



Health, Quality of Life and Employment amongst  
Thalidomide-affected People – Evidence from  
the UK

**January 2015**

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## Abbreviation List

DH	Department of Health
NAC	National Advisory Council (to the Thalidomide Trust)
PA	Personal Assistant
TT	Thalidomide Trust

## Executive Summary

### 1. Introduction and Methods

There is growing evidence, both here in the UK and internationally that Thalidomide-affected people are experiencing an increasing number of Thalidomide-related health problems as they age. They are also incurring significant costs in living with these problems. Following an earlier three year pilot, the new ten year Health Grant funded by the Health Departments in England, Scotland, Wales and Northern Ireland (awarded from 2013 to 2023) is now in place. For many Beneficiaries it will be central to managing their changing health needs and maintaining their quality of life. The Health Grant monitoring project, which has been commissioned by the Thalidomide Trust, will inform future discussions about the continuation of the Health Grant. It has three broad aims:

- To examine how the health of Thalidomide-affected people is changing over the life of the Grant
- To understand how people are using their Health Grants
- To explore the difference the Grant is making to their lives

The project, which runs from 2013 to 2020 has two main elements:

**A health related quality of life survey** – The survey will be sent to all Beneficiaries in the first year of the Health Grant and repeated at two later points. It uses the SF12 questionnaire to explore whether the health problems experienced by the Thalidomide-affected people in the UK are continuing to result in them experiencing poorer health related quality of life than their age group in the general population; compare their health related quality of life with that of people with a common neuromuscular condition and a common disabling event; and see whether there is any measurable change in the health related quality of life of Thalidomide-affected people over the life of the 10 year grant. In 2013 the survey also included a number of questions about Beneficiaries employment and financial circumstances – two areas of particular interest to the Thalidomide Trust’s National Advisory Council (NAC). The survey went to all 469 Beneficiaries living in the UK. 245 responses were received (232 on paper and 13 on-line) giving a response rate of 52%.

**Annual in depth telephone interviews with around 40 Beneficiaries** - The interviews explore three main topics – current or recent Thalidomide-related health problems (including how these health problems are affecting people both practically and emotionally and whether they had sought or received any treatment for their health problems); the use of the Health Grant (including the main reasons for choices/decision and the impact on their health and wellbeing); and the future, in particular what people think their main health related needs will be over the next 5 to 10 years, and any specific plans or ideas people had for the use of their Health Grants in the longer term. 40 Beneficiaries were interviewed in 2014 and one responded in writing. The group was broadly representative of all UK Beneficiaries, in terms of impairment band and country of residence but 65% of the group were women, compared to just over half for all UK Beneficiaries.

## **2. Health Related Quality of Life**

The SF12 questionnaire 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 results from the SF12 questionnaire show that Thalidomide-affected people do experience significantly poorer physical health compared to the general population and compared to both a group of people with multiple sclerosis (MS) and post-stroke patients, 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. However, a small group (n=38 / 16%) of those who responded to the survey had a score the same as or worse than the 2% of the general population group with the poorest mental health related quality of life. These findings are broadly similar to those from the second year of the evaluation of the initial three year Health Grant.

## **3. Employment and Financial Circumstances**

The second part of the survey looked at whether peoples' Thalidomide-related disabilities and health problems were affecting their ability to work, and the extent to which they felt able to meet the cost of living with these disabilities and health problems.

Half of those who responded to the survey (n=122) said that they were unable to work because of their disability or health problems; 17% (n=40) of respondents were working full time and 20% (n=47) part time. The majority of these latter two groups said that they had to work to maintain their standard of living. However, half said that working was having a negative effect on their health. Fifty-eight respondents said that they had changed their job or the type of work they did because of their disability or health problems. From around 2001 onwards there was a marked increase in the (cumulative) number of Beneficiaries who had changed their working situation. After 2012, when the ten-year Health Grant was confirmed, there was a jump in the number of Beneficiaries who stopped working or reduced their working hours, which may well reflect the fact that the Grant in part enabled people to change their working situation in order to 'preserve' their health and wellbeing.

The survey also asked Beneficiaries to estimate what proportion of their current household income comes from the Thalidomide Trust (i.e. Annual Grant and Health Grant together). 38% (n=92) of the Beneficiaries who answered this question said that over 80% of their household income came from the Trust. Not surprisingly, the majority of this group were not currently working. Even amongst the Beneficiaries who were working, their Annual and Health Grant represented a significant proportion of their household income. Lastly, people were asked to rate (on a scale of 1 to 10) the extent to which they felt their current household income was enough to meet their Thalidomide-related disability and health needs. The majority felt that their current household income only partially enabled them to meet their Thalidomide related disability and health needs.

## **4. Thalidomide-related Health Problems**

Fifty-eight people added general comments to their Health Related Quality of Life and Employment survey, and these suggest that many Beneficiaries have growing

concerns about their health. The in-depth interviews with 41 Beneficiaries provided an opportunity to explore further the Thalidomide-related health problems people were experiencing and examine how they are affecting people daily lives. Four main themes emerged:

**Reduced flexibility and mobility** - in particular, reduced ability to reach, stretch, and bend. The root cause of this varied but often appeared to be related to perceived deterioration in the spine or joints and muscular problems. Several lower limb-affected interviewees said that they now had to use an electric wheelchair at least some of the time. Other interviewees said they were no longer able to walk as far as they could just a few years ago, and some had had falls which had led to a loss of confidence. Many interviewees reported facing difficult decisions about treatment (e.g. surgery to replace joints or fuse bones), whilst other were struggling to get a reliable diagnosis and clear treatment options. Some were reluctant to seek conventional medical help because of bad experiences in the past or a fear that any intervention might simply make their situation worse.

**Pain and stiffness** - reduced flexibility was often closely linked to increasing pain, either more severe pain or pain in more areas of the body or pain being more continuous. Explanations of the causes of peoples' pain varied and were often multiple, including arthritis, joint deterioration, trapped nerves and muscle strain/spasm. However, almost all interviewees said that their pain was made worse by everyday tasks such as using a computer keyboard, driving, housework etc.

