MRC/CSO Social and Public Health Sciences Unit Consultation Response

Title of consultation
HIV testing: Increasing the uptake of HIV testing among people at higher risk of exposure

Name of the consulting body
National Institute for Health and Care Executive

Link to consultation

Why did the MRC/CSO Social and Public Health Sciences Unit contribute to this consultation?
The 2016 NICE HIV testing guidelines have been updated to expand HIV testing to non-specialist health services and to address self-testing, self-sampling and point of care testing. The MRC/CSO Social and Public Health Sciences Unit, and the Social Relationships and Health Improvement Programme in particular, has considerable expertise in this area and has conducted extensive research on this topic.

Our consultation response

Comment 1:
We recognise that the guidelines have removed explicit recommendations on community engagement and involvement as the “principles underpinning it are now part of the implementation section or covered elsewhere in the guidelines” (p27). And while we recognise separate community engagement guidelines as helpful (NG44) and the specific reference to community consultation when setting up self-sampling services (1.2.5, line 6-7, p 8), there is an ongoing need for community engagement and consultation for all testing services and opportunities, not simply with the introduction new testing technologies.

It is therefore disappointing that many sections of relevant and useful guidance have been removed from the new 2016 draft guidance’. In particular, the previous 2011 guidelines made several references to the need for consultation with communities when developing strategies and delivering testing in outreach settings. Our work at the MRC/CSO Social and Public Health Unit continues to find that this kind of consultation is vitally important.

For instance, our recent, in-depth research on HIV with migrant African communities (Smith, 2016) has highlighted a strong distrust of medical services by some migrants, and rejection of testing when approached in non-specialist services. This was due primarily to perceived low HIV risk and high perceptions of racism within health institutions. Smith’s findings underscore the necessity of ongoing collaboration with community and organisational stakeholders in the development and implementation of HIV testing promotional material and services. This is particularly important for black Africans who continue to be disproportionately affected by HIV.

We also recognise that the new guidelines recommend aligning implementation with local priorities (line 28, p63). However, it is essential to continue to have community engagement as a critical component of establishing local priority, as well as ensuring successful and sustainable
implementation of testing services. As such, we do not feel that the recommendations in 2011 guidelines which were deleted (p.27) have been appropriately re-integrated into the 2016 guidelines. Meaningful consultation and engagement with communities and groups most at risk of HIV would help to address challenges to increasing uptake of existing HIV testing services, as well as barriers in access to, and uptake of, using newer technologies such as self-sampling and self-testing.

Comment 2:
Although there is reference to men who have sex with men and women, there is no reference to trans people in the draft guidelines. The guidelines do not address issues around trans people's access to testing and HIV care and how the complexity around gendered and sexual identities will affect their access to, and experience of, services.

Comment 3:
While the guidelines acknowledge the need to reduce stigma (1.3.5), there appears to be less explicit discussion of how to reduce stigma around HIV testing in the 2016 draft guidelines than there had been in the previous 2011 guidelines. This is disappointing since stigma poses a significant challenge to implementation of any guidelines. The evidence suggests that stigma continues to be a significant barrier to testing (Flowers et al 2013, Bolsewicz et al 2015) and stigma and discrimination against MSM continue to shape patient responses to HIV (Altman et al 2012).

Comment 4:
Recommendation 1.2.7 – 1.2.9 on repeat testing will be challenging to implement effectively. Our published research from UK community-based and online surveys has demonstrated that the current UK minimum recommendations for the frequency of HIV testing are not being met. Only half of men who have sex with men surveyed reported at least two HIV tests in the last two years. This is suggestive of annual testing (the minimum recommended in current UK guidelines), and just one quarter of men who have sex with men reporting higher risk UAI also reported the frequent testing recommended (up to every three months for those at high risk of HIV infection) (McDaid LM et al 2016).

The call-recall and electronic reminders suggested in the recommendations and other innovative approaches to increasing uptake, such as self-sampling and online testing initiatives have been and are being evaluated. However, we have little evidence on how to increase the frequency of testing or how to routinize this behaviour.

Increasing the frequency of HIV testing will be essential to reducing undiagnosed HIV infection in the UK and further research is required to understand how to achieve this. This guideline should acknowledge this evidence gap and recommend further research on specifically increasing the frequency of testing in addition to the guidelines ade on increasing awareness and uptake.

Furthermore, our recent, qualitative research on patterns of HIV testing among young men who have sex with men (aged 18-29) (Boydell, Buston and McDaid, under review) found social support and open communication around HIV testing in men's friendship groups served to support the development of a routine of regular (repeat) HIV testing (and STI screening). This suggests that promotion materials could usefully include a focus on supporting positive testing practices within young men's friendship groups.

