



Looking to the Future: Evaluation of the Health
Grant to Thalidomide-Impaired People

Year 2 Final Report – July 2012

Acknowledgements

We would like to thank all the members of our study group who kindly gave up their time to be interviewed and provide expenditure information. We greatly appreciate their willingness to share their experiences and personal stories with us.

We are also indebted to our Advisory Group, who have provided invaluable support and guidance, and helped us shape this report.

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Foreword

This second interim report by Firefly into the impact of the government's Health Grant on Thalidomide Trust beneficiaries is also a comprehensive and in-depth report on the current life circumstances of thalidomide survivors. The evidence in this report sadly comes as no surprise; the Thalidomide Trust is fully aware of the complex nature of the disabilities affecting beneficiaries, their chronic and worsening health problems, and the difficulty many experience in getting adequate and effective treatment.

Of great concern to the Trustees is the evidence, both within the report and from our own records, of the seemingly rapid deterioration in health, physical functioning, independence and overall quality of life now being experienced by many beneficiaries. In 2007 the Trust set up a health support service for beneficiaries - HealthLink. Over the past five years, HealthLink has supported 261 beneficiaries (some 55 per cent of beneficiaries), who have reported 1,608 separate health issues to date, an average of six per person. Only 339 issues (21 per cent) have in that time been recorded as "closed", indicating the chronic nature of most of the health problems affecting beneficiaries. These problems have profound implications for beneficiaries' ability to maintain any meaningful degree of independent life.

The extreme rarity of the disabilities affecting our beneficiaries, especially the impact of multiple-limb deficiencies, means that the supporting agencies can often be slow to understand the impact of what might appear to be otherwise relatively minor problems in able-bodied people. For example, the impact on an individual with shortened arms of losing the use of a single leg or foot can easily mean the transition from functional independence to not even being able to use the toilet unaided. The independence of beneficiaries is often maintained on a very fragile basis, supported by adaptive technology that is extremely expensive.

We are currently witnessing many major step-changes in the degree of disability among beneficiaries. Thus several have given up attempting to walk using what legs they have and resorted to using manual wheelchairs. The transition to use of a wheelchair for someone who also has upper limb disabilities is very different from the experience of most wheelchair users. Others, because of arm and shoulder deterioration, have had to exchange manual wheelchairs for powered ones. Each of these changes involves considerable additional costs in enlarging and adapting homes and in changing private vehicles.

We are also observing a considerable increase in the number of beneficiaries reporting chronic pain, from around 25 per cent ten years ago to over 50 per cent today. Again, this report accurately reflects this deterioration. A further issue of considerable concern to Trustees is the evidence of neurological decay, which the Trust first began studying 10 years ago, when it was evident that more than 20 per cent of beneficiaries were affected. That percentage too appears to have increased, and this field has now been the subject of two specialist medical studies commissioned by the Trust. Whatever the cause of these symptoms, we are not yet aware of any effective treatment to remedy them. We cannot foresee the full consequences of this problem, but clearly the impact on the ability of those affected to use their (already damaged) limbs could be profound, severely compromising their independence in everyday living and their use of the communication devices that are essential to maintaining day to day independence.

The most optimistic view we can allow ourselves is that the additional Health Grant funding might help to slow down the marked deterioration our beneficiaries are experiencing. However, it could take a number of years before the benefits of the Grant are evident, and even that assumes continuing and even increasing the current level of funding. In contrast, the level of mental health reported in this evaluation undoubtedly reflects the positive attitudes typical of so many Thalidomiders. This is a manifestation of the “can do” spirit we as Trustees are so familiar with, but it also has the unfortunate consequence of people exceeding the limitations of their bodies. It is also certainly true that the underfunding of support for our beneficiaries for most of their lives has contributed to the health deterioration noted in this report and apparent in other aspects of the Trust’s activities.

Our concern as trustees is to do whatever is possible to alleviate the problems being encountered by our beneficiaries: to sustain their health and wellbeing and to work with them in every endeavour to maintain their independence and the ‘normal life’ that they continue to aspire to.

A handwritten signature in black ink, appearing to read 'Sir Robert Nelson', written in a cursive style. The signature is positioned above a horizontal line that extends across the width of the text block below it.

Sir Robert Nelson QC
Chair
The Thalidomide Trust

Contents

Chapter	Title	Page no.
	Acknowledgements	2
	Foreword	3
	Executive Summary	7
1	Chapter 1	12
	Introduction	12
1.1	Background	12
1.2	The Health Grant	13
1.3	The Evaluation	14
1.4	Approach to the Evaluation in Year 2	15
1.4.1	Study Group Participation in Year 2	16
1.5	Structure of the Report	17
2	Chapter 2	18
	Overview of Health Grant Spending	18
3	Chapter 3	21
	Health Problems and Health Related Quality of Life	21
3.1	Health Problems and Changes in Health in the Last Year	22
3.1.1	Deteriorating and Painful Joints	22
3.1.2	Muscle Weakness, Strain and Pain	23
3.1.3	Numbness and Partial Paralysis	24
3.1.4	Dental Problems and Sensory Impairment	24
3.1.5	Weight Gain	25
3.1.6	Mental Health and Psychological Wellbeing	25
3.2	Health Related Quality of Life (SF12 Survey)	26
3.3	Experiences of NHS Services	27
3.4	Experiences of Social Care Services	29
4	Chapter 4	32
	Managing Health and Wellbeing	32
4.1	Addressing Existing Health Problems	33
4.2	Use of NHS Services	34
4.3	Self-Management and Preventing Future Problems	34
4.4	Improving Wellbeing and Overall Quality of Life	36
4.5	Impact on Families, Friends and Relationships	37
5	Chapter 5	40
	Maintaining Independence and Mobility	40
5.1	Preserving Independence	40
5.2	Keeping Mobile	42
5.2.1	Vehicles	42
5.2.2	Wheelchairs	43
5.2.3	Use of Trains and Taxis	44
5.3	Future ‘Capital’ Needs	44
6	Chapter 6	45
	The Future	45
6.1	Plans for Using the Third Health Grant Payment	45
6.2	Implications of the Health Grant not being Continued	47

6.3	The Future of the Health Grant	48
7	Chapter 7	51
	Conclusions	51
	Appendix 1: Profile of the Study Group	54
	Appendix 2: SF12 Health Related Quality of Life Survey Results	56
	Abbreviation List	60

Executive Summary

1. Introduction

This report draws together the findings from the second year of the Health Grant evaluation. In particular it focuses on the impact of the grant on the health and well-being of individual Thalidomiders, and how they have used their Health Grant to address their health and support needs, and reduce future health problems. Two overarching themes emerged from the evaluation this year. The first was that in using their Health Grants people naturally focused on the ‘outcomes’ they wanted to achieve for themselves and their families. So, people may have spent their grant on the same things but the reasons for spending it in this way were often different or multiple. The second theme was flexibility. Beneficiaries have substantial flexibility in how they use their Health Grants. This gave people the freedom to really think broadly about what would make the most difference to them in the context of their needs and circumstances, and people grasped this opportunity. This very personal and flexible approach to the use of the Health Grant has ensured that after just two years the grant is making a significant difference to peoples’ ability to manage their health and maintain their independence. It has also had a demonstrable impact on people’s general wellbeing and quality of life, and for many has had wider benefits for their partners and families.

Background

Around 520 Thalidomide-impaired people were born in the UK; 472 are alive today. They were affected by the drug in a variety of ways; most commonly they have missing, short and/or deformed limbs. Some people have damage to their eyes and ears or facial disfigurement; some have damaged or missing internal organs; and a few have brain damage.

The Health Grant

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 English grant was matched proportionately by the Scottish, Welsh and Northern Ireland administrations, creating a UK wide grant of £26.4 million over three years. 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 in three annual lump sums from April 2010, in the form of an annual Health Grant to individual Thalidomiders. It was agreed that individual Thalidomiders would not be expected to account to the Department of Health for their expenditure. However, the Thalidomide Trust 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 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
- 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
- Examine the effectiveness of working through a national organisation to meet the needs of other geographically dispersed groups with highly specialised needs

There are two main parts to the evaluation – a review of the operation of the Health Grant scheme which is taking place in the first and last years of the evaluation and an in-depth study of the experiences of 60 Thalidomide-impaired people (the ‘study group’) of using their Health Grants, which runs across all three years. The study group represents just over 10% of the total population of beneficiaries in the UK; its composition is roughly in proportion to the total number living in each of the four UK nations; and is broadly reflective of the number of Thalidomide-impaired people in each of the five impairment severity bands used by the Thalidomide Trust.

The second year of the evaluation has focused on the first three aims described above and has primarily involved work with our study group. There have been four main strands to the evaluation this year:

- An expenditure survey
- In-depth interviews with the study group
- Health Grant Diaries
- SF12 Health Related Quality of Life Survey

2. Overview of Health Grant Expenditure

The pattern of expenditure in the first year suggested that many people used their first Health Grant payment to begin addressing immediate and long standing needs for home adaptations or replacement vehicles, which are high cost and often have to be paid for in a ‘lump sum’. In the second year evaluation interviews, there was a sense that people had had time to take stock, and despite the initially time limited nature of the grant, were trying to think about what would make the most difference to their health and wellbeing in the long term.

The changes in the use of the Health Grant from Year 1 to Year 2 need to be interpreted with some caution, as the data only covers two years of expenditure and so cannot be regarded as a ‘trend’. Nevertheless, the analysis suggests that whilst high cost adaptations and vehicles/ wheelchairs still accounted for almost half of the study group’s expenditure, many people were also beginning to put other on-going support arrangements in place, either to manage existing health problems or prevent or reduce further deterioration in health. ‘Deferred Expenditure/Debt Servicing’ was also important with around 40% of the study group not spending the full Health Grant available to them. There appear to be two main reasons for this – i) for some people the cost of major home adaptations/replacement of an adapted car is well in excess of one year’s Health Grant and so people were ‘pooling’ money from more than one year; ii) others were mindful that the Health Grant was initially only given for three years, so they saved some money each year so that they can continue paying for health treatments and support, should the grant cease.

3. Health Problems and Health Related Quality of Life

Thalidomide-impaired people generally feel that the rate at which their bodies are aging or the health problems they are experiencing are disproportionate to their chronological age. This view was supported by the results of the Health Related Quality of Life survey (SF12) which suggest that Thalidomide-impaired people do experience significantly poorer physical health, especially in relation to physical functioning and pain, compared to the general population and also compared to people with Multiple Sclerosis. However, overall their mental health is only marginally worse than the general population.

The majority of study group members reported further health deterioration over the last 12 months, which they believe was a result of their Thalidomide damage or because of the abnormal way they had had to use their bodies in order to compensate for missing or short limbs. People are experiencing either deteriorating and painful joints, and/or muscle weakness, strain and pain. Almost a fifth of the group also reported numbness and/or partial paralysis and some said that they had only begun to experience these problems in recent years. Weight gain was increasingly reported as a problem, which has significant implications for health and independence. In many cases this was associated with a limited ability and/or opportunity to exercise.

The changes in study group members' health and overall functioning (and the impact on their overall quality of life) have to be seen in the context of many Thalidomide-impaired people reporting poor experiences of both NHS and social care services. Whilst it is not within the scope of this evaluation to explore in depth Thalidomide-impaired people's experiences of the NHS, it is important to understand them, as these experiences often influenced people's decisions to use their Health Grants to buy both health treatments and (additional) personal assistance privately.

4. Managing Health and Well Being

From the outset most people saw their Health Grant as a fund they could use to help them 'manage' their health and generally improve their own and their families' wellbeing. Nearly two thirds of the study group used some of their Health Grant to pay for treatments to address or alleviate existing health problems. Almost half were using their grants for treatment by complementary medicine practitioners. These treatments brought much valued pain relief and increased mobility and dexterity, which in turn helped people to maintain their independence. A number of people were also paying privately for treatments or services which should have been available through the NHS, in particular physiotherapy, diagnostic tests, hearing aids and prosthetic limbs.

In the short term the Health Grant does not appear to have significantly reduced people's use of NHS services, although a few people reported reduced use of prescription painkillers and fewer GP visits. However, within the study group there was a strong view that without the Health Grant their use of NHS service would have been greater as they would not have been able to address or manage their existing health problems to the extent that they had. Others felt that the steps they were taking to prevent future problems would, in the long term, mean that they would need to make fewer demands on the NHS.

More generally, the Health Grant has enabled people make their day to day lives easier, usually through improvements to their homes or on-going support. The impact of these changes on people's daily lives was significant, both in terms of the practical difference it made and the impact on their general wellbeing. Very importantly, the Health Grant has

also given people greater peace of mind and has significantly improved the wellbeing of family carers. Thalidomide-impaired people, like their peers in the general population, are facing the twin pressures of grown-up children (who often provide significant help and support) leaving home and also aging parents, whom they may need to support (or whose support, in some cases, they are losing). Whilst this situation may not be unusual, for disabled people these experiences are often more complex. The Health Grant has enabled people to maintain their relationships with partners and children, and made it easier for them to cope with changing family circumstances.

5. Maintaining Independence and Mobility

One of the most striking findings from the first year of the evaluation was the impact the Health Grant had on people's independence and mobility. In the second year of the grant these continued to be two of the most important benefits reported by the study group. The grant has given people the resources to pay for costly changes to their homes such as adapted bathrooms and kitchen and these changes have made a demonstrable difference to people's lives. Many Thalidomide impaired people are reliant on adapted vehicles for their mobility and independence, and these are very costly to buy and maintain. Having the Health Grant as a lump sum has enabled them to meet these costs without overburdening themselves financially.

