

Evaluation of the Health Grant to Thalidomide-
Impaired People: Supplementary Survey of
Beneficiaries in Scotland

Final Report (April 2013)

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Executive Summary

Background & Purpose of this Report

In 2010, the Thalidomide Trust commissioned Firefly Research & Evaluation Limited to carry out a three-year evaluation of the impact of the government's Health Grant on Thalidomide Trust beneficiaries. The evaluation includes a review of the scheme's operation and an in-depth study of the experiences of a UK-wide representative sample of 60 Thalidomide-impaired people (the 'study group') of using their Health Grants. This current, supplementary report responds to a request from the Scotland Office to collect data from Thalidomiders living in Scotland, in particular:

- the amount of Health Grant received by beneficiaries and what they have spent it on;
- beneficiaries' spending decisions in the context of the other financial support and/or health-related treatment or support available to them (and any barriers in obtaining/using these); &
- beneficiaries' views on the adequacy of the Health Grant to meet their needs.

Data Collection & Profile of Respondents

The data were collected via a survey questionnaire, sent in late 2012 (with one reminder) to all 57 Thalidomiders living in Scotland. Sixteen people (28%) completed the survey, six of whom were also members of the UK-wide study group for the main evaluation. These 16 respondents were split evenly between men and women. Most were owner-occupiers, living with a partner/spouse and a spread of employment situations was represented. The survey results may understate the needs of Thalidomiders in Scotland, owing to the higher compensation bandings being under-represented among survey respondents compared with the wider population living in Scotland.

In addition to the bespoke Scotland survey data, a small number of quotes from Scotland beneficiaries in the main evaluation study group have been included (taken from the Year 2 main evaluation interviews), where these help to illustrate/ amplify key points.

Financial Benefits & Support

The most common benefit being received was the care component of Disability Living Allowance (n=12), followed by the mobility component of DLA (n=7). Employment and Support Allowance was being received by four respondents and Working Tax Credit by two people. The number of different benefits/ types of support being received by individuals varied between zero (n=2 people) and three (n=4 people). Most commonly (n=6), one benefit was being received, although the type varied.

Four respondents reported having experienced eligibility difficulties, either with DLA or the mobility component. Also expressed was a more general concern about the possibility of changes to benefits in the future which might render acknowledgement of some Thalidomiders' needs as even less likely.

Recent Treatment & Support for Thalidomide-related Health Problems

Eleven of the 16 respondents had received treatment or support over the previous three years for Thalidomide-related health problems. Most (n=9) related to one type of health problem; however one respondent reported five types, one of which -mental health – had not resulted in any treatment/ support, despite repeated requests to a GP. By far the most common problem requiring treatment was joint pain (n=10); also treated were respiratory, bowel, hearing and knee ligament

problems. One person also mentioned support via having a special toilet fitted which they could use unaided.

Where private treatment had been chosen, speed and an appropriate level of service compared with the NHS were the reasons most often cited.

Health Grant Allocations and Use

The value of the Health Grant received by the 16 survey respondents for 2012-13 varied between £10,000 and £31,300. With the exception of Band 1, the average Grant per Band was lower among the survey group than for Scotland as a whole, supporting the possibility that the survey data may understate the needs of Thalidomiders in Scotland.

Looking across all 16 survey respondents and using a range of measures, 'independent mobility' and 'home adaptations' stood out as key categories of Health Grant expenditure. Independent mobility was the most common category (only one person did not spend on this), followed by home adaptations (13 people spending); taken together these two categories accounted for 57% of all expenditure. One person spent the whole of their grant on independent mobility and two others spent over 50% of their grant on this category. A quarter of respondents spent over 50% of their grant on home adaptations, with one person spending just over 60%. These two categories also stand out as having the highest average spend. Three quarters of respondents also saved some their Health Grant, amounting to 12% across the board. Alongside these general trends, however, analysis of individual spending patterns reveals considerable variation in how the grant was spent, according to personal needs and priorities.

Adequacy & Impact of the Health Grant

Ten of the 16 respondents felt that the amount of the Health Grant had been adequate so far, although several people drew attention to the likelihood of their health-related needs increasing in the future, owing to deterioration in their own health and/or that of a main carer.

The six respondents who felt that the Health Grant had not proved adequate identified areas of need on which in they had topped up spending from other sources, or would have liked to do so. The number of categories cited by any individual as warranting extra expenditure varied between one and five. While individual needs varied, the categories of independent mobility and home adaptations were cited most often (n=5).

Several respondents commented positively on the impact of the Health Grant, the predominant theme being the contribution the grant had made to their health and well-being and to the overall quality of life of themselves and family carers. Taking together data from the survey respondents and interviews with Scotland study group members for the main evaluation, these outcomes appear to arise not only from the results of direct spending (on physiotherapy sessions, for example) but also on flexibility in how the Grant may be used, which gave beneficiaries peace of mind arising from a degree of financial security. For example some people were using the Grant to cover some living costs, thereby enabling a reduction in their working hours where this had been affecting their health. Other people saved some of their grant so that they could plan more confidently for future needs (especially where this involved capital costs, such as major house adaptations).

Key Findings and Messages

Financial benefits and support

- Most commonly, one benefit was being received (which varied in type) and not all Thalidomiders were receiving benefits
- Disability Living Allowance, followed by the mobility component of DLA, were the benefits most commonly received

- Eligibility problems were reported with DLA and the mobility component
- There was general concern about the possibility of changes to benefits in the future, should this render acknowledgement of Thalidomiders' needs even less likely

Treatment and support for Thalidomide-related health problems

- Most respondents had received treatment or support over the previous three years for Thalidomide-related health problems; and most commonly for joint pain
- Reasons for opting for private provision rather than the NHS included shorter waiting times, a more appropriate type of service and a more personalised approach
- A lack of mental health treatment/support was reported

Use of the Health Grant

- Independent Mobility and Home Adaptations stood out as the key categories of Health Grant expenditure, across a variety of measures
- Three quarters of respondents saved some their grant
- Individual spending patterns revealed considerable variation in personal needs and priorities

Adequacy and impact of the Health Grant

- Most respondents thought the Health Grant adequate so far, although health-related needs were foreseen as increasing in the future
- Flexibility in the Grant's terms of use resulted in a wide range of spending choices
- The Grant was most likely to be viewed as inadequate where it could not meet the level of high capital cost required for Independent Mobility and Home Adaptations
- The benefit of the Grant was commonly described by Thalidomiders as its impact on overall well-being.

Chapter 1

Introduction

In this Chapter, we set out the context for this supplementary report: its background in terms of the broader evaluation of the Health Grant across the UK; the purpose of the current report; the method and process of data collection; and a profile of the respondents. The Chapter concludes by outlining the structure of the remainder of the report.

