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Practice and procedure

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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 describe how the issue of criminal prosecution for HIV transmission arose in their engagement with service users, what information or advice they provided and how criminal prosecutions were supported or discouraged. They were also asked about their record keeping, including what data was included or omitted as well as how confidentiality was discussed and data protection assured.

RAISING THE ISSUE: WHEN IS CRIMINALISATION DISCUSSED?

There were numerous occasions in clinical and community services when the issue of criminal prosecution for HIV transmission arose. This was sometimes raised by service users, or more commonly, it was mentioned by professionals in the course of consultations. Choosing the first time to raise the issue of criminalisation was difficult, and there was an understandable desire not to burden those newly diagnosed with too much information.

Participants working in clinical settings described how new patients would usually undergo an 'induction' regarding their diagnosis, including an introduction to HIV treatments, their long-term prognosis, and issues such as managing disclosure. Most participants stated it would be unusual to raise any issue relating to HIV and the law at this early stage, for fear of overloading patients with too much information or causing unnecessary alarm. Numerous clinics described the use of a proforma – a list of topics, including HIV and the law – that should be discussed with the patient at some stage. In the majority of cases this initial discussion about HIV and the law was conducted by a health advisor or a clinical nurse specialist. However, use of such a proforma was rarely prescriptive and most participants stressed the need for any information about the legal situation to be tailored to the individual, depending on how they appeared to be coping with their diagnosis and their level of English language proficiency.

In community settings, participants said it was also common for new users of a service to undergo some form of 'induction', which involved discussion of a range of issues relating to living with HIV. In the larger charities this often took place within a series of workshops for newly diagnosed people, while in smaller organisations it often took the form of a one-to-one session or, occasionally, an invited speaker to a regular support group.

We do a nine week [newly diagnosed] course and two and a half hours of that is about criminalisation. For and against, looking at it from the very beginning. What has happened, what it has come to, what the police have to investigate before it goes forward. (community service provider)

In addition to these initial discussions, HIV and the law arose at other stages of service user engagement with clinical and community services. Most often this was because of an assessment made by a professional regarding behaviour that may place the service user at risk of a complaint or prosecution. Some examples included: service users who said that they regularly had unprotected sex with someone who was not aware of their status, or people with diagnosed HIV presenting with STIs or unplanned pregnancies. In such instances, service providers might initiate not only a discussion (either immediately or via a referral to another member of the team) about the risks of HIV transmission and how to avoid it, but also offer information about criminal prosecutions for HIV transmission.

In every consultation there is the potential for it [for criminalisation to arise in discussion] because you are taking their sexual history. And then you can identify their level of transmission risk. I check if the health advisor has discussed it with them [...] and refer them on if needs be. (clinical service provider)

Concern was also raised by several participants about the particular complexities of discussing the issue of criminalisation with young people, especially around the time that they begin

transition into adult services. It was not always clear what information they had been provided with regarding the risk of criminalisation, and some participants expressed a belief that children's services often leave discussion about how to avoid sexual transmission until well after young people have become sexually active.

In other instances, participants described how service users raised the issue with their providers because they wanted advice as a complainant or because they had been accused of infecting someone. New diagnosis and relationship breakdown were described as triggers for some queries about making a complaint, whereas media attention to cases was a common reason for heightened alarm among people with diagnosed HIV or their sexual partners.

PROVIDING ADVICE

Regardless of whether the issue of criminalisation was raised by the service user or the provider, participants were asked to describe precisely what information or advice was given. In initial consultations at the point of diagnosis, or on entry into a community service, it was generally emphasised that the best means of preventing transmission was to use a condom for all instances of vaginal or anal sex. Participants felt this removed any possibility of a successful prosecution because it would successfully avoid transmission, which is a necessary requirement to bring a prosecution in England and Wales. Where service users were in long-term relationships there was some recognition that advising them to 'use a condom every time' may not accommodate needs relating to intimacy or conception, and individuals in this situation were often advised about disclosure and the best means to reduce the possibility of transmission.

There was some discussion of the concept of 'treatment as prevention' and the extent to which this may inform practice. This refers to the emerging scientific consensus (based on studies of those having vaginal intercourse) that a person with diagnosed HIV who is on effective anti-retroviral therapy with an undetectable viral load, and is otherwise healthy, is not infectious. In several focus groups, consultants or registrars stated that they may be more likely to put a patient on HIV treatment if they were frequently reporting high risk sexual behaviour with partners to whom they had not disclosed.

Treatment as prevention is a complicating factor. It is almost as good as a condom. So if someone was being risky within a discordant relationship it lowers my threshold for prescribing them treatment as a means of protecting their partner.
(clinical service provider)

The issue of disclosure was also discussed in considerable detail and service users were generally made aware that if they had disclosed to a sexual partner, that consent to risk would be a valid defence. However, all participants acknowledged the complexities of HIV status disclosure: who to tell; when to tell; how to tell; how receptive the person might be; and the potential longer term consequences of a negative reaction to disclosure (issues also raised in Report 4).