The changes in the pattern of expenditure in Year 2, in particular the increase in both the amount spent on Personal Assistance and the number of study group members using their grants in this way, suggests that alongside 'capital' expenditure people are also putting on-going support in place to help maintain their independence. However, there was a strong view that expenditure on home adaptations and adapted vehicles should not be regarded as a 'one-off'. It might be assumed that the need for capital expenditure has been largely dealt with through the Health Grant but the experiences of the study group show that this is clearly not the case. Many people had a 'backlog' of much needed adaptations or vehicles that they had been waiting to replace. The high cost of adaptations and vehicles means that people have had to use more than one year's grant to fund a project/purchase, and so they have only been able to tackle one or two of these issues. Equally importantly, because the health and functioning of most Thalidomide-impaired people is deteriorating, their needs are not static. They therefore anticipated needing further adaptations and equipment in the future. Furthermore, people's circumstances are also not static, and like their peers in the general population, Thalidomide impaired people anticipated needing to move house to be near family or down size as their children leave home, which will once again result in the need for home adaptations.

6. The Future

Looking to the future, whilst people knew that the initial Health Grant was given for three years, the uncertainty of not knowing whether it was to continue or not was unsettling for many people and they expressed real anxiety about the possibility of it ceasing. In particular, there was a strong view that if the Health Grant ceased many of the health benefits gained by having the grant over the past few years would be put in jeopardy. People were also worried about the effect of losing the Health Grant on their families. They felt they would inevitably become more reliant on them and more dependent on their care if they were not able to purchase paid assistance using the grant.

Understandably, the majority of study group members were keen for the Health Grant to be made permanent. However, it was clear that this desire was about much more than just the money the grant provided. They emphasised the ‘peace of mind’ and sense of financial security a permanent Health Grant would give them, and highlighted the wider impact of this on their general well-being. They also felt it would help them to plan for the future and give them choices in their working lives. Importantly, they felt it would enable them to do the things they needed to do to manage their health and prevent or slow down the expected continuing deterioration in their health and independence.

7. Conclusions

When the Departments of Health established the Health Grant in 2010 they clearly stated that its primary purpose was to enable Thalidomide-impaired people to address the exceptional health and health related needs they were experiencing as they grow older. In this second year of the evaluation of the health Grant it was evident that the grant is enabling them to do this. More broadly, four key messages emerged:

- The health of Thalidomide-impaired people is deteriorating, and is likely to continue to do so at a more rapid rate than their peers in the general population
- People have used their grants flexibly to purchase or put in place the things that they felt would make the most difference to their health and well-being
- The Health Grant has had a direct impact on peoples’ ability to address existing health problems and has enabled people to take steps to prevent or reduce further deterioration
- There is real anxiety about the Health Grant ceasing and a strong view that a permanent Health Grant is required if people are to address on-going issues and changing needs

Perhaps the final point to note is one that sets the Health Grant in the much wider context of the Thalidomide story. There is a strong sense within the Thalidomide community that the Health Grant is not only about recognising the exceptional health problems Thalidomide-impaired people are experiencing as they age, it is also about achieving social justice for the damage they suffered, and enabling them to live a ‘normal life’ in spite of this. Its continuation is for many Thalidomide-impaired people a concrete acknowledgement of this.

Chapter 1

Introduction

This report is the second of three reports from the Health Grant evaluation (the Year 1 Interim Report is available via the Thalidomide Trust website¹). It draws together the findings from the second year of the evaluation. In particular it focuses on the impact of the grant on the health and well being of individual Thalidomiders, and how they have used their Health Grant to address their health and support needs, and reduce future health problems.

Two overarching themes emerged from the evaluation this year. The first was that in using their Health Grants people naturally focused on the ‘outcomes’ they wanted to achieve for themselves and their families. They didn’t use the term ‘outcomes’ but they did talk about what the grant had enabled them to achieve or what they wanted to be different, for example managing their own health, maintaining their independence, and reducing the burden on their families. So, people may have spent their grant on the same things but the reasons for spending it in this way were often different or multiple.

The second theme was flexibility. Although the ‘health-related needs’ categories agreed with the Departments of Health (see Section 1.2 below) are there to guide people in their expenditure decisions, beneficiaries have substantial flexibility in how they use their Health Grants. This gave people the freedom to think broadly about what would make the most difference to them in the context of their needs and circumstances, and people grasped this opportunity.

This very personal and flexible approach to the use of the Health Grant has ensured that after just two years the grant is making a significant difference to peoples’ ability to manage their health and maintain their independence. It has also had a significant impact on peoples’ general wellbeing and quality of life, and for many has had wider benefits for their partners and families.

1.1 Background

Between 1958 and 1962 the drug Thalidomide was given to thousands of pregnant women in the UK to relieve morning sickness². Many babies born to these women were still born or died soon after birth, and many others died in early childhood. However, around 520 Thalidomide-impaired people survived to adulthood. They were affected by the drug in a variety of ways, most commonly they have missing, short and/or deformed limbs. The most severely affected Thalidomide-impaired people have damage to all four limbs, others to arms or legs. Some people have damage to their eyes and ears or facial disfigurement and a few have brain damage. However, Thalidomide damage can also be unseen and includes damaged or missing internal organs (e.g. heart defects or only having one kidney). There is also clear and growing evidence that Thalidomide-impaired people are experiencing new, previously undiagnosed symptoms, almost certainly caused by the drug. These include numbness, tingling, and partial paralysis in different areas of the body, due to nerve damage, and extreme fatigue. Many more are also

¹ <http://www.thalidomidetrust.org/docs/HealthGrantInterimReportJune2011.pdf>

² Taken from an unpublished paper by Dr Martin Johnson, Director of the Thalidomide Trust

developing health problems caused by the way they have had to use their bodies to compensate for missing or damaged limbs.

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 within the Thalidomide community that the Health Grant goes some way to both achieving social justice for the damage Thalidomide-impaired people suffered, and recognising the exceptional health problems Thalidomide-impaired people are experiencing as they age.

1.2 The Health Grant

In March 2010 the Departments of Health (DHs) for England, Scotland, Wales and Northern Ireland agreed to make a UK wide grant of £26.4 million to Thalidomide-impaired people, to help to address the exceptional health and health-related needs they are experiencing as they grow older. The grant is being distributed by the Thalidomide Trust over three years from April 2010, in the form of an annual lump sum to individual Thalidomiders. When they confirmed the grant, the DHs 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 DHs for how the money is used
- The impact of the pilot scheme must be evaluated.

They agreed that individual Thalidomiders would not be expected to account to the DHs for their expenditure and would be free to spend it as they wished in order to meet their health and health-related needs. However, the Thalidomide Trust and the DHs did develop a set of ‘health-related needs’ which are intended 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.

The Thalidomide Trust has a well-established and well-accepted system for distributing its Annual Grants³ to beneficiaries, which is based on each person’s level of impairment. Beneficiaries fall into one of five impairment severity bands, although people can move between bands if their impairments change (e.g. if previously undetected problems emerge). At an early stage it was agreed that the Health Grant should be distributed on the same basis.

In 2010 the Health Grant was set at 75% of Beneficiaries Annual Grants as in the first year there were a number of issues influencing the distribution of the Health Grant. In 2011 the Health Grants were adjusted and are now approximately 90% of the Annual Grant. In Year 2, the study group members’ Health Grants ranged from £8,832 (for the lowest in Band 1) to £41,311 (for the highest in Band 5). Table 1 below provides a more detailed picture.

Table 1 Health Grant by Band for the study group

Grant Year	For Band:	Band 1	Band 2	Band 3	Band 4	Band 5	Year Total
Year 1	Max	£9,798	£14,439	£20,112	£24,454	£36,098	
	Min	£7,735	£10,829	£15,470	£20,627	£18,049	
	Average	£8,767	£12,093	£17,469	£22,217	£28,534	
	Total	£35,066	£120,927	£349,373	£244,391	£428,014	£1,177,772
Year 2	Max	£11,213	£16,524	£23,606	£27,985	£41,311	
	Min	£8,852	£12,393	£17,705	£23,606	£20,656	
	Average	£10,033	£13,839	£20,485	£25,426	£32,774	
	Total	£40,131	£138,393	£389,211	£279,689	£491,603	£1,339,026

1.3 The Evaluation

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

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.

- 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
- 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/or the Annual Grant in meeting these 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).

There are two main parts to the evaluation – a review of the operation of the Health Grant scheme which is taking place in the first and last years of the evaluation and an in-depth study of the experiences of 60 Thalidomide-impaired people (the ‘study group’) of using their Health Grants, which runs across all three years. The study group represents just over 10% of the total population of beneficiaries in the UK, and its composition is roughly in proportion to the total number living in each of the four UK nations. The group is also broadly reflective of the number of Thalidomide-impaired people in each of the five impairment bands used by the Thalidomide Trust. A brief profile of the study group is contained in Appendix 1.

1.4 Approach to the Evaluation in Year 2

The second year of the evaluation has focused on the first three aims described above and has primarily involved work with our study group. There have been four main strands to the evaluation:

- **Expenditure Survey** - in Autumn 2011 we asked all study group members to complete a simple expenditure survey, designed to gather broad information about how people have used their second Health Grant. As in Year 1, the survey asked people to allocate their Health Grant expenditure to the ‘health related needs’ categories agreed with the Departments of Health and/or three additional categories added by the evaluation team– ‘General Living Expenses’, ‘Other’ and (on the basis of the first year’s expenditure) ‘Deferred Expenditure/Debt Servicing’.
- **In-depth Interviews** – In February/March 2012, 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 was explored in more depth. All the interviews were recorded and transcribed as detailed notes and quotes.
- **Health Grant Diaries** – A small number (14) of study group members offered to keep a Health Grant diary, to record their thoughts and experiences in ‘real time’ as they

spent part of their grant. In practice only 6 people did this and largely on an ad hoc basis. However, some material from the diaries has been used to supplement the findings from the interviews.

- SF12 Health Related Quality of Life Survey** – SF12 is a widely used health survey designed to measure health related quality of life. It consists of eight scaled sections which can also be ‘aggregated’ into two domains - the physical health domain and the mental health domain. The survey questionnaire was completed at the end of the in-depth interviews. When answering the survey questions we asked people to try and differentiate between their original impairment (and the effect this has always had on their physical functioning) and their overall health (including any deterioration in their physical functioning). This was difficult for some people and so we acknowledge that the results of the SF12 survey therefore need to be interpreted with some caution. The results for the study group have been compared with a similar age group in the general population and with people of a similar age with Multiple Sclerosis (10 years from the on-set of symptoms). The key findings from the survey are included in Chapter 2 and a detailed breakdown of the results is shown in Appendix 2.

In addition, and where appropriate, we have briefly drawn on relevant information from other sources, including data held by HealthLink (the Thalidomide Trust’s health advisory service) and a neuropathy study commissioned by the Thalidomide Trust and conducted by medical researchers from Imperial College Healthcare NHS Trust⁴.

1.4.1

Study Group Participation in Year 2

Seven of those who volunteered to be members of the original study group have subsequently not participated in either year. A further three study group members who were involved in Year 1 declined to be involved in Year 2 though one study group member who did not get involved in Year 1 did become involved in Year 2.

Table 2 shows the response rates to the expenditure survey and the interviews for each year.

Table 2 Study group response rates

	Band 1	Band 2	Band 3	Band 4	Band 5	Total
Original Study Group	4	10	19	12	15	60
Year 1 Spend data	3	7	16	9	14	49
Year 1 interviews	4	8	16	10	15	53
Year 2 Spend data	4	9	14	9	13	49
Year 2 interviews	4	9	14	9	13	49

Note: One study group member has recently moved from Band 3 to Band 4 so the figures in Table 1 differ from the profile presented in last year’s Interim Report.

⁴ Malik O, Nicholas R, and Nicotra A (2011) *Evaluation of the peripheral nervous system in patients with thalidomide-induced limb malformations*. Unpublished report for the Thalidomide Trust

1.5 Structure of the Report

The structure of this year's report is designed to reflect the overall themes of outcomes and flexibility described at the beginning of this introduction. Chapter 2 gives a brief overview of Health Grant expenditure in Year 2. Chapter 3 sets the scene by describing the health problems people are experiencing and the changes which have occurred in the last year. It also sets out the findings from the SF12 Health Related Quality of Life Survey, and outlines the difficulties people have experienced in using NHS and social care services. Chapter 4 focuses on how people have used their Health Grants to manage their health and improve their general wellbeing. In Chapter 5 we focus on independence and mobility and the ways in which the Health Grant has enabled people to maintain or regain their independence, and the implications this has had for their families. Chapter 6 brings together people's views about the future of the Health Grant, in particular the implications of it ceasing and how they would use it if it was made permanent. Lastly, Chapter 7 draws together the main conclusions from the second year of the evaluation.

Chapter 2 Overview of Health Grant Spending

The pattern of expenditure in the first year suggested that many people used their first Health Grant payment to begin addressing immediate and long standing needs for home adaptations or replacement vehicles, which are high cost and often have to be paid for in a ‘lump sum’. In the second year evaluation interviews, there was a sense that people had had time to take stock, and despite the initially time limited nature of the grant, were trying to think about what would make the most difference to their health and wellbeing in the long term.

The main analysis in this report is based on the seven ‘health related needs’ categories plus the three additional categories added for the evaluation. However, we have undertaken some more detailed analysis using keywords based on the information provided in the expenditure surveys and this analysis is used where relevant in the main chapters.

The analysis of Health Grant expenditure by study group members showed that there have been some changes from Year 1 to Year 2 (see Figures 1 to 3 below). The proportion spent on Home Adaptations decreased by 5% but the number of study group members using some or all of their grants for this purpose remained the same. Similarly, Independent Mobility has seen the proportion of spend decrease by 7% with the number of study group members remaining about the same. Interestingly, the proportion spent on General Living Expenses has nearly doubled and the number of study group members who used their grants in this way has increase by 28%. Similarly, Personal Assistance has seen the spend proportion treble whilst the number of study group members increased by over a third, and the proportion spent on Social Activities has trebled with the number of study group members increasing by 20%. Respite, Medical Treatments and Communications Technology have seen little change.

