Delivery of HIV test results, post-test discussion and referral in health care settings: a review of guidance for European countries

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Objectives
HIV testing and counselling (HTC) guidelines support and promote best practice among service providers. Few European countries have national HTC guidelines and most rely on guidance from regional and international bodies. This study examines recommendations in current pan-European and global guidelines regarding test result delivery, post-test discussion and referral pathways in health care settings, and reviews the types of evidence upon which recommendations are based.

Methods
A systematic review and comparative content analysis of relevant guidelines identified through a literature search and review of targeted organization websites were carried out.

Results
One global and three pan-European guidelines were reviewed. There was general consensus that any test result should be confidential and delivered privately to a patient; positive results should be delivered in person by a health care professional; negative test results could also be delivered by telephone, text message or post. Analyses show conflicting guidance relating to the provision of post-test counselling, and inconsistencies in referral pathways to specialist treatment for positive test results. There is limited reference to published evidence in support of recommendations. Instead there is heavy reliance on expert opinion/consultation and other previous/existing guidelines when developing guidelines. Scientific evidence, where stated, is often more than ten years old, and based predominantly on US/UK research.

Conclusions
While largely in agreement, current pan-European and global HTC guidelines have inconsistencies, particularly regarding post-test counselling and referral pathways to specialized services. Our findings highlight the need for an up-to-date review of more current evidence from wider European settings to support the process of expert consultation.

Keywords: Europe, guidelines, HIV testing, post-test counselling, referral

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Introduction
HIV testing and counselling (HTC) is a critical gateway to further services, and is essential for effective HIV prevention and treatment [1]. The overall goal for HTC in national HIV responses is to identify as many people as possible with HIV infection early in their infection and enable them to make choices about their practices and health [1,2]. This also involves linking them successfully to prevention, treatment and care services, as well as linking those who test negative to prevention services [1,2]. This paper focuses on guidance for European countries about the latter stages of the HTC
process. This includes the delivery of test results, post-test counselling, and referral to specialist services. Various client- and provider-initiated strategies for HTC are offered through health facility and community-based approaches. The expansion of HTC in communities beyond health care facilities remains vital for providing large numbers of people with timely access to regular HTC [3]. This paper focuses on guidelines relevant to health care settings.

Clinical guidelines and recommendations about best clinical practice are systematically developed statements and documents designed to assist health practitioners and patients make decisions about appropriate health care in specific circumstances [4–6]. Guidelines exist at national, regional and global levels, and are important for a number of reasons. For health care professionals, guidelines can improve the quality of clinical decisions and activities, offering specific recommendations for professionals who are uncertain about how best to proceed or are not aware of the latest information [6]. In a context of rising costs of health care, guidelines are also useful for ensuring cost-effective quality improvement in health care settings [6]. From a patient perspective, guidelines are designed to improve quality and consistency of care, and health outcomes. Guidelines can identify under-recognized health problems, clinical services and preventative interventions, as well as marginalized patient populations and high-risk groups [6].

There are potential limitations of guidelines, and the development of guidelines does not ensure their implementation and use in practice [7,8]. Guidelines may be substantively constrained when the scientific evidence about what to recommend is limited [6], and/or when recommendations substantially reflect the opinions and clinical experience, and the composition, of the team developing the guidelines [6]. In such situations, particular health care practices may be prioritized without sufficient appropriate evidence, and with insufficient focus on patients’ needs as a priority in decisions [6]. Regional and global guidelines may be developed without sufficient attention to the variety of national contexts to which they may apply.

A number of European and global guideline documents have been developed to support and promote best practice in relation to HIV testing. These include regional guidelines from the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) [9], HIV in Europe [10], the European Centre for Disease Prevention and Control (ECDC) [11], the European Office of the International Union against Sexually Transmitted Infections (IUSTI Europe) [2] and the World Health Organization Regional Office for Europe (WHO Europe) [12], and global guidelines from the Joint United Nations Programme on AIDS (UNAIDS) and WHO Headquarters [13,14]. To date, little work has examined the recommendations contained in these guidelines. In this paper, we review and synthesize the best practice guidelines for European contexts, including global guidelines, relating to the delivery of an HIV test result, post-test discussion/counselling, and referral to specialist services. This is done with the aim of documenting the various best practice recommendations made in guidance documents, establishing the extent of variation across recommendations in these documents, and examining the evidence used to support the recommendations.

