

NCRI Cancer Informatics Initiative - frequently asked questions

What are you trying to achieve?

The cancer research community is now generating massive amounts of data, much more than it was say 10 years ago. This is due to of the advent of new high-throughput technologies (the “omics” revolution) and initiatives such as the Human Genome Project. This is a good thing, but we want to make sure that we are in a position to make maximum use of this data for the benefit of cancer patients. Currently this is hard to do.

Why are we not using all this data now?

Partly because there is so much of it and partly because it's either, difficult to access or stored in many different formats.

Why aren't researchers sharing their data now?

The research community does share its data now, but we need to make it much easier to share data by encouraging people to collect and store data in standard ways. We also need to ensure that we develop a culture where data sharing amongst the scientific community is routine.

How will the Strategic Framework help?

The “NCRI Strategic Framework for the Development of Cancer Research Informatics in the UK” describes a shared vision of how we think things should develop. Lots of people need to pull in the same direction if we are to achieve this vision and the Strategic Framework will act like a “road-map” that can be used by all the different stakeholders.

Can you give me an analogy to describe how the Framework will work?

If you think of data from research as money, at the moment different scientific disciplines such as genetics and pathology are storing data using different currencies (often more than one currency in any given area!). We need to a) ensure that within a given area of cancer research everyone agrees to use the same currency and then b) ensure that we can “exchange” data between the different currencies. The Framework will act like a ‘bureau de change’ and ensure that we can move data between the different currencies.

Why is this happening now?

There is growing recognition of the importance of this issue and the creation of an umbrella organisation like the NCRI means that it is now possible for us to jointly tackle complex issues like this.

What will the Task Force do?

The NCRI Partners have indicated a ‘direction of travel’, we need the ‘Implementation Task Force’ to work with the experts in the community to map out the detail of what we need to do to achieve the vision.

Is the UK leading the world with this initiative?

The fact that we have a national co-ordinating body for cancer research like the NCRI means that we have been able to tackle this problem on a larger scale than anyone else. However, this is an international issue and we've been working very closely with American and Europe, through the NCI and EBI. The NCI in particular has done a lot of work in this area through its caBIG Programme.

What does the Framework mean to me as a cancer researcher?

In the long-term it will create scientific opportunity and should add power to the research you do by providing access to data from other researchers. It will also ensure that your data can be used by others to advance knowledge. The system will ensure that you receive recognition for this. In the medium term it will mean that you may have to think about data sharing and use of common data standards a bit more than you might have done in the past. In the short-term, the Framework is an invitation for you to help us get things right.

What does this mean to me as a cancer clinician?

If this vision is realised, cancer care will become more efficient, with much faster translation of results from research to practice. The informatics platform could provide selected items of information on the genetic, proteomic and pathway analysis of the cancer being investigated by a clinician, which would indicate investigations likely to be relevant to the diagnosis, prognosis and treatment chosen.

What does this mean to me as a cancer patient?

The short answer is that this should help speed the research process up!

Treatment and care of cancer patients would be revolutionised by this informatics platform, leading to much more individualised treatment regimens. Patients would find themselves, at least for much of their care, part of a system which tracked their therapy and outcomes and linked them to samples and images. , Enabling the sharing of knowledge across disciplines, from genomics through to clinical trials, will benefit patients by channelling the development of novel therapeutics and diagnostics in a more effective way.

Are there issues of patient confidentiality?

The Framework encourages access to all data that will add to the research process and speed up the prevention and cure of cancer. Where this might include identifiable patient data, we are not proposing anything new and the security and confidentiality standards demanded by the Department of Health and the Information Commissioner will be applied.

How will this initiative be funded?

The cancer research funders have asked the Task Force to identify what is needed in terms of resources for infrastructure and training to take forward the Cancer Informatics initiative.

What is the NCRI?

The National Cancer Research Institute (NCRI) is a partnership between Government, charitable and private sectors. Over the past few years there has been much debate about cancer research in the UK and many individuals and organisations have been asking the same question 'are we being as effective as we could be?' A Government initiative brought the main funding organisations together at the beginning of 2000 in a 'Cancer Research Funders Forum'.

This move was embraced by the research charities and the NCRI was established formally as a key element of the English [National Cancer Plan](#) in April 2001. The [NCRI Partners](#) and [NCRI Board](#) are developing a national strategy for cancer research and co-ordinating activities between member organisations. The NCRI secretariat is funded half by Government and half by the cancer research charities.

What is the joint data sharing policy?

The NCRI is working with the funding community to develop a joint data sharing policy for cancer-related grant applications that all the NCRI Partners are happy to adopt. A copy of the draft policy can be viewed at <http://www.cancerinformatics.org.uk/documents.htm#framework>.

How can I get involved?

To find out more about the NCRI Informatics initiative please visit www.cancerinformatics.org.uk. The NCRI Informatics Coordination Unit can be contacted at info@cancerinformatics.org.uk.