



## MEETING REPORT

# Expert meeting: Evaluation of ECDC HIV Testing Guidance in the EU/EEA

Stockholm 28-29 January 2016

## Background and meeting objectives

In 2010, ECDC published the guidance *HIV testing: increasing uptake and effectiveness in the European Union* (from now on referred to as “2010 guidance”). In consideration of the recent developments in the field, ECDC is planning to update the guidance in 2016-2017. In the light of several International and National testing guidelines/guidances released recently, ECDC has to carefully consider if an update of the testing guidance is needed and would be of added value.

As preparatory work, ECDC undertook an external evaluation of the impact of the 2010 guidance with regards to the development or implementation of testing policies in the EU/EEA at national, sub-national or supra-national levels. A needs assessment to identify the current requirements in the EU/EEA for an up-to-date revised ECDC HIV testing guidance was also conducted in parallel.

As a final step ECDC organized an expert consultation which was hosted in Stockholm on 28-29 January 2016 with the aim to discuss the findings and collect expert advice to better understand the use and impact, if any, of the 2010 guidance in the EU/EEA and to advise ECDC on any future steps in this area, including a possible guidance update. The objectives of the meeting were:

- Contribute to the interpretation of the findings from the 2010 guidance evaluation and needs assessment;
- Formulate recommendations to ECDC on next steps with respect to:
  - o Need for an updated HIV testing guidance
  - o Format and content of the updated HIV testing guidance
  - o Methodology to be used

Meeting participants were selected by ECDC with the view of achieving a comprehensive representation of the different institutions and constituencies' active in the HIV epidemic response in the EU/EEA region: Member States (MS) public health institutes and Ministry of Health, service providers and health care workers, civil society organizations, learned societies and professional associations, EU-funded projects and international organizations; as well as broad geographical representativeness.

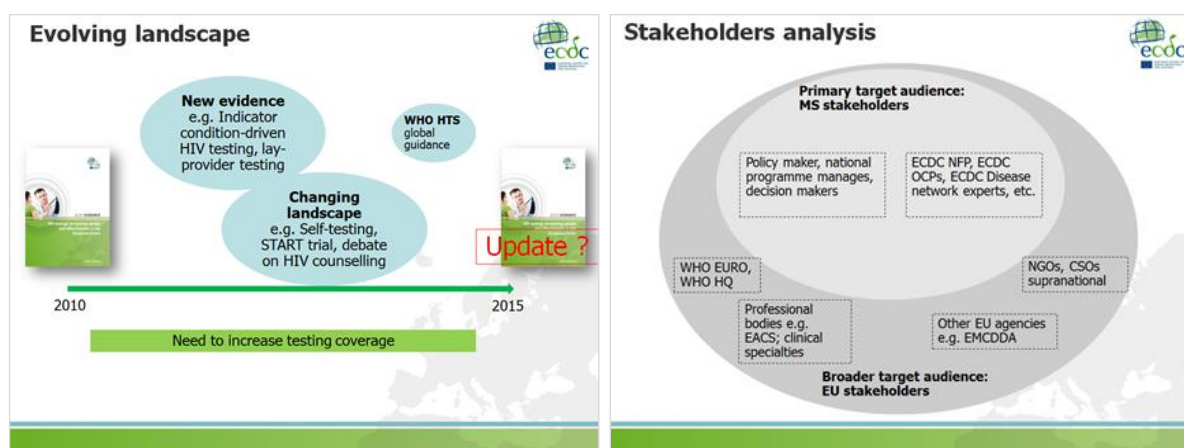
## Introduction

Johann Fontaine, who was on the original drafting team, provided an overview of the production of the 2010 Guidance highlighting the conditions that were relevant then as well as the strategic approach that guided the development of the document.

The 2010 guidance consisted of three products, an evidence synthesis, the full guidance document and a shorter summary version. The objectives of the guidance were to inform the development, monitoring and evaluation of national HIV testing strategies or programmes in the countries of the EU and the EEA and to complement existing guidance. The target audience was identified in policy makers and national programme managers/coordinators.

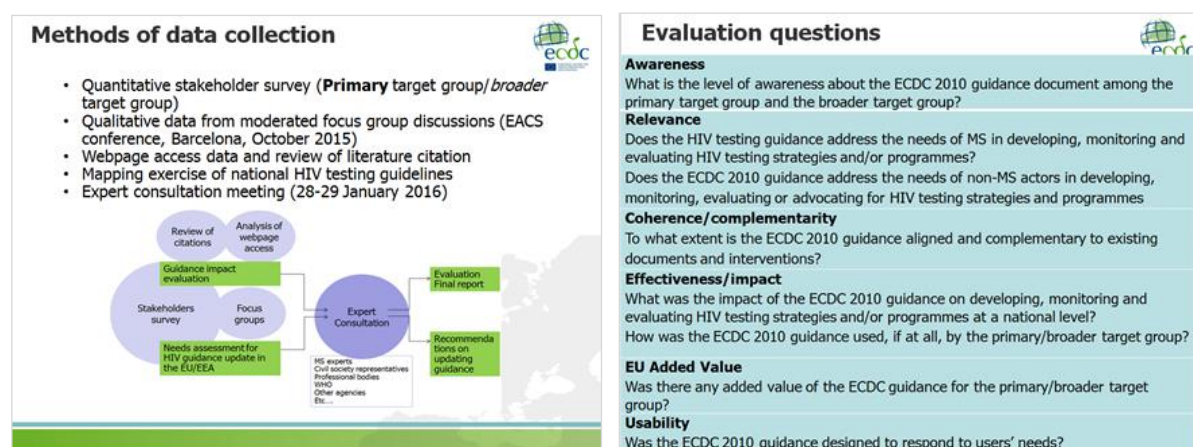
Johann illustrated how the 2010 guidance was of use by reporting his personal experience at the NGO Casa Blanca in Hamburg as a case study. The 2010 guidance initiated internal discussions leading to communication with the Ministry of Health in Germany and implementation of a monitoring and evaluation framework at local level. He opined that the objectives of a potential future guidance need to be re-thought and should consider including other sexually transmitted infections (STIs) and blood borne viruses (BBVs) in the context of HIV.

