



Taking the Pressure Off: Evaluation of the Health
Grant to Thalidomide-Impaired People

Interim Report – June 2011

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Abbreviation List

DFG	Disabled Facilities Grant
DLA	Disability Living Allowance
FACS	Fair Access to Care Services
IBR	Individual Beneficiary Review
ILF	Independent Living Fund
PA	Personal Assistant
PB	Personal Budget
SDA	Severe Disablement Allowance#

Executive Summary

In March 2010 the English Department of Health (DH) confirmed it was to make a grant of £20 million to Thalidomide-impaired people in England. The grant was matched proportionately by the Scottish, Welsh and Northern Ireland administrations, creating a UK wide grant of £26.4 million. The grant is intended to help Thalidomide-impaired people to address the exceptional health and health related needs they are experiencing as they grow older. It is being distributed by the Thalidomide Trust over three years from April 2010, in the form of an annual Health Grant to individual Thalidomiders. The DH stipulated that the impact of the grant should be evaluated and so the Trust commissioned Firefly Research & Evaluation to carry out a three year evaluation of the pilot scheme. This first interim report brings together the main findings from the first year of the evaluation.

Background

The agreement to make a 'Health Grant' to Thalidomide-impaired people in the UK was the culmination of a number of years campaigning by a small group of Thalidomiders, supported by the Thalidomide Trust. They see the grant very clearly as compensation or reparation for the UK government licensing Thalidomide back in the late 1950s and early 1960s without adequate checks and controls. It was important to the campaigners that individual Thalidomiders would not be expected to account to the Department of Health for their expenditure. The Trust therefore agreed a set of health related needs which are intended to guide Thalidomiders in their expenditure. These are - Independent Mobility; Home Adaptations; Communications Technology; Medical Treatment Costs; Respite; Personal Assistance; and Social Activities.

Approach to the Evaluation

The evaluation began in May 2010 and will run for three years until Spring 2013. Its main aims (which were agreed with the DH) are to:

- provide evidence of the impact of the grant on the health and well being of individual Thalidomiders
- assess how the provision of the Health Grant has (or may have) enabled individual Thalidomiders to reduce or avoid predicted future health needs
- examine the effectiveness of working through a national organisation to meet the needs of other geographically dispersed groups with highly specialised needs
- bring together the learning from the evaluation to support a decision on whether and how to create a permanent scheme after the current three-year pilot has ended,

There are two main parts to the evaluation – a) an in-depth study of the experiences of 60 Thalidomide-impaired people of using their Health Grants, based on annual interviews and the collection of data about health grant expenditure. This 'study group' was recruited through an open invitation to all thalidomide-impaired people in the UK. Its composition is roughly in proportion to the total number of Thalidomide-impaired people in each of the four UK nations and is broadly reflective of the numbers in each of the five

impairment bands used by the Thalidomide Trust and; b) a review of the operation of the Health Grant scheme, including work with the Thalidomide Trust to understand processes and costs involved in the management of the Health Grant. This report is based on the findings from the first round of interviews and data collection with the study group, and a series of interviews and discussions with key officers from the Thalidomide Trust.

Current Health Problems

There is already evidence that many Thalidomiders are experiencing significant health problems which are in some way related to their original Thalidomide damage. For some people there is a very obvious link between their impairments and the wear and tear on their bodies. For others, the problems are less obvious, for example, numbness and pain which may be linked to generalised nerve damage. The vast majority of participants (well over three quarters) said they were experiencing increasing levels of pain in their joints, neck, shoulders or back. Some participants described it as ‘arthritic’ pain but it had not always been formally diagnosed as such. For many, the pain was linked to having to over-rely on certain limbs (in compensating for shortened or missing limbs), or having to move/carry out certain actions in ways that stressed parts of their body. A large number of participants experiencing these problems were taking medication for pain management and some described unpleasant side effects associated with this medication.

A small number of the Thalidomiders involved in the study had a sensory impairment linked to the original Thalidomide damage and these participants also reported deterioration. Other participants relied on mouth pieces to aid communication, while one noted that he had to open bottles and containers with his teeth, which had caused dental problems. Just one person reported a specific ongoing mental health problem (anxiety), which they believed to be linked to the impact of Thalidomide but several participants described how their more recent health problems had made them more ‘irritable’, ‘grumpy’ or ‘low’. The consequences of the health problems described by participants went beyond dealing with pain and discomfort. A large number described feeling easily fatigued and how they needed to pace themselves and conserve their energy

A number of participants were taking prescribed medication for pain management, and a few reported having treatment or interventions, including surgery, chiropody, prosthetics and hearing aids. Several people had had physiotherapy through the NHS but in several cases this had not been a positive experience. Many people had previously bought health treatments and services privately because they felt they were more able to get what they wanted, when they wanted it. However, the majority of participants were actively trying to self-manage the impact of their condition.

Using the Health Grant

In using their Health Grants people interpreted health and health needs in a very broad way and used their funds for both treatment and prevention, and to address wider well-being issues. The information which the study group provided in late Autumn 2010 about the use of their Health Grants provided a useful early indication of the main areas of expenditure. Perhaps not surprisingly, Independent Mobility and Home Adaptations

were the top two 'health related needs' categories in terms of the percentage of participants who used their Health Grants on these things, and the proportion of total Health Grant expenditure. However, the range of expenditure varied considerably. Within the categories, types of expenditure linked to independent mobility (e.g. a new vehicle) and home adaptations (e.g. property improvements) were again the most common. However, holidays, accessibility aids, alternative therapies and medical/health treatments were also listed by many participants.

In terms of the adequacy of the Health Grant, around half the study group felt that it was significantly less than they needed to meet their health needs now, and many were particularly concerned for the future. Of those participants who felt the level of their Health Grant was adequate, nearly all said that it would only be adequate if it is continued after the initial three years.

Impact of the Health Grant

For many participants, getting the Health Grant had made them focus on their own health and well-being and often people had thought very carefully about how the money could be used to improve or maintain it. In that sense, having the Health Grant was empowering but some people also found it unsettling because it had forced them to confront their increased level of impairment or reduced independence. Many people felt that their Health Grant had enabled them to reduce the rate at which their health was deteriorating, although how they achieved this varied considerably between individuals. For many, having the Health Grant meant that they could do things like adaptations in the way they wanted or have much greater choice and flexibility, for example, in purchasing a new wheelchair or vehicle. This had clear practical benefits but it also had psychological benefits.

The impact of the Health Grant on participants' independence was particularly striking and this had important knock-on effects on people's emotional well-being, their personal safety and their family relationships. For many people, especially those with more severe impairments, the scope the Health Grant had given them to maintain or improve mobility had been very important. For some people the adaptations they had been able to make or their improved mobility had not only increased their independence, it had also made them feel safer and less vulnerable.

Perhaps the most widespread and positive benefit that participants described was the way in which the grant had taken away or substantially reduced their financial worries, and, again, the effect this had had on their emotional well-being. For some people, this was because the grant had made an immediate difference to their financial position, while for others it had given them a more general sense of financial security and made them feel more positive about the future. A very small number of people felt that their Health Grant hadn't made a significant difference because it was not enough money, or that it was too early to tell because they were waiting for adaptations to be completed or things they had bought to be delivered.

Conclusions

The findings from the first year of the Health Grant evaluation suggest that many Thalidomide-impaired people are experiencing a range of health problems, which they are in some way related to their Thalidomide damage. There was also a perception that level and complexity of these health problems was higher than those being experienced by contemporaries in the population as a whole.

In talking about the treatment or help people had accessed (or tried to access) to address their health problems, participants revealed widespread frustration with mainstream health and social care services. Many clearly felt that statutory services were either not meeting their needs, or were not meeting them in the way or to the standard that they wanted. There were a wide range of reasons for this but people often cited a lack of awareness of how Thalidomide damage had affected people, both in terms of their anatomy and physiology and the way they had to use their bodies. One of the conditions set down by the Department of Health when it confirmed the Health Grant was that *“it must not be used to meet needs that are already being met through NHS funding”*. The experiences of the study group (and the previous findings from the HealthLink evaluation) suggest that there is a fundamental lack of knowledge and understanding of the needs of Thalidomide-impaired people in the NHS, and as a result people often receive poor or inadequate care. In the light of this it is not surprising that a number of Thalidomiders were choosing to use their Health Grants to buy health care or alternative therapies, which are theoretically available via the NHS.

A final overarching finding was that level of impairment was not a predictor of the health problems people were experiencing, or how they were using their Health Grants to address them. Although there were certainly common themes in terms of the types of health problems described, how people were managing these problems, and their strategies for preventing further deterioration or maintaining their health and well-being, varied enormously. It is therefore vital that Thalidomide-impaired people continue to have the freedom to use their Health Grants in whatever ways work best for them, regardless of whether the expenditure appears to be health-related.

Lastly, looking to the second year of the evaluation, we feel that there are a number of issues it would be valuable to explore in greater depth, in particular:

- the cumulative or ongoing impact of the Health Grant in terms of reducing deterioration or preventing future health problems
- changes in people’s use of health and social care services
- the context in which people are using their Health Grants, notably the changes taking place in the benefits system and in social care
- linking the findings from the evaluation to the *Securing Our Futures* project¹ and the wider literature on the costs of disability.

¹ The project is being led by the National Advisory Committee, which is made up entirely of Thalidomide-impaired people. The project is focusing on the cost of living with Thalidomide-impairment, and is collecting data from a large number of Thalidomide impaired people in the UK.

Chapter 1

Introduction

In March 2010 the English Department of Health (DH) confirmed it was to make a grant of £20 million to Thalidomide-impaired people in England. The grant was matched proportionately by the Scottish, Welsh and Northern Ireland administrations, creating a UK wide grant of £26.4 million. The grant is intended to help Thalidomide-impaired people to address the exceptional health and health-related needs they are experiencing as they grow older. It is being distributed by the Thalidomide Trust over three years from April 2010, in the form of an annual Health Grant to individual Thalidomiders. When they confirmed the grant, the DH set down a number of conditions:

- The Health Grant must only be used to meet health-related needs
- It must not be used to meet needs that are already being met through NHS funding
- The Thalidomide Trust must account to the Department of Health for how the money is used
- The impact of the pilot scheme must be evaluated

To assist them in addressing these conditions, the Thalidomide Trust commissioned Firefly Research & Evaluation (previously Acton Shapiro²) to carry out a three-year evaluation of the pilot scheme. This first interim report brings together the main findings from the first year of the evaluation. It draws some early conclusions and suggests a number of issues which should be explored in greater detail in the second year of the evaluation.

1.1 Background and Context

The agreement to make a ‘Health Grant’ to Thalidomide-impaired people in the UK was the culmination of a number of years campaigning by a small group of Thalidomiders, supported by the Thalidomide Trust. They see the grant very clearly as compensation or reparation for the UK government licensing Thalidomide back in the late 1950s and early 1960s without adequate checks and controls. There is also a strong sense of achieving some social justice for the damage Thalidomiders suffered. However, there is an acceptance by many of those involved that it was politically expedient to refer to the payment made as a ‘grant’ and that referring to it as a Health Grant also went some way to recognising the exceptional health problems Thalidomide-impaired people are experiencing as they age.

There is now clear evidence that Thalidomide-impaired people are experiencing significant health problems which are either directly related to their original Thalidomide damage or the result of the way they have had to use their bodies. These health needs are very broad ranging but often very specialised in their nature. The work of the Thalidomide Trust’s HealthLink service and the findings from the evaluation of its early

² From 1 May 2011, the research and evaluation team from Acton Shapiro has formed a new organisation – Firefly Research & Evaluation - and the contract for the remaining two years of the evaluation has transferred to Firefly.

work clearly revealed that statutory health and social care services often find it difficult to understand and address the specialist needs of Thalidomide impaired people. The Health Grant gives Thalidomide-impaired people the scope to use their grants in the way that works best for them i.e. to ‘self-manage’.

