

Dear PPI panel members,

We hope you are enjoying 2019 so far, and looking forward to the year ahead. We are pleased to be sharing our news from the project, particularly as we have some new research sites that we are working in. Thank you for your continued interest and involvement in the research!

What we've been up to

Since our last newsletter, we have been continuing our fieldwork in Leeds and Edinburgh. The Leeds team have been investigating crowdfunding for targeted therapies. We have also been continuing work on our case studies, which include observations and interviews with those experiencing ovarian, lung and breast cancer. We have begun interviews in Glasgow with pancreatic cancer patients taking part in a new research project called 'PrecisionPanc'. This is a UK-wide programme of research supported by Cancer Research UK, and we are pleased to be able to speak to patients who are involved. We have also been working to make a video based on patient experiences of involvement in genomic medicine, and have been busy writing chapters for our book!

A warm welcome to our new team member!

In October the Edinburgh team was joined by Sue Chowdhry. We asked her to write a short introduction and this is what she said.....

I'm really excited to have joined the Edinburgh team and I'm looking forward to being involved in this research. I'm going to be doing fieldwork with people affected by ovarian and lung cancer. I'm really looking forward to meeting the panel. My background is in nursing and I'm a trained counsellor. I've always been interested in research, especially research about experiences of health, illness and research from practitioners' perspectives. I'm interested in how the notion of risk shapes people's experience of their bodies and how risk is managed in the context of healthcare.



My previous research includes a narrative study exploring pregnant women and maternal healthcare professionals experience of high-risk pregnancies. I've also been involved in research investigating patient and healthcare practitioner experience of clinical research trials. My ambition is to develop engaging and creative ways of sharing and discussing research findings through storytelling, photography and performance.

Getting our findings out there

We were delighted to be asked to provide a session at the annual National Cancer Research Institute conference which took place in Glasgow in November 2019. Sarah chaired the discussion and Anne presented an excellent paper which explored how knowledge and understanding of genomics relates to experiences of care, dealing with issues around what kinds of information are helpful in what contexts. Our findings challenge the view that everyone needs to 'understand more' about genomics and health, and rather focusses on what patients need in order to experience research and care in positive ways. Two colleagues, Rikke Sand Andersen, from Aarhus University in Denmark and Sophie Day, from Imperial College London also presented papers on their anthropological research on cancer. We loved being back in Glasgow – for Anne it was a welcome return to her home area and Sarah used to live and work there too.

Book

Everyone is working hard on writing chapters for the book that will bring together everything we have learnt from the research we have done. Although this will be an academic text, we are very keen to write this in a way that a wider audience interested in cancer and cancer research today will find interesting. We especially want to make sure that the patient stories and experiences that we have heard about as well as analysed are not lost in 'academic-speak'. We'd love to hear your ideas about how best to do this. We have thought about starting each chapter with a quote from something a research participant has said to us and about including short 'patient stories' as part of some chapters.

Sharing our research with patient and public involvement members



Julia and Choon Key attended the Yorkshire and Humber Genomic Medicine Centre PPI meeting in November to present some of the findings from the research carried out with patients and practitioners involved in the 100,000 Genomes Project. During our research we have been interested in what it means for patients to consent to participate in 100,000 genomes, and what this can tell us about patient understandings of genomics, and about patients' reasons for participating in research. From our research, we have found 3 key ways in which the consent process was experienced by patients, beyond simply representing that they understood what the research was about. Patients also understood consent and participation in the research as:

- Seeking care
- A way to demonstrate competency, and represent themselves as engaged patients
- A way to reciprocate care they themselves had received

The findings were well received by both panel members and practitioners who attended the meeting.

Presentation:

On the 28th November 2018 Sarah and Emily presented our research at an event aimed at clinicians and other medical professionals working in breast cancer, hosted by the North of Scotland Cancer Network (NOSCAN). We had been invited to present by a breast oncologist and network member, who was keen that the patient perspective be represented during the day.

There were a wide variety of speakers and topics at the event, which was held at the Dewars Centre in Perth. We heard from a molecular epidemiologist who talked us through breast cancer sub-types, and also heard about patient involvement in the development of a clinical study group. It was also very interesting to hear about some research that nurses have been conducting at the Beatson Cancer Centre in Glasgow, which aimed to find out how best to protect women's nails during chemotherapy treatment.

Sarah and Emily gave a presentation about our work on patients' experiences of the *Oncotype DX* test in early stage breast cancer. We described how 14 women we have interviewed talked about being diagnosed with breast cancer, and how they discussed being offered the choice to have chemotherapy following their surgery. Sarah and I then described women's reflections on the *Oncotype DX* test, which is a genomic test offered to women to help guide decisions about chemotherapy. Many women welcomed this technique, as they said that this helped them make treatment choices, but they also pointed to inherent uncertainties regarding cancer's return.

Our presentation was well received by the audience, and we were asked lots of questions particularly by cancer clinicians. These included a question about how clinicians can tell what patient preferences are, and one about how patients understood how the *Oncotype DX* test functioned. After our talk we were also approached by a representative from the US company that makes the test, *Genomic Health*, who said she was very interested in the presentation.

It was an honour to be invited to present our research at this event, and we were very pleased that we were able to discuss patient experiences with the audience. If you would like to find out more about our research on *Oncotype DX*, please get in touch! We have also published an article about this topic in the journal *Health Expectations*, and you can read a summary [here](#).

Sarah had a wonderful opportunity to focus on analysis and writing in the delightful surroundings of Lake Como as she was awarded a prestigious academic residency by the Rockefeller Foundation. As Sarah has been a Dean in the University of Edinburgh for the past six years, this month away provided much needed time to reflect and to talk about our research with a wide range of other residents – including a choreographer, poet, storyteller as well as other academics. Needless to say, she learnt a lot!



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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