: Recommendations specific to drug user expert group and most highly relevant (mean score > 7)**

Recommendation	Mean	SD	Theme
High support from substance misuse community organizations, NGOs and family support for promoting self-test	8.5	0.7	High support from substance misuse community organizations, NGOs and family support for promoting self-test
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**Table 5: Recommendations specific to drug user expert group and most highly relevant (mean score > 7)**

Recommendation	Mean	SD	Theme
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High support from substance misuse community organizations, NGOs and family support for promoting self-test	8.5	0.7	

**Conclusions**

Results from the current study should make a significant contribution to policy decisions concerning caring 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 adequate access, information and support will contribute to facilitating a screening both for people from high risk groups and for the general population, as well as potentially making an impact into the hidden epidemic in France by bringing in vulnerable populations that have until now been reluctant to use a standard testing option.

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