Figure 1 Amount spent in each category in each year

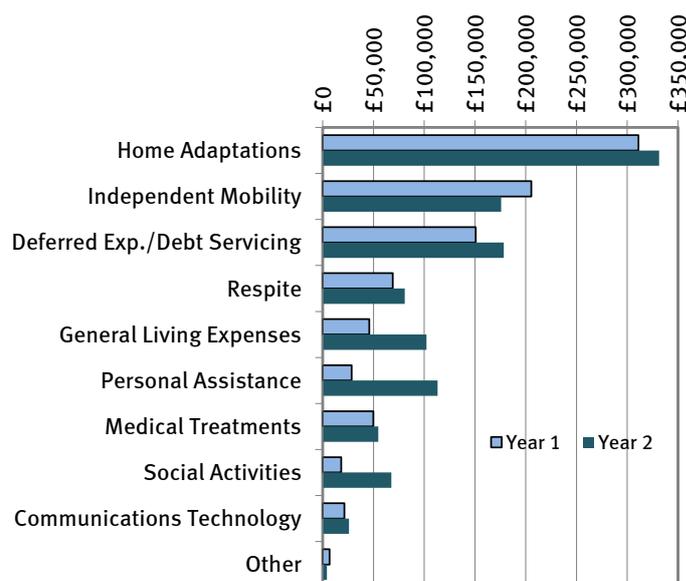


Figure 2 Each category as a proportion of total amount spent in each year

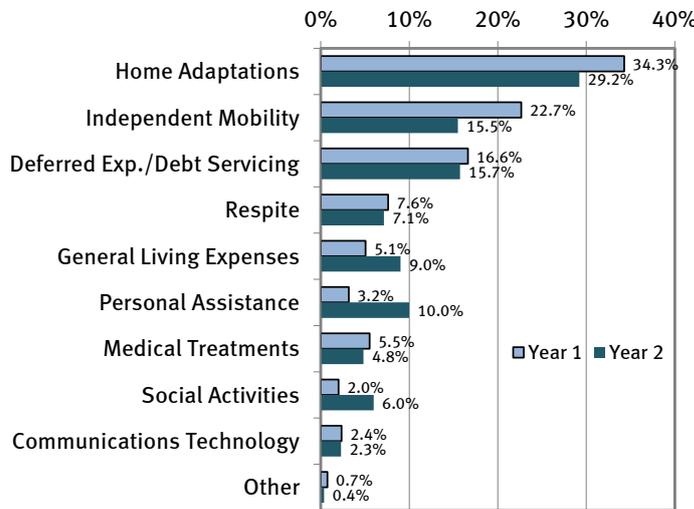
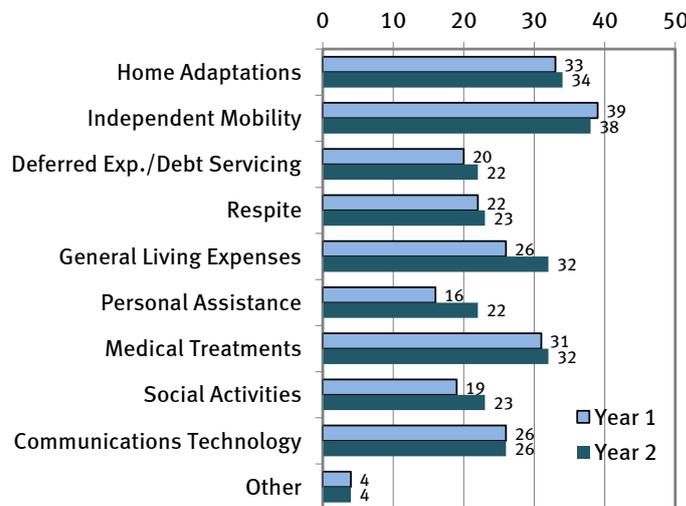


Figure 3 Number of study group members for each category in each year



The additional category ‘Deferred Expenditure/Debt Servicing’ has been introduced this year. In both years of the study around 40% of the members of the study group have not spent the full Health Grant available to them. The information gathered in the interviews suggests that there are two main reasons for this. For some people the cost of major home adaptations or the replacement of an adapted car is well in excess of one year’s Health Grant and so people were ‘pooling’ money from more than one year. Others were mindful that the Health Grant was initially only given for three years. They have saved some money each year so that they can continue paying for health treatments and

support, or have some savings to draw on for expensive items, should the Grant cease. These issues are discussed in more detail in Chapter 5. In Year 2, the proportion spent on Deferred Expenditure/Debt Servicing has decreased slightly but the number of study group members using their grants in this way has increased very slightly.

The changes in the use of the Health Grant from Year 1 to Year 2 need to be interpreted with some caution, as the data only covers two years of expenditure and so cannot be regarded as a 'trend'. Nevertheless, at an individual level there does appear to be some shift in peoples' spending patterns from 'capital' to 'revenue' or on-going support and lifestyle changes. Overall, almost half the Health Grant expenditure is still accounted for by high cost items of home adaptations and independent mobility. However, as is explained in greater depth in Chapters 3 and 4, the interviews suggest that not only has the Health Grant enabled people to tackle long standing needs for adaptations and vehicles, it has also given them the confidence and resources to begin putting in place a range of on-going support, either to manage existing health problems or prevent or reduce further deterioration.

Chapter 3

Health Problems and Health Related Quality of Life

Key Findings

- Thalidomide-impaired people feel that the rate at which their bodies are aging or the health problems they are experiencing are disproportionate to their chronological age
- The majority of study group members reported further health deterioration over the last 12 months, which they believe is caused by their Thalidomide damage
- The vast majority of people are experiencing either deteriorating and painful joints, and/or muscle weakness and strain. Several have numbness and/or partial paralysis
- Weight gain was increasingly reported as a problem, which has significant implications for health and independence. In many cases this was associated with a limited ability and/or opportunity to exercise
- A Health Related Quality of Life survey (SF12) suggests that Thalidomiders do experience poorer health compared to the general population and compared to a group of people with Multiple Sclerosis, especially in relation to physical functioning and pain.
- Thalidomide-impaired people's often negative experiences of both NHS and social care services influenced study group members' decisions to use their Health Grants to buy health treatments privately, and to supplement their social care services

Anecdotal reports from the Thalidomide community as a whole suggest that many Thalidomide-impaired people feel that the rate at which their bodies are aging or the health problems they are experiencing are disproportionate to their chronological age. The study group reflected this saying things like - *"I feel like I have the body of a 70 year old"* and *"We're 10 years older than our age"*. As is noted in Section 1.1, people were experiencing new symptoms and problems related to their Thalidomide damage. There was also a strong sense that many study group members felt their bodies were *"wearing out"* either as a direct result of the original Thalidomide damage or because of the abnormal way they had had to use their bodies in order to compensate for missing or short limbs. Many felt that the deterioration in their health was resulting in an incremental loss of function and was having a significant effect on their quality of life.

In this Chapter we describe the type of health problems that people said they had been experiencing over the last 12 months, and also summarise the results of the SF12 Health Related Quality of Life survey which has enabled us to compare the health related quality of life of Thalidomide-impaired people, with the general population in a similar age group, and with people with Multiple Sclerosis, a relatively common neuromuscular condition.

The changes in study group members' health and overall functioning (and the impact on their overall quality of life) have to be seen in the context of many Thalidomide-

impaired people reporting poor experience of both NHS and social care services. There is wider evidence that the NHS often struggles to care effectively for people with complex conditions⁵, especially complex rare conditions⁶⁷. Whilst it is not within the scope of this evaluation to explore in depth Thalidomide-impaired people's experiences of the NHS, it is important to understand them, as these experiences often influenced people's decisions to use their Health Grants to buy health treatments (both conventional and complementary) privately. In relation to social care services, whilst only a fifth of study group members were in receipt of these services, around half of them reported some problems with either the level, nature or quality of the services they received. Again, this often influenced people's decisions to use their grants in certain ways, in particular to 'top up' personal assistant hours. These issues are explored more fully at the end of this Chapter.

3.1 Health Problems and Changes in Health in the Last Year

The majority of study group members said that they had experienced further deterioration in their health over the last year, and three people reported new health problems. In almost all cases people believed that this was linked to Thalidomide damage, although a very small number said their health had deteriorated due to other causes, such as unrelated conditions (e.g. diabetes) or accidents. Just one person said that there had been no change in their health and six people reported a general improvement. This group all attributed the improvement to the services/support they had purchased with the Health Grant or the changes in their lives it had enabled them to make. These are discussed more detail in Chapters 3 and 4. The main health problems that people said they had experienced over the last 12 months are described below. They are illustrated with a number of short personal stories.

3.1.1 Deteriorating and Painful Joints

As highlighted in last year's report, the majority of those interviewed were experiencing deteriorating and painful joints. The interviews this year demonstrated that these problems have by no means gone away, and some people reported new or worsening problems. Some people have elected for joint replacement operations within the last 12 months, some privately and some within the NHS, because of the deterioration and pain they have been experiencing. For many Thalidomiders, deciding to go forward with such operations is not at all straightforward.

⁵ K Barnett, S W Mercer, M Norbury, G Watt, S Wyke, B Guthrie (2012) Epidemiology of multi-morbidity and implications for health care, research, and medical education: a cross-sectional study. *The Lancet*, Early Online Publication, 10 May 2012.

⁶ Muscular Dystrophy Campaign (2011) *Hospitals in Focus: Health Care Not Health Risk*. See <http://www.muscular-dystrophy.org/>

⁷ Williams B, Copestake P, Eversley J and Stafford B (2008) *Experiences and Expectations of Disabled People*. A Research Report for the Office for Disability Issues.

Personal Story

D, who lives alone, has two short arms and his hands are incomplete. His right shoulder ‘joint’ has severely deteriorated. He has lost movement and strength in his right arm and he is in constant pain, which also affects him sleeping. He needs a shoulder replacement but the doctors he has seen are not sure what to do and whether an operation would be successful. He explained:

“They might have to shorten the arm to put a ball joint in because I don’t have a ball type thing. The bones are so thin too that they’ll have to make special pins to put it back together....They want to hold it off as long as possible because there’s no guarantee that I’ll be able to use my hand afterwards and when you’ve only got one working digit on each hand its difficult....Its unbearably painful but what can you do....”

3.1.2

Muscle Weakness, Strain and Pain

Around a fifth of study group members reported problems with muscle weakness and strain. These problems included loss of strength in hands and arms, general muscular weakness and pain, and muscle strain due to over use, especially in backs, necks and the limbs they use for everyday tasks.

Personal Story

R has no arms and uses her feet and legs for most everyday tasks. She now has pain in her lower back and left leg (the one she uses most) when she lifts it. The doctors think this is caused by muscle damage due to overuse. Recently, she sprained her right ankle (the leg she balances on) and has now lost some strength in it. Again the doctors think this was caused by overuse of the joint.

“Depending on what I’ve done, I have days when I don’t have any energy and it takes longer to function. It’s like I do everything with my legs and so it’s not like you can sit down, have a rest and read a book and do everything with your hands. If I want to read a book I have to use my legs so they never get a break.”

She is currently having physiotherapy (from a physiotherapist she has seen for a number of years) for the problem with her back and leg, which she pays for from her Health Grant.

“I am now able to receive treatment on a weekly basis and my well being has improved. The times I go without this treatment because of my physio being on holiday, I notice a difference in my condition. I am unable to go any longer than two weeks between treatments. Each visit costs £30.00 and this is money is well spent, as it helps to decrease my pain level.”

However, the problems she has experienced have already limited what she can do for herself, including personal care, and this has made her feel far less independent.

3.1.3

Numbness and Partial Paralysis

Numbness and tingling in different areas of the body, loss of dexterity, and even partial paralysis of hands and feet was a significant and growing concern for almost a fifth of the group. Some reported that they had only begun to experience these problems in recent years. They felt they were due to previously undiagnosed or little understood effects of Thalidomide. A recent study commissioned by the Thalidomide Trust and conducted by medical researchers from Imperial College Healthcare NHS Trust, appears to support this view. The study explored *‘whether people born with Thalidomide induced limb abnormalities have any evidence of a peripheral neuropathy’*. In the conclusion to their report⁸, the researchers said:

“This study showed differences between nerve function of people born with Thalidomide induced limb abnormalities compared to controls. One possibility could be that the peripheral nerves of people who were exposed to the drug whilst in their mother’s womb have been somehow affected in parts of the body which appear and feel normal.”

Some Thalidomide-impaired people within the Imperial College study also suffered pins and needles due to compression of the nerves in the limb, spine or neck. This was attributed to the abnormal use of these body parts or the altered anatomy due to the effects of the Thalidomide. Medication is available to treat pins and needles but it can cause weight gain, which as is noted in Section 2.1.4 is a real concern for many Thalidomide-impaired people. Alternative drugs without this side-effect are available but can be much more expensive for the NHS to prescribe.

These problems led to real practical difficulties for some people. They reported that their balance was often affected, resulting in more falls or the fear of falling (and all the knock-on effects of this, such as reluctance to use public transport, escalators etc.), and loss of dexterity and partial paralysis meant that people were less able to do everyday tasks resulting in reduced independence and greater reliance on family or paid personal assistants. For one person the experience of partial paralysis had added complications because as a deaf person she uses sign language and relies on technology to communicate. Losing her dexterity has huge implications as she is finding it harder to sign or use the computer for long periods of time. She is still awaiting a referral to see a specialist to determine the cause of the partial paralysis.

3.1.4

Dental Problems and Sensory Impairment

Those with sensory impairment also reported deterioration. The implications of this were more apparent this year; for example, two people reported that they were now finding it very difficult to manipulate spectacles or contact lenses. One of them has been considering laser eye treatment to address this.