Lara Tavoschi (ECDC) provided an overview of the evaluation project. She stressed that despite HIV testing has evolved from 2010 to 2015, there still exists a need to significantly increase HIV testing in the EU/EEA. In this scenario ECDC devised an evaluation project which consisted of two parts: an impact evaluation and a needs assessment. The selected target groups were divided into: the guidance primary target group (PTG) and a broader target group (BTG) so as to be able to evaluate the impact of the 2010 guidance on and to collect inputs from a wider audience.



The methodology used in the evaluation project was presented by Dorte Raben. The methods of data collection involved a stakeholder survey for the primary and broader target groups, focus group discussions at the European AIDS Clinical Conference (EACS), citation review, website access analysis and mapping of national guidelines. The aim and objectives of the evaluation project were presented alongside evaluation questions covering the following dimensions: awareness, relevance, coherence/complementarity, effectiveness/impact, EU added value and usability. The methodology

was adapted from previous ECDC project (Chlamydia guidance impact evaluation<sup>1</sup>) and from the European Commission “Better Regulation Toolbox”<sup>2</sup>.



Two online surveys were set up in REDCap to reflect the different backgrounds and potential use in the two identified respondents groups. The PTG respondents were selected via official ECDC MS nominations aiming at obtaining a representative sample. The BTG respondents were recruited through convenience sampling via newsletters, a link on the HIV in Europe website and by invitation on flyers at EACS and IUSTI Conferences. Twenty-eight PTG and 51 BTG responses were received. Two responses were received from four MS. Where country level information was required the denominator employed was 23 (being the number of MS providing a response), and when individual opinion was required the denominator used was 28 (all PTG responses).

Two focus group discussions were held at the EACS Conference in Barcelona involving a total of 17 experts. The citation review covered the period December 2010 to December 2015 and website access analysis the period 1 June 2011-31 December 2015. Additional data from the EU funded project OptTEST<sup>3</sup>, national HIV testing guidelines and HIDES study data, are still in the process of being examined for inclusion in the project report.

Important limitations with the methodology were presented and included:

- Low number of replies from the BTG (51 out of target of 150)
- Potential bias with respondents familiar with the ECDC 2010 guidance more likely to respond to the survey
- Language barrier as the surveys were not translated
- Pre-defined answer categories – relevant options may have not been included
- Potential ambiguity with nomenclature used, e.g. policy, strategy and programme.

During the discussion it was highlighted how the methodology used could possibly be further improved in view of future similar exercises. In particular it was observed that the dimension of “coherence/complementarity” may require the development of more objective scoring system, and that the division of the target audience in two groups was artificial as it was subject to country specific procedures in developing national guidelines/strategy/programmes targeting HIV testing. Finally it was noted that the inclusion in the BTG of non-EU/EEA actors would be desirable, and of particular relevance for EU accessing and neighboring countries.

<sup>1</sup> Available at: [http://ecdc.europa.eu/en/publications/\\_layouts/forms/Publication\\_DispForm.aspx?List=4f55ad51-4aed-4d32-b960-af70113dbb90&ID=1284](http://ecdc.europa.eu/en/publications/_layouts/forms/Publication_DispForm.aspx?List=4f55ad51-4aed-4d32-b960-af70113dbb90&ID=1284)

<sup>2</sup> Available at: [http://ec.europa.eu/smart-regulation/index\\_en.htm](http://ec.europa.eu/smart-regulation/index_en.htm)

<sup>3</sup> <http://www.opttest.eu/>

# HIV Testing Guidance Impact Evaluation

Ann Sullivan presented the results of the impact evaluation.

The key findings on who was reached and how (awareness dimension) were:

- The level of awareness of the ECDC 2010 guidance was high in both groups (PTG: 100%, BTG: 82%). However, a concern was raised regarding internal validity of the responses as 10 PTG respondents reported looking at the guidance, while 14 reported having used it for work;
- 79 citations were identified in the citations review, being predominantly peer-reviewed journal articles (82%);
- The website statistics review had important limitations due to system set-up. It showed that there had been 530 unique page views, and that guidances were the 3rd most popular type of publication and HIV/STI the 2nd most popular topic on the ECDC platform.

The subsequent discussion raised the issue of dissemination. Various suggestions were proposed for an iterative approach to dissemination e.g. one e-mail at launch on World AIDS Day (WAD) with follow up e-mails at six months and then annually. Staff turnover was also mentioned as a potential factor to impact on current awareness alongside the possibility to assess this based on data collected from the survey. A question was raised regarding possible comparison with other disease areas, e.g. TB or cancer guidance. However, as HIV is a larger focus area comparison may be skewed. In addition it was also mentioned that the reach and impact of an ECDC product is now greater than it was in 2010 (ECDC became operational in 2005).

The potential for monitoring guidance implementation through a set of key indicators was also proposed as a measure to ensure continuous awareness and to foster guidance implementation in the region. The Dublin Declaration monitoring process was mentioned as a possible platform for such a process. Reflections were also made on the need for a more dynamic process of guidance development that could allow for more frequent updates – yearly updates were referred to as the preferred option. The meeting recognized the time constraints for the development of a state-of-the-art guidance, but voiced the urgent need for an up-to-date guidance at European level. Guidances constitute the highest level of scientific advice output that ECDC produces – guidances are developed based on systematic review of existing evidence, sourced appropriately from published literature and grey literature and complemented by expert opinion, in the form of expert panel contribution.

Ann Sullivan presented the impact evaluation results on whether the guidance was addressing the needs of the users and how it was used (impact, usability and relevance dimensions). Key findings included:

- The 2010 guidance was considered the most relevant among several international guidances. Respondents considered it relevant, with little decline over time, as a source of information on testing approaches, as a reference policy document, for national guidance/policy/strategy development and for advocacy purposes.

