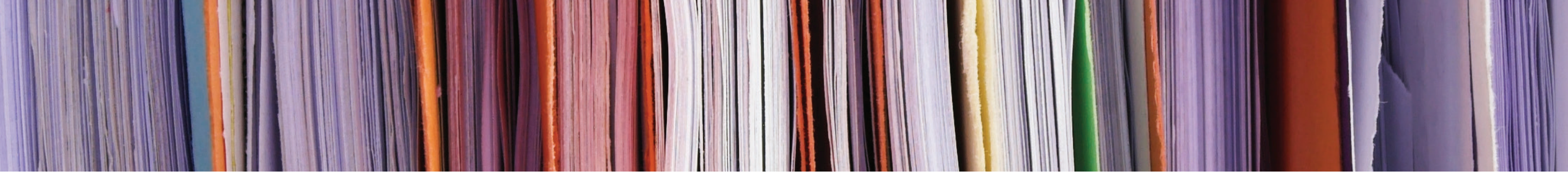

KEEPING CONFIDENCE HIV AND THE CRIMINAL LAW FROM SERVICE PROVIDER PERSPECTIVES

Responsibility and public health

Reports in this series

1 Executive summary
2 Understanding the law
3 Practice and procedure
4 Responsibility and public health
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Keeping Confidence is a qualitative research study that explores the perceptions of criminal prosecutions for HIV transmission among those providing support, health and social care services for people with HIV. For further information about the study methods and sample please see Report 1 – *Executive summary.*

All participants were asked to consider where responsibility for HIV transmission should reside and how they felt that criminal prosecutions for HIV transmission interacted with public health efforts. This report explores the various types of responsibility that arose, as well as its limits. These include consideration of individual responsibilities for transmission and acquisition, as well as the way that professional responsibility sometimes influenced their decision-making. Finally, this report summarises service providers' perspectives on the public health outcomes criminalisation.

PERSONAL RESPONSIBILITIES

Here we describe those responses where participants focused on the responsibilities of those who are directly involved in the sexual transmission and acquisition of HIV infection, starting with some people's thoughts about the overarching, as well as the modified responsibilities of people with diagnosed HIV.

When considering where responsibility rested when it came to HIV transmission, some participants felt it was primarily down to people with diagnosed HIV to disclose and to take precautions.

> ***...if someone has a known infection, they should assume responsibility for themselves to keep up to date with the advice that has been given to them. (clinical service provider)***

Similar comments were expressed in every clinic-based focus group (and in some of the community provider groups as well) although these were frequently questioned and debated among colleagues in the room. A considerable proportion of participants acknowledged that at times, the behaviour of service users might seriously challenge their own principles, making it difficult to know how best to respond. In reference to one such patient to whom considerable harm reduction advice had been offered, a participant said:

> ***We kind of know that he is potentially recklessly transmitting but his stance is that, 'They are grown adults and they should take responsibility just the same as I do'. He is cruising and things like that. He is actually quite clear in his mind isn't he? [agreement from others] He does not think he is doing anything wrong and that he is going to continue to do so and that has been quite hard for us to deal with. (clinical service provider)***

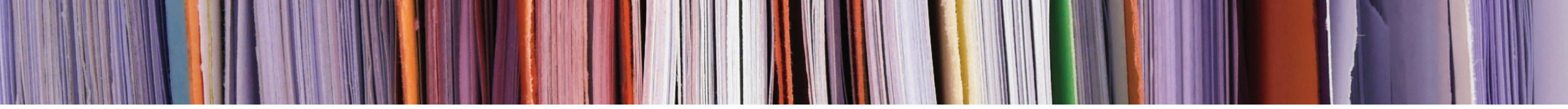
Others followed-up such discussions by describing the ways in which practitioners are called upon to suppress their own moral stance on an issue in order to best serve the needs of service users. In the following instance, a nurse talked about how her own feelings were secondary to a consistent approach which prioritises choice in sexual health.

> ***I know what you are saying, if somebody is willingly going out, and I have had patients like that that were infected, they were absolutely reckless, and they had known that they were going to infect people, and it does make you feel a bit annoyed with them. But in the long- term, I think it's all about sexual health messages. (clinical service provider)***

These findings demonstrate that at least some service providers hold the view that an HIV diagnosis confers a certain duty to protect others, and this was more evident in clinical than non-clinical service providers. However, there was considerable debate sparked by such statements, as discussed further below.

In contrast to those who held that responsibility for HIV prevention resides with the diagnosed individual, it was far more common for participants to focus on the need to contextualise responsibility within the complex dynamics of living with diagnosed HIV. Where the person with HIV had diminished power (being a woman, being very young, or having unsettled immigration status were frequently raised as examples) most felt that the security gained from concealing one's HIV status should be taken into account before assigning responsibility. If violence, blackmail or destitution loomed as a possible consequence of disclosure, participants felt that such individuals could not take full responsibility for HIV exposure.

