



Patient and public involvement update

FEBRUARY 2017

Dear PPI panel members,

A very belated happy new year! A quiet start to the year meant no newsletter in January, but there's plenty going on now that we're keen to tell you about, starting with a message from Sarah Cunningham-Burley, Principal Investigator on the project at the University of Edinburgh.



Sarah Cunningham-Burley

Sarah's message

Our research is progressing really well, although we are increasingly aware of just how complicated genomic medicine is. We think this makes it all the more important to understand patient experience as well as that of the health care providers they come into contact with.

We have conducted around 30 interviews in Scotland and around 60 in Leeds with people affected by cancer, cancer scientists, clinicians and people involved in advocacy and support groups. We are now busy reviewing what everyone has said and look forward to sharing our findings with you.

The next stage of our research in Scotland will involve an in-depth focus on two very new developments in cancer research and care, involving pancreatic and ovarian cancer. We are just finalising the ethical approval process and the logistics of starting to observe clinics and involve patients in our study.

I'm very grateful for the contribution you all make to our work and look forward to meeting some of you at upcoming meetings.

Sarah Cunningham-Burley.

HOT OFF THE PRESS

New blog post

Julia has written a [new blog on our website](#) about the recent debate on the cost-effectiveness of breast cancer drug Kadcyła. This is relevant to our research because we are interested in patients' and clinicians' hopes and expectations for new targeted therapies, and in the role that patients can play in getting new drugs made available.

If any of you have thoughts on Julia's blog, please let us know and we can include your response in the next newsletter.

We would also love to hear from anyone who wants to write a blog of their own and we can support you to do it. Let us know your ideas!



Presentation to support group

Emily and Emma recently gave a presentation about our research to the Edinburgh and Lothian Prostate Cancer Support Group. We really enjoyed meeting the group and hope they found the talk interesting.

Some members of the group were (understandably) a bit uncertain about the genomics side of things, so that's something we need to get better at explaining! Hopefully in future as you all become more familiar with the work, some of you will be able to help us to present it to patients and their families.



Upcoming panel meetings

The Leeds team is organising their first PPI panel meeting in March. It will be an informal meeting over coffee and cakes to give you an update on the progress of our study and to discuss how the panel would like to get more involved in the study.

The Edinburgh team is planning a meeting for May which will be a chance to hear about what we've learned in the scoping interviews and to get your input into the analysis of the data. It will also have some social time over lunch for everyone to get to know each other though!

Keep an eye on your emails for more details about each of these meetings.

Learning opportunity – Cancer and the Genomic Revolution

The University of Glasgow developed a free online course which examined three key questions about cancer diagnosis and treatment: Where have we come from? Where are we now? And where are we going? It looked at the biological basis of cancer, influences on causation, how it is detected and treated, and the development of new treatment strategies.

Unfortunately the course has just finished, but many of the materials are still available for anyone who would like to access them without following the formal course structure. You can also register interest to be notified when the course runs again and we'll keep an eye on it too to let you know in good time: <https://www.futurelearn.com/courses/cancer-and-the-genomic-revolution>

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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