Comment 5:
Implementation of effective and relevant promotion material needs to consider the highly varied needs of local communities, and needs to go beyond materials targeted towards specific populations.
Our published research on HIV testing among men who have sex with men in the UK has demonstrated strong regional, demographic and behavioural differences, and variations in the risk profiles of testers. The data suggest that interventions to increase the frequency of HIV testing will need to be tailored to the communities in question (McDaid LM et al 2016). In particular, careful consideration is required to ensure that written materials are understandable, address the particular HIV literacy needs of the target group, and have high appeal/acceptability. Our work on literacy in relation to HIV and sexual health (Gilbert, et al 2015) calls attention to this issue.

We are concerned that the messages currently presented in the new guidelines fail to sufficiently account for increasingly complex understandings of HIV transmission risks. For instance, suppressed HIV viral loads in HIV-positive sexual partners and the potential use of pre-exposure prophylaxis (PrEP) may complicate risk assessment (Young et al 2014). Information and approaches which are clear and in the appropriate format is needed for people to understand their HIV-related risks and test accordingly. However, the level and nature of HIV and/or sexual health literacy required to do this is unclear and deserves further research.

**Comment 6:**
In relation to recommendation 1.3.2 and the needs of non-English-speaking communities, we would make the case that the needs of first generation African migrants go beyond the translation of promotional material into different languages.

Our ethnographic research on first generation African migrants in Scotland, (PhD, Smith, M) has shown, that discussions of HIV risk are not common within the varied African communities in Scotland, and continue to be a highly stigmatised subject.

Cultural sensitivity is needed in relation to the norms of sexual health discussions (including the gendered nature of these norms), health promotion practices and high levels of reported community stigma. Smith’s research identified specific instances where discussions of HIV testing may be seen as appropriate, such as starting new relationships, marriage and screening during pregnancy.

**Comment 7:**
Information on treatment as a method to prevent onward transmission is an important new inclusion in promotional material around testing. However, our research (Young, et al 2015) highlights mixed responses to treatment as prevention, including potential individual and community ambivalence towards using treatment for prevention and a potential resistance to treatment initiation upon diagnosis. We therefore encourage increased awareness of these potential concerns and sensitivity to the complex issue of treatment initiation and prevention in testing materials.

**Comment 8:**
While we welcome the increase in opportunities to test in secondary and emergency care settings and GP surgeries (1.1.3 – 1.1.7), the capacity and skills of non-HIV specialist health workers to offer HIV testing needs critical attention.

Experiences of people living with HIV in non-specialist health care continue to be significantly affected by stigma and discrimination by health workers (Waverly Care 2014). A major barrier to offering HIV tests in these settings will be the knowledge and cultural awareness of health staff in relation to those at risk of HIV, as well as pathways to relevant HIV services. While we welcome the recommendation for further research on attitudes towards HIV testing among service providers (Recommendation 9, p.23), it will be imperative to consider the capacity of health workers and their knowledge of and skills in providing HIV information and testing. Our current work around HIV literacy (Young, Developing HIV Literacy, Scottish CSO) points to the complexity of HIV literacy and the need for comprehensive, multi-level interventions to adequately...
support testing services.

**Comment 9:**
While we welcome the inclusion of guidance on POCT and self-sampling, we caution against assuming that these will in and of themselves address issues around lack of engagement with testing and sexual health services.

The guidelines need to give greater acknowledgement of the structural drivers of HIV and how these impact on testing practices.

It is not surprising that there is a lack of UK evidence for self-testing increasing the uptake of HIV testing, given the recency of the availability of the test kits. However, we are aware of at least one paper that suggests self-testing could increase the frequency of testing among high-risk men who have sex with men (Carballo-Diegeuze et al 2012).

It is pertinent that the new guidelines recommend further research on the efficacy of self-sampling and self-testing. Our (in press) mixed methods research on preparedness for self-testing with men who have sex with men and those involved in prevention and care in the UK suggests it could increase HIV testing amongst some, but not all, MSM (Flowers P, et al, in press). We found that willingness to use the test was high (89%) among men who have sex with men in bar-based surveys, but again, HIV literacy was important; awareness of self-testing was associated with level of educational attainment and digital literacy was associated with willingness to use the test. Whether test results would be interpreted accurately in relation to the window period and to specific risk events also raised concerns. Self-testing was perceived to be convenient and in some cases preferable to going to a clinic, and so could reduce some barriers to testing, but it also presented parallel concerns on loss to follow up testing and treatment, and for opportunities for accessing prevention interventions and partner notification.

References cited:

Young, Flowers & McDaid, Key factors in the acceptability of Treatment as Prevention (TasP) in Scotland: a qualitative study with communities affected by HIV. BMJ Sexually Transmitted Infections 2015; 91:269-74

When was the response submitted?
15 June 2016

Find out more about our research in this area
www.gla.ac.uk/sphsu.mrc.ac.uk/research

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