

TRANSFORMING  
THE UK'S  
RESPONSE  
TO HIV



Report: July 2011

# Primary HIV Infection: knowledge amongst gay men



## About NAT

NAT is the UK's leading charity dedicated to transforming society's response to HIV. We provide fresh thinking, expertise and practical resources. We champion the rights of people with HIV and campaign for change.

**SHAPING ATTITUDES.  
CHALLENGING INJUSTICE.  
CHANGING LIVES.**

All NAT's work is focused on achieving four strategic goals:

- Effective HIV prevention in order to halt the spread of HIV
- Early diagnosis of HIV through ethical, accessible and appropriate testing
- Equitable access to treatment, care and support for people living with HIV
- Eradication of HIV-related stigma and discrimination.

**NAT would like to thank Dr Martin Fisher for providing his expertise to this project and Bristol-Myers Squibb for their support of our policy work on Primary HIV Infection.**

**Thank you also to Gaydar for conducting the survey of their members.**



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Foreword by

**Dr Martin Fisher**

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I really welcome this new research and was delighted to work with NAT and Gaydar on this project.

Primary (or early or recent) HIV infection represents a unique window of opportunity to diagnose HIV. For the individual, this may be the only time they experience symptoms before a long period of asymptomatic infection and then presenting with advanced HIV disease, which may respond less well to treatment. Additionally, early diagnosis allows the person with HIV to make informed choices about their sexual and other lifestyle practices that may reduce the risk of onward transmission of HIV to others. This is particularly important as people with very recent infection may be extremely likely to transmit HIV to others (possibly up to 100 or 1000 times more likely than in later stages of the infection). Furthermore, recent research suggests there may be a benefit to a person diagnosed with recent infection of starting anti-HIV therapy during the primary HIV infection stage - it may reduce the risk of subsequent deterioration of health from HIV.

Previous research in the UK has shown that whilst most individuals recently infected with HIV have symptoms, in the majority of cases these are not recognised by doctors as being due to HIV. The research presented here is amongst the first, and the first in the UK, to show that those individuals are not likely to realise what their symptoms are due to, where to best access healthcare, and the significance of correctly diagnosing HIV infection at an early stage.

If this research leads to a better awareness of the symptoms and importance of recognising early HIV infection, this could potentially have a major benefit for the health of that individual and also a major benefit for the UK HIV epidemic.

*Martin Fisher*

## Summary of conclusions and findings

- ▶ Over 60% of gay men believe, incorrectly, that there are no symptoms of primary HIV infection. Less than 1 in 10 respondents correctly stated that between 70% and 90% of people recently infected with HIV will experience symptoms.
- ▶ When presented with a list of possible symptoms of recent HIV infection, although almost 70% identified severe flu-like symptoms (which is commonly used to describe the symptoms of early HIV infection) the majority of respondents did not select the specific symptoms of sore throat (46.7%), fever (48.1%), and rash (32.7%). Only just over a third of respondents (36.5%) correctly identified this triad of symptoms - which are unusual in an otherwise healthy person - as the most common indicators of primary HIV infection.
- ▶ HIV positive respondents tended to know more than non-HIV positive respondents, but knowledge was still poor.
- ▶ This lack of knowledge is very concerning, as seroconversion illness presents one of the few opportunities to diagnose HIV early without routine testing, and if people are unaware that there are symptoms of primary HIV infection and what those symptoms are, they are less likely to recognise their potential infection and seek medical advice and an HIV test.
- ▶ If they were to experience the most common symptoms of primary HIV infection, the most popular course of action for respondents would be to make an appointment with their GP. This demonstrates the vital role that GPs have to play in maximising opportunities to diagnose HIV early, and highlights the importance of ensuring GPs have the knowledge necessary to recognise these symptoms.
- ▶ The second most popular course of action, if experiencing the symptoms of primary HIV infection, would be to wait and see if they went away. This reinforces the importance of public education around the possible cause of the specific triad of sore throat, fever and rash. As, if ignored, the symptoms will go away and the individual will usually remain asymptomatic until the immune system becomes severely compromised.
- ▶ Encouragingly 65% of respondents were aware that someone with HIV will be highly infectious in the first few weeks after infection. This indicates that if we were to improve knowledge of the symptoms gay men are likely to take action to reduce onward transmission.
- ▶ Early diagnosis has significant benefits to both public health and to individual long-term health and prognosis. Therefore it is important that we maximise the ability of people at risk of HIV and GPs to recognise the symptoms of primary HIV infection and maximise the opportunities for early diagnosis.

