



GUIDANCE FOR THE RECORDING OF HIV IDENTIFYING INFORMATION

National AIDS Trust response to BASHH consultation

Introduction

The National AIDS Trust welcomes the opportunity to respond to the BASHH consultation on 'Guidance for the recording of HIV identifying information' and congratulates the working group on its preparatory work.

The question of patient confidentiality, the particular sensitivities around HIV and effective management of care is an immensely important one which NAT intends to look at in detail over its coming 2007/08 workplan year. Unfortunately the consultation has only recently come to our attention. We have not as yet had the time to look into the issue with the level of detail we ordinarily apply to significant policy matters. Our comments are therefore brief at this stage and provisional. We hope nevertheless they are helpful, and would welcome the opportunity to be involved as BASHH finalises its Guidance.

NAT begins from the principle that personal information about an individual's health belongs to that individual, and its use by others must be justifiable and on the basis of that individual's consent.

Whilst there are practical constraints on the number of options which can be available to patients for the recording of sensitive information, a system which begins with the human right to privacy and legal right to data confidentiality cannot be driven solely by provider convenience. There must be a respect for patient choice and clear systems in place to ensure the best possible care irrespective of which choice patients make.

The consultation process

It will of course be interesting to see who responds to the consultation. We are not clear as to the details of the process by which BASHH came to the current draft document but remain concerned that the disparate voices of people living with HIV are fully and effectively heard before any Guidance is finalised. There is reference to a 2002 study (of only 6 male individuals living with HIV) in the document but none to any attempt to canvass the views of people living with HIV to inform the current document and consultation. **We recommend that focus groups of people living with HIV, representative of both regions and communities, and in particular of vulnerable groups, take place to talk through any proposals before finalisation.**

The House of Commons Health Committee has undertaken an inquiry into the Electronic Patient Record, and at the time of writing we are still awaiting the Committee's final report, to be published on 13 September 2007. The Committee inquiry has received a large amount of important written and oral evidence on a wide range of technical, clinical and human rights issues and **it would be sensible for BASHH to take account of the evidence to the Electronic Patient Record inquiry and the Health Committee's recommendations when coming to a conclusion on appropriate Guidance.**

The text of the recommendations

A number of qualifications are included in the Guidance to what are otherwise excellent principles. For example, in relation to outside organisations accessing a Trust's data, 'In this situation HIV identifying (and other sensitive) information should not **normally** be accessible' [our emphasis]. Or '**Ideally** access should be role based, so that for example all doctors ... can access HIV related information, but administration staff cannot' [our emphasis].

Whilst Guidance cannot cover every contingency, further detail and examples are needed of the situations, if indeed there are any, where the principle should be breached or ignored.

An odd impression is made by the document singling out apparently for special treatment NHS staff and 'high profile individuals'. We are told it is 'especially important' for these groups to be told about how HIV identifying information is held.

The recommendations also state that the alternative recording process of HIV identifying information 'should be offered to members of staff and high profile individuals'. The implication is that it should not be offered to others, although it may be available.

This section is in itself a tacit admission that anti-discrimination and confidentiality processes are far from perfect in many Trusts. And if that is the case all people living with HIV should be told of how HIV identifying information is held and of their right to keep their HIV status separate from their other medical information on the Trust's EPR system.

It is not clear, in relation to these two recommendations, whether the main focus is the general patient's rights or the particular needs of NHS staff and high profile individuals. Whilst in the explanatory sections some reference to the particular sensitivities of NHS staff and high profile individuals might possibly be appropriate, the recommendations as they stand come over badly and seem to undermine the principle of equality which should be at the heart of NHS culture.

We recommend that the Guidance state simply that all patients be told of how HIV identifying information is held and of their right to have their HIV status recorded in an alternative way. There should be no reference to, or implied preferential treatment of, NHS staff or high profile individuals.

Stigma and Discrimination

Training on HIV-related stigma and discrimination should be given to all staff before an EPR system goes live which is likely to bring the HIV status of many patients to the attention of medical (and possibly non-medical staff) for the first time. There should be clear detail as to what constitutes HIV-related stigma and discrimination with information on complaints and disciplinary procedures in place to address possibly stigmatising and/or discriminatory behaviour.

Clear explanation should also be provided both verbally and in writing for patients living with HIV of their right not to be treated in a discriminatory way

by any healthcare staff, and of how to complain should they experience discrimination or breaches of confidentiality.

Facilitating self-disclosure to other clinical staff

It is quite reasonable for many people living with HIV to be keen for all responsible for their clinical care to know of their HIV status but nevertheless be unwilling for their personal details to be available on a Trust EPR system over which they have no control, and with little knowledge of who in reality might access the system and use their data.

To this end, **patients should be told clearly and on a regular basis by their HIV clinicians of the importance of other clinical staff knowing of the patient's HIV status if they are to ensure appropriate treatment and care.**

Any system should allow and support patients to give consent to other clinicians accessing 'protected information' ordinarily available only to HIV staff – either communicating directly to the non-HIV clinician their permission or permitting their HIV clinician to inform them.

Other non-HIV clinicians should be trained not to assume they have access to all relevant information about an individual who comes to them for treatment and care. In some circumstances it may be appropriate to ask if the patient has medical information not on the EPR they might wish to inform them of, to ensure the best possible care, assuring the patient of total confidentiality and respect.

The current draft Guidance does not propose how those who keep their HIV information off a Trust EPR can nevertheless be supported in receiving appropriate medical care – this omission needs to be rectified in the final version of the Guidance.

**National AIDS Trust
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