	Primary target group respondents (N=21)	Broader target group respondents (N=30)	Total (N=51)
As general information about approaches to HIV testing	76% (16)	57% (17)	60% (29)
As comparison among different countries' testing policies	38% (8)	20% (6)	25% (12)
As a reference policy document	86% (18)	63% (19)	65% (31)
To provide technical feed-back to policy makers/decision-makers	38% (8)	20% (6)	19% (9)
For national HIV testing policy/guidelines/strategy development/monitoring/evaluation	76% (16)	37% (11)	49% (22)
For HIV testing programme development/monitoring/evaluation	62% (13)	47% (14)	44% (21)
To support advocacy work on HIV testing/influence decision makers/raise awareness about HIV testing	NA*	33% (10)	NA*
To fundraise /mobilise resources for HIV testing	NA*	10% (3)	NA*
Other	2 (10%)	7% (2)	4% (2)

*"The guidance document was useful, but provides very large lines (general lines). It is not specific enough, so therefore difficult to include (in national guidelines)."* [focus group]

- Usability was reportedly good as respondents indicated satisfaction with format, content and accessibility.
- Considering the 23 MS with at least one PTG response, 48% reported having used the guidance in the development, monitoring and/or evaluation of their national HIV testing policy/guidelines/programme/strategy. 56% of BTG respondents reported having used the ECDC 2010 guidance for their work. Reasons for non-use (N=7) among PTG respondents were focusing on timing of release in relation to national documents. Of the 11 PTG respondents reporting use of the 2010 guidance, 27% used the guidance to develop new or revise existing HIV testing policies/guidelines/programmes and 55% to support monitoring/evaluation. Of the 29 BTG respondents 62% used the guidance for advocacy purposes. Regarding which parts were used, the majority of respondents reported using the *core principles for national HIV testing strategies and programmes; whom, where and when to test and how to test*.
- About two thirds of the respondents reported seeing changes in HIV testing nationally since 2010, with a third considering the 2010 guidance as one of the possible co-factors for such changes. A third of the respondents reported the changes had led to improvement.

During the discussion that followed it was noted that the results of the impact evaluation were positive and as also reflected by some of the present experts' direct experiences. In particular it was mentioned that the value and impact of the 2010 guidance was higher for smaller countries, where country capacity and resources availability is limited. It was also noted that the title of the 2010 guidance may have discouraged its use, as reported in at least one case. Suggestions were made to align the title with the proposed aim. The value of the 2010 guidance in fostering changes at national level was also noted and ascribed to the leverage offered by the ECDC recognized influence. It was suggested that ECDC should consider broadening the scope of a new guidance to include advocacy as well as support to programme implementers.

It was also suggested that perhaps the 2010 guidance was too broad and difficult to implement and thereby not meeting the needs of certain users. Suggestions were made to give more emphasis to local settings, epidemiological context and promote best practice examples exchange. Use of stronger language was also mentioned as a potential factor to increase impact of a future guidance.

Country experiences on developing and implementing national guidelines were shared. Silke David presented the role of Rijksinstituut voor Volksgezondheid en Milieu (RIVM) in developing the national plan for HIV, STI and sexual health, requested by the Ministry of Health (MoH). Several parties and stakeholders were involved, by being included in brainstorming sessions, providing written feedback on drafts and participating in mid-term reviews. Few challenges were highlighted both in the development and implementation processes, including the difficulty in maintaining the target audience engaged and the MoH supportive.



**Challenges and lessons from development**

**Challenges:**

- Impossibility to satisfy all interests put forward in the sessions
- Working closely with the MoH > difficulty in formulating SMART goals

Lessons learned included the need for an overall goal and more precise definitions of stakeholders and partners, a communications and dissemination strategy and the plan of a mid-term review with



specific indicators to measure. The presenter stressed the challenge of engaging target audience in the guidelines development to ensure participation and ownership.

Kristi Rüütel from Estonia presented on the development of the Estonian HIV testing guidelines. She reported that despite more than 10% of the population test each year in the country, testing is not targeted well enough, with most being done among blood donors and pregnant women. The national guidance was developed in 2011, just after the release of the 2010 ECDC guidance.



Testing on the basis of risk group and indicator conditions was recommended, including the recommendation for universal testing (16-49 years) in two high prevalence regions. Challenges and issues debated in the development phase were universal offer for testing upon health care access, and Emergency Department (ED) testing. On account of cost considerations, the strategy opted for was opt-out ED testing based on clinical evaluation. Challenges at implementation level included: measuring implementation, resources availability and lack of political support. It was mentioned that the ECDC guidance had been useful, as limited time and resources prevent Estonia from embarking in evidence review. During the discussion that followed it was noted that due to high levels of activity in ED and an inadequate system for feeding back results, testing in primary care is preferred. In Estonia, despite interest from general practitioners (GP), major barriers in implementation are observed.

The last country example was from Greece, provided by Nikos Dedes from Positive Voices. In December 2011 a draft guidance was circulated by the Hellenic CDC which was influenced by the 2010 guidance, but only published in 2014 with considerable delays. It was noted that according to the new guidance, proof of identification is required to obtain testing cost reimbursed. As a result, although free and confidential, anonymous testing had been foregone in most health care centres providing testing services. Monitoring and evaluation was also identified as a gap in national guidelines implementation. It was reported that in Greece, HIV community testing Checkpoints found 25% of newly diagnosed cases in 2014. Many diagnosed cases were recent HIV infections among younger MSM. The presenter stressed the importance of addressing topics such as de-medicalisation, de-counselling and de-regulation as well as HIV testing monitoring and the urge to avail programmatic data on testing implementation.

## HIV Testing in the European Context

This session started with an overview of changes in HIV testing in the EU/EEA since 2010 provided by Jens Lundgren. The presenter noted that success obtained in ante-natal screening programmes should serve as a 'positive control' and benchmark for best practice. HIV epidemic is still increasing in some areas, such as Eastern Europe, and the proportion of late diagnosis is still worrying. Few factors were identified as potential causes.

