

# RESPECT-21

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

PROJECT NEWSLETTER No. 8

March 2018

Welcome to the eighth RESPECT-21 newsletter, updating you on our study and telling you about the team.

## HIGHLIGHTS

- **NEWLY PUBLISHED PAPERS:** what matters to patients, the public and professionals in centralising specialist cancer surgery
- **UPDATE FROM OUR LATEST STUDY STEERING COMMITTEE MEETING**
- **MEET THE TEAM:** We shine the spotlight on one of our patient representatives, John Sandell

## NEW PAPER OUT NOW:

Centralising specialist cancer surgery services: what factors matter most to patients, the public, & health professionals?



We are delighted to let you know the following papers have recently been published:

**Vallejo Torres L, et al.** Discrete choice experiment to analyse preferences for centralising specialist cancer surgery services. *British Journal of Surgery* (2018)

This article presents findings from our **Discrete Choice Experiment**, a survey that looked at which aspects of centralising specialist cancer surgery matter most to people. 206 patients, 111 health professionals, and 127 members of the public took part in the survey.

Patients, health professionals, and the public all had similar preferences. We found that the risk of complications, risk of death, and access to a team of cancer specialists were **most important** to people.

Travel time was **least important** to people, and participants were willing to travel for longer to have better care and outcomes.

Our findings suggest that **people are willing to travel longer** if it means having **better care and better outcomes**. If services are **not linked with better care and outcomes**, people prefer to be treated by their **local hospital**. When planning changes of this kind, it is vital that **improvements in care and outcomes** are at the heart of proposals.

The paper is available to read online from this link:

<http://onlinelibrary.wiley.com/doi/10.1002/bjs.10761/full>

## NEW PAPER OUT NOW:

**Findings from our survey on what matters to patients, carers and health care professionals when centralising specialist cancer surgery services**



**Melnychuk, M., et al. "Centralising specialist cancer surgery services in England: survey of factors that matter to patients and carers and health professionals." *BioMed Central (BMC): Cancer* (2018)**

In this paper, we present the findings from a questionnaire asking patients, carers, and health care professionals what factors related to centralisation of specialist cancer surgery were most important to them. This was background work to the discrete choice experiment reported in paper above.

It was completed by **52 individuals** (19 members of Patient and Public Involvement groups and 33 healthcare professionals in London and Greater Manchester).

What we found:

Collective **top priorities** were:

- Highly trained staff
- Likelihood and severity of complications
- Waiting time for cancer surgery
- Access to staff members from various disciplines with specialised skills in cancer

The paper is available to read online from this link:

<https://bmccancer.biomedcentral.com/articles/10.1186/s12885-018-4137-8>

## SHARING OUR FINDINGS

Study Steering Committee



**On 25 January our Study Steering Committee met for the second time.** This meeting brought together the study team with a group of patient representatives, clinicians, commissioners, and researchers to discuss study progress and interim findings, and plan the next steps of the research.

There were some interesting presentations from the team, which sparked a lot of discussion, including:

- **Discrete Choice Experiment** (Dr Mariya Melnychuk): exploring stakeholder preferences in regard to the reorganisation of specialist cancer surgery services.
- **Major system improvement in specialist cancer surgery:** the role of provider networks from (Dr Cecilia Vindrola): new findings on ways in which a network approach facilitated implementation of change.
- **Moving from competition to cooperation:** the case of Greater Manchester cancer surgery services (Dr Catherine Perry): understanding the history of

reorganisation in Greater Manchester.

- **The cost of implementing reconfiguration:** bottom-up costing of the reorganisation of specialist cancer surgery services (Dr Caroline Clarke): little is known about the cost of implementing changes of this kind, and this analysis will help to address this important gap in knowledge.
- **The meaning and effect of losing specialist cancer surgery provision** (Dr Viki Wood): experiences of services that no longer provide specialist cancer surgery following reorganisation.
- **Bridging gaps and spanning boundaries** (Dr Cecilia Vindrola): how organisations work together following centralisation into a specialist cancer surgery provider network

All the valuable feedback, insightful discussions and points raised in this meeting will be taken forward by the team as they continue to work on the project.