Methods
Identification of guidelines

Guideline documents were identified via a targeted internet-based search of published documents on websites of organizations known to be involved in developing recommendations and guidelines regarding HIV testing and HIV service delivery, including UNAIDS, WHO, ECDC, EMCDDA and IUSTI. We also undertook an internet-based search to identify any further guideline documents, using the following search terms: ‘HIV testing AND guidelines OR recommendations’, ‘HIV counselling AND guidelines OR recommendations’, ‘HIV testing and counselling AND guidelines OR recommendations’.

We identified four guideline documents for review: ‘Scaling up HIV testing and counselling in the WHO European Region, policy framework’ from WHO Europe [12]; ‘HIV testing: increasing uptake and effectiveness in the European Union, ECDC guidance’ from the ECDC [11], ‘2014 European Guidance on HIV testing’ from IUSTI [2], and ‘Guidance on provider-initiated HIV testing and counselling in Health Facilities’ from WHO/UNAIDS [14]. These guideline documents were included as they specifically focus on the delivery of HTC in Europe (WHO Europe, ECDC and IUSTI guidelines [2,11,12]) or are globally applicable (WHO/UNAIDS guidelines [14]). This review focussed specifically on HTC in health care settings; procedures relating to self-testing and community-based testing were not addressed consistently, or with any procedural detail within the four guidelines under review. Guidelines that focus on the delivery of HTC in settings outside the WHO Europe Region were excluded from the review, as were guidelines that specifically focus on issues pertaining to particular population groups, such as couples [13], people who use drugs [9,15], refugees [16] or institutionalized adolescents or adults [17] We also excluded guidance focussing primarily on the identification of people to test [10]. National guidelines are also outside the scope of this review.
Data extraction and synthesis

The review of guideline documents consisted of three processes. First, all recommendations included across all guideline documents were listed. Recommendations were divided into three components of HTC: the delivery of HIV test results; the provision of post-test counselling; and referral pathways. Secondly, a comparative analysis of recommendations examined where there were similarities and differences between the guidance documents. Thirdly, the evidence used to support the various recommendations made in each guidelines document was examined. Three types of sources of evidence are distinguished: other guidelines (i.e. one set of guidelines refers to another set of guidelines in support of a particular recommendation), expert opinion (i.e. evidence seemingly gathered from expert committee reports, as well as through consultation of health/policy professionals and community/patient organizations), and publications documenting primary research. This evidence was then graded using the criteria developed by the US Agency for Healthcare Research and Quality for grading scientific evidence [18] (see Table 1).

The technical guidance document produced by WHO Europe [19] to support its recommendations could not be included in the assessment of evidence as it is not available online, and could not be obtained from the WHO Europe Regional Office, despite repeat email requests.

Results

Delivery of test results

Table 2 presents the different recommendations regarding the delivery of test results included in guideline documents reviewed in this study.

A main focus of recommendations regarding delivery of test results is on the confidential delivery of results in person or via other secure communication channels, which depends on whether a positive or negative test result is being communicated. There is general agreement that a positive HIV test should be given in person, in private and in confidence [2,11,12,14]. Some guidelines suggest that a positive result should be given to the patient by the health care worker who performed the test [12], while other guidelines recommended that positive test results can also be provided by other health care providers or trained lay personnel [14]. Evidence used to support these recommendations included information gathered from expert consultation (Grade IV; WHO/UNAIDS guidelines [14]), other Grade IV evidence, although specific references were not provided (ECDC and IUSTI guidelines [2,11]), and cross-reference to other current guidelines (ECDC guidelines [11]).

Guidance from the ECDC and IUSTI suggests that it may be appropriate for a health care professional to inform a

<table>
<thead>
<tr>
<th>Grade</th>
<th>Explanation</th>
</tr>
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<tbody>
<tr>
<td>Ia</td>
<td>Evidence obtained from meta-analysis of randomized controlled trials</td>
</tr>
<tr>
<td>Ib</td>
<td>Evidence obtained from at least one randomized controlled trial</td>
</tr>
<tr>
<td>Ia</td>
<td>Evidence obtained from at least one well-designed controlled study without randomization</td>
</tr>
<tr>
<td>Iib</td>
<td>Evidence obtained from at least one type of well-designed quasi-experimental study</td>
</tr>
<tr>
<td>III</td>
<td>Evidence obtained from well-designed, nonexperimental descriptive studies, such as comparative studies, correlation studies and case-control studies</td>
</tr>
<tr>
<td>IV</td>
<td>Evidence obtained from expert committee reports or opinions and/or clinical experience of respected authorities</td>
</tr>
</tbody>
</table>

