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CHANGING LIVES**



Report: May 2012

# **HIV Partner Notification: a missed opportunity?**



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## Executive summary

- ▶ **In January 2012 NAT convened an expert seminar on HIV partner notification.** This was attended by a mix of health professionals, community organisations, social researchers and people living with HIV. It aimed to achieve a cross-sector consensus on the contribution HIV partner notification can make to HIV prevention and testing efforts.
- ▶ **Where conducted thoroughly, HIV partner notification has proven to be highly effective in diagnosing people with HIV.** Some audits show up to 37% of partners traced and tested through partner notification were newly diagnosed HIV positive as a result.
- ▶ **Diagnosing individuals earlier than they would otherwise have been brings significant benefits for their future health.** The point at which someone is diagnosed remains clearly linked to life expectancy, with late and very late diagnosis strongly correlated to higher rates of morbidity and mortality.
- ▶ **Crucially, HIV partner notification should now also be considered an important HIV prevention intervention** – with benefits to public as well as personal health. New evidence around the preventive benefits of treatment and behaviour change following diagnosis potentially allow partner notification to make an important contribution to reducing onward HIV transmission.
- ▶ **However, the role of partner notification in HIV testing and prevention remains largely forgotten.** Approaches and attitudes towards it have simply not been updated to reflect advances in treatment and knowledge. It often goes under-resourced, unperformed or unacknowledged. As a result, no clear national picture of current practice around HIV partner notification currently exists.
- ▶ **There are a number of barriers faced by healthcare workers which serve to hold back HIV partner notification in the UK.** This includes a lack of specific guidance and an absence of clarity around the commissioning process, as well as a variety of complex ethical dilemmas.
- ▶ **A range of factors can also inhibit patients from engaging in HIV partner notification.** Attitudes to HIV partner notification can vary between and within different communities, but stigma around HIV, fear of reputational damage and fear of criminalisation appear to be significant themes.
- ▶ **No performance standards around partner notification currently exist for HIV, unlike for other STIs such as chlamydia.** HIV-related standards for partner notification, and clear principles and service specifications for commissioners, need to be agreed as soon as possible. This would help ensure that the potential of HIV partner notification is fully realised, and drive down both late diagnosis and onward transmission.

**Key recommendations on addressing these issues can be found at the end of this report. These seek to outline steps to high quality, consistent and cost-effective HIV partner notification in the UK.**

## Introduction

### We need to talk about HIV partner notification

Since the emergence of HIV in the UK 30 years ago, our understanding of the epidemic has been characterised by rapid change and advancement. Great strides have been made in testing, treatment and prevention. The past few years have proved no exception, with increased emphasis placed on testing – and specifically earlier diagnosis – as evidence mounts of the significant public health benefits of diagnosing HIV as promptly as possible. New testing technologies have supported this agenda, while recent NICE guidance and the 2008 UK National Guidelines for HIV Testing both put increasing testing at the heart of the UK’s response to HIV. Late HIV diagnosis has also been incorporated as an indicator within the Public Health Outcomes Framework.<sup>1</sup>

In all of this, however, HIV partner notification has been notable by its absence. Although mentioned tangentially in the now expired National Strategy for Sexual Health and HIV, it features only briefly in the 2008 Testing Guidelines and did not appear at all in NICE’s 2011 guidance.<sup>2</sup> This omission is nothing new. The contribution of HIV partner notification has long been relatively neglected in HIV prevention and testing efforts in the UK, as it has in the



**The contribution of HIV partner notification has long been relatively neglected in HIV prevention and testing efforts in the UK**

US.<sup>3</sup> Research from as far back as 1997 highlights its potential to increase HIV diagnoses, but points to divergent practice across England and the need for further research and clearer guidelines.<sup>4</sup> Fifteen years on, practice remains disparate, research remains thin and there still exists little formal guidance.<sup>5</sup>

For this reason, in January 2012 NAT convened an expert seminar on HIV partner notification. This was attended by a mix of health professionals, community organisations, social researchers and people living with HIV. The seminar examined the different dimensions and barriers to HIV partner notification. In doing so, it aimed to achieve a cross-sector consensus on the contribution HIV partner notification can make to HIV prevention and testing efforts.

This seminar has already informed NAT’s feedback to the British Association of Sexual Health and HIV (BASHH) on their forthcoming statement on partner notification, including on issues such as ongoing HIV partner notification, partner notification resolution and outcome measures. This report also draws directly on the expertise and discussion which emerged from the seminar. It highlights the importance of partner notification and steps that need to be taken at a local and national level in order to ensure high quality, consistent and cost-effective HIV partner notification in the UK.

## The importance of earlier HIV diagnosis

The past ten years has seen some room for optimism in the field of HIV testing. There have been some welcome reductions in late HIV diagnosis (and of very late diagnosis in London), while the number of men who have sex with men (MSM) who report in the Gay Men's Sex Survey 'ever testing' went up from 59% in 2003 to 75% in 2008.<sup>6</sup> Despite this, the scale and urgency of the UK's challenge around HIV testing remains clear. A quarter of people with HIV in the UK don't know they have it, and rates of late diagnosis are still too high. In 2010, half (50%) of HIV positive adults were diagnosed late, after the point at which they should have started treatment (CD4 cell count <350 cells/mm<sup>3</sup> within three months of diagnosis), and 28% very late (CD4 <200 cells/mm<sup>3</sup>).<sup>7</sup>

The personal health benefits of earlier HIV diagnosis are significant. The sooner a patient is diagnosed, the sooner they can benefit from HIV care and anti-retroviral treatment (when appropriate). As Professor Jane Anderson outlined to NAT's seminar, research suggests the CD4 count of an individual at the start of treatment is linked to their overall life expectancy. For this reason, a 20-year old diagnosed very late with HIV is thought to have a life expectancy at least ten years shorter than somebody who starts treatment at CD4 350 cells/mm<sup>3</sup>, while late diagnosis leaves an individual ten times more likely to die within a year of

diagnosis.<sup>8</sup> Two thirds of those with HIV who died in 2010 were diagnosed late.<sup>9</sup> Late diagnosis is also linked to increased morbidity, with higher rates of significant ill health and hospital admission.<sup>10</sup>

The public health benefits of earlier diagnosis also explain the emergence of HIV testing at the heart of the UK's HIV *prevention* agenda. This has two components. Firstly, research suggests most patients greatly reduce risky sexual behaviour following diagnosis.<sup>11-12</sup> Secondly, recent research around 'treatment as prevention' shows that effective HIV treatment – resulting in an undetectable viral load – can very significantly reduce transmission risk, by around 96% in sero-discordant heterosexual couples.<sup>13</sup> Getting tested and diagnosed as promptly as possible, reducing undiagnosed HIV, therefore has a significant role to play in stopping the spread of HIV.

Earlier diagnosis not only saves lives – it saves money too. Each new HIV diagnosis costs the NHS between £280,000 and £360,000 in treatment costs.<sup>14</sup> HIV care in the first year after diagnosis costs the NHS twice as much if the patient is diagnosed with a CD4 count less than 350 cells/mm<sup>3</sup>, because of increased rates of hospital admission. Thereafter, the costs of HIV care remain 50% higher for each year following diagnosis.<sup>15</sup> NICE estimates that

an improvement of just 1% of patients being diagnosed earlier could save the NHS £212,000 a year for MSM, and £265,000 for black African men and women in England.<sup>16</sup>

In light of the personal, public and economic benefits of earlier diagnosis, and against the backdrop of significant financial pressure and organisational change, it is imperative that every available opportunity is maximised to increase testing and bring rates of undiagnosed HIV down. It is in this context that the role of partner notification takes on an even greater significance.

## What is partner notification?

Partner notification (or ‘contact tracing’) is defined by the World Health Organisation (WHO) as:

“...the process of contacting the sexual partners of an individual with a sexually transmitted infection including HIV, and advising them that they have been exposed to infection. By this means, people who are at high risk of STI/HIV...are contacted and encouraged to attend for counselling, testing and other prevention and treatment services.”<sup>17</sup>

This process can take a number of different forms. ‘**Patient referral**’ sees the patient (‘index patient’) encouraged to inform their sexual partners themselves, and is broadly the most common approach taken.<sup>18-19</sup> However, ‘**provider referral**’ is also offered

to patients, and is widely used – this is where the healthcare worker, ordinarily with the index patient’s consent, notifies the partner without disclosing the patient’s identity (whether the specific STI is mentioned to the partner is discretionary). A mix of both – usually called ‘**contract referral**’ is also occasionally used. This is where a patient has an agreed period of time to refer their partner for testing before the healthcare worker makes contact directly.<sup>20-21</sup>

HIV partner notification is usually undertaken by Health Advisers within GUM clinics. Many clinics which undertake thorough HIV partner notification use a Health Adviser to verify partners have tested (for instance, through a phone call to another clinic).



