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16 April 2012

Reference Number: 32500

Email:request-112891-179920c6@whatdotheyknow.com

Dear Mr Rawlins

FREEDOM OF INFORMATION ACT 2000

We have received your request for information as detailed below:

National Evaluation of the Department of Health's Integrated Care Pilots according to page iv (page 15 of the electronic document), your organisation (or organisations you commission) took part in this research. Please could you provide the following responses to my enquiries?

- 1) Were staff who were involved in caring for service users aware that they and their patients were participating in this research?*
- 2) If the answer to question 1 is 'Yes', were patients made aware that they were participating in this research?*
- 3) Were patients asked for their consent (I am aware that NIGB and Cambridgeshire ethics committee decided that patients' consent was not required) or given an opportunity to opt out?*
- 4) If patients were not asked for their consent, would the following have prevented their automatic enrolment in the research:*
 - a) PDS flag set to 'sensitive';*
 - b) CRS flag set to 'dissent to sharing across organisational boundaries';*
 - c) I assume all patients were asked for explicit consent for information to pass between separate organisations involved in their care, so therefore could you confirm those not consenting would not have been included in the research?*
- 5) What other measures could patients adopt to prevent you or your*

providers automatically enrolling them in research in the future without their knowledge or consent, or passing their (anonymised or otherwise) information on?

6) If patients were not asked for their consent at the time, would a request under the Data Protection Act yield an accurate answer as to whether they were included in this research or not?

Your request was received on Monday, 16 April 2012 and we are dealing with it under the terms of the Freedom of Information Act 2000. I am in the process of collating this information and hope to be in a position to respond to you shortly.

In some circumstances a fee may be payable and if that is the case, we will let you know. A fees notice will be issued to you, and you will be required to pay before we will proceed to deal with your request.

If you have any queries about this request, please do not hesitate to contact us.

Yours sincerely



Lisa Kelvin
Trust Secretary
Freedom of Information Act Officer