Table 2 Recommendations in regional and global guideline documents regarding delivery of HIV test results

<table>
<thead>
<tr>
<th>Regional guidelines</th>
<th>Global guidelines</th>
<th>Grade of evidence to support guidance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any test result</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always deliver result</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Test result given clearly/directly</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Confidential delivery in private</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV-positive test result</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always provided in person</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Provided by health care worker who performed the test, or by other trained health care providers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive test result with sufficient time for discussion</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>HIV-negative test result</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Face to face, with possible delivery by telephone, text message or post</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Face-to-face delivery of a negative result enables health promotion</td>
<td>Y</td>
<td>Y</td>
</tr>
</tbody>
</table>

ECDC, European Centre for Disease Prevention and Control; IUSTI, International Union against Sexually Transmitted Infections; UNAIDS, Joint United Nations Programme on AIDS; WHO, World Health Organization; Y, yes: recommendation is included in the guideline document.
patient of a negative test result via telephone, text message or letter [2,11], if this helps to streamline service delivery and reduce the number of occasions on which patients do not receive test results because they do not return to the health service [11]. IUSTI guidance specifies that face-to-face delivery of HIV test results is generally preferred, but alternative methods may be appropriate in some (unspecified) circumstances [2]. Most guidelines recognize that providing an HIV-negative result in person offers a chance to engage patients in sexual health promotion and risk reduction [2,11,14]. Reference to published research in support of recommendations to inform a patient of a negative test result by telephone, text message or letter was provided in the ECDC guidance [11]. This included one Grade IV opinion paper [20] to argue that this is satisfactory to streamline the HIV testing process. Three Grade III studies from the USA [21,22] and Australia [23] argued that this reduces instances in which people do receive test results because they do not return for their test results. Two Grade III studies from the UK [24,25] also illustrated success in using telephone or letters as a means of delivering test results.

Post-test discussion

Post-test counselling is defined as a ‘discussion following a test result designed to provide advice on how to proceed in light of the result’ [14]. Two different approaches to such post-test discussion are evident in guidelines. The first is reflected in WHO/UNAIDS [14] and WHO Europe [12] guidelines, which recommend post-test discussion to be delivered by a health professional when the test result is communicated to a patient. The second approach is reflected in guidance from the ECDC [11], which recommends that detailed post-test discussion should be delivered by a specialist HIV team at the referral service. In this situation, the health care worker delivering a test result should at least provide details of local specialist services to patients who require further support. IUSTI guidelines specify either option as suitable, and recommend that ‘appropriate support should be available on site or through referral to address the behavioural, psycho-social and medical implications of HIV infection’ [2]. An analysis of the guidelines revealed that no published evidence is used to support either of these positions, with reliance instead on expert opinion.


Recommendations about the different components of post-test discussion for people receiving positive and negative HIV test results are not based on any published research. Instead, guidelines from WHO/UNAIDS [14] and IUSTI [2] rely on expert opinion and other guidelines. The ECDC guidelines [11] refer to a US Grade III qualitative study [26] examining HIV-positive patient experiences regarding what parts of the post-test counselling process were perceived as most important. Patient responses included the compassion and emotional support of the counsellor, HIV-related education or information, referrals for both medical and social services, safe sex education, partner notification and the confidentiality of the session.

Referral to specialist HIV-related services

In the ECDC guidelines, a referral pathway is defined as ‘[a] series of steps designed to ensure referral of patients to appropriate services [which is] developed by establishing relationships between sexual health services and relevant healthcare agencies and involves a shared understanding and agreed ways of working together to better address the sexual health needs of a defined population’ [11]. ECDC guidelines [11] recommend that clear referral pathways should be in place in advance of the delivery of test results and provision of post-test discussion, so that health care workers can contact specialist HIV services immediately to enable treatment promptly. Guideline documents from the ECDC [11] and WHO/UNAIDS [14] state that referral works best when a health care provider makes immediate contact with specialist services in the presence of a patient and schedules an appointment for them, leading to prompt specialist treatment. These recommendations are based on reference to other guidelines as evidence, rather than any published research.