It was therefore important to the campaigners that individual Thalidomiders would not be expected to account to the Department of Health for their expenditure and would be free to spend it as they wished in order to meet their health and health-related needs. The agreement reached with the Department of Health was that a) as noted above, the impact of the pilot scheme would be evaluated and b) a set of ‘health-related needs’ would be agreed between the DH and the Thalidomide Trust, and used to guide Thalidomiders in their expenditure. Seven categories of ‘health-related needs’ were set out in a guidance note:

- **Independent mobility** - (vehicles, vehicle adaptations, wheelchairs, etc.) ensuring that you can lead an independent life without subjecting yourself to unnecessary stress and strain, and reducing your vulnerability to harm.
- **Home adaptations** - to ensure you can lead a safe and independent life in your own home as far as possible, also without subjecting yourself to unnecessary stress and strain or doing things that could be harmful.
- **Communications technology** - systems relevant to your disability, again aimed at protecting your body (including sensory organs) from harm, and also reducing your vulnerability in general terms - or providing information to enable the Trust and others to support your health needs effectively.
- **Medical treatment costs** - other than those already covered by the NHS. This could include various therapies found to be helpful of types not funded for you by the NHS.
- **Respite** - therapeutic “breaks” for either yourself or your carer(s), intended to relieve such things as musculoskeletal pain, or the general stress experienced by people in unremitting care situations.
- **Personal assistance** - including care in the general sense, but also the range of tasks needed at home or work that would otherwise involve putting your body at risk of further damage. Many of you will already receive personal assistance funded by your local authority or the Independent living Fund; the Health Grant can be used to purchase additional personal assistance with activities not covered by existing funding.
- **Social activities** - activities that help you get out, reduce isolation and improve your mental and physical well-being.

Generally the campaigners regarded the overall size of the grant as acceptable and more or less what they had expected. However, there is a very strong view that the Health Grant really must be made permanent, beyond the current three years. As one campaigner put it:

“It needs to be on a more sustainable and assured basis....I think people could then plan for the future with a bit more confidence than they can at the moment.”

1.2 Approach to the Evaluation

The evaluation began in May 2010 and will run for three years until Spring 2013. Its main aims are to:

- provide evidence of the impact of the grant on the health and well being of individual Thalidomiders, in particular how they have used their Health Grant to address their health and support needs, and what this has added to the annual grant received from the Trust
- assess how the provision of the Health Grant has (or may have) enabled individual Thalidomiders to reduce or avoid predicted future health needs
- examine the effectiveness of working through a national organisation to meet the needs of other geographically dispersed groups with highly specialised needs (including providing evidence of the transferability of this model and describing the necessary conditions for wider implementation)
- bring together the learning from the evaluation to support a decision on whether and how to create a permanent scheme after the current three-year pilot has ended, including evidence on the likely future health-related needs of Thalidomiders and any anticipated shortfalls in existing statutory services and Diageo funding to meet these needs³.

There are two main parts to the evaluation – an in-depth study of the experiences of 60 Thalidomide-impaired people (the ‘study group’) of using their Health Grants, and a review of the operation of the Health Grant scheme. Both of these are described in more detail below.

1.3 Work with the Study Group

All Thalidomide-impaired people living in the UK (except those subject to Court of Protection or those where particular circumstances, e.g. terminal illness, made it inappropriate for them to be approached) were contacted via the Thalidomide Trust and invited to take part in the study. The aim was to recruit a sample of approximately 10% or 45 beneficiaries, roughly in proportion to the total number living in each of the four UK nations, and broadly reflective of the number of Thalidomide-impaired people in each of the five impairment bands used by the Thalidomide Trust. Over 70 beneficiaries expressed an interest in being involved and sixty were eventually included in the study group. A brief profile of the study groups is shown in Section 1.2.3 below.

In late Autumn 2010 the study group members were asked to complete a brief form (see Appendix 1) indicating how they had used their Health Grant in the six months since they received it, and approximately how much they had spent in each of the seven categories agreed with the DH, plus two categories added by the evaluation team – ‘General Living Expenses’ and ‘Other’. The General Living Expenses category was added because anecdotal evidence from the National Advisory Committee (NAC) and HealthLink suggested that some Thalidomiders were using their Health Grant to reduce their working

³ Following the legal settlement in the 1970s, Distillers (now Diageo) set up a trust fund which is administered by the Thalidomide Trust and pays the Annual Grants made to UK Thalidomiders.

hours, or give up work, or buy things which simply made their daily lives easier (e.g. buying ready chopped vegetables or clothes and shoes with fastenings that were easier to use). The information they provided was used to give an early overview of expenditure (see Chapter 3) but also helped inform the interviews conducted with the study group in early 2011. The survey did not attempt to look more widely at the costs Thalidomide-impaired people are incurring in simply living with their impairments, as the NAC *Securing Our Futures* project⁴ is exploring at this issue.

In February 2011, all members of the study group were asked to take part in a telephone or face-to-face interview, in which their experience of using their Health Grant and the impact it was having on their health and well-being could be explored in more depth. 52 Thalidomiders were eventually interviewed and one person opted to complete the questions by post. Of the 52 who were interviewed, two (who had hearing impairments) were interviewed face to face and two (who had communication difficulties) were interviewed via family members. A copy of the interview guide used is attached in Appendix 2. All the interviews were recorded and transcribed as ‘notes and quotes’ rather than full transcriptions.

The survey of expenditure and in-depth interviews with the study group will be repeated at the same time annually for the next two years. In addition, in Year 2, a small number of study group members have agreed to keep a Health Grant diary, in which they can record in ‘real time’ their thoughts and feelings about using their Health Grants.

1.3.1 Profile of the Study Group

When they consented to take part in the evaluation, the study group members kindly provided a small amount of biographical information, including details of their living arrangements, their housing circumstances and their employment status. They also agreed to the Thalidomide Trust providing us with very limited information about them (i.e. details of their impairment band, their Annual Grant and their Health Grant). This information is summarised in the tables and charts below.

The tables below show the number and gender of Thalidomide-impaired people in each of the four nations in the UK (Table 1) and the same information for those involved in the study group (Table 2).

TABLE 1 DEMOGRAPHIC DATA ON ALL UK THALIDOMIDERS

Country	Gender	Band 1	Band 2	Band 3	Band 4	Band 5	Total
England	M	19	47	49	28	17	160
	F	18	44	56	22	25	165
N. Ireland	M	1	4	1	1	2	9
	F		1	5	1	2	9
Scotland	M	4	7	13	3	6	33
	F	3	6	9	2	1	21
Wales	M	1	1	8	6	2	18
	F		2	7	3	1	13
Total		46 (11%)	112 (26%)	148 (35%)	66 (15%)	56 (13%)	428

⁴ The project is being led by the National Advisory Committee, which is made up entirely of Thalidomide-impaired people. The project is focusing on the cost of living with Thalidomide-impairment, and is collecting data from a large number of Thalidomide impaired people in the UK.

TABLE 2 DEMOGRAPHIC DATA ON STUDY GROUP

Country	Gender	Band 1	Band 2	Band 3	Band 4	Band 5	Total
England	M	1	2	5	5	4	17
	F	2	6	7	3	7	25
N. Ireland	M			1		2	3
	F						
Scotland	M	1	1	3		1	6
	F		1	2	1		4
Wales	M			1	1		2
	F			2	1		3
Total		4 (7%)	10 (17%)	21(35%)	66 (15%)	14 (23%)	60

Overall, while females comprise just over half of all Thalidomiders in the UK, they are only 41% of the study group. The number of study group Thalidomiders in the five impairment bands is broadly similar to the spread nationally, although the study group has a slightly higher proportion in Band 5 and a lower proportion in Band 2.

In terms of people living arrangements and housing circumstances, the majority of study group members live with a partner/spouse or family member, with 18% living alone. 87% of participants live in a home which they own.

Figure 1 Living Arrangements

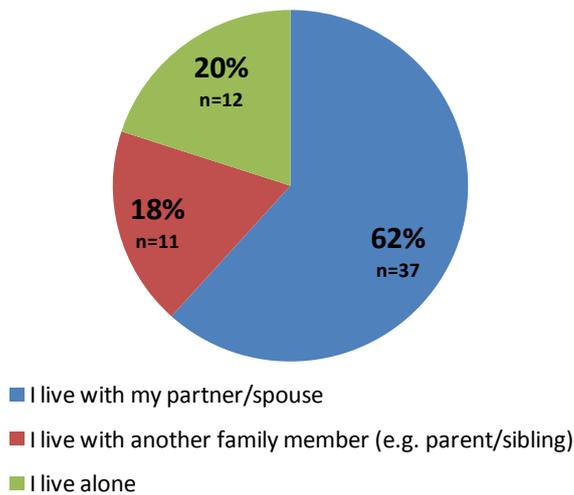
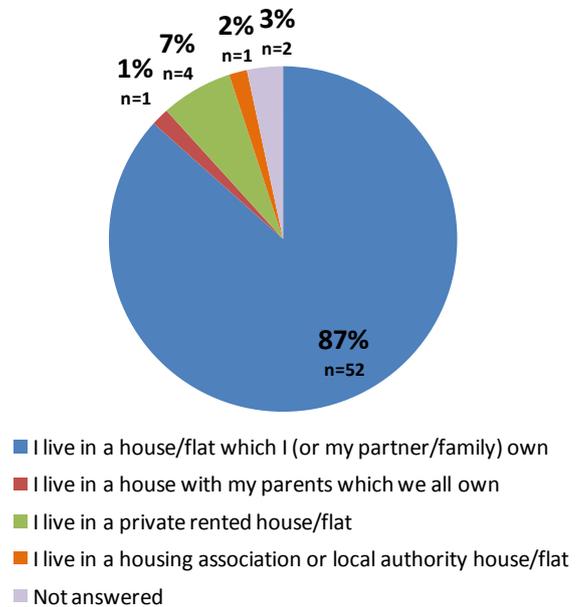
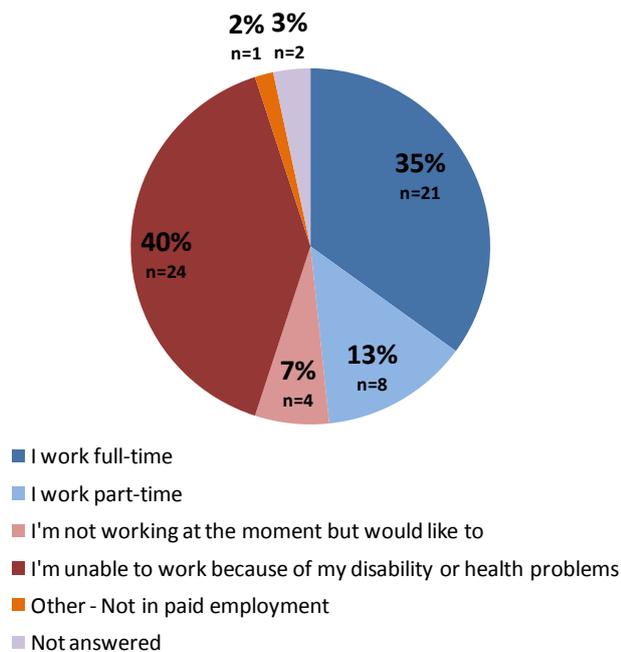


Figure 2 Housing Circumstances



In relation to employment, almost half of those involved in the study were in employment, either full or part time. 40% (n=24) said they were unable to work because of their level of impairment and a small number (7%, n=4) said they were unemployed but would like to work.

Figure 3 Employment Status



1.3.2 Benefits and other financial support

It is not within the scope of this study to consider whether the level of benefit people are in receipt of is appropriate, but the information in Table 4 below does help to give some indication of the range of benefits people are accessing, and where these might be lower than could be assumed. Further analysis shows that those in receipt of benefits are broadly clustered towards impairment bandings 3-5, as might be expected, though there was an example of a person at impairment banding 5 who is not in receipt of DLA.

