Email from Ewan Birney, European Bioinformatics Institute

(a) Train a lot of Doctors, and involve doctors throughout.
These are the people who will make or break this.
(b) Think more like the internet for setting standards (eg, use the IETF system for standards), and stay away from being influenced by big software providers
(c) Ensure patient confidentiality and mis-use of research data in insurance. Some of this must be in law, not self regulation in particular as these datasets are very long lived.

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

Obviously pervasive and fast network access, including on mobile devices. I think we should all work on the assumption that everyone can be (if desired) securely on-line at any time and at any location.

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?

The positive aspects will be I think mainly internal to the healthcare situation, ie, between doctors - GP to clinical to surgical and also between clinical practice and clinical research.

To patients, they will expect and make use of more access to more information. Most people are pretty sophisticated and can handle sensible information about risks so that people - for example - can read up on a disease before they come into hospital and doctors surgery. This has to be handled responsibly - and there will be cases where people demand inappropriate treatment where a doctor will have to make it clear that they are misinterpreting information, but the vast majority of people will both be reassurred and more trusting in the health service when they are able to - on demand - know more about the disease they have at the time.

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

I think it is crucial to get Doctors up to speed on these sorts of IT issues. The real sweet spot is making Doctors and hospitals more efficient and to allow good evidence based research permeate hospitals faster.

I think a well funded central NHS web site with a patient focus is also important; this is like NHSdirect but with things like forums for patient to patient discussion. I think NHSdirect is pretty good myself.

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?

Yes, this should be responsibly handled.

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

There should be careful thought to (a) who can access information and (b) insurance. However, the main thing is to allow researchers (mainly clinical) to have a broad database (perhaps of anonymised data) to work from. Effective anonymisation and legal controls to prevent circumvention of annoymisation (eg, the fact that genetic information on an anonymised sample means that if someone is genotyped they can be matched means that rather than _removing_ anonymised datasets or genetic datasets instead there should be a law against de-anonymising an anonymised dataset on the basis of a genetic test).

This needs to be carefully thought through to ensure both maximal research potential and also patient protection, and protection laws should be passed; we should not rely on self-regulation by the insurance industry for the key aspects as these datasets will be around for a long time.

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

Promoting Open datasets (where appropriate) or open to a broad set of researchers is crucial, and in addition, use of open source software development which will fundamentally shift costs down.

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

Careful creation of a sensible eco-system in the health care system; needs to be predominantly bottom-up not top down but with enough coordination to ensure it works. The model should the Internet protocols developed by the IETF, and _not_ "industry" standards usually developed to lock into a few players.

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

Inappropriate top-down thinking or over standardisation by large industrial software groups.

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

Doctors are the key here.