**Tingling, numbness and heat/cold** - Around two thirds of the interviewees reported experiencing sensations such as numbness, tingling, and pins and needles. A few said that at times areas of their bodies felt very cold or very hot. Many Beneficiaries said that these sensations did not substantially affect their day to day lives but for others they had a significant impact, affecting peoples' sleep patterns, their ability to drive, to walk, and to pick things up. Most said that they were a relatively recent phenomenon (i.e. developing over the last five to ten years) and a number felt that they were getting worse. Some did have a medical explanation for these sensations but a few suggested that they might be generally related to the effect of Thalidomide.

**Mental and emotional health** - a small number of people said that over the years they had experienced periods of depression or low mood. However, the increase in the Annual Grant and the introduction of the Health Grant had substantially reduced their financial worries and improved their quality of life, which in turn had led to better mental health. Several Beneficiaries, particularly those with lower levels of impairment, said that the decline they felt was occurring in their day to day functioning and the associated loss of independence was affecting their emotional health. There was also a third small group of Beneficiaries, again generally those less severely affected by Thalidomide, for whom the emotional impact of a more recent decline in health or functioning was layered on top of more long standing emotional issues, often related to their impairments.

Other health and general well-being issues discussed included tiredness and lack of energy; sight, dental and hearing problems; and weight management.

Many interviewees reported a decline in their independence as a result of the health problems they were experiencing. In particular, losing the ability to undertake everyday personal care tasks was a major concern. This affected peoples' identity

and self-esteem; it limited their lives; and it had an impact on their family members. It also had financial implications.

## **5. Ten Year Health Grant – Current Use and Future Issues**

Overall, whilst people continued to see their Health Grant as a fund to be used for their health and well-being, in practical terms it was increasingly part of their household income. The 41 in-depth interviewees were asked specifically about the main ways in which they had used their Health Grant during 2013. There were seven broad areas of expenditure:

- Self-management of health problems
- Private health and dental care
- Off-setting loss of income/higher costs of living
- Home maintenance and adaptations
- Mobility
- Domestic help and personal care
- Holidays and social activities

Both the survey and the interviews also gave Beneficiaries an opportunity to reflect on future health and well-being issues and how they might use their Health Grant to address these. The information gathered suggests that people were concerned that their ability to work was declining at the same time as the cost of managing or coping with their Thalidomide-related health problems and disabilities was increasing. Perhaps not surprisingly, one of the biggest concerns was that further deterioration in health and functioning would lead to increased dependence on family (at a time when many people's family circumstances were changing), paid care workers and/or equipment. A number of interviewees were thinking about moving to a more manageable property but the cost of both buying and adapting it was a concern.

## **6. Conclusions**

This research has been able to build on earlier work carried out or commissioned by the Trust and its National Advisory Council, to provide a fuller picture of the health and financial circumstances of Thalidomide-affected people in the UK. In particular, it suggests that trends identified in the evaluation of the initial three-year pilot Health Grant evaluation are continuing, notably the deterioration in peoples' health, their declining ability to work (or work full-time), and the use of the Health Grant to help deal with these two major issues. The in-depth interviews show that people were using their Health Grants in a wide range of ways, to manage their health problems, maintain their independence and preserve their quality of life. Whilst interviewees raised the issue of the need for more adaptations, equipment and paid help coinciding with a decline in their earned income, they also stressed the huge difference the Health Grant had made to their lives and their sense of financial security. It was also clear that many people were looking forward positively – finding (or looking for) new relationships, keeping active, travelling and replacing paid work with interesting voluntary work. In many respects the Health Grant was enabling them to do this.

## Chapter 1 Introduction

There is growing evidence, both here in the UK and internationally<sup>1 2</sup> that Thalidomide-affected people are experiencing an increasing number of Thalidomide-related health problems as they age. An earlier evaluation of the first three year pilot Health Grant (see Appendix A for more information about the Health Grant and how it is distributed), together with information collected by HealthLink<sup>3</sup>, clearly showed that because of the unusual ways in which people have had to use their bodies to compensate for their original impairments, conditions such as arthritis and other muscular-skeletal problems were becoming more common. Late on-set neurological symptoms (i.e. tingling, numbness, heat/cold and/or loss of strength/grip in hands, arms, legs and/or feet) were also increasingly prevalent<sup>4</sup>. Furthermore, these Thalidomide-related health problems, often made it more difficult for people to manage unrelated health problems such as diabetes and asthma.

Earlier studies, notably the evaluation of the three year Health Grant<sup>5</sup> and the Securing Our Futures project<sup>6</sup> carried out by the Thalidomide Trust National Advisory Council (NAC), also showed that Beneficiaries were incurring significant costs in managing or living with these problems. It is likely that the levels and types of Thalidomide-related health problems will continue, and perhaps increase, as Beneficiaries reach their early 60s. It is therefore reasonable to expect that the additional expenses incurred in addressing these health problems will continue, or even increase, as people retire from paid work, and/or adult children leave home, and/or their partners experience health problems.

The new ten year Health Grant, awarded from 2013 to 2023, is now in place and for many Beneficiaries it will be central to them managing their changing health needs and maintaining their quality of life. Although there is no requirement to evaluate the current ten year Health Grant the Thalidomide Trust and the NAC felt it would be valuable to put in place some 'light touch' monitoring to inform future discussions about the continuation of the Health Grant. The Thalidomide Trust Scientific Committee asked Firefly Research (who conducted the evaluation of the earlier pilot Health Grant) to undertake the monitoring of the new ten year Grant. The monitoring project has three broad aims:

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<sup>1</sup> Thalidomide Victims Association of Canada (2013). *Study of the current living conditions of Canadian Thalidomide survivors and their projections for the future*. TVAC

<sup>2</sup> O'Carroll A, O'Reilly F and Whitford D L (2011). What has happened to people affected by Thalidomide 50 years on? *Irish Journal of Medical Science* 2011, 180:475-478.

<sup>3</sup> HealthLink is the Thalidomide Trust's health and wellbeing advice service.

<sup>4</sup> Jankelowitz S K, Spies J M and Burke D (2013). Late onset neurological symptoms in thalidomide-exposed subjects: a study of an Australasian cohort. *European Journal of Neurology* 2013, 20: 509-514.

<sup>5</sup> Newbronner et al (2012). *Looking to the Future: Evaluation of the Health Grant to Thalidomide-impaired People*. Firefly Research & Evaluation, York.

