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Barriers to HIV testing in Europe: a systematic review

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Background: In the European Union (EU) and neighbouring countries, HIV/AIDS, of all infectious diseases, has one of the highest morbidity and mortality rates. An estimated 30% of people living with HIV are unaware of their infection, and may therefore not benefit from timely treatment or may transmit HIV to others, unknowingly. Evidence shows that opportunities are being missed to diagnose HIV infections in EU Member States, particularly in regular health care settings. There is a need to better understand the barriers to HIV testing and counselling with the aim to contribute to the decrease of the number of undiagnosed people. **Methods:** A systematic review of literature on HIV testing barriers in Europe was conducted, applying a free text strategy with a set of search terms. **Results:** A total of 24 studies published in international peer-reviewed journals and meeting the review's eligibility criteria were identified. Fourteen studies report on barriers at the level of the patient; six on barriers at health care provider level and seven on institutional barriers referring to the policy level. The barriers described are centralized around low-risk perception; fear and worries; accessibility of health services, reluctance to address HIV and to offer the test; and scarcity of financial and well trained human resources. **Conclusions:** Some barriers to HIV testing and counselling have been illustrated in the literature. Nevertheless, there is lack of structured information on barriers considering (i) legal, administrative and financial factors, (ii) attitudes and practices of health care providers and (iii) perception of patients. Such data is critical to improve effectiveness of HIV testing and counselling.

Keywords: HIV, HIV testing, Europe, missed diagnoses, barriers, systematic review

Introduction

Of all infectious diseases, HIV infection continues to significantly contribute to morbidity and mortality in the European Union (EU) and neighbouring countries.[1] EU Member States have committed themselves to provide universal access to comprehensive HIV prevention programmes, treatment, care and support services by 2010.[2,3]

Undeniably, diagnosing HIV infected persons is a necessary, however insufficient, element in achieving universal access to treatment, care and support services, as well as for prevention of further transmission. In EU Member States and European Economic Area (EEA)/European Free Trade Association (EFTA) countries, estimates of people living with HIV being unaware of their infection range from 12% to more than 50%.[4]

To facilitate diagnosis and access to HIV-related services, there is a need to move away from a sole reliance on client initiated HIV testing, venturing additional methods such as provider-initiated HIV testing. Against this background, the US CDC revised their recommendations for HIV testing for adults, adolescents and pregnant women in health care settings in 2006, proposing that HIV testing should be part of routine clinical care, while preserving patient's right to decline from the systematic HIV testing offer.[5] This call for a routine offer and recommendation of HIV testing in health care settings, including the adoption of the opt-out approach whereby people are tested unless they clearly refuse, has also been integrated in the new WHO and UNAIDS guidelines (2007) on provider-initiated HIV testing and counselling in health facilities.[6]

Antiretroviral therapy (ART) has proven to be effective in reducing the progression of HIV disease and clinical studies have indicated that maximum benefit in terms of reduced morbidity and mortality is obtained when HIV infection is diagnosed and treated early.[7,8] Although there is no common definition for late diagnosis across Europe,[9] research has revealed that a considerable number of individuals unaware of their infection remain undiagnosed until they present in an advanced stage of HIV disease or with an AIDS-related condition.[10–13]

In the UK and Ireland, a review to assess the occurrence of late diagnosis and associated features was performed among participants with newly diagnosed HIV infection. A significant number of missed opportunities for earlier diagnosis of HIV infection were identified, particularly at the time of consultations for clinical symptoms in the preceding 12 months.[14] Another study conducted in the UK revealed that either patients do not access health care when they have typical sero-conversion symptoms, or health care providers, most notably in primary care, do not make the diagnosis when patients present to them with suggestive symptoms.[13] In a survey among newly diagnosed HIV-positive Africans attending HIV treatment centres across London (UK), 50% of participants presented with late stage disease despite high primary and secondary care use prior to HIV diagnosis.[15]

Increasing uptake of HIV testing and counselling and decreasing the number of undiagnosed people is identified as a priority area for HIV prevention.[16] To this end, better understanding of the factors that obstruct (early) HIV testing, as experienced by clients (patients) and health care providers, as well as the barriers at institutional or policy

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level is urgently needed. Against this background, we conducted a systematic literature review on barriers to HIV testing and counselling in Europe.

Methods

Relevant scientific publications were searched using PubMed and ISI Web of Science, two electronic search engines integrating data from several bibliographic databases. The review was accomplished by using broad search terms and the results being checked to eliminate the possibility of relevant items being missed. A free text strategy was applied, utilizing the following terms: (testing OR testing practices OR testing barriers OR late diagnosis OR late presenter) AND (HIV OR AIDS) AND (1997–2008) AND Europe.

To be eligible, articles needed to be published in English between 1997 and 2008 in a peer-reviewed journal, and report on HIV testing barriers in Europe as a primary study endpoint.

Two of the authors independently screened all of the identified study titles. Those not deemed relevant were disregarded and duplicates removed. Based on the above eligibility criteria, both authors assessed the abstracts. For the included abstracts, the full paper was analysed and again checked for eligibility. Disagreements were solved between the two review authors. The reference lists of retrieved articles were hand searched for other key papers.

In order to gather all existing evidence, any empirical study regardless of practice setting, methodology, response rate and other bias was included. Each barrier in a study was extracted and categorized according to the level where the barrier is experienced: institutional/policy, health care provider or client/patient level. Although some barriers are exclusive to a certain level, it is acknowledged that barriers at institutional/policy level may have an impact at provider and client/patient level. To solve this overlap, barriers at institutional/policy level were defined as structural and contextual factors surrounding HIV testing, whereas barriers at provider and client/patient level were considered to be person driven.

Results

Using the predefined search terms, 1293 potential manuscripts were identified (figure 1). After initial review for relevance and duplication, 257 abstracts remained to be screened for eligibility. Seventy-four articles were retrieved for full text analysis using the same inclusion criteria. Studies for which no full text in English was obtainable were excluded, as well as those based on data from the early 1990's, before therapeutic interventions that improve the clinical outcome of HIV infection had become available. The reference list of the selected articles was checked for other key papers and this resulted in the inclusion of another six papers. In total, 24 articles met the eligibility criteria and were included in the review (table 1).