Fourteen people were in receipt of personal budgets and these people were all across impairments bandings 3-5. Nobody was in receipt of a personal health budget; indeed hardly anyone had heard of this new way of funding NHS support which is currently being piloted across England. However, this is understandable, as very few of the pilot sites are focusing on conditions which are particularly pertinent to people affected by Thalidomide.

It is of interest to note that a very low number of people had accessed the Disabled Facilities Grant, especially in light of the fact that a reasonably high number of participants chose to use their Health Grant on housing adaptations.

TABLE 4 BENEFITS

Benefit	Yes (n)	No (n)	Yes (%)	No (%)
Independent Living Fund	5	47	10%	90%
Disability Living Allowance (DLA)	44	9	83%	17%
Mobility component of DLA	27	26	51%	49%
Disabled Facilities Grant	1	51	2%	98%
NHS Continuing Care funding	1	51	2%	98%
Personal Budget (from Social Services)	14	38	27%	73%
Personal Health Budget	0	52	0%	100%
Incapacity Benefit	9	43	17%	83%
Severe Disability Allowance	5	48	9%	91%
<i>Other</i>	3	49	6%	94%
<i>No benefits</i>	5	47	10%	90%

n=53

1.4 Managing and Distributing the Grant

The Trust has a well-established and well-accepted system for distributing its funds, which is based on each person's level of impairment. Beneficiaries fall into one of five impairment bands, although people can move between bands if their impairments change (e.g. if previously undetected problems with internal organs emerge). At an early stage it was agreed that the Health Grant should be distributed on the same basis. However, in this first year the calculation of the grant was complicated by a number of factors. The publicity about the grant led to a number of people contacting the Trust to see if their impairments were the result of Thalidomide damage and so the total number of beneficiaries was changing. Also, some existing beneficiaries were moving between impairment bands. In addition there was the issue of overseas beneficiaries. The Health Grant is officially only for Thalidomiders living in the UK. However, there was a strong view within the Thalidomide community that all UK-born Thalidomiders should benefit from the grant, regardless of where they now live. The Trust has therefore had to 'adjust' the annual grants to UK resident Thalidomiders, so that a Health Grant can be paid to those living overseas.

While these issues needed to be taken into account, the Trust did not wish to delay getting the Health Grants out to people and so it was decided that, for 2010, the Health Grants would be set at 75% of people's Annual Grants and then adjusted in future years. Table 5 below shows the maximum and minimum Annual and Health Grants received by the study group members.

TABLE 5 ANNUAL GRANT AND THE HEALTH GRANT RANGES

Banding	Annual Grant 2010/2011			Health Grant 2010/2011		
	Max	Min	Average	Max	Min	Average
band 1	£13,064	£10,314	£11,689	£9,798	£7,735	£8,767
band 2	£19,252	£14,439	£16,124	£14,439	£10,829	£12,093
band 3	£26,816	£20,627	£23,329	£20,112	£15,470	£17,496
band 4	£32,605	£27,503	£29,623	£24,454	£20,627	£22,217
band 5	£48,131	£35,754	£39,045	£36,098	£26,815	£29,283

1.4.1 The cost of managing the grant

Although the system for distributing the Health Grant is based on that used for the Annual Grant, the Trust has incurred some additional costs. It had, in effect to build a parallel accounting system within their management information system. This, unfortunately had knock-on implications for the part of the Trust's website which beneficiaries use to look at the Trust-related finances, and so for much of 2010, the information shown there was incorrect. The other main direct cost will be additional time needed from the Trust's auditors to ensure that the adjustments and offsets have been done correctly.

There have also been some additional indirect costs in terms of staff time, which has been largely absorbed by the existing team. These were:

- the time required by the Finance Manager and his assistant to calculate the grants and then distribute them
- the extra work involved in contacting beneficiaries about their Health Grants (the Trust does not have an automated system for payment. To protect individuals and prevent fraud, they always require a request from the beneficiaries for payment)
- some time needed by Trust staff and the HealthLink team to respond to individual Thalidomiders questions about the use of their Health Grants.

The costs associated with managing and distributing the Health Grant will be explored more fully in years two and three of the evaluation.

1.5 Study Group Views on the Administration of the Health Grant

The vast majority of the participants thought the administration of the Health Grant had worked well.

1.5.1 Information

Most thought the information they had been sent was clear and easy to understand, and they felt it explained in detail what it could be spent on.

“I think the letter made it very clear that it was my responsibility to spend it wisely, and I think the letter made it clear that it was for three years as a pilot – and that's been very much in my mind that I need to get some things done now.”

“The impression I got was that you could spend it on anything to improve your quality of life.”

However, a small number of participants said they had found the information difficult to understand, with terms like ‘respite’ not being explained, which caused some confusion on how it could be spent.

“No, not in the first instance – I didn’t really have a clue. Initially it wasn’t very clear at all. It felt as if it was being controlled – you can’t spend it on ‘x’ but you can spend it on ‘y’.”

It was suggested by a few participants that the information on the Health Grant needs to be free from jargon, easy to read and understand and accessible to everyone. Some said that they would like clearer guidance on how the money could be spent, as they had underlying anxieties that they may not be spending it the right way. A number of participants also suggested that others might benefit from advice on how to use it wisely to promote their health and prevent further deterioration.

“I think they could have been a bit tougher saying don’t go spending it on luxury goods. They could have been much clearer and more positive about how investing in their [Thalidomiders] bodies rather than spending it on a holiday or whatever would secure them a better future, better independent living. I think they tend to ignore the fact that we do better the more independent we are, we have a better life psychologically.”

1.5.2 Apportioning the Health Grant funds

The majority of participants were satisfied that the Health Grant had been apportioned on the basis of existing impairment bands. Most thought that was the fairest way to reflect their level of impairment.

“It is the fairest way to get the measure of each person’s individual disability. I think it is fair because I think the Trust is fair. Their rationale is one of fairness. And it is a formula that has worked historically.”

A number of participants, who had less severe impairments, said that it was the right way to distribute the Health Grant because each person had different needs and these are recognised in the existing bands.

“I believe that there’s a lot worse than me with Thalidomide, and if they need more attention, then they should get more. People that are more disabled need more help – simple as that.”

However, a few participants queried the use of existing impairment bands on the basis that some people may be deteriorating at a faster rate than others. A number suggested that a re-assessment may be beneficial to re-position them in the banding system:

“I felt that was wrong. I’ve always been fit and active, I’ve always had physical jobs. Now I’m finding it more and more difficult because maybe I’ve put more strain on my body than someone who hasn’t had a physical job. I feel I’m

deteriorating quicker than someone who's maybe worked in an office all their life. Is it wrong to say that I'm deteriorating quicker than someone who has the same disabilities as myself but hasn't been as active?"

A few participants said they did not understand how the existing impairment bands had been calculated and so could not comment on whether it had been an effective way to calculate the Health Grant.

1.5.3 Overall administration

Nearly all the participants said that the overall administration of the Health Grant had been straightforward, with many saying that they *"couldn't fault it"* and that it had *"worked very well."*

"I can't fault the administration. As soon as they knew about it we were informed about it. The money came and it was a very nice surprise how much we got."

Most suggested that The Thalidomide Trust was best placed to manage the Health Grant's distribution, as it had the necessary *"experience, knowledge and expertise."* A few participants did comment, however, on the delay in the grant becoming active. They said they should have had the first year's funds in April 2010 but did not receive them until June 2010.

"I think the drawback on it in its first year was the fact I think the first payments were made in June [months late]. I think they announced what they were going to do a bit too quickly. They should have kept quieter about it until the 'i's were dotted and the 't's were crossed."

A small number of participants said it was too early for them to comment on the administration as the first year had yet to be completed. A few highlighted their fears that, as funding to social services is being cut, it may be detrimental to them to have their Health Grant money in their bank account. Some were frightened that they may lose benefits if their Health Grant money is visible in their bank account.

"It could be difficult to explain away whereas if the money was with the Trust that is easier to say it's not savings."

Chapter 2

Current Health Problems

There is already evidence that many Thalidomiders are experiencing significant health problems which are in some way related to their original Thalidomide damage. For some people there is a very obvious link between their impairments and the wear and tear on their bodies. For others, the problems are less obvious, for example, numbness and pain which may be linked to generalised nerve damage. Before looking at how people had used their Health Grants and the impact this had had on their health and well-being, we felt it was important to understand the health problems they were experiencing and any consequent effect they were having on them and their families. This chapter briefly describes these problems and the help or treatment people had accessed (or tried to access) to address them. It also considers the wider impact of these health problems on family and friends.

2.1 Health Problems linked to Thalidomide Damage

In responding to this question, participants were asked to focus on more recent health problems which they believed might be linked to the Thalidomide damage, rather than the original impact of the Thalidomide damage or more 'general' health problems.

The vast majority of participants reported negative health impacts which they believed were linked to the Thalidomide damage. Only three participants reported no adverse health impact. For the majority of those reporting difficulties, the problems appeared to be linked to 'overuse' of parts of the body which were compensating for the lack of certain limbs. However, there were many reports of acquired health problems where the cause could not be verified but which the participants believed could be linked to Thalidomide.

The reported health impacts are reported in more detail below.

2.1.1 Joint/back/neck pain

The vast majority of participants (well over three quarters) said they were experiencing increasing levels of pain in their joints, neck, shoulders or back. Some participants described it as "arthritic" pain but it had not always been formally diagnosed as such. For many, the pain was linked to having to over-rely on certain limbs (in compensating for shortened or missing limbs), or owing to having to move/carry out certain actions in ways that stressed parts of their body.

"My original disability is short arms with incomplete shoulders. [I have an] incredibly painful neck and right shoulder because my right arm is the one that does all the work. It started about ten years ago but year on year it's just getting worse and worse."

"[The strain in my lower back] was muscular. It was a strain from overuse. Because I have short arms everything I do comes from my core muscles. You know, even getting out of an arm chair, I sort of pull from my stomach not with my arms."

“I delegate an awful lot now, which I’ve never done before. It’s a mix. You can’t stand there doing hours of ironing – your body won’t let you do it. Can’t even stand now like I used to try to make a cheese sauce – just can’t do it – because that’s it – your body’s had it really – it’s just worn out from bending.”

For a smaller number of participants, they could not identify why they had recently developed aches and pains or numbness in certain limbs or joints, where it was not linked to an obvious ‘stressor’, and a couple of people were undergoing tests to establish the cause⁵.

Several participants with more ‘generalised’ aches and pains said they felt like they were prematurely ageing:

“I am probably experiencing the advanced ageing that most people experience in their late 70s...”

Many people who were experiencing painful joints/back reported reduced mobility, decreased ability to undertake household tasks (such as cleaning), reduced dexterity, reduced ability to drive distances, limitations on travel owing to not being able to sit for long periods, disruption to sleep and increased risk of falling.

“Small things get on top of you when you feel in pain. I seem to spend all day doing the basics, getting up, getting dressed, pottering around the house.”

“The implication of the numb right leg is that [my] walking becomes more scary and difficult because I’m not quite sure what my right leg is doing.”

A large number of participants experiencing these problems were taking medication for pain management and some described unpleasant side effects of these, including stomach ulcers in one case.

A few expressed concern about weight gain, which was linked to the fact that their joint pain prohibited them from undertaking necessary exercise:

“I know that everybody does [gain weight] when they get older but it’s exacerbated for me because I’m limited in the kind of exercise that I can do.”

2.1.2 **Sensory impairment, dental issues and skin problems**

A small number of the Thalidomiders involved in the study had a sensory impairment linked to the original Thalidomide damage and these participants also reported deterioration. One person who was deaf and used sign language was also experiencing pain and numbness in her arms/shoulders, bringing additional complications for signing/ communicating for any length of time. A small number of participants reported recently acquired hearing or sight impairment, which they believed was more extreme than that linked to normal ageing, and thought this might be linked to Thalidomide.

A couple of participants rely on mouth pieces to aid communication, while another noted that he had to open bottles and containers with his teeth. This had caused dental problems.

Some participants experienced sores and other skin problems, linked to the use of prosthetics or sitting in a wheelchair.