Many Thalidomide-impaired people have difficulty cleaning their teeth properly, while others rely on their teeth to do everyday tasks, and the study group members in this situation reported that they were experiencing more dental problems, and this had very worrying implications for them in terms of their level of independence:

“I use my teeth with sticks for pulling up trousers, holding my keys, opening bottles. I’m always using my teeth and I’m doing a lot of damage, but there’s nothing I can do about that because I need to use my teeth when I am doing

⁸ Op cit 4

things. I can do things with my feet, but they slip on bottles and stuff. I use my teeth for everything.”

3.1.5 **Weight Gain**

Problems with weight gain were raised quite frequently in these second year interviews. In many cases this was due to people becoming less mobile, which was in turn linked to pain management and having to rely less on certain limbs in order to inhibit further deterioration. Some study group members have now become more reliant on using wheelchairs and complained that it could be difficult to access gyms and appropriate exercise regimes; a couple of people were employing a personal trainer with their Health Grant because of this. The knock-on impact of weight gain for some was also very significant in terms of health and levels of independence.

“The last thing I want to do is put on loads of weight and then I can’t use my feet. That’s why I go to the gym... and the social life as well...I’m struggling with a lot of aches and pains in joints now, a lot of soreness you know, bad back, bad knees and we’re going to make it twice as worse if we put on a lot of weight.”

Others were concerned that being overweight would lead to additional health problems or worsen existing problems. For example, one person with diabetes was concerned that his condition was deteriorating. He felt that he might have to move from tablets to injecting insulin in future but worried that he would not be able to self-administer this.

3.1.6 **Mental Health and Psychological Wellbeing**

Generalised depression or anxiety was reported by a minority of study group members. Many people talked about feeling ‘down’ or ‘grumpy’ due to experiencing constant pain. Some reported ongoing problems linked to coming to terms with disability, or dealing with the everyday barriers that disabled people face:

“It’s the frustration more than anything else. Just generally getting things done, life is a constant battle. I try to look at the funny side of life, but simple things like trying to cross the street in a wheelchair is a nightmare. I go in somewhere. Where’s the disabled toilet? and it’s ‘Oh, we don’t have one’. It’s the frustration. Simple tasks that should be straightforward.”

One person with a history of mental health problems had attempted suicide, in part as a result of isolation and loneliness. Others described how the more recent loss of their independence and mobility was starting to affect them psychologically:

“For me, since as long as I can remember, I’ve always been active and done active jobs... I’ve never done an office job – it’s always been physical – and now I’m finding it very difficult emotionally to take this on board and find that I’m having to slow down whereas I feel as if there’s still a few more years in me. My mind’s telling me one thing and my body’s saying no, it’s just not happening.”

However, several people reported that the Health Grant has been significant in giving them an emotional ‘lift’ and reducing worries and anxieties, and the ways in which this was achieved are explored further in the next chapter.

3.2 Health Related Quality of Life (SF12 Survey)

In the second year of the evaluation we decided that it would be valuable to explore whether the health problems experienced by the Thalidomide-impaired people in our study group are in fact resulting in them experiencing poorer health related quality of life than their age group in the general population, and/or than people with a common neuromuscular condition, such as MS. To do this we used the SF12 Health Related Quality of Life Survey. It is important to note that the SF12 survey is not being used here to quantify the impact of the Health Grant on people's health but rather to gauge how the health related quality of life of our study group compares to that of non-Thalidomide-impaired people of a similar age.

As was noted in Section 1.3, the SF12 survey consists of eight scaled sections (General Health; Pain; Physical Functioning; Role Limitation Physical; Mental Health; Role Limitation Emotional; Social Functioning; Vitality) which can be 'aggregated' into two domains – physical health and mental health. The full results for the survey (including significance tests) are shown in Appendix 2. Here we present the key finding for both the physical health and mental health domains.

In the physical health domain:

- The Thalidomide study group had a significantly lower average aggregate score than people of a similar age (45 to 54 years) in the general population (24.6 compared to 50) indicating that their health related quality of life is significantly poorer
- 70% (n=35) of the study group had a score below 30 i.e. the same as or worse than the 2% of the general population group with the poorest health related quality of life, and only 2 study group members had a score above the average for the general population group
- The study group also have a lower health related quality of life, as a result of their physical health problems, than people with MS (average age 46 years) are experiencing, 10 years after onset of symptoms (i.e. an average aggregate score of 24.6 for the study group compared to 34 for the MS group)
- In the four sections which make up the physical domain, the Thalidomide study group had the lowest scores for Physical Functioning (19) and Pain (28.6).

In the mental health domain:

- The average aggregate score of the study group was 43.8, which is only marginally lower than the general population group (score 50) and compares very closely with the MS 10 year group (score 43.2)
- 28% of the study group (n=14) had a score above the average for the general population group
- However, 14% (n=7) of the study group had a score below 30 i.e. the same as or worse than the 2% of the general population group with the poorest health related quality of life.

The findings from SF12 suggest that Thalidomiders do experience poorer physical health compared to the general population and compared to a group of people with MS, especially in relation to physical functioning and pain. By contrast, on average their

mental health is only marginally worse than the general population and similar to the MS group. Findings from the second year interviews also show that many Thalidomiders are reporting that their health is noticeably deteriorating. The ways in which people have used the Health Grant to try and alleviate and manage this is explored in more detail in Chapter 4.

3.3 Experiences of NHS Services

Study group members gave a number of examples of very good NHS care. One member who sees her GP fortnightly for acupuncture for pain control described him as “*excellent*”. Following damage to her arm after an accident and misdiagnosis by the local hospital, he had also taken time to find and refer her to a specialist in a national teaching hospital. Another person who was due to have a hip replacement described how her consultant had made a real effort to understand how she uses her legs and feet so that he could select the best prosthetic hip for her needs.

However, the Interim Report from the first year of the evaluation described previous negative experiences of NHS care which the study group members reported. This issue was highlighted again this year. There were several examples of poor NHS care and continuing frustration with access to appropriate NHS services, including failure to understand and take account of the implications of Thalidomide damage, misdiagnosis, inappropriate treatment, inadequate or variable access to treatment and poor staff attitudes. There were also examples of NHS interventions for non-Thalidomide problems (such as injuries following accidents) which exacerbated problems caused by people’s original Thalidomide damage. The negative experiences that many Thalidomide-impaired people have had of NHS services often influenced their decisions to use their Health Grants to buy health treatments (both conventional and complementary) privately, and so it is important to understand them. The main issues people highlighted this year are discussed in more detail below.

- **Poor understanding of the implications of Thalidomide damage** – The failure of some GPs and secondary care clinicians to understand the implications of Thalidomide damage was a major area of concern. The effect of Thalidomide on people’s bodies, both in terms of their original impairments, and related and new problems is complex. Whilst people accepted that clinicians could not be expected to know about this as a matter of routine, they did expect clinicians to listen to them, and to take the time to find out more where necessary. In some cases the failure to do this had led to misdiagnosis and delays in treatment due to the Thalidomide condition not being properly taken into account.

“We just don’t fit in the boxes. I was sent for the MRI scan and they don’t get to see you, remember, so they only get a scan of my neck – not the whole person. So while a bit of numbness in the fingers for somebody else is not a major problem, when you don’t have fingers that work normally then that is a real problem. The surgeons did not know that ... so my rheumatologist had to write to them again and ask them to look again at me in light of my disability... and it is months and months and months down the line here”.

“As an example, a few years ago I fell out of my wheelchair and dislocated my shoulder, and I was in excruciating pain, so went to casualty, which is a place I

absolutely hate. When they X-rayed me they hadn't got a clue. They really didn't know what I'd done, what should be where and sometimes that can be scary....if it wasn't for your family and friends there would be a lot more misdiagnoses."

For other people it resulted in poor routine and elective care;

"It is difficult to contradict professionals. When I had a hysterectomy I specifically asked if it would have any impact on the fact that I was affected by Thalidomide and I was categorically told 'No',.. but I am very reliant on my stomach muscles to get in a sitting position... when I woke up in the bed I could not move ... I couldn't do anything I was literally almost paralysed.

"I don't particularly like going to my GP because I feel they are scared of me....If I go for like a basic problem they are like 'I don't know, I don't know what's wrong with you'. So I think a lot of us do a bit of self-analysis."

Personal Story

M has short arms and uses her feet for a number of tasks, in particular picking things up to avoid bending. Two years ago she had an accident resulting in an injury to her foot. She was unable to obtain a diagnosis via the NHS when she first had the accident, despite going to A&E three times and a walk-in centre twice. On all five occasions M said the NHS refused to X ray or take her concerns seriously and clinicians said it was just a sprain. M finally got an X-ray by paying privately and this did reveal that the ankle had been fractured. If it had been diagnosed earlier the consultant said her ongoing problems with it may have been avoided. She now has continuing weakness and pain, and experiences numbness if she sits in one position for too long. This year M has funded an MRI scan using her Health Grant. The private consultant feels a fitted plate might help, but again this would have to be self-funded. M is frustrated that in her contact with the NHS, staff have not taken her Thalidomide damage properly into account and do not understand how reliant she is on her legs and feet:

"My consultant said that if I was seeing you as an NHS patient I wouldn't even be discussing plating with you because it would not be seen as cost effective because I can't say that it's necessary, but then he says he thinks it is necessary based on the fact that I use my legs in a different way and I am so reliant on my feet."

Because of the huge expense and a lengthy convalescence M is still considering whether to go ahead with this operation.

- **Restricted access to specialists** – Study group members also reported that getting access to specialist who had some understanding of Thalidomide damage was difficult, either because of long waiting times (sometimes over a year) or because (in England) Primary Care Trusts (PCT) or Community Health Partnerships (in Scotland) declined to fund some treatments or refer to out of area specialists. Information collected by the Thalidomide Trust's HealthLink service supports this. HealthLink have found that in England, Thalidomide-impaired people are obliged to use the low priority appeal system within their PCTs resulting in long delays in referral to a

specialist. This suggests that commissioning organisations are failing to appreciate the complex needs of Thalidomide-impaired people. In a poster⁹ to be presented at the British Orthopaedic Association/ International Orthopaedic Association Congress in September, Professor Angus Wallace from Nottingham University explains:

“These patients provide major surgical challenges. They are better referred to an experienced surgeon who has gained experience in the management of these difficult problems. There are likely to be a significant number of these patients presenting over the next 10 years and lessons learned from treating surgeons should be shared with others.”

- **Inadequacy of routine care pathways** – For many Thalidomide-impaired people, standard NHS care pathways, especially for muscular-skeletal problems, are either inadequate or inappropriate. For example several people noted that the standard short ‘blocks’ of three to six physiotherapy treatments were of little use to them as they needed on-going treatment. Furthermore, physiotherapists working in routine outpatient physiotherapy services rarely had the experience and knowledge to treat Thalidomide-impaired people. One person who had been seen in the hospital physiotherapy service during convalesce after an operation described it as *“more of a hindrance than a help”*. NHS equipment services were reported as unsatisfactory by several study group members, especially those who use wheelchairs.

There also appeared to be regional variations in access to NHS funded care, though this is difficult to judge given that individual circumstances will vary and some people are more assertive than others in pushing their case. For example, two study group members said they required major dental treatment directly linked to the wear and tear on their teeth because they rely on them for daily tasks. In one case the person’s implant treatment was fully funded by the NHS and the work was carried out as a priority under ‘special circumstances’ because reliance on his teeth was recognised. He was also informed that the NHS route would be quicker compared to paying privately, and he said the aftercare was excellent, with additional physiotherapy provided because his legs had weakened during convalescence. By contrast, in another area a person requiring dental implants has been told that he will have to pay £20,000 for the treatment, which he cannot afford.

3.4 Experiences of Social Care Services

About a fifth of study group members said that they had support from local authority social services. There were no examples of new requests for community care assessments within the last year. Most of the people who were in receipt of social care were in the higher Thalidomide Trust impairments bandings, and most of them said that their support was in the form of a Personal Budget/Self Directed Support. Two people said that their care package was supplemented through the Independent Living Fund (which is due to be abolished). Most people had experienced a review of their social care support package within the last 12 months. One person with mental health difficulties

⁹ Wallace W A (2012) *The Challenges of Upper Limb Joint Degeneration in Thalidomide/Phocomelia Patients*. Poster presentation accepted for the British Orthopaedic Association/International Orthopaedic Association Congress 2102.

had received short term support and was unhappy that this had not been continued, but he did not think that this was linked to his receipt of the Health Grant.

There were more examples this year compared to last year of people feeling their care package was under threat. One person said that they had experienced a reduction in their care package because of local authority financial constraints and described how the Health Grant had helped compensate for this loss. Several people said that they were worried about potential reductions due to the current financial position of local authorities and shifts in eligibility levels; one described how he needed a reassessment because his needs had increased, but he was afraid to ask for a re-assessment in case his service was cut. Another person described how he maintained his existing package by describing to the social worker how his needs had risen, whilst at the same time accepting the same level of service – *“I could do with more hours but I am realistic that it is not available”*. Another said her hours had been reduced but she had successfully challenged the decision. Whilst there were no examples of changes in service that were linked to people receiving the Health Grant, two people said they felt particularly targeted by their local authority [the same one] because they have this form of income:

“They are quite open, if they could hit the Thalidomide Trust they would, but they can’t. But they are trying to take whatever we’ve got back.”

Most people were using their Health Grant to ‘top up’ their personal budgets, and this helped bring much more flexibility and independence. There were examples of people using their Health Grant to pay higher rates to their personal assistants for tasks required during anti-social hours, to pay people to accompany them on holiday and to enable greater mobility – in one case the Health Grant was used to add the personal assistant to someone’s car insurance whilst they were temporarily immobile.

