



# Patient and public involvement update

NOVEMBER 2019

## Dear PPI panel members,

As the year draws to a close we are pleased to bring you the latest news about the Project and share with you our progress in 2019.

## What we've been up to

Since our last newsletter, we have been finalising fieldwork in Leeds, setting up new fieldwork in Edinburgh, disseminating our project findings, and working on public engagement activities. We have secured an extension to the project and so we will be carrying out further fieldwork in Edinburgh and continuing with dissemination until December 2020.

We've also been busy finalising the chapters for the book and we have sent the first draft to the publisher. We are waiting for comments from reviewers.

## Fieldwork round up

### Leeds data

In Leeds (2016-2018), we carried out 157 interviews with clinical and laboratory staff, patient advocates and people affected by cancer. This included interviews with patients and family members across five main case studies where we explored a range of genomic based tests, studies and trials in NHS settings and private healthcare. We also carried out 57 observations in clinics, laboratories and at public events and a further set of observations across online platforms including cancer charity forums, Twitter, blogs and Facebook pages.

## Fieldwork round up

### Edinburgh Data

We will be continuing data collection in Edinburgh through 2020, and have already conducted 88 interviews with patients, those affected by cancer, patient representatives, family members, health care staff and scientists. This includes four main case studies. We have also trained two Masters' students in qualitative research methods both of whom conducted research that linked with our overall programme. We have also observed many events and discussed the research with others in less formal settings. We have conducted two internet research studies, focussing on patient blogs and discussions.



## Workshops, Meetings and Conferences



The team has presented at a number of conferences and meetings over the past year, including:

Anne and Julia presented at the Genomics England Ethics Advisory Committee meeting in London, discussing how patient participation in research provides a means to 'live with cancer' and make a contribution to others.

At the European Sociological Association (Manchester) where Choon Key and Julia talked about engagement and disengagement in personalised medicine.

At the British Sociological Association (York) where Julia presented on genomic literacy and the 100,000 Genomes Project.

Choon Key presented at a workshop on health care activism at University College Dublin, discussing on-line drug advocacy for targeted therapies.

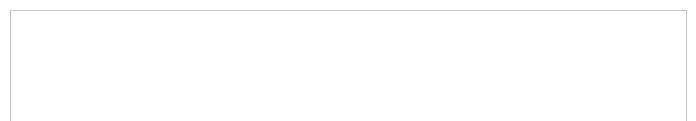
Sarah presented at the Society for the Social Studies of Science conference in New Orleans on the kinds of work and involvement that are part of personalised cancer medicine and trials. She also presented work on patient involvement and advocacy at the University of Copenhagen.

## Public Engagement

Developing our dissemination and public engagement work, Choon Key has been leading work on a short film which focusses on how being a 'public patient' is changing with genomic medicine. She has interviewed four people who are involved in support groups, patient involvement panels and online advocacy work to gather their experiences and views on how personalised medicine is changing what it means to be a 'public patient'. The Leeds Media Team have supported this and we will put the finished product on our website. Many thanks to those of you who helped with this – it's looking great!

We have also been awarded a grant from the Wellcome Trust engagement funding 'ScotPEN' to develop a graphic novel based on the research findings. The project is called 'Tailored treatments for cancer: tales of research and care'. The graphic novel and associated workshops will engage a diversity of audiences with the work of precision oncology and to encourage interactions with the findings and implications of our work beyond academic outputs. We have teamed up with Ziggy's Wish, a small, award winning company that specialises in applied narrative through a range of story telling techniques. We have already learned a lot from them and look forward to this collaboration enormously.

Steph Sinclair, who is the Public Engagement and Knowledge Exchange Co-ordinator at the Centre for Biomedicine, Self and Society, University of Edinburgh is also supporting this work.



### Staff News:

We would like to take this opportunity to offer congratulations to members of the project team and to say goodbye to others!

Congratulations to Emily who gave birth to baby Dudley in July. We have all enjoyed meeting Dudley who is a gorgeous baby. The whole family are doing well and we look forward to Emily returning in 2020 to continue to work on the project.

Sue has started a new position as a qualitative researcher on a study about preterm birth but she is still based at the University of Edinburgh and continues to have an interest in our work.

Choon Key's contract ended in October and Julia will leave on 31<sup>st</sup> January 2020. Thank you for all their hard work!

Kay who has supported us all throughout with great patience and organisational skill is retiring at the end of 2019. We have really enjoyed working with her and wish her all the best for a happy and fulfilling retirement.

Congratulations to Anne who has taken up the position of Head of Social and Political Sciences at the University of Glasgow as of 1<sup>st</sup> November 2019.

Congratulations to Julia who has been awarded a Wellcome Trust Fellowship in Humanities and Social Sciences to continue her interests in the societal implications of biomedical developments in cancer, focussing on the development and impact of novel immunotherapy. Julia will start the project in February 2020 at the Centre for Biomedicine, Self and Society at the University of Edinburgh.

Many thanks to you for your support so far for our project and Merry Christmas and Happy New Year to you all!