## Recommendations

- > Awareness must be increased amongst those at risk of HIV of the existence, prevalence and nature of the symptoms of primary HIV infection. They should be encouraged, should symptoms occur, to seek professional advice and an HIV test. However it must be emphasised that the absence of symptoms, or of the triad of most common symptoms, after a potential exposure does not mean there is no infection, as symptoms vary and are not experienced by everyone.
- > It is recommended that tailored information is developed for gay and bisexual men, African communities and injecting drug users (IDUs) as well as ensuring general HIV information is accurate with regard to early symptoms.
- > Knowledge of primary HIV infection amongst GPs and other primary healthcare professionals must be improved to ensure they are able to recognise indications of primary HIV infection, including the triad of the most common symptoms when presented with them.
- > GPs and other healthcare professionals must be comfortable talking about the potential for HIV infection when presented with symptoms of potential primary HIV infection and must know how to refer patients for an HIV test.
- > Fourth generation assay tests, the tests capable of diagnosing HIV at an early stage, must be used consistently.
- > Healthcare professionals should ensure that they refer patients with seroconversion symptoms to a clinic where fourth generation laboratory tests are used and prompt follow up will be provided.



## Introduction

### Aim

NAT worked in partnership with Gaydar to carry out a survey of the knowledge amongst gay men of recent HIV infection. This included knowledge of the existence and prevalence of symptoms and what those symptoms may be. The survey also sought to find out what action people would take if they experienced symptoms of early HIV infection.

### Methodology

The survey was conducted online via the Gaydar membership, between 31 March and 6 April 2011 (see Appendix 1). Gaydar membership has been recognised as a representative sample of gay men in relation to social and demographic characteristics.<sup>1</sup>

8,561 people responded to the survey. 75.7% of respondents

<sup>1</sup> Evans et al, Men who have sex with men in Great Britain: comparison of a self-selected internet sample with a national probability sample, Sex Transm Infect 2007;83:200–205

had had an HIV test, and 15.7% of respondents were HIV positive. The proportion of respondents who were HIV positive is higher than the average for the population group, however the proportion who had had an HIV test is similar to other research in this area, including the Gay Men's Sex Survey. It should be noted that this was a self-selecting sample.

The survey was anonymous and did not ask respondents for location or any personal details, so as to ensure that respondents felt able to comment freely.

Respondents were asked at the start of the survey to answer the questions honestly and in the order they were presented and not to go back and change answers once they learnt more. Although we cannot be sure this did not happen, there is no indication of it happening on a sufficiently large

scale to compromise the results. At the end of the survey respondents were given information about primary HIV infection, including how to recognise the symptoms of seroconversion illness (see Appendix 2).

### Interpretation of data

The results of each question are presented in order. Where there is a breakdown for HIV positive respondents this data is also included.

The results of quantitative questions are shown graphically where appropriate and outlined in the text.

Conclusions are drawn from the findings, taking into account previous knowledge and research on primary HIV infection and recommendations for action are then made.

### Terminology

**Primary/early HIV infection** - the period after an individual has been infected with HIV and before they have produced sufficient antibodies to significantly reduce their viral load. This period generally lasts up to 6 weeks.

**Recent infection** - the terms used in our survey for primary/early HIV infection as it was considered to be easily understood in this context.