Personal Story

G has two artificial legs and no hands, plus he has arthritis and cellulitis, which are getting progressively worse. G is reliant on his wife as his main carer (who is in full time employment). He has a Personal Budget (in the form of a direct payment) but feels that it is not adequate or flexible enough to cover times when his wife is away. Without the ability to top his direct payment up with his health grant G speculated that this could have a very negative impact on his wife and her ability to work:

“My wife had to work in London for 4 days, staying in a hotel. So the question, what happens to me? If it wasn’t for the extra health grant this could never happen – why? because my local [social services] support only covers for the days at three hours per day. So without the health grant does my wife work? If she doesn’t who pays our bills? But also who am I to stop someone in their career that I know she enjoys?”

The Health Grant has also funded adaptations which free people up to use their personal assistants in different ways, for example, one person had used the grant to replace their solid fuel fireplace and this has saved several hours per week of personal assistants’ time making it up and clearing it out. Only one person, who was deeply unhappy with the care she had received, had decided to opt out of local authority social care services completely, although others said that they wished they could do so.

Those who were undertaking (or considering undertaking) home adaptations using their Health Grant were asked if they had considered applying for the Disabled Facilities Grant (DFG) or Housing Adaptations Grant in Scotland (HAG). These (means tested) grants can provide disabled people with financial help towards the cost of home adaptations. Most study group members were aware of the DFG/HAG and two people had received these grants in the past. A couple of people said they had assumed they would not be eligible because it is means tested, and people who had previously accessed the DFG/HAG assumed that they would not be eligible for further adaptations. A small number of people did not know about these grants.

All except one of those who had previously accessed DFG/HAG or considered it described difficult experiences. However, the study group members living in Scotland appeared to have had slightly fewer problems. The concerns people raised were:

- Restrictions on personal preferences
- Forced options that they felt would not suit their disability requirements and would inhibit their independence
- Restrictions with provider services
- Significant delays in obtaining the grants.

To illustrate the latter point, the one person interviewed who had successfully obtained approval for a DFG within the last twelve months said that it had taken her four years from the initial application. Further details of the benefits study group members are receiving are in given in Table 5 in Appendix 1.

Chapter 4

Managing Health and Wellbeing

Key Findings

- Nearly two thirds of the study group used some of their Health Grant to pay for treatments to address or alleviate existing health problems
- Almost half were using their grants for treatment by complementary medicine practitioners. These treatments brought much valued pain relief and increased mobility and dexterity, which in turn helped people maintain a level of independence
- A number of people were also paying privately for treatments which should have been available through the NHS, in particular physiotherapy, hearing aids and prosthetic limbs
- In the short term the Health Grant does not appear to have significantly reduced people's use of NHS services, although a few people reported reduced use of prescription painkillers and fewer GP visits
- People expressed a continuing and growing desire to self-manage their health. Many felt that the steps they were taking to limit further deterioration and/or to prevent future problems would, in the long term, mean that they made fewer demands on the NHS
- The majority of study group members had used some of their grant to generally make their day to day lives easier, usually through improvements to their homes or by funding on-going support
- Very importantly, the Health Grant has significantly reduced people's financial worries and given them great peace of mind
- The grant has improved the wellbeing of family carers; enabled people to maintain the quality of their relationships; and made it easier for them to cope with changing family circumstances.

The interviews conducted with study group members in the first year of the evaluation clearly showed that from the outset most people saw their Health Grant as a fund they could use to help them 'manage' their health and generally improve their own and their families' wellbeing. These areas have continued to be a priority for the majority of the study group but (as was noted in Chapter 1) the ways in which people achieved these outcomes varied considerably. In this Chapter we describe the impact the Health Grant has had on people's ability to manage their own health, including addressing existing health problems as well as preventing (or reducing) future problems (or deterioration). We also consider the ways in which people have used their Health Grants to try to maintain or improve their general wellbeing and quality of life, often in the context of a decline in their health and functioning.

4.1 Addressing Existing Health Problems

Around half the study group reported that they were receiving NHS care for existing health problems related to their Thalidomide damage (e.g. joint replacements, pain control), as well as routine care for other health conditions (e.g. diabetes, cellulitis). As was noted in Section 3.3, some had had very positive experiences but there were many experiences of poor NHS care and continuing frustration with access to NHS services. This had often influenced how people used their Health Grants, in particular their decision to buy health treatments privately.

The expenditure survey showed that nearly two thirds of the study group used some of their Health Grant to pay for treatments to address or alleviate existing health problems. A more detailed examination of this expenditure category suggests that almost half of the study group was using their grant for treatment by complementary medicine practitioners (including osteopathy, chiropractic, acupuncture and remedial massage). However, a number were also paying privately for treatments which should or could have been available through the NHS. These included physiotherapy, private medical care, dental and ophthalmic treatment, hearing aids and prosthetic limbs.

Many people described the difference the use of complementary medicine had made to the quality of their lives. Whilst sometimes such treatments did not or could not solve the root problems, they brought much valued pain relief and increased mobility and dexterity – which in turn helped people maintain a level of independence. Several people, especially those experiencing back, neck and shoulder pain, said that being able to use their Health Grant to increase the frequency of such treatments had helped them to both manage their pain and remain active.

Personal Story

S has always been an active person but the way in which she has had to use her body to compensate for the Thalidomide damage to her arms has caused severe musculoskeletal problems, including low back pain, sciatica, coxodynia (damage to the coccyx area) and shoulder pain and stiffness. She has regular remedial massage, chiropractic and physiotherapy to manage these problems and feels that these treatments have enabled her to both continue working and control her weight:

“The medical treatments, you know, are great and they make me feel so much better and they enable me to carry on exercising at a level that keeps my weight down, which means I’m independent because I can get my clothes on and off and do all that stuff.”

There were two examples in the study group of people using the Health Grant to address mental health issues. In one case the person paid privately to get quicker access to counselling. In another a person with more severe mental health issues was able to spend part of their Health Grant to help them get out and about more. This was recommended by his mental health support worker, because isolation and loneliness were exacerbating his problems.

A few people had taken out or were considering private health insurance. A small number had paid for diagnostic tests privately and two were considering using their Health Grant to pay for private treatment for joint problems. However, private treatment was not

necessarily the best option. One person, who had considered paying privately for his hip reconstruction surgery, explained that he had been advised by his consultant (paid for privately) to have his treatment in the NHS:

“I would have been happier to pay if I had the option because I think the standard of treatment would have been better... but the reason [the surgeon] told me not to go privately, as he said, was if they found anything unusual the private hospital would only have the bog standard parts whereas the NHS would just go into a shelf in the hospital and if they didn't have it they could get it pretty quickly, whereas in the private hospital it would be a close it up and start again job .”

4.2 Use of NHS Services

With some notable exceptions, in the short term the Health Grant did not appear to have significantly reduced people's use of NHS services. In particular a large number of people said they were still reliant on prescription drugs for pain relief. This was largely because the majority of study group members were experiencing some level of continued deterioration in their health and functioning. However, a number of them argued that, without the Health Grant their use of NHS service usage would have been greater as they would not have been able to address or manage their existing health problems to the extent that they have. As is noted in Section 4.3 below, others felt that the steps they were taking to prevent future problems would, in the long term mean that they would need to make fewer demands on the NHS.

A small number of people said that they had reduced their need for prescription pain killers and had reduced the frequency with which they needed to see their GP. The reasons for this varied, for example successful surgery, lifestyle changes, and improved access to complementary medicines, but all of them were linked in some way to the use of the Health Grant.

4.3 Self-Management and Preventing Future Problems

It was evident from the second year interviews that there was a continuing and growing desire amongst many people to self-manage their health, either to cope with existing health problems, to limit further deterioration and/or to prevent future problems. In addition to specific health treatments (which were frequently used to control pain and maintain functioning), people used their Health Grants in very different ways to achieve this. For some the focus was on maintaining their fitness, and/or controlling their weight through things like gym membership, personal trainers, swimming, yoga/Pilates classes, and diet advice and support.

Personal Story

K has short arms and this has put particular strain on his neck joints. In the past K has found it difficult to exercise because of his Thalidomide damage and this resulted in him putting on a lot of weight. *“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.”* He said the more weight he gained the more stress was put on his joints and the more pain he suffered. This in turn was affecting his mental well-being. The ways in which has used the Health Grant this year have made a real difference. He has regular physiotherapy every two weeks and massage once a week which are greatly helping to keep the joints mobile and to maintain flexibility. He also takes supplements which he said can be very expensive. He goes to the gym regularly:

“I have been able to lose weight since last year; I’m probably half a stone lighter. That’s as a result of quite intense gym sessions really which has been largely funded by being able to use the Health Grant for that.”

He has also been able to install new windows in his living room and put in new heating so that he is warmer in the winter.

“I feel fitter, I feel better in myself, I feel more healthy. I don’t experience such a high degree of joint pain and I feel safer because of these security things that have been able to be possible on the house, so I would say its [Health Grant] had an extremely positive impact.”

As noted in section 3.1.4, maintaining dental health was a concern for some study group members. Study group members in this situation reported needing to go to the dentist or dental hygienist more frequently than normal and/or have more dental treatment in order to maintain their dental health. The Health Grant had enabled them to do this.

The majority of study group members were adopting self-management strategies which focused on reducing the strain on their bodies. For some this involved giving up work or reducing working hours. One person, who was severely affected by Thalidomide (i.e. Band 5 impairment), had worked all her life until this year when she took early retirement, explained:

“The rest I’m getting now from not having to work has absolutely changed my life completely. I mean if I don’t want to do anything in a morning or whatever, I won’t do it anymore whereas before I was forced to do it regardless of whether I was in pain or not.”

For others having the funds to purchase equipment or pay for improvements and adaptations to their homes was the key. One study group member who had used most of her Health Grant in this way said:

“Now my house is like I wanted it, it’s not so painful to move around....it’s hard to describe the difference it’s made – my life has completely changed.”

4.4 Improving Wellbeing and Overall Quality of Life

For many people, deteriorating health had had a significant impact on their overall quality of life. For some (as the SF12 results suggest) this was directly related to specific health problems such as joint pain and physical functioning. For others it was more generalised, for example tiredness and lack of energy leading to people finding it harder to cope with everyday tasks or less able to take part in social activities.

The majority of study group members had used some, or all, of their grant to generally make their day to day lives easier in some way. For some people this had involved improvements to their homes. These ranged from major work, such as new adapted kitchens and reshaping gardens, to smaller changes such as lifting plug sockets, fitting door handles that were easier to operate and improving heating systems. As the personal story below illustrates, the impact of these changes on people's daily lives was huge, both in terms of the practical difference it made and the impact on their general wellbeing.

Personal Story

G had been experiencing increasing pain in his back, and has pain and numbness in his hands. He was still working full time but at home he felt he was asking his wife to do more day to day task for him. He feels the Health Grant is *“the difference between an ok life and a good one”*. He had used his grant to have new windows fitted which are really easy to open; paid for work in the garden and domestic help; and bought a season ticket to his local football team. When describing the impact of the grant he said:

“At one point during the year...I sort of thought, one of the things about the Health Grant is that I suddenly actually felt like, normal, doing the same things as everybody else, being able to go out to dinner, you know, getting on the bus...everyday stuff that people do, that the Health Grant has afforded me and I actually feel like everybody else now, on a level playing field...actually, for the first time in fifty years I feel like I'm on an equal footing with everybody else.”

Other people used their Health Grants to help pay for things which might be regarded as everyday or routine but which increased a person's living costs. For example, one study group member who has arthritis in her hands buys ready prepared vegetables. She explained:

“I struggle with cutting vegetables so I tend to buy things already prepared...which does affect the food bills, but you don't tend to think about it”.

Several people noted that keeping warm improved their ability to function and reduced the levels of pain they experienced, so they kept their heating on for longer and used part of their Health Grant to pay their fuel bills. More than half the study group had used part of their grant to pay for domestic help such as cleaning, gardening and help with shopping. Most people said that buying in this help enabled them to significantly reduce the strain on their bodies but for some it was about preserving their energy for other aspects of their life such as family and work. A small number of people had used part of their Health Grant to offset loss of earnings brought about by reducing their working

hours or moving to a job which was less physical but less well paid. Most of this group wanted to continue working. The two quotes below powerfully illustrate this:

“It’s provided me with really necessary medical help that I can’t get on the NHS and that’s been vital to allow me to continue, and to expand my work and, you know, I’ve got a great sense of achievement from my work and I wouldn’t have been able to do that without the Health Grant so, you know, I’m contributing to society far more than I would’ve without the Health Grant.”

The main thing it [Health Grant] allowed me to do was to stop doing the job I was doing, where I was knocking myself to pieces....its allowed me to move to a job which is quite a bit less money but I’m not beating myself up every day.”

More than half the study group had used part of their grant for some type of ‘Respite’ or ‘Social Activity’. Often this took the form of a family holiday; many people saw these as vital for maintaining good family relationships but it also enabled them to relax and manage their pain, especially if they were able to travel to a warm climate. A number of study group members explained that prior to getting the Health Grant they had found it difficult to afford a regular holiday because travelling and staying away from home can be far more costly for Thalidomide-impaired people. There is often a need for bigger rooms and specific facilities, some people need to take their PAs on holiday with them, and most need to plan ahead and so are not able to take advantage of last minute deals.

A few people used a small amount of their grant to enable their main family carer to have a break from caring, and three people had used part of their grant to buy caravans/mobile homes which were adapted to their needs.

“I am worried about flying because I’m not sure when I need to go to the toilet, so I’ve decided to buy a caravan for holiday breaks etc, and have some adaptations made.”

Another person, who was severely affected by Thalidomide and had recently lost her sight, described her mobile home as *“a place of respite”*. It has been adapted for her needs, which she would not have been able to do without the Health Grant. She is now able to go there with one of her PAs and so does not have to rely on her parents.

More generally, but very importantly, the Health Grant had significantly reduced people’s financial worries and given them great peace of mind. This was a strong theme in last year’s interim report and people again highlighted the difference that feeling more financially secure had made to their general sense of wellbeing.