## PROGRESS UPDATE

We are continuing qualitative data collection (interviews and observations) in London and Greater Manchester:

- In **London** we have carried out 75 interviews with NHS and non-NHS employees and have observed 58 meetings related to the planning, oversight and provision of cancer services.
  - In **Greater Manchester** we have carried out 27 interviews with people involved in planning and supporting the centralisations and have observed 69 meetings.
- And we have made good progress analysing these interviews and observations to see what is involved in planning and implementing large-scale changes in health services. We are in the process of reviewing our sampling strategy to look at who we have interviewed and to make sure that we are including a wide range of perspectives.

The 10<sup>th</sup> meeting of our **Research Strategy Group** will be in June 2018, which is an important meeting as it brings together the team with a group of patient representatives, clinicians, commissioners, and researchers to discuss study progress and interim findings, and plan the next steps of the research.

## MEET THE TEAM

### ***This month - meet John Sandell, one of our Patient Representatives/ Advisors.***

*John tells us a little bit about his background, how he became involved in the pathway board at London Cancer and his involvement in RESPECT-21:*

I spent my life in IT working as a programmer and then as a project leader in a major bank. I took early retirement and now enjoy bowling on the green where I am match secretary, spending time with my wife, two children and three grandchildren, and doing a range of volunteering. I volunteer at the Macmillan Centre in my local hospital, which provides support for people with cancer and their family and friends.



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|                                   | <p>I was diagnosed with prostate cancer in October 2007 and underwent a radical prostatectomy. I have represented cancer patients on a number of different groups and boards including the NELCN Patient Partnership Group, Whipps Cross patient panel, the Barts Health Cancer CAG Executive Board, Living With and Beyond Cancer Board and the Urology Pathway Board at London Cancer.</p> <p>I feel that it is paramount that patients are valued and put at the centre of services. I have found the Urology Pathway Board to be excellent at including patient representatives, ensuring they have a voice and being genuinely interested in the thoughts of patients.</p> <p>I am really happy about my contribution to the pathway board and feel that it has been time well spent. I feel that the RESPECT 21 Research Strategy Group will offer a similar experience of valuing and appreciating time spent providing the views and experiences of patients.</p>   |
| <p><b>PROJECT SUMMARY</b></p>     | <p>North Central and North East London and West Essex (population 3.2million) and also Greater Manchester (population 3.1million) are all working to reduce the number of hospitals providing specialist surgery for a range of cancers.</p> <p>The RESPECT – 21 research team are studying the proposed changes focusing on changes to bladder and prostate, kidney and oesophago-gastric (OG) pathways.</p> <p>We are using various research methods to study changes in the way specialist cancer surgery services are organised and provided in London and Greater Manchester.</p> <ul style="list-style-type: none"> <li>• We will assess key processes in the London and Manchester service centralisations.</li> <li>• 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.</li> <li>• Finally, we will consider the implications for future reorganisation.</li> </ul>                        |
| <p><b>FUNDING</b></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><b>DISCLAIMER</b></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><b>FURTHER INFORMATION</b></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> <p style="text-align: center;">  Prof Naomi Fulop, Chief Investigator <a href="mailto:n.fulop@ucl.ac.uk">n.fulop@ucl.ac.uk</a><br/>  Dr Angus Ramsay <a href="mailto:angus.ramsay@ucl.ac.uk">angus.ramsay@ucl.ac.uk</a>, tel 020 3108 3239 </p> <p>Please visit the RESPECT-21 project website for the latest news and links:</p> <p style="text-align: center;">  <a href="https://www.ucl.ac.uk/dahr/research-pages/RESPECT_21">https://www.ucl.ac.uk/dahr/research-pages/RESPECT_21</a><br/>  We are on Twitter! Please follow us on <a href="https://twitter.com/Respect21Cancer">@Respect21Cancer</a> </p> |

Find out more about the service centralisations we are studying here:



<http://www.londoncancer.org/>



<http://www.gmcancer.org.uk/>

**NEXT NEWSLETTER: JUNE 2018**

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](mailto:c.vindrola@ucl.ac.uk) and we will be happy to remove your details.