



Patient and public involvement update

JULY 2017

Dear PPI panel members,

Things are a bit quiet over the summer months, but there's still plenty to update you on from the world of research!



Cancer Innovation Challenge

Last month, the Edinburgh team met up with Steph from the [Cancer Innovation Challenge](#) to hear more about the work it's doing.

The Cancer Innovation Challenge is a project which encourages Innovation Centres in Scotland to work in partnership.

The three Innovation Centres are [The Data Lab](#), the [Digital Health and Care Institute \(DHI\)](#) and [Stratified Medicine Scotland \(SMS\)](#).

The Innovation Centres aim to support 'transformational collaboration' between universities and businesses.

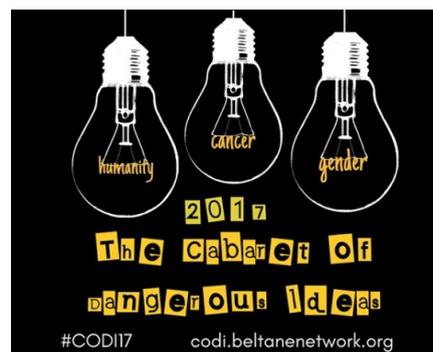
The Challenge provides funding for two main areas:

- Innovative cancer data science solutions
- New tools for cancer patient reported outcomes and experience measures

They invited Emily to write a [blog](#) for their website about our research. Hopefully we'll be able to work with them more in future.

The challenge is currently [recruiting patient/carer reviewers](#), which is an opportunity some of you may be interested in.

Finally, for those who will be in Edinburgh this August, they are running an event at the Fringe called [Dr Data: The Answer to Cancer](#).



INVOLVE standards - have your say!

INVOLVE (the national programme to support public involvement in NHS, public health and social care research) is inviting people to [respond to a consultation](#) on their draft national standards for public involvement in research.

This is a set of 6 core standards and indicators which have been developed over the past year with the aim of improving the quality and consistency of public involvement in research.

Developing standards was a commitment made in the [Going the Extra Mile](#) report into public involvement in research.



Survey about finding people to take part in medical research

A student at the University of Edinburgh, Adam Wilson, is working on a proposal for a new way to recruit patients to take part in studies. He is currently looking for people to respond to a survey about the proposal.

For more information, and to complete the survey (it should only take about 5 minutes), [see here](#). If you'd like to know more, you can get in touch with Adam directly: adam.wilson@ed.ac.uk.

Presentation to lung cancer support group in Leeds

Julia and Choon Key attended a lung cancer support group in Leeds today to chat about our research. They gave a short presentation and handed out information about the project and about participating in the research.

There was a good discussion afterwards - group members asked about the ethics of bio banking tissue for research generally, and specifically for large scale studies such as the 100,000 genomes project. There was a brief debate about why consent to archive tissue is necessary and important.

The group were interested in targeted treatments and had recently had a speaker who presented targeted treatments as increasingly important compared to traditional 'blanket approach' ways of managing cancer, such as surgery.

They also discussed the role of the environment in relation to cancer development and growth as well as where the environment sits with respect to genomics; they felt that there needs to be more of an emphasis on the role of the environment as well as molecular changes.

The group was keen to hear more about the research so we'll keep them updated, and go back to present the findings at a future date.

Learning opportunity – Cancer and the Genomic Revolution

Earlier this year, we mentioned a free online course run by the University of Glasgow which examined three key questions about cancer diagnosis and treatment: Where have we come from? Where are we now? And where are we going? It looked at the biological basis of cancer, influences on causation, how it is detected and treated, and the development of new treatment strategies. All very relevant to this project!

This course is being run again, starting on the 18th of September and running for 6 weeks. If you're interested, you can [sign up here](#).

Keep in touch

Don't forget to check out our website at www.cancerandsociety.ac.uk.

The website has more information about the research team and some blogs about what we've been doing so far.

Let us know if there's anything else you'd like to see on the website or in these newsletters by emailing cas21c@ed.ac.uk or cas21c@leeds.ac.uk.

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