The studies included were conducted in the UK ($n=15$); the Netherlands ($n=4$); Russia ($n=2$); Hungary ($n=2$); Italy ($n=1$); Switzerland ($n=1$); the Balkans ($n=1$). The majority of studies—14 out of 24—provided information on barriers experienced at clients' or patients' level. Six studies identified barriers at health care provider level revealed by general practitioners (GPs), midwives and key informants working in the field of HIV and African communities in the UK, including clinical doctors, health promotion specialists and volunteers. Barriers at institutional or policy levels were highlighted in seven studies, incorporating the views of public health officials, prison authorities and directors of drug treatment centres (table 2).

Barriers at client/patient level

At this level, barriers identified were categorized into low-risk perception, fear of HIV disease, fear of disclosure and accessibility of health services.

Low-risk perception

According to a retrospective study of a large ethnically diverse HIV infected clinic population in South London, only 41% of the HIV infected black Africans were administered an HIV test because they perceived to be at high risk, compared to 72% of the HIV infected native population.[17] Key informants working in the field of HIV and African communities felt that HIV awareness within African communities in Britain is high but this does not translate into a perception of individual risk. This was considered a major issue influencing the uptake of HIV services.[18] In a survey among newly diagnosed HIV-positive Africans attending HIV treatment centres across London (UK), nearly 70% of respondents (169/256) declared that before being diagnosed they had not considered the possibility of being HIV positive. This was reflected in the fact that 64% were not expecting a positive result at the time they tested HIV positive. More than half the respondents did not perceive ill health.[15]

A questionnaire survey among pregnant women, who did not accept an HIV test in an antenatal clinic in London, showed that the main reason for declining was that they did not consider themselves at risk. However, it was also demonstrated that this belief was based on patchy HIV knowledge and that some women did not have enough information to decide on HIV testing even after having received an information leaflet on HIV in pregnancy.[19]

In a large-scale Internet-based survey among Dutch men who have sex with men (MSM), 43% of respondents ($n=1627$) stated that they had never taken an HIV test. In this group of test naïve MSM, low-risk perception was considered as an important reason for not taking an HIV test although 56% of them reported risky sexual behaviour.[20] In a survey among MSM in a sexually transmitted infections

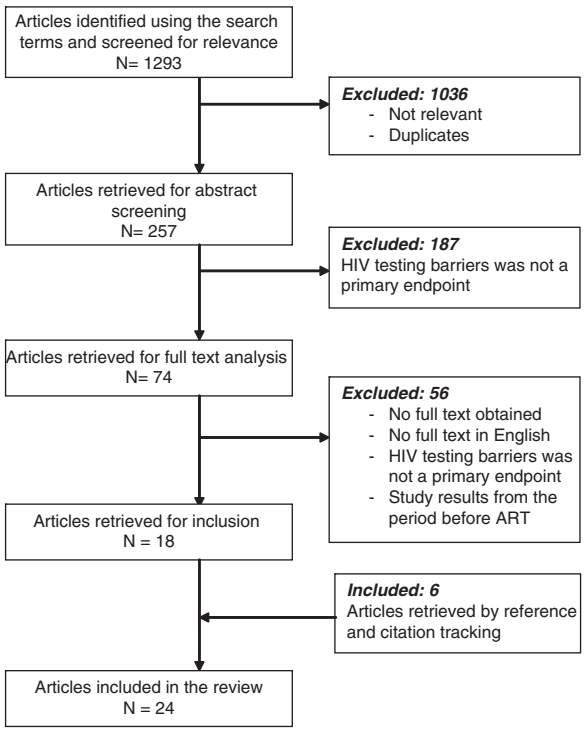

Figure 1 Flow diagram of the article selection process

Table 1 Barriers to HIV testing and counselling—overview retrieved studies

	References	Country	Aims of the study	Study design	Study population	Sample
1	Gibb *et al.*[30]	UK	To measure the uptake of antenatal HIV testing and determine its relation to risk of HIV and to screening practices	Multicentre prospective questionnaire survey	Pregnant women attending six maternity units	$n = 18\,791$
2	Kellock and Rogstad,[34]	UK	To identify which HIV risk groups are identified by GPs, and to elicit their anxiety associated with the discussion of HIV testing with patients in specific situations	Questionnaire survey	General practitioners	$n = 48$
3	Tookey *et al.*[35]	UK	To determine the relationship between screening strategy, uptake of testing and detection rate	Survey making use of data from unlinked anonymous sero-prevalence studies and a postal questionnaire survey	UK respondents to the National Study of HIV in Pregnancy	$n = 239$ maternity units
4	Simpson *et al.*[31]	UK	To determine the uptake and acceptability of different methods of a universal offer of voluntary HIV testing to pregnant women	Randomized controlled trial in the main maternity of the city of Edinburg (Scotland) during a 10 month period from May 1996 to February 1997	Pregnant women	$n = 3024$
5	Boyd FM *et al.*[32]	UK	To investigate the effect of the midwife on women's uptake of testing	Knowledge and attitude questionnaire survey, nested within a randomized controlled trial in the main maternity of the city of Edinburg (Scotland)	Midwives	$n = 10$
6	Bollini *et al.*[37]	Hungary; Switzerland and Italy	To assess national HIV prevention policies in prison in a selected group of countries and to determine which factors influenced such policies at the country level	Policy analysis making use of quantitative and qualitative methods including interviews	In each country, informants sought from government officials, non-governmental organizations concerned with HIV/AIDS and prisoners' human rights, and professionals involved in this field	Not mentioned
7	Erwin *et al.*[27]	UK	To examine factors associated with uptake of HIV clinic services by black African HIV-positive people living in London	Questionnaire survey between July 1999 and March 2000	HIV-positive patients attending an outpatient clinic in south London	$n = 392$
8	Aral *et al.*[40]	Russia	To describe the social–organizational patterns of sex work in Moscow	Qualitative study making use of semi-structured telephone interviews, semi-structured face-to-face individual and focus group interviews, systematic and unobtrusive naturalistic observations, and geo-mapping	Sex workers; Key individuals in public health and in charge of STI/HIV prevention; Members of the Moscow City Police; Clinicians providing health services to sex workers in governmental and non-governmental healthcare facilities	Interviews with 30 key informants
9.	Campbell *et al.*[19]	UK	To identify factors that contribute to women's decision to decline and HIV test during their pregnancy	Questionnaire survey conducted from October to December 1997 in an antenatal clinic in London	Pregnant women attending the 16-week antenatal booking appointment and who declined the HIV test	$n = 393$
10	Flowers *et al.*[23]	UK	To provide insight into the psychosocial factors associated with decision-making processes relating to the HIV antibody test	Qualitative study making use of individual in-depth interviews and focus group discussions	Gay men	$n = 19$ interviewees $n = 18$ FGD participants