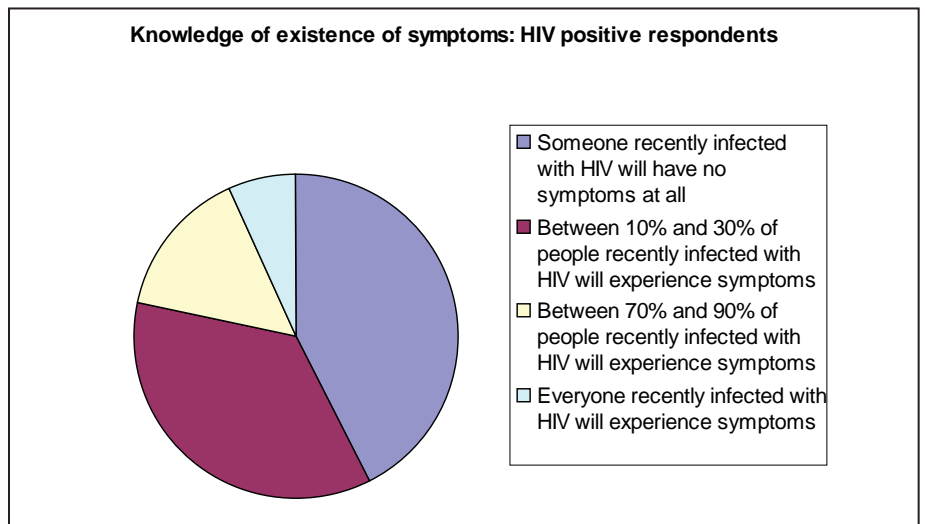
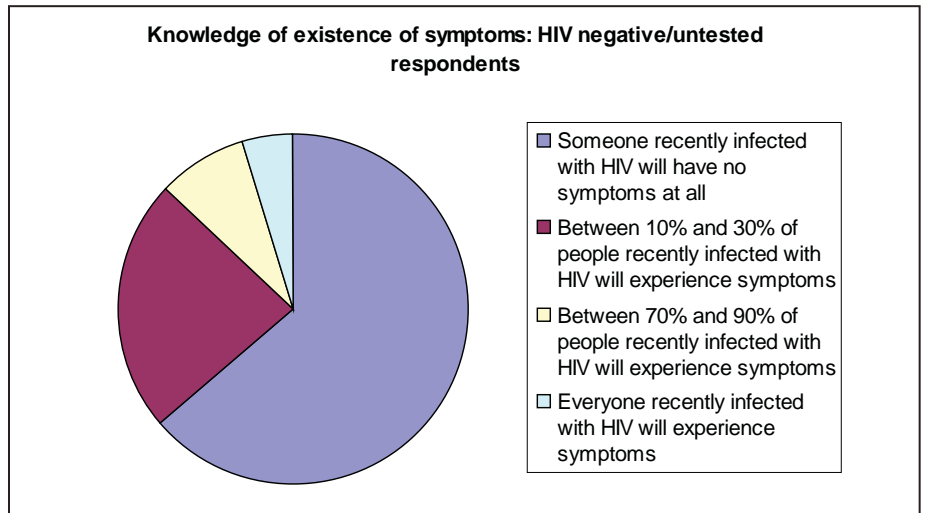
**Seroconversion** - the process by which the immune system responds to the HIV virus by creating antibodies in the blood. This happens during the initial phase of HIV infection.

## Findings

### Knowledge of the existence of symptoms

The survey began by asking respondents about whether someone recently infected with HIV experienced symptoms. Respondents were able to select one of four options. Only 8.3% of HIV negative/untested respondents (hereafter referred to as ‘other respondents’) selected the correct statement – ‘between 70% and 90% of people recently infected with HIV will experience symptoms’. This rose to 14.9% of HIV positive respondents. Two-thirds of other respondents (63.6%) selected the statement: ‘someone recently infected with HIV will have no symptoms at all’, almost half (42.6%) of HIV positive respondents selected this answer. The other options available to respondents were ‘between 10% and 30% of people recently infected with HIV will experience symptoms’ which was selected by 35.8% of HIV positive respondents and 23.2% of other respondents, and ‘everyone recently infected with HIV will experience symptoms’ was selected by 6.7% of HIV positive respondents and 4.7% of other respondents.

This illustrates a lack of basic knowledge about primary HIV infection. The lack of knowledge of the existence of symptoms and



their widespread nature acts as a barrier to people seeking testing and receiving an early diagnosis. It is to be expected that the results

show HIV positive respondents to be more knowledgeable however there remains a lack of basic knowledge amongst this group also.