### Where is the problem ?

1. Is evidence-base sufficiently comprehensive as reflected in guidelines?
2. Are guidelines adopted by national authorities?
3. Is adoption = implementation

Despite new evidence accumulating since 2010 with the START Study, Partner Study on public health benefit of early testing and treatment, the number of tests performed remains constant due to a number of outstanding issues (see below). UNAIDS 90-90-90 goals may be overly ambitious taking current coverage rates in the best performing countries into account (72-80%). The need for simple performance indicators was stressed to allow for effective monitoring and targeting of testing initiatives. Such indicators could be: numbers tested, numbers positive and numbers linked to care. Ideally such data should be stratified by risk groups and by setting (e.g. community setting, health care setting).

### Outstanding issues in relation to approach to testing

- Continue to innovate testing concepts – recommendations remains evidence based
  - Type, periods, approach
- Continue to develop and create country-specific modelling of the epidemic
- Continue to understand barriers for testing guidance to be implemented
- What works and what do not work ?
  - Dynamic testing approaches – tailored to the need of the population in question
  - Guiding principles ?
    - Size and type of the undiagnosed fraction of the population
    - How well does the testing programs work
      - How do we best evaluate their performance
    - Key performance indicators
      - Number of tests
      - Coverage rate of the population they are intended to reach
      - % of tested found to be positive
      - % of HIV+ linked to care within reasonable time ?
    - How are these indicators captured and evaluated – and who are responsible ?

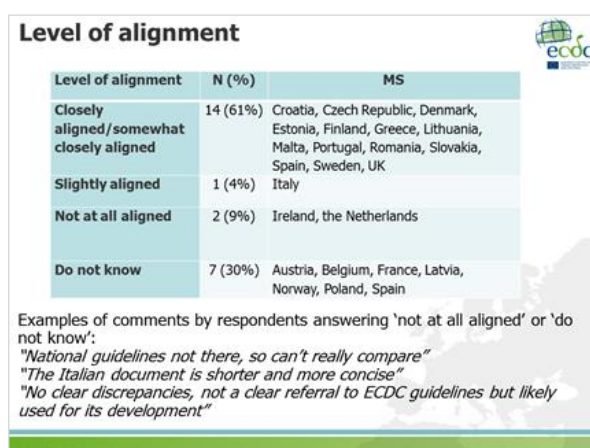
Lali Khotenashvili provided an overview of the implementation of the WHO HTS guidelines and the proceedings from a recent regional consultation in Astana with a wide group of stakeholders. The implementation of the HTS guidelines is challenging in many countries as it would require revision of national guidelines and policy, ensuring alignment of practice, applying the 5Cs principle<sup>4</sup>, preventing misdiagnosis and monitoring and evaluation of linkage to care. While the number of tests performed is considered an indicator of success, test efficiency may be sub-optimal.

	Number tested	Number HIV positive
Clinical indication	35 717	92
STI patients	4 883	8
TB patients	6 311	27
Donors	30 320	7
<b>Pregnant women</b>	<b>162 336</b>	<b>5</b>
Health care staff	35 095	6
Prisoners	6 984	208
<b>PWID</b>	<b>2 193</b>	<b>149</b>
Sex workers	284	1
<b>MSM</b>	<b>15</b>	<b>1</b>
Certificate	13 125	11
<b>Total</b>	<b>339 887</b>	<b>687</b>

<sup>4</sup> 5Cs principles: consent; confidentiality; counselling; correct (diagnosis); connection (linkage to care)

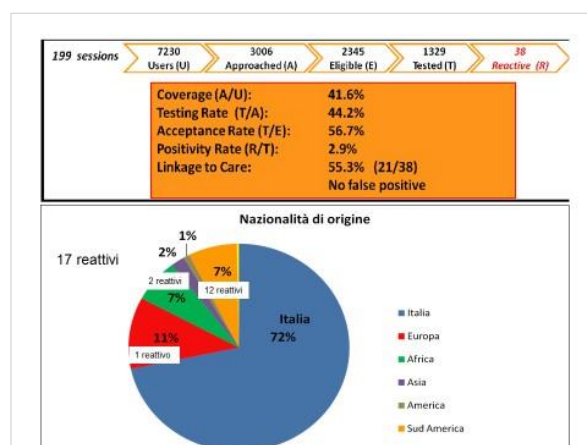
Identified barriers for expanding HIV testing in EU countries include: stigmatisation; discrimination; low risk perception; insufficient access to free testing for high risk groups; low uptake by MSM and sex workers (SWs); challenges in reaching heterosexual men and migrants; limited access to rapid testing; lack of general practitioners (GP) engagement; lack of leadership, resources and funding etc. Proposed actions to expand HTS include maintaining political will and funding; update of national guidelines; sustainability; and strengthening of monitoring and evaluation.

Dorthe Raben presented the findings from the evaluation survey with a focus on HIV testing policies and practices in the EU/EEA countries (coherence/complementarity dimension). Despite the majority of respondents reporting using the national HIV testing strategy/policy (64%) as main national reference documents, the national mapping exercise also identified that several different documents may co-exist.



Level of alignment between national guidance/strategy/policy and the 2010 guidance seems difficult to estimate and was largely based on personal opinion. A case study was performed on indicator-condition (IC) guided testing. While many PTG respondents reported IC guided testing being included in national HIV testing guidance/strategy/policy, according to recently published data<sup>5</sup>, it is poorly implemented in practice.

