

Identifying resources

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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 focus group participants were asked how they gained information and understanding about criminal prosecutions for HIV transmission, what resources they drew upon to support their existing practice and what, if any, support they accessed if such a case emerged in the course of their work. They were also asked to consider what further resources, training or support might improve their capacity to respond, and how these might best be disseminated.

CURRENT INFORMATION SOURCES

Clinic and community service providers had drawn their current understanding of the relevant criminal law, and appropriate practices, from many different sources. Generally participants said they received information through meetings, workshops, experienced colleagues and lawyers associated with their clinic or organisation. Some described meetings that addressed (at least in part) the criminalisation of HIV transmission.

We so frequently have the conversation and it will often come to the consultant. And we have a weekly multi-disciplinary meeting where it often comes up. And we have a meeting every Friday where often we talk about new patients and sero-discordant couples. So there are lots of spaces in which we can talk about it, so we are always rehearsing the conversation. (clinical service provider)

However, such opportunities were not universal, and it was apparent throughout the course of the fieldwork that many individuals were rarely afforded the opportunity to fully explore these issues with their colleagues, unless a case emerged involving a service user.

Participants described diverse access to resources and activities addressing the topic. Some larger community organisations described hosting workshops for both service providers and service users to address issues arising in criminal

investigations and trials. However, such interventions are not widespread and typical training or internal resource provision relating to criminal prosecutions for HIV transmission was *ad hoc*.

Those who worked in clinical settings said they had access to the Hospital Trust's legal services, and there were some community organizations who described having some access to legal advice. However, in almost all cases, the lawyers to which professionals had access were of limited benefit in such circumstances, given that they tended not to be criminal lawyers, nor did they have sufficient expertise in dealing with cases involving HIV transmission. Instead, participants said that for support and advice about criminal prosecutions (should the need arise) they would probably turn to a senior colleague at work.

A: I would go to the consultant or a doctor at that point. If there were nobody available, which would be very rare... I have not had anyone within the clinic that I could not go and talk to and raise it with.

Why would you in relation to legal matters go to a clinical expert?

A: Because I do not know who the legal person is [laughter].

B: My experience of the [hospital] legal department is that they are not up to speed with HIV issues and they were not very helpful. (clinical service providers)

Many participants described one colleague in their organisation who they relied upon for up-to-date information on the subject of criminalisation. This expertise demonstrated itself within the focus groups themselves, where such individuals would frequently take the lead when explaining the technicalities of the law.

Participants often explained how they obtained basic knowledge of the law from sources outside of their workplace, such as written materials and webpages on the topic produced by national organisations (see Figure 1). In particular, many said they turned to *Terrence Higgins Trust*, *NAM* and *National Aids Trust* for information and guidance. Also mentioned were the *Crown Prosecution Service* guidance and the *British HIV Association* and *British Association for Sexual Health's* document on the role of the clinical team.

Many talked about how they used these sources to familiarise themselves with the law, and some also served as useful resources to which they could refer their service users. Those working in clinics talked about making reference to the General Medical Council (GMC) guidelines on confidentiality when communicating with patients about the specific circumstances in which confidentiality may be breached.

I would have a discussion with them about what my responsibilities are, and what the GMC guidance is, if you think that other people are currently being put at risk, you can breach confidentiality. Which is quite a rare situation. That obviously, frequently happens, that you don't know who the partner is, so you couldn't do anything anyway. So you start off with the GMC, and then you move on to the legal. (clinical service provider)

Even though many described that they had obtained information from these sources, not all participants expressed confidence in knowing how they would respond to questions about prosecutions from service users. Nor did all participants feel that these written resources were sufficient to help them manage circumstances where a service user may be involved in a criminal case (either as complainant or defendant).

RESOURCE GAPS

Most participants displayed some understanding of the law relating to criminal prosecution for HIV transmission (see Report 2 for an assessment of such understanding). However, the majority had difficulties clarifying for service users the many 'grey areas' that they perceived in the law.

The law is so, kind of, not clear that it is very hard to clarify anything and we do have documentation we give out occasionally from the criminal ... CPS. I would find it to be very hard to be very clear, honestly. It is very vague I think, how we talk. (clinical service provider)

Such feelings of uncertainty were widely expressed, particularly by those who had limited experience dealing with criminalisation cases in their organisation. Questions from service users on this topic could be wide-ranging, and the general lack of organisational policies on how to communicate with service users with HIV about the criminal law exacerbated the unease expressed by service providers. Many felt unable to keep up with developments in case law that were constantly changing, worrying that what they had learned may be out-of-date. In fact, the law in this area is relatively stable and is accurately reflected in the most recent clinical and crown prosecution guidance documents listed in Figure 1. However,

FIGURE 1: USEFUL RESOURCES

The following resources provide accessible information, advice and professional guidance.

