

The NHS Spine and Opting Out

What is the NHS Spine?

The government is wanting to transfer the medical records of everyone in the country onto an enormously expensive (£20 billion estimated cost) centrally held, centrally controlled database called the NHS Spine, making patients' medical records potentially viewable to anyone working within the NHS.

Your GP records would ultimately be no longer held at the surgery and the Department of Health would become the data-controller for your medical records, replacing your GP.

Whilst we realise the importance of the appropriate sharing of medical information with other clinicians and health professionals to ensure the best medical care, we at Ivy Grove Surgery strongly believe that the plan to transfer (upload) and share medical data using the NHS Spine is fundamentally wrong in many ways. This leaflet will explain why.

Why should I be bothered?

The government has an appalling track record for keeping safe the personal data it has in its possession (see Appendix 1).

There is every reason to believe that the government will abuse the uploaded medical data, for example, to sell to pharmaceutical firms, big business and insurance companies. The DVLA alone has sold 5.3 million driver records to private companies since 2002.

Your data will be available, without your consent and in an identifiable way, to thousands of non-clinical health administrators under what is known as 'Secondary Use Services'. Currently nearly 450,000 people registered to use NHS computer 'smartcards' could have access to your data.

There is every reason to believe that the government intends linking the NHS Spine to its other huge databases – such as the Child Records Database, the DVLA databases, Revenue & Customs databases and, most worryingly, the National Identity Register (ID Cards) and the DNA Database.

Many believe that these databases, including the NHS Spine, represent fundamental attacks on our basic right to privacy. In the words of the Information Commissioner himself, the UK is 'in danger of sleepwalking into a surveillance society'. Britain has more CCTV cameras than any country in the world. We have the biggest DNA Database in the world. We have become one of the most bugged, surveilled and monitored countries on Earth.

The government wants patient medical records to be uploaded by default, unless the patient actively objects – that is, if you do and say nothing, your notes will be uploaded. The government does not believe that patients should be given the active choice in saying no to having their data uploaded.

Doctors' views on the NHS Spine

In January 2008 a poll by the British Medical Association (BMA) revealed that nine out of ten doctors have no confidence in the government's ability to safeguard patients' data online or felt that they were in a position to assure patients that their data would be safe.

Many doctors feel that complete centralisation of medical data is not an essential requirement for good continuity and quality of care. They consider it is more important (and a better use of scarce NHS resources) to concentrate efforts on establishing and maintaining robust electronic transfers of the necessary medical data between GP surgeries and their surrounding local hospitals and clinics.

The BMA, as well as the majority of GPs, believes that patient should be asked for their explicit consent before any of their information is uploaded. Your notes should remain with your GP until such time that you actively wish for them to be uploaded (if ever).

More than eight out of ten doctors in the BMA's poll said that they would not want their own personal information stored on the NHS Spine. Some doctors here at Ivy Grove Surgery have already opted themselves and their families out of the NHS Spine.

Even MPs are starting to opt out of the NHS Spine!

Maintaining your confidentiality and privacy here at Ivy Grove Surgery

Because the government wants to upload patient data automatically, and may, in the future, coerce or force GPs to upload the data, we at Ivy Grove Surgery feel it is important that patients have actively consented to have their data uploaded. To ensure that the data of our patients remains safe, we have decided that by default, patients should be opted out of the NHS Spine, until such time that their active consent has been gained.

The reason for this is that if this consent was not gained, and the data was then uploaded, it would be almost impossible for your data to be removed from the NHS Spine should you then refuse consent. It would be too late, and the government would keep hold of your data or a copy of it. Therefore we will assume that you do not want your data to be uploaded to the NHS Spine and we will add a marker to your records to indicate this. This simple modification will help to protect your privacy and keep your records here at the surgery. If at any point in the future, after informed discussion with your GP, you do wish for your data to be uploaded to the NHS Spine, we can always remove this marker and allow the uploading of your records.

Although we will do this opting out for you, you can ask us to do it immediately. Please complete one of our opt out forms at the end of this leaflet and hand it back to reception. You can also opt out on our website by visiting <http://www.ivygrove.org.uk/news/opt-out>

But what about my future NHS care if I opt out?

Contrary to what government officials say, opting out of the NHS Spine will not affect your NHS care in any way. It will not affect the medical care and treatment that you receive from Ivy Grove Surgery, or affect the ability of your GP to refer you to a specialist for further care, should this be necessary. You remain fully (and legally) entitled to all the NHS care that you require, either from a GP, hospital A&E department or a hospital specialist.

Again contrary to what the government says, you do not have to give any reasons why you are opting out. You do not have to justify your fundamental right to privacy.