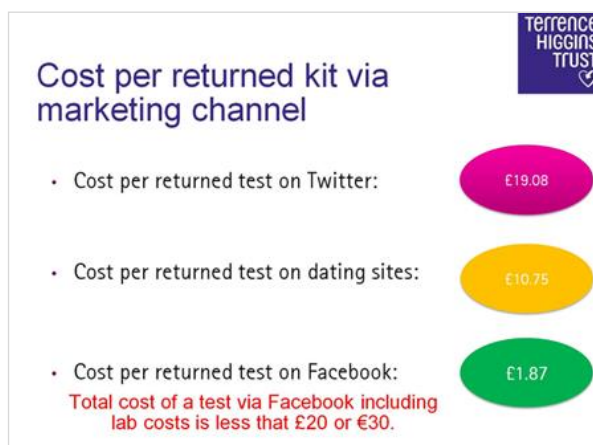
Examples of innovative testing approaches were presented by four speakers. Lella Cosmaro provided examples of community testing in Italy. Despite lack of direct support from MoH a network of national non-governmental organizations (NGO) in collaboration with local hospitals carried out a multicentre project to deliver rapid HIV testing in unconventional settings. Results indicate a high level of acceptance and high positivity rate among those tested. Despite the results, there is no political will in the country to advance community testing approach as well as de-medicalize testing. Economic appraisal of the community testing may be needed.



<sup>5</sup> Raben D et al. Auditing HIV Testing Rates across Europe: Results from the HIDES 2 Study. PLOS One, 2015. Available at: <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0140845>



Cary James presented the outcomes of the home sampling project piloted in UK during 2015. The project aimed at targeting people who would normally not attend services despite being aware of their risks. More than 65,000 testing kits were made available. The return rate was 60-65% and the positivity rate 1.9%. The services reached largely young (under 25 years of age) and non-urban people. 40% of users had never tested before. The tests were promoted through social media and during European Testing Week only 15,000 tests were ordered. For tests ordered through Facebook, positivity rate was three times higher than when ordered through other sources and overall cost per returned test was lower.



A question was raised regarding linkage to care and follow up for those who tested positive. Careful instructions are included in the home testing packages and people are asked to inform the clinic when they present for care if they were diagnosed through postal/home sampling. The high return rate was noted and comparison made with 30% return rate on postal Chlamydia tests in the Netherlands.

Irena Klavs presented the Euro HIV EDAT project on behalf of Jordi Casabona. EURO HIV EDAT project started in 2014 (2014-2017) as the continuation of HIV COBATEST (2010-2013). It focuses on HIV testing in community settings. Results of a mapping exercise of community testing services in the EU/EEA revealed that number of tests had increased in recent years, test performance was highly medicalized, rapid testing was only accepted in 64% of countries and national focal points often lacked information about community testing services in their country<sup>6</sup>. Core indicators to monitor and evaluate community based voluntary counselling and testing (CBVCT) for HIV were agreed upon within COBATEST and are available on the Euro HIV EDAT web site ([www.euroedat.org](http://www.euroedat.org)). A data collection tool to collect data on HIV testing performed in community settings was developed. Preliminary results from 2014 data indicate an overall positivity rate of 1.6% out of the approximate 10 000 tests reported<sup>7</sup>. It was suggested that ECDC considers including a sub-set of the agreed indicators (e.g. number of clients tested for HIV with a screening test at CBVCT sites, proportion of tested clients at CBVCT sites with reactive screening HIV test results, proportion of clients at CBVCT sites with positive confirmatory HIV test results, proportion of clients at CBVCT sites with positive confirmatory HIV test results linked to care) in the Dublin Declaration (DD) monitoring process.

Ann Sullivan presented recently published results on IC guided HIV testing<sup>8</sup>. Audit data from the UK highlights poor performance and great variability; showing only a 78% offer rate of HIV testing to

<sup>6</sup> Reyes-Urueña J, Breveglieri M, Furegato M, Fernández-López L, Agusti C, Casabona J. [Heterogeneity of community-based voluntary, counselling and testing services for HIV in Europe: the HIV-COBATEST survey](https://doi.org/10.1186/s13051-015-0240-2). Int J STD AIDS. 2015 Dec 14. pii: 0956462415623402.

<sup>7</sup> L. Fernández-López, J. Reyes-Urueña, C. Agustí, T. Kustec, I. Klavs, C. Casabona & the COBATEST Network group (2016): The COBATEST network: a platform to perform monitoring and evaluation of HIV community-based testing practices in Europe and conduct operational research. AIDS Care. 2016 Feb 17:1-5. [Epub ahead of print]. Available at: <http://dx.doi.org/10.1080/09540121.2016.1146218>

<sup>8</sup> Raben D et al. Auditing HIV Testing Rates across Europe: Results from the HIDES 2 Study. PLOS One, 2015. Available at: <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0140845>

patients presenting with hepatitis B/C and only 3.6% for anal cancer patients. The uptake of testing is generally high as is patient acceptability. Work Package 5 in the EU funded project OptTEST is developing tools and implementing quality interventions to increase the offer of HIV testing to patients diagnosed with ICs.

### Routine HIV testing in indicator conditions (ICs): audit of UK practice, HIDES II

Twelve audits were undertaken across six UK sites for six different ICs involving a total of 2312 patients

Indicator Condition (IC)	Number patients according to context(s) with IC	Proportion offered an HIV test	Prevalence new diagnosis of HIV (%)	"Missed" diagnoses (95%CI)
Lymphoma	373	41.2%	8.49%	19 [7-35]
Hepatitis B / C	682	78%	0.75%	1 [-2-8]
Cervical cancer	43	4.7%	0	-
Anal cancer	190	3.6%	0	-
Oesophageal candidiasis	524	11%	8.89%	39 [24-80]
Tuberculosis	500	69%	2.42%	4 [-2-16]

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The discussion following these presentations revolved around how the economic arguments are an important element to be captured in the new guidance and financial arguments are needed to inform decision making. It was suggested that case-study or country examples may be used for this purpose if complemented with cost dimension.

## Priorities for HIV testing in the EU/EEA

Ida Sperle presented the results from the evaluation project on the added value dimension.

