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**NIHR Evaluation of the Thalidomide Health Grant**

**Expert by Experience Panel Member Role Description**

**About the Evaluation and the Expert by Experience Panel**

The National Institute for Health Research has asked a joint team from RAND Europe and the University of York to carry out an evaluation of the Thalidomide Health Grant. The aims of the evaluation are to:

* Provide an up to date picture of the changing health and wellbeing needs of Thalidomide survivors
* Explore how Thalidomide survivors are using their grants to meet current needs and plan for the future
* Examine whether these changing needs have implications for the level and distribution of the grant

The evaluation is being carried out between October 2024 and February 2027. It will involve: looking at information held by the Thalidomide Trust that they have permission to share (no names or personal details will be shared with the research team); talking to thalidomide survivors in discussion groups and interviews; a short health and wellbeing survey; and gathering the views of Trust staff and others involved in supporting thalidomide survivors.

As a research team, we want the voice of thalidomide survivors to be central to the evaluation. Within the team we have an Expert by Experience Lead who is a thalidomide survivor. We also have three thalidomide survivors on the Research Advisory Group. Now we are looking to recruit around six thalidomide survivors to join our Experts by Experience (EbE) Panel. The Panel will help shape how the evaluation is carried out and ensure that what we do is relevant and acceptable to thalidomide survivors.

**Responsibilities of Panel Members**

The responsibilities of the Experts by Experience Panel are likely to change and develop in response to feedback from members but examples may include:

* Using your own experience, and perceptions of the issues faced by people in the thalidomide community to shape how the study is conducted (e.g. how we communicate with thalidomide survivors with different needs and interests)
* Reviewing study documents, such as ‘Participant Information Sheets’ to ensure information is accessible and jargon-free
* Helping shape the questions to be asked in interviews and discussion groups
* Working with the research team to understand the possible implications of findings from the evaluation
* Supporting the communication of research findings to the thalidomide community

**Commitment and Qualifications**

We plan to hold up to five in-person/virtual panel meetings at key points during the evaluation. Ideally you would be able to attend most of the meetings but we know people lead busy lives or sometimes find it hard to travel or join online events, so we would work with you to find the best way for you to contribute. Panel members don’t need any specific qualifications or previous experience of research but you should:

* Be comfortable in meetings and working with people who may have different views to your own
* Have an email address or phone number
* Ideally be able to use a computer to receive and comment on documents using Microsoft Word but this is not essential and support and training can be provided

**Support and Benefits**

EbE Panel members will be supported by the researcher with responsibility for involvement of thalidomide survivors and the Expert by Experience lead. They will ensure individual needs for taking part are met (e.g. BSL interpreters, large print documents, Zoom/Teams training). There will also be opportunities to attend training, events, conferences as these arise. Members will receive payment for the activities they take part in. All travel and related expenses will also be met.The level of payments will vary according to the time commitment involved but will be based on the University of York Policy on the Payment of Individuals for Involvement with and Contribution to Research. See:

<https://www.york.ac.uk/staff/research/governance/research-policies/payments-policy-involvement/>

**I’m interested! Who do I contact?**

If you would like to talk to someone about becoming a member of our Expert by Experience Panel, please contact Liz Newbronner on 01904 321630 or email liz.newbronner@york.ac.uk