



NCRI INFORMATICS INITIATIVE

Implementation Plan FAQ's

General Section

What is this all about?

There's been general consensus for some time that it should be possible to improve the impact of cancer research by making it easier to identify, share and re-use information about cancer. The NCRI is taking a coordinating role through its Informatics Initiative to do practical things to help. The activities fall into two main areas: fostering a climate where data "owners" are prepared to share their information (where this is appropriate) and helping to build the necessary technology to make this possible. These Frequently Asked Questions (FAQ) tell you a little more about what's being done, by whom and when.



How can I find out more?

This website has a wealth of information on the Informatics Initiative and related news and events. As well as the Frequently Asked Questions ([General](#), [Platform](#) and [Community Alliances](#)), there are several documents available for download. These include:

- A vision for cancer informatics in the UK (<http://www.cancerinformatics.org.uk/documents.htm#framework>)
- A business case to outline the rationale for acting (<http://www.cancerinformatics.org.uk/documents.htm#buscase>)
- The Implementation Plan for proceeding (<http://www.cancerinformatics.org.uk/documents.htm#implan>)

You can also contact us at info@cancerinformatics.org.uk Specific topics are being dealt with by nominated individuals and you may wish to contact them directly.

- **Funding questions** - Abigail Evans at Cancer Research UK
email: Abigail.Evans@cancer.org.uk, tel: 020 7438 5351, Fax: 020 7438 5454
- **Community alliances and communications** - Dr Fiona Reddington, NCRI Informatics Coordination Unit
email: fiona.reddington@ncri.org.uk, tel: 020 7438 5410, fax: 020 7430 2178
- **Informatics Platform questions** - Dr Alan Hogg, NCRI Informatics Coordination Unit
email: alan.hogg@ncri.org.uk, tel: 020 7438 5412, fax: 020 7430 2178

The unit also publish a regular newsletter. Please contact us at info@cancerinformatics.org.uk if you'd like to be included in the distribution list.

What about funding?

This work is being funded by several NCRI partners and other organisations from industry, government and charity. Some of this money is dedicated to central coordinating activities, with the rest being dedicated to funding independent projects. These projects can come from any aspect of the cancer research community that can advance the goals of the initiative. Funding for such projects is competitive and decisions are made by peer-review. For further information on peer-review funding please contact Abigail Evans at Cancer Research UK [Abigail.Evans@cancer.org.uk, tel: 020 7438 5351] in the first instance.



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Platform Development Section



What is the NCRI Informatics Platform?

The Informatics Platform is a geographically distributed but centrally directed integrated environment with a consistent interface (illustrated in the figure below). This integrated environment allows resources in the form of biomedical data, data services, or tools to be accessible through a common user interface.

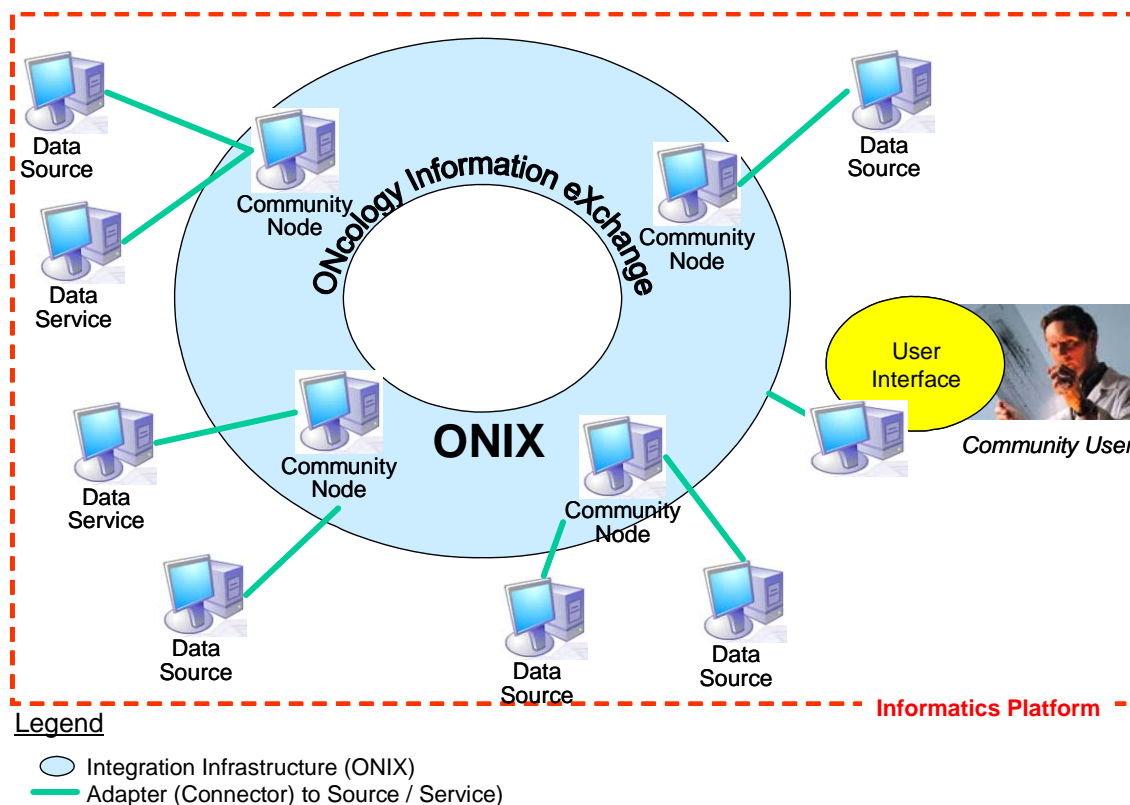


Figure – Conceptual Architecture of the Informatics Platform

What is ONIX?