11	Gyarmathy *et al.*[39]	Hungary	To assess HIV and hepatitis testing in counselling in drug treatment programmes	Qualitative study making use of telephone interviews	Key informants from the largest and most frequently visited drug treatment centres	*n* = 8 key informants (4 in Budapest and 4 in the countryside)
12	Knussen *et al.*[24]	UK	To determine the contributions of a range of psychosocial, demographic and behavioural variables to gay men's to take an HIV test	Cross-sectional questionnaire survey conducted in May 2000	Visitors of gay bars in Glasgow and Edinburgh	*n* = 803 men
13	Aral *et al.*[41]	Russia	To assess the relationship between commercial sex work, drug use and STI (including HIV) in St Petersburg	Rapid assessment methodology including in-depth interviews, naturalistic observations of commercial sex work and drug use sites, geo-mapping, and a critical review of the available surveillance, epidemiology and sociological data	Key informants	*n* = 40 interviewees in St. Petersburg and Moscow: Individuals responsible for AIDS and STI prevention (12); Coordinators of outreach and service programmes (16); Social scientists (6); Needle exchange services (1); Individuals involved in sex industry (8); Police unit tasked with regulating the sex industry (2)
14	Boyd *et al.*[17]	UK	To establish whether there are ethnic differences in demographic characteristics, the stage at HIV diagnosis and reasons for and location of HIV testing in a large ethnically diverse HIV-1-infected clinic population in south London	Retrospective review abstracting data from the hospital computerized database and patient records	All persons >18 years attending King's College Hospital and a random sample of patients attending St Thomas' hospital	*n* = 491 patients with an HIV diagnosis between 1 January 1998 and 31 December 2000
15	Mikolajczak *et al.*[20]	Netherlands	To analyse the reasons for not taking an HIV test among untested MSM	Internet-based survey making use of a questionnaire	Visitors of the largest, free of charge Dutch MSM chat site	*n* = 1627 MSM who had never tested for HIV
16	Burns *et al.*[18]	UK	To identify the key issues affecting utilization of HIV services for Africans in Britain	Qualitative study making use of face-to-face interviews	Key constituencies in the field of HIV and African communities and organizations within these	*n* = 13 interviewees: 3 clinical doctors 1 epidemiologists 5 individuals from voluntary sector 2 health service researchers 2 health promotion specialists
17	Prost *et al.*[29]	UK	To explore the feasibility and acceptability of translating a successful VCT service model from Kenya to African communities in London.	Qualitative study making use of data from focus group discussions and a workshop	People living in African communities in London, and key informants	*n* = 42 respondents from 14 African countries, including young people, people living with HIV and women. 28 key informants including members of African community-based organizations and staff from clinical HIV services.
18	Stokes *et al.*[33]	UK	To determine the uptake of current antenatal testing, the prevalence of risk factors for HIV in pregnant women and the acceptability of the rapid point of care HIV test among pregnant women and their midwives	Cross-sectional survey at a university teaching hospital in the West Midlands, making use of a questionnaire	Midwives	*n* = 72 midwives on the delivery ward

(continued)

Table 1 Continued

	References	Country	Aims of the study	Study design	Study population	Sample
19	Stolte *et al.*[21]	Netherlands	To investigate HIV testing behaviour and HIV prevalence among homosexual visitors of an STI outpatient clinic, and to investigate determinants of unknown HIV status, and of HIV testing separately for men with unknown and negative HIV status.	Cross-sectional survey conducted from March 2002 to December 2003	MSM with negative or unknown HIV status visiting the Amsterdam STI clinic	*n* = 1201
20	Burns *et al.*[15]	UK	To identify opportunities for earlier HIV diagnosis within primary and secondary care settings in the UK in Africans with newly diagnosed HIV infection	Questionnaire survey conducted between April 2004 and February 2006	Newly diagnosed HIV-positive Africans attending 15 HIV treatment centres across London	*n* = 263
21	Delva *et al.*[28]	Bosnia and Herzegovina, FYR Macedonia, Serbia and Montenegro	To examine the uptake of HIV testing and associated predictors	Cross-sectional survey making use of a multiple-choice questionnaire, conducted in December 2004	High school students	*n* = 2150
22	Forsyth *et al.*[22]	UK	To describe reasons why high-risk patients decline HIV testing and whether offering rapid point of care testing along with standard testing would increase the uptake of HIV testing in two London GU medicine clinics	Cross-sectional survey making use of a questionnaire, conducted from May 2006 to February 2007	First time or rebooked patients attending GU medicine clinics in London	*n* = 899 patients with unknown HIV status
23	Dukers *et al.*[26]	Netherlands	To evaluate the effectiveness of the opt-out approach in HIV testing	Document analysis making use of data from laboratory surveillance data and consultation records from the period 2003–07	Patients attending an STI clinic in South Limburg	*n* = 12 949 consultation records
24	Heijman *et al.*[25]	Netherlands	To assess the effect of the opt-out strategy on the uptake of HIV testing and to identify factors associated with refusal of HIV testing	Document analysis based on consultation records from 1995 to 2007	Patients attending an STI outpatient clinic in Amsterdam	*n* = 25 221 consultation records from 2007

