



Patient and public involvement update

MAY 2017

Dear PPI panel members,

The whole team has been quite busy recently and so there has been a bit of a newsletter gap, but we were delighted to see many of you in person at the recent meetings in Edinburgh and Leeds. More about those on the next page...



New blog post

Alasdair has written a blog for the project website about his experience of being on the panel. It will be [on the website](#) in the next day or so.

If any of you have thoughts on Alasdair's blog, or would like to write one of your own, please let us know. A couple of people have already said they are interested, so watch this space for more!



Project Advisory Group

On the 3rd of April we had another meeting of our Project Advisory Group, this time in Edinburgh. This is a group of people from a range of academic, clinical and scientific backgrounds who help to steer our research. The PPI panel was represented at the meeting by Alasdair Ferguson.

The team updated the Advisory Group on how the project is going and gave presentations about the work so far. We had a good discussion about some of the challenges the research is exploring, such as the line between research and care, and how confusing that can sometimes be for patients (and clinicians!).

We also talked about the impact of patient advocacy groups on what type of research gets done and which types of cancer are researched.



Emma and Tineke at the Usher Institute showcase

Spreading the word about the 'Cancer and Society' project

In May, we had information stands at the International Clinical Trials day in St James' Hospital, Leeds and at the Usher Institute showcase in Edinburgh.

These were both good opportunities to talk to people about the project and hand out some leaflets.

The Leeds team spoke to patients and their relatives, while the Edinburgh team made links with other researchers and policy-makers.



Panel meetings

The Leeds panel had their first meeting on the 21st of March. The group discussed the 3 trials that are being followed in Leeds including the [100,000 genomes project](#). Panel members were also able to advise the research team about ways to recruit research participants, including attending support groups, and using social media and local media.

The Edinburgh panel had a meeting on the 8th of May where we discussed the interviews that have been done so far. The group learned a bit about how social scientists analyse qualitative data and had a go at reading some interview extracts analytically. This was really useful as the panel members looked at the data from a very different perspective to the one we have as researchers and highlighted different issues as being important – everyone learned something new!

Patient Involvement Fair

Emily went to the Asthma UK patient involvement fair in March and had an interesting day hearing from patients about why they get involved in research and what they get out of involvement.

She also heard from researchers about the added value PPI brings to their work and picked up some tips on things like writing for a lay audience and using social media to involve a broad range of people.



Useful reading...

This [article on technology website CNET](#) is a nice introduction to the concept of personalised medicine and some of the exciting scientific developments that are happening.

Researchers in Australia have become the first to [map the entire prostate cancer genome](#).

The Guardian [reported on a study](#) about the potential to use platelets, a component of blood, to diagnose cancer, but Cancer Research UK argue that the study was 'overhyped' and that [the link is not so clear cut](#). This raises interesting questions about how the media report on scientific developments – is there danger in raising expectations about new tests and treatments before the evidence is good enough? Tell us your thoughts for the next edition of the newsletter!

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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