

## **BHIVA Standards of care online consultation comments**

**7 October 2012**

### **Standard 12: Data, Audit and Research**

**12 September 2012**

**John O'Callaghan-Williamson sent the following message:**

"Confidentiality of the personal and clinical details of people with HIV is of paramount importance. Any data collection processes that involve people with HIV must deliver the appropriate level of confidentiality that is required by law, ethics and policy." I remain very concerned about who may have access to identifiable data concerning a HIV person outside of the clinical experience. Whereas gathering data provided an evidence base being able to be anonymous can be a key factor in patients remaining in clinical care. What may start as 'data linking' could expand to complete integration of data in to readily accessible data available to all within the NHS (and externally to independent providers) without the patient having any degree of control. Yes normalising HIV is important but in the instance of a GP having this data to hand and being asked for a medical report they may "out a patient" causing trust with healthcare. May GP's do not consult patients when such a request is made. Whereas these are guidelines I feel confidentiality deserves a standard of its own. Set clearly to address all healthcare professionals, at all levels and reflecting this particular standard.

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**12 September 2012**

**A H sent the following message:**

I wouldn't want any of my data on any national system as the NHS does not offer enough security on personal info. Too much info is passed on about HIV without the knowledge of the patient. There are still medical professionals writing "HIV +" IN CAPITAL LETTERS.

Also a dermatology registrar said she would double glove with a patient with HIV. The same doctor also stated that she thought a 40 year old man with a skin lesion might have HIV and be gay because he was single.

Double standards from the medical profession!!!

For the record this is happening in Brighton - the enlightened city!

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**3 October 2012**

**Roger Pebody from NAM sent the following message:**

The quality statements includes an important point about people with HIV needing to CONSENT to the use of their NHS number. As this is so important to patient trust and confidence, please add a reference to this issue within the rationale section.

I suggest the following should be inserted before the final paragraph of the rationale.

"In view of the particular sensitivities of HIV, it is important to seek explicit consent from patients for the use of the NHS number in data linking."

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**7 October 2012**

**Jacqueline Stevenson from African Health Policy Network (Ffena) sent the following message:**

In addition to complying with confidentiality, data collection processes must also have the understanding and permission of the individual patient. This is a particular concern related to use of the NHS number, about which there is a lack of general information and understanding.

Data, as we have called for elsewhere in our response, should always include collection, monitoring and disaggregation of equalities data.