



# Patient and public involvement update

SEPTEMBER 2017

Dear PPI panel members,

Hopefully you have all had a restful summer. Things have started to get busy in Edinburgh and Leeds universities with the start of the new academic year, and we've also been busy on the project, with lots of conference presentations in exciting locations. Read on to hear more about those, and also about two conferences that *you* can get involved in...



## Cancer in the 21<sup>st</sup> Century - Boston

In August, Sarah, Anne and Tineke were in Boston for a sociology conference. We organised a session on some of the changes in cancer research, treatment, and the experience of those affected by cancer. Sociologists from the UK, France and Canada contributed to the session.



Anne gave a presentation entitled *From big C to little c's*, in which she discussed the molecular stratification of cancer (the way cancer subtypes are diagnosed based on their molecular makeup) and the consequences of this, in particular for those affected by cancer.

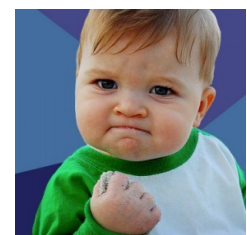
Anne used some of the interviews we've been doing in Leeds and Edinburgh. She talked about the ways in which people affected by cancer are actively trying to get into trials, sometimes as a way of taking control or as a way of giving back to the medical profession and to people who've gone on trials before them.

The other presenters covered a range of interesting topics. One focused on 'molecular tumour boards', which are meetings where clinicians caring for patients with cancer meet to discuss specific patients and advise one another on the best treatment plans.

Another talked about breast cancer becoming more of a chronic disease in some ways, and another focussed on the medicalisation of advanced cancer in the search for a cure or a prolonging of life. If you want to know more about any of these topics, please just get in touch.



In the discussion after all of the presentations, we talked about the extent to which these developments can be considered 'new'. We ran out of time before we ran out of questions and the room was full, so we think the session can be considered a success!





### Emily and Julia in Athens

While half the team were in Boston, Julia and Emily were at the European Sociological Association conference in beautiful Athens.

Julia presented some research that they are both working on, looking at women's experiences of the Oncotype DX test. This test looks at the activity of genes in tumour tissue, to predict the likelihood of cancer recurrence in some types of early stage breast cancer.

Julia talked about women's descriptions of the Oncotype DX test, and experiences of treatment decision making, accessed from online forum posts.



She gave an excellent presentation, and we received interesting questions from the audience, including how experiences might compare to other types of tests, such as cholesterol testing or PSA testing for prostate cancer.

The conference allowed us to hear about research projects from all over Europe, and we heard about research looking at genetic risk prediction for cardiovascular disease, and also about how the term 'trust' is used in the context of using patient data.

Julia and Emily also got to see some of the sights in Athens, including the *Acropolis* (which had very long queues!) and, as a little reminder of Scotland, *Hadrian's Arch*. They were very grateful to have attended this conference, and pleased to be able to share our research with international academics.

### Upcoming conferences - do you want to be involved?

The Edinburgh team are hoping to have a stand at the [Scottish Cancer Conference 2017](#), which will be on Monday 20<sup>th</sup> November in Edinburgh. This will be a chance to tell people about the research, hear people's views, and let people know how they can participate. This is yet to be confirmed, but we will hopefully have spaces for one or two panel members to attend with Emma or Emily, so if you're interested let us know and we'll keep you posted.



The Leeds team will have a stand at the [Life with Cancer 2017](#) event, which will be on Thursday 16 November 2017 at Harrogate Convention Centre. We will introduce our project and recruit research participants. We would love to have a couple of panel members at this event with Julia and Choon Key.

### Please let us know if you are interested in joining us for either of these events.

We will organise an induction session before each one to make sure you know a bit more about the project and feel confident to talk about it.

### Genomics: Transforming Healthcare/Improving Patient Care & Outcomes

Wednesday 27th September 2017, Studio Venues, Leeds

The Yorkshire and Humber NHS Genomic Medicine Centre hosts a free educational event for both healthcare professionals and interested members of public to explore the impact of genomics on patient care, diagnosis and treatment. [See here for more information and registration](#). There were still spaces last time we checked!

### Learning opportunity – Cancer and the Genomic Revolution

Just another reminder that the free online course 'Cancer and the Genomic Revolution', run by the University of Glasgow, starts **today** and will run for 6 weeks. It will examine three key questions about cancer diagnosis and treatment: Where have we come from? Where are we now? And where are we going? It looks at the biological basis of cancer, influences on causation, how it is detected and treated, and the development of new treatment strategies. It is likely to be very helpful to anyone who would like to gain a better understanding of some of the issues this project aims to address. 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](http://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](mailto:cas21c@ed.ac.uk) or [cas21c@leeds.ac.uk](mailto:cas21c@leeds.ac.uk).

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