

Dear PPI panel members,

Welcome to the September newsletter. Apologies that there was no update in August, it's because we've all been busy presenting about the project at conferences – read on to hear more about that.



Kay is on the right of the picture

Meet Kay - our study administrator

Kay Lindsay is the study administrator, based in Edinburgh. Kay has previously worked as a project administrator on several projects in the Centre for Population Health Sciences and is the one who knows how to keep things running smoothly! If you are part of the Scottish panel, Kay is the one who will help with things like booking travel or accommodation.

Ethics update

Thanks again to the panel members in Scotland who joined Emma and Emily for a tour of the Cancer Research UK labs and a great discussion about research ethics.

For those who weren't there, the discussion raised some really important points about our proposed methods, particularly around observations in waiting rooms and observations of biopsies. We also talked about inequalities and communicating our research to people in an accessible way, and about the importance of asking about things like post-trial support.

Emma gave a presentation at a conference 2 weeks ago about the way we involved the panel in thinking about ethics. The audience agreed that it was a good approach, and hopefully we've inspired more people to do this too!



It's all go in Leeds!

The Leeds team now have NHS approval and so we're almost ready to go ahead with fieldwork!

Since the good news, the Leeds team have been busy getting in touch with key contacts in Leeds Hospital to organise the hospital fieldwork.

And in Edinburgh...

The scoping interviews are going well, we've interviewed scientists and people directly affected by cancer. We're still looking for family members of people who have had cancer, so get in touch if you have ideas about ways to recruit people.



Barcelona International Convention Centre

Barcelona Conference

5 members of the research team went to a conference about science and technology studies in Barcelona 3 weeks ago. Anne (one of the project leads) presented about biopsies, while Sarah (the other project lead) presented about public health in the age of personalised medicine.

Tineke presented about the CRUK science blog which is a brilliant source of information about the latest discoveries in cancer science. You can read the blog yourself [here](#). For example, there was a recent post about the [history of genetics and DNA sequencing](#), which gives a useful overview and introduction, with links to further information.

And closer to home...

Sarah also gave a presentation about the theories we're using to frame our research questions at a recent medical sociology conference in Birmingham, where Emma also presented about ethics. Tineke, Choon Key and Julia were all there too, keeping up to date with the latest research in our field and taking lots of notes!

Choon Key is doing science!

This week, Choon Key is attending [VOICE 2016](#) (VOICE stands for Vision on Information, Confidence and Engagement), which is a clinical study week aimed at patient advocates.

This annual course is organised by [Independent Cancer Patients' Voice](#) (ICPV) and will involve intensive training in basic cancer biology, an introduction to research terminology and study design, and critical evaluation of research proposals and scientific papers.

This year the course is being run with Warwick Clinical Trials Unit at the University of Warwick and University Hospitals Coventry and Warwickshire who have access to modern up to date imaging facilities and a state of the art surgical teaching centre. Choon Key will report back what she has learnt from this course in the next newsletter.



A slide from Detect Cancer Early

Detect Cancer Early conference

While the others were in sunny Barcelona, Emily was in (less sunny) Glasgow at the Detect Cancer Early conference. She enjoyed listening to Dr Douglas Rigg from Possilpark (a very deprived area of Glasgow) talking about how deprivation leads to later diagnosis and higher mortality. She also heard from the people involved in 'the wee c' social marketing campaign.

The best bit was meeting fellow participants, particularly other people involved in PPI work who she is hoping to interview for our project.

Learning opportunity – Whole Genome Sequencing

Want to learn more about genomics? Future Learn and Health Education England are offering a free online course which will introduce you to whole genome sequencing and what it means for healthcare.

You will learn about England's pioneering 100,000 Genomes Project and its potential impact on how we understand and care for patients with rare diseases and cancer.

You don't need specialist knowledge to take part in the course as it will cover the basics.

The course starts today and lasts for 3 weeks, taking 3 hours per week.

For more information or to enroll on the course, see: <https://www.futurelearn.com/courses/whole-genome-sequencing>

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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