

## Liberating the NHS:

### Transparency in outcomes – a framework for the NHS

#### A consultation on proposals

The Information Commissioner has responsibility for promoting and enforcing the Data Protection Act 1998 (DPA) and the Freedom of Information Act 2000 (FOIA). He is independent from government and upholds information rights in the public interest, promoting openness by public bodies and data privacy for individuals. The Commissioner does this by providing guidance to individuals and organisations, solving problems where he can, and taking appropriate action where the law is broken.

The Information Commissioner's Office (ICO) welcomes the opportunity to respond to this consultation. In the response we shall focus on issues that have transparency, data protection and privacy implications.

The consultation covers some of the most wide reaching changes to the NHS yet introduced. It would appear that all parts of the NHS will be affected by these proposals to some degree or other. The proposals inevitably engage the Information Commissioner's information rights responsibilities.

The consultation document sets out some very broad proposals for reform of the NHS including the abolition of Strategic Health Authorities and Primary Care Trusts. In addition, as part of the reform process, other issues such as the position of the various NHS Arms Length Bodies (ALB) have been reviewed, as well as proposals put forward to increase local democratic involvement in the delivery of healthcare.

At this stage the proposals have not been fully worked up. When they have been, it is likely that we will have detailed comments to make about both data protection and freedom of information issues (including the Environmental Information Regulations). However we

would like to respond to question 31 of the consultation and make some comments around the proposals.

## General comments

With the introduction of a completely new structure we think that it is an ideal opportunity to make sure that all parts of the NHS understand and discharge their data protection and freedom of information responsibilities. The proposals will alter existing responsibilities and it is possible that with greater fragmentation effective governance becomes increasingly difficult in practice. We consider that one of the bodies in this new structure should have a clear lead for the maintenance of proportionate and effective information governance within the NHS.

The second part of "Equity and Excellence: Liberating the NHS" is entitled "Putting patient and the public first" and sets out at a very high level the intention to become a patient centred service with the use of information (both personal and non-personal) key to making the intention a reality. While this is something that has both data protection and freedom of information implications, in broad terms we welcome these proposals. Increased availability of non-personal information will help to improve transparency and accountability while putting patients in charge of their own records will, if done effectively, improve data protection safeguards. We will contribute to the discussion about the Department of Health's information strategy when it is published in the autumn.

## Freedom of Information

In his foreword to the consultation paper, the Secretary of State states that overall these proposals are about improving healthcare outcomes. He goes on to say that this will be achieved by establishing clear accountabilities at a national level in an "open and transparent way". At the same time in "Equity and Excellence: Liberating the NHS" there is clear reference to this process generating "an information revolution".

With this in mind our view is that freedom of information should be at the centre of these proposals. In particular the publication scheme provisions (section 19) of the Freedom of Information Act provide what would appear to be an ideal legally supported mechanism to place information into the public domain. This accords well with the intention to develop a culture of "open information, active responsibility and challenge".

In particular we regard it as essential that the proposed GP consortia are set up in such a way that they will be classified as public authorities under the provisions of the FOIA.

## Data Protection

### Summary Care Records

Information is at the heart of providing effective healthcare. Frequently this information is in the form of an individual's sensitive personal data and as such great care needs to be taken in the way that it is handled. This is especially the case with manual records being replaced with electronic ones.

In recent years the NHS has begun one of the biggest conversions of such records yet with the development of electronic health records. In the next few years this will potentially see all NHS patients in England being allocated their own electronic Summary Care Record (SCR). The ICO has worked closely over the past few years with Connecting for Health during the development of the SCR to ensure that data protection issues were addressed.

However as this work has developed there are some issues that are still to be resolved. In particular there is continuing uncertainty about who will be legally responsible for the SCR (in data protection terms the 'data controller'). In practice this may be a combination of GPs, hospitals and the Department of Health who will either in common, or jointly control the record. A clear understanding of the shared and the different responsibilities of those concerned is essential to ensuring that they comply with their legal obligations. This needs addressing and cannot be left open to misinterpretation.