1.1 Background: the main Evaluation

In 2010, the Thalidomide Trust commissioned Firefly Research & Evaluation Ltd (Firefly) to carry out an evaluation over three years of the impact of the Health Grant made to Thalidomide-impaired people by the four UK Health Departments. The key aims of the evaluation were to (a) provide evidence of the impact of the grant on the health and well-being of individual Thalidomiders; and (b) assess how the provision of the Health Grant has (or may have) enabled individuals to reduce or avoid predicted future health needs. The timescale of the main evaluation straddles the decision (in December 2012) to extend the life of the then pilot Health Grant for a further ten years.

There are two main parts to the evaluation: a review of the operation of the Health Grant scheme and an in-depth study of the experiences of 60 Thalidomide-impaired people (the ‘study group’) of using their Health Grants. The study group represents just over 10% of the total population of beneficiaries in the UK, with a composition roughly in proportion to the total numbers living in each of the four UK nations and broadly reflective of the number of people in each of the Thalidomide Trust’s five impairment severity bands.

1.2 Purpose of this Report

This report – along with a ‘sister’ version for Wales – is the result of a request from the Scotland and Wales health departments to collect data on the use of the Health Grant from the broader population of beneficiaries living in these two countries; that is, beyond those included in the main evaluation ‘study group’. While the needs of Thalidomiders are no greater or less according to their country of residence, health and social care responses may vary owing to different policy decisions of devolved governments. Such variations may affect the extent to which Thalidomiders in different countries report their needs as being met.

It follows that, while this report is intended to be read alongside the findings in the Firefly main evaluation, the Scottish Department of Health is interested to understand more about the experiences of local Thalidomiders in their use of the Health Grant, in particular:

- the amount of Health Grant received by beneficiaries and what they have spent it on;
- beneficiaries’ spending decisions in the context of the other financial and/or health-related treatment or support available to them (and any barriers in obtaining/using these); and
- beneficiaries’ views on the adequacy of the Health Grant to meet their needs.

1.3 Data Collection

Data collection was carried out by a survey, which all 57 beneficiaries living in Scotland were invited to complete, including the 10 beneficiaries who are also in the study group for the main Firefly evaluation. Two slightly different versions of the survey questionnaire were used, to take account of the fact that some relevant information had already been collected from study group members on their earlier use of the Health Grant. The version of the questionnaire used with the 48 non-study group beneficiaries is included at Appendix A, for information.

The survey was posted to beneficiaries during the week commencing 19 November 2012 (from Firefly to those in the main study group and by the Thalidomide Trust to the other beneficiaries). Where there was no response, a reminder was sent during the week commencing 3 December. Beneficiaries were offered the choice to complete the questionnaire on paper (a freepost envelope was provided) or on-line.

At the time of writing this report, we also had access to the Year 2 main evaluation data, including interviews with all 10 study group members living in Scotland. Where these interviews help to illustrate/amplify key points arising from the current survey, we have included short verbatim (and anonymised) extracts.

1.4 Profile of Respondents

Sixteen (28%) of the beneficiaries in Scotland completed the survey, just one of whom opted to do so on-line. Six of these 16 respondents were also members of the main evaluation study group. The 16 survey respondents were split evenly between men and women. In terms of their home circumstances, 11 people reported living with a partner/spouse, while three people were living with other family members (two mentioned that these were sons/daughters, the other did not say) and the remaining two respondents lived alone. Fourteen people were owner-occupiers, with the remaining two living in private rented accommodation. With regard to work circumstances, the most common situation was part-time employment (n=7), followed by the person being unable to carry out paid work owing to disability or health problems (n=5). Three people were in full-time employment and one person reported that they were not working at the moment, but would like to.

In respect of their spread across the five impairment bands used by the Thalidomide Trust to distribute its funds, Figure 1 and Table 1 both show the spread of bandings among survey respondents and compare this with the population of Thalidomiders in Scotland. This comparison reveals that the group of survey respondents is not entirely representative of the broader population, with Bands 4 and 5 under-represented among survey respondents, while Band 3 is over-represented. It follows that the survey results on their own may understate the needs of Thalidomiders in Scotland.

Figure 1: Bandings of Survey Respondents compared with all Beneficiaries who live in Scotland

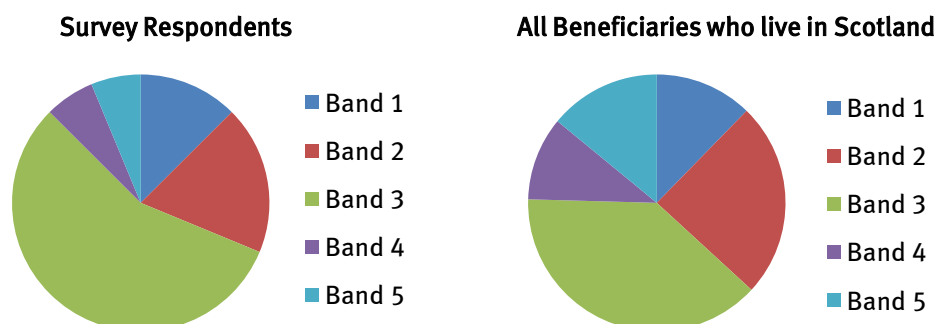


TABLE 1: BANDINGS COMPARISON OF SURVEY RESPONDENTS & ALL SCOTLAND BENEFICIARIES

	Band 1	Band 2	Band 3	Band 4	Band 5	Total
Survey respondents	2	3	9	1	1	16
All Beneficiaries who live in Scotland	7	14	22	6	8	57

1.5 Report Structure

The remainder of this report presents the survey findings. Chapters 2 and 3 report information from beneficiaries on their receipt of existing support - financial and health-related respectively – along with any difficulties they experienced in obtaining and using such provision. These data set the context within which beneficiaries have made decisions about best to use their Health Grant.

Chapters 4 and 5 focus on the Health Grant: Chapter 4 details the amounts the beneficiaries received in 2012 and how they have spent these funds; Chapter 5 reports beneficiaries’ reflections on the adequacy of the grant to meet their health-related needs and comments about its impact. In Chapter 6 we draw together the key findings and messages from the survey.

Chapter 2

Financial Benefits and Support

In this Chapter, we report the survey findings on the range of financial benefits and/or support beneficiaries were receiving in Scotland, along with any difficulties they had experienced in obtaining and/or using these.

2.1 Types of financial Benefits & Support received

The survey questionnaire listed a range of key benefits and support, along with space for respondents to note any other provision. The results are summarised in Table 2.

