



# Patient and public involvement update

SPRING 2018

## Dear PPI panel members,

Many thanks for your ongoing support for our research. We can't believe how quickly the time is flying by. We are still very involved in data collection, analysis and writing and are looking forward to meeting with you again during 2018.

## What we've been up to

We have designed an exciting research programme across different aspects of patienthood and cancer. We have thought a lot about on-line research, using the really interesting stories that people blog about as well as other forms of information on social media. We have also conducted many interviews and observations, with patients, family members, health care professionals and scientists.

We have paid close attention to different types of clinical research as well as looked at new tests that may be offered to some cancer patients.

## We are in print!

We wrote an article that reviewed much of the research about cancer that has been done by sociologists. At last this is in print: 'The Sociology of Cancer' has been published by the Sociology of Health and Illness, one of the prestigious academic journals in our field. This article reviews sociological analyses of a diversity of patient and practitioner experiences and accounts of cancer during the last decade (2007-17). This is an open access article, which means it is free to read and you can download the full text here:

<https://t.co/WH8eXoOXSM>

## And we keep on writing:

A number of academic papers are in the pipeline:

- ❖ An analysis of personal blogs on hereditary colorectal cancer syndromes.
- ❖ An analysis of the Cancer Research UK's 'Science Blog'.
- ❖ An analysis of online forum discussions of Oncotype DX.

We are writing short summaries of each of our papers and will put these on our website. Do watch out for these. We can also send them to you directly if you wish.

We are also planning a book that brings all the research we are doing together.



### Ethics amendments approved

Thanks to our PPI panels' helpful feedback, the Leeds team now has its University ethics amendments approved. This means now we can conduct two new case studies.

The first case study will be looking at private cancer care experiences by conducting interviews and observations in order to compare and contrast their experience with people who receive NHS health care.

The second case study will be looking at the experience of crowdfunding for new genomic tests or treatments. This is when people may raise funds on line through donations. We have noticed this happening more and more and think it is a very important issue to investigate.



### Ongoing Film Project

This year, in collaboration with both our PPI panels, we will create a new film focusing on patients' and family members' experiences of genomic cancer medicine.

You can still watch first film ***The Implications of Genomic Medicine for Cancer Patients: Opportunities & Challenges***

<https://www.youtube.com/watch?v=LUQr3hpYJ4U>

## Reaching out .....

### NICE Meeting Discussing the Future Tumour Profiling Tests

In March, Emily Ross attended a meeting held by the National Institute for Health and Care Excellence (NICE) as a public observer. The Committee was discussing potential changes to existing guidance around the use of tumour profiling tests in early-stage breast cancer. These tests are used to help clinicians and patients make decisions about chemotherapy following surgery. Over the last two years NICE have been re-assessing the clinical and cost-effectiveness of these tests. At the meeting the NICE Committee considered feedback from the public and interested parties on their initial findings. In total there were 255 comments from 92 representatives or organisations, with these coming from individuals, breast cancer charities and the companies who make these tests.

Emily reflected that it was very interesting to hear the debates around tumour profiling tests, including their cost and long-term impact. It was very encouraging to see how much consideration was given to public and stakeholder comments on this issue, with each taken seriously and many discussed at length. There were three patient representatives on the committee too, with one emphasising how important and emotional this issue is. Emily and the other public attendees were only allowed to be there for the first part of the meeting. The outcome of the meeting, and implications for the use of tumour profiling tests within the NHS, is expected in June 2018. Emily also made contact with other public observers, with whom she was able to share information about our research. If you want to find out more about attending NICE meetings as a public observer, here is the website: <https://www.nice.org.uk/get-involved/meetings-in-public>

## Yorkshire & Humber Genomic Medicine Centre Outreach Event

In Leeds, Choon Key attended a special public event organised by the Yorkshire & Humber Genomic Medicine Centre (Y&H GMC) in order to raise awareness about cancer genomics among the black, Asian and minority ethnic (BAME) communities. Debbie Beirne (St James's Hospital) gave a presentation on cancer genomics and the 100,000 Genomes Project. This was followed by lively discussion about data security issues and how the BAME communities could benefit from a project like this, especially given the high cancer incidence and mortality rates within these communities. In order to involve the BAME communities further, the Y&H GMC announced that they will produce a 20 minute theatre piece as an innovative way of engagement. This theatre piece will draw on the culturally specific hopes and concerns about genomic cancer medicine that were expressed in this, and subsequent meetings.



## Edinburgh International Science Festival - 2018

Sarah Cunningham-Burley was delighted to be asked to participate in an evening of presentations and debate on the theme 'Realistic Medicine, Data and Me' as part of the Edinburgh International Science Festival on 11<sup>th</sup> April 2018 at the National Museum of Scotland. The event was organised by Cancer Innovation Challenge and chaired by Dr Brian Robson of Healthcare Improvement Scotland. Scotland's Chief Medical Officer, Dr Catherine Calderwood, talked about her goal of creating and delivering 'Realistic Medicine' which puts the person receiving care at the



heart of decision making and creates a personalised approach. Much of this depends on using best possible evidence and the event therefore also heard from Gillian Docherty from The Data Lab and Ian Welsh from the Health and Social Care Alliance Scotland. Sarah focussed particularly on the social and ethical challenges of data driven innovation, particularly for preventing and treating cancer, thinking about this from the perspective of society as a whole, the NHS and then for individual patients. The questions from the audience stimulated a great discussion about these issues which affect us all.

Image by Douglas Robertson for the 'Cancer Innovation Challenge'

### 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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