Table 2 Barriers to HIV testing and counselling by population group

Population group concerned	References	Country	Barriers encountered	How barriers were ascertained
IDU	Gyarmathy *et al.*[39]	Hungary	Institutional/policy level: Lack of resources Lack of training of staff Lack of guidelines	In-depth interviews with key informants based on an interview guide addressing the provision of HIV testing and counselling services and if the case, reasons for not providing these services
Migrants	Erwin *et al.*[27]	UK	Client/patient level: Fear of dying Worries about confidentiality Concerns about entitlement to medical care Lack of knowledge on where to obtain an HIV test	Survey respondents indicated pre-test concerns from a provided list of alternatives
Migrants	Boyd *et al.*[17]	UK	Client/patient level: Misperception of risk	Reasons for the HIV test were retrieved from medical records: Study site 1: reasons for the HIV test, based on a pre-fined list of alternatives. Study site 2: patients were assumed to have tested for perceived risk if the patient or the physician viewed the behaviour or exposure as high risk, or if there was no alternative documented reason
Migrants	Burns *et al.*[18]	UK	Client/patient level: Low perception of personal risk Worries about confidentiality, related to stigma and the immigration process Lack of accessible information on the use of health services Lack of knowledge on where to obtain an HIV test Language problems Health care provider level: Inability of clinicians to address HIV effectively Reluctance to offer the HIV test Institutional/policy level: Lack of resources Lack of political will Lack of advocacy	In-depth interviews with key informants based on an interview guide addressing perception of health services, the barriers to accessing care and the pathways into HIV care
Migrants	Prost *et al.*[29]	UK	Client/patient level: Worries about confidentiality Worries due to HIV-related stigma Worries about professional standards in community-based testing services	FGD based on an interview guide exploring the opportunities and challenges in setting up community-based VCT services in London, including barriers related to the uptake of an HIV test
Migrants	Burns *et al.*[15]	UK	Client/patient level: Low appreciation of personal risk Lack of perceived ill health Afraid of the result Lack of knowledge on the benefits of testing Afraid of stigma associated with HIV Health care provider level: Clinicians are failing to be proactive in addressing HIV testing with patients coming from high-endemic countries	Survey respondents filled out a set of close-ended questions, covering topics such as utilization of health services prior to HIV diagnosis, behavioural and social factors associated with delayed presentation to treatment services, sexual health and behaviour, HIV history, KAP around HIV/AIDS
MSM	Flowers *et al.*[23]	UK	Client/patient level: Uncertainty about the ability to cope with a positive result	In-depth interviews and FGD based on an interview guide exploring the reasons for (not) having an HIV test; advantages and disadvantages of an HIV test; costs and benefits of knowing one's HIV status
MSM	Knussen *et al.*[24]	UK	Client/patient level: Fear of a positive test result	Based on the answers to the questionnaire, psychosocial, demographic and behavioural variables were linked to intentions to take an HIV test
MSM	Mikolajczak *et al.*[20]	Netherlands	Client/patient level: Fear of a positive test result Fear of the detrimental consequences of a positive test	Survey respondents indicated reasons for not taking an HIV test from a provided list of alternatives

(continued)

Table 2 Continued

Population group concerned	References	Country	Barriers encountered	How barriers were ascertained
MSM	Stolte *et al.*[21]	Netherlands	Client/patient level: Fear of positive test result Not ready to cope with a positive test	Survey respondents indicated reasons for not testing from a provided list of alternatives
Pregnant women	Gibb *et al.*[30]		Health care provider level: No HIV pre-test discussion in one-fifth of the booking interviews Institutional/policy level: Universal offer policy not implemented Maternity unit as the most important factor determining uptake of HIV testing	Within each maternity unit, data on demographic and obstetric factors, including risk factors for HIV infection, were collected by questionnaire. Data were analysed with logistic regression models controlling for hospital, risk category, ethnic group, place of booking interview, age, whether HIV was discussed and testing offered, and the interaction between hospital and risk category
Pregnant women	Simpson *et al.*[31]	UK	Health care provider level: Even providing midwives with the same information during training and clear protocols to work from, uptake rates differ significantly among midwives	Pregnant women in four intervention groups—involving four combinations of written and verbal communication, followed by the direct offer of a test The control group received no information and no direct offer of an HIV test, although testing was available on request
Pregnant women	Tookey *et al.*[35]	UK	Institutional/policy level: Poor performance of antenatal screening strategies in practice	Survey respondents indicated the antenatal HIV testing strategy currently adopted in their unit (universal, selective or on request), the selection criteria and they provided data on uptake of HIV testing over the previous 12 months
Pregnant women	Boyd *et al.*[32]		Health care provider level: Midwives doubting on the benefits of HIV testing achieved lower uptake rates	Survey respondents filled out a set of closed questions assessing knowledge and attitudes with regard to HIV testing Impact of midwives was assessed by examining women's uptake of testing
Pregnant women	Campbell *et al.*[19]		Client/patient level: Do not feel at risk Cannot cope with the result Do not want to know Patchy HIV knowledge	Survey respondents indicated reasons for not taking an HIV test from a provided list of alternatives Survey respondents responded a set of questions covering HIV knowledge
Pregnant women	Stokes *et al.*[33]	UK	Health care provider level: Perceived lack of adequate training in order to cope with the challenges of HIV in pregnancy	Survey respondents filled out a set of questions covering rapid point of care HIV testing
Prisoners	Bollini *et al.*[37]	Hungary; Switzerland and Italy	Institutional/policy level: Prison authorities lack knowledge on the content of international guidelines on HIV/AIDS management in prisons Prison authorities lack knowledge on HIV monitoring techniques	Researchers reviewed in each country national HIV prevention policies, HIV/AIDS surveillance data and data collected through the prison health information system In-depth interviews with key informants
Sex workers	Aral *et al.*[40]	Russia	Institutional/policy level: Repressive measures for performing commercial sex work No free health care for non-Muscovites Voluntary medical insurance available to non-Muscovites does not cover STI services Need for identity papers in order to receive treatment No regular health screening programmes for sex workers as they are not legally recognized as such	In-depth interviews with key informants based on an interview guide addressing the availability, accessibility and acceptability of health services
Sex workers	Aral *et al.*[41]	Russia	Institutional/policy level: Repressive measures for performing commercial sex work and drug use	In-depth interviews with key informants exploring the relative contribution of a series of risk factors to the spread of STIs, including HIV