TABLE 2: FINANCIAL BENEFITS & SUPPORT BEING RECEIVED

Type of benefit/ support	Number of recipients	
Disability Living Allowance (DLA)	Highest rate	2
	Middle rate	4
	Lowest rate	6
Mobility component of DLA	Higher rate	6
	Lower rate	1
Housing Adaptations Grant	1	
Employment and Support Allowance (previously Incapacity Benefit)	4	
Independent Living Fund	0	
NHS Continuing Care funding/Free Nursing Care	0	
Personal Budget/Self-Directed Support (from Social Services)	0	
Social Care Services	0	
Working Tax Credit	2	
Any other benefit/ support	0	

The Table shows that the most common benefit being received (by 12 of the 16 respondents) was Disability Living Allowance, followed by the mobility component of DLA (n=7). Employment and Support Allowance was being received by four respondents and Working Tax Credit by two people. No other types of benefit/ support were reported as being received.

The number of different benefits/ types of support being received by individuals varied, as shown below in Table 3.

TABLE 3: NUMBER OF BENEFITS CLAIMED BY BENEFICIARIES

Banding	Number of benefits				Total
	0	1	2	3	
1	1		1		2
2	1	1	1		3
3		5	2	2	9
4				1	1
5				1	1
Total	2	6	4	4	16

The Table shows that, most commonly (n=6), one benefit was reported as being received, although the type of the benefit did vary. Four people reported being in receipt of two different benefits and a further four people were receiving three types of benefit, including the single Band 5 beneficiary. However two people reported receiving no benefits.

2.2 Difficulties experienced in obtaining Benefits

Four of the 16 respondents reported having experienced problems regarding their eligibility for financial benefits/support. Three people had applied for benefits but been told that they were ineligible:

“I have applied for DLA and been rejected on several occasions.”

“Despite my disability I do not qualify for mobility allowance. As I am unable to use public transport I have to purchase a car and pay for the adaptations and maintenance myself.”

“I would like some acknowledgement of mobility issues, as I struggle carrying things.”

A fourth person reported having managed to secure mobility-related benefit, but only after a long struggle:

“It took 15 years to get mobility benefit because I could not walk.”

The further person raised the more general concern that *“changes to the system have been on-going”*. While the nature of any changes was not spelt out, one of the respondents who had experienced eligibility difficulties appeared to share this concern, saying they were *“very worried about changes to tax credits and DLA”*. In this case the worry was directly related to the possibility of a reduction in funds and so the likelihood of continued lack of acknowledgement of mobility problems as eligible for benefit support.

Chapter 3

Recent Treatment and Support for Thalidomide-related Health Problems

In this Chapter, we report the survey findings on treatment and/or support beneficiaries had received within the previous three years for any Thalidomide-related health problems. Beneficiaries were asked to give a brief description of any such treatment and/or support and to indicate whether they had used the NHS or a private provider. Where private provision had been used, respondents were asked to indicate the reason for this choice.

Respondents were also asked whether they had experienced any difficulties in obtaining or receiving health treatment or support they needed. The survey questionnaire listed a range of potential difficulties (identified in the year 1 and 2 interviews with the study group), along with space for respondents to note any other problems experienced.

3.1 Types of Health-related Treatment/Support and Source of Provision

Eleven respondents reported having received treatment or support over the previous three years for Thalidomide-related health problems. Most (n=9) reported that treatment/ support had related to one type of health problem; however one respondent reported three types of problem and another had experienced five types. In this person's case, one of the five problems mentioned – mental health - appeared not to have resulted in any treatment/support, despite requests for support via their GP (and no private provision was cited):

“mental health issues - asked many times for support from GP but told that there are no options available for me...NHS is absolutely non-existent for mental health.”

Table 4 summarises the nature of health-related problems reported for which respondents *had* received treatment or support. The Table also indicates whether the NHS or private providers had been used, along with reasons for choosing private provision.

TABLE 4: HEALTH-RELATED PROBLEMS, TYPES & SOURCES OF TREATMENT OR SUPPORT

Nature of health-related problem	Type of treatment/ support	NHS provision	Private provision	Reasons for private provision
Painful joints (n=10)	'physical therapies': physiotherapist; osteopath; remedial massage (n=6)	1	5	NHS waiting list too long and/or treatment insufficient (n=3). Did not believe NHS treatment was available (n=2)
	Medication (n=2) ¹	2	0	
	joint replacement & bone graft (n=1)	1	1	no reason given (or indication which treatment was NHS/ private)
	Unspecified (n=2)	1	1	no reason given
Respiratory problems (n=2)	operations and a scan (n=1)	1	1	NHS long waiting times & lack of "personalisation"
	regular chest infections (owing to constriction) (n=1)	1	0	
Bowel problems (n=1)	scan	0	1	Quick diagnosis from private provider (but expensive)
Hearing problems (n=1)	unspecified	0	1	no reason given

Nature of health-related problem	Type of treatment/support	NHS provision	Private provision	Reasons for private provision
Knee ligament damage (n=1)	unspecified	1	0	
Using the toilet unaided (n=1)	provision of Clos-o-mat toilet	1	0	

¹one respondent reported having physiotherapy and steroid and cortisone injections, hence the citing of 11 treatments by 10 respondents reporting joint pain.

The Table shows painful joints as by far the most common health problem cited as having received recent treatment, mentioned by 10 people. The most common treatment, mentioned by 6 of these respondents, might be grouped under the heading of ‘physical therapies’, with physiotherapy, remedial massage and an osteopath all mentioned. Five of the six respondents mentioning these types of service had opted for private provision. Reasons for doing so were the belief that NHS treatment was either unavailable, insufficient and/or that they would have to wait too long for a service. For example, speaking about their NHS experience, one person said:

“18 week waiting list for physio and given only exercises.”

Other treatment received recently for painful joints included medications. This was mentioned by two people, both using the NHS (one of whom was also the only person to have reported using NHS physiotherapy). Another respondent had recently had a joint replacement and bone grafting; this person reported both NHS and private provision, although the mix was unspecified and no reason for the private provision was given. A further two people who said they had received treatment for painful joints did not specify the type of treatment. One person had received this provision via the NHS and the other via private provision, although no reason for the latter choice was given.

Two respondents reported respiratory problems as having received recent treatment. In one case, owing to the constricted shape of their chest, the person was prone to regular chest infections, treated by the NHS. In the other case, the person had required a scan and operations, for which they had used the NHS *“but sometimes”* private provision, owing to experiencing problems with the NHS of *“lack of personalisation and waiting times”*.