<sup>6</sup> National Advisory Council to the Thalidomide Trust (2012). *Securing Our Future: the disability and health costs of UK Thalidomide-affected people*. [http://www.thalidomidetrust.org/wp-content/uploads/2014/05/HealthGrant\\_FinalReport\\_2012-compressed.pdf](http://www.thalidomidetrust.org/wp-content/uploads/2014/05/HealthGrant_FinalReport_2012-compressed.pdf)



- To examine how the health of Thalidomide-affected people is changing over the life of the Grant
- To understand how people are using their Health Grants
- To explore the difference the Grant is making to their lives

The proposal for the monitoring project and an accompanying Research Ethics and Governance plan was reviewed by an independent academic reviewer, and was approved by the Scientific Committee. In 2013/14 the monitoring project included a health related quality of life and employment survey which went to all UK resident Beneficiaries, and in-depth telephone interviews with a smaller group of Beneficiaries. The methods used in the project are described in more detail below.

This overview report brings together findings from both parts of the project. The results of the Health Related Quality of Life and Employment Survey are presented in full, alongside emerging themes from the interviews with the study group. The report begins by presenting the findings from the health related quality of life survey (Chapter 2). In Chapter 3 the key issues emerging from the employment and financial circumstances questions are considered. Chapter 4 highlights the Thalidomide-related health problems which the Beneficiaries in the study group were experiencing and briefly discusses the impact of these on peoples' independence and lifestyle. Chapter 5 describes how Beneficiaries are using their ten year Health Grants and notes the concerns for the future which people most commonly raised. Finally Chapter 6 draws a number of conclusions from this first phase of the research.

## **1.1 Methods**

The Health Grant Monitoring project, which will run from 2013 to 2020, has two main elements:

- A survey of the health related quality of life of all Beneficiaries planned for the first year of the Health Grant and repeated at two later points. In 2013 the survey also included a number of questions about employment and financial circumstances – two areas of particular interest to the NAC
- Annual in-depth telephone interviews with group of around 50 Beneficiaries, designed to explore how peoples' health and wellbeing are changing and how people are using their Health Grant to address specific Thalidomide-related health problems

The methods used in both these elements of the project are described further below.

### **1.1.1 Health Related Quality of Life and Employment Survey**

The Health Related Quality of Life and Employment Survey (see Appendix B) was developed by Firefly, with colleagues from the NAC and the Trust. Two Beneficiaries piloted the draft survey. It comprised two parts – the SF12 Health Related Quality of Life Survey and a set of question about peoples' employment and financial circumstances. These are described in more detail below.

- **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. When answering the SF12 questions people were asked 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 can be difficult for some people and so the results of the SF12 survey do need to be interpreted with some caution. The results for Beneficiaries have been compared with a similar age group in the general population, with people of a similar age with Multiple Sclerosis (10 years from the on-set of symptoms), and with post-stroke patients. The key findings from the survey are included in Chapter 2 and a detailed breakdown of the results is shown in Appendix B. The statistical analysis of the SF12 responses has been undertaken by colleagues at the School of Health and Related Research at the University of Sheffield, which has particular expertise in the use of the SF ‘family’ of surveys.

- **Employment and Financial Circumstances Questions** - The employment situation and financial circumstances of Beneficiaries is an area of particular interest to the NAC and they asked for a small number of key questions to be included in the survey. The questions were designed and tested with NAC members. The questions about household income and peoples’ ability to meet their Thalidomide related disability and health needs need to be treated with some caution, as people are likely to interpret these concepts in different ways. Nevertheless they do provide a useful overview of peoples’ circumstances.

The survey was sent by post from the Thalidomide Trust to all Beneficiaries living in the UK (n=469) in early December 2013. The survey form was accompanied by a supporting letter from the Director of the Trust and a Firefly Freepost return envelope. Beneficiaries also had the option to complete the survey on-line and the web address for this was given in the introduction to the survey. Although the survey was completely anonymous, Beneficiaries were asked, if possible, to let the administrative team at the Trust know that they had returned their survey, so that they were not troubled again when reminders were sent out.

After 4 weeks 190 responses had been received. To improve the response rate, the survey was re-sent to all Beneficiaries (except those who had advised the Trust that they had completed it). Those Beneficiaries who had provided the Trust with an email address were sent the reminder and survey form by email. The remainder were sent by post. By the end of February, when the survey closed, 245 responses had been received (232 on paper and 13 on-line), giving a response rate of 52%. Three responses were received after the survey closed. It was too late to include their answers to the SF12 questions, as these had already been analysed, but their answers to the employment questions have been included (i.e. n=248).

To ensure complete anonymity, the survey did not ask respondents to provide information about their Trust impairment band, country of residence or gender. The absence of this information does make it difficult to comment on representativeness of those who responded. However, the response rate was good and the survey did capture a wide range of views and experiences.

### 1.1.2 In-depth Interviews

Participants for the in depth interviews were recruited using two approaches:

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- Information about the project was distributed at the 2013 annual conference of the National Advisory Council and those interested in being involved were invited to contact Firefly research
- All those Beneficiaries who took part in the earlier Securing Our Futures project and the three year Health Grant Evaluation were written to via the Thalidomide Trust and asked if they would like to take part in the longer term monitoring of the current ten year Health Grant

Initially 53 Beneficiaries indicated that they would be willing to take part in the in depth interviews. However, five withdrew when contacted about the first interview. A further seven either did not respond or it proved impossible to arrange a date for the interview. Forty Beneficiaries were eventually interviewed by telephone and one responded in writing. The make-up of the group in terms of the Thalidomide Trust’s impairment bands<sup>7</sup> and county of residence, compared to all UK Beneficiaries is shown in the table below. The group is broadly representative, although Beneficiaries in Band 2 are under-represented and those in band 5 over-represented. In addition, whilst just over half the Beneficiaries in the UK are women, the study group was made up of 65% women.

