

## Data Subject Notification

Help on completing this form is shown on the next page

### My details

*(To be completed by the data subject)*

|            |                    |
|------------|--------------------|
| My Name    |                    |
| My address | NHS number         |
|            | Date of birth      |
|            | Sex                |
|            | Telephone number   |
|            | Place last treated |
| Post code  | Date last treated  |

*Please complete as fully as possible*

### My request

I wish the cancer registration system in England to

- 1) **retain** my record but ensure that it is not released to any research projects which would involve researchers contacting me.
- 2) **remove** all clinical and personal information relating to me but retain my NHS number so that any further submissions referencing that NHS number will **NOT** be processed by the national cancer registration system.
- 3) **delete** all my records from the cancer registration system where they currently reside. I understand the registry will not keep any record of my details, so, will not know that any information received about me in the future should not be processed.

I confirm that I have read the leaflet "About Cancer Registration" and the Frequently Asked Questions\* (FAQs) about cancer registration.

\* The answer to question 11 explains the implications of opting out of the cancer registration scheme

Signed..... Date.....

### Notification of receipt

*(To be completed by the cancer registry)*

I acknowledge receipt of your Data Subject Notification on .....(date received.)

- I can confirm that your request to exclude your record from all research projects which might involve contacting you
- I can confirm that your request to remove your record from the national cancer registration system but to retain the NHS number
- I can confirm that your request to have your whole record deleted from the national cancer registration system.  
*(Please tick only one box)*

was completed on .....(Date processed).

Signed ..... Date.....

**Dr Jem Rashbass**  
**Director**

**ECRIC, Unit C, Magog Court, Shelford Bottom, Hinton Way, Cambridge CB22 3AD**

# **Cancer Registration System**

## **Completing the data subject notification form**

### **When should this form be used?**

This form should be used in consultation with your local cancer registry. You should read the cancer registration leaflet and the accompanying Frequently Asked Questions about Cancer Registration document. The registry will provide a contact with whom to discuss your concerns and explore the implications of opting out of the cancer registration scheme. If you decide to go ahead with opting out of the cancer registration system then use this form to notify your local cancer registry of your decision.

### **Why do you need my personal details?**

The registry will need to identify any records about you. To do that they need information about you, including your address at the time your cancer was diagnosed and details of where you were treated.

### **Who else will need to know?**

This information will be kept strictly confidential. It will only be shared with another organisation when your local registry knows that the other organisation already knows about you and solely in order to ensure that your record is treated in accordance with your wishes. Other organisations that might potentially hold information about you include the Office for National Statistics and other cancer registries that cover hospitals where you received treatment. The local cancer registry will take responsibility for ensuring that all recipients of your data, which are known to it, comply with your request.

### **Which option should I choose?**

You will need to choose one action for the registry to carry out. If you have any questions about which is best for you, discuss it, in confidence, with the contact at your local registry. The registry representative will take time to ensure you understand the implications of the different options.

### **How will I know that the registry has complied with my request?**

The registry will complete the lower half of the notification form, confirming that your request has been received, processed and successfully completed. The completed form will be sent to you. Once that is done the registry will not contact you again.

### **What records will you keep of my request?**

The local registry has experience of keeping highly confidential information and will only hold information if it is absolutely necessary. The information retained by the registry depends upon the option you select.

If you have asked for your record to be retained but withheld from any research projects involving the researchers contacting you (option 1) then your request will be stored securely. There will be a flag on your records specifying that the information should not be released to any research projects involving patient contact.

If you opted to have your personal and clinical details removed (option 2) only the NHS number will be retained for use in identifying and removing any further notifications that the registry receives.

If you opted for deletion of the whole record (option 3) then the registry will destroy your request once it has confirmed to you that your record has been deleted. If you contact your registry after this has been done it will be necessary to explain your circumstances again as no record will exist.

### **Where do I send a completed form?**

Please return it to the address at the foot of the form. This is the address of the registry that will deal with your request. It is not necessary to contact more than one registry. Any registry that is known to hold data about you will be asked to comply with your request.

### **What if I have further queries?**

Please contact your local registry and talk to the patient information officer or to the nominated contact person. They should be able to answer your questions.