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**NIHR Evaluation of the Thalidomide Health Grant**

**Q&A**

**Q. Why has an evaluation of the Health Grant been commissioned?**

**A.** The Department of Health and Social Care (DHSC) has to get approval for all non-competitive grants from a Cabinet Office panel. Lifetime funding for the Health Grant has been agreed, but the panel recommended that the previous 10-year grant should be evaluated ahead of the review of the current four year grant agreement in 2026/27. The DHSC commissions research through the National Institute for Health and Care Research (NIHR), with independent researchers carrying out the evaluation.

**Q. What are the aims of the Health Grant evaluation?**

**A.** Put briefly, the main 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 how they are planning for their future
* Examine whether these changing needs have implications for the level and distribution of the grant.

You can see the full research brief produced by the DHSC and NIHR by clicking [here](https://eur02.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.nihr.ac.uk%2Fdocuments%2Fprp-37-01-07-understanding-how-to-support-people-affected-by-thalidomides-health-needs-an-evaluation-of-the-thalidomide-health-grant-research-specification%2F34402%3Ffbclid%3DIwAR2nVhfBz3bm-NQInzoKe3aL8RlFr_YvlWHZq22CqEh7iZjKxoG-3FhnoQQ_aem_AfDKOi6veyORdCUGtRlkeLGQneR1WTwxx4TlSiv__r3TIF6jDweJLFREiWWK9cwai1I%23timetable-and-budget&data=05%7C02%7Cdeborah.jack%40thalidomidetrust.org%7C858d9379347a42ebb1da08dc09ff423e%7C0f3b87af26b447149206387641360d96%7C0%7C0%7C638396239145375964%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=IYDr2BHfcZQAnEyFhCVA5gjxFJkfS6nx2i2%2BlirPAEI%3D&reserved=0).

**Q. Who is carrying out the evaluation?**

**A.** A joint team from RAND Europe and the University of York are carrying out the evaluation. The overall lead for the research is Dr Jenny Bousfield from RAND Europe. She is supported by Dr Liz Newbronner from the University of York.

**Q. How will the research team evaluate the Health Grant**

**A.** Our first step in the evaluation is to talk to key people at the Thalidomide Trust to identify: what information the Trust can share with us about the health and wellbeing of beneficiaries; understand how the grant is administered and beneficiaries are supported to use their grants; and shape plans for the evaluation in more detail. We will then use several different approaches to understand how the Health Grant is working:

* Reviewing existing UK and international literature about the health and wellbeing of thalidomide survivors
* Looking at information held by the Thalidomide Trust that they have permission to share (e.g. from the Holistic Needs Assessments). No names or personal details will be shared with the research team
* Conducting a short health and wellbeing survey of all UK thalidomide survivors
* Talking to around 50 thalidomide survivors in discussion groups and interviews about how they have used their grants and the impact on their health and well being. We will also seek peoples’ views about the level of the grant and its distribution
* Interviews with Trust staff and other thalidomide organisations, academics, clinicians, policy representatives involved in supporting thalidomide survivors in the UK and internationally.
* The research team members will use their experience to pull all this information together and present it.

**Q. How will the voice of thalidomide survivors shape the evaluation?**

**A.** We want the voice of thalidomide survivors to be central to the evaluation. Liz Buckle, a thalidomide survivor herself, has joined the team as Expert by Experience Lead. There will also be three thalidomide survivors on the Research Advisory Group and an Experts by Experience Panel of six thalidomide survivors, who will help shape how the research is carried out.

**Q. How can I take part in the evaluation?**

**A.** You don’t have to take part in the evaluation if you don’t want to. However, if you would like to contribute your views and ideas, there are three valuable things you can do: volunteer to join the Experts By Experience Panel; complete the health and wellbeing survey when it goes live next year; and offer to take part in a focus group or interview.

**Q. What is the timetable for the evaluation?**

**A.** The evaluation is being carried out between October 2024 and February 2027. We will share initial findings with the DHSC in Summer 2026 and then the final report will be available in early 2027.

**Q. How will the Trust contribute to the evaluation?**

A. The evaluation is independent but the Trust will assist the research team by: contributing their knowledge of the Health Grant; sharing information about beneficiaries’ needs and Health Grant expenditure that they have your consent to share (this will only be done anonymously and in accordance with the consent you have given the Trust to do so. No identifiable information will be provided); and helping us invite beneficiaries to take part in the survey, and/or interviews and focus groups.

**Q. How will the findings from the evaluation be used?**

**A.** The findings will be used by the government in discussion with the Thalidomide Trust about how the grant operates and supported people affected by Thalidomide e.g. options for improving the distribution of the grant and/or additional support through the grant, to help thalidomide survivors maintain their quality of life.

**Q. Will the findings from the evaluation be shared with the thalidomide community?**

**A.** Yes. We will share findings from the evaluation with the thalidomide community in a number of ways, such as reports/summaries, newsletter pieces/videos, and presentations at thalidomide events.