> ***Where the woman may not have the power to be able to truly consent to having sexual relationships. Plus, added on to that,***



> ***she definitely doesn't have the power to be able to disclose. But she also, because of immigration and things like that, may not have the power to leave at that moment. So, I mean that is where recklessness becomes really...I mean, is it reckless behaviour if it is potentially lifesaving for her? (community service provider)***

It is worth noting that such views were just as commonly expressed by those providing clinical services as non-clinical services in the community. Many felt that the stigma associated with HIV infection reinforced existing inequalities, and was a considerable barrier to disclosure, given that it sometimes resulted in social isolation, violence or harassment for those who were already socially vulnerable.

Smaller numbers of participants also mentioned that there are a range of settings and sub-cultural contexts where there can be considerable pressure to have unprotected sex, and refusing to do so could raise questions about trustworthiness. They felt that some people with HIV can struggle to negotiate such pressures, particularly where sexual negotiation skills are lacking. Others mentioned intervening factors such as brain impairment or the use of drugs and alcohol leading up to a sexual encounter as factors that hamper precautionary behaviours.

In contrast, a few participants talked about the fact that responsible precaution is practiced by many people with HIV through more than just condom use and disclosure. In such contexts, they felt that account should be taken of a range of additional behaviours used to substantially reduce the likelihood of HIV transmission, including: the maintenance of an undetectable viral load (thereby reducing or eliminating infectiousness); ensuring that they are not the insertive sexual partner (or avoidance of penetrative sex altogether); and the prompt treatment of other sexually acquired infections.

An overarching factor that contextualised responsibility in the minds of many participants was their experience with the vast majority of people with diagnosed HIV who believe and hope that they will never pass on their infection – even if they cannot always act to ensure this.

There were participants in most groups who considered the extent to which responsibility should ideally extend beyond the person who knows that they have HIV, to be shared between consenting sexual partners. However, it was once again acknowledged that not all sexual relationships are equal, thereby presenting a challenge to the shared responsibility model, as conveyed in the following exchange.

> ***A: I support the saying 'it takes two to tango', but the two aren't necessarily equal.***
>
> ***B: It depends which two! [agreement from others] (community service providers)***

A range of participants felt that widespread naiveté about risk and sex should be challenged through improved education, information and advice – rather than being reinforced by assigning exclusive blame to those who know they have an infection. If risk were to be more broadly acknowledged, then, they argued, responsibility for risk behaviour could be equally accepted.

> ***Am I reckless because I asked him to put a condom on and he didn't? Or I told him we need to and he chose not to? Is that reckless?***
>
> **What would you say to that?**
>
> ***Well, no! (clinical service provider)***

Service providers demonstrated considerable variation in the ways that they regarded individual responsibility for sexual health and HIV prevention. While some rationalised that the additional knowledge of an HIV diagnosis conferred a burden of responsibility on that individual, it was far more common for participants to consider the limitations posed by social inequalities, alongside a general sense that consensual sex should involve shared responsibility for managing risk.

PROFESSIONAL RESPONSIBILITIES

Providers also considered their own responsibilities to service users and others when making professional decisions. Report 3 in this series discusses in greater detail the activities undertaken by professionals in relation to criminal prosecutions. This section will maintain a focus on the motivations that underpin their actions.

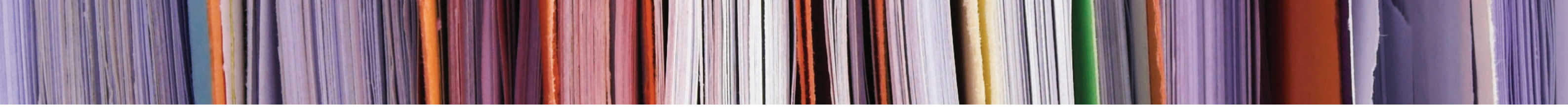
Most participants maintained that their role was to provide individually tailored support and unbiased information for people with diagnosed HIV, no matter what the circumstances. They framed this as a cornerstone of service delivery that helped to ensure that people with HIV would remain engaged with their services.

> ***What we try to do is to be open and honest, so that we even get to that dialogue so we can make those shared decisions, choices, and they can make their own choices where they want to go really. What we do not want is to shut it down beforehand. (community service provider)***

This commitment to non-judgemental user-led support underscored the reasoning described by many participants, especially those working in community settings, to wait for a person to raise the topic of criminal prosecutions before doing so themselves. This afforded them the opportunity, for example, to assess if underlying support needs were motivating their interest in the criminal law, and also to help clarify what the actual process of proceeding with a complaint might entail.

