Working together and caring for carers: The story of the Research User Group (RUG) in the Organising Support for Carers of Stroke Survivors (OSCARSS) study

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OSCARSS is a cluster randomised controlled trial of a professionally-delivered intervention to support caregivers of stroke survivors (see our poster at board OG09 for more information)

A dedicated OSCARSS Research User Group (RUG) was established in December 2015 to work in partnership with the research team.

ROLE OF THE RUG
The RUG has met regularly since Dec 2015. They worked closely with the research team, and other experts, to co-develop the intervention for carer support being evaluated in the OSCARSS study. The RUG have also supported development of:

- the study design
- the choice of meaningful outcome measures
- accessible study documentation and materials
- staff training
- strategies to maximise participant recruitment

They also help manage the project through input and involvement in the Trial Management Group.

Members engage in social media and presentations to promote the project.

HOW THE RUG WORK
- Regular meetings build understanding and trust
- Open and honest discussions
- Valuing all opinions; everyone is given a chance to speak
- Individual tasks, preparation & reflection
- Review and feedback on processes and study documents
- The researchers support engagement by:
  - preparing and providing materials in advance
  - avoiding jargon and using accessible format
  - providing opportunity to discuss materials outside meetings
  - reimbursing for time and travel expenses

WHAT HAS THE RUG BROUGHT TO OSCARSS?
The RUG has provided:

- stroke carer input into the development of a stroke carer specific intervention
- valuable “lived experience” as a diverse group of carers
- carer input into the study processes that encourage other carers to reflect on the importance of considering their own needs and wellbeing
- a method to check if recruitment and other processes are acceptable to carers

WHAT HAS OSCARSS BROUGHT TO THE RUG?
“As an Ambassador for the Stroke Association, my role is to educate others on Stroke and what it’s like to live as a Carer of a Stroke survivor, and so I felt this study fit perfectly in helping others at their time of need as well as educating coordinators and researchers along the way” Natalie

“I became involved in contributing to the carers experience in research as I was interested in meeting other carers. The RUG was initially a source of welcome contact with other carers in similar circumstances and helped me reflect on my own circumstances and role as a carer” Kelly

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https://www.clahrc-gm.nihr.ac.uk/projects/oscarss