

# **The National Programme for IT and sexual/reproductive health services**

## Briefing paper for Sexual Health Independent Advisory Group

**Connie Smith and Imtyaz Ahmed-Jushuf July 2006**

### **1. Background**

*The NHS Confidentiality Code of Practice 2003* outlines the statutory protection of confidentiality of personal information which applies for all NHS clinical records.<sup>1</sup>

Since 1916 it has been recognised in statute that promoting access to services diagnosing and treating sexually transmitted infections (STIs) is of importance to the public health. Open access to services with assurance of anonymity and confidentiality of clinical information are keystones in this approach.

There are therefore special legal restrictions governing disclosure of information capable of identifying an individual obtained with respect to persons examined or treated for any STI.<sup>2</sup>

Disclosure is not allowed except:

- For the purpose of communicating that information to a medical practitioner, or to a person employed under the direction of a medical practitioner in connection with the treatment of persons suffering from such disease or the prevention of the spread thereof;

and

- For the purpose of such treatment or prevention.

Confidentiality of identifiable patient information is negotiated at first contact with Community Contraceptive Services (CCS) and Genito-Urinary medicine (GUM). The extent of information sharing is clearly specified by the patient and can if required be exclusive beyond the clinical team, subject only to Child Protection and Public Interest disclosure or as otherwise required by law.

As open-access services provided in the interest of the public health GUM and CCS have not been required to check eligibility for NHS treatment except for HIV treatment and care and referral for abortion.

### **2. Confidentiality and sexual health records**

There is a lack of clarity about the practical measures necessary for fulfilling the requirements of the special legislation for services diagnosing and treating STIs<sup>2</sup>, especially in relation to electronic records.

The overwhelming majority of GUM departments in England currently hold their paper records within their departments and separately from their Trusts' medical records systems.

Existing implementation of electronic patient records or more simple clinical databases in GUM departments are limited to stand-alone systems without connectivity to their Trust's electronic patient databases<sup>3</sup>.

---

<sup>1</sup> *The NHS Confidentiality Code of Practice 2003*

[http://www.dh.gov.uk/PolicyAndGuidance/InformationPolicy/PatientConfidentialityAndCaldicotGuardians/AccessHealthRecordsArticle/fs/en?CONTENT\\_ID=4100550&chk=1w6ljh](http://www.dh.gov.uk/PolicyAndGuidance/InformationPolicy/PatientConfidentialityAndCaldicotGuardians/AccessHealthRecordsArticle/fs/en?CONTENT_ID=4100550&chk=1w6ljh)

<sup>2</sup> AIDS (Control) Act 1987; NHS (Venereal Diseases) Regulations 1974; NHS Act 1977, NHS Trusts and Primary Care Trusts (Sexually Transmitted Diseases) Directions 2000.

<sup>3</sup> Personal communication BASHH

### **3. The National Programme for IT (NPFIT)**

NPFIT systems are designed to be increasingly compliant with the National Care Records Service<sup>4</sup> providing data to the Spine, a national, central database where summary patient records are to be stored and viewed by those with appropriate access permissions. When fully implemented, local records will automatically upload medical information (eg, allergies, medication, test results) to the summary patient record on the Spine<sup>5</sup>, and demographic information will flow from local patient records to the Personal Demographics service. There is much debate as to the extent of clinical information that is to be uploaded to the Spine and the options that will be available for patient consent or dissent from this information sharing<sup>6</sup>.

The special challenges of maintaining appropriate confidentiality of clinical records and patient identification in sexual health services has meant that there has not been any significant implementation to date of early National Care Records Service systems supporting GUM services.

### **4. Problems with current NPFIT systems available for implementation**

Current NPFIT systems available for implementation in 2006 do not have the full range of access controls planned for fully Spine-compliant systems<sup>7</sup> and this presents a number of immediate problems for services providing sexual health care.

- i) Preserving adequate confidentiality of their patient data if it is to be included in their Trusts' general databases before full access controls are available
- ii). Having access to (suitably anonymised) information about clinical work delivered at clinic attendances in order to receive funding under Payment by Results. This is a problem for services that only have elderly computer systems used to generate their mandatory returns to the DH or still rely on paper for recording the work they do. Obtaining information necessary for Local Delivery Plans monitoring is also problematic.
- iii). Funding for NHS IT is now focused on delivery of NPFIT but some Trusts are investigating stand-alone (and locally funded) systems for GUM services to overcome the issues outlined above.