⁵ Researchers from Imperial College London are currently studying neuropathic symptoms being experienced by Thalidomide-impaired people.

“The skin is so tender and that is the major issue that I have, and unfortunately that’s the problem why I had to pack up work....You just can’t even touch the skin, it’s just so painful.”

2.1.3 Complications linked to accidents/multiple health problems

A small number of participants had experienced an accident/health problems unrelated to Thalidomide, but their treatment and recovery from this was complicated by their by Thalidomide damage. For example, one person had been involved in a car accident which had damaged their leg, which was already shortened as a result of Thalidomide; the resulting treatment has in turn altered their gait and is causing pain, requiring further treatment. Another person described the complications for recovery after surgery:

“I don’t believe that was Thalidomide-related but I do believe the aftermath of getting over it was. And of course people had to be around me a long time because of course I was bandaged so I was being lifted – you can imagine, not having arms to push yourself up with. I can laugh now but it wasn’t pleasant at the time.”

Some participants noted that it was not necessarily the severity of a particular condition or health problem but the combination that caused the problems:

“None of my symptoms are very severe but they are constant and together are very debilitating.”

2.1.4 Mental health

Just one person reported a specific ongoing mental health problem (anxiety), which they believed to be linked to the impact of Thalidomide and this had affected the whole family. However, several participants described how their more recent health problems had made them more ‘irritable’, ‘grumpy’ or ‘low’.

“It perhaps leads on to be more tired, irritable and frustrated.... if I push myself too much it tends to make me bad tempered.”

“People do not always understand or want to know about the level of pain you are in.”

“In terms of the mental side - I have been getting depression more and more over the last few years. And I don’t know what has caused that – it’s just kind of a general thing...certainly putting on weight has not been good for my mental well-being.”

“When I talk about aches and pains in my body with Thalidomide – it’s like – if I can’t bend because my back is aching or hurting, then I can’t functionally do the things that I need to do. I need to have someone come and literally wipe my bottom. Pain goes everywhere else. It becomes a whole, psychological, damaging thing. You’re in pain physically and you’re in pain emotionally and mentally – because nobody likes to have their bottoms wiped.”

A small number of people also said that their confidence had been undermined and several reported how difficult it was to accept becoming more dependent on others to assist with certain tasks:

“There are simple tasks I feel I could do and I simply can’t - opening a jar or something. For my own peace of mind I feel I should be able to do things myself and I can’t. This does affect my attitude. It feels so frustrating. Everybody wants to feel self-reliant.”

2.1.5 Fatigue

The consequences of these health impacts described by participants went beyond dealing with pain and discomfort. A large number described feeling easily fatigued and how they needed to pace themselves and conserve their energy:

“All you want to do is just lie down and sleep. I mean I’m only 48 and I shouldn’t be having to do that.”

“I used to wake up in the morning and hit the ground with my feet running... I can go full pelt for 48 hours but then I absolutely crash afterwards, I’m absolutely wiped for several days. My batteries don’t re-charge very well anymore.”

“If I want a glass out of the cupboard, I have a stool in the kitchen, so I have to pull the stool across, stand on the stool, reach up, get the glass, come back down, put the stool back. Prior to that, before having a stool, I used to stand on the work surface – so all those extra activities in order just to get a glass out of the cupboard, obviously is going to make me more tired than someone who can just reach up and get it out themselves.”

2.2 Treatment or Help with Health Problems

2.2.1 NHS healthcare

Few participants described any substantive interventions by the NHS in relation to their health issues other than medication for pain management. Of those who had received treatments linked to Thalidomide damage, these included surgery, chiropody, prosthetics and hearing devices, but numbers were low. A much larger number of participants had been in receipt of physiotherapy services at some point in the past.

A very small number of people were undergoing investigations for health problems to see if they were Thalidomide-related, which were not yet resolved. One person had requested laser eye treatment (linked to sight problems) and this had been declined by the PCT.

A few participants were happy with the NHS treatment they received at a primary or secondary level, with an example of one GP providing beneficial acupuncture treatment. However, a much larger number of respondents were dissatisfied with NHS responses, for example:

- **Availability** – for example, some participants described how difficult it had been for them to attend chiropody/physiotherapy appointments at inflexible times, often at some distance away. Physiotherapy was frequently criticised because it was only available for short periods:

“You have to be re-referred to be seen again. And actually they really don’t like you to be a long-term patient. To be honest, by the time you’ve had the six weeks and then you go away – by the time you’re re-referred, re-seen and re-evaluated,

they give you another six weeks – you’re back to square one. You need to have something that is ongoing all the time.”

Some also described long waiting lists for access to these services:

“To be honest, the NHS physiotherapy services in [the city] are absolutely appalling. There’s a six to twelve week waiting...probably twelve to fourteen now actually. And then you get there and are told to go away and do these exercises.”

- **Standardised responses** – for example, many participants were unhappy that health service responses did not take into account the impact Thalidomide had on them and the way in which it might need to be taken into account in certain interventions. Again, physiotherapy came in for particular criticism here:

“It was vague/generalised - focused on walking.”

“It was not adequate. The exercises were not geared to me as a disabled person and posture... not tailored to me.”

“In my case that is no good because the way I do things remains the same. I can’t change the way I do things. Consequently, a few weeks later the problem crops up again so I would have to go back to the doctors on a regular basis [to be re-referred] and I just can’t be bothered. I just haven’t got time in my life to do that. So I just put up with the pain.”

“The trouble I find with the NHS is that you get given six weeks. And six weeks is not enough time. It’s not a mend-it job. It’s a maintenance job. And the NHS doesn’t do that. I’ve got more to do with my life than sit around dealing with the inefficiency of the NHS. It’s much easier now that I’ve got the money to have my own dignity.”

In other examples, medical equipment was not suitably tailored:

“They struggled with the mechanical equipment to take a blood pressure reading and eventually realised that it was giving an incorrect reading ... Again, because of my condition, there was a lack of knowledge of how to deal with it. It actually got quite serious – they almost lost me as a result of it.”

- **Staff attitudes/responses** – a few participants described poor attitudes or poor professional responses among health staff. For some they did not feel their GP understood their condition or took any interest; there were extremes where some people felt their condition was ignored and others where they thought that every health issue was interpreted as being linked to Thalidomide. Others described circumstances in which there was a lack of understanding of disability issues:

“NHS staff couldn’t understand why I rely on my feet to do things. They did not understand the reasons why I was so manic and so insistent for them to X ray. It was almost beyond their comprehension. I tried to tell them how dependent I was on [my feet]... I told the consultant that I used my feet to go to the toilet and she actually laughed.”

“It’s so rushed, you don’t always have time to explain.”

“[Health professionals] don’t actually see you as a whole person.”

“I’ve never managed to find any support that’s been constructive. There’s a complete blank ‘don’t-know-what-to-do,’ because I’m not that badly affected. And so there is no support.”

It should be noted that a significant number of people interviewed described these as *past* experiences of health services. Several had elected to stop using NHS secondary health services where this was possible/desirable and some had chosen to seek support from the private sector instead.

2.2.2 Private sector healthcare

Many of those interviewed had purchased treatments privately prior to the Health Grant, including hearing aids, alternative therapies, oscillation therapy or ultrasound, treatments from back specialists/chiropractors and chiropody. The most commonly cited were physiotherapy and remedial or relaxation massage.

A small number of people who required surgical interventions (or were considering this) stated that they had chosen to/would choose to pay privately. In one case this was because of a bad experience with the NHS, after which trust was seriously undermined; also the interviewee doubted whether the NHS would fund the treatment. In another example, it was because the person’s private care plan enabled the carer to stay in hospital at the same time.

Other examples were where people had already selected, or were considering, privately-sourced support, included dentistry, prosthetics, wheelchairs and hearing aids. The primary reason for this was that participants did not feel they could access the quality of support/equipment or obtain advanced technology via the NHS.

Satisfaction with privately-sourced healthcare appeared to be much higher, in part because people could access it as and when they wanted (in their own homes in some examples) and also because they could select from a wider range of treatments, as many of the services people purchased are not necessarily available on the NHS. In the case of physiotherapy, however, the majority of those accessing this privately had had previous experience of NHS services and they were much happier with the private services because these were tailored to their condition and circumstances. However, there were a couple of exceptions where people had utilised private sector therapists, who they felt had not taken their condition into account and could have caused potential harm.

Cost had been a barrier to some in accessing privately-funded services and many welcomed the Health Grant in enabling them to access support for the first time, to increase the amount of sessions they were having or to reduce the financial burden of paying for treatments.

2.2.3 Social care

A very small number of participants were in receipt of social care support and this was generally in the form of personal budgets to fund personal assistants to carry out tasks such as cleaning and personal care. Those interviewed commented on how empowering it had been to have a personal budget and the choice and control this had given them.

For one person who was not on a personal budget their experience had been more negative:

“[the homecare service] was awful. Their time slots changed on a daily basis. The person coming in changed. I’ve got an autistic child in the house who doesn’t like change. And it was just too awful. I had to cancel it in the end – I just couldn’t cope with all the changes and all the different people coming in.”

A small number of participants said that they had previously had a community care assessment but had been below the council’s eligibility threshold. People trying to access equipment or occupational therapy support via social services expressed frustration, linked to lack of professional understanding or service responsiveness:

“They are one-dimensional and focused on the over 60s.”

“[The occupational therapist] was all very vague and suggestive.”

“The thing that we’ve always found is that they don’t listen to what you say. They seem to sit here and say that they understand and they know what we want but when they actually come back, they give you things that you’ve told them you can’t manage with.”

“I never, ever bothered with social services because every time I’ve been to bother them I’ve always been knocked back. They don’t deliver. The only thing they have supplied us with in the last year is a stool to get into the bath. But they wouldn’t knock the bathroom and toilet into one which is what I needed.”

There were also frustrations with adult social care systems, which people felt put them into ‘boxes’, for example, one person, who was profoundly deaf and also had physical health problems, said she had given up trying to get support from social service because she felt the physical impairment social workers did not understand sensory impairment issues and vice versa for the sensory impairment social workers.

2.2.4 Mental health

None of those interviewed said they were in receipt of mental health support (either public or private) or that they necessarily needed this. However, one person said they had had ongoing anxiety, which they believed to be a consequence of their Thalidomide damage and their parents’ divorce. Another person commented on the fact that she needed more emotional support now and that this was not always forthcoming from people around her:

“People tend to think of me as a person who copes. I have noticed that I need support more now and I am not getting it – I have to ask for it”.

2.2.5 Self-management

The majority of participants were actively trying to manage the impact of their condition. For some this involved accessing gym/yoga/Alexander technique sessions and/or doing exercises at home. A large number also said that they were having to do less, to rest more and accept help from others. For some people their increased fatigue had meant giving up work or reducing their hours:

“Getting myself into work I was just doing myself terrible damage, I just don’t feel I want to do that anymore, not sure I can do it anymore.”

One person said how much her increasing health problems had changed her attitude to risk and changed her behaviour:

“Just a small accident, if you are not careful, can have enormous implications for Thalidomiders.”

2.3 Impact of Health Problems on Family and Friends

2.3.1 Impact on partners

The majority of participants with partners described how they were more reliant on them now for a range of tasks, such as cleaning and driving and childcare:

“The impact on him is that he’s had to do a lot more in the home and driving. He’s taken on all of the driving really and it means I’ve had to ask him to drive me especially to things where he wouldn’t normally have had to go.”

In one example, a man’s partner was having to work more hours, because he could not work as many, and this was causing strain for them both. In another example, a partner had changed their job to be closer to home:

“My husband had to give up a good job travelling all over the place and he’s now self-employed... so when I’m bad, he can be around. It was no good when he was away. We’ve had to re-evaluate things over the last 6-7 years. Yes – huge changes we’ve had.”

One person was concerned about the impact on his partner’s health:

“She is having to do an awful lot more now in terms of driving and carrying shopping.”

He explained that this is not good for her because she has neck, shoulder and back problems from a previous injury, and these are being ‘re-activated’ by having to compensate for his deteriorating physical health.

