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

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

Expert group	N° experts	N° recommen-dations
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
Total	263	100

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)

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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)		

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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

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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

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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 ≥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

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Recommendations specific
to the drug user expert group

Recommendations scored highly relevant (mean score ≥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

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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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Poster PS03/03

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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