

Consultation Liberating the NHS: Greater choice and Control Response from the Information Commissioner

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.

Consultation questions

Q4 – What would help more people to have more choice over where they are referred?

In the example helpfully provided between paragraphs 2.7 and 2.8 there is a reference to a patient looking up information about different NHS service providers on the NHS Choices website. To us this encapsulates what needs to be done to help people to have more choice over where they are referred. Not only does information need to be made available but it has to be done in an easily accessible manner. This applies to information provided via a public authority's publication scheme as well as what is made available through websites such as NHS Choices.

Q36 – How should people be told about relevant research and how should their preferences be recorded?

Our concern is that the system for recording individuals' preferences about research is robust and protects individuals' data protection rights. This is because people will want to contribute in different ways to research programmes. Some will want to be actively

involved in trials and tests while others might only want to contribute relevant but anonymised information. It is important that individuals are clear about what their commitment involves and about what will happen to their personal information. A further important consideration is that such systems should allow individuals to amend their participation in research or even withdraw from it all together if they do not want to be further involved.

If the process is not well managed and people become aware of poor handling of personal data then this is likely to undermine public confidence in research programmes using personal data from the NHS.

We do not have any further comments to make about this consultation.

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