**Table 1 In-depth interview sample Compared to all UK Beneficiaries**

	Band 1	Band 2	Band 3	Band 4	Band 5	Total	In-depth interview sample	UK Overall
England	4	4	10	5	9	32	78%	76%
N. Ireland		1	1	1		3	7%	4%
Scotland	1	1	1	1		4	10%	13%
Wales			1		1	2	5%	7%
Total	5	6	13	7	10	41		
In depth interview sample	12%	15%	32%	17%	24%			
UK Overall	11%	26%	35%	15%	13%			

The interviews explored three main topics:

- **Current and recent health problems** – the nature of any Thalidomide-related health problems; how these health problems were affecting people both practically

<sup>7</sup> Following the legal settlement in the 1970s, Distillers (now Diageo) set up a trust fund which pays an Annual Grant to Thalidomide-affected people in the UK. Beneficiaries fall into one of five impairment severity bands (although people can move between bands if there is a significant loss of their functional ability) and the size of their Annual Grant is based on their level of impairment.

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and emotionally; and whether they had sought or received any treatment for their health problems

- **Use of the Health Grant** – how people had used their 2013/14 Health Grant; the main reasons for choices/decision; and the impact on their health and wellbeing
- **The future** – in particular what people think their main health related needs will be over the next 5 to 10 years, and any specific plans or ideas people had for the use of their Health Grants in the longer term

The interviews were conducted by telephone and lasted between 40 minutes and 1½ hours. All except two were recorded, with the Beneficiaries' consent (two people did not wish their interviews to be recorded), and all recordings have been transcribed in full. The analysis carried out for the highlight report was designed to pick out key themes and issues. More in depth analysis of the interviews will be undertaken in early 2015 and used to both inform the next stage of the monitoring project and wider work within the Trust.

## Chapter 2

### Health Related Quality of Life

The second report from the evaluation of the three year Health Grant<sup>8</sup> reported the results of the SF12 Health Related Quality of Life Survey carried out with 49 Beneficiaries. The results of that survey clearly suggested that the health problems experienced by the Thalidomide-affected people in the UK were resulting in them experiencing poorer health related quality of life than their age group in the general population. It was therefore decided that as part of the monitoring of the ten year Health Grant it would be valuable to repeat the SF12 Survey with all Beneficiaries in the UK, at three points in the life of the new grant to:

- Explore whether the health problems experienced by the Thalidomide-affected people in the UK are continuing to result in them experiencing poorer health related quality of life than their age group in the general population
- Compare their health related quality of life with people with a common neuromuscular condition, such as Multiple Sclerosis (MS) and a common disabling event such as stroke
- See whether there is any measurable change in the health related quality of life of Thalidomide-affected people over the life of the ten year grant.

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 and comparative data for people with MS and post-stroke) are shown in Appendix B. Here we present the key finding for both the physical health and mental health domains. 245 Thalidomiders returned their SF12 questionnaire, just over 50% of the Thalidomide population, of which 234 questionnaires were useable for the analysis<sup>9</sup>.

All the results presented here are in what is called 'normalised form' i.e. the scores for the general population group in all the sections and the two main domains are adjusted such that the mean is 50 and the standard deviation i.e. the spread, is 10. This means that 96% of the population in the normalised general population group will have SF12 scores between 30 and 70 (+/- 2 standard deviations). This is simply a device to facilitate easy comparison between 'special' groups and the 'normal' population.

Figure 1 shows the results for Thalidomide-affected people in the UK compared to the general population aged 45-54 (based on responses to the Central England Healthy Life Survey<sup>10</sup>).

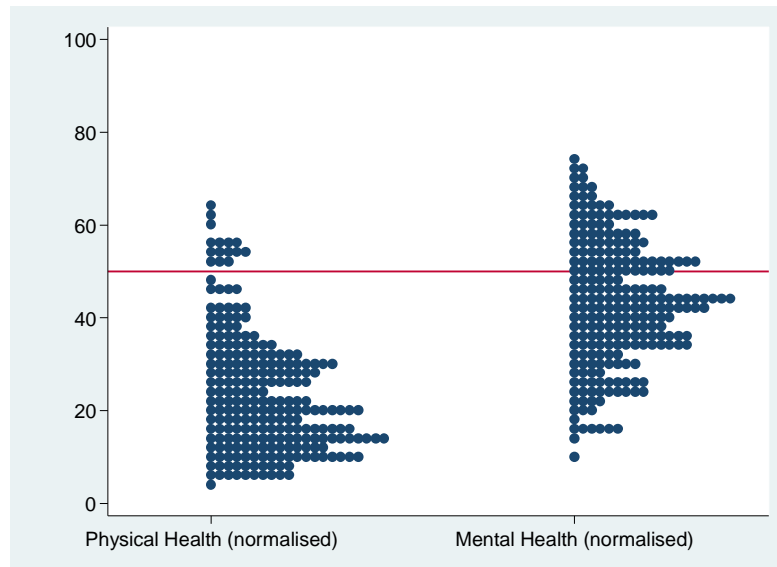
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<sup>8</sup> Newbronner et al (2012). *Looking to the Future: Evaluation of the Health Grant to Thalidomide-impaired People*. Firefly Research & Evaluation, York.

<sup>9</sup> Questionnaires which have not been completed in full cannot be used in the analysis.

<sup>10</sup> Jenkinson C, Wright L, Coulter A. Quality of Life measurement in health care. A review of measures, and population norms for the UKSF-36. Oxford: Health Services Research Unit, 1993.

Figure 1 – Normalised SF-12 physical and mental health scores



Note: The red horizontal line shows the normalised mean score for the general population

In the physical health domain:

- Thalidomide-affected people had a significantly lower average aggregate score than people of a similar age (45 to 54 years) in the general population (i.e. mean of 23.7 compared to 50) indicating that their health related quality of life is significantly poorer.
- 68.4% (n=160) of the Beneficiaries who responded 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 6.4% (n=15) of the Beneficiaries had a score above the average for the general population group
- Thalidomide-affected people also have a lower health related quality of life as a result of their physical health problems, compared with that experienced by people with MS 10 years after onset of symptoms (mean score 34.2)<sup>11</sup>, and compared to that experienced by post stroke patients (mean score 39.7)<sup>12</sup>.
- In the four sections which make up the physical domain, the Beneficiaries had the lowest scores for Physical Functioning (15.4) and Pain (31.2), which was also the case for the Beneficiaries in Health Grant Evaluation study group.