Many participants said how the irritability linked to pain resulted in them taking it out on people close to them:

“Obviously you’re not just not sleeping but you can be a bit grouchy during the day. You can be very temperamental as well at times, you know, and snappy. But it’s not that you’re having a pop at him - it’s just that you’re so tired.”

“I don’t think that’s done our relationship much good to be honest. You know, we’re having to sort of adapt to me asking for much more help and him spending a lot more time on me and my needs.”

“I didn’t feel quite as sexy I suppose because I couldn’t wear my high shoes. And therefore you don’t feel such a gorgeous wifey. And self-esteem...when I can’t wear my high shoes my self-esteem plummets. And I did get quite depressed. I don’t think I was much fun to be with, so I suppose that is how it affected me.”

Another participant said how embarrassing and upsetting he found it to ask his partner to help dress him, for example, zipping up trousers or fastening laces.

2.3.2 Impact on children

Several participants had children and were very concerned that their deteriorating health should not impact upon them, but in some cases a level of reliance was emerging and this was causing some distress:

“My children are used to me being far more independent and they’ve actually had to do more. Particularly I find it much harder to wriggle in to underpants now so they sometimes have to help me with that. They’re teenagers, and I mean [my daughter] is fine, but sometimes it’s only [my son] in the house and he says ‘Oh Mum, why can’t you do that?!’ They’re very helpful but the impact is that they’re having to do more caring.”

There were also examples of older children at an age to leave home, where they had selected not to live too far away in order to be able to provide support:

“I think [my daughter] felt so responsible - and I’ve had to push her away over the years – that she actually commuted every day to Uni instead of going away.”

Several participants also noted an impact on family activities, where options were now more circumscribed linked to health or mobility difficulties or general fatigue:

“If we go on a holiday or we go anywhere I just want to slouch, I can’t get round the way I used to.”

2.3.3 Impact on parents

A small number of those interviewed said their deteriorating health was impacting on their parents, for example, through diminishing the participants’ ability to travel and visit them:

“They are witnessing my deterioration - having had 40 years of relative independence and not being a regular worry to them, they are now very well aware of my decline. But they cannot do much about it because they are very elderly and have the same issues themselves - about mobility and stamina and tiredness and things like that.”

Chapter 3 Using the Health Grant

In using their Health Grants people interpreted health and health needs in a very broad way and used their funds for both treatment and prevention, and to address wider well-being issues. In many respects this reflected the World Health Organisation's definition of health which states:

“Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”

This chapter provides an early overview of Health Grant expenditure and describes in more depth how and why people used their funds in certain ways.

3.1 Perceptions of the Health Grant

Participants were asked how they viewed the Health Grant. The majority said they saw it as distinct and separate from their annual grant, not just as an addition to their income:

“I’ve seen it [Health Grant] as something completely different and distinct. It’s enabled me to do things in the house thinking about my own future. It’s helped me as an individual rather than as a family. It’s helped me as a person, it’s given me more time, more freedom and brought me less pain because I’ve been able to employ people to help, it’s made me a lot better within myself.”

A small number of the participants opened bank accounts to keep their Health Grant separate from their other finances so that it was easier to manage it and spend it differently. Most participants said they saw it as a means to maintain (or regain) their independence, and many said they saw it as an opportunity to make changes to their life which would prevent further deterioration to their health.

Only a few of the participants said that they regarded the Health Grant as an addition to their income where it was seen as an ‘extra’ or a ‘bonus’ to make life easier and ‘take the pressure off’.

“If you get an extra lump of money that you’re not expecting, suddenly it opens up the doors to all the things that you haven’t been doing. It actually makes things possible. What you didn’t use to do and you’d think you can’t do that, suddenly you can - it’s life changing.”

“I must admit I probably saw it as an addition to my income. Apart from my Disabled Living Allowance, that is the only extra money I get. I don’t get any other benefits. I don’t work so without that extra money then there are no extras in my life.”

The participants were all asked what they thought of the ‘categories’ of expenditure agreed with the Department of Health and nearly all thought they were open and flexible:

“I was quite surprised. I thought they would be tighter. I think that actually they’re very broad and very much open to interpretation. Really I think that anything that anyone does can be fitted into one of those.”

“There were things in the categories that I wouldn’t have expected. I was impressed at how flexible they were. I was quite surprised. I didn’t realise that they would respect the fact that maybe a bit of respite or something. You know that’s very important to some people. The other thing I never expected was if you needed a holiday time. I was pleased at the variety of what they’d allowed you to use it for.”

However, a small number said they thought having categories was inappropriate, considering what a diverse range of needs people with Thalidomide damage have:

“Everybody’s an individual so I think you can’t really put it into any category what the personal needs of anybody would be.”

Additionally a few participants said that there should be a category for ‘clothes’ because they said that they wear out clothes more quickly than normal people and clothes tend to be more expensive, as they often have to be handmade or altered.

3.2 How People used their Health Grants

This section outlines the decision-making processes people went through in considering how they wanted to use the grant and an overview of spending profiles in Year 1 of the grant allocation. It is followed by a summary of participants’ rationales for how they chose to use the grant and their experiences of accessing support and treatment.

3.2.1 Decision-making processes

The great majority of participants said that they decided how to use their Health Grant by themselves without input from other people. About one third of people living with a partner said that they had talked it through with them on some level. One person commented that, as their spouse spent a lot of time caring for them, it was only right to think about the grant in terms of how it might benefit them both.

A couple of people commented on how positive it was for them to have a budget for their health to spend how they wanted:

“I have to live my life. No health professional lives my life. I spend it on what I need.”

“I’m one of those people who sort of decides what’s good for myself really. Sometimes I make the odd mistake but I go on the premise that I know myself better than anyone else.”

A small number of participants had sought information from specialists/professionals and this related to purchase of large items. Three people said that they had sought information or advice from HealthLink⁶ and again this tended to be where larger items were being considered, such as adaptations to homes, vehicles or specialised equipment.

A couple of participants commented that they had used Facebook to see how other people affected by Thalidomide were using their Health Grant and found this very beneficial:

⁶ HealthLink is a telephone and web-based advice service run by the Thalidomide Trust.

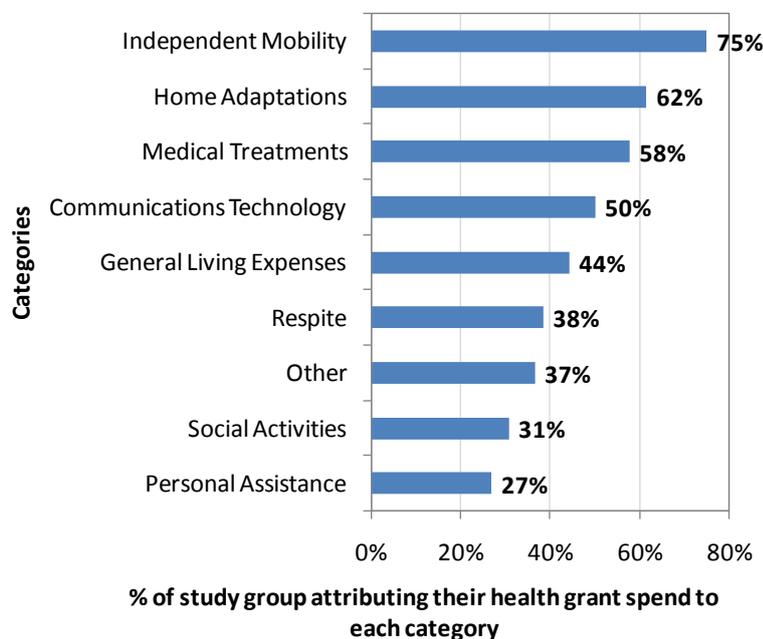
“People ‘poo-poo’ Facebook and stuff like that but it’s such a fantastic tool for communicating around the world instantly. I participate in all the Thalidomide Facebook forums and it has huge benefits – if you need advice or experience on something then somebody out there knows something about it. I think it’s terrific.”

3.2.2 Overview of Year 1 Expenditure

The information which the study group provided in late Autumn 2010 about the use of their Health Grants (six months after receiving them) provided a useful early indication of the main areas of expenditure. Figure 4 shows the percentage of study group members who had used their Health Grants on each of the nine health-related needs categories being used in the evaluation⁷. Table 6 shows expenditure by these same categories.

Perhaps not surprisingly, Independent Mobility and Home Adaptations were the top two categories in terms of the percentage of participants who used their Health Grants on these things, and the proportion of total Health Grant expenditure. However, the range of expenditure varied considerably. It is also interesting to note that at the time people completed their surveys, only 7% were using their Health Grants for daily living expenses but the interviews revealed that a significant number had since or were contemplating giving up work or reducing their working hours, and would therefore be using their Health Grant to replace lost earnings.

Figure 4 Pattern of Expenditure by Health-related Needs Categories



⁷ Note: Six study group members described their expenditure but did not tick a category. In these cases the evaluation team made their own judgement about which category the expenditure fell into.

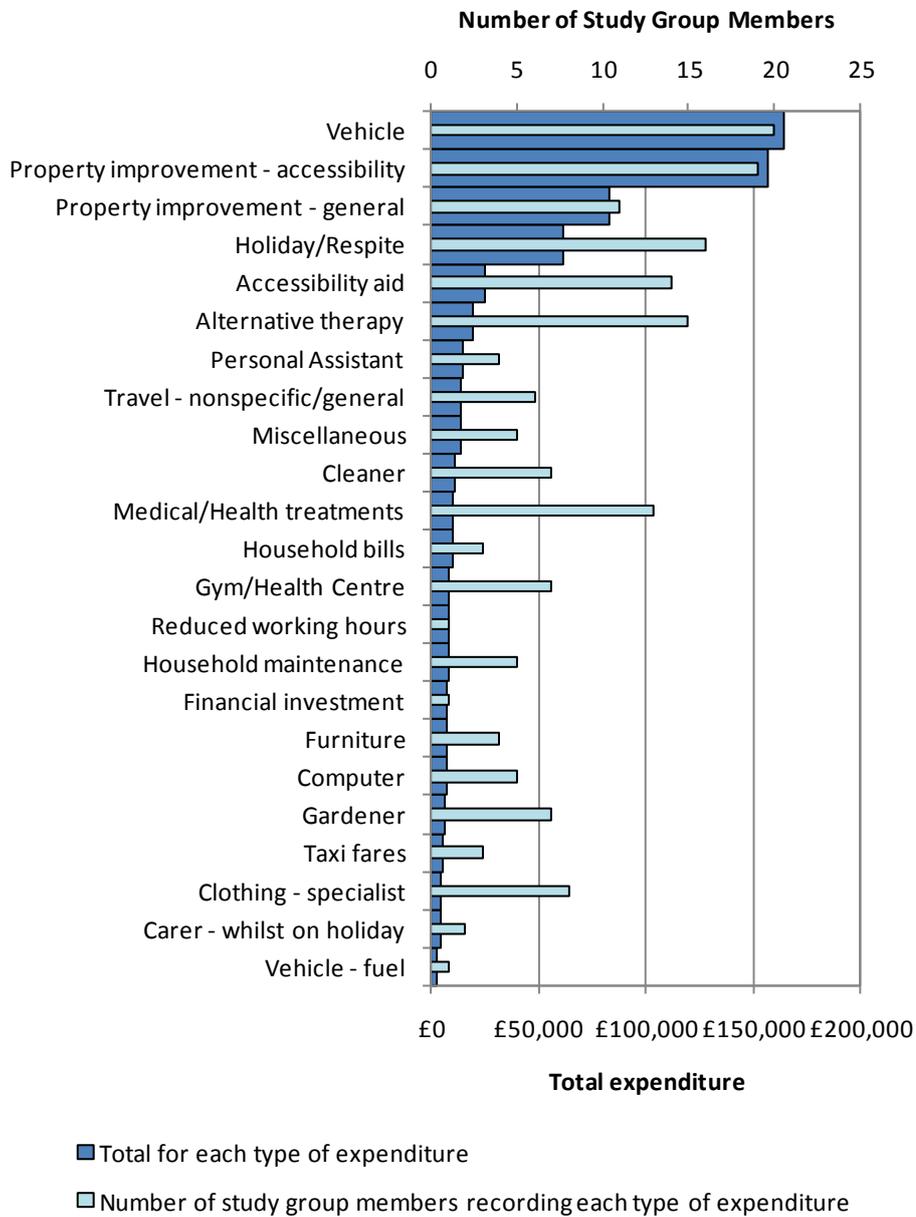
TABLE 6 CATEGORIES OF EXPENDITURE

	Total spent	Min spend	Max spend	Average spend	Proportion of total spend
Communications Technology	£22,219	£44	£2,102	£717	3%
General Living Expenses	£48,523	£90	£8,000	£1,797	7%
Home Adaptations	£234,987	£150	£26,238	£5,000	33%
Independent Mobility	£210,997	£20	£24,409	£3,907	29%
Medical Treatments	£39,394	£15	£3,994	£961	5%
Other	£55,342	£120	£13,422	£2,406	8%
Personal Assistance	£29,869	£90	£5,162	£1,659	4%
Respite	£63,454	£30	£8,299	£2,441	9%
Social Activities	£16,896	£8	£2,614	£805	2%
Grand Total	£721,681				

