

The PROACT Study

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

Thank you

For taking part in the PROACT study and sharing your views and experiences to help with this important research. We are sending you this information sheet because when we met, you said that you would be interested in the findings of the research.



Val Shilling

Over the last 10 months we have been interviewing people with cancer about the impacts that cancer and cancer treatment has had on their life. We also interviewed the person identified as their main support.

This information sheet will tell you a little bit about what we did, what we found, and how that information helped us develop two new questionnaires for use in research or in discussions between doctors and families.



Rachel Starkings

What did we do?

- We have conducted two studies.
- In Study One we interviewed people about different areas of their life, asking how important these were to them and how they had been impacted by their cancer or that of the person they support.
- We used the content of these interviews to identify the most important areas of impact for the people we had interviewed.
- Based on this, we wrote lists of possible items to include in our new questionnaires.
- We also included some topics that had been reported in other research, to make sure that our lists were as thorough as possible at this stage.
- In Study Two we asked a new group of participants to test out these possible questions.
- The purpose of Study Two was to make sure that the final questionnaires are relevant, appropriate and easy to understand and answer.
- Questions were changed or dropped altogether on the basis of what you told us.

Who took part?

- 24 pairs of people with cancer and the person that supports them took part in Study One and 20 pairs took part in Study Two.
- The groups were a mixture of people who have lung, breast, ovarian/gynaecological cancer or malignant melanoma.
- The people that supported them were partners/spouses, children, sisters, in-laws and friends.
- The age of people involved in these studies ranged from 39 to 84 years for people with cancer and 18 to 85 years for the people who support them.

What did we find?

- We recorded around 40 hours of interview material in Study One.
- This was transcribed word for word to ensure no detail was missed.
- When we analysed the interviews we identified 20 topics that people talked about, which broke down into 33 smaller topics.

- When we made our first list of possible questions it came to 179 for people with cancer and 182 for their supporters – this was far too many!
- By the end of Study 2 the final number of items on the questionnaires was 29 for people with cancer and 60 for the people who support them.
- They are different because our questionnaire for people with cancer will always be given with an existing one that measures issues like support and emotional wellbeing.
- The questionnaire for people who offer support will be used on its own, so it needs to be more detailed.

The questions are grouped into sections about:

People with cancer	People who offer support
Family and home life	Family and support
Financial wellbeing	Relationships & communication
Jobs and careers	Lifestyle and outlook
	Health and wellbeing
	Financial wellbeing
	Jobs and careers

Example items from the completed questionnaires

People with cancer:					
	Not at all	A little bit	Some-what	Quite a bit	Very much
I worry about the impact of my illness on my partner (or the person who is my main support)	0	1	2	3	4
People who offer support:					
	Not at all	A little bit	Some-what	Quite a bit	Very much
I make time to do things for myself	0	1	2	3	4
Items on both questionnaires:					
	Not at all	A little bit	Some-what	Quite a bit	Very much
My family and I support each other	0	1	2	3	4
I am concerned about keeping my job and income	0	1	2	3	4

What happens next?

- The final study in this piece of research will begin in the autumn of 2016.
- The purpose of this study is to test the new questionnaires to make sure that they are reliable and valid measures of wellbeing and impact.
- This is an important stage in the research to ensure that the questionnaires can be used with confidence in the future.
- We hope that around 240 people will take part in this study (120 people with cancer, 120 people who offer support).
- When we have demonstrated that the questionnaires are valid and reliable, they will be made freely available for people around the world to use in research and practice.

Additional Information

- We would like to thank everyone who took part in this research, all of the members of the cancer teams who introduced the study to patients and their family and friends, 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.
- 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: 15/LO/1323).
- If you have any questions about this research please don't hesitate to contact us:

Dr Val Shilling email: v.m.shilling@sussex.ac.uk

telephone: 01273 877934