Table 4 presents recommendations about treatment and prevention services that should be provided to people receiving a positive test result. WHO/UNAIDS global guidelines [14] are substantially more comprehensive with respect to referral recommendations than regional European guidelines. Expert opinion is used more than published research to support recommendations for referral to specialist services for people who test HIV positive. The ECDC guidelines reference three Grade III studies [27–29] to highlight the need for partner referral, partner contact tracing, and counselling and support for behaviour change to prevent transmission to sexual and drug use partners. IUSTI guidelines draw on one Grade III study [30] to recommend the need for continuous monitoring of viral and immunological parameters for HIV infection, regular, comprehensive and easily accessible monitoring of other sexually transmitted infections (STIs), and repeated sexual
risk reduction counselling in a context of sympathetic, nonjudgemental sexual history taking.

Recommendations about referral to services for people receiving a negative test result include referral to HIV and other prevention services (e.g. sexual health services, drug-dependence treatment and needle exchange programmes) [11,14], extensive post-test counselling [11,14], post-exposure prophylaxis [14], and retesting for negative partners in serodiscordant relationships [11,12]. No published research is referenced to support recommendations regarding services needed for patients receiving a negative HIV test result.

Discussion

This study examined recommendations in current regional and global guidelines regarding HIV testing in health care settings in Europe, with respect to delivery of the test result, post-test discussion and referral to specialist services. The study also assessed the evidence upon which recommendations were based. This analysis is particularly timely given the dates when the guidelines under review were last published. The guidelines by IUSTI [2] were recently updated, in 2014. However, given the pace of change in HIV testing practice – including rapid and home-based testing, for which guidelines are very limited – it is important that regional guidelines by ECDC and WHO Europe (both published in 2010) and global guidelines by WHO/UNAIDS (published in 2007) are updated.

There are several important areas of agreement that stand out in the recommendations across these guidelines. With regard to the delivery of HIV test results, there is consensus in recommendations that any test result should be confidential and delivered to a patient in private. It is also generally recommended that a positive result should be delivered in person by a health care professional, while
there may be circumstances in which a negative test result could be delivered by telephone, text message or post. Nevertheless, guidelines from ECDC, IUSTI and WHO/UNAIDS [2,11,14] emphasize that face-to-face delivery of a negative HIV test result offers an opportunity to provide a patient with health promotion activities.

With regard to post-test discussion after a positive HIV test result, all guidelines recommend that patients are provided with information about the follow-up treatment services available in the health facility and at other services in the community, and that an appointment is made for immediate referral to specialist services [2,11,12,14]. There is also consensus across IUSTI [2], WHO Europe [12] and WHO/UNAIDS [11,12,14] guidelines that a patient should be assisted with determining which friends or family may be available and acceptable to offer support, and that the health professional should provide information about transmission prevention and discuss possible disclosure of the test result and contact tracing, including partner notification.

There is also general agreement about the desirability of specifying referral pathways prior to an HIV test being undertaken and the test result being delivered. The guideline documents also agree that the following specialist services should be included in the referral pathway for a positive test result: antiretroviral therapy, psychosocial support services, risk reduction counselling, and voluntary disclosure, partner notification and contact tracing. Three of the four guideline documents agree that sexual/reproductive health services (ECDC, WHO Europe and WHO/UNAIDS [11,12,14]) and drug treatment, access to sterile needles, and opioid substitution therapy (IUSTI, WHO Europe and WHO/UNAIDS [2,12,14]) should also be included in referral pathways.

However, there are also areas where recommendations provided by guidelines differ. Only the recent WHO/UNAIDS [14] guidelines suggest that aspects of HTC can be provided by trained lay personnel, under the supervision of health care professionals, to help overcome chronic staff shortages in some settings. Furthermore, whereas WHO/UNAIDS [14] and WHO Europe [12] guideline documents advise that post-test discussion should be provided by a health professional or other trained person at the time of test result delivery, the ECDC [11] guidelines propose that this should be done by a specialist HIV team after referral. The former model ensures that each patient tested for HIV receives some form of post-test discussion, whether they test positive or negative, whereas the latter model may favour the provision of quality post-test discussion, but only for people who test HIV positive; people who test HIV negative may not receive post-test discussion and there is also a risk that someone in need of immediate post-test discussion may not receive it sufficiently quickly.

