Quality of Life After Transplant

Summary of cognitive testing findings

Thank you to all the transplant recipients and healthcare professionals who took part in the 'Quality of Life After Transplant' study. We have now completed the 'cognitive interview' stage of this research. This sheet summarises our findings and actions and outlines further opportunities to take part in this research.

What we did... We interviewed people who have received a solid organ (heart, lung, kidney, liver) transplant and healthcare professionals to 'test' two patient-reported outcome measures (PROMs) of quality of life and symptoms after transplant.

We asked people whether they thought the instructions and questions were easy to understand, and whether all relevant outcomes and symptoms had been considered. We listened to the issues that people had with the PROMs and made recommended changes after every few participants until no further issues were raised. We spoke to people from a variety of backgrounds to capture a wide range of experiences and perspectives.

Quality of Life After Transplant Survey (QoL-AT)

The QoL-AT asks transplant recipients how they have felt about their day-to-day life in the last month. The survey includes 35 questions about a broad range of feelings and emotions, social and role activities.

We interviewed 13 transplant recipients and 8 healthcare professionals.

How we acted on feedback:

- We made changes to the instructions to make them clearer and easier to understand. For example, being clearer about why people are being asked to complete the survey, the number of questions, and estimated time to complete the survey.
- We made changes to the survey design to emphasise the focus on the last month and made sure the 'not applicable' response option was clearly separate from the other options.
- We added one new question about dietary restrictions. No questions needed to be removed.
- We reordered some questions to group related outcomes closer together in the survey; for example, worry about infection and avoiding crowded spaces.
- We revised the wording of 12 questions to make them easier to understand. For example, 'I have felt satisfied with my sex life' was changed to 'I have worried about my sex life'; 'I have felt able to plan for the future' was changed to 'I have felt that I can plan for the future'.
- Participants generally reported that the length of the survey was about right. They thought that all questions asked about something different. Being asked to recall the last month and respond from 'not at all' to 'very much' was also reported to feel appropriate.

Quality of Life After Transplant survey – Symptoms module (QoL-AT+S)

The QoL-AT+S asks transplant recipients how much they have been bothered by symptoms they might have experienced in the last month. The survey includes 30 questions about a broad range of symptoms that may be related to the transplant or medication side effects.

We interviewed 8 transplant recipients and 8 healthcare professionals.

How we acted on feedback:

- We made changes to the instructions to make them clearer and easier to understand. For example, being clearer that symptoms may or may not be related to your transplant, and to respond 'not at all' if you have not experienced a symptom.
- We made changes to the survey design for ease of reading, by having multiple sections with a small number of questions each, rather than one long list. We also added instructions for how to respond to the questions that are specific to men and women.
- We added two new questions about 'a lack of energy' and 'pain in my scar or transplanted organ'. One question about 'irritability, mood swings and low mood' was split into two questions. No questions needed to be removed.
- We revised the wording of six questions to make them easier to understand. For example, 'heart palpitations' was changed to 'unusual sensations in my heartbeat'; 'swelling from fluid retention' was changed to 'swelling in my legs, feet or belly'.
- As with QoL-AT, participants generally reported that the length of the survey was about right, with all questions asking about something different. Being asked to recall the last month and respond from 'not at all' to 'very much' was also reported to feel appropriate.

Next steps... In the next stages of this research we will test each survey with a large sample of transplant recipients to understand how they work in practice. This will identify any further issues with their completion before we look to use these surveys in the real world.

We are presenting findings at conferences and preparing papers for publication in scientific journals. All papers (with lay summaries) will be added to the project website as and when they are published. This can be accessed here: http://odt.btru.nihr.ac.uk/theme-6/

For more information, to register your interest, or if you have any questions:

Email: ODT.experiences@newcastle.ac.uk | Website: http://odt.btru.nihr.ac.uk/theme-6/