4.5 Impact on Families, Friends and Relationships

In year one, study group members described how the damage they had experienced impacted on their family and friends. People described having to rely on spouses, partners, children and friends for a wide range of tasks. Interviews during years one and two of the Health Grant have shown that it is making a material difference to these family carers; one person described how his wife’s back problems had eased since he was less reliant on her. Other people described how they did not have to rely so much on ageing and increasingly infirm parents, because the Health Grant allowed them to employ

people instead. However, several people said that they still have to rely somewhat on relatives.

One person explained that increased pain and problems with his hips and back mean that his wife now has to do much more for him, including helping him transfer to the toilet. She has also become the main driver in the household. All this had *“changed the dynamics of the family”* but the Health Grant had begun to make a real difference:

“It has taken a lot of the stress off. It makes life a lot easier. For one thing it has given me the ability to go out more and do things independently from my partner, because I have a PA and that has given her a rest period. And this year I was able to go on holiday with the children....It was really great to be able to go as one family.”

As the personal story below illustrates, other were concerned about the implications for their independence.

Personal Story

A is profoundly deaf and uses BSL to communicate. She explained that she is now experiencing intermittent paralysis in her hands and arms, and this is affecting her ability to sign and use a computer. She is becoming increasingly dependent on her children to sign for her and feels very unhappy about this, partly because she does not feel it is fair on them but also because it affects the quality of her communication.

She has used some of her grant to pay for more interpreter time. She feels this has made a big difference to her independence because she is less reliant on her family, and a fully qualified interpreter is able to convey information more accurately. She has also invested in an iPhone and iPad which are invaluable as they enable her to sign on screen.

Thalidomide-impaired people, like their peers in the general population, are a ‘squeezed generation’. They are facing the twin pressures of grown-up children (who often provide significant help and support) leaving home and also aging parents, whom they may need to support (or whose support, in some cases, they are losing). Whilst this situation may not be unusual, for disabled people these experiences are often more complex. They can also be significant extra burdens for people who are already struggling to cope with additional health problems which are not typical for their age group and which can affect their day to day functioning and ability to work.

A few people described how the Health Grant had enabled them to provide more of a caring role themselves and have more contact with ageing parents, as it enabled them to travel to see them. Several also described how the grant had transformed their relationships with their children, as they were less irritable and were able to have more opportunities for family outings. However, as was the case last year, whilst study group members with children said how much they tried to avoid relying on them for support, many of them expressed increasing concern about how they would manage when their children left home:

“I know that is going to have much more of an effect on my life than I would like. There are an awful lot of things that he does. I will be on my own for the first time

in over 20 years...I am actually not sure how that is going to go and actually I do not want to think about it.”

The Health Grant had also been really valuable in enabling people to maintain the quality of their relationships. Several people described how the things they could now do with the grant had helped improve or re-establish relationships with partners. The personal story below highlights this and illustrates how the Health Grant had helped people come to terms with the need to buy in help.

Personal Story

L has short arms with weak and twisted fingers. She has osteoarthritis in the toes on her right foot, which she uses to do many everyday tasks, and back pain. She feels that she has generally “*slowed down*” and her ability to do things is reducing year on year. She lives with her partner and is concerned that he is having to do more and more for her, so she has been using her Health Grant to buy in help, although this has not been an easy process:

“He finds it very difficult and it’s not particularly good for our relationship but I have learnt to ask for more help from other people and buy in help. It relieves the pressure a little bit but it’s actually hard work finding people, organising for them to come and when you don’t really want to do it, it feels like double the work....’cause my brain is still wanting to maintain some independence and I still haven’t fully accepted the fact that I need so much more help nowadays.”

She has also purchased a number of ‘gadgets’ (e.g. a rise and fall table with remote control) which make tasks around the home easier and is also planning an adapted kitchen and bathroom.

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

Chapter 5

Maintaining Independence and Mobility

Key Findings

- Regaining, maintaining or increasing independence has been one of the most important benefits of the Health Grant
- The grant has given people the resources to pay for costly changes to their homes such as adapted bathrooms and kitchens and the impact of these on their lives has been huge
- Changes in the pattern of expenditure in particular the increase in the use of personal assistance, suggests that alongside ‘capital’ expenditure people are also putting on-going support in place to help maintain their independence
- There was a strong view that expenditure on home adaptations and adapted vehicles should not be regarded as a ‘one-off’. People’s needs and circumstances continue to change and so further ‘capital’ expenditure will be needed in the future
- Many Thalidomide-impaired people are reliant on adapted vehicles for their mobility and independence. These are very costly to buy and maintain. Having the Health Grant as a lump sum has enabled them to meet these costs without overburdening themselves financially
- Spending on wheelchairs tripled from year 1 to year 2, which in part reflected people’s frustration with NHS provision

One of the most striking findings from the first year of the evaluation was the impact the Health Grant had on people’s independence and mobility. In the second year of the grant these continued to be two of the most important benefits reported by the study group. In this chapter we consider how people had used the Health Grant to maintain their independence and mobility, often balancing expenditure on major capital projects/vehicles against the need for on-going practical support.

5.1 Preserving Independence

People described how home adaptations, access to more personal assistant hours, gadgets and equipment, and communications technology had helped them regain, maintain or increase their independence. They felt safer, less reliant on family or friends and had a real sense of satisfaction when they were able to do things for themselves again. This in turn had an important knock on effect on people’s emotional well-being. However, how people achieved this improvement in their independence varied between individuals and between the first and second years of the grant.

For many people the Health Grant provided a lump sum which they used to pay for major adaptations to their homes, in particular adapted kitchens and bathrooms. As was noted in Chapter 1, the proportion spent on ‘Home Adaptations’ by the study group decreased

slightly in year 2 but the number of study group members using part of their grant for this purpose remained the same. Major adaptations are often extremely costly and some people had to use all or part of both their first and second year grant on just one project. Others took out mortgages and planned to use their Health Grant to help pay them off. It is hard to overstate how important these changes were to people. One person who had decided to get an adapted kitchen, despite the high cost explained:

“I’ve been in the house some days and it’s just impossible for me to make myself something decent to eat because I can’t reach or can’t use certain things. That is really praying on my mind...with my on-going care problems as well, I’m going to have to gamble and go with the kitchen.”

Another study group member who had used both his first and second year grant to pay for an extension and adapted kitchen, explained that he had begun to feel very unsafe in his kitchen and was having to rely more and more on his personal assistants to do things for him. His new kitchen had made an enormous difference to his independence:

“Routine stuff I can now do in the kitchen much more easily by myself... I even use it sometimes as a workspace. Generally I am much happier to be in the kitchen and there are fewer obstacles between me and what I need to do. There are fewer risks through using my body inappropriately, for example, standing on chairs and worktops. Things are where I need them.”

A more detailed examination of this category of expenditure revealed that many people were also using their grants for more modest changes to their homes, such as lifting plug sockets, changing the handles on doors and windows to make them easier to open, fitting boiling water taps which removed the need to lift a kettle, and buying small items of equipment such as special can openers, rise and fall remote control tables and special beds which were easier to get in and out of unaided. More people appeared to use their grants in this way in year 2 than in year 1.

The changes in the pattern of expenditure noted in Section 1.4, in particular the increase in both the amount spent on Personal Assistance and the number of study group members using their grants in this way, suggests that alongside ‘capital’ expenditure people are also putting on-going support in place to help maintain their independence. This support included both the use of personal assistants and help with a range of domestic tasks such as cleaning and gardening. The personal story below illustrates this.

Personal Story

L lives with her husband and children and is unable to work because of her disabilities. Both her arms were affected by Thalidomide and last year she broke her 'best' arm in a fall at home. It has not healed properly and is very painful. She is contemplating having a major operation to put an 'elbow' in her arm. She also has low back problems which mean that she can no longer do many of the household tasks she used to do. She thought very carefully about how best to use her grant, splitting it between 'capital' expenditure (e.g. a new adapted bathroom with a walk in shower and special toilet which means she can use the bathroom safely on her own) and on-going help, in particular additional Personal Assistant time (to top up what she gets from Social Services), regular massage for pain relief and gym membership to help her manage her weight. She explained:

"It's about independence. The bathroom was a major thing but it's a one off. The main thing is like now, when I broke my arm X [husband] was still able to go to work to bring in the money to pay the bills whereas he would have had to stay at home and help. So, me having the money to buy in extra help meant we can have this normal life which you're supposed to have....It is buying your independence."

For other people, communications technology enabled them to maintain their independence and keep in touch with others - *"My laptop is a vital piece of equipment as it enables me to keep in touch with my friends, do online shopping and do my voluntary work for the Thalidomide Trust."* This was particularly important for people in rural areas:

"My PC can be my life line to the outside world, as I live out in the country. During winter months the PC gives me independence to do my own shopping & stay in touch with family and friends."

5.2 Keeping Mobile

Independence and mobility are closely linked, especially for those people with severe impairments. The Health Grant had given them the resources to address often long standing needs for new adapted vehicles or bespoke wheelchairs but it had also helped with the on-going cost of keeping mobile. Three quarters of the study group used their Health Grant in some way to support their mobility. This related to a range of items and services that enabled people to keep mobile and in some cases it really enhanced their independence. The interviews provided more information on people's decision making linked to mobility and the impact the Health Grant had made.

5.2.1 Vehicles

More than half the study group used all or part of their Year 2 grant on 'vehicles'. The expenditure was on all aspects of owning a vehicle: purchase, adaptations, servicing, fuel, insurance, repairs, and regular cleaning. One person had used her Health Grant to pay for her personal assistant to be covered by insurance, thus relieving her from driving so much. The ability to have a lump sum was really appreciated and this liberated people to make the adaptations to vehicles they really needed, often reducing reliance on others.

In some cases these adaptations were very expensive, and even with the Health Grant they were not always able to fully cover the cost of keeping mobile. As the story below illustrates, to spread the cost of buying an adapted vehicle some people obtained a loan from the Thalidomide Trust and were using their Health Grant to pay it off.

Personal Story

G is a wheelchair user and has a hearing impairment. She said her new van is essential for her mobility and independence and for looking after her teenage sons, who need transporting to school and other activities. The process of getting the vehicle sorted out has been quite “traumatic” as the adaptations were not quite right and it has had to go back for further work. The van cost £44k - half the cost was the adaptations and the additional adjustments she requires will be a further cost.

Even with her Health Grant G has had to take a separate loan from the Thalidomide Trust for her car because she didn't have the money 'up-front'. She'll be using next year's Health Grant to start to pay it back.

A very small number of people were considering the Motability option to obtain a vehicle, but experiences of this were not always positive. One person recounted how he had spent a long time arguing his case for a specific van that would enable him to travel independently with his wheelchair, but the vehicle that was being suggested by the Motability agent would not be big enough to accommodate this. Some people had used the grant to purchase back-up vehicles, as an adapted vehicle was so crucial for their mobility and independence, particularly for those living in rural areas. It could also take months to obtain a replacement adapted vehicle, as the story below highlights.

Personal Story

E has a fused spine which causes a lot of pain. Last year E purchased a car with adaptations using his Health Grant. Unfortunately, this year the brakes failed and it was written off. E said the insurance did not cover anywhere near the full cost of replacement so he had to use this year's Health Grant again to get it replaced. There was a delay of eight months before the new vehicle was purchased and adapted so he also had to buy a car for the interim so that his wife could drive him and the family around. E explained how important the Health Grant had been saying - *“Without it, it would be very difficult indeed – very difficult... It would have been a disaster.”*

5.2.2

Wheelchairs

As was noted in Chapter 1, spending on wheelchairs tripled from year 1 (£6,555) to year 2 (£19,108), although in both years this expenditure was accounted for by just a handful people - three in year 1 and five in year 2.

Similar to those using the Health Grant for vehicles, the interviews showed that having a lump sum available to help fund a new wheelchair or to service and maintain existing ones was invaluable, as many people pointed out how expensive it is to purchase and maintain them. In some cases the grant enabled study group members to buy a second wheelchair, which greatly enhanced mobility and independence. For example, several people commented that it was very risky taking a wheelchair on holiday, as they easily

got damaged in transit, so having a back-up provided considerable peace of mind. As is the case for adapted vehicles, study group members said that replacement wheelchairs take a long time to become available, so having a second wheelchair was really valued: *“I can’t go and say ‘I want one’ – it has to be specially adapted.”* The knock-on impact of using a wheelchair could also lead to considerable expense. Electric wheelchairs are very liberating but can be large, and for some this has necessitated alterations to houses and changes to vehicles in order to accommodate them.

People also said they had to self-fund wheelchair repairs and maintenance as they found it hard to obtain NHS help. Many reported NHS wheelchair services to be unsatisfactory, because the models on offer did not provide a good level of mobility and independence, and servicing and maintenance was not always covered. One person said they had been waiting 10 months for a manual wheelchair from the NHS.

5.2.3 Use of Trains and Taxis

People also used their Health Grants to make greater use of trains and taxis. One person said how helpful it had been to be able to have the lump sum to pay for his season ticket (he takes the train to go to work). Another person said that it had enabled her to travel on the train to see her aging parents; for her these journeys are very expensive as she needs the extra space and service that are only available in first class accommodation. One person who purchased an electric wheelchair with his Health Grant last year said *“certainly it has enabled me to get out and about much more than I did previously”*, but it cannot be accommodated in the car so his spend on taxis this year has been £4000.