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## Why HIV partner notification matters

By diagnosing partners of the index patient earlier than they would otherwise have been, partner notification allows HIV positive partners to enter into care in good time and benefit fully from treatment. Evidence also suggests that being diagnosed enables patients to reduce risk in their sexual behaviour while, most importantly, treatment dramatically reduces viral load and thus infectiousness.<sup>22-23</sup> HIV partner notification therefore has an important role to play as a prevention intervention, and in attempts to reduce transmissions. Being notified also allows individuals to inform their own sexual partners (if appropriate) who in turn embark on the same process. In this way, HIV partner notification can work to interrupt the complex sexual networks through which HIV is often transmitted, and make a significant contribution to reducing undiagnosed HIV and onward transmission.

Historically, partner notification has been partly hindered by doubts over the efficacy of the process in reducing transmission in this way.<sup>24</sup> The recent evidence around treatment as prevention and behaviour change, therefore, demand renewed consideration of HIV partner notification as a prevention intervention – on top of its vast benefits for individual health. The recent Pan-London HIV Prevention Programme Needs Assessment endorses this approach, judging partner notification an effective intervention for influencing the sexual risk of people living with HIV.<sup>25</sup>

Audits from across the UK show that, where conducted thoroughly, HIV partner notification can return significant gains in new diagnoses among those partners reached. A detailed case study is given below, alongside some other examples.<sup>26</sup>

**56 Dean St, London (2010):** 26% of partners traced and tested after notification were newly diagnosed HIV positive.<sup>27</sup>

**South Yorkshire HIV Network (2010):** 34% of partners traced and tested after notification were newly diagnosed HIV positive.<sup>28</sup>

**North East of England (2011):** 34% of partners traced and tested after notification were newly diagnosed HIV positive.<sup>29</sup>

**Trafford, Manchester (2011):** 25% of partners traced and tested after notification were newly diagnosed HIV positive.<sup>30</sup>

**South Wales (2008):** 25% of partners traced and tested after notification were newly diagnosed HIV positive.<sup>31</sup>

**Mortimer Market (2010):** 10% of partners traced and tested after notification were newly diagnosed HIV positive.<sup>32</sup>

### Sheffield (2009): HIV PN outcomes for 2009

135 partners recorded from 74 newly diagnosed index patients  
63% traced. Of those,  
51% had not tested and did so after notification  
17% were ongoing or outcome was unknown  
32% had already tested

Of those traced and tested after notification, **37%** were newly identified as HIV positive.

## Why HIV partner notification matters

The average positivity rate across these audits (27%) is also broadly consistent with findings abroad. For instance, a recent study in Denmark looked at the HIV partner notification outcomes for 254 consecutive newly diagnosed HIV positive individuals, finding a new positivity rate among traced and tested partners of 28%.<sup>33</sup> A pan-European study of HIV partner notification conducted in the mid-1990s also found around 29% of patients traced and tested to be newly diagnosed HIV positive.<sup>34</sup> The high levels of newly diagnosed individuals displayed in the audits above compares favourably to other highly rated testing interventions, such as opt-out HIV testing in relevant primary and secondary care settings.<sup>35</sup>

There is also reason to believe HIV partner notification can increase rates of testing among at-risk groups. For instance, a study by Chelsea and Westminster's 56 Dean St clinic found that 23% of attendees who had never previously had an HIV test only tested as a result of partner notification. Sigma Research have found formal partner notification to be the most likely message that would prompt HIV negative MSM to get an STI screening. When asked, "What do you think someone could say to you or tell you that might prompt you to go for an STI screening?", 31.8% of MSM said partner notification from someone diagnosed with an STI, scoring

far above the next most likely, 'as part of a regular screening' (18.2%).<sup>36</sup>

The effectiveness of HIV partner notification for getting people with undiagnosed HIV tested and diagnosed is particularly pronounced among partners of recently infected patients. One study, for example, found that when traced and tested, 53% of partners of recently infected index patients were HIV positive, compared to 21% of partners of index patients with established HIV infection.<sup>37</sup> Detailed studies in the US have also observed a higher proportion of newly identified positives among partners of recently infected index patients.<sup>38</sup>

There are higher levels of infectiousness at the early stage of infection. Tracing and testing sexual partners of someone recently infected means it is much more likely you will diagnose someone also recently infected by the index patient. Alternatively, you may be diagnosing the person who transmitted HIV to the index patient – who may have done so because s/he is in the same highly infectious acute stage. Either way the consequences are substantial, given the personal or public health benefits of diagnosing HIV as early as possible. In particular, diagnosis during the early stages of infection may have a significant impact in reducing HIV incidence,

owing to the high proportion of HIV transmissions which occur between people where one partner is unknowingly in this hyper-infectious stage.

All of this suggests there is a strong case for incorporating the Recently Infected Testing Algorithm (RITA) test within HIV partner notification processes, using it to define a 'look back period' for 'RITA positive' patients. RITA tests (or 'avidity tests') identify the likelihood of recent HIV infection.<sup>39</sup> Indeed, there may be a case for prioritising patients with probable recent infection in HIV partner notification processes. HIV specialists are – to varying degrees – amenable to all of these ideas, according to research shared with NAT's seminar by Dr Valerie Delpech from the Health Protection Agency (HPA).<sup>40</sup>

More research would be useful in this area, and to more clearly define the place of RITA within HIV partner notification. It would also be useful to know more about the characteristics of those diagnosed as a result of partner notification. For example, routinely collecting the CD4 count of people newly diagnosed as a result of partner notification would give us a better insight into the impact it can have in diagnosing people early on in infection. While this may be too labour intensive for every clinic, where it is feasible to do so it should be done, with clinics encouraged

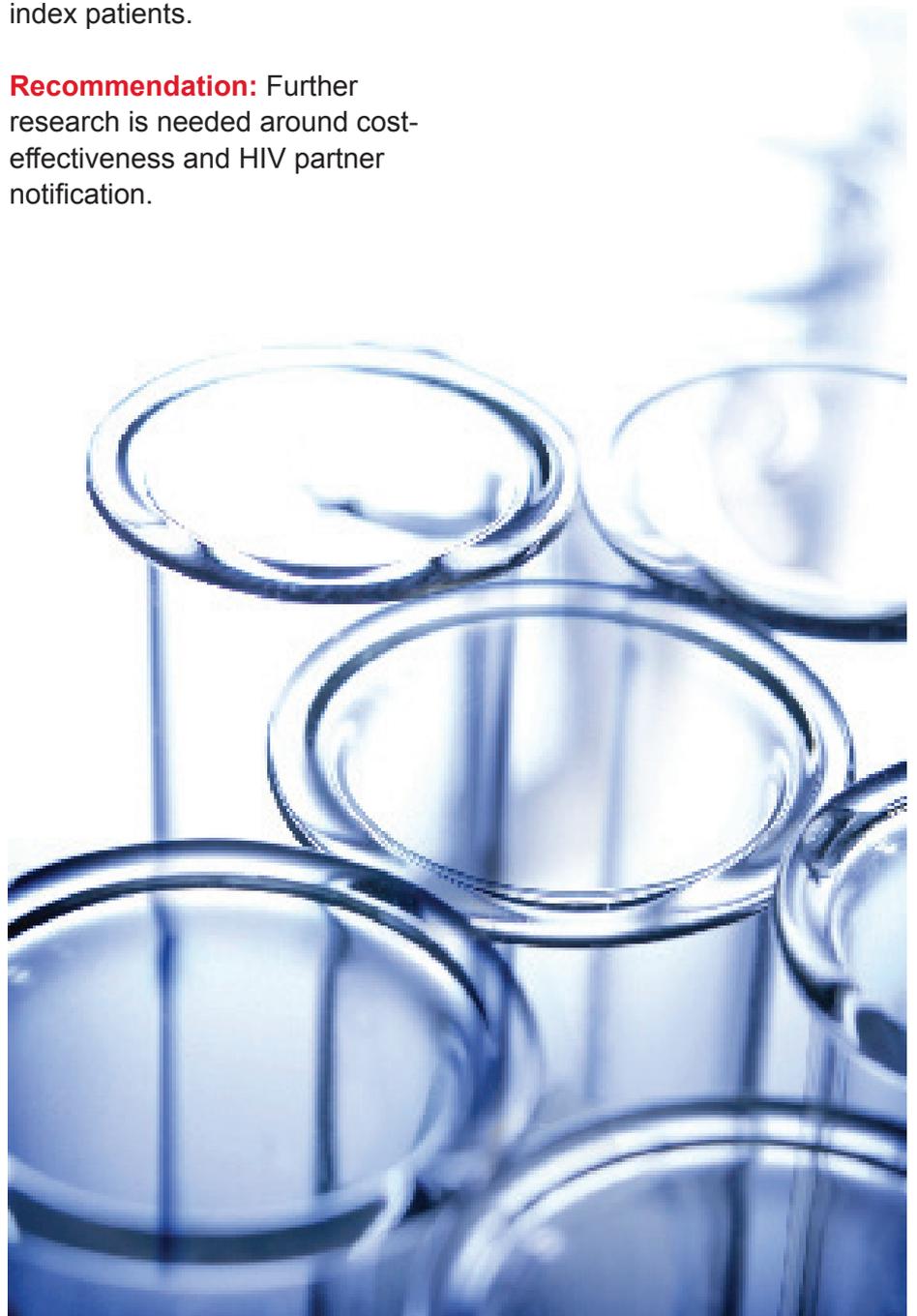
## Why HIV partner notification matters

to collect the first CD4 counts of newly identified positive partners as part of their auditing processes.