Several organisations, particularly community providers, recommended to their service users that they tell a friend or advocate that they had disclosed to a sexual partner so that there was a 'witness' to this disclosure, albeit usually absent from the event itself. Some organisations were careful to note in their own records when their service users reported a disclosure (explored further below). All organisations demonstrated a desire to support their service users to make a disclosure when and where they were comfortable doing so. While they described supported disclosure activities and joint partner testing, this was clearly differentiated from the practice of breaching confidence, which was regarded as a serious and rare occurrence by most, and ruled out entirely by others.

Echoing the decision made about *when* is the right time to discuss the issue, nearly all participants stressed the importance of tailoring the advice and information about criminalisation depending on the circumstances of the service user and the extent to which it was felt they could manage or understand the information. A particular challenge was expressed regarding advising people who were not fluent in English, especially in the absence of multi-language resources.

Our initial assessments of HIV understanding are that they are abysmal a lot of the times. My guess is that transmission and criminalisation is not something that is immediately discussed [in clinics] and even if it were it might not be discussed in a way that the individual can understand or relate to.
(community service provider)

Participants from community and clinical settings described the provision of a leaflet about *How the law works*, produced by the Terrence Higgins Trust, as a means of supplementing more in-depth conversations about the technicalities of how a criminalisation case could be brought, managed or avoided.

FACILITATING OR DISCOURAGING CRIMINAL INVESTIGATIONS

When asked about their direct dealings with criminal prosecutions for HIV transmission, nearly all participants said they had concerns about the process of enquiry and the possible impact of the proceedings on their service users. There were those who had supported a service user who wanted to seek prosecution of the person who infected them, but they clearly distinguished this from facilitating such prosecution.

Technically if they want our help we should be supporting them. But I think supporting them is very different though to actually facilitating it. (clinical service provider)

Others working in community settings were clear that they would not provide support to someone wanting to pursue a criminal prosecution. In such cases they were following organisational policies, informed by a carefully considered view on the role of criminal prosecutions in the wider HIV prevention and public health agenda (a point explored in more detail in Report 4, with examples of such policies given in Report 5).

And this person is sat opposite me, and has been lied to. And [he] has contracted gonorrhoea and HIV. [...] And he asked me, 'You know, how much support will you offer me around this prosecution if I go forwards with it?' and [me] saying, 'Well actually, we would not support any criminalisation case. We would offer you the support you need to deal with your diagnosis, to move forwards for as long as you need to. But we wouldn't actually support a criminalisation case.' But feeling like that was probably the most difficult non-supportive discussion I have ever had. (community service provider)

Many participants discussed how they approached this situation when it arose and there was broad consensus that, while it may serve as a focus for their anger or frustration in the short-term, pursuing a prosecution may not be in the best interests of their service users. The technicalities of police proceedings, the public visibility of cases and the low probability of success were all used as disincentives to proceeding with a complaint. A small number of people described how they had discouraged those with newly diagnosed HIV from making a criminal complaint, by helping to meet other support needs which were underpinning their response to diagnosis.

I cannot think of any case where someone came and said they wanted to prosecute and then actually walked away and still wanted to prosecute. As soon as you give information and emotional support, you find an immediate shift. Especially if you signpost them onto services. You see a change of mind very fast if you support them in the right way. (community service provider)

Added to this, there was reluctance from some participants, particularly hospital-based staff, to be drawn into criminal investigations, which could carry a heavy administrative burden and be quite time-consuming.

In contrast to the majority of responses, two participants working in different clinics mentioned that they asked newly diagnosed patients if they had considered taking things any further. As one said:

I sometimes ask them if they will take further action. Are you doing anything more about it? (clinical service provider)

In this particular focus group, colleagues debated the appropriateness and utility of this approach. While this participant went on to clarify the unique context that had led to this question being posed on one occasion, it does demonstrate that staff, even in the same clinic, can lack a unified agreement about their role.

Participants' approaches to criminal prosecutions were also influenced by their perceived duty of care (discussed further in Report 4). In some respects this was treated as straightforward – as community or clinical care providers they felt their duty of care remained with their service user and not necessarily with any sexual partner who may be exposed to HIV.

It's about duty of care as well. We have a duty of care to the index patient but not necessarily the person who might be infected. (clinical service provider)

On occasion, this was difficult for some to rationalise, particularly when faced with clients who were engaging in sex that posed a very real risk of transmission without informing their sexual partners. At no time in the focus groups did a participant describe actually having broken the confidence of a service user to meet the possible HIV prevention needs of a third party (despite it being raised in some clinical settings as a hypothetical possibility).

Where the situation became more complex was in respect of cases where both the person with diagnosed HIV and their sexual partner (assumed to be HIV negative) were both under the care of the same clinician or community-based professional.