Ways in which the EU Level Guidance provides value			
Only respondents who reported having an EU level guidance as very important, important or somewhat important: PTG (N=25) and broader (N=50):			
	Primary target group (N=25)	Broader target group (N=50)	Total (N=75)
Saves time/resources by providing up to date review of evidence relevant to the EU/EEA country	15 (60%)	30 (60%)	45 (60%)
Provides a benchmark	13 (52%)	26 (52%)	39 (52%)
Influences the development of national policies in the EU/EEA countries	14 (56%)	35 (70%)	49 (65%)
Fosters change in individual countries in EU/EEA by providing an EU/EEA standard	15 (60%)	26 (52%)	41 (55%)
It is well accepted as a reference policy document	18 (72%)	26 (52%)	44 (59%)
Provides leverage for advocacy purposes	12 (48%)	25 (50%)	37 (49%)
Other	0 (0%)	1 (2%)	1 (1.3%)

Survey respondents indicated a need for a guidance update and identified the following as key areas for such an update: new testing technology, continuum of care, monitoring and evaluation, economic appraisal of testing.

A round table discussion followed aimed at addressing the following questions:

- ✓ Is there a need for ECDC to take action?
- ✓ What are the key content elements ECDC may provide added value on: e.g. testing approaches, testing technologies, monitoring of testing, priority population, economic evaluation?
- ✓ What are the open/key questions an ECDC product shall provide guidance on?

There was consensus on the need for an update of the 2010 guidance complemented by practice and implementation-oriented companion products. In particular it was stressed the added value of a European guidance over the existing guidelines (e.g. WHO). It was mentioned that IUSTI 2014

guidelines are restricted to a specific setting (i.e. STI clinics) and to a specific target audience (i.e. STI, dermatovenereology and genitourinary medicine specialists), while WHO HTS guidelines may not sufficiently target the European context and epidemic situation.

It was advocated for ECDC to promote the implementation of the new guidance and its recommendations through a coordinated system of monitoring and evaluation at European level (e.g. Dublin Declaration monitoring platform), possibly including the definition of specific targets. This would allow for frequent evaluation of the impact and the level of endorsement and implementation both at national and supranational level.

Monitoring and evaluation of testing provision and testing programmes implementation was discussed in depth. The participants agreed on the pressing need for the development of a standard tool that could support the collection of testing performance data. There were different views on the primary scope of such tool, if it should support monitoring at national and/or regional level, programmatic planning and decision making, service provider quality management or local implementation. It was considered that the definition of a core set of key indicators (e.g. test uptake, number of tests performed, positivity rate, proportion of tested positive linked to care) would be the necessary starting point for such a process to be coordinated by ECDC. It was also suggested that guidance implementation targets should be designed to match the agreed indicators.

Another key theme that resulted from the discussion was the need to promote complementarity of different testing approaches in order to effectively decrease the undiagnosed fraction and meet the UNAIDS 90-90-90 target. In this view, the updated guidance should have a focus on novel approaches to testing, including both technologies and strategies, e.g. self-testing, home testing, community testing, IC guided testing.

The following additional themes/suggestions were mentioned during the discussion:

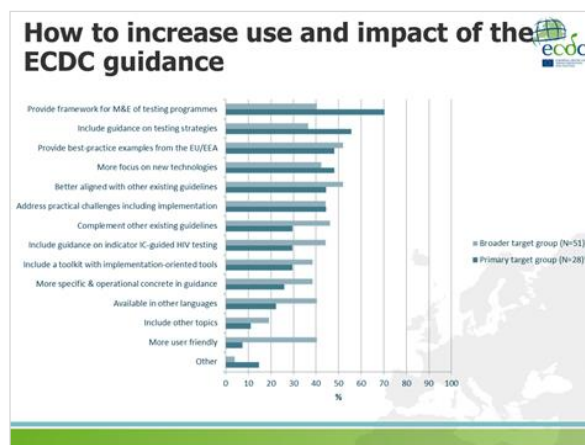
- Content updates should include testing among youth (under 18 years), targeted testing among minorities (e.g. Roma population) and specific groups (e.g. high risk MSM), testing for PrEP, frequency of testing, partner notification, testing for multiple diseases (e.g. HBV, HCV).
- Regular update of the guidance, e.g. yearly update
- Use of a stronger language and a more prescriptive approach in providing recommendations.
- Foster collaboration with WHO Euro and ensure engagement of non-EU countries

## What product is needed?

The session started with a brief summary of day one provided by Lara Tavoschi.

Dorthe Raben presented the summary findings from the evaluation project on how to increase use, impact and relevance of the guidance.

	Primary target group (N=28)*	Broader target group (N=51)*	Total (N=79)
Translation into other EU/EEA languages	36%(10)	65% (33)	54%(43)
Produce a collection of documents tailored to specific users (e.g. policy makers, advocacy activists)	50%(14)	45% (23)	47%(37)
Be practical oriented e.g. with a toolkit with implementation-oriented tools	57%(16)	55% (28)	56%(44)
Complement the guidance with a peer-reviewed publication	32% (9)	15% (15)	34%(24)
Upload the guidance on additional websites other than ECDC	29% (8)	51% (26)	43%(34)
Provide best-practice examples from EU/EEA countries	54%(15)	61% (31)	58%(46)
Organise workshops for MS and other stakeholders to promote its implementation	36%(10)	43% (22)	41%(32)
Supplement the guidance with additional resources like information leaflets and posters for download	21%(6)	31% (16)	28%(22)
Other	4% (1)	2% (1)	3%(2)



The results from the evaluation project were in line with the themes highlighted previously during the meeting. Notable additions were the identified needs for a tool to support MS in developing national guidelines, as well as to promote implementation by e.g. holding regional workshops on the development and implementation of national guidelines. The exchange of best practice at EU/EEA level was seen as highly beneficial and stressed also as a complementary element of the updated guidance. Finally translation was seen as an important gap in 2010 guidance. It was mentioned that it is ECDC policy not to translate any of the technical documents but informal translations are possible.

A round table discussion followed targeting the following open questions:

- ✓ Who should be the target audience?
- ✓ What should be the format of the new product?
- ✓ How should ECDC promote its dissemination, awareness and implementation?