There were four other types of health problem mentioned, each cited once. Two people were involved. One person mentioned having a special toilet installed so that they could use the bathroom unaided; the same person had also received (unspecified) treatment for knee ligament damage. Both of these services had been provided by the NHS. A different respondent reported a hearing problem (unspecified) and a bowel problem (which had required a scan), for both of which they had sought private provision. No information was supplied about the treatment for the hearing problem, nor why private treatment had been sought. In the case of the bowel scan, clearly the speed of the service had been important, the person commenting:

“very expensive, but got a quick diagnosis.”

3.2 Difficulties in Obtaining or Receiving the Health Treatment or Support Needed

Six of the 16 respondents reported having experienced difficulties in obtaining or receiving the health-related treatment or support they needed. Multiple difficulties were common, with five of these six respondents experiencing four or more different types of difficulty. Table 5 outlines the range of difficulties experienced and their frequency. The categories in the Table were listed in the questionnaire as known potential problem areas, with an extra ‘other difficulties’ category also included.

TABLE 5: DIFFICULTIES EXPERIENCED IN OBTAINING HEALTH-RELATED TREATMENT OR SUPPORT

Type of difficulty	No of respondents (n= 6 reporting at least one difficulty)
Lack of knowledge/understanding of Thalidomide damage amongst health professionals	6
Difficulties/delays in seeing a suitably experienced health professional/specialist	4
Misdiagnosis or delayed diagnosis	3
Lack of involvement/choice in decisions made about my care and treatment	3
Problems with the quality or choice of equipment (e.g. wheelchairs, hearing aids, prosthetics) available through the NHS	3
Delays in getting treatment	2
Incorrect or inappropriate treatment	2
Inflexible care or treatment (e.g. blocks of physiotherapy treatments rather than on-going care)	2
Other difficulties: lack of wheelchair provision	1

The Table shows that the most common difficulty (experienced by all six people reporting any kind of problem) was the lack of knowledge/understanding of Thalidomide damage amongst health professionals. One person included a comment, which indicates how this lack of knowledge could make someone feel:

“there is no knowledge and GPs make you feel like you are making up problems.”

The same person said that:

“Scottish Government should give GPs a kick up the bum and ask them to be more proactive and take an interest in our specific needs and prioritise our overall quality of life.”

The next most common difficulty (mentioned by four people) was difficulty/delay in seeing a suitably experienced health professional/specialist:

“if you can get an appointment at all - waiting times can be 6 months.”

Another three types of difficulty were each experienced by three people (i.e. half of those reporting any problems): misdiagnosis or delayed diagnosis; the lack of involvement/choice in care or treatment decisions; and problems with equipment quality or choice. The single response in the ‘other difficulties’ category was also equipment-related, with one person suggesting a lack of wheelchair provision:

“need to buy wheelchair privately.”

A third of those reporting difficulties had experienced problems with care or treatment itself, such as delays, incorrect/inappropriate and/or inflexible treatment.

Chapter 4 Health Grant Allocations and Use

In this Chapter we report the survey findings on the amount of Health Grant beneficiaries received for 2012-2013 (including a comparison with all beneficiaries in Scotland) and how they spent the Grant. Beneficiaries were asked to indicate the total amount of Health Grant they had received for the year and to classify how they had spent their allocation across the categories agreed with the Departments of Health Guidance for using the Health Grant (see Appendix B). Within these categories, respondents were invited to give a brief description of what the Grant had been spent on.

The findings which categorise how the Grant was used are presented in a series of figures, which examine both the overall expenditure by the 16 beneficiaries and indicate the variation between individuals in their patterns of spend. Most of the figures break down the different types of spend by proportion rather than their monetary total. This decision arises from variation in the periods over which the spend data was available: where respondents were also in the main evaluation study group, we had spend data covering one, two or even three years, while the non-study group beneficiaries (who have taken part in this Scotland survey only) reported a mix of overall spend to date and the most recent year.

4.1 Amount of Health Grant received in April 2012

Tables 6 and 7 present information on Health Grants received for the current year (2012-2013) for all beneficiaries who live in Scotland (Table 6) compared with the 16 survey respondents (Table 7).

TABLE 6: HEALTH GRANT VALUES FOR ALL BENEFICIARIES WHO LIVE IN SCOTLAND (CURRENT YEAR)

Band	Number of Beneficiaries	Minimum Health Grant	Average Health Grant	Maximum Health Grant
1	7	£7,672	£9,780	£10,918
2	14	£11,803	£14,164	£16,820
3	22	£17,705	£19,576	£22,426
4	6	£23,606	£25,201	£27,448
5	8	£29,508	£32,408	£35,410

TABLE 7: HEALTH GRANT VALUES FOR SURVEY RESPONDENTS (CURRENT YEAR)

Band	Number of Beneficiaries	Minimum Health Grant	Average Health Grant	Maximum Health Grant
1	2	£10,000	£10,015	£10,030
2	3	£12,000	£12,667	£13,600
3	9	£15,000 ¹	£18,639	£22,000
4	1	£23,606	£23,606	£23,606
5	1	£31,300	£31,300	£31,300

¹Three of the survey respondents in Band 3 underestimated their Health Grant, reporting its value below the minimum for all those in Band 3 in Scotland.

Table 7 shows that the value of the Health Grant received by the 16 survey respondents for 2012-13 varied between £10,000 and £31,300, a narrower range than for beneficiaries in Scotland as a whole (£7,672 to £35,410, shown in Table 6). Comparing the group of survey respondents with all Thalidomiders in Scotland in terms of the average Health Grant per Band shows that, with the exception of those in Band 1, averages for the survey group were lower than for Scotland as a

whole. Coupled with the knowledge that Band 4 and 5 recipients are under-represented in the survey group (see section 1.4), this difference supports the possibility that the survey data, taken on their own, may understate the needs of Thalidomiders in Scotland.

4.2 Analysis of Overall Expenditure

In this section we use figures to present an analysis of overall expenditure by the survey respondents across the Health Grant guidance note categories. The graphs are intended to provide a broad picture of the use of the health grant rather than a detailed breakdown. They also need to be interpreted with some caution as a) they are based on a limited number of responses and b) people's recollection of their expenditure may be incomplete.

Figure 2 (below) shows the number of respondents (from the total of 16) who declared expenditure in each category. Independent mobility was the most popular category (all but one of the respondents spending at least some of their grant on this), with home adaptations the next most common area (n=13). Three quarters of respondents also saved some their grant.