			Limited coverage of existing STI/HIV prevention programmes	
			Lack of resources to undertake outreach activities for sex workers	
			Lack of ability/resources to maintain prevention efforts which have been initiated by international donors	
STI clinic attendees	Dukers *et al.*[26]	Netherlands	Client/patient level:	Researchers analysed consultation records, retrieving the reasons for test refusal
			Fear of positive test result	
STI clinic attendees	Forsyth *et al.*[22]	UK	Client/patient level:	Survey respondents indicated reasons for not testing from a provided list of alternatives
			Fear of positive test result	
STI clinic attendees	Heijman *et al.*[25]	Netherlands	Client/patient level: Fear of positive test result	Researchers analysed consultation records, retrieving the reasons reported by patient for opting out for an HIV test
Youth	Delva *et al.*[28]	Bosnia and Herzegovina, FYR Macedonia, Serbia and Montenegro	Client/patient level:	Survey respondents indicated reasons for not taking an HIV test from a provided list of alternatives
			Fear of positive test result	
			Worries about confidentiality	
			Uncertainty regarding testing location	
Patients (in general) attending a GP	Kellock *et al.*[34]	UK	Health care provider level:	Respondents were asked about their likelihood to encourage testing in various risk groups, their own feelings of anxiety when discussing the issue of HIV testing. The questionnaire was designed with closed questions and simple linear visual analogue rating scales
			Anxiety when raising the subject of HIV testing	

FGD, focus group discussions; GU, genitourinary medicine clinics; IDU, injecting drug users; KAP, knowledge, attitudes and practices; VCT, voluntary counselling and testing

(STI) clinic in Amsterdam (the Netherlands) and a study among high-risk attendees of two genitourinary medicine clinics in London (UK), low-risk perception was the most important reason for declining an HIV test.[21,22]

Fear of HIV disease

An in-depth exploratory study among MSM in Scotland described the complexity of the decision-making processes related to HIV testing, incorporating psychological and social factors. The uncertainty about the perceived ability to cope with a positive result, leading to fear is highlighted as an important barrier to HIV testing.[23] Another survey among Scottish gay bar visitors showed that the intention to test in those with two or more recent unprotected anal sex partners was attenuated if accompanied by increased fear of a positive test result.[24] The earlier mentioned Internet-based survey among at-risk Dutch MSM indicated that fear of a positive test result and the detrimental consequences for their life and future is the most important obstacle to undertake an HIV test.[20] Fear and not wanting to know or not feeling ready to cope with a positive result were also frequently mentioned reasons for not accepting an HIV test in the cross-sectional survey among MSM in an STI clinic in Amsterdam,[21] as well as in the study among high-risk genitourinary clinic attendees in London.[22]

Although the introduction of the opt-out strategy in a large STI clinic in the Netherlands resulted in a sharp increase in the uptake of HIV testing, Heijman et al.[25] demonstrated that a small group at high risk for HIV, especially MSM, continues to decline the test and that fear is the major reason for opting out. This finding is in accordance with a study evaluating 4 years of standard HIV testing in an STI clinic in South Limburg in the Netherlands.[26]

In a survey among HIV-positive patients attending an HIV outpatient clinic in south London (UK), two-thirds of the black African respondents ($n = 392$) reported fear of dying as an important pre-test concern.[27] In the same line, being afraid of the result was identified as a significant factor refraining from earlier testing in the survey among newly diagnosed Africans in London.[15]

A survey among sexually active youth in Bosnia and Herzegovina, Former Yugoslav Republic of Macedonia, Serbia and Montenegro demonstrated that 6.9% from the test naive respondents reported having renounced from HIV testing despite feeling the need for it. The most frequently mentioned reason for not having sought an HIV test was fear of the diagnosis.[28]

Fear of disclosure

Worries about disclosure and breaches of confidentiality were also considered as an obstacle for seeking HIV testing. Some African migrants reported to be fearful to present for a test as it carries a possibility of meeting people they know—an indirect form of disclosure—potentially resulting in blame and future discrimination.[15] Black Africans testing for HIV at a London hospital were found to be twice as likely as non-Black UK residents to be worried about future discrimination if they tested positive.[27] This fear of disclosure increases when accessing community-based services offering HIV testing[29] as well as when accessing specialist services located in sexual health clinics.[18,27] On the other hand, confidentiality concerns seem also to be related to fears that a positive HIV diagnosis might adversely affect the immigration process.[15,18,27]

In the Balkan survey, fear that confidentiality would be violated was the second most frequently identified barrier to HIV testing among sexually active, untested youth.[28]

Accessibility of health services

Data from studies in the UK showed that migrants experience barriers to access health services for HIV testing and care. A survey among HIV-positive patients attending an HIV outpatient clinic in south London (UK) and a survey among Black African communities in London (UK), reported concerns about where to obtain an HIV test and about entitlement to medical care due to immigration status.[27] This finding has been confirmed by key informants working in the field of HIV and African communities in the UK[18] as well as in the survey among newly diagnosed HIV-positive Africans in London.[15]

African migrants in the UK are frequently not aware that an HIV test can be obtained at sexual health clinics without the need of referral. Appointment systems within clinics were also viewed as intimidating for people not familiar with the system, or with poor knowledge of English.[18]

Uncertainty regarding the location where HIV testing could be obtained was identified as an additional, although less important, barrier to HIV testing among sexually active youth in the Balkans.[28]

