

Virtual Patients, Real-life Dilemmas

EPR & Information-sharing

BHIVA Autumn 2007

Paul Clift

Consultation – snapshot survey

- African HIV Policy Network
- Black Health Agency
- Bloomsbury, Mortimer Market UCH
- Feedback South London
- George House Trust
- HIV Scotland
- Kobler, Chelsea & Westminster
- Lawson Unit, Brighton
- NAT
- North Yorkshire AIDS Action
- UK-CAB

Guideline questions:

- Are you aware of the proposed National Spine?
- How do you feel about your details being uploaded to the NS?
- Does the clinic share info about you with your GP?
- How do you feel about proposed safeguards – ‘sealed envelope’ etc?

Virtual Patients, Real-life Dilemmas

- Connecting for Health views illness as a clinical issue
- HIV is not an exclusively clinical issue
- Non-clinical aspects inform patients’ views

Lack of Awareness

- Many, if not most, people are simply not yet aware of what is being implemented.
(North Yorks AIDS Action)
- People know very little about EPR and, particularly, the National Spine. They would in fact like more information and discussion on this.
(Black Health Agency)

The National Spine & EPR

- Clinical benefits fairly self-evident
- “my haemophilia centre will finally know what HIV drugs I am taking without me telling them”
- “A&E won't kill people because they do not know they have certain conditions”
Brighton patients' group
- We will get much better data on how disease affects different communities

Unequal access to care?

- A tool for assessing eligibility?
- Potential to sustain, not diminish, existing healthcare inequalities

Your new EPR will be used -

Like paper records, your new electronic records will be used as follows:

With your name included, to provide you with care and check the quality of that care.

Your new EPR will be used -

With your name and other identifying details removed (to protect your confidentiality), to:

1. find out what the NHS does well or needs to improve
2. **compare treatments to see what works best**
3. carry out research
4. **manage NHS services and finances**

Do 2 and 4 override the doctor/patient discussion?

Shared information

- Not always used to optimum advantage
- “Most were quite dissatisfied with the care they received from their GP (although some were not)”
- “Most agreed that GPs need more training”
- “Some feel that they - GPs - stigmatise and discriminate”

Black Health Agency

Confidentiality

- Significant concerns about confidentiality
- Concerns about the security and confidentiality of the summary care records
- “My fear is that the safeguard against unauthorised people reading my notes will be cut at some point to save money and replaced with a wishy-washy ‘we promise not to look’ policy” *Brighton patient*

Patients tend to be positive when

- They are ‘expert patients’ who can navigate their way through the NHS
- They have an open relationship with their GP
- Their eligibility to NHS care and treatment is incontestable

EPR might work when:

- HIV is normalised at societal and political level
- HIV-related Stigma & Discrimination are addressed
- GPs are HIV-aware
- NHS IT systems are robust
- Shared information is used well and accurately
- Patients have real control over information

Summary

- EPR appears fine in principle
- In practice, too many concerns remain for it to be widely acceptable at present
- Meaningful consultation with patients is needed