<sup>11</sup> Stephenson JJ, Kern DM, Agarwal SS, Zeidman R, Rajagopalan K, Kamat SA, Foley J. Impact of natalizumab on patient-reported outcomes in multiple sclerosis: a longitudinal study. *Health and Quality of Life Outcomes* 2012, 10:155

<sup>12</sup> Xie J, Wu EQ, Zheng ZJ, Croft JB, Greenlund KJ, Mensah GA, Labarthe DR. Impact of Stroke on Health-Related Quality of Life in the Noninstitutionalized Population in the United States. *Stroke*. 2006;37:2567-2572

In the mental health domain:

- The average aggregate score for Thalidomide-affected people was 43.2, which is only marginally lower than the general population group (score 50) and is the same as the MS 10 year group (score 43.2)
- 30% of the Beneficiaries (n=71) had a score above the average for the general population group
- However, 16% (n=38) of Thalidomide-affected people 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 this SF12 survey show that Thalidomide-affected people do experience significantly poorer physical health compared to the general population and compared to both a group of people with MS, and post-stroke patients, 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. These findings are broadly similar to those from the second year of the evaluation of the three year Health Grant.

Looking ahead it should be possible to compare the results from this and future SF12 surveys with the findings from studies with Thalidomide-affected people in other countries. In particular, SF12 is currently being used in a Japanese health and quality of life study, and a German study is using SF36 which is from the same 'family' of health related quality of life surveys as SF12 and therefore comparable. However, the results from these studies are not currently available. In addition, SF36 has been used to assess the health related quality of life of Thalidomide-affected people in Australia and New Zealand. Comparisons with these three countries will be undertaken when all the data is available.

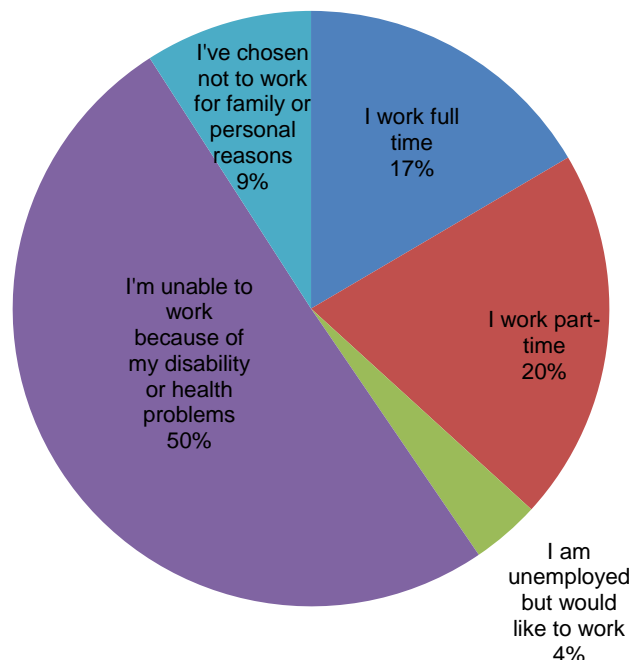
## Chapter 3 Employment and Financial Circumstances

The second part of the survey looked at whether peoples' Thalidomide-related disabilities and health problems were affecting their ability to work, and the extent to which they felt able to meet the cost of living with these disabilities and health problems. 248 Beneficiaries completed this part of the survey, although not all respondents completed all questions. The numbers and percentages shown in this chapter reflect the responses to each question.

### 3.1 Work Situation

Half of those who responded to the survey (n=122) said that they were unable to work because of their disability or health problems. Of this group, just ten people said that they had never worked. As Figure 2 shows, 17% (n=40) were working full time and 20% (n=47) part time. The majority of these two groups said that they had to work to maintain their standard of living. However, half said that working was having a negative effect on their health. Of the group who were working part time, almost two thirds (n=29) said that they had reduced their working hours because of their disability or health problems. Only six had always worked part time because of their disability or health problems. Interestingly, 58 respondents said that they had changed their job or the type of work they did because of their disability or health problems.

Figure 2 Work Situation

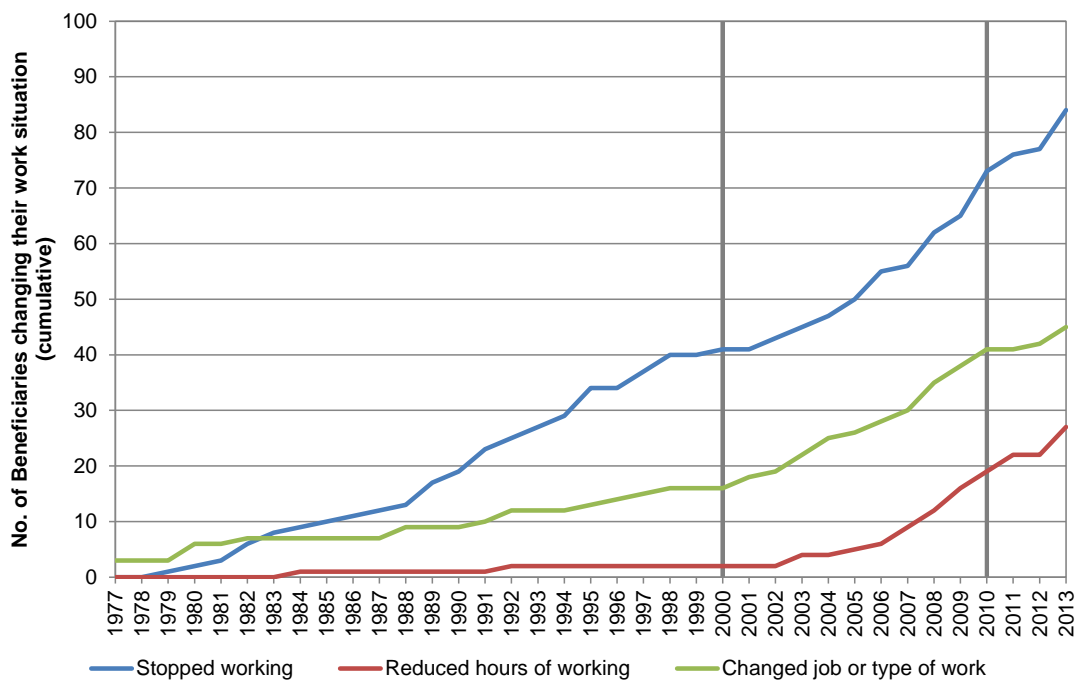


In the survey we also asked people when they had changed their working situation because of their disability or health problems (i.e. stopped working; began working



part-time or changed their job). Figure 3 show that from around 2000/01 onwards there was a marked increase in the (cumulative) number of Beneficiaries who had changed their working situation. After 2012, when the ten year Health Grant was confirmed, there was a jump in the number of Beneficiaries who stopped working or reduced their working hours. As was noted in the final report from the evaluation of the three year Health Grant<sup>13</sup>, this may well reflect the fact that the Health Grant in part enabled people to change their working situation in order to ‘preserve’ their health and wellbeing.