With plans being set out to establish GP consortia working with the new NHS Commissioning Board as the main mechanism for delivering healthcare, from our perspective this is the ideal time to provide clarity about the legal status of the SCRs, setting out the involvement of different parts of the healthcare system in determining how the individual records of millions of patients will be used.

Underpinning the need to see this work undertaken is the clear flagging of the fact that the intention is for individuals to have increased control over their own care records. We consider that this can only be achieved where there is a clear structure and also clarity about who the data controllers are.

## Security

Currently one of our biggest concerns is the security of information held by the health service. Since November 2007 a total of 1011 security breaches have been reported to the ICO and of these 307 (30%) relate to the NHS<sup>1</sup>. In the last year 21 NHS organisations have signed undertakings with us to comply with the requirements of the Data Protection Act<sup>2</sup>. All these undertakings focus on failures to take appropriate security measures thus breaching the requirements of the seventh data protection principle.

In our view the establishment of a new structure for delivering healthcare is a good opportunity to ensure that security considerations are thoroughly incorporated into the normal business processes of the various NHS organisations.

## Specific document comments

In addition to the general points set out above we also wish to comment on some of the proposals set out in the various accompanying documents.

### 1. Transparency in outcomes – a framework for the NHS A consultation on proposals

Our responses are in respect of Q31 which asks for views on any issues not covered by previous questions.

P9, para 2.3 and 2.4 – These paragraphs refer to the necessity of developing close links between NHS bodies and local authorities. With patients at the heart of these proposals it is important that from the outset that the data protection considerations are incorporated into the design of these links. This is not to hinder this process rather it is so patients are clear about who will see and use their personal records and the level of control they may exercise and local authorities are clear about the particular sensitivity of patient information entrusted to them.

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<sup>1</sup> Security Breaches Reported to the ICO  
[http://www.ico.gov.uk/upload/documents/library/corporate/research\\_and\\_reports/breach\\_notification\\_spreadsheet.pdf](http://www.ico.gov.uk/upload/documents/library/corporate/research_and_reports/breach_notification_spreadsheet.pdf)

<sup>2</sup> Information Commissioner's Annual Report 2009/10  
[http://www.ico.gov.uk/upload/documents/library/corporate/detailed\\_specialist\\_guides/annual\\_report\\_2010.pdf](http://www.ico.gov.uk/upload/documents/library/corporate/detailed_specialist_guides/annual_report_2010.pdf)

## 2. Equity and excellence: Liberating the NHS

P15, para 2.13 – if standardised aggregated (and non-personal) data is to be made available then in the spirit of transparency and openness this type of information should be pro-actively released and not just provided to those who request it. Where the information is environmental in nature this would help relevant public authorities to meet their obligation under the Environmental Information Regulations to progressively make environmental information available to the public by easily accessible electronic means (Regulation 4 (1)).

P16, para 2.15 - this part of the report sets out the proposal to centralise all data returns in the Health and Social Care Information Centre. From our perspective the Centre should be at the heart of NHS transparency being in a position to make a large amount of performance information available.

P24, para 3.17 – Incentives for quality improvement – the report refers to the Department commencing the design and implementation of a more comprehensive and transparent structure of payment for performance. From our point of view this should be done in an open way with again information being made available through organisations' publication schemes. This will further support the aim of accountability

P30, para 4.10 – An autonomous NHS Commissioning Board - we welcome the intention for the NHS Commissioning Board to publish information on the quality of healthcare services commissioned by consortia. This is a firm start to placing openness at the heart of the Board's operation and should help it to achieve its objectives. It will also aid the intention ("Commissioning for patients", p10, para 2.19 – Partnership) for consortia to work closely with patients and the local communities that they serve.

