

RESPECT-21

Reorganising specialist cancer surgery for the 21st century: a mixed methods evaluation

PROJECT NEWSLETTER No. 6

September 2017

Welcome to the sixth RESPECT-21 newsletter - updating you on how our study is progressing and what the team have been doing.

Catch up on earlier editions of the newsletter by using the following link:

https://www.ucl.ac.uk/dahr/research-pages/RESPECT_21

Highlights this month -

- **How we've been sharing our findings** at major conferences across the UK
- **"Spotlight"** - we meet our patient representative, Veronica Brinton
- **Update** on our survey of patients, professionals, and members of the public

PROGRESS UPDATE

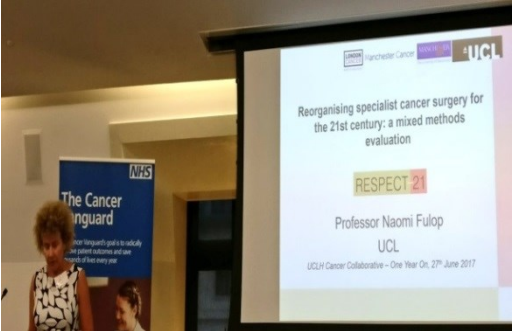

We are pushing forward with our qualitative data collection (interviews and observations) in London and Greater Manchester:

- In **London** we have done 72 interviews with NHS and non-NHS employees and observed 50 meetings related to the planning, oversight and provision of cancer services such as Commissioning meetings, Pathway-specific meetings and Specialist Multi-Disciplinary Team meetings.
- In **Greater Manchester** we have done 19 interviews with stakeholders involved in planning and supporting the centralisations. We have observed 49 meetings - including the Greater Manchester Cancer Board, Pathway Boards and Implementation Boards.

We have started analysing some of our London interviews to identify lessons that can be learned about how to implement large-scale changes in health services successfully.

Based on our survey of patients, health professionals and the general public we have put together two papers which look at centralising specialist cancer surgery services. These are under review in peer reviewed journals.

Our Research Strategy Group (RSG) is due to meet again for the seventh time in September 2017. This is always stimulating as the RSG brings together co-investigators, researchers, patient representatives and clinicians – so the discussion can be wide-ranging. We have just recruited a new patient representative from Greater Manchester to the RSG, and are currently looking for others to join from both Greater Manchester and London.

<p>REMEMBERING OUR PPI COLLEAGUE</p> <p>Neil Cameron</p>	<p>Very sadly we learned that our PPI colleague, Neil Cameron, died on 15th May. Neil contributed a great deal to the study, from the development of the proposal, in particular providing essential feedback on our research questions in relation to patient experience, through to the work of the study to date.</p> <p>We will continue to acknowledge his role in outputs from the study.</p>
<p>SHARING OUR FINDINGS</p> <p>Health Economics Events June 2017</p> <p>UCLH Cancer collaborative</p> <p>HSRUK July 2017</p>	<p>Professor Steve Morris presented papers at Health Economics Bristol, based in the School of Social and Community Medicine at the University of Bristol, on 20 July 2017. In these he shared the findings from our survey.</p> <p>He also presented at the Health Economists' Study Group (HESG) meeting at the University of Aberdeen on 28-30 June. https://www.abdn.ac.uk/heru/hesg2017/</p> <p>The title of these talks was: Preferences of patients, health professionals and the general public for centralising specialist cancer surgery services: a discrete choice experiment</p> <p>In July Professor Naomi Fulop presented an overview of the many different strands of RESPECT-21 at the UCLH cancer collaborative event.</p> <p>It was our survey that seemed to really catch people's attention. This highlighted their interest in knowing more about people's priorities for cancer care and how these varied between healthcare professionals, patients and members of the public.</p>  <p>In July members of our qualitative team were at the Health Services Research UK symposium in Nottingham to introduce a poster highlighting what we have learned so far about the role of networks in implementing major systems change.</p> <p>Beyond the poster itself people wanted to know about the methods we used to explore the impact of networks on systems.</p> <p>In addition to this Professor Steve Morris presented a paper at HSRUK on our survey (discrete choice experiment survey).</p> 

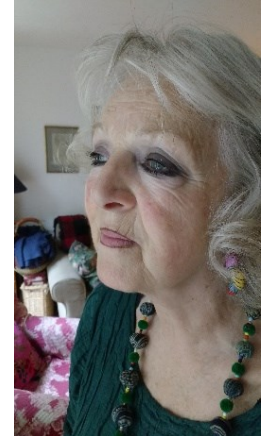
MEET THE TEAM

This month we meet Veronica Brinton, one of our Patient Representatives/Advisors.