**Figure 3 Cumulative number of Beneficiaries changing their working situation**



### 3.1.1 Peoples Comments on their Work Situation

Thirty-eight people added comments about their work situations. Many emphasised that they had given up work (including taking voluntary redundancy, early retirement, or ill-health retirement) because of health problems or disability, saying things like – “left work in 2013 in part due to health reasons” or “ill health retired 4 years ago”. Others said that they planned or anticipated giving up work in the near future because of deterioration in their health or disability. Often they did not want to give up work, partly for financial reasons but also because they found work fulfilling. The quotes below illustrate this:

*“Next year I will probably have to stop working completely as the pain from my hands means I can only use them for a small amount of time and then have to*

<sup>13</sup> Newbronner E, Borthwick R, Chamberlain R and Baxter M (2013). *A Securer Future - Evaluation of the Health Grant to Thalidomide-affected People*. Firefly Research & Evaluation, York.

*rest for an hour or so. I'm not sure I will be able to find a job where I do not need to use my hands." (Survey Respondent 2)*

*"I do not think I'll be able to work after my operation so I will have to take redundancy which is sad as I enjoy my job." (Survey Respondent 43)*

Three people felt they had had to leave work (including one case of constructive dismissal) because of discrimination or lack of understanding of the health problems caused by Thalidomide damage:

*"My job was physically demanding and stressful but I wouldn't have changed a thing [but] in 2010 my body had had enough and my employer was fed up with my sickness record – over 25 years of service didn't seem to count – but to be honest I'm glad I retired." (Survey Respondent 209)*

Others explained that they had had to reduce their working hours as a result of the Thalidomide-related health problems they were experiencing, saying things like - *"I'm too tired to work full time"* and *"have had to cut down from 5 days to 4 due to pain"*. Those who were self-employed noted that the decline in their ability to work was affecting their businesses and therefore their income:

*"My work has dropped off considerably and I find it hard to go out cold calling to generate more work, therefore my standard of living has dropped." (Survey Respondent 4)*

*"I'm working at the moment but I'm having to adapt the way I work e.g. having to sit down more as I can't stand due to back problems. Working is necessary as I can't afford not to but I will have to consider how and when I work soon, as my body is disintegrating." (Survey Respondent 175)*

For some the pressure of trying to work and look after their families (including dependent children, older parents and acting as primary carers for partners who were unwell) had or was becoming too much:

*"I struggle to juggle home/work responsibilities and get more pain if I rush, so I can foresee my retiring early – maybe next year in which case I will be much more challenged financially." (Survey Respondent 134)*

*"Currently trying to balance my health needs with helping to support ageing and unwell parents. Not working out well for me health-wise but they have done everything for me in my life." (Survey Respondent 183)*

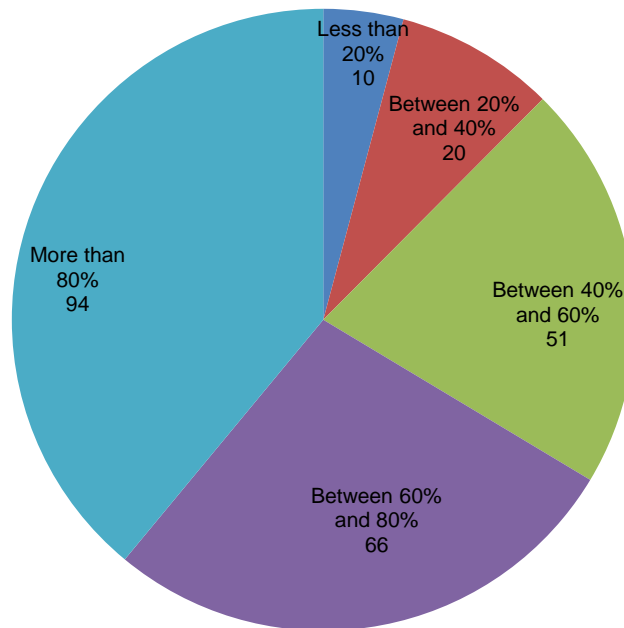
Whilst a few people were positive about continuing to work for personal reasons, others felt they had to work in order to maintain their standard of living.

### **3.2 Meeting the Cost of Disability and Health Needs**

The survey asked Beneficiaries to estimate what proportion of their current household income comes from the Thalidomide Trust (i.e. Annual Grant and Health Grant together). The results do need to be treated with some caution because people may have interpreted or 'calculated' household income in different ways, and also because we have not been able to control for household size. Nevertheless, as Figure 4 below shows, 38% (n=92) of the Beneficiaries who answered this question said that over 80% of their household income came from the Trust. Not surprisingly, the majority of

this group were not currently working. Even amongst the Beneficiaries who were working, their Annual and Health Grant represented a significant proportion of their household income. Just under half of those in part-time work and a third of those in full time work said that 60% or more of their household income came from the Trust.

**Figure 4 Proportion of household income accounted for by Annual Grant and Health Grant**



Lastly the survey asked people to rate the extent to which they felt their current household income was enough to meet their thalidomide related disability and health needs (i.e. for practical/personal assistance at home and away from home, equipment, home or car adaptations etc.). The question gave a scale of 1 to 10 with 1 being 'I can't afford any of the things I need when I need them' and 10 being 'I can afford all the things I need when I need them'. Figure 5 shows the results.