The scope of an updated guidance was discussed in depth and there was general agreement that such a document should provide recommendations at strategic level. It was stressed that the title should reflect accurately the content to avoid misconception and encourage its use in the appropriate context.

The format of the update guidance was also discussed at length. There was general agreement on the need for a comprehensive package that should include the guidance, and be complemented by a set of companion products such as: 1. Tool on how to develop national guidelines; 2. Monitoring and evaluation tool; 3. Country case studies and service models repository; 4. Implementation tool (e.g. set of context-specific testing approaches, economic appraisal). An interactive format was also preferred to a static printed version. A testing portal was mentioned as a possible suitable platform to collect all the relevant products.

The primary target audience was identified as the professionals engaged in developing guidelines at national level. It was recognized that this may be quite a diverse group constituted by: 1. Policy makers/policy adviser and program managers; 2. Service providers, including health care workers, clinicians, civil society organization members etc.; 3. Advocates. A secondary and much broader target audience was also identified. This shall include technical experts with an interest in HIV testing, including policy maker/advisor, program managers, service providers, clinicians, civil society organizations, etc. The importance of targeting clinical specialist societies or associations to promote integration of HIV testing was particularly stressed. Along the same lines, it was also suggested to consider broadening the geographical scope of the guidance to countries of the wider European region, EU neighboring countries etc. Finally, it was clarified that it is not in the ECDC mandate to address the general public, this communication channel being the responsibility of each Member State. Nevertheless it would be possible to plan for an open consultation of the draft guidance before its release.

Possible dissemination strategies were proposed and discussed. These included plans to improve dissemination at the time of the launch; but also, and possibly more importantly, approaches to ensure continuous engagement and awareness in the following period.

Suggested strategies to increase dissemination at the launch included:

- The use of 'teasers' to be sent out ahead of the release via social media
- Identification of "country ambassador" to promote the guidance
- Timing the launch alongside established events such as the "HIV testing week"
- Devising a set of key messages tailored to different audience groups

Strategies to ensure continuous engagement of the target audience included:

- Organize face to face workshops with country representatives to facilitate implementation at national level
- Engage national clinical specialties societies (e.g. national society of hepatology)
- Ensure continuous updates of the guidance, e.g. on yearly basis

- Best practice spotlight – identify and disseminate best practice examples on a regular basis (e.g. 6-monthly) to highlight specific guidance content/recommendations.

Various dissemination tools were discussed, such as newsletters and apps. It was proposed that a mobile optimized website/portal would probably be sufficient in addressing the audience needs, and easily updatable.

## The way forward

The final session of the meeting was dedicated to formulate a few key conclusions and/or suggestions on ECDC's role and future steps. The session started with a panel discussion with five invited panelists representing different constituencies, namely Justyna Kowalska, Tamás Bereczky, Deniz Gokengin, Silke David, and Irena Klavs, followed by a round table discussion engaging all participants. The discussion was centered on the following key questions:

- ✓ How can ECDC contribute to increase HIV testing in the EU/EEA?
- ✓ What is your key recommendation for ECDC on the way forward?
- ✓ What is your take home message?

Participants' reflections are summarized in the following key points:

- Collaborative approach and engagement with different constituencies and organizations such as WHO, EACS and IUSTI was appreciated and considered an essential component of future activities, with potential expansion to include e.g. clinical specialties professional societies.
- ECDC HIV testing guidance is considered relevant and of added value by EU/EEA MS and by a broader group of stakeholders in the region.
- A comprehensive package of products to foster HIV testing coverage and uptake is needed. ECDC should embark in an update of the guidance and consider complementing it with specific companion products to promote monitoring and evaluation as well as development and implementation of national guidelines/guidance documents. Regular updates, collection and dissemination of country case studies and service models, economic appraisal and assistance for implementation were considered key components of ECDC future outputs.
- The target audience of ECDC outputs and activities should not be confined to MS actors only but include a broader group of stakeholders who are engaged in guidance development and implementation within and beyond the EU/EEA region and across a range of clinical specialties.
- Appropriate and continuous dissemination of the guidance is needed. ECDC shall devise an effective and multi-layered communication plan to maintain interest and momentum.

Lara Tavoschi and Andrew Amato closed the meeting thanking all the participants for their contribution to an interesting, informative and effective meeting.





# HIV TESTING GUIDANCE EVALUATION

ECDC Expert Panel Meeting  
Stockholm  
28-29<sup>th</sup> January 2016

## Scope and purpose

In 2010, ECDC published the guidance *HIV testing: increasing uptake and effectiveness in the European Union*<sup>9</sup> (from now on referred to as “2010 guidance”). In consideration of the recent developments in the field, ECDC is planning to update the guidance in 2016-2017.

As preparatory work ECDC is currently undertaking an evaluation of the impact of the 2010 guidance with regards to: the development or implementation of testing policies in the EU/EEA at national, sub-national or supra-national levels. A needs assessment to identify the current needs in the EU/EEA for an up-to-date revised ECDC HIV testing guidance is being conducted in parallel.

The methodological approach includes: 1. Survey the EU/EEA Member States and other key stakeholders; 2. Review and analysis of the ECDC HIV guidance citation in the published literature; 3. Review and analysis of ECDC HIV guidance webpage access records; 4. Expert Panel consultation. Preliminary results obtained from points 1-3 will be presented during the meeting, covering:

- a. A summary of the current practices and guidelines/policies on HIV testing in EU/EEA, including specific areas such as self-testing/home testing; community-based testing;
- b. The impact and perceived contribution of the ECDC 2010 guidance to the process of development, implementation and improvement of national guidelines on HIV testing in the EU/EEA;
- c. The current needs for an ECDC HIV testing guidance update, including priority areas to be addressed.