This integrated 'Platform' environment allows resources to connect to and be shared by users. The infrastructure that 'glues' resources together is called the NCRI Informatics ONcology Information eXchange (referred to as "ONIX" in this document).

Is this an IT project?

No, it is not - although IT components will be needed to allow access to data or services from remote sites. It is the culture of sharing, coupled to usage of common data standards and vocabularies, that is essential to allow meaningful co-operation to occur. The value of the Platform is in providing meaningful links to and between existing data and services related to cancer.

Are NCRI building the platform?

The Informatics Coordination Unit are not there to define what research, data or services the cancer community requires. These activities will continue to be developed by the research community. The Unit's role is to work with the community to define useful common functions for the platform, such as a central portal for users to log into. The Unit will also work on support services to ensure operational availability of the Platform, training of the community and technical advice, including the development of an accreditation scheme.

Who is involved in the Platform?

A wide variety of groups are involved in the overall programme to develop an Informatics Platform



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within the UK and beyond. These include:

- Cancer community researchers
- Strategic alliance partners, such as the US National Cancer Institute and the European Bioinformatics Initiative
- NCRI partners, including government organisations, charities and industry
- Patient representatives

How can I get involved with the Platform?

In these initial phases the Unit is working with a small group of researchers from the wider community, both to contain risk as well as achieve the initial steps in a reasonable timescale. During this time if you would like to be kept apprised of progress then please contact the Unit via our website.

In the medium term, anyone who has data or services they wish to share with others, or would like to search for services and data already attached to the Platform, will be able to apply for access rights and join the community. All that is expected is that anyone becoming involved in the Platform supports the principle of sharing cancer research knowledge with the community.





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Community Alliances Section



What is the Implementation Plan?

The vision of the NCRI Informatics Unit is to create an internationally compatible informatics platform in the UK. The platform facilitates access to, and integrated analysis of, data across the broad spectrum from genomics to clinical trials. The implementation plan describes in detail how this vision can be achieved through the combination of the development of an informatics platform alongside a supporting cultural change and training programme.

How did it all come about?

Once the vision was identified through the 'NCRI Strategic Framework for the Development of Cancer Research Informatics in the UK' it needed a structured and focused plan of action plus a tangible method of monitoring the progress of making the vision a reality. Thus the implementation plan was born as a natural progression of that vision.

What areas does the plan cover?

The implementation plan is a UK focussed plan that covers four main areas:

1. Technical

- the development of a common data sharing, integration and analysis infrastructure (Informatics Platform) with methods of connectivity
- development of documentation and definitions relating to the platform
- development of an accreditation process for devices or tools for connection to the platform
- transition and support of the launch of each phase of the platform
- user training

2. Community

- Facilitation of a cultural change to support the development and use of the informatics platform.
- Collaboration with groups linking into the platform
- Promotion of multi-disciplinary collaborations
- Key stakeholder management
- Identification and promotion of data standards
- Creating effective working relationships with national and international strategic partners e.g.: EBI, NCICB, HSCIC etc.

3. Policies

- Development and promotion of data sharing policies

4. Financial

- Refinement of cost and resource estimates of realising the vision

What is the timeframe for the plan?

The implementation plan will be rolled out in three consecutive phases

- Phase 1 will run for 18 months and will involve defining and designing the core elements of the informatics platform focussing on UK cancer communities
- Phase 2 will run for 9 months and will build on the activities carried out in phase 1 incorporating community built tools and data sources and expanding to include international cancer communities.
- Phase 3 will run for 12 months and will involve continued development and expansion to include non cancer related groups



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Why do we need a plan?

In order for the implementation of the platform to be successful there needs to be a structured and focused plan of action and a tangible method of monitoring progress against that plan and the usefulness of the work done. The plan thus serves both as a tool for managing the project, and a method of clearly communicating what will be achieved and when.

Who wrote/approved the plan?

The writing of the plan was undertaken by the Informatics Coordination Unit with support and guidance from the NCRI Task Force. The plan encompassed the views of a large number of diverse contributors (e.g. Funders, Patients, Scientists, Clinicians, etc) who were interviewed to obtain their views on what should be proposed in the plan. The plan was endorsed by the Informatics Management Board in their capacity as representatives of the NCRI Board.

How is the plan managed?

On a day-to-day basis the plan is managed via the Informatics Coordination Unit. The progress made will be reviewed on a regular basis at a series of independent gate reviews that will be undertaken by the Informatics Management Board on behalf of the NCRI Board.

What are the major points of the plan?

There are three major points to the plan:

Technical: Development of a common informatics platform

Community Alliances: Facilitation of cultural change to support the development and use of the platform

Implementation: Active development of a platform by the UK Cancer Community in partnership with existing programmes in order to accelerate deployment and maximise already established learning.

For the plan to succeed we will need to ensure that the community is properly engaged, technology is developed to facilitate the identification, sharing and re-use of data and that appropriate information dissemination and training is provided.

How does this fit with other projects?

There are several large-scale initiatives already in existence that we can learn from and collaborate with. These include the US National Cancer Institute Cancer Biomedical Informatics Grid (NCI caBIG™) program and the National Health Service Connecting for Health programme and its equivalents in Scotland, Wales and Northern Ireland. The NCRI Informatics Initiative has formed strategic alliances with both the NCI Center for Bioinformatics and the European Bioinformatics Institute whereby we agree to work together where appropriate and to share knowledge and expertise. The NCRI Informatics Initiative also works closely alongside a number of community-led projects which are developing tools and resources that may be connected to ONIX in the future. The Initiative welcomes collaboration with other groups and projects, those interested in finding out more should contact info@cancerinformatics.org.uk.