Figure 2: Number of Beneficiaries spending against each Spend Category

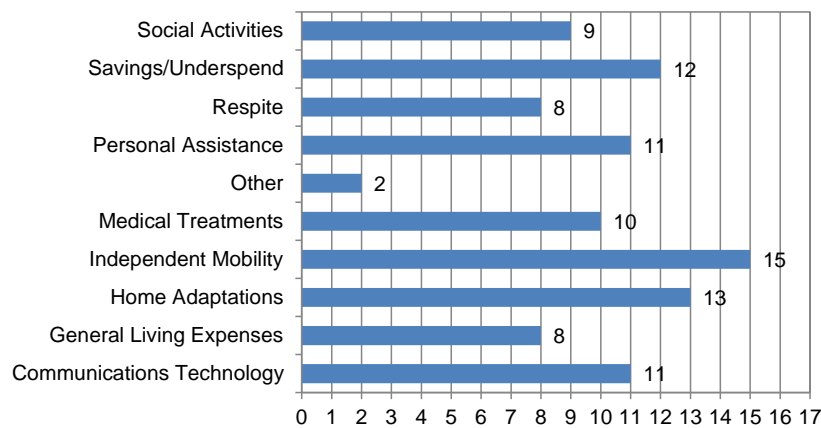


Figure 3 (below) examines the proportion of spend against each category. This analysis shows that home adaptations and independent mobility were not only the most popular spend categories (as shown above in Figure 2), but also attracted the highest proportions of spend, together accounting for 57% of all expenditure. Figure 2 also reveals that 12% of the Health Grant was saved by beneficiaries.

Figure 3: Proportion of Spend by Category

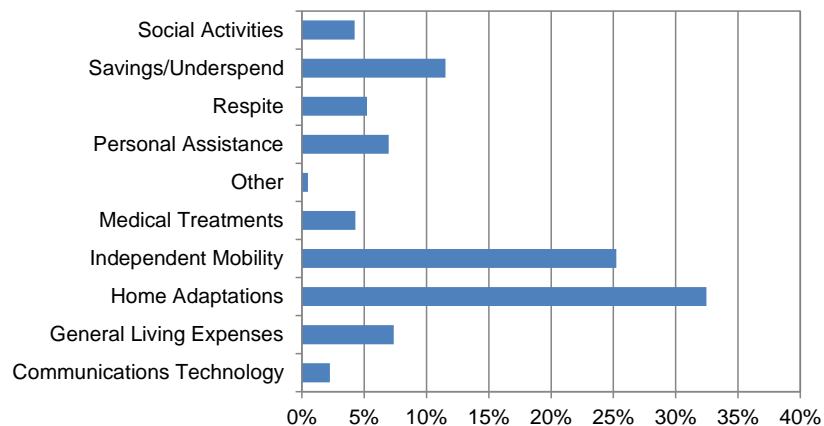


Figure 4 (below) shows the maximum proportion of spend any individual incurred on a category. It shows, for example, that one person spent the whole of their grant on independent mobility (this individual was a non-study group beneficiary and so provided only a single year of spend); two others spent over 50% of their grant on this category. A quarter of respondents spent over 50% of their grant on home adaptations, with one person spending just over 60%.

Figure 4: Maximum Proportion of Spend by Individuals on each Spend Category

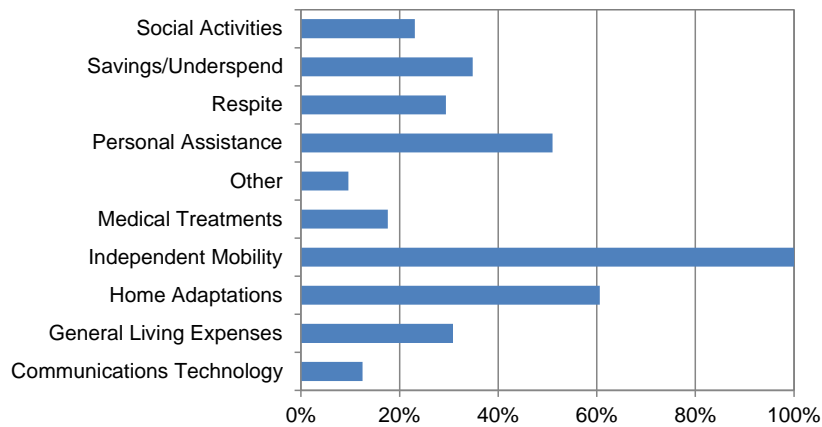
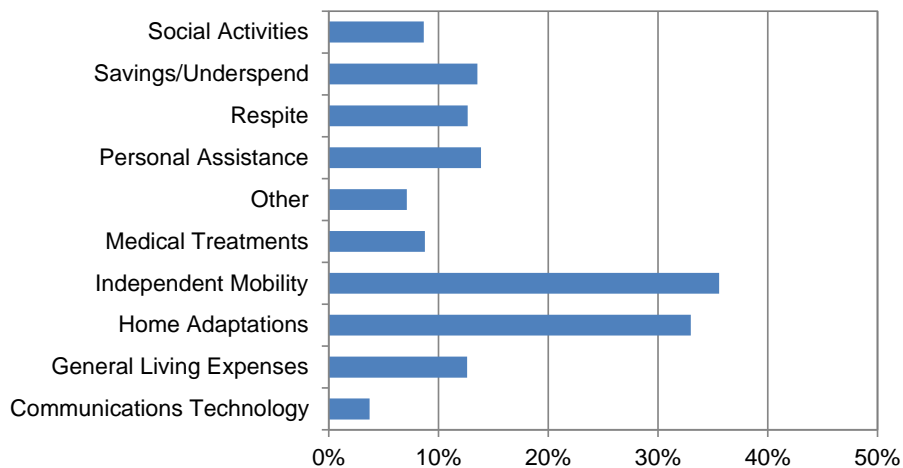


Figure 5 (below) shows the average proportion of spend for each category. Again, independent mobility and home adaptations stand out as having the highest average spend.

Figure 5: Average Proportion of Spend on each Spend Category



Respondents were also asked for brief details about what they actually spent their health grant on; the results are shown in Table 8.

TABLE 8: DETAILS OF SPEND PROVIDED

Health Grant Category	Details	No of survey respondents providing information
Independent Mobility	car (n=3) car with adaptations (n=4) car running costs (n=2)	7
Home Adaptations	garden (n=2) doorbell (n=1) kitchen (n=3) bathroom/ toilet (n=4) decorating and general maintenance (n=2) driveway (n=1)	7
Communications Technology	home phone (n=3) computers and peripherals (n=3) computer furniture (n=1) broadband (n=1) software (speech recognition) (n=1)	5
Medical Treatments	physical therapy (n=2) special furniture (n=1) hearing aid (n=1)	4
Respite	Holidays (n=3)	3
Personal Assistance	cleaning (n=3) ironing (n=1) gardening (n=3) decorating (n=1) private care (n=1)	4
Social Activities	football season ticket (n=2) meals (n=1) social clubs (n=1)	3
General Living Expenses	furniture (n=1) utilities (n=2) council tax (n=1)	3
Savings underspend	insurance (n=1) investments (n=2)	3