In contrast, there were those who felt that their professional responsibility meant they had a duty to protect. For instance, where participants had introduced the topic of criminal prosecution with those who may be sexually exposing others to infection, such professionals regarded this as providing two-fold protection, by reducing the likelihood of onward transmission to others, and protecting the service user from a criminal complaint. By and large, however, most participants acknowledged that a strong focus on criminalisation did not empower people with HIV to lead healthier or happier lives.

A different dimension of protection was raised by a small number of participants who described the responsibility that they may owe to a clearly identified third party who was at risk of HIV exposure. In such instances (as also described in



Report 3), they would consider the option of breaching confidentiality.

> *I guess... [if]....you are aware of who they are potentially putting at risk. Where there is a certain responsibility for you to breach confidentiality. [agreement from others] (clinical service provider)*

When this was mentioned, it was stipulated that in these rare cases, their motivation would be to protect a specific individual, only after numerous interventions with the service user with diagnosed HIV.

There were also some participants who said their decisions were sometimes motivated by a concern about public liability, often leading to the types of documentation practices detailed in Report 3. Their concern was that that they might be accused of having provided insufficient advice to a service user about managing risk, and the criminal law. Where this matter arose, senior managers and clinical leads sought to address it within the focus group, assuring their colleagues that ultimate liability would rest at the top of the organisational hierarchy.

Many participants in all focus groups discussed the ethical dilemmas and personal conflicts that confronted them when dealing with service users whose behaviour might put others at risk. Thus it was not uncommon to hear participants describe feeling frustrated that after a certain point, they could do no more and were powerless to control the actions of others. Some were also aware that service users could easily keep the truth from them, making it even more difficult to know how to intervene.

> *So that was quite a difficult situation, because [the patient] told me that they were not sexually active, and the interpreter was aware that they were sexually active, and he strongly suspected that they were not using condoms. (clinical service provider)*

Underlying these concerns is a sense of professionals feeling torn between duties to service users and to the broader health of the public, an issue that emerged in almost all of the focus groups. One participant described a case where a patient who was known to be abusive had been named as a sexual contact by other patients.

> *It was a very uncomfortable position to be in, because I still didn't say, 'Are you going to take him to court?' or whatever. I would have happily listened and given them information if they wanted to, or if they had suggested it, but you know, you kind of have two hats on: you have got your clinical hat on, and your public health hat on. You do not want to be colluding with people like this guy... they are a minority, but they are potentially involved in transmission. (clinical service provider)*

There were others who argued that instead of worrying about all of the things that might be happening outside of the room, decisions should instead be undertaken based on the most pressing issue presenting for each service user on each visit, and that professional boundaries should help to put distance between their own and their service users' choices.

> *If they are knowledgeable and consenting in some ways, to be honest, it is none of my business. (clinical service provider)*

These discussions about responsibility help to reveal the many aspects considered by professionals with regard to the ethics of their own conduct as well as that of their service users. Sometimes these perspectives elicited disagreements between participants, who were clear about where they placed responsibility, whereas others described unresolved personal dilemmas around this issue (the latter position being most frequently occupied by those who were in junior or non-managerial roles). The focus groups made it clear that junior staff in particular might particularly benefit from an increased opportunity to discuss and debate the diverse views and values frameworks with colleagues, and that in some cases this could even lead to the development of an organisational values statement to assist in the training and induction of new staff.

PUBLIC HEALTH OUTCOMES

Participants were also asked to reflect on the extent to which criminal prosecutions supported or challenged HIV prevention and broader health promotion goals. Although there were participants who talked in broad terms about using the law (or the threat of the law) to alter behaviour, there was no one who clearly stated that this use of the law supported the aims of their work. In contrast, it was more common for participants to focus on negative HIV prevention outcomes from any potential use of the criminal law.

From the outset of many groups, a proportion of those taking part made clear their opposition to criminal prosecutions, arguing that this use of the law was underscoring pre-existing narratives of blame and stigma connected with HIV. One participant who felt that extensive focus on criminal prosecutions with a newly diagnosed person could prove to be entirely counterproductive, said:

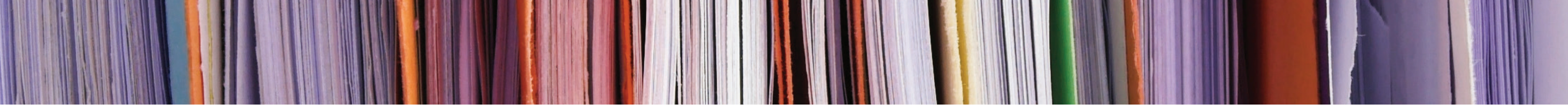
> *They already feel that they are dangerous and dirty. (clinical service provider)*

There was also a perception that the most vulnerable sub-groups of people with HIV were disproportionately involved as defendants in such cases.

