



## Patient Opt-Out Request Form

This form is for use by patients to request that their personal information be excluded from processing onto the national cancer registry, rare disease or congenital anomaly database.

If you would like to opt-out of the national data opt-out, please visit this webpage: [National data opt-out - NHS Digital](#). The national data opt-out allows patients to opt-out of all their patient information being used for research and planning.

We need the personal information collected on this form so that we can process your request correctly. It will only be used in connection with carrying out your request.

To be completed by the patient. Please complete as fully as possible.

My Details	
Name:	
Address:	NHS Number:
	Date of Birth:
	Sex:
	Telephone Number:
	Email (optional):
	Place Last Treated:
Postcode:	Date Last Treated:

Which registry/registries would you like to opt out of?

- The cancer registry
- The rare disease registry
- The congenital anomaly registry

My request:

I instruct the cancer, rare disease and/or congenital anomaly registration system in England to stop adding information about me to the disease registration database and remove, as far as possible, all clinical information relating to me including information provided in the 'my details' section above. I understand that the disease registration system will automatically ensure that the cancer, rare disease and/or congenital anomaly registry will not process further details about me in future.

I have included copies of the necessary ID verification documents

Acceptable ID documents include:

Photo identification (a copy of your passport/driving licence)

Proof of address (a copy of a utility bill)

(These documents will be destroyed once your opt out is complete)

Signed \_\_\_\_\_ Date \_\_\_\_\_

Please return to

NDRS Data Opt-Out

2<sup>nd</sup> floor

The Government Hub

23 St Stephenson Street

Birmingham

B2 4BH

### **Disease Registries Patient Opt Out Policy Advice**

The law permits the cancer, rare disease and congenital anomaly registries to collect information on patients in England. The law gives you, the patient, the right to object to your personal information being used for disease registration purposes.

If you want to opt out from cancer, rare disease and/or congenital anomaly registration, you must apply in writing preferably by using the Patient Opt-Out Request form above.

On receipt of your completed form and proof of identity documents, our Caldicott Guardian\* will seek to contact you directly to ensure that you are fully aware of the value of your information to research and for improving treatments.

If after this conversation you still wish to opt out, we will search all disease registration files and records and delete any existing information relating to you that it may have.

We will ensure that the registry or registries will not collect or process any further information about you.

We will also check whether we have sent any identifiable information to other permitted organisations, such as the Office for National Statistics or NHS Digital, and if so will contact them to instruct them to delete the information.

Information will stop being collected or processed within 20 days of receiving the signed opt out form. We will confirm this in writing to you.

\* A Caldicott Guardian is a senior person responsible for protecting the confidentiality of patient and service-user information and enabling appropriate information-sharing. The Guardian plays a key role in ensuring that NHS, Councils with Social Services Responsibilities and partner organisations satisfy the highest practical standards for handling patient identifiable information.