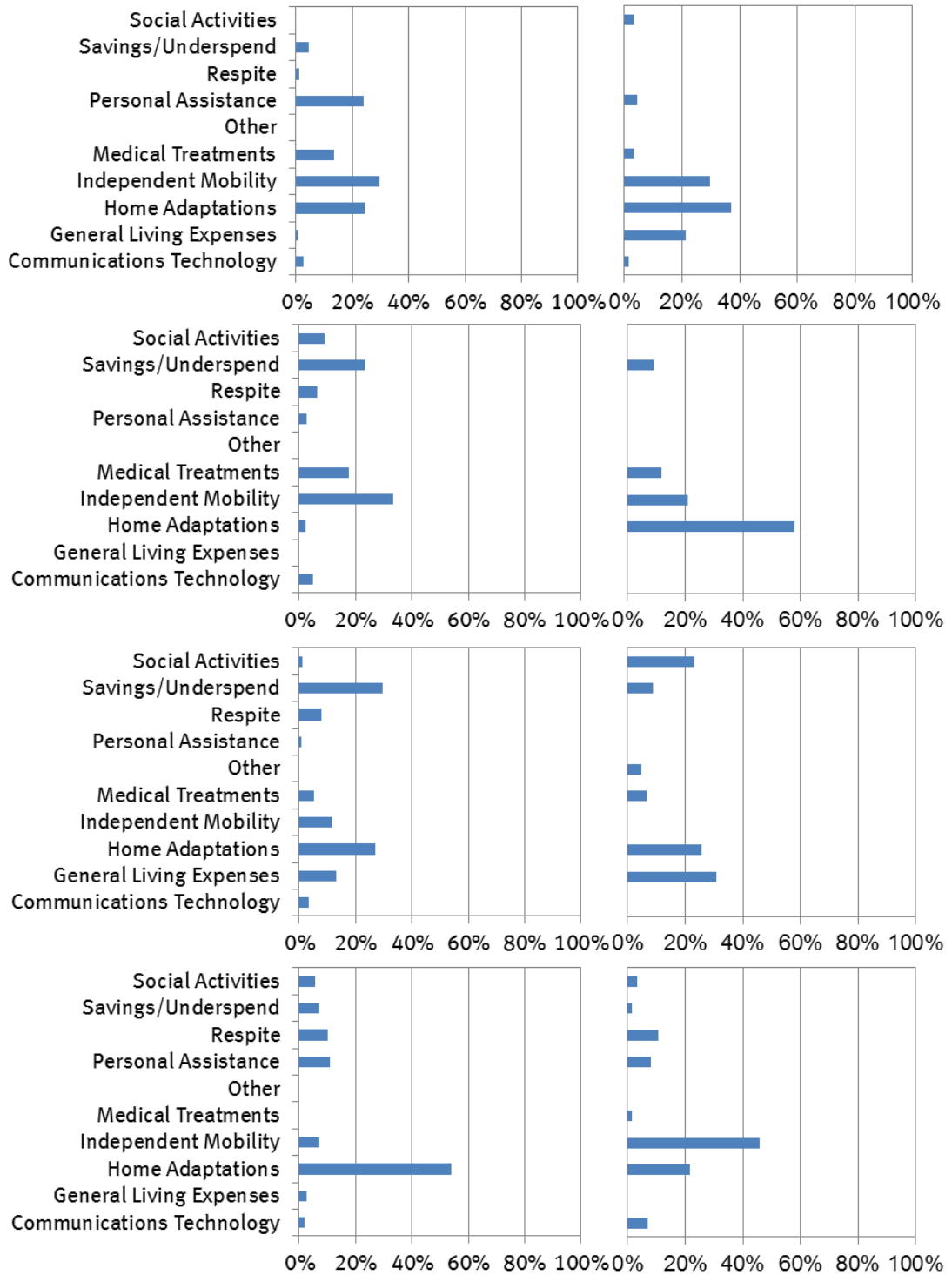
In the independent mobility category, the Table draws attention to the importance of cars, with areas of expenditure including both general running/ servicing costs and adaptations for specific impairments. Home adaptations included modifications to the house and/or garden, with the general aims of improving accessibility and for ease of cleaning the inside of the house or for working in the garden. With regard to spending on personal assistance, respondents found support with household tasks helpful owing to the time it would otherwise take to carry out these tasks themselves. In the respite category, Thalidomiders using funds for holidays valued the time spent in a warmer climate for relieving pain.

4.3 Patterns of Individual Expenditure

While overall figures are useful for summarising trends across all respondents, they mask variation in spending patterns by individual beneficiaries. Looking at the data across individuals

reveals considerable variation in how they decided to allocate their spend. Figure 6 gives a flavour of this variation, using a sample of 8 of the 16 respondents.

Figure 6: Individual Expenditure Patterns



Chapter 5

Adequacy of the Health Grant & its Impact

In this Chapter we present the survey findings on the adequacy of the Health Grant. Respondents were asked first whether the amount of the grant had been adequate to meet their main health-related needs. For those replying 'no', respondents were asked to describe briefly which areas of health need (using the Health Grant spend categories) had required additional expenditure from other resources. We also include in this Chapter the reflective comments about the impact of Health Grant, which was the focus of comments made in the 'free text' box at the end of the questionnaire. In addition to the survey data, we have included some short quotes from interviews with Scotland members of the main evaluation study group, where these help to explain the notions of adequacy and impact in respect of the Grant.

5.1 Adequacy of the Health Grant & Areas incurring additional Expenditure

Ten of the 16 beneficiaries felt that the amount of the Health Grant had so far been adequate. Three drew attention to the likelihood of their needs increasing in the future:

"The Health Grant has been adequate. However my wife is terminally ill and she has been my carer/personal assistant so in future years I will need to pay/employ someone to help me."

"The Health Grant is currently adequate. However, I feel that it will not be in the future. I broke a finger on my 'good' hand this year which made me realise how handicapped I would be if I have reduced function in that hand."

"I do know that in the future I will need to purchase an electric wheelchair and a vehicle take the wheelchair in."

The six respondents who felt that the Health Grant had not been adequate to meet their needs were asked to indicate in which categories of health need they had incurred additional expenditure. In completing this section, three respondents were either unclear as to whether an actual additional spend had taken place, or referred to a mix of actual and *desired* additional spend. For example, one respondent said that they *"have had to use money from my Mum's estate for a new kitchen"* (an area of definite spend), but also said *"require new head set"* (the wording suggesting a spend had not taken place). However, we have taken the view that, whether or not an additional spend had actually taken place or was desired, these data still highlight examples of where the Health Grant has fallen short of what was felt needed, and so both are reported here. For clarity, we have separated areas of actual and desired spend.