Further research is also needed on the cost-effectiveness of HIV partner notification in the UK. However, the significant rates of newly identified HIV infections suggest thorough HIV partner notification is cost-effective. While not directly transferable to the UK, it is worth noting a model of cost-effectiveness used in the US. This deems an HIV partner notification programme (when added to standard HIV testing) cost-effective when one new infection is identified for every 9.3 (or below) index patients interviewed.<sup>41</sup>

**Recommendation:** Clinics should consider incorporating the results of Recently Infected Testing Algorithm (RITA) tests within their partner notification processes, in order to ensure prompt and focused notification of partners of recently infected index patients.

**Recommendation:** Further research is needed around cost-effectiveness and HIV partner notification.



## The current state of HIV partner notification

### Sinking without a trace?

Despite its personal and preventive benefits, and a handful of clinics which regularly audit and undertake HIV partner notification, the consensus at NAT's seminar was that in many areas of the UK HIV partner notification too often goes under-resourced, unperformed or unacknowledged. It is frequently deemed to be at the bottom of a long list of needs for newly diagnosed HIV patients. By contrast partner notification is deeply embedded within the clinical processes and culture of, for instance, chlamydia, where clear national standards also exist – this is simply not the case for HIV.

Some of this is evident in audits and research shared with NAT around the seminar. For instance, an estimated 31% of HIV patients at the Trinity Centre for Sexual Health in Bradford did not have a partner notification sheet in their notes. Their audit, based on

a random sample, also showed partner notification sheets to be incomplete for 35% of HIV patients while 34% were not seen by a Health Adviser.<sup>42</sup> London-based Mortimer Market Centre's audit showed HIV partner notification was not documented for 15% of newly diagnosed patients.<sup>43</sup> In another, separate study a case note review of 145 HIV positive pregnant women revealed 18% had no record of partner notification discussion with a healthcare worker.<sup>44</sup>

Based on discussions and research around the seminar, NAT believes this is by no means exceptional. Despite the hard work of individual members of staff, HIV partner notification is too often neglected or 'falls between the gaps'. Indeed, a large part of the problem is that many clinics, unlike the Trinity Centre and Mortimer Market, do not audit their processes and outcomes for HIV partner notification – so current performance is not even known,

and consequently no basis exists for improving it. This needs to be addressed through an immediate period of data gathering.

However, the reasons that HIV partner notification often goes underperformed are complex and varied, from both a provider and a patient perspective. These will be explored in the following section.

**Recommendation:** An immediate 12-month period of 'data gathering' should be undertaken by all sexual health clinics, documenting current performance, activity and outcomes around HIV partner notification. This could be co-ordinated by BASHH National Audit Group and supported by BHIVA and the Society of Sexual Health Advisers (SSHA). Results will provide a much better national picture of the state of HIV partner notification, and provide data to inform the agreement of HIV-specific outcome standards.



**In many areas of the UK HIV partner notification too often goes under-resourced, unperformed or unacknowledged.**

## Barriers to better HIV partner notification

### Modern day challenges

There are a number of challenges relating to the nature of the modern world which can serve to inhibit the effectiveness of HIV partner notification. These relate primarily to the traceability of identified partners.

Rates of casual and anonymous sex have increased over recent generations in the UK, aided by increased inter-connectivity and the rise of online dating websites.<sup>45-46</sup> This is particularly the case among MSM – one piece of meta-analysis showed that 40% of MSM living in the UK had used the internet to look for sex partners.<sup>47</sup> Index patients, then, may not have the phone number, address or even the name of a previous sexual partner. For this reason provider referral methods should look to keep pace with the means by which people develop or establish sexual relationships, such as internet dating sites and phone applications. This should be in addition to SMS (texting) technology.<sup>48</sup> GMFA, for example, has piloted an online Sexual Health Messaging Service, which can confidentially notify partners through dating websites such as Gaydar – this idea has proven acceptable to MSM.<sup>49</sup>

A second problem is posed by the increased movement of people within and particularly between countries. Globalisation has brought with it increased

movement of labour, which in turn has seen a higher turnover of people entering and leaving the country over short spaces of time. The result is that many partners – particularly in African communities – can prove untraceable for the simple reason that they have moved abroad. If the patient does not have up-to-date contact details for the partner, it may be harder for the healthcare worker to co-ordinate with clinics operating outside the UK (for example, to share details or verify testing). The consensus at NAT's seminar was that this issue is especially pronounced in London, where there are a higher proportion of migrant communities, and that any outcome standards developed should reflect this (see section on standards).

**Recommendation:** Sexual health clinics should investigate incorporating online technology, such as messaging via gay dating sites and phone applications, within their partner notification processes for STIs and HIV (both patient referral and provider referral).

### Barriers among providers of HIV partner notification

A wide variety of factors impede providers of HIV partner notification in the UK. The first is that healthcare workers operate in an environment where cost is paramount and resources

are stretched. Consequently, as President of the SSHA, Martin Murchie, pointed out, some Health Advisers currently see it as more beneficial to spend an hour seeing five clients than an hour doing one patient's partner notification. This relates back to ignorance of the effectiveness of partner notification among staff, which in turn is owing to the lack of consistent auditing and subsequent evidence base. In this way, poor performance in HIV partner notification can reinforce itself. Numerous participants made clear at NAT's seminar their concerns that with financial pressure increasing, on top of large scale organisational change, partner notification could become further neglected.

The key to interrupting this vicious circle lies in the development of clear national standards for HIV partner notification and in an effective commissioning process.

There is a lack of HIV-specific guidance on partner notification at a national level, including as an ongoing process for those living with HIV who continue to have sex involving risk of transmission. NAT hopes this – as well as clear standards around process and documentation – will be to a significant extent addressed in the forthcoming BASHH partner notification statement. But further national guidance on good practice will continue to be urgently needed

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for HIV partner notification around such issues as outcome measures and standards. Most importantly, any agreed standard around HIV partner notification should also be integrated within wider relevant guidelines. NICE guidance on HIV testing should incorporate recommendations on partner notification, as should any other national testing guidance. We look at outcome measures in greater detail later on in this report.

Following the Health and Social Care Act 2012, commissioning for partner notification in England will now lie with Local Authorities. It is vital that STI partner notification, including for HIV, is contained within the specification and tariffs for sexual health services as an essential service. Commissioners should commission this service in line with the standards set out in the BASHH partner notification statement, and any further outcome measures determined in relation to HIV. Quality requirements around HIV partner notification must also be contained within such specification (for more detail see this report's section on standards). Local decision makers should look to commission high quality HIV partner notification as a prioritised part of sexual health services.

There has been concern over the fate of sexual health services when local authorities

take over commissioning responsibility. This concern extends even for elements which are currently well established. Those aspects of a service which may be undervalued, or lack clear national standards and expectations, may well be especially vulnerable to under-resourcing or neglect. Public Health England should specify in some detail in its mandate for local authorities what an appropriate and comprehensive sexual health service entails – and STI and HIV partner notification processes should be explicitly included in this national requirement, citing appropriate standards. The inclusion of partner notification in the integrated Sexual Health Service Specification for London is very welcome.

Further challenges are presented by the varied settings in which HIV services are provided. For example, treatment and care for HIV are provided in some areas not by GU but by Infectious Disease (ID) units. Furthermore, as HIV testing is rolled out outside of GUM, diagnoses will increasingly take place in secondary care, primary care and in the community. A key issue therefore is that service specifications make absolutely clear in every local area who is responsible for HIV partner notification and how it will be paid for.

More practical considerations can also play a part in hindering HIV partner notification. For instance, for clinics that still use paper systems, relevant partner notification notes or processes can often get lost or not passed on when a patient is diagnosed outside of sexual health clinic. Mortimer Market found that of those newly diagnosed HIV patients who did not see a Health Adviser about partner notification, 75% were diagnosed in hospital. Only 62% of patients diagnosed in hospital had documentation of partner notification, compared to 85% of those diagnosed in the clinic.<sup>50</sup> This problem may increase as testing is expanded outside of traditional settings.