## Findings

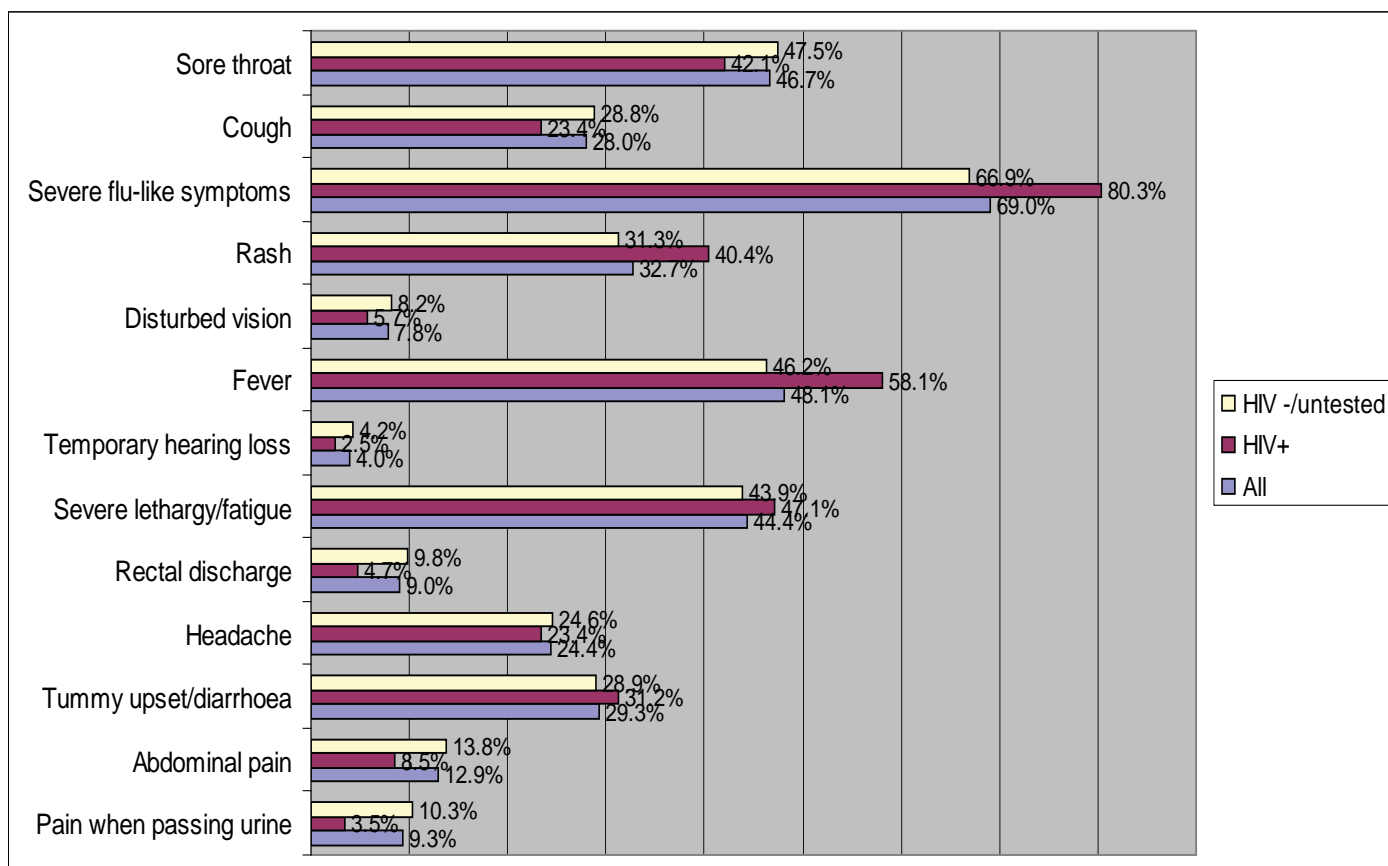
### Knowledge of common symptoms

Respondents were then presented with a list of possible symptoms and asked to select those which they thought are common symptoms of recent HIV infection. This question, necessarily, informed respondents of the existence of symptoms. The possible symptoms presented were: sore throat, cough, severe flu-like symptoms, rash, disturbed vision, fever, temporary hearing loss, severe lethargy/fatigue, rectal discharge, headache, tummy upset/diarrhoea, abdominal pain, and pain when passing urine. Respondents were able to select as many options as they wanted.