Table 9 summarises the detailed data from the six respondents on their areas of additional spend over and above the Health Grant which had either been required and/or would be required to meet their health-related needs. The number of spend categories cited by an individual respondent varied between one and five.

TABLE 9: AREAS OF ADDITIONAL SPEND (ACTUAL OR DESIRED) WHERE HEALTH GRANT PROVED INADEQUATE

Health Grant spend categories	Actual spend	Desired spend	Total respondents per category
Independent Mobility	n=4 -car -wheelchair	n=1 -replacement car	5
Home Adaptations	n=4 -garage conversion - improved access/ use of doors & windows -new kitchen	n=1 -home alterations	5
Communications Technology	n=1 -unspecified	n=2 -regular updating needed (every 3 years). -would like telehealthcare service. -require new headset for phone.	3
Medical Treatments	n=1 -hearing aids	n=1 -physiotherapy & massage	2
Personal Assistance	n=1 -so as to follow football team	n=1 -on-going costs (and desire to increase) support for daily living	2
Respite	n=0	n=1 -to recover mental health	1
Social Activities	0 (but see personal assistance, above)	0	0
Other	-general living expenses & savings (1) -holiday (1)	0	2

Perhaps unsurprisingly, the areas deemed important for additional spend, along with the reasons cited for these, echo to a large extent the findings in the previous chapter on the decisions and rationale for allocating the actual Grant itself, as shown in Table 8. The Table shows ‘independent mobility’ and ‘home adaptations’ as the two most commonly cited categories requiring spending over and above the value of the Health Grant, both categories being mentioned by five of the six respondents. Regarding independent mobility, the focus of the need for additional spending was on cars and wheelchairs. Car costs included servicing and running costs, but also repairs when adaptations broke down. One person said that they would like to be able to replace their current car, which was 20 years old, increasingly unreliable and costly to maintain. Wheelchair costs involved servicing and repairs. A variety of home adaptations was mentioned: one person cited a garage conversion to create a ground-floor bedroom, another person mentioned having new doors and windows fitted which were easier to open, a third had replaced a kitchen and a fourth person

said they had made (unspecified) changes to improve access. A fifth person said that they would like to make alterations to their home to *“make it easier to live in.”*

Comments about ‘communications technology’ (mentioned by three people) drew attention to the need for on-going expenditure so as to keep up with the pace of change via updates and the wish to take advantage of new developments, such as telehealthcare. The person who had already incurred extra costs in this area did not specify the nature of the expenditure, but that the aim was to achieve *“ease of use”*. Two people spoke about extra costs for ‘personal assistance’. In one case, the person was receiving extra support so as to enable them to achieve the social activity of following their football team. The second person spoke about the need to meet the on-going cost of personal assistance and the desire to increase its level for support with daily living: *“I take so long to do simple tasks.”* With regard to ‘respite’, while no-one reported spending additional funds in this area, one person said they would like *“therapeutic respite”* to help recover their mental health (this person had previously visited an overseas spa as a means of accessing such respite).

Two respondents made entries in the ‘Other’ category. One person drew attention to having spent funds additional to the Health Grant on general living expenses and savings; the other person had taken a holiday: *“one week in hot weather to relieve pain in body.”*

In the main Firefly evaluation of the Health Grant, interviews with members of the UK-wide study group living in Scotland also help to gain insight into why the concept of the “adequacy” of the Health Grant is problematic (which could help to explain why the survey respondents differed in their handling of this section of the questionnaire). While the study group interviewees noted the positive impact their grant had made, nevertheless where their needs were wide-ranging and/or required capital expenditure, the grant still fell short of the sum which would be required. For example, while the following person felt that their grant had been adequate, needs could still remain unmet:

“There’s so much you want to get done and you try to cram them in but it doesn’t work...there’s always something you have to leave.”

Another person judged the grant inadequate, since she needed a new kitchen (requiring a house extension), the capital cost of which could not be met from one year’s grant:

“It’s just impossible for me to make myself something decent to eat because I can’t reach or can’t use certain things...I don’t want to seem greedy or ungrateful, but it’s just not enough.”

5.2 Impact of the Health Grant

Several survey respondents made comments about the Health Grant in their questionnaire. Most commonly, beneficiaries wanted to summarise the positive impact of the Health Grant on their quality of life:

“The Health Grant has helped me to go part-time, which has made a big difference to me and I would say was the most important change regarding my health and well-being.”

“Very welcome. The grant has enabled me to keep my head above water and work without completely overstretching myself.”

“The Health Grant has been a god-send as my brother did not go out of the house as he had no transport owing to living on benefits for a long time. It was hard to watch him struggle every day. Now due to all the help he now receives from the Health Grant he has a good quality of life and it is good to see him smile again.”

“The Health Grant has made life easier and it is reassuring to have the financial benefit it has given and this has also helped my mental well-being.”

“Health Grant is vital for my continued quality of life.”

“Without the Health Grant I would suffer at the loss of my well-being.”

These comments point to the success of the Health Grant in enabling beneficiaries to improve not only specific aspects of their physical or mental health but also their overall sense of well-being.

Interviews for the Firefly main evaluation with UK-wide study group members living in Scotland both echo and amplify these sentiments. For example one person spoke about the impact of the Grant on their own acceptance of the need for support and experience in putting this in place:

“My state of mind is different. I think that’s one of the things the Health Grant has done for me and probably for other people. It’s helped us accept that we need things and how to go about getting them.”

These main evaluation respondents also spoke about the impact of the Grant in changing their state of mind in a different way; that is, in achieving peace of mind from the financial security it offered:

“It’s given me a sense of security and the opportunity to get things that I really, really need but couldn’t afford.” (speaking about a planned kitchen extension.)

“Emotionally it gives you a better feeling of well-being, that your future’s a bit more secure health-wise, if anything goes wrong.” (speaking about being able to opt for speedier private health provision, so avoiding a long NHS wait in pain.)