Even within the GU clinic system there can be problems verifying whether people have been traced and referred, and whether they have then attended for testing. This is because GU is an 'open-access' service and people can attend any clinic within or outside their local area. There is a need for notes to be computerised. I.T. systems to improve the efficiency and effectiveness of HIV partner notification should also be explored. At the seminar, Dr Ann Sullivan discussed Mikom's Electronic-Partner Notification (or 'E-PN'). E-PN is a secure, cross-clinic, web-based programme. It can be used to log episodes of partner notification, send messages for provider referral and verify partner attendance across the network

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**Relevant partner notification notes or processes can often get lost or not passed on when a patient is diagnosed outside of sexual health clinics.**

of participating clinics.<sup>51</sup> In doing so, it can make the process of HIV partner notification, particularly verification, far less time consuming. The programme is currently being trialled in eight clinics across the UK. If successful, it could greatly assist the development and use of outcome measures for partner notification.

As previously alluded to, in many parts of the country HIV treatment is not provided in GU clinics but ID units. Clinical Nurse Specialists (CNS) working within these units may well not be trained in partner notification. In such instances, it is very important that clear protocols are agreed between ID units and GU clinics. These must ensure that Health Advisers undertake partner notification for all newly diagnosed patients, and as appropriate, on an ongoing basis. Complex ethical dilemmas facing the healthcare worker also contribute to incomplete or unperformed HIV partner

notification. These are particularly acute with HIV because of the potential seriousness of the condition. They were outlined at NAT's seminar by Dr Mary Poulton and largely coalesce around the tension between responsibility to the care of the patient and the duty of care towards the partner. What if, for instance, a patient is refusing to engage with partner notification but the health adviser knows they are continuing to expose partners to high levels of ongoing risk? How, if at all, should they intervene? Would non-consensual disclosure undermine trust in sexual health clinics? What is the line between encouragement and coercion? Conversely, what if the healthcare worker has reason to believe that the patient will experience domestic violence upon notification?<sup>52</sup>

Such questions can serve to inhibit a healthcare worker from properly pursuing or prioritising HIV partner notification,

particularly if they lack confidence or training in the first place. Confusion over the law around criminalisation, and how much information to provide to the patient (including by law), adds a further layer of intricacy. There is a need to keep HIV partner notification as an ethical, voluntary process rather than a coercive one involving the law. All of these issues should be incorporated within wide-ranging training for relevant healthcare providers around partner notification. The issue of law and criminalisation is looked at in more detail in the next section.

## Barriers to better HIV partner notification

**Recommendation:** Partner notification should be commissioned as a prioritised and essential part of sexual health services by local authorities, with appropriate funding for Health Advisers, and with service specifications in line with national standards.

**Recommendation:** In every local area, service specifications must make absolutely clear who is responsible for HIV partner notification and how it will be paid for.

**Recommendation:** Public Health England should explicitly refer to partner notification - including HIV partner notification - within its mandate for local authorities and set out the requirements for the commissioning of local sexual health services.

**Recommendation:** If E-PN proves successful, clinics should consider integrating it, or other similar technologies, within their partner notification processes to facilitate communication and verification between clinics.

**Recommendation:** BHIVA should work with BASHH to consider the possibility of a more detailed, HIV-specific annex to the forthcoming BASHH partner notification statement. This should look to specify outcome measures and standards, as well as clarify good practice (e.g. whether to factor partners 'already tested' into audited outcomes).

**Recommendation:** All clinics, whether GU or ID, should ensure appropriately trained staff undertake HIV partner notification.

**Recommendation:** Steps should be taken to fund and deliver wider provision of comprehensive training for relevant healthcare workers in partner notification for STIs and HIV, including Clinical Nurse Specialists.

**Recommendation:** NICE guidance on HIV testing should incorporate recommendations on partner notification.

## Supporting patients to engage in HIV partner notification

The consensus at NAT's seminar was that different attitudes and barriers to engaging with HIV partner notification will exist among different risk-groups. However, there are a number of general barriers that exist for people in all groups.

### Stigma

Stigma around HIV is far more endemic than that for other STIs. HIV stigma often manifests itself in fear of rejection, gossip and reputational damage, or in some cases verbal and physical abuse. These fears can prevent patients from attending partner notification sessions, talking to the healthcare worker or giving details of appropriate partners. Quite obviously, it can also inhibit them from informing partners if they are undertaking partner notification themselves. One audit showed 22% of patients did not contact any of their contactable partners.<sup>53</sup> Although the HIV sector strives for the normalisation of HIV in society, the reality is that being diagnosed with HIV remains a very distressing, disorientating process for many people. Often, NAT's seminar learnt, newly diagnosed patients can spend the first two sessions following diagnoses just crying or in shock. Trying to get the patient to engage in the daunting task of



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partner notification may not even be appropriate at such an early stage, when what they need most is reassurance and support.

There are a number of steps that can be taken to address this. It is not reasonable for HIV patients to be expected to have documented outcomes for partner notification within four weeks, as it currently stands with other STIs. Rather it should be considered good practice to, within four weeks, have documented outcomes for HIV partner notification *or* an agreed timeline to address partner notification going forward. Reassuring the patient of the importance the clinic places on confidentiality also becomes even more important, as Jonathan Roberts told the seminar.<sup>54</sup> Any patient perceptions to the contrary are potentially damaging, and must be assuaged at the earliest possible opportunity.

In addition, a number of community and voluntary sector groups currently offer a great deal of help to people living with HIV needing extra support around disclosure. Many of these groups run courses for newly diagnosed patients which focus on partner notification through support groups and a peer-led approach. Often these services will work in tandem with multi-disciplinary teams within hospitals and sexual health clinics. The help with partner notification available from peer support and community and

voluntary sector organisations needs to be considered within the commissioning process for HIV partner notification. Such community-based support can provide additional resources, time and detailed discussion of disclosure strategies with the newly diagnosed, freeing up scarce time for the clinic. Positive East is just one example cited at our seminar of a voluntary sector organisation very involved in such processes. In dealing with issues of fear and stigma there is real benefit in the newly diagnosed person being able to talk through issues with someone living with HIV and appropriately trained to provide support.

Good practice in this regard needs to be identified and shared across the country, perhaps via the SSHA and their 'Manual'. Appropriate protocols and quality standards, especially where there is a 'joined up' approach with the HIV clinic, need to be agreed. As community testing undertaken by voluntary sector organisations is rolled out across the country, there should also be clarity around responsibility for partner notification. Positive East said that they had agreed protocols with the local hospital in relation to partner notification work within their community testing service. It will be important as testing is undertaken by a wider range of providers that HIV partner notification is consistently commissioned, properly resourced, and that there are

clear allocations of responsibility for partner notification processes – including both audit and reporting of outcomes.

**Recommendation:** Clinics and commissioners should look to incorporate community groups and voluntary sector organisations within partner notification processes to provide support for the patient around HIV disclosure.

### Criminalisation

The second general barrier to HIV partner notification frequently mentioned at NAT's seminar is criminalisation. The fear of being prosecuted for HIV transmission can stop a patient engaging thoroughly in partner notification from a concern that, for example, a healthcare professional will inform the police over any ongoing risk. These fears can be misplaced, and based on a misunderstanding of the law, such as thinking one can be criminalised for transmission prior to diagnosis.

There was discussion at the seminar of the legal complexities around the notification of current sexual partners, following diagnosis. The patient will now know his or her HIV positive status and so criminal liability begins from this point on. But it was agreed that to expect

## Barriers to better HIV partner notification

**In England and Wales there is an offence under section 20 of the Offences Against the Person Act (1860) of ‘reckless transmission’. This requires the accused to have known, in advance of the sexual act, of his or her own HIV positive status. This also applies to Scotland, despite the offence there being contained under a different legal provision and the law allowing for prosecution of exposure to risk. Therefore, since the relevant sex took place before the patient knew they had HIV, partner notification of past partners of someone newly diagnosed should not raise any legal concerns.<sup>55</sup>**

someone to disclose their HIV positive status immediately is in most cases wholly unrealistic.

We were glad to have at the seminar representatives of both the Crown Prosecution Service (CPS), the prosecution authority for England and Wales, and the Crown Office and Procurator Fiscal Service (COPFS), the prosecution authority in Scotland. The CPS pointed out that a key consideration in any prosecution is whether or not the individual acted ‘reasonably’. Every case has to be considered on its individual merits and circumstances, but the fact that someone recently diagnosed is actively engaged in therapy for partner notification, will clearly be relevant when considering the ‘reasonableness’ (or recklessness) of their behaviour.

Of course, separately, it could prove difficult to establish that any transmission occurred after diagnosis anyway. But in Scotland where intentional or reckless exposure can be a

crime, this becomes a particularly important question to address. At the time of the seminar, COPFS were in the process of drafting a policy on the intentional or reckless sexual transmission of, or exposure to, infection and so were limited in relation to what reassurance they could provide.

