Cancer Innovation Challenge consultation - Innovative data science solutions for cancer data

Comments from the Royal College of Physicians of Edinburgh

The Royal College of Physicians of Edinburgh ("the College") was founded in 1681. We support and educate doctors in the hospital sector throughout the UK and the world with over 12,000 Fellows and Members in 91 countries, covering 30 medical specialties. The College welcomes the opportunity to provide views on the Cancer Innovation Challenge - *Innovative data science solutions for cancer data*.

What has been learned from other projects which have sought to analyse/access healthcare data?
Fellows have indicated to us that the main issues which have been learned from other projects include:

- The importance of quality of data (accuracy, consistent coding and interpretation), core data not recorded for a variety of reasons when looked for retrospectively and inferences made;
- Timeliness and relevance to current medical practice;
- Access (data held in different formats so difficult to merge and compare across Scotland) – information in paper case notes that may be difficult to retrieve from store or clinical use, local databases in a variety of different forms;
- IT access – not everyone has access to a mobile device or the skills to use it – some people are apprehensive about using new technology – it is vital to establish how to engage with them effectively to collect PROMS & PREMS to ensure equity.

What are the obstacles to the use by/within the NHS of clinical data? How might these barriers be overcome?
- Confidentiality – particularly for small numbers where patients may be identifiable. Concern about use outwith NHS;
- Patient consent – this is already being addressed with SPIRE initiative in primary care, however it may need a general consent for all of the NHS;
- Data management –the manpower to enter data and maintain it to a high standard;
- IT – multiple clinical databases holding local and departmental information that cannot be easily accessed/ shared/ merged – better national databases for agreed data sets;
- Lag times in data being available due to quality management;
- Data collected is often focused on HIS questions for QPIs, and it is less easy to collect data to address issues outwith these areas.

What examples are available of the quality deficits, inefficiency and waste in the current system which this proposed approach will address?
- It has been suggested it would be helpful to initially focus on areas of discrepancy in data used to inform the Chief Medical Officer's reports – *Realistic Medicine* and *Realising Realistic Medicine;*
- Evaluate outcomes of systemic anti-cancer therapies approved by SMC to see if they match data used for their approval. It is often very difficult to collect this data via current systems as they fall outwith QPIs so are not a focus of the cancer data team;

- Cancer network reports are limited in what data they can report, and they are retrospective so any practice change is slow.

What potential key benefits to patients and the NHS should be further highlighted as a priority for the call?
- Better, more equitable care across the NHS with improved outcomes for all;
- Better use of limited resources in NHS budget ;
- More informed data about how we compare with other countries in terms of outcomes.

What technological solutions or opportunities relevant to this challenge are available?
- Electronic records increasingly used – these are easier to search and can be used without affecting patient care – paper case notes are often less accessible;
- Clinician engagement in improving outcomes;
- ChemoCare (CEPAS) now used across Scotland for prescribing of systemic anti-cancer therapies – this allows data to be gathered about multiple lines of chemotherapy.

What additional specific information about the objectives of the call would promote a worthwhile outcome without stifling innovation?
- Opportunity to engage in dialogue with patients, SGHD and clinicians to identify agreed priorities for areas of data collection and analysis.

Are there any other considerations that need to be stated explicitly in the call to promote a worthwhile outcome?
- Confidentiality of data assured to ensure the confidence of all involved;
- Busy NHS staff will not have to complete more forms/ proformas/ grapple with more IT;
- Reassurance that data will not be shared with/ sold to non-governmental bodies e.g. pharmaceutical industry, insurance companies etc.
- Data is presented and shared in a transparent and meaningful way to the population so that they see value and benefit of investment even when "politically" difficult – e.g. if it means withdrawal of health services in a particular geographical area, treatment funding stopped (e.g. as has been the case with homeopathy).
- This project will deliver – other projects have failed and this engenders scepticism;
- Recognition that we are dealing with patients who have a multiplicity of reasons for the decisions that they make which may be subtle and difficult to capture – there is no one size fits all in terms of pathways/ treatment etc. when considering variance, particularly in cancer treatment.

How should the wording of the call be changed to maximise the potential for emergent impact and value?
- Data collection method needs to be adaptable enough to answer questions that may have not yet have been thought of without being overwhelmed with data points.
- Real engagement with data presentation to make it meaningful and easy to interpret, particularly by the public who have varying levels of health and numerical literacy.