While the health-related needs categories provide valuable guidance, they are very broad categories and people did interpret them in different ways. They also placed similar types of expenditure in different categories, often because it meant different things to them. For example, sometimes people categorised a holiday as ‘respite’ because going to a warm climate gave them pain relief and a break from the stresses of everyday life. Other people listed holidays as ‘other’ because for them it was about general well-being for them or their family. To explore the pattern of expenditure in more depth, we therefore decided to look at the main ‘types’ of expenditure people listed.

Figure 5 below shows the total spend for each type of expenditure and the number of study group members who recorded this type of expenditure. Again types of expenditure linked to independent mobility (e.g. a new vehicle) and home adaptations (e.g. property improvements) are the top two categories. However, holidays, accessibility aids, alternative therapies and medical/health treatments were also listed by many participants.

Figure 5 Health Grant Expenditure by 'Type'



3.2.3

Rationale for use of the Health Grant

Participants' rationale for choosing to use their Health Grant in certain ways reflected a wide interpretation of the term 'health', as indicated in 3.1 and in Figure 5, which summarises the various ways in which people have used the funding. For many participants, they said they would not have been able to afford some of these treatments/facilities/services at all without the Health Grant; some said they would have been forced to use other income and would therefore have incurred some financial

hardship. The payment of the Health Grant as a lump sum was very important for several of those interviewed, as it made it more possible/attractive to purchase large items, such as adaptations to housing or vehicles. There were a number of comments emphasising how buying disability specific/specialised items could be very costly:

“It’s very expensive being disabled. Everything you do costs a lot of money.”

Many participants talked about the preventive aspects of the grant: they saw their increased use of treatments (such as massage, physiotherapy), increased access to exercise and labour saving adaptations, devices or services as important elements in preserving what mobility/dexterity they had. For a small number prevention involved reducing their working hours. People were concerned that the short term nature of the grant would limit their ability to maintain these preventive elements over the longer term. Some people were also looking forward, imagining what they might need in older age:

“[I] am desperate this year to get one of these wonderful loos – the wriggling on the loo can’t go on forever – we’re not going to be able to wriggle like that in our 60s and 70s.”

For a smaller number of people, another key reason for spending the grant was to reduce their reliance on carers and some of these participants were particularly concerned to reduce the impact of caring on their partner and /or children:

“If you have diabetes the chance of you getting up to go to the toilet in the middle of the night are quite high. And if the wheelchair happens to be on charge then I have to wake [my partner] up to take it off the charge so that I can go to the toilet.”

This person continued saying that if his carer is sleep deprived, it impairs her ability to function and therefore it was justifiable to use the Health Grant for a second wheelchair, so that he did not have to disturb her.

One person had used the grant to pay privately for an operation for their carer and saw this as legitimate, because if their carer’s health deteriorated and they were unable to support them, their own ability to manage would have sharply deteriorated.

Many of these participants did not just wish to use the grant to reduce their reliance on carers, but to help preserve or transform caring relationships. For example, one father described how important it was to have a bit more money to spend quality time with his children and many people described how important it was to have some holiday respite with their partner.

A small number of participant explained that decisions about how they used their Health Grant had partly been driven by feeling that their home was no longer safe or they had been undertaking certain activities in unsafe ways. For example, one person described how much safer it was having a shower in the wetroom they had had installed, compared to previously getting into their shower/bath, and others described how previously they had clambered on worktops to reach cupboards before their kitchen had been made more accessible:

“I couldn’t keep standing on chairs and jumping any more – I was getting petrified.”

3.2.4 Accessing support and treatment

The majority of those consulted said that they did not have any problems accessing the services or equipment they acquired through their Health Grant. A small number were experiencing problems accessing quality professional services for adaptations/equipment. Some had ongoing difficulties accessing health specialists who were suitably skilled and informed in relation to Thalidomide. A person who relied on interpreters for British Sign Language said how difficult (and costly) it was to source interpreters, especially at short notice.

A large number of participants said that they used their grant for treatment, items or services which they had previously had difficulty sourcing through statutory services (for reasons outlined in (chapter 2). Many really appreciated having the money to initiate privately-funded alternatives, or to increase the amount of time and money on services/facilities they already purchased.

3.3 Adequacy of the Health Grant

Over half of the participants (and unrelated to the impairment band they were in) thought the level of the Health Grant was “*nowhere near adequate*” for meeting their health-related needs. Some said it needed to be doubled and a few suggested trebling it. Many said that it was not enough to allow them to pay for major adaptations to their houses. These were necessary to make their life safer and to slow down the rate at which their health was deteriorating.

“It’s such a small sum that it only allows you to do one or two major things per year. I mean I could do with my kitchen changing. I could do with my bathroom changing. But they’re such major expenses that you could only cope with one of those in a year from that grant, and then there’s nothing left to do anything else with. So no, it doesn’t adequately cover anything really.”

“I could spend double that, and I don’t mean I could waste double that, but doubling that would make my life easier.”

“We need an adapted kitchen. And the quotes that we’re getting at the minute is anything from fifty to seventy thousand pound. We need an accessible vehicle but we can’t afford a vehicle because that’s another seventy grand.”

“It’s not adequate in terms of meeting my immediate needs and it’s not adequate in terms of meeting my ongoing needs.”

A number of participants mentioned that people with Thalidomide damage have health needs which are going to increase more rapidly over time and that the gap between what they have from their Annual Grants, employment and statutory services, and what they require is going to become greater.

“Life is becoming increasingly difficult and we are slowing up, and the body’s overcompensating for the bits that are missing. As you get older, the problem intensifies – for everyone – but we are on an accelerated scale.”

“If my arthritis keeps on getting worse, I might not be able to drive the vehicle I’m driving at the moment so you’re talking about extensive adaptations there, and that would be costly. And also, my right hip has gone and a hip replacement

might mean that I need an electric wheelchair. And then I'd need my doors widening and I'd need ramps put on and all that. So you're talking about a lot of money needed to maintain your independence."

Of those participants who felt the level of their Health Grant was adequate, nearly all said that it would only be adequate if it is continued after the initial three years.

"I suppose it depends, I mean you can't really say because none of us know what's going to happen in the future but at the moment my grant would be enough, yes."

"Personally for me at this present time, yes it [Health Grant] is adequate."

"It has been great. It has really improved my quality of life this year. But if this is it – for the three years – then the answer is an un-resounding 'no'."

Many of those who said they thought the level of the Health Grant was adequate to meet their health needs at present highlighted the issue that their health needs are likely to increase substantially in years to come. They said that even if the Health Grant is continued after the initial three years, it may not be adequate to meet their increasing needs.

"It would be nice to think that it was index linked. The trouble is that you don't know what the future holds. You don't know how your health is going to deteriorate."

There were only a couple of participants, who were less severely impaired, who felt the Health Grant was unconditionally adequate.

"As an individual, and I'm only speaking as an individual, I'm most sincerely grateful. It's been absolutely, unbelievably brilliant for me. For the first time in my life I haven't had to have a compromise."

"I'm probably at the extreme end compared with a lot of the others. At the moment, from my end, it was a very nice additional income to have coming in but it wasn't like I couldn't live on what I had before."

The overwhelming feeling was that the Health Grant must be continued after the initial three years.

Chapter 4

Impact of the Health Grant

An important aim of the evaluation is to explore the impact of the Health Grant on people's health and well-being. Although for some of the study group members it was still 'early days', many were already able to talk about the difference the grant had made. This chapter sets this out in some depth and then goes on to examine the wider impact on family and friends and any changes in people's use of health and social care services.

4.1 Impact on People's Health and Well-being

For many participants, getting the Health Grant had made them focus on their own health and well-being and often people had thought very carefully about how the money could be used to improve or maintain it. In that sense, having the Health Grant was empowering but as one participant explained, it was also unsettling because she had had to confront her increasing level of impairment. As another participant put it:

"I have the point of view that I've never had a disability. Although I don't have arms, I don't have a disability. Everything in life I've wanted to do I've done. But this grant has come at the right time because this last year I've come to realise that my body isn't working the way it used to".

As was noted in section 3.1, many people used their grants to pay for things which they felt were 'preventive', for example, joining a gym or buying an adapted bicycle in order to get fitter and manage their weight. Often people said they felt they should have addressed these issues years ago but didn't feel they could because they couldn't afford it or because it seemed like a 'luxury'. Getting the Health Grant gave them both the means and the 'permission' to look after themselves:

"It's been great, particularly the gym membership, which I'd always previously considered something of a luxury. It's difficult to put your finger on but it makes you feel better, happier for it. I could see that if I hadn't taken steps like that I could have turned into a couch potato!"

4.1.1 Reducing deterioration and improving well-being

People often described how their health, well-being or mobility had declined because of how they had had to use their bodies or the long-term impact of the drug (see section 2.1). Many saw using their Health Grants to stop or reduce the rate of this deterioration as absolutely crucial. How they achieved this varied considerably between individuals. For some it was about being able to pay for adaptations to their homes, so that on a day-to-day basis they were putting less strain on their bodies. For others it was the freedom to pay for treatments which they wouldn't otherwise have been able to afford (e.g. massage) or to have more regular treatment than the NHS could provide (e.g. ongoing physiotherapy or chiropody).

"It has enabled me to identify my health needs widely and ameliorate the negative impact, but it has also had a direct affect on my sense of well-being, it

has been of psychological benefit....the massage, the physio....these things altogether have made me healthier and happier”.

The ability to pay for mundane things or routine help often had a disproportional impact on people’s well-being. For example, being able to pay for help in the house or garden had made a huge difference for many people. One participant explained the impact that just being able to buy in help with housework had had:

“It’s fantastic – I’m thinking, why on earth didn’t I do this before. It’s just heaven, freeing up time and energy to do other things....housework took up a huge amount of my physical strength.”

For others, being able to afford just to look after themselves in everyday ways, such as going to the hairdresser more frequently, or seeing the dental hygienist regularly, or paying for someone to alter their clothes properly, had greatly improved people’s sense of well-being. For those on lower incomes, it had enabled them to get out and socialise, so they feel less isolated.

4.1.2 **Choice, Independence and personal safety**

For many, having the Health Grant meant that they could do things like adaptation in the way they wanted or have much greater choice and flexibility, for example, in purchasing a new wheelchair or vehicle, or taking advantage of new, often more expensive technology. This had clear practical benefits (e.g. one participant had had a prosthetic leg made by a private company, as she had never had one through the NHS which fitted her properly) but it also had psychological benefits, as the following quotes illustrate:

“We’re not stressed out about where the next wheelchair is going to come from....the NHS ones aren’t such good quality....the expensive ones don’t need charging as often and what interests me now is how long the battery will last and how reliable it is.”