The current financial problems faced by many NHS Trusts may compromise the development of stand-alone systems. The stand-alone approach risks diverting attention from getting the NPFIT systems under development fit for purpose for use in sexual health services. More collaborative work is urgently needed between the sexual and reproductive health clinicians and the NPFIT developers to ensure that NPFIT systems can provide the necessary support for the clinical process and recording clinical information (developing the electronic patient record) and appropriate confidentiality of individual patient information.

iv) GU and CCS clinic records may contain identifiable third party information collected to enable partner notification, an essential component of STI management. This needs to be considered further when planning to extend access to clinical records beyond the immediate sexual health team.

v) NPFIT systems will necessitate the use of a uniquely identifying NHS number. Patients of sexual and reproductive health services not otherwise entitled to NHS care will not have an NHS number. Systems must enable continuing care for these often especially vulnerable people who have no other access to treatment and care of STIs or to contraception via General Practice.

---

<sup>4</sup> [http://www.connectingforhealth.nhs.uk/publications/its\\_coming\\_leaflet.pdf](http://www.connectingforhealth.nhs.uk/publications/its_coming_leaflet.pdf)

<sup>5</sup> [http://www.connectingforhealth.nhs.uk/publications/comms\\_tkjune05/spine\\_factsheet.pdf](http://www.connectingforhealth.nhs.uk/publications/comms_tkjune05/spine_factsheet.pdf)

<sup>6</sup> <http://www.connectingforhealth.nhs.uk/crdb/>

<sup>7</sup> <http://www.e-health-insider.com/news/item.cfm?ID=1562>

## **5. Community Contraceptive Services (CCS)**

These services share similar confidentiality requirements with the other sexual health services where uptake of care is dependent on the perception of clinical confidentiality.

Although not covered by specific legislation, good practice in CCS includes an explicit negotiation of the confidentiality of clinical records or other information about attendance with each individual client at the point of first registration.

CCS are increasingly diagnosing and treating STIs so will need the same security of information flows as GUM services.

Open access to CCS services to maximise uptake of contraception is also of concern unless the issues raised by requirements for NHS number are adequately resolved.

## **6. CCS and current NPfIT implementations**

CCS also share the difficulties experienced by GUM services in implementing IT systems outlined above, and in addition start from a much lower base of computerisation, funding and management support. PCT providers deliver the large majority of CCS and the uncertainty of their future engendered by the policy directions of *Commissioning a Patient Led NHS* has further compromised development and modernisation of these services.

The position in the London Connecting for Health cluster provides an example of the problems that are occurring for CCS confidentiality. It has not been possible to date to ascertain the access controls, and hence the confidentiality of client information available in the interim NPfIT system (RiO) being offered now to community services. It would seem from information currently available that the demographic data of clients attending CCS would appear on a master index accessible to members of all the other community services, and this does not fulfil the promise of confidentiality and anonymity<sup>8</sup> negotiated with CCS clients.

PCTs adopting NPfIT interim solutions will turn off the legacy IT systems now used by some CCS and these services may have to choose between compromising confidentiality or losing any IT support for their work. The problems in relation to PBR and funding for any stand-alone solution are shared with GUM (see above).

## **8. Abortion Services**

Further investigation is necessary of the position in relation to patient confidentiality in services providing both abortion assessment and abortion procedures (some CCS, some Acute Trusts, and non-NHS providers). There are stringent rules for the confidentiality of data sent to the Chief Medical Officer and analyses of the data at national level, but it is not clear whether the access controls available in current interim NPfIT systems fully protect the identity of women seeking abortion.

---

<sup>8</sup> Confidentiality of identifiable client information is negotiated at first contact with CCS and is clearly specified by the client and can if, required be exclusive beyond the clinical team, subject only to Child Protection and Public Interest Disclosure or as otherwise required by law.

## 9. Summary of key issues

Connecting for Health (CfH) must urgently address the confidentiality requirements of sexual health services in systems to be implemented in 2006-7 and beyond in Acute Trusts and in PCTs.

Stakeholder consultation with sexual health clinicians is necessary to work with CfH to ensure NPfIT systems meet the requirements for confidentiality in sexual health services.

DH needs to consider its position in relation to Venereal Diseases Regulation and the electronic world post CPLNHS and Payment by Results (PbR).

This work is necessary to ensure that NPfIT implementations are secure enough to enable full participation of sexual health services or, if necessary, to find other solutions to the capture and management of data from the activity of sexual health services.

The risks of not tackling these issues now are of a loss of capacity to collect data from sexual health services that is required for clinical service provision, management, planning, epidemiological surveillance, PbR, monitoring of LDP targets etc.

Engaging now will minimise the risk of sexual health services missing the opportunity to replace current inadequate systems of data collection and be part of the current developments of IT support for clinical care.

All web references accessed 9-6-06

Dr Connie Smith  
Consultant in Family Planning and Reproductive Health Care  
Westminster PCT  
[connie.smith@westminster-pct.nhs.uk](mailto:connie.smith@westminster-pct.nhs.uk)

Member Sexual Health IAG

Dr Imtyaz Ahmed-Jushuf  
Consultant in Genitourinary Medicine  
Nottingham City Hospital

Vice President British Association for Sexual Health and HIV