Dedicated web pages

- National AIDS Trust: Offers an overview, details past UK prosecutions and gives information about the use of evidence in such cases
- Terrence Higgins Trust: Includes links to research studies, professional guidance, and advice for people with HIV
- NAM/aidsmap: Broad range of criminalisation materials, including summaries of public health impact studies, and patient resources to download

For service users

- How the law works (Terrence Higgins Trust)
- Prosecutions for HIV Transmission: a guide for people living with HIV in England and Wales (National AIDS Trust / Terrence Higgins Trust)
- Police investigation of HIV transmission: a guide for people living with HIV in England, Wales and Northern Ireland (National AIDS Trust)

For clinical professionals

- HIV transmission, the law and the work of the clinical team, January 2013 (British HIV Association and British Association of Sexual Health and HIV)
- The code: standards of conduct, performance and ethics for nurses and midwives (Nursing and Midwifery Council)
- Criminalisation of HIV transmission: guidelines regarding confidentiality and disclosure (British Psychological Society)
- Confidentiality: disclosing information about serious communicable disease (General Medical Council)

For non-clinical professionals

- Statement on the criminalisation of the transmission of HIV and STIs (Yorkshire Mesmac)
- Organisational policy on criminalisation (Terrence Higgins Trust)

For lawyers and police

- Legal guidance: intentional or reckless sexual transmission of infection (Crown Prosecution Service)
- Investigation guidance relating to the criminal transmission of HIV (Association of Chief Police Officers)

clinical and scientific developments in the treatment of HIV will continue to raise issues, many of which the courts have not addressed (for example, the significance of viral load and perceptions of infectiousness). In addition, the emergence of prosecutions for other sexually transmitted infections including Hepatitis B and herpes, also warrants the desire to be kept updated.

None of the participants who worked in clinics had any internal policy or standardised procedure related to criminal prosecutions for HIV transmission that they could draw upon, despite many describing a standard proforma used with new patients that explicitly addressed criminalisation. Again, most relied on material produced by charitable organisations to inform service users and address their concerns. Many of the participants felt that there should be more training or an official policy with information available about the best means of supporting service users.

That is why we should come up with teaching about it, like someone else just said. Like we have on sexual assault, we should have something around criminalisation as well. (clinical service provider)

A small number of those working in community-based organisations described having in-house policies on criminalisation, sometimes following on from their involvement in criminalisation cases. Some of these policies stated clearly that they would not facilitate or support any service user wishing to pursue a prosecution for HIV transmission, beyond the emotional and social support they would offer anyone with diagnosed HIV. It is possible that the lack of in-house policies on the management of criminal prosecutions relate to perceptions that the law is complex and frequently changing. It is also just as likely that the development of such policies is not regarded as a priority (although some wished they had something to rely upon once a case involving a service user emerged).

An additional barrier to the establishment of confidence in handling this issue, was the perception expressed by many participants that they lacked the legal know-how that might help them to better grasp the technicalities of the law relating to criminal prosecution for HIV transmission.

People in this room have no legal training or minimal legal training. So we might have in front of us a report or a piece of case law and we will read it and... so there is a case law but one also needs 'the idiots guide' that says where we are currently at. (community service provider)

In community-based groups in particular, participants reported that even if they did want to consult with criminal legal experts who knew about HIV, they would not know where to find them, or expressed concern that such legal expertise may not be locally available.

In addition to the issues already raised, a few participants highlighted the role of police investigating HIV transmission cases, in terms of the way they gathered evidence, dealt with potential defendants, and prepared formal charges. Both clinical and community groups described frustrating encounters with

the police who lacked awareness of the evidence required in such cases, and had unrealistic expectations regarding access to service user records during investigations. A few participants described situations where police had 'tried it on' to see if they would surrender confidential files without a warrant.

They [the police] do not know what they are dealing with, so they go in here. Our experiences, in the young people services, is that it is the police who cause loads of anxiety and problems when they are looking into things. (community service provider)

There are few opportunities for police and those providing services for people with HIV at a local level to discuss best practice in managing cases relating to HIV transmission. We note that at no time during the focus groups did anyone mention the professional guidance from the *Association of Chief Police Officers* on police handling of HIV transmission cases (this is included in the list of resources in Figure 1 in this report). There is considerable potential for this resource to be used as an advocacy and training tool, and to support complaints if required.