“It’s really opened up choices for me”.

“It’s given me the dignity to choose my own future”.

The impact the Health Grant has had on many participants’ independence was striking. People described how home adaptations, access to more personal assistant hours or a new wheelchair had helped them regain, maintain or increase their independence. They felt less reliant on family or friends and had a real sense of satisfaction when they were able to do things for themselves again. For many people, especially those with more severe impairments, the scope the Health Grant had given them to maintain or improve mobility has been very important. Several participants noted that it would have been hard for them to afford major items, such as a new vehicle or electric wheelchair, from their annual grants. They often noted that the decline in their mobility had made them feel more vulnerable and dependent, which in turn had affected their emotional well-being. As these participants explained:

“Now I go out in the 4x4 by myself, whereas before I had to have someone with me to get the wheelchair out of the boot.”

“The fact that you don’t have to ask people all the time to help you is hugely beneficial. I think it helps you psychologically”.

“It’s given me more freedom, more independence and given me hope”.

For some people the adaptations they had been able to make had not only increased their independence, it had made them feel safer and less vulnerable, which in turn had had a positive impact on their family and friends (see section 4.2 below). One participant described the impact which alterations to her front door and drive had had:

“It’s made me a lot more independent. I’m able to come and go from the house to the car safely now which has been a lifeline really. The Health Grant has made it possible to do things that I had put on the back burner because I couldn’t afford them.”

For a few people the Health Grant had led to them feeling less dependent on social care services. Some felt that if their personal assistant hours were reduced owing to budget cuts (see section 4.3 below) they would have some money to plug the gap, while others had stopped using home care services and now employed their own PAs or purchased more PA hours.

4.1.3 The impact on peoples working lives

As was noted in Chapter 2, a number of participants had used their Health Grants to enable them to reduce their working hours or stop working altogether. Many people felt this was the most important thing they could do to maintain their well-being or reduce the strain on their bodies, and the Health Grant had enabled them to do this without a drastic reduction in their standard of living or creating financial worries. Several participants who are self employed explained that they had found it increasingly difficult to work a full week or were having significant chunks of time off work. Again, the Health Grant had enabled them to alter the way they worked, or even take a job which was less well paid but put less strain on them. It was clear that such changes had had a very immediate and often substantial impact on people’s health and well-being:

“I’ve gone part-time but I’ve also moved away from direct management. The difference is massive....I’m more relaxed and I don’t feel stressed when I come home from work.”

“I was self-employed before, a mechanic doing washing machine repairs and that sort of thing, but the job was doing a lot of damage to me. It [the Health Grant] meant that I was able to change my career but still have enough to live on.”

Others felt that the Health Grant had enabled them to continue working or would prolong their working lives. For some, especially those with physical jobs, it meant that they had the money to buy equipment which would make their job easier and put less strain on their bodies. Others explained that by taking steps to look after themselves or address existing health problems, they felt able to continue working. As one participant explained:

“At one stage I wouldn’t have been able to work but the grant has allowed me access to healthcare I can’t normally get or can’t normally afford....by keeping working, I’m saving the State a bloody fortune!”

4.1.4 Reducing financial worries

Perhaps the most widespread and positive benefit that participants described was the way in which the grant had taken away, or substantially reduced, their financial worries, and the knock-on effect this had had on their emotional well-being. For some people,

this was because the grant had made an immediate difference to their financial position, as the quotes below illustrate:

“It has taken a lot of stress off me, for example knowing that I can get repairs to the van done when they are needed. It’s the same for everyone isn’t it – money takes the stress away.”

“I have a total general feeling of well-being. A feeling of being capable of doing things without worrying about whether I can afford it. A total feeling of betterment.”

“To me, I think it’s more my emotional health because my physical health is getting worse at the moment with my hip but I’m managing it emotionally because of the extra support I can get with my Health Grant.”

For others, their Health Grant had given them a more general sense of financial security and made them feel more positive about the future:

“It means I can look forward to the next ten years rather than dreading them – it’s made that much difference to me.”

“It’s a comfort to know it’s there if anything goes wrong.”

“It’s improved my quality of life and it’s certainly taken away the worry that my disability worsening would cause me.”

For those participants who were on very low incomes or in particularly difficult circumstances, their Health Grants had really only enabled them to keep their heads above water or address immediately pressing issues, such as mortgage arrears or paying their heating bills. These uses did, however, help to reduce the stress caused by financial problems and eased people day to day circumstances. A very small number of people felt that their Health Grant hadn’t made a significant difference because it was not enough money. As one participant put it:

“The fact that it’s there is a safety net but it’s a very thin safety net – it wouldn’t stop me falling.”

4.1.5 Future impact

Some people also said that it was too early to tell what the full impact of their Health Grants would be because they were waiting for adaptations to be completed or things they had bought to be delivered, or felt that it might take a while to see the benefits, noting:

“It is only the first year. I expect to see bigger improvements in the second year”.

Others had deliberately saved some of their grant money or had only used part of it, sometimes because they knew the present grant is only for three years. These participants found it difficult to judge what the physical benefits would be but many noted that it had already made them feel more positive and financially secure.

Finally, some participants commented on the implications of the Health Grant ceasing after three years. Several participants who had given up work feared the grant would end but also said they felt they had no choice because of the impact working was having on them. As one participant explained:

“The Health Grant not continuing doesn’t bear thinking about. I would probably end up having to go on to benefits – I don’t think I could go back to the job I was doing.”

One participant neatly summed up many people’s feeling about the impact their first Health Grant has had. She said:

“The Health Grant has taken away a lot of financial concerns, emotional concerns and concerns about my physical well-being. It’s enabled me to access medical assistance that is not available on the NHS. It’s allowed me to continue working. It’s allowed me to carry on at a level of physical lifestyle that I wanted to but was concerned about doing....Instead of retracting from life, it’s enabled me to carry on engaging with life.”

4.2 Impact on Family and Friends

Participants highlighted a number of ways in which the Health Grant had had a positive impact on their family and friends. Many people noted that the adaptations they had been able to make, the things they had purchased or the support they had been able to buy had meant that they were less reliant on their families for help. This was extremely important to people, partly for their own sense of independence, but also because they could see the additional pressure it placed on their partners and family. One participant who had used her Health Grant to have more PA hours noted:

“Basically anything I want to do, I do now and I don’t have to rely on my family.”

Other participants explained that the deterioration in their health had led to their partners having to provide more care or more intimate care, such as help with dressing. So, for example, being able to use their Health Grants to pay a friend to provide some help or get clothes altered helped people preserve their ‘partner relationship’. A participant who now pays a friend to accompany him on trips said:

“It’s meant she’s not just my carer all the time, which means we can have a more normal partner relationship. When you’re stuck together 24/7, no matter how well you get on it does have an impact and the Health Grant has made a huge difference.”

A few participants noted that, with the Health Grant money, they had been able to go on holiday as a couple without a PA or care worker because they could afford to stay somewhere with the facilities they needed or where assistance was available. This had given them much needed privacy and helped their relationships:

“It’s really helped us as a couple not just me as a person.”

Others explained that being able to take their family on holiday had been really important to them because it had allowed them to relax together and come home feeling less stressed.

Participants whose children were still at home felt this very acutely. While many appreciated what their children did for them, they were adamant that they did not want them to be young carers. One participant with two teenage sons explained:

“If my life is easier it has a knock-on effect on them. They do jobs around the house like feeding the cat but I don’t want my boys to have to do too much for me.”

Many Thalidomidors also have older parents. Several participants said that they feel their parents still worry about them and feel they have to help them both financially and practically. Having the Health Grant has made this less of a concern.

Where family members could see that the Health Grant had enabled people to be safer, more independent or just more able to take care of themselves, they felt less worried about them. The two quotes below illustrate this:

“Because if I’m ok then he doesn’t have to worry about me, or if I get a problem sorted then it’s one less thing for him to worry about.”

“My sons are 26 and 22. One of them has decided to stay single because he thinks he is going to have to look after me for the rest of my life. I say to him ‘no, you have a life of your own and you need to live it’. Since the Health Grant I can do a bit more for myself and because he knows I’m safe, he’s been able to go to college. To me it’s perfect on both sides.”

Many people explained that they felt less stressed or were in less pain and this had generally made them better to be with. They often noted that they had more time, energy and money to do things as a family and this had had a very positive effect on their family life. As one participant put it:

“The bottom line is that it’s probably made me a better person to live with and deal with.”

4.3 Changes in Use of Health and Social Care Services

The majority of participants did not report any particular changes to NHS support, but these responses were largely linked to the fact that many people had already chosen not to use NHS services, owing to the issues raised in 2.2. A significant number of people had chosen (or felt they had no option but) to buy services privately that they could, in principle, have got through the NHS, in particular, physiotherapy, chiropody, wheelchairs, prosthetic limbs and hearing aids. The main reason for this was that the NHS did not offer them the quality and/or choice they wanted, or the NHS services they were offered were inappropriate or inadequate for their needs. For example in the case of physiotherapy and chiropody, they were only offered a ‘course of treatment’ (usually a few weeks) or infrequent treatments rather than ongoing support. Ironically, a few people said that because they didn’t feel reliant on the NHS, they had now started to explore what the NHS could offer them. One participant gave an example:

“I would never have gone to a neurological physiotherapy department. It would have wasted a whole morning before but now it’s much better because if they can’t help me I can get it elsewhere.”

A small number of participants felt that the Health Grant had led to a significant reduction in their use of NHS services, in particular fewer visits to their GP and substantial reductions in the use of prescribed pain killers. One participant explained that he had to make heavy use of pain killers which had caused a stomach ulcer and led

to him having several endoscopies. The Health Grant had enabled him to move to a job which was putting less strain on his body and he estimated that he had reduced his use of pain killers by 40%. Another participant said:

“Before I had the work done [home adaptations] I was at the doctor’s maybe once or twice a fortnight. Now I see him maybe every three months because I’m not so dependent on having to go and get pain killers, which I’m trying to do without.”

The responses were slightly different in relation to social care, where there was some unease among people in receipt of personal budgets. Interestingly, a couple of participants who had been involved in the national campaign for the Health Grant were very clear about it being ‘ringfenced’ (as one participant put it) and felt confident to challenge any attempts to cut or charge for social care services. However, the majority of participants on personal budgets said they feared their budget would be cut. For some this had already occurred, linked to council spending cuts, but some were suspicious about this rationale and thought the Health Grant had made them less of a priority:

“My needs haven’t changed. My disability hasn’t got any better so I’m going to appeal.”

Another person said that he worried that the short-term nature of the grant might complicate things, where his social care service may be cut, but then not raised again once the grant ceases.

In addition to worries about social care, one person expressed concern about the proposed changes to DLA and incapacity benefit and they feared they could be forced back to work and/or have to use their Health Grant to supplement this loss of income.

Chapter 5 Conclusions

The findings from the first year of the Health Grant evaluation suggest that many Thalidomide-impaired people are experiencing a range of health problems, which are in some way related to their Thalidomide damage. There was also a perception that the level and complexity of these health problems were considerably higher than those being experienced by contemporaries in the population as a whole. For many people there was a very obvious link between their impairments and the wear and tear on their bodies, with the majority of the problems people described being associated with damage to and overuse of joints and muscles. This affected people's mobility and/or dexterity but also caused pain (often requiring significant use of pain control medication), fatigue and stress. Other problems included numbness and tingling which may be linked to generalised nerve damage, worsening hearing and sight impairment, and dental problems. Many people also explained that these physical health problems led to them feeling 'low' or 'irritable', or generally made them feel less independent and able to cope.