**Figure 5 Extent to which current household income was enough to meet peoples' thalidomide related disability and health needs**

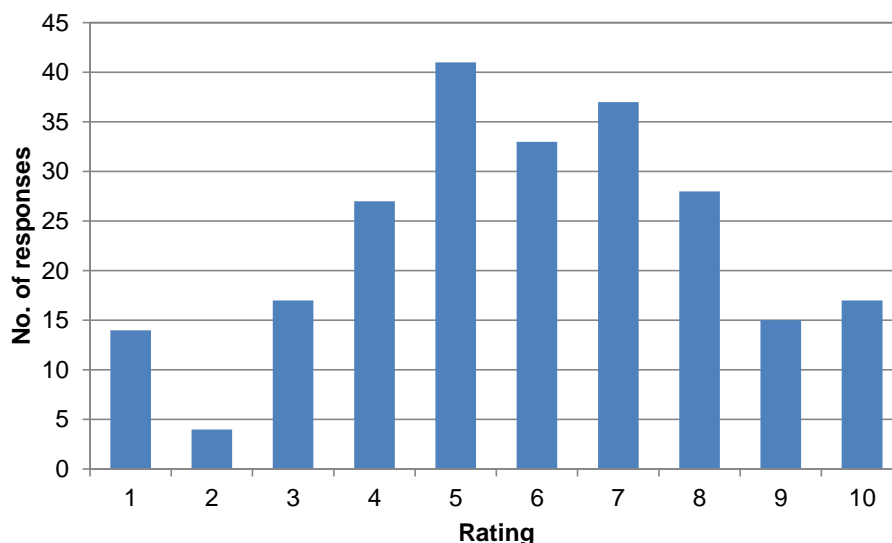


Figure 5 suggests that the majority of people felt that their current household income only partially enabled them to meet their thalidomide related disability and health needs. A small percentage (c8% / n=18) reported that they couldn't afford many of the things they needed (i.e. gave a rating of 1 or 2), and none of this group were in employment. A slightly higher proportion (c14% / n=32) said that they could afford to meet all or most of their needs but interesting this was largely unrelated to peoples' working situation.

At the end of the questionnaire there was a box for any general comments people wanted to make about their health/disability, employment or financial circumstances. Fifty-eight people made additional comments. The comments relating to financial circumstances suggest that for most people the money they received from the Trust (i.e. Annual Grant and Health Grant) was an important part of their household income. Not surprisingly those who were not working or were on low incomes were most likely to emphasise how important the Health Grant was in helping them meet the cost of managing or coping with their Thalidomide-related health problems and disabilities:

*“Because I have a low salary I rely on my trust fund money [but] I don't think I will be working in a few years because of the pain in my arms and hands.”  
(Survey Respondent 75)*

*“My husband is unable to work as he is my full time carer so we are totally reliant on the TT money and benefits.” (Survey Respondent 66)*

Just a handful of people said that because their partners had well paid full time jobs, they were less reliant on the income from the Trust and one person said that the Health Grant had actually enabled them to start working part-time.

Many people also gave quite detailed information about their health problems/disabilities, the deterioration they were experiencing and their concerns for the future. This information has been used to supplement the data from the in-depth interviews, and is briefly described in Chapters 4 and 5.

## Chapter 4

### Thalidomide Related Health Problems

The general comments people added to the Health Related Quality of Life and Employment survey, although brief, suggest that many Beneficiaries have growing concerns about their health. These comments build on information being gathered by HealthLink (the Thalidomide Trust's health and wellbeing advice service) and evidence from the Health Grant Evaluation<sup>14 15</sup>. In particular, of the 58 people who added comments, 21 specifically mentioned increasing pain and 17 highlighted reduced function, flexibility and/or mobility. The in-depth interviews with 41 Beneficiaries provided an opportunity to explore further the Thalidomide-related health problems people were experiencing and examine how they were affecting peoples' daily lives. This chapter highlights the main problems discussed in the in-depth interviews.

#### 4.1 Reduced Flexibility and/or Mobility

Perhaps the most commonly reported health problem was reduced flexibility and/or mobility, in particular reduced ability to reach, stretch, and bend. The root cause of this varied but often appeared to be related to perceived deterioration in the spine or joints and muscular problems. Upper limb affected Beneficiaries commonly reported that their shoulders, elbows and wrists were affected, and a number of those who used their feet to perform everyday tasks reported problems with their hips and knees. For many, reduced manual dexterity and declining strength/grip in the arms and hands was also a concern.

Lower limb affected Beneficiaries also reported problems with their shoulders, often linked to overuse from pushing manual wheelchairs and transferring to/from chair to chair, but also deterioration in their spines. Several said that they now had to use an electric wheelchair at least some of the time, or had to have someone to push their manual wheelchair. A small number of Beneficiaries explained that they had used prosthetic legs for much of their lives but in recent years had taken the decision to use a wheelchair. This was because they were finding it increasingly difficult to walk on their prosthetic limbs and/or had recurrent infections in their stumps.

A number of the Beneficiaries interviewed said that they were no longer able to walk as far as they could just a few years ago, and some were now using mobility scooters for longer distances. Others had had falls which had led to a loss of confidence. As one Beneficiary explained:

*"I'm losing function and confidence in walking and getting about, having been such a powerful walker all my life I never expected to have this kind of problem. My legs have always been my powerhouse – it's quite alarming".*  
(Study Group ID 105)

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<sup>14</sup> Newbronner et al (2012). *Looking to the Future: Evaluation of the Health Grant to Thalidomide-impaired People*. Firefly Research & Evaluation, York.

<sup>15</sup> Newbronner E, Borthwick R, Chamberlain R and Baxter M (2013). *A Securer Future - Evaluation of the Health Grant to Thalidomide-affected People*. Firefly Research & Evaluation, York.

Many interviewees reported facing difficult decisions about treatment (e.g. surgery to replace joints or fuse bones), whilst others were struggling to get a reliable diagnosis and clear treatment options. Some were reluctant to seek conventional medical help because of bad experiences in the past or a fear that any intervention might simply make their situation worse.

## 4.2 Pain and Stiffness

For many of the interviewees, reduced flexibility was closely linked to increasing pain - either more severe pain or pain in more areas of the body or pain being more continuous. One Beneficiary described the change in her pain levels:

*“Well the pain situation I feel has got slightly worse. Whereas in the past I used to get respite from it – it would flare up every few weeks and then would go away and I would be well for a while – I would say over the last 8 months or so, I’m not getting any respite from the pain.”* (Study Group ID 119)

Explanations of the causes of peoples’ pain varied and were often multiple, including arthritis, joint deterioration, trapped nerves and muscle strain/spasm. However, almost all interviewees said that their pain was made worse by everyday tasks such as using a computer keyboard and mouse, driving, housework etc.