Barriers at health care provider level

A multicentre prospective study carried out in 1995–96 in maternity units in London showed that the uptake of the HIV test was higher among women with whom a pre-test discussion about HIV transmission had taken place but that in more than one-fifth of the booking interviews no such discussion was reported.[30] In a randomized controlled trial of pregnant women in Scotland, it was demonstrated that even providing midwives with equal information and clear protocols on how to offer the HIV test, uptake rates differ significantly among midwives, ranging from 15% to 48%.[31] Overall, midwives doubting whether testing was beneficial for all women and whether testing should be promoted achieved lower uptake rates.[32] Based on this, it was concluded that the uptake of an HIV test depends more on the attitude of the individual midwife than the method of offering the test and the time spent on pre-test counselling.[31] A survey among midwives in one antenatal clinic and a number of postnatal wards in a low-prevalence area in the UK showed that all respondents agreed that antenatal HIV testing is important. However, 31 of 70 felt that their training had not adequately prepared them for understanding the challenges of HIV in pregnancy and delivery.[33]

A survey among GPs in the UK revealed that raising the issue of HIV testing in primary care was associated with a high level of anxiety. The majority of GPs rather avoided than promoted the issue of HIV testing, even in high-risk patient groups.[34] Key informants in the field of HIV and working with African communities reported that clinicians outside sexual health clinics and antenatal settings were perceived to be failing to address HIV with their patients. As a consequence, they preferred to recommend attendance at a sexual health clinic rather than to offer an HIV test themselves. This failure implies multiple exposures to health services before an HIV test is undertaken and this process of onward referral complicates the pathway into care.[18] In a survey among newly diagnosed HIV-positive Africans attending HIV treatment centres across London (UK), a total of 59% (146/247) of respondents believed they would have tested earlier if someone had told them they were at risk of HIV, and advice from a doctor was the principal reason for having an HIV test for 40% of respondents. Although primary care was extremely well utilized by this group, HIV testing was not broached by the GP for 82.4% (145/176) of Africans who subsequently tested HIV positive.[15]

Barriers at institutional/policy level

The impact of antenatal HIV testing strategies on the uptake of the test has been demonstrated in the UK throughout the 1990s. At the time when most maternity units in the UK provided testing only at the explicit request of the individual woman or for selected groups of women perceived to be at higher risk, detection rates were low resulting in most HIV infected women remaining undiagnosed at delivery.[35] Possible reasons for this include the difficulty of targeting the appropriate high-risk groups, the poor uptake of testing in those groups, as well as the potentially discriminatory nature of a testing strategy on basis of ethnicity or country of origin. In addition, it was shown that the national policy recommending universal testing in high-prevalence areas was not being implemented. The offer of the test was an exception rather than the norm and the uptake was very low with the maternity unit as the strongest predictor.[30] As a consequence, a universal offer policy was rolled out across the UK during the period 2000–03, resulting in significant improvements in uptake of antenatal HIV testing.[36]

A review of HIV prevention policies in prisons in Hungary, Switzerland and Italy,[37] indicated that these countries adopted some kind of policy irrespective of the burden of HIV infection in the prison system. However, it was also demonstrated that the World Health Organisation (WHO) guidelines (1993) on HIV/AIDS in prisons[38] were fully implemented in the penitentiary HIV prevention policies in Switzerland while only partially in Hungary and Italy. Although these guidelines were written to provide indications to prison administrators on the most appropriate way to perform HIV testing practices among prisoners, as well as to manage and prevent new infections, the most important factor that hampered implementation was the lack of awareness and knowledge on the content of the guidelines.

A survey among key informants to assess the practice of HIV testing and counselling in Hungarian drug treatment settings revealed that testing and counselling services are not provided consistently, and did not have a guidance document or protocol. Lack of funding, staff and office space, as well as lack of training of the staff were identified as main barriers to offering on-site HIV testing and counselling.[39]

Key informants in the field of HIV and working with African communities in the UK noted that political will, advocacy, as well as financial and human resources, are often lacking in order to target African communities in the UK appropriately.[18]

Two qualitative studies among commercial sex workers, one in Moscow and another in St. Petersburg (Russia), demonstrated a few barriers at policy level.[40,41] They describe administrative and legal consequences for performing sex work, including detainment. There is a similar law for anyone suspected of being a drug user. They impact accessing health care, creating hidden populations. In addition, the programme coverage of the existing STI/HIV prevention programmes appears to be limited due to scarcity of financial and human resources.

Discussion

While there is substantial literature on factors associated with higher and lower testing rates, the body of literature addressing barriers that are critical to effective HIV testing is relatively sparse. This finding on the paucity of relevant literature is in accordance with a recent synthesis of literature assessing reasons why physicians do not test for HIV in the USA[42] and a summary of literature on psychosocial barriers to HIV

testing in high-income countries.[43] Although the number of relevant studies was limited, identified barriers could be extracted and categorized.

It appears that low-risk perception constitutes a barrier to HIV testing among HIV infected individuals. A second barrier is associated with fear and worries. The perception of HIV as a deadly rather than a chronic manageable disease is an important cause of fear.[23] African migrants in the UK often seemed concerned about disclosure and confidentiality that are closely related to issues of stigma, discrimination and the migration process.[18,44]

In addition, this population group experiences barriers to access health care services for HIV: black African migrants in the UK reported concerns about where to obtain an HIV test and about entitlement to medical care due to immigration status. Unfamiliarity with the health care system and the concept of routinely seeking HIV testing is an additional obstructing factor to HIV testing.[18,27]

However, as it has been shown that decisions about testing are complex and contextualized, promoting awareness of risk and educating people about the benefits of HIV testing and potential interventions may help to shift the balance toward a decision to be tested.[17,18,20,27] It may also be beneficial to make people aware of laws that protect HIV-positive persons from discrimination and to tackle, through community involvement, HIV-related stigma.[18,28] New approaches to the delivery of testing, including the use of rapid tests and providing tests in locations and conditions that are convenient to clients/patients are highlighted as strategies to overcome barriers.[28,33]

The attitude and the perseverance of the individual health care provider with regard to the offer of the HIV test proved to be important when considering uptake of testing.[31,32] Nevertheless, clinicians, in particular in primary care, seem to be either reluctant to address HIV or are focussing on HIV ineffectively.

