



# Cancer and Society

in the 21<sup>st</sup> century



## Patient and public involvement update

DECEMBER 2017



### Dear PPI panel members,

This is the final newsletter of 2017 and we hope it has been a good year for you. We'd like to wish you all a peaceful Christmas and New Year and to thank you for all of your input to the project this year. All of your work is very much appreciated.

We look forward to continuing to work with you all in 2018!

Here's a round-up of what's been going on this month...



### Scottish Parliament Pancreatic Cancer Event

Emily attended an event at the Scottish Parliament for Pancreatic Cancer Awareness month. She heard more about pancreatic cancer from clinicians and charity workers, but also from those with first-hand experience of the disease as loved ones or carers.

Campaigners are working to increase awareness of pancreatic cancer, which has a 5 year survival rate of 5%. More research is needed, because prognosis and treatments have not improved significantly over the last 40 years.

As part of our project we will be conducting interviews with patients taking part in the *Precision Panc* study. This is research inviting pancreatic cancer patients to participate in a study analysing molecular and genetic changes in tumour tissue. [You can read more about the \*Precision Panc\* study here.](#)

At the event, Emily met clinicians involved in treating the disease, researchers, and those affected by the condition, either as a patient or family member. Attendees were very positive about our research, and Emily hopes to conduct some interviews with some of them over the next few months. She will be asking for feedback from the PPI panel about the planned interviews and priorities for this part of the research, so stay tuned!



### New on the blog

Julia and Choon Key attended the Life with Cancer 2017 event in Harrogate and have written about it on the [Cancer and Society Blog](#) – check out our website to read all about it.





### PPI panel meeting in Leeds

The Leeds panel had a meeting to look at some preliminary data and how we analyse it, in the same way the Edinburgh panel did earlier this year. Choon Key and Julia gave a short presentation about our data collection and data analysis strategies and introduced 3 case studies. The group were interested in how non-verbal cues such as body language are taken into account, and Anne explained how we use things like observation notes to add context.

The group looked at 4 examples of data and there was a lively discussion about them. The first was from an interview with an ovarian cancer patient who participated in a molecular profiling trial – the panel picked up a number of threads to discuss such as ‘grey areas’ in clinical decision-making and issues around the patient’s sample being sent overseas. It was interesting that, while some medical experts are cautious about cross-national transfer of specimens, some patients regard it as ‘cutting edge’.

The second excerpt was from an interview with someone whose wife had participated in a molecular profiling trial. The panel picked up ‘hope’ as a keyword in this example and discussed how couples work together in their therapeutic journey, and the difference for single patients dealing with their illness alone. The third excerpt was from an interview with two sisters whose elderly father has consented to the 100,000 genomes project. ‘Hope’ was a key theme again, and there was also discussion about what is ‘informed’ consent when patients make a decision based on their family members’ wishes. The last excerpt was from an interview with an oncologist specialising in lung cancer. The group discussed the sense of self-blame amongst patients in lung and pancreatic cancer in particular, and also how to go about providing proper support and education for patients who have other serious issues such as homelessness and alcoholism.

The panel members who attended gave us very positive feedback about this exercise, and the team also found it very useful, so thank you to those who participated!

### Scottish Cancer Conference

Emma and Emily attended the Scottish Cancer Conference where we had a stall in the exhibition area. Lots of people approached us over the course of the day to hear more about the research and tell us their thoughts about some of the research questions. It was also an opportunity to make links with some other organisations who may potentially help with recruiting interview participants in future.

During the afternoon, there was a session on the impact of inequalities on cancer outcomes. We heard from the panel about the importance of addressing poverty and the environments people live in, though many questions from the audience focussed on individual behaviour and the choices people make. The key message was – we need to use all the tools we have to reduce poverty, improve people’s opportunities to live healthily, and educate people about prevention, screening and early detection. There’s no simple answer!



Emily and Emma at the Scottish Cancer Conference



## Our new film: the implications of genomic medicine for cancer patients

As part of the project, the team in Leeds have been researching the development of the Genomics Medicine Centre and the 100,000 Genomes Project in Yorkshire and the Humber. We have produced a short film, starring our very own Anne, to explore the opportunities and challenges of these initiatives with some of the key people involved. It's available on our website:

<http://www.cancerandsociety.ac.uk/film/>

We'd love to hear what you think about the film, and also if you'd be interested in exploring opportunities to make further films with more involvement from PPI panel members?



### Genome screening: a Pandora's box?

This house believes the UK should have whole genome screening

7pm, Tuesday 14 November



### Sarah at the Edinburgh Medical Debate

Sarah spoke at the Edinburgh Medical Debate on 14th November. She, along with colleague Professor Graeme Laurie, successfully argued against the motion: "This house believes that the UK population should have whole genome screening"

Although accepting that whole genome sequencing has a role to play in health care, especially in diagnosing disease and deciding treatments, Sarah noted that the key criteria for a successful screening programme would not be met by such a population wide approach – most particularly that we do not yet have enough knowledge about the meaning of such tests and therefore what should be done based on the results.

For Sarah, speaking in a debate format took her quite outside her comfort zone, but she enjoyed the experience and there was excellent discussion after each talk with the audience really engaged with the issues. Emily was there in the audience and covered the debate on Twitter, and [the recording is also available if you'd like to watch it.](#)



### And finally... goodbye from Emma

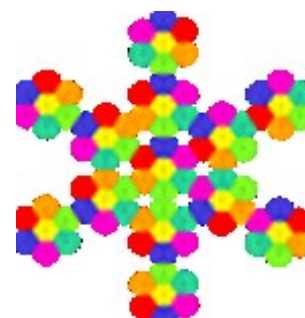
After two years on the project setting up and working with the PPI panel, and writing (semi!) regular newsletters, I'm finishing up work with the team at the end of December.



It has been wonderful meeting and getting to know so many of you, and thank you so much for all of your input to the project so far.

Emily and Tineke will continue to be the main points of contact for those of you based in Scotland, and I'll still be in touch so I look forward to hearing how the project continues and what you all get involved in.

*Best wishes, Emma x*



**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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