Please feel free to copy or show this leaflet to family, friends and neighbours who may be registered at Ivy Grove Surgery. This leaflet is also available at <http://www.ivygrove.org.uk/downloads/>

IVY GROVE SURGERY WILL NOT ALLOW YOUR MEDICAL DATA TO BE UPLOADED TO THE NHS SPINE WITHOUT YOUR FULLY INFORMED CONSENT --- IN THE ABSENCE OF SUCH CONSENT WE WILL OPT YOU OUT TO PROTECT THE SECURITY AND PRIVACY OF YOUR SENSITIVE AND CONFIDENTIAL MEDICAL RECORDS

Useful addresses, links and other sources of information

NHS Spine information

<http://www.connectingforhealth.nhs.uk/systemsandservices/spine>

Official NHS Records site

<http://www.nhscarerecords.nhs.uk/>

The Big Opt Out

<http://www.nhsconfidentiality.org/>

Ivy Grove Surgery website for more links

<http://www.ivygrove.org.uk>

Appendix 1 – Data breaches by this government

In April 2007, the Department of Health (DoH) made the personal details – including religious beliefs and sexual orientation – of medical students applying for their first posts as doctors available to view on a public and unsecured website. The Information Commissioner's Office declared the DoH in breach of the Data Protection Act over this appalling action.

In May 2007, the Foreign and Commonwealth Office (FCO) was responsible for personal data of people applying for visas to enter the UK being visible to others visiting the application website. The Information Commissioner's Office declared the FCO in breach of the Data Protection Act over this lapse in security.

In November 2007, Revenue and Customs lost the personal details of 25 million child benefit claimants in the biggest data breach ever in the UK. In the same month it also lost data for 15,000 pension policy records.

In December 2007, the personal details of 6,000 people and details of 3 million candidates for the driving theory test by the DVLA were lost. In the same month the Department of Work and Pensions lost the personal financial details of 40,000 housing benefit claimants.

In January 2008 the Ministry of Defence (MoD) admitted to losing unencrypted personal, medical and financial details of 600,000 applicants for the Armed Forces. And again in the same month, the Ministry of Justice admitted that four computer discs containing personal and confidential details of magistrate court cases went missing in the post.

Official figures revealed through parliamentary answers show that in the last year all government departments reported at least 208 laptops, and a number of PCs, stolen – many holding sensitive (and probably unencrypted) information.

Multiple NHS trusts have also admitted to losing sensitive details of hundreds of thousands of patients, adults and children, as well as personal details of their own NHS staff. Examples include Bolton PCT dumping the records of 3200 patients onto a landfill site instead of shredding or burning the data; Dudley NHS trust had a laptop stolen containing personal details of more than 5000 patients; Stockport PCT lost a memory stick containing medical records of 4000 patients.

More than 4000 NHS smartcards, used to give access to confidential patient records on the NHS Spine, have been reported as lost or stolen.

There seems to be no end to the amount of personal, medical and financial data this government is able to lose.

On the 3rd January 2008 the Justice Select Committee produced a damning report into the way that the Government mishandles private data in the wake of the HMRC child benefit records scandal. To quote the report:

“The roll call of banks, retailers, Government departments, public bodies and other organisations which have admitted serious security lapses is frankly horrifying.”

“We are extremely concerned to hear from the Information Commissioner that there are more cases involving the loss of personal data which have not yet fully come to light. The warning which he issued in the summer about the dangers of mishandling personal data and the extensive security lapses in a wide range of organisations has been proved correct.”

“There are, however, substantial risks associated with large databases which contain personal data and which are open to large numbers of licensed users.”

“There is evidence of a widespread problem within Government relating to establishing systems for data protection and operating them adequately.”

Opt Out Form

Dear Practice Manager

Opting Out of the NHS Spine (National Care Record Service)

I would be grateful if you would ensure that none of my records held by you are uploaded to the NHS Spine. Would you please also file or scan a copy of this letter in my records and also record my dissent by entering the following codes onto my computer record:

93C3 Refused consent for upload to national shared electronic record

93C1 Refused consent for upload to local shared electronic record

9Nd1 No consent for electronic record sharing

Please note that I do not want you to upload my GP-held computerised records either to create the Summary Care Record or the Detailed Care Record. I do not want you to process my sensitive personal medical data in this way.

This is an explicit refusal and I am exercising my right to give you notice of my refusal as entitled under section 10 of the Data Protection Act.

I understand that I can opt back into the NHS Spine at any time in the future; and if and when I choose to, I will inform you.

I am not objecting to the surgery maintaining and updating the computerised medical records held by my GP and that are essential for the surgery to provide me with appropriate and effective medical care.

This request is itself confidential. Please do not divulge my decision, in an identifiable manner, to anyone other than to clinicians who are providing care to me and who might otherwise place information about me on the NHS Spine.

Ivy Grove Surgery unconditionally accepts all requests to opt out of the NHS Spine and so I am happy not to receive written confirmation from the practice that my request has been accepted, as would ordinarily be required under paragraph 3 of section 10 of the Data Protection Act. I am aware that I can, at any time in the future, request confirmation in writing that my request has been accepted, or that I can check with my GP that my opt-out has been registered in my notes.

Thank you.

Please find below the name and date of birth of each adult and child that this request applies to:

Name	Date of Birth	Signature of patient/parent/guardian	Office Use Only