In an effort to increase the access to and the uptake of HIV-related services, some authors support the idea that clinicians should be trained to be more proactive and confident in addressing HIV testing.[15,34] This proposal is to be contextualized within the world-wide paradigm shift, the so called normalization, whereby HIV/AIDS is treated like other infectious diseases for which early diagnosis is essential for appropriate treatment and prevention, within the requirements of informed consent and confidentiality.[45] There is even a call for changing the views on how directly health care providers should seek to influence patient choices on testing, in the sense that a kind of soft paternalism is a feature of medical practice which may serve the interest of the fearful.[46]

A survey on unmet needs in Europe for HIV testing, treatment and care showed that testing strategies in a number of countries are also changing, promoting an expansion of testing.[47] In this view, the reported barriers at institutional and policy level, such as scarcity of financial and human resources, as well as the need for more trained staff will require considerable investment.

The methodology applied has limitations that may influence the findings in that it is not a full review, as we only included peer-reviewed studies, published in English language. In this way, grey literature was excluded from the review and this may have biased the results. Another limitation derives from the sparse literature available. More than half of the retrieved articles concern studies performed in the UK, followed by those in the Netherlands. Although a small number of studies were conducted in Hungary, Italy, Switzerland, the Balkans and Russia, we found no evidence in the remaining European countries. This knowledge gap needs to be addressed.

The majority of studies provided information on barriers experienced at client or patient level. Most of these studies were based on data from cross-sectional surveys among HIV-positive migrant patients or untested or HIV-negative MSM reporting testing behaviour and reasons for not taking up an HIV test. The few studies reporting on barriers at health care provider level relied on the experiences from pregnant women, midwives and GPs, as well as from key informants working with African communities and indicating the missed opportunities to diagnose HIV infection earlier. Apart from the evidence which served as background for the shift in the antenatal HIV testing strategy in the UK, information with regard to barriers at policy level is fragmented, lacking a conceptual framework that offers an insight on what works, where and why.

The results of this review showed that there is a need for additional research on HIV testing barriers addressing, amongst others, the views and experiences from clients/patients representing several population groups, health professionals and policy makers. In the context of the current debate to make HIV testing more routinely available in health care settings, it will be crucial to assess whether health care providers are willing and adequately equipped to implement and emphasize provider-initiated HIV testing. It also remains to be seen whether people who undergo HIV testing initiated by a health care provider are as prepared as those who actively seek HIV testing, to cope with the HIV testing process and its follow up. Finally, what impact will the scale up of provider-initiated testing have at the level of the organization of HIV-related services? In other words, it is worth to study whether other barriers will appear, meaning that provider-initiated HIV testing may not be as effective as expected to increase the access to and the uptake of HIV prevention, treatment, care and support services.

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Key points

- The barriers described are centralized around low-risk perception; fear and worries; accessibility of health services; reluctance to address HIV and to offer the test; and scarcity of financial and well trained human resources.
- Most of the data were drawn from cross-sectional studies among HIV-positive African migrants in the UK and untested or HIV-negative MSM in the Netherlands and the UK.
- Studies reporting on barriers at health care provider level relied on the experiences from pregnant women and midwives, as well as on information from key informants working with African communities in the UK.
- Based on the fact that the body of literature addressing barriers to HIV testing in Europe is relatively sparse, it is clear that further exploration of the barriers to HIV testing is needed.

References

1 UNAIDS/WHO. 2008 Report on the global AIDS epidemic, Geneva: UNAIDS/WHO, 2008. http://www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2008/2008_Global_report.asp (15 September 2008, date accessed).

2 UN Declaration of Commitment on HIV/AIDS. United Nations General Assembly Special Session on HIV/AIDS 25-27 June 2001, General Assembly Resolution R.A/RES/S-26/2, 2001. http://www.armaids.am/Download%20Texts/UNGASS_2001_eng.pdf (28 January 2008 date accessed).

3 Dublin Declaration on Partnership to fight HIV/AIDS in Europe and Central Asia. Dublin: Irish EU Presidency 2004 Website. http://www.eu2004.ie/templates/meeting.asp?sNavlocator=5,13&list_id=25 (28 January 2008, date accessed).

4 Hamers FF, Phillips AN. Diagnosed and undiagnosed HIV-infected populations in Europe. *HIV Med* 2008;9(Suppl 2): 6–12.

5 US Centers for Disease Control and Prevention (CDC). Revised recommendations for HIV testing of adults, adolescents and pregnant women in healthcare settings. *MMWR Morb Mortal Wkly Rep* 2006;55:1–17.

6 WHO/UNAIDS. Guidance on provider-initiated HIV testing and counselling in health facilities. Geneva: WHO, 2007.

7 Palella FJ, Delaney KM, Moorman AC, et al. Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. *N Engl J Med* 1998;338:853–60.

8 Kitahata MM, Gange SJ, Abraham AG, et al. Effect of early versus deferred antiretroviral therapy for HIV on survival. *N Engl J* 2009;360:1815–26.

9 Adler A, Mounier-Jack S, Coker RJ. Late diagnosis of HIV in Europe: definitional and public health challenges. *AIDS Care* 2008;21:284–93.

10 Castilla J, Sobrino P, De La FL, et al. Late diagnosis of HIV infection in the era of highly active antiretroviral therapy: consequences for AIDS incidence. *AIDS* 2002;16:1945–51.

11 Easterbrook PJ, Yua LM, Goetghebeur E, et al. Ten-year trends in CD4 cell counts at HIV and AIDS diagnosis in a London HIV clinic. *AIDS* 2000;14:561–71.

12 Sabin CA, Smith CJ, Gumley H, et al. Late presenters in the era of highly active antiretroviral therapy: uptake of and responses to antiretroviral therapy. *AIDS* 2004;18:2145–51.

13 Sudarshi D, Pao D, Murphy G, et al. Missed opportunities for diagnosing primary HIV infection. *Sex Transm Infect* 2008;84:14–16.

14 Sullivan AK, Curtis H, Sabin CA, et al. Newly diagnosed HIV infections: review in UK and Ireland. *BMJ* 2005;330:1301–2.

15 Burns FM, Johnson AM, Nazroo J, et al. on behalf of the SONHIA Collaboration Group. Missed opportunities for earlier HIV diagnosis within primary and secondary healthcare settings in the UK. *AIDS* 2008;22:115–22.