The COPFS should at least provide similar reassurance to the CPS, acknowledging that disclosure to a current sexual partner after diagnosis is difficult and a ‘process’, and that additionally a patient’s engagement with partner notification will be factored into any analysis of the ‘reasonableness’ or ‘recklessness’ of their behaviour.

The greater difficulty is the implications of criminalisation for ‘ongoing’ partner notification. That is, where someone living with HIV has continued to have sex with a risk of transmission, often with new or casual partners. This may become apparent, for example, when someone

living with HIV presents with STIs. Of course, whether a criminal offence has occurred will depend on whether they had disclosed their HIV status, and in England and Wales on whether transmission has taken place. But it is clear that the threat of investigation and prosecution can deter people living with HIV from being honest with their clinic about their sex lives and about their need for safer sex support, for example around condom use or disclosure.

Recent evidence suggests that some people with HIV are seeking treatment for STIs in a different clinic from where they attend for HIV care to possibly avoid disapproval or legal implications.<sup>56</sup> Clearly this is a public health harm arising from criminalisation – it would be far better in these circumstances for people with HIV to seek support around safer sex and engage in partner notification without fear of legal consequences for themselves.

There are a number of steps clinics should, at the very least, take to mitigate such harm. They should ensure that their approach to service users is non-judgemental, that confidentiality is emphasised and respected and that it is made clear that the police are not approached by clinic staff in relation to issues around reckless transmission (and in Scotland, reckless exposure).

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In some instances police have approached sexual health clinics for information, wishing to inform sexual partners of patients about their possible risk of HIV transmission. In England and Wales this contravenes guidance on investigations produced by the Association of Chief Police Officers (ACPO). Clinics should only provide information to police without the consent of the relevant individuals if police produce a court order. Forthcoming guidance from BASHH and BHIVA on the implications of criminalisation on the work of the clinic will be important support for clinics in this complex and sensitive area.

### Other legal issues

Even putting aside criminalisation of HIV transmission, HIV partner notification has always raised complex ethical and legal questions. This is particularly true in relation to index patients who continue to have unprotected sex with a partner to whom they refuse to disclose their HIV diagnosis. Guidance from the General Medical Council on confidentiality makes clear that where someone is at risk of serious infection and the index patient refuses to consent to disclosure, the clinician can disclose without consent.<sup>57</sup> A number of seminar participants discussed the ethical dilemmas around care for the index patient and care for the sexual partner at risk of infection. In one instance

cited, partner notification had not been pursued because there was a fear of domestic violence to the female index patient should her status be disclosed. In other cases, however, cooperation from a reluctant patient had been forthcoming once it was made clear that in the last resort disclosure could and would take place without the patient's consent. In addition to balancing the different needs of the patient and his/her sexual partners, consideration must also be given to the reputation of the sexual health clinic and wider community trust in its confidentiality.

In practice these ethical issues can usually be resolved, and guidance and case studies in the forthcoming revision of the Manual for Sexual Health Advisers would be immensely useful in this regard. On the other hand, the sensitivities and complexities around partner notification, the law, ethics and confidentiality do underline the need for experienced professionals undertaking partner notification and the importance of sexual health advisers being trained, resourced and employed in all clinics.

**Recommendation:** The Manual of Sexual Health Advisers should provide up-to-date information on legal issues around criminalisation and partner notification, drawing on the forthcoming BASHH/BHIVA guidance on reckless

transmission and the work of the clinic.

**Recommendation:** The Society of Sexual Health Advisers should consider additionally whether resources (online and/or printed) both for sexual health advisers and for the newly diagnosed might be useful to explain the law and allay misconceptions or misplaced concerns.

**Recommendation:** Clinics should ensure that partner notification remains, to the maximum extent possible, a consensual, confidential and cooperative process, minimising appropriately the intrusion of the criminal law.

**Recommendation:** The COPFS should provide reassurance that a patient's engagement with partner notification will be factored into any analysis of the 'reasonableness' or 'recklessness' of their behaviour.

### Patient attitudes towards HIV partner notification: men who have sex with men (MSM)

Extensive research in 1997 amongst GUM clinics in England found 'unacceptability of HIV partner notification to patients' to be the most common limiting factor around the process<sup>58</sup>. At the time, statistically most of these patients would have been

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MSM. Fifteen years on, following huge strides in treatment, there are signs that gay and bisexual men may – in theory – be more amenable to the process of partner notification. Dr Ford Hickson shared findings from Sigma Research’s survey of MSM attitudes towards notifying former partners about an STI diagnosis. The survey found a strong normative sense of ‘doing the right thing’ attached to partner notification: participants described it as being the honourable and mature thing to do, seeing it as showing respect to partners and giving peace of mind. The health benefits of partner notification were also cited.

There is, though, a continuing disparity between the acceptability of partner notification in theory and in practice. GMFA’s survey of over 3,000 gay men found that 98% would want a partner to notify them if they had been diagnosed with HIV or another STI, while 96% said they would be willing to notify in the future after an STI diagnosis (98% for HIV). But it also found that one-fifth of respondents diagnosed with an STI had not, in practice, notified any partners.<sup>59</sup> Sigma Research corroborates this, finding that nearly 30% of individuals did not notify partners when diagnosed with an STI. Though a large part of this is often due to not having contact details for the partner, GMFA’s research found that not wanting further contact with ex

partners, embarrassment, fear and awkwardness still featured prominently in reasons for not notifying.

This is again supported by Sigma’s research, with many men pointing to the risk that a regular partner would end a relationship as a reason not to engage with partner notification.<sup>60</sup> Indeed, most of the perceived possible ‘costs’ of notification centred on the partners reaction: other than break-up, partner revenge, anger and gossip all featured strongly.<sup>61</sup>

Attitudes to partner notification among MSM, then, remain firmly embedded in one’s sex and social life. Furthermore, stigma around HIV means barriers to STI partner notification are likely to be heightened when it comes to HIV partner notification. Yet studies indicate fears around relationship break-up may be unfounded. One study in the US found that HIV partner notification did not actually increase relationship break-up and was associated only with increased condom use.<sup>62</sup> Another, also in the US, suggested partner notification for HIV led to relationship break-up no more than it did for syphilis.<sup>63</sup>

All of this suggests, as Sigma argue, that advice and literature around HIV partner notification for MSM should look to highlight the possible positive experiences of the process.<sup>64</sup> As Dr Hickson told NAT’s seminar, with MSM attitudes towards partner notification broadly going in the right direction, promotion of HIV partner notification is an “open door” at a community level if it is done properly.

**Recommendation:** Partner notification should be incorporated within health promotion and HIV prevention messages for MSM.

**Recommendation:** Advice and literature around HIV partner notification aimed at MSM should highlight the possible positive experiences of the process.



**Promotion of HIV partner notification is an “open door” at a community level if it is done properly.**

## Barriers to better HIV partner notification



**There is a pronounced gender dynamic to the issue of HIV partner notification in many African communities in the UK.**

### **Patient attitudes towards HIV partner notification: African communities**

There are many complexities facing HIV partner notification among African communities living in the UK. Dr Martha Chinouya explained some of these to NAT's seminar. Although it is always difficult to generalise about any risk-group, it is especially hard to do so about Africans in England. As Dr Chinouya pointed out, this is because African communities are very diverse, encompassing a variety of different norms and practices, and feature MSM as well as heterosexuals. However, heightened stigma around HIV is often a common feature across many of these communities. For instance, many young women who have lost partners to HIV or AIDS call themselves single due to the stigma of being a widow. Racially loaded preconceptions in the wider population around HIV being an 'African disease' can further inhibit notification.

There is also a pronounced gender dynamic to the issue of HIV partner notification in many African communities in the UK. Dr Chinouya said that African women are more likely to stay in a relationship if a man is HIV positive, whereas men are more likely to leave. Given that many African women are diagnosed in antenatal settings, the fear of abandonment, isolation and partner violence – as the woman thinks about her child's welfare as well as her own – can be even more intense. This can create an obvious barrier to engaging with HIV partner notification in straight-forward ways, if indeed at all. For instance, a newly diagnosed woman may wish to delay partner notification until her baby is tested negative, in order to present her partner with 'good and bad' news (this was a real life case study provided by Dr Poulton). To be effective the process of HIV partner notification needs, as far as possible, to be flexible, supportive and individualised to fit the needs of each patient.

Legal complications, beyond criminalisation, can also interfere with effective engagement with HIV partner notification by Africans in the UK. Uncertain immigration status is perhaps the most prominent one. In many cases, Dr Chinouya said, an African patient will think they know who passed HIV onto them, or who they may have passed it on to – but they will not inform the healthcare worker for fear that they will bring this person to the attention of the Home Office. This once more highlights the need for partner notification to operate as a purely voluntary, confidential process. However, recent news that NHS charges for HIV treatment are to be ended is a positive development for HIV partner notification and removes what was, hitherto, another barrier to engagement amongst migrant communities.<sup>65</sup>

Particular cultural differences or trends within African communities can contribute to limiting patient engagement with formal HIV

## Barriers to better HIV partner notification



The intertwining of many HIV positive Africans with faith communities has the potential to present challenges to HIV partner notification.

partner notification. Some of these can be seemingly minor, but nevertheless play their part. For instance, the tendency for some African couples to share mobile phones may make clinic SMS messaging inappropriate if a patient wishes to confidentially inform a partner who is in a separate relationship.