> *What I see in terms of the trends that are coming through, is that it is affecting the BME [black minority ethnic] community more than the MSM [men who have sex with men] community, in terms of the cases that we are actually presented with. And is in some cases about revenge aspects. But also, there is an overlying aspect is that there is also an overlying immigration fear that kicks in around these cases as well. And fear around whether, if people want to cooperate and deal with it, whether this will affect their immigration status. And there are people disappearing as a result of that. So I guess there are so many layers to actually unpick. (community service provider)*

There were those who made the argument that in addition to decreased well-being, the increased stigma caused by prosecutions directly interfered with the likelihood of HIV disclosure to sexual partners.

> *I must say I find the whole issue of criminalisation to be kind of a red herring, because it helps in no way. The issues for us are around disclosure. They are about empowering. They are*



> *around stigma. And those are the issues that we struggle with, the basic – although they are never basic, they are incredibly complicated – issues around disclosure. And for that to be within a criminalisation context is really, really unhelpful. (clinical service provider)*

In association with concerns about increased HIV-related stigma, it was also argued that lack of HIV expertise within the criminal justice system contributed to the perpetuation of myths about transmission. One participant had heard an arresting police officer make erroneous comments about HIV transmission through spitting, and others expressed concern that cases can continue to confuse the difference between timing of diagnosis and timing of HIV infection. Such misunderstandings, they argued, were bound up in the stigma and blame that continue to hamper HIV prevention efforts.

It was also noted that criminal prosecutions ran the risk of damaging good relations between people with HIV and their service providers. Many stated strongly that the most important priority was to establish and maintain trust with service users. There was a concern that too much focus on legalities of all kinds would damage trust, and that in turn, service users would then be less forthcoming about their HIV prevention needs. When asked to explain why they did not see themselves as facilitators of criminal complaints, one participant responded:

> *I think if it came down to the patients as a whole, if we were getting involved with that it would really affect our relationship with the patients in terms of whether they trust us. That is the biggest reason. (clinical service provider)*

Many service providers felt that the preservation of the trust relationship, and the on-going contact with services that this engenders, was far more essential and effective for the preservation of public health than taking legal action.

> *I think it also affects the trust relationship between workers and service users, and clinicians and service users at times, sometimes in quite a negative way. You see quite a few people who have been damaged by the process. And it's a long bridge-building process to re-establish the trust in procedures. (community service provider)*

Such notions were also reflected earlier in this report, where participants focused on the need to be non-judgemental in order to ensure an on-going relationship between service providers and their users.

Another way in which participants considered the public health impact of prosecutions was to consider involvement as a complainant in a case as a threat to service users' progress toward stability, acceptance and successful HIV treatment.

> *When people come to our organisation, our aim is not to harvest resentment and to feed into the idea that this is the end of the positive wonderful life that you were expecting to have, it is to, sort of, move forward. (community service provider)*

As already described in Report 3, some participants working in both clinics and community settings described their experience supporting those who had initiated and proceeded with criminal complaints. The outcome for complainants (particularly where a case did not progress to trial) was described as profoundly destabilising for their well-being. Participants told of service users who had stopped all treatment, suffered mental health crises, and had regressed back to the early distress of their diagnosis as a result of making the complaint.

> *It felt like we were going back to the day when she got the diagnosis, and we stayed there with her for about six months in terms of the infection and not being able to move on from how this happened to her. (clinical service provider)*

There were no accounts given by any of the participants of the beneficial physical or psychological impacts that involvement in criminal cases might have for those making a complaint.

SUMMARY

In comparison to the other reports in this series, this one examined slightly more conceptual themes arising from service providers' reflections on criminal prosecutions for the transmission of HIV. Where they considered the individual responsibilities of those involved in HIV transmission, most participants (but not all) considered the complex social relations and structures that could interfere with precautionary behaviours. Many felt that criminal investigations did not take sufficient account of inequality and vulnerability among people with diagnosed HIV, or the degree to which responsibility is a shared aspect of consensual sex.

Participants also considered how service providers owed contrasting and sometimes conflicting obligations to support their service users (whether they might be prospective complainants or defendants) and to protect the health of others who may be at risk of infection. Such discussions elicited considerable debate, demonstrating lack of consensus on the role of the service provider in such circumstances, particularly among clinical teams. Despite a small proportion of individuals describing their impulse to take action of some sort to protect individuals at risk of HIV infection, when asked to consider the interaction between criminal prosecutions and public health outcomes, the general consensus was that they were at odds. Concerns raised here included the notion that criminal prosecutions reinforced HIV-related stigma, threatened relationships of trust between service users and providers, and had the potential to considerably hamper the physical and psychological well-being of complainants.

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Authors: **Catherine Dodds**, Matthew Weait, Adam Bourne, Siri Egede, Kathie Jessup and Peter Weatherburn.