In this piece Veronica tells us a little bit about her background, how she became involved in RESPECT-21, and her thoughts on the study:

I have been working on behalf of Patients and Public since 2003, as well as several years before that at Great Ormond Street Hospital.

My background profession is journalism. I became a cancer patient in 2007.



I was already on a London Cancer Pathway Board when I was invited to be a Patient Representative on this study, so for me this was an extraordinary opportunity to learn how an important research project would develop.

On one hand **I bring an experienced voice** which represents thousands of patients and on the other, I have a personal understanding of the complexities and challenges behind each patient's treatment.

I have been fascinated and impressed by this study, and privileged to be part of the process. It is very encouraging to see the depth and breadth of consultation which ensures that these ARE the views of the widest cross section of existing and future cancer patients.

To me this confirms that patient representation should always be at the heart of healthcare service design.

It is no longer appropriate just to improve systems or processes without consulting with people who are already experienced 'users'. Their representation is an integral part of the 'checks and balances' that need to be applied to all cancer care. To be a cancer patient is to be at your most vulnerable as a human being.

Fear, expressed or unexpressed, is a 24/7 experience for most, and they long for relief. Meeting their individual needs is a vital part of this, so the information that supports them in their treatment is crucial.





You can take patients with you if they feel informed and also heard, to help them feel more positive and hopeful of the best of outcomes. Achieving this will be part of the ongoing challenges.

SURVEY ON HOW CANCER SERVICES SHOULD BE ORGANISED



We are pleased to report that we have been writing up the findings from our survey of cancer patients, healthcare professionals, and members of the public on how cancer services should be reorganised.

We hope that these will be published later this year – so watch out for our findings!

<p>PPI ENGAGEMENT WE NEED YOUR HELP!</p>	<p>Would you like to be a PPI representative, working as part of our RESPECT 21 team?</p> <p>We are currently looking to increase our PPI representation in London and Manchester. Being a PPI rep is a very important role, involving attendance at our quarterly RSG meetings, and providing us with regular feedback on some of the different aspects of our work.</p> <p>So, if you or anybody that you know would be interested in this role then please contact Dr Angus Ramsay on: angus.ramsay@ucl.ac.uk or Dr Victoria J Wood: v.wood@ucl.ac.uk for further information.</p>
<p>PROJECT SUMMARY</p>	<p>The RESPECT-21 research team are studying changes in specialist cancer surgery services across North Central and North East London and West Essex (population 3.2million) and across Greater Manchester (population 3.1million). Both areas are working to reduce the number of hospitals providing specialist surgery for a range of cancers. We are focusing on changes to bladder and prostate, kidney and oesophago-gastric (OG) pathways.</p> <p>We are using a range of research methods to study changes in the way specialist cancer surgery services are organised and provided in London and Greater Manchester. We will assess key processes in London and Manchester service centralisation. We will also look at the impact on care processes and outcomes, and the cost and cost-effectiveness of the changes. The impact on staff and patients will be explored, and we will study people's preferences in relation to centralisation. Finally, we will consider what lessons can be learned for future centralisations.</p>
<p>FUNDING</p>	<p>This project is funded by the National Institute for Health Research Health Services and Delivery Research Programme (project number 14/46/19).</p>
<p>DISCLAIMER</p>	<p>The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the Health Services and Delivery Research Programme, NIHR, NHS or the Department of Health.</p>
<p>FURTHER INFORMATION</p>	<p>If you'd like to know more about RESPECT-21, or have ideas about what you'd like to see in this newsletter, please contact</p> <ul style="list-style-type: none"> ① Prof Naomi Fulop, Chief Investigator (n.fulop@ucl.ac.uk) ① Dr Angus Ramsay (angus.ramsay@ucl.ac.uk, tel 020 3108 3239) <p>Please visit the RESPECT-21 project website for the latest news and links:</p> <p> https://www.ucl.ac.uk/dahr/research-pages/RESPECT_21</p> <p> We are now on twitter! Please follow us on @Respect21Cancer</p> <p>Find out more about the service centralisations we are studying here:</p> <ul style="list-style-type: none">  http://www.londoncancer.org/  http://www.gmcancer.org.uk/

NEXT NEWSLETTER: December 2017

Please forward this newsletter to anyone who you think would be interested in our work.

If you would prefer not to receive these newsletters, please contact c.vindrola@ucl.ac.uk and we will be happy to remove your details.