Recency of the development of the guidelines does not seem to explain this difference in recommendations, with WHO/UNAIDS guidelines published in 2007 and WHO Europe as well as ECDC guidelines published in 2010. The latest guidelines from IUSTI [2], published in 2014, specify either option as suitable, as long as appropriate support is in place. This divergence in recommended models for delivery of post-test discussion may reflect the finding that

<table>
<thead>
<tr>
<th>Treatment services</th>
<th>Regional guidelines</th>
<th>Prevention services</th>
<th>Regional guidelines</th>
</tr>
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<tbody>
<tr>
<td><strong>Management and treatment of opportunistic infections</strong></td>
<td></td>
<td><strong>Sexual/reproductive health services</strong></td>
<td></td>
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<tr>
<td><strong>Co-trimoxazole prophylaxis</strong></td>
<td></td>
<td><strong>Conception counselling for serodiscordant couples</strong></td>
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<tr>
<td><strong>TB screening and treatment</strong></td>
<td></td>
<td><strong>ART for prevention in serodiscordant couples</strong></td>
<td></td>
</tr>
<tr>
<td><strong>STI case management/treatment</strong></td>
<td></td>
<td><strong>Drug treatment, access to sterile needles, and opioid substitution therapy</strong></td>
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both recommendations are based on expert opinion rather than published research directly comparing the different approaches and/or gathering information on user client preferences.

The reviewed guideline documents, including the most recent IUSTI guidelines [2], provide limited recommendations regarding the specialist services that patients receiving a negative test result should be referred to. There are also notable gaps in regional guidelines from WHO Europe [12] and ECDC [11] about the specialist services that should be available to patients receiving a positive test result. Clinicians prefer simple, patient-specific and user-friendly guidelines that are limited to the major decision points, ensuring that guidelines do not become too unwieldy to use in practice [5]. However, the lack of guidance regarding which specific services might be required for a newly diagnosed HIV-positive person raises questions about the extent to which these patients gain access to appropriate services. The lack of guidance regarding referral pathways may also have an impact on drop-off throughout the HIV continuum of care. There is no mention in the reviewed guidelines of referring people who test HIV negative for pre-exposure prophylaxis (PrEP) to prevent HIV infection. While guidelines were mostly developed before publications on the efficacy of PrEP, this absence in the most recent HIV testing guidelines may also reflect the broader paucity of referral recommendations for people who test HIV negative. Alternatively, debate regarding the role of PrEP in HIV prevention is ongoing and dedicated guidelines are emerging [31,32].

There is a heavy reliance across guidelines on expert consultation in support of recommendations. While expert opinion is invaluable, it is unclear to what extent such expert opinion is based on familiarity with and/or systematic reviews of the published evidence base, experience in health service delivery, patient perspectives and preferences, and/or concerns about service efficiency and cost savings. We also do not know the extent to which experts from different parts of the WHO European Region were involved in guideline consultation processes. Furthermore, there are many instances throughout the reviewed guideline documents where evidence to support recommendations is possibly self-referential (i.e., they reference other existing guidelines as evidence for recommendations). It is unclear why published research is rarely referenced in support of recommendations made in the guidance documents. It remains to be established if the required research evidence does not exist, if it is not perceived to exist, if there is insufficient access to the full range of research that has been published, or if there is no perceived need to access this evidence, possibly because experts are being consulted in the process of guideline development.

Much of the limited published research evidence that is referred to in the reviewed guidelines is over ten years old. Updates of guidelines are needed to incorporate more recent studies. Also, the majority of research studies referenced as evidence in these guideline documents are based on research conducted in the USA or the UK. The extent to which these research findings are relevant to diverse European contexts, especially to countries in Central and Eastern Europe, is unknown. Our findings highlight the need for up-to-date reviews of recent evidence of best practice regarding the delivery of test results, the provision of post-test counselling and referral pathways to specialist care. Such reviews would usefully inform and complement expert consultation processes in the development of future HTC guidelines. Given the cost and ethical challenges of undertaking rigorous experimental evaluation of testing models, it would also be useful to document experiences of poor practice, from the perspectives of clients, as a way of learning about what can be done better in the future.

As relevant research evidence may be limited, there is a clear need for original research to inform recommendations regarding delivery of HIV test results, post-test discussion and referral pathways. In view of the paucity of patient perspectives included in the evidence used to date, we stress the importance of conducting well-planned, rigorous qualitative and quantitative studies examining clients’ perspectives and preferences relating to their experiences of receiving test results, post-test discussion and referral to other services. Such service user perspectives are particularly important when trying to understand the impact of current changes in testing paradigms and the introduction of new technologies, such as rapid and home-based testing.

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