The most frequently selected symptom was ‘severe flu-like symptoms’, selected by 66.9% of other respondents and 80.3% of HIV positive respondents. This term is frequently used to describe the combination of symptoms experienced at the time of seroconversion.

It is encouraging that, once informed that there are symptoms of recent infection, 66.9% of other respondents and 80.3% of HIV positive respondents opted for ‘severe flu-like symptoms’ - but there is real doubt as to what respondents understood by this term. The most common symptoms of recent HIV infection experienced together

are fever, rash and a sore throat - all of which were identified as symptoms by only a minority of respondents (sore throat: 47.5% of other respondents and 42.1% of HIV positive respondents, fever: 46.2% of other respondents and 58.1% of HIV positive respondents, rash: 32.7% of all respondents and 40.4% of HIV positive respondents). It seems that the majority of gay men do not have a sufficiently clear and useful knowledge of the symptoms of primary HIV infection. And, of course, many respondents would have been guessing in response to the question since over 60% had said there were no symptoms of recent infection in response to question one.



## Findings

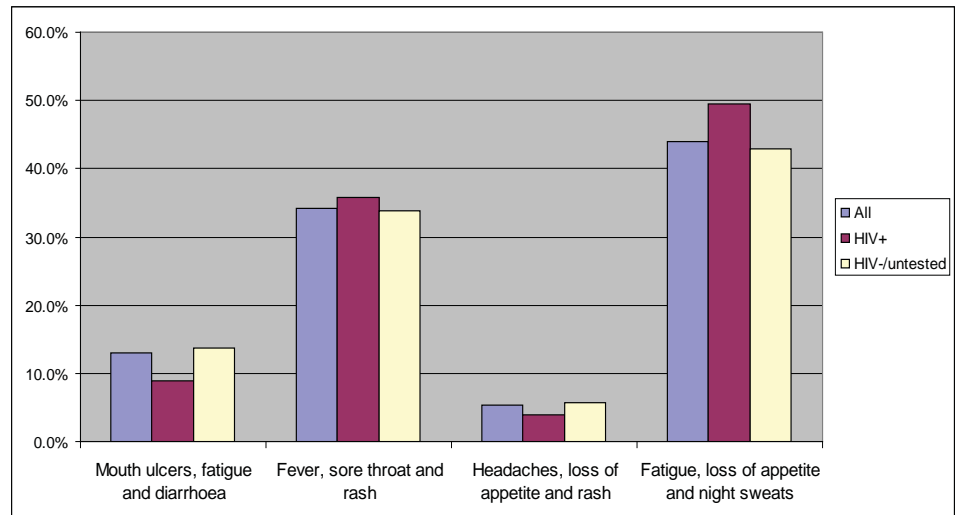
The survey also asked respondents which three symptoms – occurring together – are most commonly experienced soon after HIV infection. Respondents were only able to select one answer. Respondents had not been informed of the correct answers after the previous question, ensuring that answers to this question were not influenced.

Approximately a third of respondents (33% of other respondents and 36.5% of HIV positive respondents) selected the most common triad of symptoms – fever, sore throat and rash. The most commonly selected answer for all respondents and HIV positive respondents was ‘fatigue, loss of appetite and night sweats’, which was selected by 42.9% of other respondents and 49.4% of HIV positive respondents. The popularity of this option may be due to the recognition of these symptoms through their association with late stage HIV infection.

### Level of infectiousness

Respondents were asked about whether recent infection affected the level of infectiousness.

Encouragingly the majority of respondents (61.8% of other respondents and 76.3% of HIV positive respondents) correctly thought that ‘someone with HIV will be highly infectious in the first



few weeks after being infected and very likely to pass HIV on during that time’.

### Symptoms experienced

HIV positive respondents were asked whether they experienced symptoms in the first few weeks after HIV infection. 42.3% stated that they had experienced symptoms, 29% did not, and 28.6% were unsure or could not remember.

