

# Understanding factors behind the late testing and diagnosis of HIV: Findings from phase 1 of the IMPRESS Health 2 (Interreg IVA Channel Programme) Project

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## Background and aims of the study

Over 100,000 people have HIV in the UK. However, while effective treatment exists, there is neither a cure nor a preventive vaccine. As a consequence, more than 500 people die from AIDS every year with many others dying undiagnosed (Public Health England, 2014). Health policy focuses on prevention of transmission and support for those affected, but it is also necessary to increase the number of early diagnoses and reduce the rate of spread (Public Health England, 2014). Approximately 25% of HIV positive individuals do not know their status however, and almost half of all UK diagnoses occur late.

The reasons for late presentation, testing and diagnosis are many and varied. Results from a literature review conducted by the authors suggest that barriers exist at individual, societal, professional and public policy levels. At an individual level barriers include the stigma associated with HIV, unrealistic cognitive appraisal of actual or potential risk factors, denial, and fear of the consequences of a positive HIV test.

Evidence also suggests that many opportunities to identify and test HIV positive individuals are being missed within the healthcare system. Potential barriers include lack of time and uncertainty about consenting and pre-test counselling, logistical barriers such as competing priorities, language barriers and discomfort of healthcare professionals discussing sexual orientation or risk factors for transmission. Deficits in the knowledge, education and the training of physicians and other healthcare professionals to undertake this task have also been identified.

Current policies in the UK target individuals who are deemed at 'high risk' of being infected. As a consequence, those deemed to be at lower risk are provided with fewer opportunities for HIV testing than men who have sex with men, injecting drug users, people from areas of the world with a high prevalence of HIV; and women attending antenatal care where HIV testing is routinely undertaken.

The overall aim of the cross-channel IMPRESS Health 2 Project was to identify causes for the high rates of late testing and diagnosis of HIV in Kent and Medway in the UK and two comparable areas (Amiens and Creil) in Picardy, France, and to propose new interventions aimed at increasing the earlier uptake of HIV in both regions. For a second, intervention phase of the project, the success of which would then be evaluated in the final evaluation stage of the project. The two regions were paired because despite differences in the methods used to identify and test patients for HIV in England and France, both regions had similar prevalence rates for new and late HIV diagnoses (i.e. with a CD4 count of <350 cells/mm<sup>3</sup> within three months of diagnosis). This poster presents UK data from phase one of the project.

## Methodology

As part of this mixed-methods study, clinical data for 240 patients diagnosed with HIV within the five year period in Kent and Medway were reviewed to establish possible correlations between criteria such as gender, age, sexual orientation, ethnic origin, educational level, occupational status, current or most recent employment, country or region of birth, relationship status at the time of infection/diagnosis and the most likely transmission route. Data were also collected about whether or not patients were registered with a GP, their CD4 count, and details of any HIV/AIDS defining illnesses they had at the time of diagnosis. Statistical data were analysed using SPSS.

In addition, thirty seven patients diagnosed between December 2008 and December 2013 were interviewed to elicit their personal experiences of HIV testing and identify potential barriers to testing. Sixteen healthcare professionals from four local trusts in Kent and Medway were also interviewed to ascertain their views about the challenges and barriers faced by those seeing an HIV test in their areas. Both sets of interviews were semi-structured in nature and were transcribed verbatim prior to thematic analysis using the Nvivo software package.

## Findings

Patients (of whom 67.5% were male) were aged 19-81 years (mean 40). Women were more likely to be diagnosed late (67.9% versus 56.8%). Late diagnosis in the region was higher than the national average for both sexes (60.4%) with the highest rates in Medway (66.1%) and Maidstone and Tunbridge Wells (64.6%). Patients diagnosed late were on average, 4 years older than those diagnosed early, and late diagnosis was higher in ethnic minority patients (70.2%) compared to white British patients (53.0%). Those born outside the UK were also generally diagnosed later (69.8%). The most frequent categories affected were heterosexuals (56.2%), men who have sex with men (36.6%) and intravenous drug users (2.0%). Patients diagnosed during an acute hospital admission were more likely to be diagnosed late (89.1%) compared to other settings (49.6% - 57.1%).

Qualitative data suggested that outmoded notions of HIV as a 'gay' disease still prevailed and heterosexuals did not generally consider themselves to be at risk. Patient respondents were extremely positive about the care received from staff in genitourinary (GUM) clinics, but on the whole, they were very critical of the care received by GPs in the time leading up to their diagnosis and in many cases afterwards. Experiences of acute hospital care were mixed, with some positive and some very negative examples cited. Patients acknowledged having only limited knowledge about HIV risk, transmission, diagnostic methods, treatment options and long-term outcomes prior to diagnosis. Nearly all of them had been shocked and surprised to learn of their positive HIV status, even those in so called 'high risk' groups. Most respondents were surprised that routine screening was not more common. Many older respondents recalled the graphic public health campaigns of the 1980s and 1990s in relation to HIV/AIDS and recalled that these were depressing and anxiety inducing, but younger respondents often failed to recall a single incidence of seeing or hearing any public health messages about HIV transmission risk or the benefits of early testing.

Healthcare professionals highlighted areas of poor practice and a general lack of HIV awareness and training amongst the profession. Several intimated that HIV was simply 'not on the radar' of their colleagues and suggested that healthcare professionals sometimes failed to acknowledge risks in 'non-traditional' groups and often overlooked HIV as a likely cause of symptoms until patients were seriously unwell or in some cases, not at all.

## Discussion

Heterosexuals formed the majority of the HIV positive population in Kent and Medway and were more likely, along with injecting drug users, to present late for testing with subsequent poorer outcomes and additional treatment costs for health and social care providers. It was clear that an intervention was needed to address the apparent lack of engagement in HIV surveillance, testing and diagnosis within primary healthcare settings – most notably amongst GPs. Recommendations for a GP training programme were made and it was also recommended that all clinical areas develop clear policies and procedures to identify those in need of an HIV test and the means to refer them for specialist assessment if necessary. It was deemed essential to change cultural attitudes towards the discussion of sexual health and HIV risk in clinical consultations and the ways in which HIV testing is delivered in some areas, making testing more routine, accessible, and non-stigmatising.

Tailored ways in which to raise awareness amongst the general population and not just those deemed to be at 'high risk' were also deemed necessary. Recommendations were also made for the conduct of a social media and public health campaign in the run up to World AIDS Day in December 2014 to run alongside a continuing professional development programme for healthcare professionals in the region. These were developed and delivered by the project partners. Outcome data for these interventions are still being analysed, but it is already clear in relation to both the total number of HIV tests conducted, and the number of early HIV diagnoses for the same comparable five month period in 2013/14 and 2014/15 that these have been positive and well above the CDC threshold for 'cost effectiveness' of public health interventions. Complete results of the intervention phases of the study will be published in May 2015 but preliminary findings from both the UK and France are now available for download on <http://www.impresshealth2.eu/>