In talking about the treatment or help people had accessed (or tried to access) to address their health problems, participants revealed widespread frustration with health and social care services. Many clearly felt that statutory services were either not meeting their needs, or were not meeting them in the way or to the standard that they wanted. There were a wide range of reasons for this. In particular people felt there was a lack of awareness of how Thalidomide damage had affected people, both in terms of their anatomy and physiology and the way they had to use their bodies. However, they also felt frustrated by other things, such as long waiting times, time limited services and staff attitudes. These views very much mirror those of the Thalidomiders who contributed to the HealthLink evaluation⁸. One of the conditions set down by the Department of Health when it confirmed the Health Grant was that *"it must not be used to meet needs that are already being met through NHS funding"*. The experiences of the study group (and the previous findings from the HealthLink evaluation) suggest that there is a fundamental lack of knowledge and understanding of the needs of Thalidomide-impaired people in the NHS, and as a result people often receive poor or inadequate care. In the light of this it is not surprising that a number of Thalidomiders are choosing to use their Health Grants to buy health care and even alternative therapies, which are theoretically available via the NHS.

More generally the evaluation shows that in using their Health Grants people interpreted 'health' and 'health needs' very broadly and used their grants for both treatment and prevention, but also to address wider well-being issues. So, although most people saw their Health Grant as distinct from their Annual Grant, and noted the health-related needs categories agreed with the Department of Health, they felt able to use their Health Grant in a range of ways that would make the most difference to their health and well-being. While Independent Mobility and Home Adaptations were the top two 'categories' in terms of the percentage of participants who used their Health Grants on these things, and the proportion of total Health Grant expenditure, the range of expenditure varied considerably. It is also interesting to note that six months after receiving their Health Grants, only 7% were using them for daily living expenses but the interviews conducted

⁸ *The Evaluation of HealthLink – Final Report (2009)* Acton Shapiro.

two months later revealed that several more had since given up (or were contemplating giving up) work or reducing their working hours. Within the categories, types of expenditure linked to Independent Mobility (e.g. a new vehicle) and Home Adaptations (e.g. property improvements) were the most frequently recorded. However, holidays, accessibility aids, alternative therapies and medical/health treatments were also listed by many participants.

Even at this early stage in the evaluation, it is clear that the Health Grant is beginning to make a difference to the health and well-being of the study group members. The Health Grant had made many participants focus on their health and in that sense it was empowering. However, some people also found it unsettling because it had forced them to confront their increased level of impairment or reduced independence. Many people felt that their Health Grants had enabled them to reduce the rate at which their health was deteriorating, although how they achieved this varied considerably between individuals. The impact of the Health Grant on participants' independence was particularly striking and this had important knock-on effects on people's emotional well-being, their personal safety and their family relationships. Perhaps the most widespread and positive benefit that participants described was the way in which the grant had taken away or substantially reduced their financial worries, and, again, the effect this had had on their emotional well-being. For some people, this was because the grant had made an immediate difference to their financial position, while for others it had given them a more general sense of financial security and made them feel more positive about the future. A very small number of people felt that their Health Grant hadn't made a significant difference because it was not enough money, or that it was too early to tell because they were waiting for adaptations to be completed or things they had bought to be delivered.

Perhaps a final overarching finding was that level of impairment was not a predictor of the health problems people were experiencing, or how they were using their Health Grants to address them. Although there were certainly common themes in terms of the types of health problems described, how people were managing these problems, and their strategies for preventing further deterioration or maintaining their health and well-being, varied enormously. It is therefore vital that Thalidomide-impaired people continue to have the freedom to use their Health Grants in whatever ways work best for them, regardless of whether the expenditure appears to be health-related.

Lastly, looking to the second year of the evaluation, we feel that there are a number of issues it would be valuable to explore in greater depth, in particular:

- the cumulative or ongoing impact of the Health Grant in terms of reducing deterioration or preventing future health problems
- changes in people's use of health and social care services
- the context in which people are using their Health Grants, notably other changes taking place in the benefits system and in social care
- linking the findings from the evaluation to the *Securing Our Futures* project and the wider literature on the costs of disability.

Appendix 1 - Study Group Pre-Interview Questionnaire



Thalidomide Trust Health Grant Evaluation

Study Group Pre-Interview Questionnaire – Year 1

Name:	
Date:	

		Please tick the health related need category that you think your expenditure best fits into									
	Approx. Spend £	Independent Mobility	Home Adaptations	Communications Technology	Medical Treatments	Respite	Personal Assistance	Social Activities	General Living Expenses	Other	
What have you spent your 2010 Health Grant on?											

What have you spent your 2010 Health Grant on?	Approx. Spend £	Independent Mobility	Home Adaptations	Communications Technology	Medical Treatments	Respite	Personal Assistance	Social Activities	General Living Expenses	Other

Many thanks for completing this questionnaire

Please email the completed form to chris.bartlett@actonshapiro.co.uk

Appendix 2 - Interview Topic Guide



Thalidomide Trust Health Grant Evaluation

Topic Guide for Year 1 Study Group Interviews – Abridged Version

Current or Recent Health Problems

1. What health problems (if any) have you experienced over the past few years that you believe are connected to the Thalidomide damage you experienced?

*Prompt for: How long have they have been experiencing the problem/s
Whether the problem is static or deteriorating*

2. Have you had any treatment or help with the health problems you are experiencing? If yes:

*Prompt for: Where this help has come from i.e. NHS; social services; Thalidomide Trust; paid for privately; other sources?
What difference this treatment/help has made
Availability of services/support needed*

3. Have any of the issues you have talked about had a wider impact on people close to you (e.g. your partner/family)?

Using Your Health Grant

4. When you first heard about the health grant, did you see it as distinct from your Annual Grant and/or other income/financial benefits?

*Prompt for: Whether they see the money as specifically to help with their health and support needs or just part of their family income
How they felt about the Department of Health 'categories'*

5. How did you decide what you wanted to spend your health grant on?

*Prompt for: Whether they wanted or received any help or advice e.g. from health professionals; HealthLink; social services?
Involvement of family*

If the study group member has completed the pre-interview questionnaire:

You explained on your pre-interview questionnaire that you used (or plan to use) your health grant to pay for:

Insert information from questionnaire here:

If the study group member has not completed the pre-interview questionnaire:

6. How have you used (or plan to use) your health grant?

Link responses to categories agreed with DH i.e.

- *Independent Mobility*
- *Home adaptations*
- *Communications technology*
- *Medical treatment costs*
- *Respite*
- *Personal assistance*
- *Social Activities*
- *Other (e.g. re-training for different job)*

7. What were the main reasons for spending your health grant in these ways?

*Prompt for: NHS service inadequate or not available
Wanted to do it before but couldn't afford it
Major item so needed a lump sum
Felt it would give most benefit etc*

8. Have you had any difficulties accessing the kind of support that you want/require?
If 'yes', what were these were these difficulties/how were they overcome?

9. Has the level of health grant you received been adequate in terms of meeting your main health or health related needs?

*Prompt for: Any trade offs/compromises they have had to make
Details of any unmet needs*

10. Has getting the health grant led to any of your existing health or social care services being changed or charged for?

11. Would you mind telling me if you are in receipt of any financial benefits/support for your current health or social care needs in addition to your Annual Grant and Health Grant from the Thalidomide Trust (we don't need any financial details just yes or no)?

Type of benefit/support	Yes/No
Independent Living Fund	
Disability Living Allowance (DLA)	Highest
	Middle
	Lowest
Mobility component of DLA	Higher
	Lower
Disabled Facilities Grant	
NHS Continuing Care funding	
Personal Budget (from Social Services)	
Personal Health Budget	
Other?	

Impact of the Grant

12. Do you think that the things you have been able to pay for with the health grant have had an impact on your health and wellbeing?

*Prompt for: If yes, in what ways (e.g. changes in a specific health problem; lifestyle change so less stress)?
If no, why not (e.g. too early to tell)?*

13. Has your use of the health grant so far had any indirect benefits? (e.g. enabling you to go back to work or reduce your working hours; increased independence; spending more quality time with your family?)

14. (If relevant) Has your use of the health grant had any wider impact on people close to you? (e.g. your partner/family)

15. Since you got your health grant, has there been any change in your use of NHS and or social care services?

If yes, what has changed? Do you think things might change further in the future?

16. Overall, if/how has your health grant made a difference to your life?

Prompt for: Quality of life/lifestyle change

Physical/emotional health

Greater sense of empowerment/recognition by DH

Administration of the Health Grant

17. Was the information that you received about the health grant clear about how it was calculated and what it could be spent on?

18. Are you satisfied with the way in which the health grant has been calculated (i.e. based on existing impairment bands)? If no, why not?

19. Overall, how well would you say the administration of the health grant has worked in this first year?

20. Is there anything further you would like to add or any questions you would like to ask?

Glossary

Disabled Facilities Grant

The Disabled Facilities Grant (DFG) is a local council grant to help towards the cost of adapting a disabled person's home to enable them to continue to live there. A grant is paid when the council considers that changes are necessary to meet someone's needs, and that the work is reasonable and practical. DFG is means tested, but certain benefits including Disability Living Allowance and Income Support are generally ignored.

Disability Living Allowance

Disability Living Allowance (DLA) is a tax-free benefit for disabled children and adults to help with extra costs they may have because they are disabled. It is not based on their disability but the needs arising from it. For example, if they need someone to help look after themselves. DLA is paid at three different rates; higher, middle and lower.

Fair Access to Care Service Eligibility Criteria

Since April 2003, people who ask for support from social services are assessed using the same national framework, called Fair Access to Care Services (FACS). This applies both to new clients, and to existing clients when they are reassessed. The FACS framework covers four levels: low; moderate; substantial and critical, and local councils can decide at what point they set their eligibility threshold, across these four levels.

Incapacity Benefit

Incapacity Benefit is only paid to existing claimants and is for people of working age who cannot work because of illness or disability, and who are not entitled to Statutory Sick Pay. Entitlement usually depends upon your National Insurance record, and may be subject to a medical assessment.

Independent Living Fund

The Independent Living Fund (now closed to new claimants) provides discretionary cash payments directly to disabled people so they can purchase care from an agency or pay the wages of a privately employed Personal Assistant (PA). This support enables disabled people to choose to live in their communities rather than in residential care.

Motability

The Motability Scheme - run by the independent charity Motability - gives disabled people the opportunity to own or lease a car at an affordable price. People can access the scheme if they are on the higher rate of the mobility component of Disability Living Allowance. Even if the person does not drive themselves, they can apply for a car as a passenger and propose two other people as drivers. Motability may be able to provide a grant through their own charitable fund or the Specialised Vehicle Funds, which they administer for the government. Disabled people don't have to pay VAT on the cost of hiring a car through the Motability Scheme. The cost

of any work involved in adapting a vehicle for a disabled person is also eligible for VAT relief.

NHS Continuing Care Funding

NHS Continuing Care is the name given to a package of services and funding for long term care which is paid for by NHS for people outside hospital with ongoing health needs. You can get continuing healthcare in any setting, including your own home or in a care home. Anyone assessed as requiring a certain level of care need can get NHS continuing healthcare. It is not dependent on a particular disease, diagnosis or condition, nor on who provides the care or where that care is provided.

Personal Budgets

Personal Budgets are cash payments given to service users in lieu of community care services they have been assessed as needing, and are intended to give users greater choice in their care. They confer responsibilities on recipients to employ people or to commission services for themselves. Users can either take their personal budget as a 'direct payment', or – while still choosing how their care needs are met and by whom – leave councils with the responsibility to commission the services. Or they can take have some combination of the two.

Personal Health Budgets

Personal Health Budgets in principle offer the same increased choice and control as personal budgets, but relate to health rather than social care. They are not as developed as personal budgets and are currently being piloted in some health services across England.

Severe Disablement Allowance

Severe Disablement Allowance (SDA) is a benefit which was abolished for new claims in April 2001. However, many people continue to receive it. SDA was for people under 65 and incapable of work, but whose National Insurance contributions were not enough to claim long-term Incapacity Benefit.

Thalidomide 'Impairment Bandings'

The Thalidomide Trust operates five impairment bandings, by which individuals affected by Thalidomide are assessed in relation to their level of impairment. Thalidomide annual grants are paid on a sliding scale in accordance with this. Band One is the lowest impairment level and Band Five is the highest level of impairment.

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