The figure of those experiencing symptoms appears lower than previous research which has indicated that 70% to 90% of people experience symptoms. There are a number of possible reasons for this. This survey relied on respondents’ memory, which therefore introduces a strong element of fallibility. Although respondents were given the option of ‘can’t remember’, this does not fully negate the natural inconsistencies of recollection, as

many respondents will have been infected a considerable length of time ago or will not have known when exactly they were infected. Those unaware that primary HIV infection can have symptoms may well not have taken note of them when they occurred. However the figure of 29% definitely not experiencing symptoms is consistent with other research.

### Likely action taken if experiencing symptoms

Non HIV positive respondents (those with a negative test result at their last test and those who have never tested) were asked what they would most likely do if they experienced a sore throat, fever and rash at the same time (they had not previously been told these were the most common symptoms of primary HIV infection however it is likely that this question will have revealed these symptoms as the correct ones).

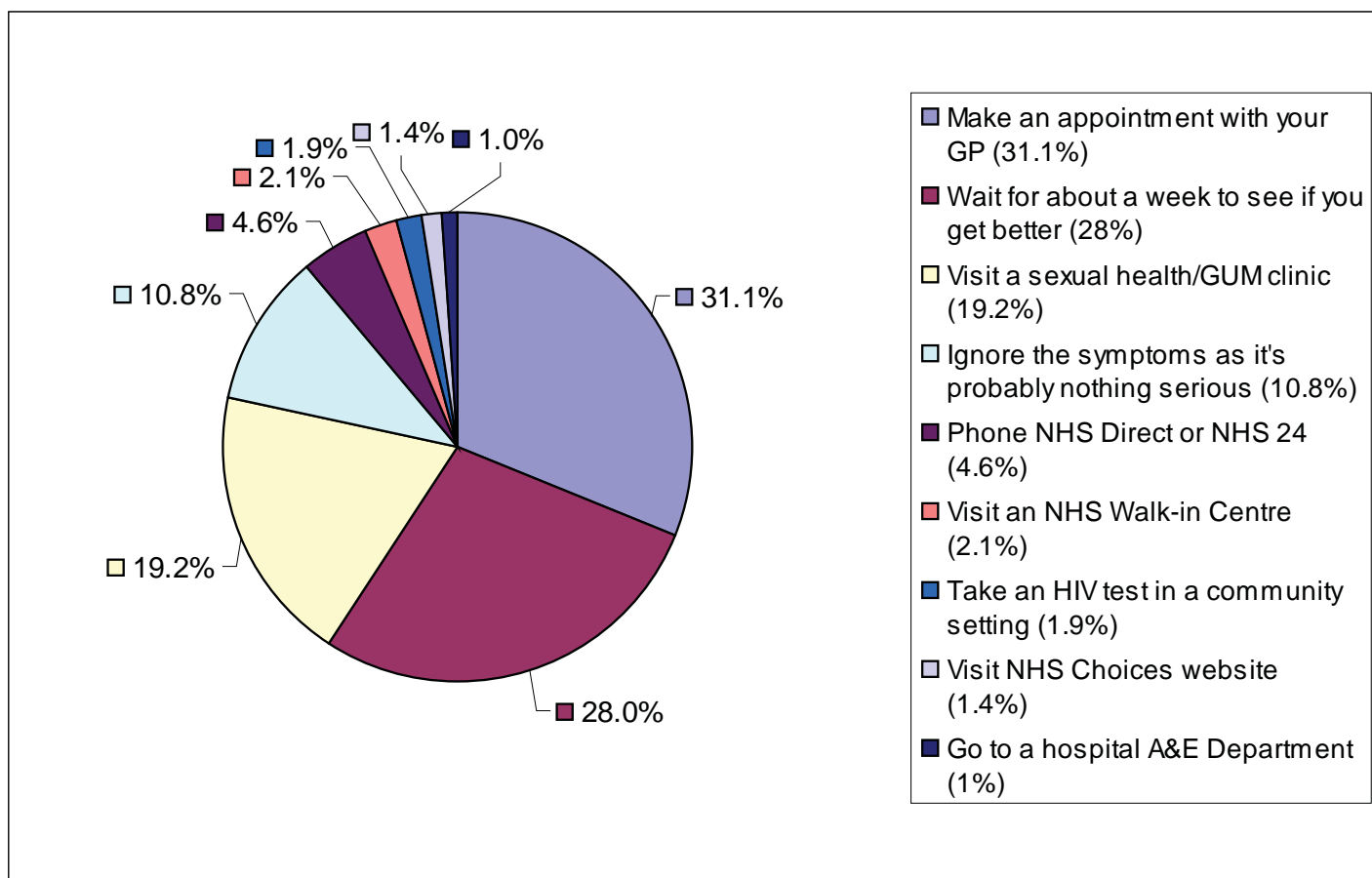
## Findings

The most frequently selected option was ‘make an appointment with your GP’, with 31.1% selecting this as the action they would take. Other popular answers were: ‘wait for about a week to see if you get better before seeking any advice’ with 28% selecting this option: ‘visit a sexual health/GUM clinic’ with 19.2% selecting this option, and ‘ignore the symptoms as it’s probably nothing serious’ with 10.8% selecting this option.

This data highlights the importance of ensuring that both GPs and individuals at risk of HIV infection are sufficiently well informed to recognise the possible implication of these symptoms so that they are not ignored, as they will go away in time leaving the individual with asymptomatic HIV. It is possible that the relatively high level of respondents selecting ‘visit a sexual health/GUM clinic’ may be an indication that respondents have been influenced

by the implication that sore throat, fever and rash are the symptoms of primary HIV infection, as none of these symptoms are commonly associated with sexually transmitted infections (STIs).

It is particularly concerning that almost 40% are unlikely to seek any sort of medical intervention (10.8% would ignore symptoms and 28% would wait a week), given that symptoms can disappear within a week.



## Discussion

The importance of early diagnosis of HIV has become increasingly apparent over recent years, both in terms of preventing onward transmission and in terms of maximising the long-term health of people once infected.