16 Hamers FF, Devaux I, Alix J, et al. HIV/AIDS in Europe: trends and EU-wide priorities. *Euro Surveill* 2006;11:pii = 3083.

17 Boyd AE, Murad S, O'Shea S, et al. Ethnic differences in stage of presentation of adults newly diagnosed with HIV-1 infection in south London. *HIV Med* 2005;6:59–65.

18 Burns FM, Imrie J, Nazroo JY, et al. Why the(y) wait? Key informant understandings of factors contributing to late presentation and poor utilization of HIV health and social care services by African migrants in Britain. *AIDS Care* 2007;19:102–8.

19 Campbell T, Bernhardt S. Factors that contribute to women declining antenatal HIV testing. *Health Care Women Int* 2003;24:544–51.

20 Mikolajczak J, Hospers HJ, Kok G. Reasons for not taking an HIV-test among untested men who have sex with men: an internet study. *AIDS Behav* 2006;10:431–5.

21 Stolte IG, de Wit JB, Kolader ME, et al. Low HIV-testing rates among younger high risk homosexual men in Amsterdam. *Sex Transm Infect* 2007;83:387–91.

22 Forsyth SF, Agogo EA, Lau L, et al. Would offering rapid point of care testing or non-invasive methods improve uptake of HIV testing among high-risk genitourinary medicine clinic attendees? A patient perspective. *Int J STD AIDS* 2008;19:550–2.

23 Flowers P, Duncan B, Knussen C. Re-appraising HIV testing: an exploration of the psychosocial costs and benefits associated with learning one's HIV status in a purposive sample of Scottish gay men. *Br J Health Psychol* 2003;8:179–94.

24 Knussen C, Flowers P, Church S. The intentions of gay men in taking an HIV test. *Cult Health Sex* 2004;6:45–59.

25 Heijman T, Stolte I, Thiebrummel H, et al. Opting out increases HIV testing in a large STI outpatient clinic. *Sex Transm Infect* 2009;85:249–55.

26 Dukers NH, Niekamp AM, Vergoossen MM, et al. Effectiveness of opting-out strategy for HIV testing; evaluation of four years of standard HIV testing in an STI clinic. *Sex Transm Infect* 2009;85:226–30.

27 Erwin J, Morgan M, Britten N, et al. Pathways to HIV testing and care by black African and white patients in London. *Sex Transm Infect* 2002;78:37–9.

28 Delva W, Wuillaume F, Vansteelandt S, et al. HIV testing and sexually transmitted infection care among sexually active youth in the Balkans. *AIDS Patient Care* 2008;22:817–21.

29 Prost A, Sseruma WS, Fakoya I, et al. HIV voluntary counselling and testing for African communities in London: learning from experiences in Kenya. *Sex Transm Infect* 2007;83:547–51.

30 Gibb DM, MacDonagh SE, Gupta R, et al. Factors affecting uptake of antenatal HIV testing in London: results of a multicentre study. *BMJ* 1998;316:259–61.

31 Simpson WM, Johnstone FD, Boyd FM, et al. Uptake and acceptability of antenatal HIV testing: randomised controlled trial of different methods of offering the test. *BMJ* 1998;316:262–7.

32 Boyd FM, Simpson WM, Johnstone FD, et al. Uptake and acceptability of antenatal HIV testing. *Br J Midwifery* 1999;7:151–6.

33 Stokes SH, McMaster P, Ismail KM. Acceptability of perinatal rapid point of care HIV testing in an area of low HIV prevalence in the UK. *Arch Dis Child* 2007;92:505–8.

34 Kellock DJ, Rogstad KE. Attitudes to HIV testing in general practice. *Int J STD AIDS* 1998;9:263–7.

35 Tookey PA, Gibb DM, Ades AE, et al. Performance of antenatal HIV screening strategies in the United Kingdom. *J Med Screen* 1998;5:133–6.

36 Townsend C, Cliffe S, Tookey PA. Uptake of antenatal HIV testing in the United Kingdom: 2000–2003. *J Public Health* 2006;28:248–52.

37 Bollini P, Laporte JD, Harding TW. HIV prevention in prisons. Do international guidelines matter? *Eur J Public Health* 2002;12:83–9.

38 WHO. Global Programme on AIDS. WHO Guidelines on HIV Infection and AIDS in prisons, WHO: Geneva, 1993. WHO/GPA/DIR/93.3.

39 Gyarmathy VA, Rácz J, Neaigus A, et al. The urgent need for HIV and hepatitis prevention in drug treatment programs in Hungary. *AIDS Educ Prev* 2004;16:276–287.

40 Aral SO, Lawrence JSS, Tikhonova L, et al. The social organization of commercial sex work in Moscow, Russia. *Sex Transm Dis* 2003;30:39–45.

41 Aral SO, Lawrence JSS, Dyatlov R, et al. Commercial sex work, drug use, and sexually transmitted infections in St. Petersburg, Russia. *Soc Sci Med* 2005;60:2181–90.

42 Burke RC, Sepkowitz KA, Bernstein KT, et al. Why don't physicians test for HIV? A review of the US literature. *AIDS* 2007;21:1617–1624.

43 de Wit JBF, Adam PCG. To test or not to test: psychosocial barriers to HIV testing in high income countries. *HIV Med* 2008;9(Suppl 2): 20–2.

44 Flowers P, Davis M, Hart G, et al. Diagnosis and stigma and identity amongst HIV positive Black Africans living in the UK. *Psychol Health* 2006;21:109–22.

45 de Cock KM, Johnson AM. From exceptionalism to normalization: a reappraisal of attitudes and practice around HIV testing. *BMJ* 1998;316:290–3.

46 Bayer R. Testing: Looking Back, Looking Forward in ECDC (2008) Meeting report, Assessment of HIV testing in Europe: from policy tot effectiveness. Stockholm, Sweden.

47 Mounier-Jack S, Nielsen S, Coker RJ. HIV testing strategies across European countries. *HIV Med* 2008;9(suppl. 2): 13–19.

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