

**Evaluation of the Health Grant by** **NIHR (National Institute for Health and Care Research)**

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| We have produced this Q&A to try to answer your questions although this is not a Trust activity so we do not have all the answers. |

**Q: Who made the decision to carry out an evaluation of the Health Grant?**

**A:** The evaluation was initiated by the Cabinet Office. Ever since the problems identified with the charity, Kids Company, in 2015, the Cabinet Office have had a duty to ensure effective scrutiny of all large grants awarded to charities on a non-competitive basis (non-competitive means other charities can’t apply for the same funding).

**Q: Why is evaluation being carried out now?**

**A:** The Cabinet Office would have liked to carry out a detailed evaluation at the end of the original 10-year Health Grant funding agreement we had (which ran from 2012 to 2022) before any decision was made to renew the agreement. However, this was pre-empted by the then Chancellor, Rishi Sunak’s, announcement of a commitment to lifetime Health Grant funding in March 2021 (on the basis of the detailed Case for Support produced by the Trust).

Our new agreement with the Department of Health & Social Care (DHSC) specifies that the level of funding provided will be reviewed every four years to reflect the number of beneficiaries and their changing health and wellbeing needs. The Cabinet Office approved the new agreement on condition that an evaluation was carried out before the first of these four-year reviews.

**Q: Why is the research being commissioned by the NIHR?**

**A:** All major research projects that relate to health and social care are undertaken by the NIHR. The NIHR has its own separate research budget which is separate from the NHS budget.

**Q: What exactly will the evaluation look at?**

**A:** The DHSC and NIHR have produced a research brief which you can see here. [https://www.nihr.ac.uk/documents/prp-37-01-07-understanding-how-to-support-people-affected-by-thalidomides-health-needs-an-evaluation-of-the-thalidomide-health-grant-research-specification/34402?fbclid=IwAR2nVhfBz3bm-NQInzoKe3aL8RlFr\_YvlWHZq22CqEh7iZjKxoG-3FhnoQQ\_aem\_AfDKOi6veyORdCUGtRlkeLGQneR1WTwxx4TlSiv\_\_r3TIF6jDweJLFREiWWK9cwai1I#timetable-and-budget](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: Did the Trust agree the research brief?**

**A:** No. We were sent a copy of the research brief by the DHSC and we raised a number of important concerns, including around what the research covered and the lack of background information for researchers about the Trust and about beneficiaries. These were not taken into account in the final research brief, but an Annex was included with the research brief which includes some (but not all) of the information we provided.

**Q: Why didn’t you tell beneficiaries about the evaluation as soon as you found out about it?**

**A:** We were aware that the planned evaluation may cause anxiety to some beneficiaries, and we didn’t want to worry them before we had a better understanding of what would be involved in the research and were in a position to answer questions about it. A number of beneficiaries have now become aware of the research which is why we have produced this Q&A to share what we do know.

**Q: How will the evaluation be done?**

**A:** This is not clear at this stage. Final applications from potential researchers do not have to be submitted until July 2024 and the project is not scheduled to start until two months after this date.

**Q: Will the Trust be involved in the evaluation?**

**A:** No funding has been allocated for Trust staff time and we do not want to divert staff time away from providing vital support to beneficiaries, so our involvement is likely to be limited.

We will share the aggregated information (that is total overall numbers) we have on beneficiaries increasing needs and the analysis of Health Grant expenditure that is produced every year from the data collected at HNAs and Health Grant Reviews. This will only be done anonymously and in accordance with the consent you have given us to do so. No identifiable information will be provided.

In addition, any communication with beneficiaries from researchers will need to be managed by the Trust.

**Q: Will I have to take part in any research that is done?**

**A:** No. Beneficiaries will have to agree to take part in any new research so you will only have to take part if you want to.

**Q: Is the evaluation likely to result in any changes to my Health Grant?**

**A:** The findings of the evaluation will be considered, alongside the Trust’s own data on beneficiaries and their changing needs, when we have the first of our four-yearly reviews of Health Grant funding in 2026. Any changes will have to be agreed with the Trust as part of this review process.

Because we have not been involved in the process, we asked the DHSC to respond directly to the early questions raised by beneficiaries - most of which relate to potential changes to the Health Grant – and their responses are attached.

**Q: Where can I find out more about the evaluation?**

**A:** At this stage we do not have any further information, but when we do, we will share it with beneficiaries.

**Answers to Beneficiary Questions asked of the DHSC**

1. **Why are you undertaking the review? what are you expecting to learn that the Trust doesn't already know (and has shared with you)?**

Conducting this review is a key opportunity for us to understand how well the current grant agreement operates in order to make improvements in the future.

We have to seek approval for each specific grant agreement from a central Cabinet Office panel. When we did this for the current four-year grant (2023-2027), the panel recommended that we do an evaluation of the previous 10-year grant beforehand. Given that we were working to tight timelines, we agreed to commission an external, independent evaluation before the next four-year review of the grant. Therefore, there is a risk that if we don’t do this evaluation, as agreed with the Cabinet Office, it may be more challenging to secure approval for future thalidomide grant agreements

The way the fund is currently distributed has remained the same for at least 10 years. We are mindful that a lot may have changed in that time as beneficiaries age and their health needs evolve– We would like to understand whether the way the fund is currently distributed is appropriately allocating funds in line with beneficiaries’ needs. Commissioning external research will help us better understand this.

1. **Are the Government looking to save money?**

The purpose of the evaluation is not for the government to save money. The aim is to understand how the distribution of the fund could be more equitable and efficient, and to learn about the impact of the fund on thalidomiders, which could improve future funding agreements.

1. **Are there likely to be big changes made to the way the Health Grant funds are distributed or what the funding can be used for?**

The researchers themselves are not able to make any changes to the Health Grant funds. The findings of the research may be used by the government in discussion with the Thalidomide Trust in order to improve the distribution of the fund and/or further support thalidomiders’ quality of life through the fund.

1. **Will beneficiaries have less control over the way their funding can be spent (i.e. will there be a move away from the current personalised, beneficiary-centred approach?)**

The researchers are not able to make any changes to how the grant funds are used. The findings may be used by the government in discussion with the Thalidomide Trust to make decisions about how future grants will operate, but there are currently no plans to move away from the current personalised, beneficiary-centred approach. The views of Thalidomiders will be key to the evaluation and we expect researchers to engage with Thalidomiders as part of their research.

1. **How was the budget set? And why is such a large amount of money being spent on this when it is so badly needed to support NHS services?**

A budget range is indicated based on the expected scale and timeframes needed for teams with the relevant expertise to undertake high-quality research. All applications submitted to the National Institute for Health and Care Research (NIHR) are subject to expert review, with value for money being one of the key criteria that peer reviewers and funding committees assess applications against.

The budget for the research comes from a separate pot of money that could not be used for NHS services.