



National Cancer Research Institute Informatics Coordination Unit

NCRI Cancer Informatics Platform Privacy Policy

Version 2-00

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1 Purpose

This document is a statement of policy related to the privacy of personal information that individuals may provide to the NCRI Informatics Platform (“the platform”).

2 Scope

The policy applies to personal information, that is information that may be used to identify an individual. Within the platform, personal data may be held within NCRI ONIX component (the NCRI Oncology Information Exchange). This document describes what personal information is collected, how it is used and to what extent it is shared with third parties.

Personal information that is stored within external resources or websites connected to platform is out of scope of this document and any policies relating to its storage and use is the responsibility of the relevant resource controller.

3 Information collection and use

3.1 Unregistered Users

The platform is made available to public users without registering. In this mode no personal information is collected or used, although cookies may be used to track the usage of the website. These cookies are not used to identify individuals but simply to analyse how people use the website to allow us to provide a better service.

Personal information **is** collected in the following scenarios:

1. When a user chooses to apply for platform usage registration
2. When a Resource Controller publishes information through ONIX

3.2 User Registration

If an individual chooses to register as an informatics platform user they are required to provide some personal information. Typical examples of personal data requested may include:

1. Name
2. eMail address
3. Affiliated Organisation
4. Referee

The information collected is primarily used to request access to informatics platform resources and data that you ask for through the platform interface. We may also use this information to communicate with you. If you apply for access to a specific resource connected to the platform then these details may be passed to the registered controller of this resource to allow them to assess your application.

If you have consented to we may pass on your name, email addresses and organisation to strategic alliance partners (see Appendix 1 – Strategic Alliance Partners) so that they may contact you with details of scientific congresses and other events that you may be interested in attending.

If you have consented we may make that subset of your personal data that you have agreed to being made available to other *registered* users of the platform.

We will provide facilities for you to view and amend your own personal information.

We will not pass on names, email addresses or organisation affiliation details to other third party organisations.

We will not pass on any other personal details to any organisations unless we are required to do so by law.

We reserve the right to audit operations performed by individuals through ONIX. We may use this to record events such as those prohibited under the Terms of Use [1] and/or to monitor usage of the system and specific resources. Although transactions are initially tracked to specific individuals, audit trail entries will be pseudonymised¹ six months following the date of the transaction.

3.3 Resource Registration

The purpose of the cancer informatics platform is to provide data and resources to legitimate users who are interest in or involved in cancer research. The connection of appropriate resources to the platform is voluntary but encouraged.

The general policy on sharing resource information is detailed under Platform Resource Registry Sharing Policy [2]. Controllers of resources may be asked during registration to provide details of their resource, and this may include personal data. Where this is the case the following additional criteria apply:

1. Resource Registry information may include contact names, addresses, telephone numbers and similar personal data. The purpose of this is to allow platform users to contact individuals with knowledge of the resource to ask for more detailed information or to pose questions. Resource Controllers may choose which Resource Registry elements may be made available through ONIX. Any additional personal information (ie beyond that requested for Resource Registration) that may be curated by a resource is shared at the sole responsibility of the Resource Controller.
2. Only registered platform users will be allowed access to personal Resource Registry data items that are shared.
3. Resource Controllers are responsible for the provision, accuracy and maintenance of this data and shall seek the permission of all individuals identified by the Resource Controller to use their details in this way.
4. Resources will be passed authenticated credentials of platform users wishing to access their resource. It is a condition of Resource Registration that Resource Controllers agree to treat any personal information passed to them with a duty of care at least as rigorous as if it were provided to them directly by the user themselves.

¹ Details that identify real people are replaced by arbitrary keys that simply correlate activities of separate, but non-identifiable, users.

4 Appendix 1 – Strategic Alliance Partners

As at April 2008 the following organisations are strategic alliance partners of the NCRI Informatics Initiative. If you consent to us doing so, we may pass on details listed under “User Registration” to these organisations.

1. EBI – The European Bioinformatics Institute
2. caBIG – The US National Cancer Institute’s Cancer Biomedical Informatics Grid

5 Appendix 2 – Related Documents

Ref. No.	Document Name
1	NCRI Informatics Platform Terms of Use
2	NCRI Informatics Platform Resource Registry Sharing Policy