

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

Who are the Research User Group (RUG)?



From left to right: Kelly, Natalie, Christine, Ben, Kath, Geoff.

"I'm a carer and I matter too!"

"You may think you can put yourself in my shoes but until you're there, you really can't"

"As a carer myself, I would like to help other carers"



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>