Presentation with the symptoms of seroconversion illness is currently one of the few opportunities available to most people for their infection to be diagnosed at an early stage (as HIV generally becomes asymptomatic approximately 6 weeks after infection and symptoms are unlikely to be experienced again until the person has reached an advanced stage of HIV). However, the alarming lack of knowledge amongst gay men (the group most likely to be infected with HIV in the UK) revealed in this survey seriously undermines opportunities for early diagnosis.

Increasing knowledge amongst gay men and other people at risk of HIV infection has the potential to increase the numbers of people presenting with the symptoms of primary HIV infection and requesting a test. This is a positive, pro-active approach to the problem of late diagnosis which affects the UK (52% of people diagnosed with HIV were diagnosed late in 2009).

However, increasing knowledge amongst people at risk of HIV infection is only one half of the solution. As reported in

the survey, if experiencing the triad of symptoms particular to seroconversion illness the highest proportion of people would consult their GP. This is particularly concerning as previous studies have suggested that a significant percentage of opportunities to diagnose primary HIV infection are missed in primary care. Therefore the findings of this survey add further weight to the need for GPs to be better informed about the existence and prevalence of symptoms of primary HIV infection, what the symptoms are, and also to feel comfortable talking to patients about the risk of infection and the need for a test.

The findings revealed that gay men who are HIV positive, although a little better informed than their counterparts, are still not particularly knowledgeable about the existence or nature of the symptoms, suggesting that they are unlikely to identify them as indicators of HIV infection in a sexual partner.

There are multiple benefits to improving knowledge and recognition of the symptoms of primary HIV infection. Studies have suggested that up to 50% of HIV transmissions are from people who have themselves been recently infected because someone is highly infectious during primary HIV infection. If people are diagnosed within this period they have the information available to them to enable them

to make safer sex choices so as to prevent onward transmission. This has a cost saving of up to £360,000 in direct lifetime medical costs for each infection prevented.

There is also a benefit of being diagnosed early to an individual's long-term health and prognosis. Once diagnosed, monitoring of viral load and CD4 count means that people are put onto treatment when needed, rather than when they are symptomatic and already ill. Once diagnosed people also have the ability to manage their health and lifestyle, potentially enabling them to remain healthier longer.

Recent research suggests that there may be benefit from early treatment to an individual diagnosed when recently infected. This adds to the health benefits of diagnosing HIV as early as possible.