5.3 Future ‘Capital’ Needs

The Health Grant has undoubtedly enabled many people to begin to address long standing needs for adaptations to their homes, as well as new adapted vehicles and wheelchairs, and acquiring these things has made an enormous difference to people’s independence and quality of life. It might be assumed that the need for capital expenditure has been largely dealt with through the Health Grant but the experiences of the study group show that this is clearly not the case. There are a number of important reasons for this:

- Many people had a ‘backlog’ of much needed adaptations or vehicles that they had been waiting to replace, and have so far only been able to tackle one or two of these
- The high cost of adaptations (especially for kitchens and bathrooms) and vehicles, means that people have had to use more than one years’ grant to fund a project/purchase or take out mortgages/loans to spread the cost
- The health and functioning of most Thalidomide-impaired people is deteriorating and so their needs are not static. They anticipated needing further adaptations and equipment in the future
- People’s circumstances are not static, and like their peers in the general population, some Thalidomide-impaired people anticipated moving house to be near family or down size as their children leave home, which will once again result in the need for home adaptations

Chapter 6

The Future

Key Findings

- Many people were planning further capital projects with their third year's grant but a few people felt unable to make any plans until they knew if the Health Grant was going to be continued
- The uncertainty of not knowing whether the Health Grant was to continue was unsettling for many people and a large number expressed real anxiety about the possibility of it ceasing
- Study group members thought that one of the main implications of the Health Grant ceasing would be that the benefits gained by having the grant over the past few years would be put in jeopardy
- Some people were worried about the effect of losing the Health Grant on their families; they feared becoming more dependent on their care if they were not able to purchase help using the grant.
- A number of study group members felt that losing the Health Grant would have implications for their mental health
- Those who had made changes in their working lives were worried that they would have to go back to work or increase their hours again despite the deleterious effect it may have on them
- The Health Grant being made permanent would give people 'peace of mind' and financial security, help them plan for the future, give them choices in their working lives, increase their independence and prevent the deterioration of their health
- Some people felt that, although the grant was enough for them at present, it may not be sufficient in the future if their health deteriorated.

We talked to the study participants about their plans for the third year of the Health Grant and also about their hopes and fears for the future in the event of either the Health Grant ceasing or, alternatively, being continued. When the Health Grant was made it was clear that it was for three years with no commitment as to the longer term future. Nevertheless, the uncertainty of not knowing whether the Health Grant was going to continue or not was unsettling for many participants and was having an effect on how they were using and planned to use their grants.

6.1 Plans for Using the Third Health Grant Payment

The interviews for the second year of the evaluation took place in February and March 2012 and study group members were due to receive their third Health Grant payment in April. As the future of the Health Grant is still to be decided, we felt that it was important to understand how people planned to use what could be their final grant payment.

Almost half the study group indicated that they would use some or all of their third year's Health Grant to fund continuing or further house adaptations and improvements. Some of these capital projects were very expensive and so people had to spread the cost over more than one year. More than a quarter of respondents planned to continue using their money in the same way as they had been over the previous two years; for example, buying in help with household tasks, personal assistance, health treatments, interpreting services and gym membership. The other most common planned uses of the Health Grant were for holidays and respite care, with ten participants mentioning that they would spend some of their money on these. A few people considering buying new vehicles, having vehicles adapted or using the money for maintenance of existing vehicles and one person was planning the purchase of a new wheelchair. Five participants had plans to pay for private health treatment, including elective surgery, and a few said that they would be using the money to pay for new complementary therapies or extra therapies.

A number of study group members expressed uncertainty about using their Health Grant pending a decision on whether it would be continued. They felt that they needed to be cautious with the money and save whatever they could in case the Health Grant came to an end:

"It's a worry – should I spend it or should I save it? Until we know what's going on I think I'll be more careful and save a bit so that we can eke out the benefits over several years."

One person felt that she had to put the money on one side because she might have to pay for an expensive operation in the future and she was also concerned about what might be needed in the years to come to deal with the effects of physical decline/wear and tear. Some people gave the impression that they were unable to make any plans, because they did not know what the future of the grant was to be.

Personal Story

H's arms and hands were affected by Thalidomide. She suffers increasingly from pain in her neck (due to fused and deteriorating vertebrae), shoulders, arms and back and also has numbness in her fingers. She lives with her teenage son who is likely to leave home within the next year. She has used her Health Grant to pay for massage which has significantly reduced her pain and she has also used it to travel to see her elderly parents and to go on holiday. She expressed anxiety and uncertainty about what to do with her third year's Health Grant because she felt it depended on whether the grant was renewed or not.

"My main worry is that you make all these changes and I am terrified about what impact that will have. If I think that is the last money I am going to get I am absolutely going to be hoarding every penny for things I absolutely need. Am I now supposed to give up my massage and gardener and cleaner? Am I now supposed to give up seeing my family? ... I cannot imagine that I am going to spend anything other than what is absolutely necessarily until I know it is definitely going to be renewed."

"It is frightening. You do so many computations about what you can afford and what you would do if it was taken away."

6.2 Implications of the Health Grant not being Continued

A large number of study group members expressed real anxiety about the possibility of the Health Grant ceasing. Many used emotive descriptors to make it clear how worried they were, such as “devastating”, “disastrous”, “panic”, “scared to death”, and “cruel”. Some found it difficult to imagine being without the grant and had started to become reliant on it.

“I’m actually quite scared to think about it stopping. It’s really not something I want to contemplate at the moment.”

According to many of the participants, one of the main implications of the Health Grant ceasing would be that the health benefits gained over the past few years would be put in jeopardy. Expenditure on a large variety of services, projects and supports purchased through the Health Grant would have to be cut back or stopped completely which would in turn lead to a potential deterioration in health, both physical and mental. Others talked about drawing on other funds, such as their Annual Grant¹⁰, to try and maintain some of the benefits that they have been receiving through the Health Grant.

“I would anticipate a deterioration in health because I would no longer be able to afford the massages, physio or the gym.”

“It would be a huge reversal of all that’s been positive over the last three years.”

Some people were concerned that losing the Health Grant would lead to them relying more on local authority social care services and the NHS, which they found inadequate or inappropriate for their needs. Another participant made a pertinent point:

“I think not having [the Health Grant], I would cost the National Health Service far more than I do at the moment.”

Quite a number of people talked about losing the grant as having to “go back to square one” or as having to go back to how it was before they had the Health Grant. For some this was the difference between having a life and just existing:

“It would be a dreadful blow to me and my family. It would be absolutely awful to have to go backwards and for all the extra things to have to stop and make life a hundred times more difficult in all sorts of ways, just normal living... It would mean cutting back, well, living a very basic existence really.”

Some people were concerned about going back to having money worries (which the Health Grant had removed) or feeling like there was a lot of pressure on their budget. It was felt that difficult choices about what to spend their money on were going to have to be made and planning for the future would become extremely difficult; there would no longer be a financial ‘cushion’ to fall back on. One person summed it up - “We would go back to the days of worrying about finances.” A few people were very concerned about the effect losing the Health Grant would have on their families and those they were close to. They felt that they would, of necessity, become more reliant on them and more dependent on their care if they were not able to buy in help using the Health Grant.

¹⁰ Op cit

“What I wouldn’t want to happen in the future is to put too much reliance on the family to have to look after me, the more I can look after myself the better I will feel.”

A number of participants felt that losing the Health Grant would be so significant for them that there could be implications for their mental health. One person felt that she would get “*down and depressed*” because everything would have to go except the “*bare minimum*”; she would be worried about making her money last. Some felt that there would be an increased risk of isolation because there would not be any extra money to pay for help with mobility and hence social activities would have to be curtailed.

“Basically I would be back to square one. I might not be even here, you know. You know, not having something to help me out, like moneywise... There’s nothing to live for really. I’m not trying to give you a sad story, but that’s just the way I feel.”

A number of people were very worried about the effect that losing the grant would have on their working lives. Some felt that they would have no choice but to return to work (if they had given up) or increase their hours (again), and this would have a detrimental effect on their health. Others felt that they would have to stay in work longer than would be good for their health because they would not have enough other income to retire. These scenarios would then have implications for their health, which some felt was being adversely affected by working, or working long hours.

“I’d feel the pressure to go back to work five days a week or take a second job. My wife would probably feel a bit of pressure to increase her hours. I’m trying not to think about it but it’s a reality, it could happen.”

However, as the personal story below illustrates, others felt the Health Grant had enabled them to continue working, and the impact of it stopping would be significant.

Personal Story

S lives with his wife and children and works full time in a job which involves travelling across the country. He has short arms and is affected by arthritis, with problems in his knees and hips. He has used the Health Grant to enable him to continue working (by employing extra carers to provide assistance when he is travelling), to adapt his bathroom and to take holidays in warm places in order to ease his arthritis. S feels that the Health Grant has had a very positive effect on his wellbeing and has reduced his reliance on his wife. He was very keen to emphasise the negative effect it would have on him and his family if the Health Grant were to stop.

“I could not cope without it. I couldn’t say that too strongly. To lose it would be like losing another limb.”

6.3 The Future of the Health Grant

We asked the study group whether they thought the current level of the Health Grant was adequate to meet their needs. People gave thoughtful responses, often linked to whether the Health Grant was made permanent or not. Many people felt that the level of their current Health Grant would be sufficient if it became permanent. However, as the

personal story below illustrates, others felt they may need more financial help if their health deteriorated or their circumstances changed.

Personal Story

C lives with her husband and teenage children. She has shortened arms and also experiences problems with her hips and knees. She got a loan from the Trust for a new adapted car and is using her Health Grant to pay that off and she is also buying help with house and garden tasks. She is concerned that there may come a time when her husband, who is several years older than her, will not be able to provide the level of support he does now and they will have to buy in more help. Currently she works full time but is finding it hard. She is awaiting a hip replacement but has been told that she will not regain the level of mobility she had prior to her hip deteriorating.

“It’s adequate for how I am at the moment but my worry is that I won’t be able to carry on working full time. I’ve been getting very, very tired.... I can’t give up work but I could perhaps cut down my hours but would we manage [financially]? It all depends on how this hip goes and whether I can get back to a degree of fitness again. So yes, the grant is ok for me now but I’m not sure it would be if I became more incapacitated.”

Understandably, the majority of study group members were keen for the Health Grant to be made permanent. They highlighted a number of key benefits of the grant being made permanent. They felt it would give them:

- **Ability to plan ahead to ‘manage’ their health** - For many people the ability to plan ahead, in particular to respond to their deteriorating health, was one of the greatest perceived benefits of the grant being made permanent. They felt that they would be able to make decisions about what they needed long term to manage their health problems, as well as put money aside for unforeseen circumstances. They also felt it would help them to think positively about the future and give them ‘peace of mind’.

“There’s a sense of going forward and being able to just plan for the future without having to worry about it.”

- **Resources to maintain their independence** - For a large number of people, a permanent Health Grant would enable them to maintain their independence and mobility. Nearly half the respondents said that they would be able to do things that they had not yet been able to, in particular fund the ‘backlog’ of changes to their home and vehicles/wheelchairs but also fund expensive health treatments.

“I am now being very selective on my purchases from this year’s Health Grant, I desperately need a accessible kitchen, we have had quotes, the kitchen has to meet the needs of myself and my husband, so has to be bespoke, figures from £50,000 up.”

- **A healthier family life** - A few people mentioned the positive impact that the grant being made permanent would have on their families and those close to them. They felt it would take the pressure off them and mean that they would be able to buy-in care and help so that they would not feel like they were a burden.

“I don’t want my daughter to inherit my disability; it’s not fair.”

- **Options in their working lives** - Nearly a quarter of the study group said that the Health Grant being made permanent would enable them to either cut down their working hours or to consider early retirement, again to slow down or prevent further deterioration in their health. A few people said that it would mean they could stay in work for longer or move to jobs which were less physically demanding but lower paid.

“I am doing a lot of damage – wear and tear to my teeth. I do keyboard work. I use my eyes a lot; I am at the keyboard all day. I would either consider looking at going shorter hours or possibly retiring early...”

Chapter 7 Conclusions

When the Departments of Health established the three-year Health Grant in 2010 they clearly stated that its primary purpose was to enable Thalidomide-impaired people to address the exceptional health and health-related needs they were experiencing as they grow older. In this second year of the evaluation of the Health Grant it was evident that the grant is enabling them to do this. More broadly, four key messages emerged:

The health of Thalidomide-impaired people is deteriorating, and is likely to continue to do so at a more rapid rate than their peers in the general population

The findings from the evaluation and the work of HealthLink clearly show that Thalidomide-impaired people are experiencing deterioration in their health as a result of their original Thalidomide damage or because of the abnormal way they have had to use their bodies in order to compensate for missing or short limbs. They are also experiencing new, previously undiagnosed problems, in particular numbness and partial paralysis. They generally feel that the rate at which their bodies are aging or the health problems they are experiencing are disproportionate to their chronological age. This view was supported by the results of the Health Related Quality of Life survey (SF12) which suggests that Thalidomide-impaired people do experience significantly poorer physical health, especially in relation to physical functioning and pain, compared to their peers in the general population and compared to people of a similar age with the common neuromuscular condition, Multiple Sclerosis. However, the survey also showed that their mental health is only marginally worse than the general population, which perhaps reflects the resilience of many Thalidomide-impaired people.

People have used their grants flexibly to purchase or put in place the things that they felt would make the most difference to their health and well-being

In the first year of the Health Grant, many people focused on addressing immediate and long-standing needs for home adaptations or replacement vehicles. By the second year, there was a sense that people had had time to reflect on the 'outcomes' they wanted to achieve for themselves and their families, and they were trying to think about what would make the most difference to their health and wellbeing in the long term. Whilst high cost adaptations and vehicles/wheelchairs still accounted for almost half of the study groups' expenditure, many people were also beginning to put other on-going support arrangements in place, either to manage existing health problems or to prevent or reduce further deterioration. A significant minority of study group members had saved (some of) their second year Health Grant, either because they were waiting for the third year's payment in order to afford very high cost items like housing adaptations or new vehicles, or because they were anxious about the future of the Grant and wanted to ensure they could continue to pay for beneficial treatments and services.

The choices people made in spending the grants also helped to enhance their independence and reduced reliance on family members. This was a key concern to many study group members, especially where their partner had health problems of their own or where it was affecting their children's lives.