Chapter 6

Key Findings and Messages

In this short Chapter, we pull together a set of ‘key findings and messages’ from this supplementary survey of the use of the Health Grant by beneficiaries in Scotland. The survey findings are broadly consistent with those of the more comprehensive, UK-wide main evaluation, which we recommend is read alongside the Scotland survey evidence. This is because, on their own, the survey results should be interpreted with caution, for two reasons. First, the findings are drawn from a relatively small group of 16 people, which comprises 28% of beneficiaries in Scotland. Secondly, since beneficiaries in Bands 4 and 5 are under-represented among the survey respondents, the results may tend to understate the needs of Thalidomiders in Scotland. It follows that the key messages and findings are best regarded as pointers for attention. These are:

Financial benefits and support

- Most commonly, one benefit was being received (which varied in type) and not all Thalidomiders were receiving benefits
- Disability Living Allowance, followed by the mobility component of DLA, were the benefits most commonly received
- Eligibility problems were reported with DLA and the mobility component; the evidence suggests that eligibility criteria may not be taking Thalidomiders’ mobility difficulties sufficiently into account
- There was general concern about the possibility of changes to benefits in the future, should this render acknowledgement of Thalidomiders’ needs even less likely

Treatment and support for Thalidomide-related health problems

- Most respondents had received treatment or support over the previous three years for Thalidomide-related health problems; and most commonly for joint pain
- Reasons for opting for private provision rather than the NHS included shorter waiting times, a more appropriate type of service and a more personalised approach
- A lack of mental health treatment/support was reported

Use of the Health Grant

- Independent Mobility and Home Adaptations stood out as the key categories of Health Grant expenditure, across a variety of measures (most common spend, highest average spend, highest individual spend)
- Three quarters of respondents saved some their grant (which may be partly because the 10 year health grant had not been confirmed at the time of the survey)
- Individual spending patterns revealed considerable variation in personal needs and priorities

Adequacy and impact of the Health Grant

- Most respondents thought the Health Grant adequate so far, although health-related needs were foreseen as increasing in the future
- Flexibility in the Grant’s terms of use resulted in a wide range of spending choices, including: aspects of health care; living costs (enabling a reduction in hours of paid work); and saving (towards capital costs requiring more than one year’s grant)

Evaluation of the Health Grant to Thalidomide-Impaired People: Supplementary Survey of Beneficiaries in Scotland Final Report (April 2013)

- The Grant was most likely to be viewed as inadequate where it could not meet the level of high capital cost required for Independent Mobility and Home Adaptations and these categories were mentioned most often as requiring additional spend from other sources
- The benefit of the Grant was commonly described by Thalidomiders as its impact on overall well-being. This stemmed both from the results of expenditure to date and from improved financial confidence/ peace of mind to tackle future health-related needs as they arise

Appendix A: Survey Questionnaire



Evaluating the Impact of the Department of Health Grant to Thalidomide-Impaired People

Survey of Scottish and Welsh Beneficiaries

Your Details

Name:	
Telephone:	
Email:	

About You

1. Which of the following best describes your home circumstances (please tick)?		
I live alone		
I live with my partner/spouse		
I live with another family member (e.g. parent or sibling)		
Other (please describe)		
2. Which of the following best describes your housing situation (please tick)?		
I live in a house/flat which I (or my partner/family) own		
I live in a private rented house/flat		
I live in a housing association or local authority house/flat		
Other (please describe)		
3. Which of the following best describes your work situation (please tick)?		
I work full-time		
I work part-time		
I'm not working at the moment but would like to		
I'm unable to work because of my disability or health problems		
I've chosen not to work for family or personal reasons		
I'm in full or part-time education		
Other (please describe)		
4. Are you in receipt of the following financial benefits/support? (please tick all that apply)		
Disability Living Allowance (DLA)	Highest	
	Middle	
	Lowest	
Mobility component of DLA	Higher	
	Lower	

Disabled Facilities Grant/Housing Adaptations Grant		
Employment and Support Allowance (previously Incapacity Benefit)		
Independent Living Fund		
NHS Continuing Care funding/Free Nursing Care		
Personal Budget/Self-Directed Support (from Social Services)		
Social Care Services		
Working Tax Credit		
Other? (please describe)		
5. Have you experienced any problems obtaining or using these financial benefits/support (e.g. with means-testing; delays in receiving funds; restrictions on use)?		Yes/ No
If Yes, please briefly describe the problem(s) you experienced:		
6. In the past three years, have you had any treatment or support for health problems connected to the Thalidomide damage you experienced (e.g. joint replacements; pain medication; physiotherapy; help with hearing or sight problems)?		Yes/No
If Yes, please briefly describe the treatment/support you have had.		
Was this treatment provided by: (please tick those that apply)	NHS/ Local Authority	A Private provider
If your treatment was not through the NHS/LA please say why.		
7. Have you experienced any problems obtaining or receiving the health treatment or care you needed?		Yes/ No
If No, please go to Question 8.		
If Yes, please indicate the problem(s) you have experienced in the table below (please tick all that apply):		
Lack of knowledge/understanding of Thalidomide damage amongst health professionals		
Lack of involvement/choice in decisions made about my care and treatment		
Difficulties/delays in seeing a suitably experienced health professional/specialist		
Misdiagnosis or delayed diagnosis		

Delays in getting treatment	
Incorrect or inappropriate treatment	
Inflexible care or treatment (e.g. blocks of physiotherapy treatments rather than ongoing care)	
Problems with the quality or choice of equipment (e.g. wheelchairs, hearing aids, prosthetics) available through the NHS	
Other (please describe)	

Using Your Health Grant

8. What is the approximate value of the health Grant you received in April 2012?		£
9. Looking back over the last three years, please estimate how much of your Health Grant you have spent in each of the following categories.		
Spend categories	Brief description of what the money was spent on	Approx. Spend £
Independent Mobility		£
Home Adaptations		£
Communications Technology		£
Medical Treatments		£
Respite		£
Personal Assistance		£
Social Activities		£
General Living Expenses		£
Savings/underspend		£
Other		£
Total		£
<i>Please note: The expenditure you record above should not exceed the total you have been given in your Health Grant for the three years</i>		

10. Has the level of health grant you received been adequate in terms of meeting your main health or health related needs?		Yes/No
11. If you answered No, in which of the following areas have you had to use your other income/funds (e.g. income from employment; Thalidomide Trust Annual Grant; personal saving; loans/mortgages etc)		
Health Grant spend categories	Please briefly describe what it was you spent your other income/funds on	
Independent Mobility		
Home Adaptations		
Communications Technology		
Medical Treatments		
Respite		
Personal Assistance		
Social Activities		
Other		
12. Any further comments?		

Many thanks for taking the time to complete this survey
Please use the Freepost envelope to return the survey to Firefly Research

Appendix B: Categories of Health-related Need

The following categories of 'health related need' were set out in a guidance note on use of the Health Grant agreed between the Thalidomide Trust and the four Departments of Health.

These were:

- **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.

During the Firefly evaluation of how the Health Grant has been used three further categories were added:

- **General living expenses** – much of this is accounted for by assistance not covered by the Personal assistance category e.g. gardeners, cleaning etc., by higher utility bills because of the need to keep their home warmer to reduce pain
- **Savings/Underspend** – many beneficiaries did not spend their Health Grant in case it ended after the 3 year pilot.
- **Other** – spend on items which could not be allocated to any other category.



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