Late diagnosis of HIV also has an impact on mortality. The Health Protection Agency found that of those who died of HIV-related causes in 2009, 75% had been diagnosed late. It is vital that we diagnose people as early as possible to ensure they live as long a life as possible.

For further reading on this topic please see 'Primary HIV Infection' NAT, 2008 (<http://www.nat.org.uk/Our-thinking/Prevention-and-testing/Testing.aspx>).

## Appendix 1

### Questions for Gaydar Members

We really want to find out how much you know about HIV so please answer these questions honestly and in the order that they are presented. Thank you!

1. Which of these statements do you think is true? (select only one)

- Someone recently infected with HIV will have no symptoms at all.
- Between 10% and 30% of people recently infected with HIV will experience symptoms.
- Between 70% and 90% of people recently infected with HIV will experience symptoms.
- Everyone recently infected with HIV will experience symptoms.

2. Which of the following do you think are common symptoms of recent HIV infection? (tick all that apply)

- Sore throat
- Cough
- Severe flu-like symptoms
- Rash
- Disturbed vision
- Fever
- Temporary hearing loss
- Severe lethargy/fatigue
- Rectal discharge
- Headache
- Tummy upset/diarrhoea
- Abdominal pain
- Pain when passing urine

3. Which three symptoms – occurring all together – do you think are most commonly experienced soon after HIV infection? (select just one answer)

- Mouth ulcers, fatigue and diarrhoea
- Fever, sore throat and rash
- Headaches, loss of appetite and rash
- Fatigue, loss of appetite and night sweats

4. Which of these two statements is true?

- Someone with HIV will be highly infectious in the first few weeks after becoming infected and very likely to pass HIV on during that time.
- It is very difficult to pass HIV on in the first few weeks after infection.

## Appendix 1

5. Have you ever had an HIV test?

- Yes – my last test was positive
- Yes – my last test was negative
- No
- I'd rather not say

6. If you are HIV positive, did you experience symptoms in the first few weeks after HIV infection?

- Yes
- No
- Not sure/can't remember

7. If you are not HIV positive, and experienced a sore throat, fever and a rash at the same time, what are you most likely to do? (tick only one)

- Phone NHS Direct or NHS 24
- Visit NHS Choices website
- Wait for about a week to see if you get better before seeking any advice
- Make an appointment with your GP
- Visit a sexual health/GUM clinic
- Visit an NHS Walk-in Centre
- Take an HIV test in a community setting
- Ignore the symptoms as it's probably nothing serious
- Go to a hospital A&E Department

## Appendix 2

### Information on Primary HIV Infection given to all survey respondents

Some information from Dr Martin Fisher on early symptoms of HIV

Recognising early HIV infection may be very important.

In the early stages of infection with HIV, approximately 70-90% of people experience symptoms. These are usually non-specific and may feel like a severe flu-like illness. The most common symptoms are fever, sore throat and a skin rash – all occurring together - but other frequent symptoms include: enlarged glands, tummy upset, weight loss, headache, joint and muscle pains. The symptoms usually occur from 1-2 weeks until about 3-6 weeks after infection and then get better on their own. These may be the only symptoms a person with HIV experiences before becoming very ill with an extremely damaged immune system several years later.

If the diagnosis of recent HIV infection is successfully made, this gives that person the opportunity to consider their sexual lifestyle in order to reduce the chance of transmitting the virus to others. This is particularly important during the early stages of infection as it is highly infectious during this stage when levels of the virus are very, very high.

It may be possible with anti-HIV treatment for a short period of time (3-12 months) at this stage to protect the immune system from early damage by the virus and possibly give long-lasting benefits to the system without the need for starting long-term therapy. A large clinical trial (the SPARTAC study) should answer this question later in 2011.

If you think you may be at risk of having been recently infected with HIV, it is recommended that you go and see a doctor or nurse to get an HIV test. Since the symptoms are so non-specific, if you are worried they may represent early HIV infection it is better if you tell your GP (or practice nurse) that this may be HIV or you attend a GUM (sexual health) clinic. HIV testing is also available in community settings but the tests used there may be less effective at picking up very early HIV infection.

Martin Fisher is an HIV doctor in Brighton and leads a research group studying early HIV infection.

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