There is the duty of care so if there is a positive patient in our clinic and their partner is negative we do have the duty of care to the negative partner. If it is not our patient the area is much more grey. And it is something, if we know they are not our patient then we do not have that duty of care. But if the negative is our patient, then we do have a duty of care, if their partner isn't having protected sex, to move toward disclosure to that patient. (clinical service provider)

On this point, confusion among participants was common. Deciding how to act and whether disclosure to the negative partner was warranted, was described as something that should be considered on a case-by-case basis. The unique circumstances of their sexual relationship, including issues relating to power and control within that relationship, were always taken into account. No instances of HIV status disclosure to a partner in this kind of situation were reported by participants, but several suggested that it remained a possibility for the future.

RECORDING AND MANAGING SENSITIVE INFORMATION

Participants talked in some detail about the way in which they recorded, or indeed omitted, information from patient records that may be relevant to criminal prosecutions for sexual transmission of infection. In hospital settings, it was common for medical history, drug history, STI diagnoses, HIV status disclosure, pregnancies, sexual partners and sexual risk behaviours (among other things) to be recorded. Having a detailed case history meant that professionals were able to offer a high standard of personal care. This was particularly important in multidisciplinary teams where patients were handed from one colleague to the next. Several clinics described how processes for conveying and reporting information may at one time have been more relaxed, but high profile criminal prosecutions for both HIV and herpes meant they were now much more careful and structured in the way information was recorded.

It [recent criminal prosecution] has affected my practice. I will check that I have been through everything. I'll write, 'I have discussed condom use and what that means'. I'll write that we have discussed risk reduction. More detail and documentation. (clinical service provider)

Motivations for recording information relating to safer sex advice, whether or not disclosure had occurred and whether the issue of criminalisation had been discussed appeared to differ somewhat between participants from clinical care settings and those operating in community based organisations. Most clinic based participants highlighted the need to keep records of such events because of professional standards of administration they were expected to uphold by bodies such as the *Nursing and Midwifery Council* and the *General Medical Council*. Many clinic staff also stressed a perceived need to protect themselves from criminal or civil proceedings were it ever the case that a prosecution of one of their patients was pursued (which is also discussed in Report 4). Having on record the date and context of their discussion about, for example, the need to use condoms, meant that the professional and their organisation could not face any blame for HIV transmission that might occur.

There was a patient from here involved in a case that made a claim [against the hospital]. He said that basically he had never been told about the risks of sexual transmission. So they asked for our notes from here to see what had been told [...] we document that we tell them to use condoms and that it is sexually transmitted. (clinical service provider)

In contrast, participants from community based organisations more commonly described their record keeping decisions as a means of supporting service users if a criminal complaint was ever made against them. It is for this reason that most community based organisations carefully recorded when disclosure to a sexual partner was reported, or when problems that had prevented disclosure (such as unequal or abusive relationships) were described.

You cannot fax someone a disclosure, but we can write down that we met with the client on this day and on that day she told her partner about her HIV status. What we often find it's that the positive person wants to continue to have protected sex but the partner is putting pressure on them and manipulating them. If the relationship fails and other person wants to prosecute, we can say he was aware. (community service provider)

Conversely, some community based organisations also described ensuring that some information was not noted in their records if they felt it may reflect badly on their service users in the event of any prosecution. One organisation described not including the HIV status of service users on their records, while others limited the amount of detail they included regarding sexual risk behaviours.

If I am working with a person who has high risk behaviour I do not document it in detail, just in case further down the line there is someone with a warrant. (community service provider)

Concerns about records being seized by police in criminal investigations for HIV transmission prompted discussion with participants about confidentiality and how this was usually explained to service users. Most participants working in clinics and community based organisations said that they took care to explain to service users how their data would be protected, while also mentioning that there were specific circumstances in which they could be forced to release it to the police.

I've stopped saying confidential. I say as confidential as can be. (clinical service provider)

All participants were clear that if a police officer arrived asking to see service user records there was no possibility of such records being released without a clear court order in writing and, where available, legal advice. A few organisations had put in place systems that they hoped would limit the possibility of their notes being used to support a prosecution case – by the way they stored their service user records – however it is uncertain whether these would be sufficient if faced with a court order to release them.

SUMMARY

Both community-based organisations and clinics took the issue of criminal prosecution for HIV transmission very seriously and took steps to inform their service users about what it means and how it might best be avoided by using condoms or by disclosing their status. Participants acknowledged this was complex information to convey, which needed to be well-timed and appropriately tailored for each individual. They were sometimes faced with clients who wanted to pursue criminal prosecutions, usually when first diagnosed, but the vast majority tried to discourage this. In most instances participants were clear that their duty of care remained with their patient or service user, and not with the sexual partners who *may* be exposed to HIV, but conflicts arose when both parties were service users at the same organisation. Service providers could do with more clarity about the extent to which professional guidelines may consider duty of care as a rationale that *enables* them to consider a breach in confidentiality, rather than *obliging* them to do so. There was an obvious need for both clinics and community based organisations to record some information about service users, but while clinics were keen to document as much as possible to protect themselves from possible litigation, community based organisations were more selective about what was and was not recorded in order to protect their service users in the event that the records were seized by the courts.

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