POSSIBLE SOLUTIONS

Not only did participants identify what they felt was lacking in terms of resources to address these issues within their services, they also provided suggestions on how to improve information access, provision of training and the dissemination of best practice.

An obvious approach would be to significantly expand current provision of expert-led seminars and workshops to service providers, enabling them to put into practice the skills and information that will best meet the needs of their service users. Those participants who had already attended such events described them in very positive terms.

It was also suggested that staff teams should set aside time to talk about HIV and the criminal law, as well as other issues that can pose moral or ethical dilemmas, on a more regular basis. Such discussions among staff members might encourage greater consistency in approach and communication styles related to the issue, and the mixing of community and clinical service providers in such discussions may facilitate exchanges of views and approaches. The focus groups themselves appeared to offer a rare opportunity for teams to collectively consider the issue, which some reported as beneficial.

We can have our own session leading on from this, with the issues it has raised for us, I will arrange [it]. (clinical service provider)

A representative of one community-based organisation described how they had offered to provide HIV training for the local police service (as a means of limiting investigations into criminal prosecution for transmission), but this had been turned down. In this same group it was felt that the police were not in contact with the CPS early enough when a case was opened and that this had caused misunderstandings and problems for service users. An initiative to provide HIV training for police, in collaboration with CPS was suggested as a vital

solution to this problem. In direct contrast to this, participants from another community organisation described how local police asked if the HIV charity could provide a programme of training in order to improve their general procedures when interacting with those who have been diagnosed with HIV. There is little doubt that provision of police training by HIV specialists could improve the relationship between police and service providers, while also contributing to improved police interactions with those who have HIV, including criminal cases related to HIV transmission (which in themselves will be relatively unique to any officer called upon to investigate).

The most common suggestion made by participants was for the provision of an easily accessed location that compiled and provided accurate and detailed information relating to criminal prosecution for HIV transmission. They experienced the situation as constantly changing, and felt uncertain about the current state of the law, recent prosecutions and convictions.

But I would not say we have a clinic policy or anything written and perhaps something that could come out of this is we have a resource... a place for resources where we could all go to if we felt the need. (clinical service provider)

I think it would be nice to have regular updates because things are changing so quickly. (clinical service provider)

One participant described a need for a written resource that could serve as a 'neutral' source of information relating to new cases and developments in how the law was applied, while others stressed a need for more simplistic legal advice.

I think giving examples or reading about actual legal cases. Most of the popular press is quite biased and giving a one-sided view of what actually happened and perhaps having a legalistic view as to what went wrong, without naming people would be a useful resource. (clinical service provider)

And maybe a 'criminal transmission for dummies' kind of approach, that is legal as well. (community service provider)

Participants from both clinical and community focus groups described a need for external information sources that service users could be directed to, which would limit the need for them to discuss criminalisation and risk a negative impact on their relationship with the client or patient (described in more detail in Report 4).

I'd like a resource for patients that we can show them, because sometimes they can be very defensive if we are trying to go through the legal aspects and advising them [on] safe sex and not to transmit to other people, they can take it quite personally. So it would be nice to have something that is sort of neutral. I am not making this objective judgement on their behaviour, I am saying: 'I will show you on this webpage on this screen, here is the law, this is how the law stands at the moment'. (clinical service provider)

There are, in fact, several websites and information briefings that already serve this purpose (as described above in Figure 1, however this quote highlights that many individuals who have frequent contact with those both newly and long-term diagnosed are not always aware of them). This emphasises the point, as suggested by another participant above, that perhaps a centralised website accompanied by a newsletter that readily points readers to existing resources, would be of greatest use.

SUMMARY

While some participants were able to accurately name and identify some of the key written resources designed to provide information and guidance about criminal prosecutions for the transmission of HIV, awareness was by no means universal. Also familiarity with their contents was uneven, and confidence in applying best practice, and communicating with service users about the topic was generally low. It appears that most participants managed the topic when it arose by turning to better informed individuals within their team (an approach that can be further supported by ensuring that such individuals are assured a simple means of accessing high-quality, up-to-date resources).

Perhaps the most challenging difficulty is the lack of access to qualified legal advice from lawyers with criminal legal expertise in this area. With cases emerging so rarely, across a large geographic area, it is difficult to know how this can be adequately addressed. However, at the very least, the details of those with criminal law expertise in this area should be circulated alongside other written resources.

With the exception of this gap in access to qualified lawyers, many of the information needs identified in this report are substantially (if not completely) met through the contents of many of the resources compiled in Figure 1 above. Therefore, the key challenge remains the dissemination of existing information and guidance through well-designed programmes of training and simplified online access.

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