Finally, while Africans diagnosed with HIV may present themselves at clinic as individuals, they can be very involved in faith communities. Research suggests that a large number of HIV positive Africans living in the UK are deeply spiritual about their approach to coping with HIV.<sup>66</sup> While religion can be a great source of support for these individuals, some faith forums (whether churches, mosques or other religious organisations) can at times be a place where misinformation, stigma and hostility towards people with HIV are spread particularly quickly. Many are thus left fearful that

their confidentiality will not be respected and that their HIV status will become known to their faith community. In this way, the intertwining of many HIV positive Africans with faith communities has the potential to present challenges to HIV partner notification. For instance, a recently diagnosed woman may be reticent to notify her partner or husband for fear that he will tell members of their church, who will spread that information about her within the tight-knit community.

However, little is currently known about HIV partner notification in the context of faith communities in the UK and more research is needed. In fact, Dr Chinouya's presentation was one of the few insights into African attitudes towards HIV partner notification in the UK at all – more research is sorely needed on this topic in order to inform better strategy and practice.

**Recommendation:** Further research is needed on attitudes and barriers to HIV partner notification among African communities in the UK, including the role of faith groups. It would be useful for audits of partner notification to disaggregate data by sexuality and ethnicity to get a better sense of community-specific challenges.

## Whose standard is it anyway?

### Outcome standards

Unlike many other STIs, no national performance standard currently exists for HIV partner notification. Perhaps the biggest debate within the HIV sector over partner notification relates to what any such standard should look like. Failure to reach agreement over this has itself proven a barrier to better practice around HIV partner notification. It currently prevents the development of a coherent basis for evidencing and advancing the process on a national scale. As a result, practice remains disparate and un-coordinated, with one clinic documenting performance in a different way to the next.

As Gill Bell (Nurse Consultant Sexual Health Adviser at Royal Hallamshire Hospital) explained at NAT's seminar, the right standard can help keep performance levels high. However, an unrealistic or inappropriate standard can demoralise or disengage staff with the process. A good standard should get the balance right, be clearly measurable and unambiguous but achievable with effort; it should look to both identify and promote best practice.

So what standard is it reasonable to hold clinics accountable to on HIV partner notification? There was a general consensus that looking at partners tested was the best starting point, especially

from a commissioning point of view, when considering outcomes. However, there was disagreement on the details of the professional standard and how to calculate it. To illustrate this, below (**Table 1**) are South Yorkshire HIV Network's HIV partner notification outcomes for 2010 as provided by Gill Bell, covering the seven clinics in the network.

### HIV partner notification outcomes

At 360 days, for instance, South Yorkshire HIV Network have calculated their outcome by taking the number of partners tested (131) and dividing it by the number of newly diagnosed index patients (112), to reach an outcome of 1.17 partners tested for every index patient. That might then suggest an appropriate national outcome measure if similar results appear

possible elsewhere.

However, both sides of this calculation – the numerator and the denominator – are hotly disputed and issues around both need to be resolved before any agreement on standards is possible.

### Numerator: 'Partner verified tested' or 'partner reported tested'? Already tested?

The first dispute over outcomes relates to what is meant by 'partners tested'. In the above example, South Yorkshire HIV Network have only counted partners *verified* to have tested. This means confirmed from clinical records by a healthcare worker (for instance, through a phone call to another clinic). However, while this is preferable, verifying partner attendance can be difficult to do and is quite resource intensive. It is

Partners verified tested / case	Total	Range between clinics
< 90 days	118/112 <b>1.05</b>	0.17-1.30
< 180 days	123/112 <b>1.10</b>	0.17-1.33
< 360 days	131/112 <b>1.17</b>	0.17-1.50

**Table 1:** South Yorkshire HIV Network (2010)<sup>67</sup>

## Whose standard is it anyway?

something clinics with a reasonably small number of index patients could perform, but that under-resourced, busy clinics in cities like London might find considerably more challenging. These clinics may not just have more partners to trace but, as discussed above, have higher proportions of partners that have gone abroad.

For this reason, many at NAT's seminar preferred to calculate outcomes on the basis of partners 'reported' to have tested. This is where the index patient reports to the healthcare worker that a partner has tested, or where the partner reports to the Health Adviser. This is much more realistic for many clinics. For example, Brighton's HIV partner notification outcomes were 0.45 tested contacts per index patient when calculated only by 'reported to have tested', but dropped down to 0.3 when looking only at 'partners verified'.<sup>68</sup> But a standard based on this outcome presents its own problems: do we really just want to encourage clinics to take a patient's word for it, if more conclusive verification is possible?

A middle way in this debate is to create two separate standards – a primary 'gold' standard based on partners verified tested, and a secondary standard based on partners 'believed tested' (partners verified *and* partners reported to have tested). This

would take account of the different capacities of different clinics, while not discouraging best practice. The secondary standard should be set higher than the primary standard. Both should be informed by current performance data gathered through a national audit process. Whether it is also appropriate to make either of these regionally sensitive (e.g. inside/outside London) should also be informed by current performance.

One final issue around the numerator when calculating outcomes is whether to factor in those partners 'already tested'. This refers to any patient that has tested since their last exposure to risk from the index patient (bearing in mind the relevant 'window period'<sup>69</sup>) and whose HIV status has been ascertained. There is differing practice here, with some clinics only counting partners tested after notification and discounting those already tested. NAT believes that partners already tested should count towards outcomes (on the same verified and/or reported basis), and that BASHH need to make this clear in any future statement on HIV partner notification.

### Denominator: 'Index patients' or 'partner traced'?

The second part of the debate over standards relates to what the denominator should be when calculating outcomes. In the example data given above, South Yorkshire HIV Network have used the number of index patients as the denominator. Some at NAT's seminar, though, believed this to be unreasonable for clinics in areas with a high proportion of migrant communities. Because many more partners will be untraceable, they argued, their performance outcomes will naturally be lower because they will trace and test fewer partners. Because of this, it was suggested that 'partners traced' would be a better denominator. The calculation undertaken to reach an outcome would therefore be 'partners tested/partners traced', and an appropriate standard set to this measure.

However, a strong argument against this is that it would engender a perverse incentive within the practice of HIV partner notification. If untraced partners are not reflected at all in outcomes, staff may consider there to be no reason to spend extra time trying to trace hard-to-reach partners. Index patients, in NAT's view, should therefore remain the denominator, with demographic differences reflected in different regional outcome measures if necessary.

## Whose standard is it anyway?

**Recommendation:** There should be a primary and secondary standard for HIV partner notification outcomes.

The primary outcome should be calculated by: “Number of partners verified tested/index patients”.

The secondary outcome should be calculated by: “Number of partners believed tested/index patients”.<sup>70</sup>

The relevant standard for these outcomes should be formulated by BASHH after a period of national data gathering, and may need to be regionally sensitive (e.g. inside/outside London).

### Time taken for partner notification

There was debate at the seminar over a ‘standard’ for the completion of HIV partner notification. Some standard as to how long the process should take is clearly necessary if we are to know when to measure outcomes, and also to give a sense of how to plan the process and when to intensify efforts, or conversely decide no further action can be taken. But, as discussed above, many people pointed out that the usual standard for STIs of four weeks cannot be applied to HIV in the same way. The fact is that HIV is not only incurable but highly stigmatised; those diagnosed are coming to terms very often with traumatic news and may not be ready at once to begin the notification process. All this means an HIV-specific standard needs to be devised for the time-spans around partner notification.

Drawing on the discussion at the seminar, NAT has proposed to BASHH that progress on HIV partner notification should be discussed and documented four weeks after diagnosis. This should include clear timelines for further notification. Ideally, HIV partner notification outcomes should be completed at three months, and this is often sufficient. However, it should be stressed that if still incomplete at this stage, the process is still worth pursuing with clear timelines; successful outcomes have been documented up to 12 months after diagnosis, for instance. Performance audits should document outcomes at different points in time. South Yorkshire HIV Network’s table (Table 1), based on a simple algorithm (Annex A), is a good model of clear auditing in this respect.



