NCRI Cancer Informatics Initiative - Response to Royal Society call for evidence: impact of ICT on health and healthcare

1. What relevant technology trends are likely to impact on health and healthcare in the next ten to fifteen years?

Development of high-throughput technologies based on genomics and proteomics as diagnostic tools or as predictors of response to drugs.
Development of electronic data capture and management tools and resources.
The GRID as a means of doing large-scale multidisciplinary science that will underpin development of therapies

Assessing the potential positive and negative impacts of relevant future technological developments

2 What areas in the provision of health and healthcare could be positively or negatively affected by these developments?

3 What actions should be undertaken now to maximise positive impacts, or to prevent or minimise adverse effects?

Coordination of data standards between the health and healthcare providers, researchers assessing the technologies, and the technology manufacturers will help maximise the positive impact of emerging new technologies and technological developments.

Evaluating the wider implications of relevant future technological developments

4 Do you have any concerns associated with the generation, release and subsequent use of personal data?

Technology is there, this is more of a cultural issue. It's vital that there is appropriate user consultation regarding confidentiality and security around the use of patient data so people know what is planned and how it will work.

5 What medico-legal and ethical issues merit consideration when introducing new technologies, such as the responsibilities, processes and liabilities for decision making?

As above: transparency about policy issues and decision making are key. People tend to support things that advance science and medicine if they are properly informed about them.

6 What regulations or other mechanisms (including standards) would facilitate the responsible development of relevant technologies?

A multi-disciplinary technical panel, with end user representation to oversee technical development and ensure use of appropriate standards etc would be invaluable. A model for this has been established in the cancer domain in the formation of a multi-disciplinary Task Force (www.cancerinformatics.org.uk/TaskForce.htm)
If technologies have to adopt existing terminologies, ontologies, and standards which are part of an existing informatics platform that supports research and healthcare this would facilitate development.

7 What infrastructure would be required to allow any new technologies to be used effectively?

New healthcare technologies generally emerge from the cutting-edge medical research domain. Infrastructure that allows new technologies to be designed so that they can quickly plug into the established healthcare infrastructure e.g. compatibility standards and guidelines.
An effective training programme for the end users of the new technology.

8 What are the most likely promoters and barriers to the take up of new ICT devices and systems?

Involvement of end users of the technology in the design and development will be key to promotion and similarly a lack of involvement will be a barrier.
Effective training in place for new systems or devices will be key.

9 What education and training would need to accompany the introduction of any technologies, and who would need to be involved?

Joining together of large amounts of data (including information) will require not only an understanding of un-related disciplines but also an appreciation of how solutions in one field can be used to solve problems in another. The term multi-disciplinary training (MDT) has been coined to describe the requirements but provision of this training is not straightforward. The NCRI Informatics Initiative is reviewing and assessing the requirements of MDT in areas of our concern and wish to actively support initiatives that can effectively provide the much-needed training

10 How are professional roles and responsibilities likely to be affected by the increasing use of ICT?

The NCRI Informatics Initiative sees a change in the roles of professions and researchers and other personnel involved in the disease knowledge pathway evolve. Possibly the most important issue will be the access required to both learn new skill sets and apply present knowledge and expertise in different fields. Possibly the most apparent is the active involvement of clinicians in research and researchers in clinical processes. But this integration across allied fields will also be required to drive a change in disciplines used to favouring the status quo (either culturally or required to legally).

11 How can the development of technologies that meet patients' and informal carers' needs and are practically useable be best facilitated?

As above, involvement of patients and carers in the design and development of the technologies.

12 What are the potential impacts of the costs of any of these new technologies?

13 What are the implications of the international use of future technological developments, such as global use of health data, variability of ICT-enabled support, and interoperability?

Availability and use of data in a form that allows it to be easily integrated with other sources and types of data will increase the power of the questions that can be asked of it. This should lead to better epidemiological and public health studies and should reduce the repetition of studies either for statistical reasons or because data was not available. Global use of data should therefore be cost-effective as long as appropriate security and confidentiality procedures are in place.
Interoperability will be vital for shared international technology. A number of developments are already underway trying to address this issue e.g. in the cancer domain, the US NCI and UK NCRI are collaborating to develop an international interoperable cancer informatics platform for cancer research and care.

Are there any other important issues that have not been addressed by the questions above and that you think the working group should address?

Technological advances are exciting but ultimately limited unless they meet the needs of the user-communities. Communication between disciplines will be key to achieving this.