



Patient and public involvement update

SUMMER 2018

Dear PPI panel members,

We hope you enjoyed the lovely summer weather! As always, we appreciate your interest and involvement and we want to update you on our latest work.

What we've been up to

Since our last newsletter, we have been continuing our fieldwork in Leeds and Edinburgh. We have been working on our case studies, which include observations and interviews with those experiencing lung, ovarian, pancreatic and breast cancer. We have been interviewing clinicians and pathologists too.

We have been working on academic publications, and presented at several conferences - including one in Italy!

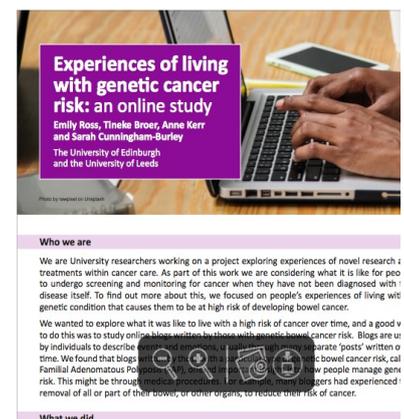
We are in print!

We have published an article based on some online research we did last year, looking at online blogs written by those living with a genetic condition that raises the risk of colorectal cancer. We studied blogs written by eight people living with this condition, and developed three topics that we felt best captured the key issues discussed by the eight bloggers: identity, community and care. We found that the eight authors used the blogs as a way to connect with other people experiencing their condition, but also with those who had received similar operations or other medical tests. The blogs allowed their authors to express emotions about their condition, including histories of family cancer, and care for themselves and others.

We have produced a summary of the research, and you can access it on the 'Publications' section of our website.

This is an open access article, which means it is free to read and you can download the full text here:

<https://www.tandfonline.com/doi/full/10.1080/14636778.2018.1469974>



Conference presentations

In June, Anne and Julia attended a workshop titled 'Crafting values in cancer care' at University College London. Julia gave a presentation co-authored with Anne and Choon Key titled 'Enacting values in a clinical trial for cancer'. Julia discussed how a complex lung cancer trial is practised as part of everyday patient care. She talked about the ways in which practitioners, particularly research nurses and clinical trials assistants, deal with the difficulties recruiting patients to the trial, as well as looking at how they manage patients' hopes and expectations as part of their care. In the second half of the workshop, Anne gave a presentation as part of a session discussing the opportunities and challenges of carrying out social science research in cancer care. Julia also gave this presentation at the European Association for the Social Studies of Science conference in Lancaster in July.

Julia attended a two day workshop at Monash University, Prato called 'Making Biofutures: Anticipating the futures of biomedicine, healthcare, and life itself' in June. She gave a presentation titled 'Molecular futures'. Julia used interviews from two of the case studies that we've been working on in Leeds and Edinburgh to discuss how molecular techniques such as diagnosis and treatment decision-aids in cancer might generate uncertainties and disrupt cancer pathways and experiences of time. These presentations form the basis of academic papers but we will also be writing lay summaries of the key findings for clinical teams and patients.

Book

We are pleased to announce that we have signed a contract with Manchester University Press to publish a book based on our research. The book will be called 'Personalised Cancer Medicine: A sociological study', and is due to be published in October 2020. A special thanks to Anne who negotiated this on behalf of the team.

The book will draw on all the research conducted during our project to explore how cancer research and care is changing as new technologies such as genomics take shape. We are particularly interested to examine what this means for personalised care and how patients and others affected by cancer or cancer risk experience these changes.

We will write chapters on topics including patient and family members experiences of clinical trials, shared decision making around risk of cancer recurrence and how healthcare professionals are engaged in novel forms of research and care in cancer. The 14 chapters will be written by different combinations of the research team. While the book is aimed at an academic audience, we really want to make sure it is clearly written and accessible.

We would be very keen to get your input in different ways – for example by reading our draft chapters and providing comments – and by contributing to a Foreword to the book. If you would like to find out more, or want to have input in other ways, please get in touch!



Access to cancer drugs

Choon Key and Tineke are currently working on an article about access to cancer drugs. This is a topic which comes up often in the media. For example, we see stories of people not able to access a certain drug, and people fundraising to pay for drugs themselves (and/or to go overseas). With advances in genomics, more (and more targeted) drugs are becoming available, although these aren't always approved for use in the NHS. Moreover, whether in clinical trials or not, not all patients are considered eligible for these drugs, based for instance on the genomic profile of their tumours or other health related factors. This makes access to drugs potentially an even more pressing issue in the present era. For our article, we are looking what patients and family members are saying, to examine how they talk about access to drugs. We consider the different things they are doing to try to access new or experimental drugs. Some patients and family members argue that they have to be very proactive in order to be able to access drugs, and that health care professionals are not always sympathetic regarding access. We also look at the emotions involved in accessing drugs: either of not being able to access new drugs, or if they are successful, feeling 'guilty' that not all patients are able to get this particular drug.

Focus group research

As a project team, we have been keen to ensure that a wide range of voices are involved in our project on experiences of cancer. This includes those who are sometimes not heard from in research, due to issues including access or exclusion. As a team we have been developing an ethical approval application to conduct **focus group research** with particular groups of people, including ethnic minority communities and those living in rural or deprived areas. We want to access these voices and ensure their experiences are heard in our research. We also want to talk with people in a range of cancer support groups. Unlike interviews, which generally involve one participant and a researcher, focus groups involve several participants. As the participants interact with each other, the data created are more spontaneous than we might obtain during a one-to-one interview.

We are hoping that some of our PPI panel members might like to assist in the organisation or even facilitation of some focus groups, where we be exploring issues around cancer screening, perceptions of cancer in society, and more. We will provide an introduction to focus groups and how to run these, to those who would like to help facilitate. In the next few weeks we will be emailing our members with more information. If you have any questions in the meantime please do feel free to get in touch.

Tineke leaving the project

Tineke Broer, one of the Research Fellows in Edinburgh, will sadly be leaving us, but this is to take up a job in Tilburg, the Netherlands. Congratulations! Tineke will still be involved in writing up some of the publications and in the book project. Thank you Tineke for everything you have done while working with us and we look forward to staying in touch.

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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