Many Thalidomide-impaired people feel that the NHS has often struggled to deal with the complex nature of their problems. As a result, study group members had a strong and growing desire to ‘manage’ their own health, and from the outset they saw the Health Grant as a fund that they could use to do this. Most of the health-related treatments purchased with the Health Grant were complementary therapies and other treatments not normally available through the NHS. However, a few had been unable to find adequate or appropriate treatments through the NHS and had used their Grant to fund these. Flexibility in the use of the Health Grant was crucial because it gave people the freedom to spend it on the things that they felt would make the most difference to them in the context of their needs and circumstances.

The Health Grant has had a direct impact on peoples’ ability to address existing health problems and has enabled people to take steps to prevent or reduce further deterioration

Nearly two thirds of the study group used some of their Health Grant to pay for treatments to address or alleviate existing health problems. These brought much valued pain relief and increased mobility and dexterity, which in turn helped people to maintain their independence. However, people also used much broader strategies to address their health and health related problems. These often centred on making their day to day lives easier and so reducing the strain on their bodies. The impact of these things on people’s health, wellbeing and general quality of life has been demonstrable.

In the short term the Health Grant does not appear to have significantly reduced people’s use of NHS services. However, there was a strong view within the study group that the steps they were taking to prevent future problems would, in the long term, mean that they would need to make fewer demands on the NHS.

There is real anxiety about the Health Grant ceasing and a strong view that a permanent Health Grant is required if people are to address on-going issues and changing needs

The prospect of the Health Grant ending was a cause of real anxiety for study group members and there was concern that many of the improvements in people’s health and well-being achieved over the past two years might be lost. Not surprisingly, the overwhelming majority of the study group were keen for the Health Grant to be made permanent. They emphasised that the issues they were facing could not be resolved with a ‘one-off’ grant. In particular, many people were trying to address a ‘backlog’ of need for home adaptations or vehicles and often more than one years’ grant was required to fund such high cost projects/purchases. It was also clear that many of the things people were putting in place to manage their health and prevent or slow down the deterioration in their health and independence would have to be paid for on an on-going basis. Furthermore, neither the health needs nor the circumstances of Thalidomide-impaired people are static, and so they anticipated needing further adaptations and equipment in the future.

However, many people felt that a permanent Health Grant would also bring equally important but less tangible benefits. They emphasised the ‘peace of mind’ that a permanent Health Grant would give them, and highlighted the fact that it would help them to plan positively for the future, including giving them choices in their working lives.

Perhaps the final point to note is one that sets the Health Grant in the much wider context of the Thalidomide story. As was noted at the beginning of this report, there is a strong sense within the Thalidomide community that the Health Grant is not only about recognising the exceptional health problems Thalidomide-impaired people are experiencing as they age, it is also about achieving social justice for the damage they suffered, and enabling them to live a 'normal life' in spite of this. Its continuation is for many Thalidomide-impaired people a concrete acknowledgement of this.

Appendix 1: Profile of the Study Group

At the start of the evaluation in 2011, 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. Demographic data on all UK Thalidomiders and the study group Thalidomiders are shown in Tables 3 and 4 respectively.

Table 3 Demographic data on all UK Thalidomiders

Country	Band 1	Band 2	Band 3	Band 4	Band 5	Total
England	37	91	105	50	42	325
N. Ireland	1	5	6	2	4	18
Scotland	7	13	22	5	7	54
Wales	1	3	15	9	3	31
Total	46 (11%)	112 (26%)	148 (35%)	66 (15%)	56 (13%)	428

Table 4 Demographic data on study group members contributing spend data and/or interview

Grant Year	Country	Band 1	Band 2	Band 3	Band 4	Band 5	Grand Total
Year 1	England	3	6	9	8	12	38
	Northern Ireland			1		2	3
	Scotland	1	2	3		1	7
	Wales			3	2		5
Year 1 Total		4(8%)	8(15%)	16(30%)	10(19%)	15(28%)	53
Year 2	England	3	7	9	8	11	38
	Northern Ireland			1		2	3
	Scotland	1	2	3		1	7
	Wales			2	1		3
Year 2 Total		4(8%)	9(18%)	14(28%)	9(18%)	14(28%)	50
Original Study Group		4(7%)	10(16%)	20(33%)	11(18%)	15(25%)	60

Table 5 below shows the benefits and services that Thalidomiders in the study group reported that they are receiving. There are a few differences between Year 1 and year 2, which are probably accounted for by:

- People’s recall of benefits will naturally vary
- Researchers probed in more depth in year two about DLA receipts
- The slightly different interview cohorts in Year 1 and 2

Table 5 Benefits claimed by study group members

	Year 1	Year 2
Independent Living Fund	4	2
Disability Living Allowance (DLA)	45	42
Mobility component of DLA	26	26
Disabled Facilities Grant (England)/Housing Adaptations Grant (Scotland)	1	1
NHS Continuing Care funding	0	0
Personal Budget/Direct payment	16	11
Personal Health Budget	0	0
Severe Disability allowance	6	2
Incapacity benefit	9	6
Income support	1	1
Sickness benefit	1	1
Access to work	0	1
Carers allowance	1	0

Appendix 2: SF12 Health Related Quality of Life Survey Results

The Short Form (36) Health Survey is a survey of patient health developed in the 1980s. It is a measure of health status and is commonly used in health economics as a variable in the quality-adjusted life year calculation to determine the cost-effectiveness of a health treatment. It consists of eight scaled sections:

- Physical Functioning (PF)
- Role Limitation Physical (RP)
- Pain (BP)
- General Health (GH)
- Vitality (VT)
- Role Limitation Emotional (RE)
- Social Functioning (SF)
- Mental Health (MH)

These can also be ‘aggregated’ into two groups – the first four sections make up the physical health domain and the other four the mental health domain.

The SF12 was developed in the 1990s and uses the same sections but with the number of questions reduced from 36 to 12. All the study group members who were interviewed completed an SF12 survey at the end of the interview. The data from this survey was analysed by the ScHARR group at the University of Sheffield.

In order to determine the relative health of the group being studied, in our case our Thalidomide Health Grant study group, other groups are needed to provide a comparison in each of the eight sections and the two domains. In this study the scores for the study group were compared with a *general population group* of participants in the ‘The Central England Healthy Life Survey’¹¹, using the age group from that survey (45-54 year olds) which was closest to those of the Thalidomiders.

The study group were also compared with a group with a common neuromuscular condition (Multiple Sclerosis) that might be expected to have similar implications for health related quality of life. There were two available:

- A group of Multiple Sclerosis patients (average age 43) who had presented (to the health service), within one year of onset of the symptoms. This group was further divided into those with the disease in a progressive stage, those in a relapsing stage and those who were stable
- A group of Multiple Sclerosis patients (average age 46) who had presented with a mean of 10 years since onset of symptoms

¹¹ Bowling A, Bond M, Jenkinson C, Lamping D L (1999) Short Form 36 (SF-36) Health Survey questionnaire: which normative data should be used? Comparisons between the norms provided by the Omnibus Survey in Britain, the Health Survey for England and the Oxford Healthy Life Survey. *Journal of Public Health Medicine* Volume: 21, Issue: 3, Publisher: OXFORD UNIV PRESS, Pages: 255-270

When comparing the study and MS comparison group with the ‘general population group’ the results are presented in what is called ‘normalised form’ i.e. the scores for the general population group in all the sections and the two domains are adjusted such that the mean is 50 and the spread – standard deviation (sd) – is 10. The study and MS comparison groups are also adjusted in the same way. For the general population group their scores are assumed to follow a *normal distribution*, which means that we would therefore expect 96% of the members of the general population to have a score in all the sections and domains of between 30 and 70 (+/- 2sd). However, there is no reason to expect the MS or Thalidomide study groups to have a normal distribution.

Table 6 below shows the figures for each of the groups in the two main domains.

Table 6 Normalised data comparing general population, MS group and study group

		Number of respondents	Age	Physical Health		Mental Health	
				mean	sd	mean	sd
General Population	General population group	Unknown	45-54	50.0	10.0	50.0	10.0
Multiple Sclerosis	10 Year	504	Average 46.1	34.0	10.7	43.2	11.6
	1 year - Progressive disease	639	Average 44.9	41.8	10.2	48.1	7.8
	1 year - Relapsing	1582	Average 40.9	41.3	10.7	46.1	7.9
	1 year - Stable	787	Average 40.9	50.4	8.2	50.1	6.5
Study Group	Aggregate	50		24.6	13.5	43.8	11.7

It is clear that the mean value of the aggregate physical health for the study group (24.6) is much lower than either the population average (50) or MS comparison groups (34-50.4) though the variation of the results, as shown by the value of the sd, for the study group (13.5) is quite a lot higher than the variation in the other groups (8.2-10.7). The p value for the differences between the study group and the MS comparison groups is <0.001 in all cases. The aggregate score of the study group in the mental health domain however, is only marginally lower than the general population group and compares very closely with the Multiple Sclerosis 10 year group. The p value for the differences between the study group and the MS comparison group varies from <0.001 for the progressive disease and stable groups, 0.039 for the relapsing group, and 0.732 for the 10 year group.

The study group’s individual scores for aggregate physical and mental health are illustrated in Figure 4. Each dot on this graph represents the aggregated score for each

study group member grouped together in the two domains. Note that the horizontal axis on this graph does not have a value and is used only to spread out the individual points horizontally for clarity. The red line shows the average score for the ‘average’ group and, because of the way the scores have been normalised we would expect only 2% of that group to have a score below 30 or above 70. The dots show that 35 members of the study group (70%) have a physical health domain score below 30 i.e. outside the 96% normal range of the general population group, and only 2 have a score above the average for the ‘average’ group. The mental health scores are much higher with only 7 (14%) of the study group outside the 96% range and 14 (28%) above the mean for the general population group.

Table 6 and Figure 4 provide a clear indication that the physical health of the study group is significantly worse than the average population and even of the MS 10 year comparison group. However, the mental health scores are very similar to the MS 10 year comparison group with the mean at 43.8 only a little below the general population group.

Figure 4 Aggregate physical health and mental health for the study group

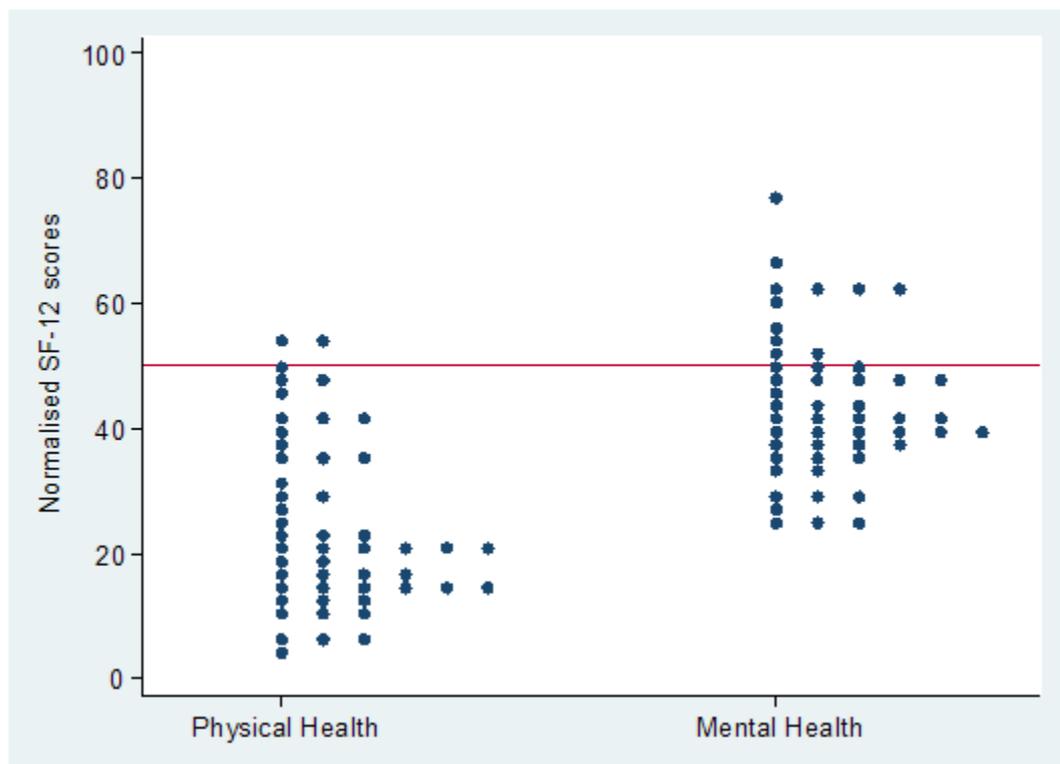


Table 7 shows the mean and standard deviation for each of the 8 sections in the survey. It clearly shows that all the physical domain scores for the study group are much lower than those of the general population group (mean 50), in particular those for physical functioning and pain, though the former has a very high sd indicating a wide variation within the study group. In the mental health domain the social functioning section also has a very low mean score. Any mean values less than 30 (or greater than 70) are outside the 96% spread (+/- 2sd) of the general population group.

Table 7 SF12 normalised domain results for study group

	Component	mean	sd	Min	Max
Physical domain	Physical Functioning (PF)	19.0	18.4	1.7	57.6
	Role Limitation Physical (RP)	33.5	8.7	21.9	55.0
	Pain (BP)	28.6	13.6	14.2	59.2
	General Health (GH)	33.4	13.5	13.7	63.7
Mental health domain	Vitality (VT)	41.0	12.2	21.3	68.2
	Role Limitation Emotional (RE)	41.3	9.2	23.7	55.3
	Social Functioning (SF)	29.5	15.1	2.0	55.5
	Mental Health (MH)	36.9	13.1	14.5	64.5

Abbreviation List

DFG	Disabled Facilities Grant
DH	Department of Health
DLA	Disability Living Allowance
HAG	Housing Adaptations Grant
IBR	Individual Beneficiary Review
ILF	Independent Living Fund
PA	Personal Assistant
PB	Personal Budget
PCT	Primary Care Trust
SDA	Severe Disablement Allowance
sd	Standard deviation

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