



Cancer and Society

in the 21st century

Patient and public involvement panel update

JULY 2016

Dear PPI Panel members,

We hope this finds you well. It has been a busy month on the project with lots going on in both Edinburgh and Leeds!

Scoping interviews have started in Leeds and are about to start in Edinburgh, which is an exciting step. We plan to interview people with experience of cancer, as well as members of the general public, and we may ask the panel to help us to recruit people to interview.

In Edinburgh, we've also been busy organising a debate which you are all invited to attend (see details in the box below).



Our debate won't include this guy...

Information about the research process

Thank you for the suggestion from panel member Penny that it would be useful to have an overview of the research process, highlighting where there will be opportunities for involvement at various stages. This is now available here:



Research process and PPI involvement

We'd welcome feedback on this and suggestions of other information you would like to see, just get in touch: cas21c@ed.ac.uk or 0131 650 3233.

There are also links at the bottom of this newsletter to some sources of further information about genes and genomics. We'll continue to share information like this as we come across it.



Thinking about ethical issues

We are planning to hold a focus group session with PPI panel members in early August about the ethical issues that need to be considered in our research.

More information will follow in next month's newsletter, but if you're interested in this the debate next week should help to get ideas flowing and raise some issues for us to discuss further!

Genomics debate:

Who owns my genome? Debating public and private uses of genetic data

We are holding a public debate about the implications of genomic medicine for privacy and the NHS.

The debate will take place next Thursday 7th July from 18.30-20.30 in the University of Edinburgh Medical School and you are all welcome to attend.

The discussion will hopefully be a useful introduction to some of the ethical issues around genomics, which will be especially helpful to those of you who would like to be involved in our ethics focus group later in the summer.

If you would like to attend the debate, please sign up via the link below:

<https://www.eventbrite.co.uk/e/future-debates-who-owns-my-genome-debating-public-and-private-uses-of-genetic-data-tickets-25570821014>

Please also email or phone us to let us know that you're planning to attend and if you need us to arrange travel for you. This is a public debate so family and friends are welcome to come along, but we can only cover expenses for panel members.

FURTHER INFORMATION ...

The Sanger Institute has [videos on a whole range of topics about genes and genomics](#), including some specifically about cancer. The same website also has lots of helpful [factsheets](#).

You might enjoy this [Guardian article from 2013](#) which is a really accessible introduction to what genomics might mean for individuals and for healthcare, from the perspective of a journalist who had her own genome sequenced.

Website

In case you haven't seen our website yet, you can find it 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!

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