## Whose standard is it anyway?

### Minimum standards

Incomplete or inconsistent documentation is a significant barrier to developing an evidence base from which to improve HIV partner notification. Consequently, there are certain minimum process standards on HIV partner notification that all clinics should meet. Firstly, all newly diagnosed patients should have a documented offer of at least one discussion of partner notification with a trained healthcare worker. Secondly, the outcome of an agreed contact action, or the decision not to trace, should be documented for all contacts. These are set out in BASHH's forthcoming statement on partner notification. Finally, every individual diagnosed with HIV should have a sexual health check up every six months, of which appropriate STI partner notification should as necessary form a crucial part. This is also recommended in the 2007 sexual health guidelines for people living with HIV.<sup>71</sup> These minimum standards should be reflected in all relevant standards of care, such as BHIVA standards of care for people living with HIV.

In the long term, clinics should also undertake an annual audit of HIV partner notification outcomes for patients diagnosed that year. The core clinical data collected should be:

- (1) Index patients
- (2) Total partners identified
- (3) Partners reported as tested
- (4) Partners verified as tested
- (5) Result of partners' tests – including the number of new positive diagnoses.

It would also be beneficial, if possible, to collect the CD4 count of all partners diagnosed positive through partner notification. Although this may be too labour intensive for all clinics to undertake, it would allow an explicit judgement on whether HIV partner notification was diagnosing patients in early infection. This could then be used to build the local case for the effectiveness of HIV partner notification in reducing late and very late diagnosis, in light of the indicator for late HIV diagnosis in the Public Health Outcomes Framework. Finally, financial incentives, such as CQUIN (Commissioning for Quality and Innovation) payments, need to be used to incentivise good practice in HIV partner notification.<sup>72</sup>

**Recommendation:** All newly diagnosed patients should at least have an offer of a discussion about HIV partner notification. All outcomes of agreed actions should be clearly documented. Partner notification should also form a crucial part of the sexual health check ups of people living with HIV, which should be undertaken at six-monthly intervals.

**Recommendation:** Within four weeks of HIV diagnosis, there should be documentation of either outcomes *or* an agreed timeline for further action.

**Recommendation:** HIV partner notification should ideally be completed within three months, but it is worth pursuing further than that provided there are clear timelines.

**Recommendation:** Financial incentives should be used to encourage good practice around HIV partner notification

**Recommendation:** All clinics should undertake an annual audit of HIV partner notification outcomes for that year, in line with agreed outcome measures.

## Recommendations

### Data gathering

► An immediate 12-month period of ‘data gathering’ should be undertaken by all sexual health clinics, documenting current performance, activity and outcomes around HIV partner notification. This could be co-ordinated by BASHH National Audit Group and supported by BHIVA and the Society of Sexual Health Advisers (SSHA). The results will provide a much better national picture of the state of HIV partner notification, and provide data to inform the agreement of HIV-specific outcome standards.

► Thereafter, all clinics should undertake an annual audit of HIV partner notification outcomes for that year, in line with agreed outcome measures.

► The core clinical outcome measures documented by clinics should be:

- (1) Index patients
- (2) Total partners identified
- (3) Partners reported as tested
- (4) Partners verified as tested
- (5) Result of partners’ tests – including number of new positive diagnoses.

If possible, it should also be considered good practice to collect:

- (6) Disease stage (i.e CD4 count) of positive partner

### Standards and good practice

► There should be a primary and secondary standard for HIV partner notification outcomes.

The primary outcome should be calculated by: “Number of partners verified tested/index patients”.

The secondary outcome should be calculated by: “Number of partners believed tested/index patients”.<sup>73</sup>

The relevant standard for these outcomes should be formulated by BASHH after a period of national data gathering, and may need to be regionally sensitive (e.g. inside/outside London).

► All newly diagnosed patients should at least have an offer of a discussion about HIV partner notification, with all outcomes of agreed actions clearly documented. Partner notification should also form a crucial part of the sexual health check ups of people living with HIV, which should be undertaken at six-monthly intervals.

► Within four weeks of HIV diagnosis, there should be documentation of either outcomes or an agreed timeline for further action.

► HIV partner notification should ideally be completed within three months, but it is worth pursuing further than that provided there are clear timelines.

► Financial incentives should be used to encourage good practice around HIV partner notification.

► BHIVA should work with BASHH to consider the possibility of a more detailed, HIV-specific annex to the forthcoming BASHH partner notification statement. This should look to specify outcome measures and standards, as well as clarify good practice (e.g. whether to factor partners ‘already tested’ into audited outcomes).

► NICE guidance on HIV testing should incorporate recommendations on partner notification.

► All clinics, whether GU or ID, should ensure appropriately trained staff undertake HIV partner notification.

► In their audits on HIV partner notification, it would be useful for clinics to disaggregate data by sexuality and ethnicity to get a better sense of community-specific challenges.

► Further research is needed around cost-effectiveness and HIV partner notification.

## Recommendations

### Commissioning

- ▶ Partner notification should be commissioned as a prioritised and essential part of sexual health services by local authorities, with appropriate funding for Health Advisers, and with service specifications in line with national standards.
- ▶ In every local area, service specifications must make absolutely clear who is responsible for HIV partner notification and how it will be paid for.
- ▶ Public Health England should explicitly refer to partner notification, including HIV partner notification, within its mandate for local authorities setting out the requirements for the commissioning of local sexual health services.
- ▶ Clinics and commissioners should look to incorporate community groups and voluntary sector organisations within partner notification processes to provide support for the patient around disclosure.

### Technology

- ▶ Clinics should consider incorporating the results of Recently Infected Testing Algorithm (RITA) tests within their partner notification processes, in order to ensure prompt and focused notification of partners of

recently infected index patients.

- ▶ Sexual health clinics should investigate incorporating online technology, such as messaging via gay dating sites and phone applications, within their partner notification processes for STIs and HIV (both patient referral and provider referral).
- ▶ If E-PN proves successful, clinics should consider integrating it, or other similar technologies, within their partner notification processes to facilitate communication and verification between clinics.

### Breaking down barriers to HIV partner notification

- ▶ The Manual of Sexual Health Advisers should provide up-to-date information on legal issues around criminalisation and partner notification, drawing on the forthcoming BASHH/ BHIVA Guidance on reckless transmission and the work of the clinic.
- ▶ The Society of Sexual Health Advisers should consider additionally whether resources (online and/or printed) both for sexual health advisers and for the newly diagnosed might be useful to explain the law and allay misconceptions or misplaced concerns.
- ▶ Clinics should ensure that

partner notification remains to the maximum extent possible a consensual, confidential and cooperative process, minimising appropriately the intrusion of criminal law.

- ▶ The Crown Office and Procurator Fiscal Service (COPFS) should provide reassurance that a patient's engagement with partner notification will be factored into any analysis of the 'reasonableness' or 'recklessness' of their behaviour.
- ▶ Partner notification should be incorporated within health promotion and HIV prevention messages for MSM.
- ▶ Advice and literature around HIV partner notification aimed at MSM should highlight the possibly positive experiences of the process.
- ▶ Further research is needed on attitudes and barriers to HIV partner notification among African communities in the UK, including the role of faith groups.
- ▶ Steps should be taken to fund and deliver wider provision of comprehensive training for relevant healthcare workers in partner notification for STIs and HIV, including for Clinical Nurse Specialists.

## Endnotes

### Introduction: we need to talk about HIV partner notification

<sup>1</sup> NICE (2011): *Public guidance on increasing the uptake of HIV testing among men who have sex with men*. NICE (2011): *Public guidance on increasing the uptake of HIV testing among black Africans in England*. BHIVA, BASHH, BIS (2008): *UK National Guidelines for HIV Testing*

<sup>2</sup> Department of Health (2001): *The National Strategy for Sexual Health and HIV*

<sup>3</sup> Golden, M (2002): 'HIV Partner Notification: A Neglected Prevention Intervention', *Sexually Transmitted Diseases*, Vol. 29, no. 8; Potterat J (2003): 'Partner Notification for HIV: Running Out of Excuses?', *Sexually Transmitted Diseases*, vol. 30, no. 1.

<sup>4</sup> Fenton K, Copas A, Johnson A, French R, Petruckevitch A, Adler M (1997): 'HIV partner notification policy and practice within GUM clinics in England: Where are we now?', *Genitourin Medicine*, vol. 73.

<sup>5</sup> However, the Society of Sexual Health Advisers (SSHA)'s 'Manual for Sexual Health Advisers' does contain a section on partner notification, which includes a chapter on HIV. Source: SSHA (2004): *The Manual for Sexual Health Advisers: Section A*

### The importance of earlier HIV diagnosis

<sup>6</sup> HPA (2010): 'Survey results to the end of 2010 (late diagnosis)', <http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/HIV/CD4TcellData/Surveillance/>; Gay Men's Sex Survey (2003), Sigma Research; Gay Men's Sex Survey (2008), Sigma Research.