## 3. Equity and excellence: Analytical strategy for the White Paper and associated documents

P2, para 8 – we welcome the proposals to involve patients and public more in decisions about their own care. To help patients make the necessary informed choices they must be aware of the bodies that are responsible for and make decisions about the individual's personal data. However patient control should not be illusory, it should be clear to patients what they have effective control over and what they do not, and effective mechanisms in

place to allow them to exercise that control. In addition patients need to know as much as possible about these bodies which they are entrusting their health care to. Using the publication scheme provisions of the FOIA is one way of making a large amount of information pro-actively available.

P3, para 11 – we would like to know more about what is regarded as “unnecessary bureaucracy associated with medical research...” We would not like to see the overall protections around the use of sensitive personal data weakened or the importance of individual patient control eroded.

#### 4. Local democratic legitimacy in health

P4, Strengthening public and patient involvement – this part of the paper sets out plans to establish Local HealthWatch arrangements to act as consumer champions (and possibly as “citizen’s advice bureau”) across health and care. We consider that their role can only be enhanced by these bodies being provided with a clear understanding of both the Data Protection Act and the Freedom of Information Act.

P8, Functions of health and wellbeing boards – these are set out very broadly as promoting integration and partnership working between the NHS, social care, public health and other local services and improving democratic accountability. Making these boards public authorities, as defined by the FOIA, can only help with all these aims and especially the last one. The importance of doing this is increased if these boards become a vehicle for taking on joint commissioning and pooled budgets (p9, para 32).

#### 5. Report of the arm’s-length bodies review

P9, para 2.9 – see comments under “Equity and excellence: Liberating the NHS” in connection with the proposed changes to the Health and Social Care Information Centre.

The other proposed arms-length bodies should be covered by the FOIA (if not already). It is also likely, given their proposed roles, that the Care Quality Commission and HealthWatch England may have increased data protection responsibilities.

P18, para 3.21 – we welcome the possibility of creating one specific research regulator. This should ensure that confidentiality and in particular data protection considerations

are effectively dealt with in a research context.

## 6. Commissioning for patients

P9, para 2.16 – Freedoms and accountabilities – NHS Commissioning Board - see comments under “Equity and Excellence: Liberating the NHS”.

P18, para 3.27 – providing national leadership on commissioning for quality improvement – the proposal to make available accessible information on commissioner performance is also a very welcome development.

P21 – Question – What features should be considered essential for the governance of GP consortia?

The ICO considers that GP consortia should become listed as “public authorities” as defined by the FOIA. This is essential if the consortia are going to meet the objectives of being at the heart of the patient experience of the NHS. Making the consortia subject to the FOIA can only help in making them completely transparent and accountable public bodies like over a 100,000 others.

While we are very much aware that GPs (and other medical professionals) usually take great care with the security of individual medical records, given the proportionately large number of self reported data security breaches that have occurred within the NHS, GP consortia must be fully aware of their data protection responsibilities. It would be a matter of significant concern if any new consortia arrangements lead to confusion over roles and responsibilities in such a vital area. Ensuring that the new arrangements improve the current situation and do not exacerbate it will be of crucial importance. We also consider it important that the obligation on NHS bodies to report data security breaches to the ICO is maintained in the new structure and applies to GP consortia when they are established.

P27 – Question – What safeguards are likely to be most effective in demonstrating transparency and fairness in investment decisions and in promoting choice and competition?

See our comments under the essential features for the governance of GP consortia about making them public authorities

P31, para 6.6 – Local government and public health – we are keen to see that this proposed integrated working firstly does not put individual patient records at risk because of potential mishandling and secondly that such arrangements are set up in such a way that they are covered by the FOIA.

## Conclusion

The proposals on 'Liberating the NHS' represent significant opportunities to improve transparency in healthcare delivery and increase patient control over their personal details. There is though an allied risk that changes to current responsibilities and governance arrangements could lead to confusion and undermine these important objectives. We look forward to working with all concerned to ensure that as further detailed proposals are developed, the opportunities to increase transparency and patient control, whilst minimising information risks are seized and put into practice.