

The PROACT Study

Patient Reported Outcomes in cancer, impact of Age and Carer role demands associated with Treatment

Thank you

For taking part in PROACT study 3 and helping with this research. We are sending you this information sheet because you indicated that you would be interested in what we found.



Val Shilling

In PROACT study 3 we tested questionnaires that we have developed to measure the impacts that cancer and cancer treatment have on many aspects of life for both patients and their informal caregivers.

We needed to test the questionnaires to make sure that they are reliable and valid measures. This is an important stage in the research to ensure that the questionnaires can be used with confidence in the future.

This information sheet will tell you about what we did, what we found, and how these results helped further shape the questionnaires.



Rachel Starkings

What did we do?

- We invited people with breast, gynaecological or lung cancer or malignant melanoma to complete the patient questionnaires.
- We also asked them to nominate the person who is their main source of emotional and/or practical support to complete the informal caregiver questionnaires.
- Participants completed sets of questionnaires three times: at baseline, a week later and then 2 months after baseline.
- Participants completed the questionnaires on paper or online, whichever they preferred.
- Collecting these data meant we could test the new questionnaires in two ways:
 - 1) by seeing if they are reliable when completed more than once (reliability)
 - 2) by comparing them with other questionnaires that measure quality of life and wellbeing (validity)

Who took part?

- 135 people with cancer completed at least one set of questionnaires.
- 38 had breast cancer, 35 gynaecological cancer, 32 lung cancer and 30 malignant melanoma.
- 110 informal caregivers completed at least one set of questionnaires.
- Their relationship to the person they support was partner/spouse (83), child (14), friend (5), sibling (4), parent (2) or other (2).
- Ages ranged from 33 to 85 years for people with cancer and 18 to 88 years for the informal caregivers.
- Because of the types of cancer included in this study, more patients were women (77%). Slightly more caregivers were men (57%).
- 123 people chose to complete at least the first set of questionnaires by post. 122 completed them online.

What did we find?

- The new questionnaire showed good reliability. One of the ways we tested this was to check that scores were very similar when the questionnaires were completed just 7 days apart (called test-retest reliability).
- They also showed good validity. One of the ways we tested this was to check that scores were strongly related to scores on other measures of quality of life and wellbeing (called convergent validity).
- This is good news as it means that we can continue to use the questionnaires in our research with confidence.

What changes did we make?

- Overall, the new questionnaires performed well however not all of the individual questions did. When we performed the analysis, some items did not 'add' to our understanding of people's wellbeing.
- It is important to remove these items because we don't want to waste people's time completing questions that don't give us any further information about how they are feeling.
- Also, we looked at items that people sometimes chose not to answer. Some of these we removed from the questionnaires, others have been reworded. Also, we have added instructions to answer 'N/A' if not applicable.
- In total we removed 5 items from the patient questionnaire and changed the wording of 2, and 10 items from the caregiver questionnaire and changed the wording of 3.
- Also, we added an option for people to tell us if they are on sick leave when we ask about employment status.

Examples of how item wording was changed

Item as completed in PROACT study 3	Item as it will appear in PROACT study 4
I feel that support is available from the health system/ social services should I need it	I feel that support is available from the health system
I have stopped work altogether because of my illness	I have stopped paid employment altogether because of my illness
My family have to help me financially	My family and/or friends have to help me financially

What happens next?

- The questionnaires worked well when we tested them with patients with breast, gynaecological or lung cancer or malignant melanoma and their caregivers.
- We will conduct another study in this programme of research beginning in early 2018.
- In the next study we will invite people who have different types of cancer, of different stages, to take part in the research.
- We hope that around another 300 people will take part in this study (150 people with cancer, 150 people who offer support).
- The next stage is important to make sure the questionnaires are suitable and acceptable for use in research and practice across other types of cancer.

Additional Information

- We would like to thank everyone who took part in this research, all of the members of the cancer teams and our group of patient and caregiver advisors.
- The research was conducted by SHORE-C (Sussex Health Outcomes Research and Education in Cancer), Brighton and Sussex Medical School, University of Sussex.
- SHORE-C is led by Professor Dame Lesley Fallowfield, the Deputy Director is Dr Val Jenkins.
- Read more about our research at shore-c.sussex.ac.uk
- The research was funded by the pharmaceutical company Bristol-Myers Squibb. The funder had no influence over the way the research was conducted or the findings.
- The study received ethics approval from the NRES Committee London – Queen Square (ref: 16/LO/1125).
- If you have any questions about this research please contact Val: v.m.shilling@sussex.ac.uk or 01273 877934