A. The purpose of the Expert Panel meeting is to:

- Contribute to the interpretation of the findings from the 2010 guidance evaluation and needs assessment;
- Formulate recommendations to ECDC on next steps with respect to:
  - o Need for an updated HIV testing guidance
  - o Format and content of the updated HIV testing guidance
  - o Methodology -to develop the updated HIV testing guidance

<sup>9</sup> Available at: [http://www.ecdc.europa.eu/en/publications/Publications/101129\\_GUI\\_HIV\\_testing.pdf](http://www.ecdc.europa.eu/en/publications/Publications/101129_GUI_HIV_testing.pdf)



## PROGRAM

## HIV TESTING GUIDANCE EVALUATION

28-29<sup>th</sup> January 2016

Room N514

Thursday 28<sup>th</sup> January**SESSION 1: INTRODUCTION****Chair:** Andrew Amato & Lara Tavoschi**Objective:** Inform participants about ECDC scope of activities and plans on HIV testing

09:00 – 09:15	Welcome and scope of the meeting (Andrew Amato, Lara Tavoschi)
09:15 – 09:25	The making of “The 2010 Guidance”: conditions, objectives, reception (Johann Fontaine)
09:25 – 09:35	ECDC HIV Testing guidance impact evaluation and guidance update: overview of the project (Lara Tavoschi)
09:35 - 09:50	Methodology (Dorthe Raben)
09:50 – 10:00	Discussion
10:00 - 10:20	<b>COFFEE</b>

**SESSION 2: HIV TESTING GUIDANCE IMPACT EVALUATION****Chair:** Irena Klavs & Teymur Noori**Objective:** Present the results from the impact assessment and elicit experts' inputs on the interpretation

10:20 - 10:30	Who has been reached by the guidance and how? (Ann Sullivan)
10:30 - 10:45	Discussion
10:45 – 11:10 Sullivan)	Was the guidance addressing the needs of the users and how was it used? (Ann Sullivan)
11:10 – 11:30	Discussion

- 11:30 – 12:15 Country experiences: Developing and implementing national guidelines  
 Silke David – The Netherlands  
 Kristi Ruutel – Estonia  
 Nikos Dedes - Greece

12:15 – 13:15 **LUNCH**

### **SESSION 3: HIV TESTING IN THE EUROPEAN CONTEXT**

**Chair: Jens Lundgren & Anna Zakowicz**

**Objective: Provide an overview of the current situation and developments in the field of HIV testing in the EU/EEA**

- 13:15 – 13:35 Evolution of HIV testing in the EU/EEA since 2010 (Jens Lundgren)  
 13:35 – 13:50 WHO HTS guidance implementation in Europe (Lali Khotenashvili)  
 13:50—14:00 HIV testing policies and practices in the EU/EEA and complementarity with ECDC  
 2010 guidance – summary findings from the survey (Dorthe Raben)  
 14:00 – 14:50 Innovative approaches for HIV testing – case studies  
 Lella Cosmaro – Italy  
 Cary James – UK  
 Jordi Casabona – Spain  
 Ann Sullivan – UK  
 14:50 – 15:20 Discussion  
 15:20—15:45 **COFFEE**

### **SESSION 4: PRIORITIES FOR HIV TESTING IN THE EU/EEA**

**Chair: Nikos Dedes & Anastasia Pharris**

**Objective: Determine whether there is a need for an updated ECDC HIV testing product/s and provide expert input on the priority content areas**

- 15:45—16:00 Needs and priority areas for an ECDC HIV testing guidance and EU-added value of the ECDC guidance – feedback from the survey and focus groups (Ida Sperle)  
 16:00 – 17:30 Round table discussion  
 17:30 Closure of day 1  
 19:00 **ECDC hosted dinner (Restaurant Pressklubben, Vasagatan 50, 111 20 Stockholm)**

## Friday, 29th January

### **SESSION 5: WHAT PRODUCT IS NEEDED?**

**Chair:** Tamas Bereczky & Deniz Gokengin

**Objective:** Provide expert input on the most suitable format and target audience for an ECDC product/s

- |               |  |
|---------------|--|
| 09:00— 09:15  | Recap from day 1 (Lara Tavoschi)   |
| 09:15 – 09:30 | Audience and format for an ECDC HIV testing products – summary findings from the survey (Dorthe Raben) |
| 09:30 – 10:30 | Round table discussion   |
| 10:30—11:00   | <b>COFFEE</b>  |

### **SESSION 6: THE WAY FORWARD**

**Chair:** Andrew Amato & Lara Tavoschi

**Objective:** Agree and endorse a suitable way forward for ECDC

- |               |  |
|---------------|--|
| 11:00—11:45   | Panel discussion                       |
| 11:45 – 12:15 | Round table discussion                 |
| 12:15 – 12:30 | Conclusions and closure of the meeting |
| 12:30         | <b>LUNCH</b>                           |

## Participants list

Stakeholder category	Name	Country
EU/EEA Member States	Kristi Rüütel	Estonia
	Silke David	The Netherlands
	Catherine Issaris	Greece
	Maria Axelsson	Sweden
	Johann Fontaine	Germany
	Irena Klavs	Slovenia
Non-Governmental Organizations, Civil Society Organizations	Cary James	United Kingdom
	Tamás Bereczky	Hungary
	Lella Cosmaro	Italy
	Monica Dan	Romania
	Nikos Dedes	Greece
	Anna Zakowicz	The Netherlands
Learned Societies and Academia	Jens Lundgren	Denmark
	Deniz Gokengin	Turkey
Euro HIV EDAT project	Jordi Casabona	Spain
Clinicians	Justyna Kowalska	Poland
International agencies	Lali Khotenashvili	WHO EURO
Contractor-HIV in Europe	Dorthe Raben	Denmark
	Ann Sullivan	United Kingdom
	Ida Sperle	Denmark
ECDC	Andrew Amato	
	Caroline Daamen	
	Helena de Carvalho Gomes	
	Teymur Noori	
	Anastasia Pharris	
	Lara Tavoschi	
	Goritsa Zlatanova	
Apologies	Anne-Françoise Gennotte	Belgium
	Dagmar Hedrich	EMCDDA