<sup>7</sup> HPA (2011): *Surveillance of CD4 cell counts: survey results to the end of 2010*. [http://www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb\\_C/1203064758366](http://www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb_C/1203064758366)

<sup>8</sup> HPA (2011) <http://www.nat.org.uk/HIV-Facts/Statistics/Latest-UK-statistics/Late-diagnosis.aspx>

<sup>9</sup> UK Chic (2011). 'Impact of late diagnosis and treatment on life expectancy in people with HIV-1: UK Collaborative HIV Cohort (UK CHIC) Study', *BMJ*

<sup>10</sup> HPA (2012): *Evidence and resources to commission expanded HIV testing in priority medical services in high prevalence areas*

<sup>11</sup> NAM (2008): *Preventing HIV*

<sup>12</sup> Fox J et al (2009): 'Reductions in HIV transmission risk behaviour following diagnosis of primary HIV infection: a cohort of high-risk men who have sex with men', *HIV Medicine*, vol. 10.

<sup>13</sup> NAT (2011): *HIV Treatment as Prevention*

<sup>14</sup> HPA (2011): *HIV in the United Kingdom: 2011 report*

<sup>15</sup> NICE (2011): *Increasing the uptake of HIV testing among black Africans in England and increasing the uptake of HIV testing among men who have sex with men: costing report*

– implementing NICE guidance.

<sup>16</sup> Ibid

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<sup>17</sup> WHO (1999): Questions and answers on reporting, partner notification and disclosure of HIV serostatus and/or AIDS, public health and human rights implications.

<sup>18</sup> Apoola A, Radcliffe KW, Das S, et al (2006). 'Patient preferences for partner notification', *Sexually Transmitted Infections*, vol. 82.

<sup>19</sup> Woodward C, Roedling S, Edwards S, Armstrong A, Richens J (2010): 'Computer-assisted survey of attitudes to HIV and sexually transmissible infection partner notification in HIV-positive men who have sex with men', *Sexual Health*, vol. 7.

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### Why HIV partner notification matters

<sup>22</sup> Hoxworth T, Spencer N, Peterman T et al (2003): 'Changes in Partnerships and HIV Risks After Partner Notification', *Sexually Transmitted Diseases*, vol. 30, no. 1; Kissinger P, Niccolai L, Magnus M et al (2003): 'Partner Notification for HIV Syphilis: Effects on Sexual Behaviours and Relationship Stability', *Sexually Transmitted Diseases*, vol. 30, no 1; NAT (2011): *HIV Treatment as Prevention*

<sup>23</sup> NAT (2011): *Treatment as Prevention*

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### Whose standard is it anyway?

<sup>67</sup> These numbers were taken from an outcome algorithm contained in Annex A, and provided to NAT's seminar by Gill Bell.

<sup>68</sup> Roberts J (2012): *What next for HIV PN? Promoting best practice*. Presentation (unpublished).

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<sup>70</sup> 'Believed tested' = verified and reported.

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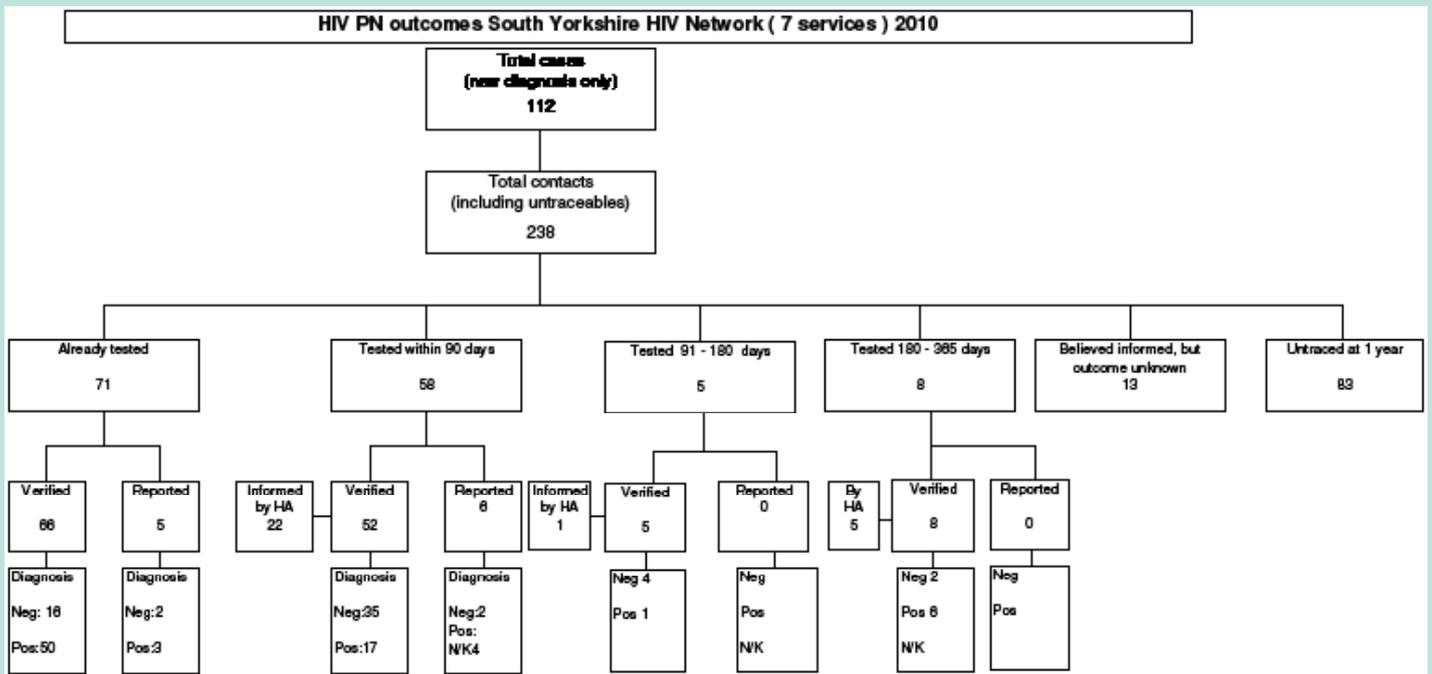
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### Recommendations

<sup>73</sup> 'Believed tested' = verified and reported.

## Annex A

### HIV partner notification outcomes South Yorkshire HIV Network (2010) algorithm



## Annex B

### HIV partner notification seminar attendees 16th January 2012

Steven Akehurst	NAT	Jonathan Roberts	Brighton and Sussex University Hospital
Lorraine Almand	Crown Office	Liz Rodrigo	Leicester City Council
Professor Jane Anderson	British HIV Association (BHIVA)	Marco Rossi	56 Dean St Clinic
Colin Armstead	George House Trust (GHT)	Lisa Ruxton	St Georges Hospital
Renee Aroney	St George's Hospital	Dr Nathan Sankar	Newcastle PCT
Yusef Azad	NAT	Jacqueline Stevenson	AHPN
Gary Barker	St Helens Hospital	Grant Sugden	Waverley Care
Hannah Bate	NAT	Ann Sullivan	Chelsea and Westminster
Gill Bell	Royal Hallamshire, Sheffield	Merle Symonds	Barts and the London
Mr Martha Chinouya	Northumbria University	Sam Thompson	Crown Prosecution Service
Jabulani Chwaula	National African HIV Prevention Programme (NAHIP)	George Valiotis	HIV Scotland
Annette Colcutt	Mortimer Market	Jason Warriner	THT
Susan Cole	NAT	Sonali Wayal	University College London (UCL)
Dr Valerie Delpech	Health Protection Agency (HPA)	Lee Winter	Lambeth PCT
Dr Gayle Dolan	HPA North East	Steve Worrall	Positive East
Dr Claudia Estcourt	Barts and the London		
Babs Evans	Elton John AIDS Foundation		
Ceri Evans	Chelsea and Westminster		
Dr Kirsty Foster	HPA North East		
Vicky Gilbert	HPA		
Donal Heath	GMFA		
Dr Ford Hickson	Sigma Research		
Ewan Jenkins	Inner NW London PCTs		
Francis Kaikumba	African Health Policy Network (AHPN)		
Tope Kaikumba	AHPN		
Ruth Lowbury	MedFASH		
Catherine Lowndes	HPA		
Hayley Lynch	Luton & Dunstable Hospital		
Jan Meechan	One to One, Newcastle		
Justine Mellor	Trafford Centre for Sexual Health		
Martin Murchie	The Sandyford, Glasgow		
Catherine Murphy	Terrence Higgins Trust (THT)		
Dumisani Ngwenya	Centre for African Families Positive Health		
Kay Orton	Department of Health		
Roger Pebody	NAM		
Mary Poulton	Kings College London		

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- equitable access to treatment, care and support for people living with HIV
- enhanced understanding of the facts about HIV and living with HIV in the UK
- eradication of HIV-related stigma and discrimination.

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NAT, New City Cloisters, 196 Old Street, London EC1V 9FR  
T: +44 (0)20 7814 6767 F: +44 (0)20 7216 0111 E: [info@nat.org.uk](mailto:info@nat.org.uk)

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