



# Patient and public involvement panel update

AUGUST 2016

Dear PPI Panel members,

We hope you're enjoying the summer!

This update brings you information about what we've been up to over the month of July and what's coming up next for the project.



## Who owns my genome?

On the 7<sup>th</sup> of July we held a public debate in Edinburgh, in collaboration with the British Science Association (BSA), called 'Who owns my genome? Debating public and private uses of genetic data'.

The event was attended by around 50 people from all sorts of backgrounds including scientists, academics and interested members of the public.

We started with an introduction to DNA from **John Bradshaw**, chair of the local branch of the BSA. John also showed this [short video](#). Then there were talks by three panellists from the University of Edinburgh.

**Catherine Heeney**, from the School of Social and Political Science, described some of the ways in which genomic data may be used, and how it might be stored and accessed.

**Sarah Chan**, from the Usher Institute, argued that we have a moral responsibility to provide genomic data for research, which, she contended, is not only a moral duty but also in our own interest.

**Claudia Pagliari** from the Centre for Medical Informatics talked about some of the controversies surrounding the use of genomic data including possibilities for data exploitation and the potential dangers of the blurring boundaries between companies, clinicians and scientists.

After the presentations, the audience was invited to put forward questions and reflections. This led to a lively discussion which covered three broad themes: consenting to the use of data; issues of commercialisation; and social benefits and inequalities.



We're planning to do a blog post about the event for our website so we'll let you know when that's available.

## The research process

A couple of people have told us that they missed the research process diagram that was in last month's newsletter. In case you haven't seen it, it's now on our website [here](#).

## 'Your Choice' Edinburgh Fringe event from Cancer Out Loud and CRUK

What will you choose to do about cancer? Join us for an inspiring hour of interactive games and verbatim theatre taking you on the journeys of patients, clinicians and researchers involved in cancer clinical trials.

If you're in Edinburgh this week, Cancer Out Loud and Cancer Research UK have an event at the Edinburgh Fringe each day until the 13<sup>th</sup> of August:

<https://tickets.edfringe.com/whats-on/your-choice>

### Project Advisory Group

On the 14<sup>th</sup> of July we had a meeting of our Project Advisory Group in Leeds. This group includes a number of advisors from a range of different academic, clinical and scientific backgrounds who help to steer our research. Patients and the public are represented on the Project Advisory Group by Derek Stewart who is part of the Leeds PPI panel.

The research team updated the Advisory Group on what has been happening with the project so far. The Group was able to help us with some questions we had about genomics and cancer research because of their varied experience. Derek is going to write an update from his perspective for a future newsletter.



Derek Stewart

### INTERESTED IN GENOME RESEARCH?

Here's an old but interesting article from 2007 that explains the early use of genome research to identify breast cancer genes: <http://www.cancerresearchuk.org/about-us/cancer-news/press-release/2007-05-27-scientists-home-in-on-new-breast-cancer-genes-in-groundbreaking-study>