Again many people were having to make difficult choices about how best to manage their pain. Some were making significant use of prescription pain killers but were concerned about both the short term effect of them (e.g. drowsiness, reduced ability to think clearly) and the long term implication (e.g. stomach problems, escalating strength of the drugs). Others were reluctant to use prescription painkillers, either because of a general distrust of prescribed medicines or a sense that they wanted to keep these stronger painkillers ‘in reserve’ in case their pain got worse at a later point. A few had had pain relieving injections, but often the frequency with which these could be given was insufficient to really keep on top of the pain. Others had had surgical procedures to relieve pain and talked about the consequences of that decision. They reported both positive and negative outcomes but a common theme was the trade-off between relieving pain and some loss of movement. One Beneficiary who has had several operations on his arms and shoulders to relieve severe pain said:

*“It has taken the pain away but there’s things now that I can’t do – a lot of things I can’t do now with my arms – but I knew that would happen but I didn’t want the pain”.* (Study Group ID 112)

## 4.3 Tingling, Numbness and Heat/Cold

Around two thirds of the interviewees reported experiencing sensations such as numbness, tingling, and pins and needles. A few said that at times areas of their bodies felt very cold or very hot. For several of the women in the group this was complicated by the effects of the menopause. Many Beneficiaries said that these sensations did not substantially affect their day to day lives but for others they had a

significant impact, affecting peoples' sleep patterns, their ability to drive, to walk, and to pick things up.

*"The other thing I've noticed, which is quite scary is my grip – my fingers – they don't – they've sort of got more numb at the ends and I drop things a lot more".* (Study Group ID 115)

A few people said that, to some degree they had had these sensations most of their lives but most said that they were a relatively recent phenomenon (i.e. developing over the last five to ten years) and a number felt that they were getting worse. Some did have a medical explanation for these sensations, the most common being 'a trapped nerve' or 'nerve damage' or more specifically carpal tunnel syndrome. A few people suggested that they might be generally related to the effect of Thalidomide on their bodies.

#### 4.4 Mental and Emotional Health

The mental and emotional health issues raised by the in-depth interviewees fell into three broad areas. A small number of people said that over the years they had experienced periods of depression or low mood. However, the increase in the Annual Grant and the introduction of the Health Grant had substantially reduced their financial worries and improved their quality of life, which in turn had led to better mental health. Several Beneficiaries, particularly those in the lower impairment bands (i.e. bands 1, 2 and 3), said that the decline they felt was occurring in their day to day functioning and the associated loss of independence was affecting their emotional health. Some talked about "*frustration*" or "*feeling irritable*" whereas others felt "*low*" or "*anxious*". Again the menopause was a complicating factor for a number of the women in the group. The following quotes illustrate this. The first is from a Band 1 Beneficiary who had been very active all her life but who now has severe back problems arising from the way she has had to use her body. The second is from a Band 3 Beneficiary:

*"I've been much more angry and frustrated over the last two years. Its [back problems] really curtailed what I've been able to do. When I was younger I was fine. I was fit. I could do everything. I didn't need any help. Even just thinking into the future and thinking well maybe in 10 years' time when I'm 63 I'll be like a bloomin' 80 year old and I will need help. That makes me angry."* (Study Group ID 130)

*"It depresses you because you realise what you can't do now. I wouldn't go out shopping on my own because of the simple fact that I can't lift and I'd be scared of falling because of my leg."* (Study Group ID 107)

There was also a third small group of Beneficiaries, again generally those less severely affected by Thalidomide, for whom the emotional impact of a more recent decline in health or functioning was layered on top of more long standing emotional issues, often related to their impairments or to the impact of Thalidomide on their wider family (e.g. the emotional problems experienced by their mothers, difficult sibling relationships). Some people had sought counselling to help them deal with these problems.

## 4.5 Other Health and Wellbeing Issues

The interviews highlighted a number of other health and general well-being issues, in particular increasing tiredness, sight, dental and hearing problems, and weight management.

**Tiredness and Lack of Energy** - A general sense of having less energy or getting tired more quickly was a common theme within the interview group. Whilst people acknowledge that this might be something that most people experience as they get into their 50s, there was a strong view that it was more extreme for Thalidomide-affected people.

*“I know you’re slowing down in your 50’s anyway but I just feel it’s coming a bit too early. I’ve got three sisters all about the same age and they are able to do far more than I am. I think that’s the best comparison because obviously we were brought up in the same household, the same genetics, and they are much more able”.* (Study Group ID 102)

For many, this lack of energy was one of the main reasons for giving up work or reducing working hours.

**Sight, Dental and Hearing Problems** - Many Thalidomide-affected people use their teeth as an ‘extra hand’, to grip and hold things. Most of the interviewees who did this reported that they had damaged their teeth as a result. This was an on-going problem and many had had to have significant dental treatment, including in-plants and metal rods inserted into their teeth. Others found it difficult to clean their teeth thoroughly and so needed to see a dental hygienist regularly.

Three members of the study group have a visual impairment and two reported that their sight was deteriorating, which had led to falls and further limitations on the things they could do on a day to day basis. Two people had a hearing impairment but these were unchanged. Other reported having to have regular if minor treatment for narrow Eustachian Tubes.

**Weight Management** - Weight loss and weight management was an issue for a number of interviewees. Being overweight exacerbated other problems such as reduced flexibility and pain but, as with the general population, it had implications for other conditions such as diabetes and asthma. Study group members were often taking very active steps to reduce or manage their weight (ranging from gastric bands, to buying special meals, to very structured diet and exercise regimens) but this was often challenging, and costly in both money and time, and many reported that they lacked access to good advice about weight management and fitness.

## 4.6 Impact of Health Problems and Impairments

There was a strong sense that compared to the final year of the Health Grant Evaluation, more Beneficiaries were reporting a decline in their independence, as a result of the health problems they were experiencing. In particular, losing the ability to undertake everyday personal care tasks (e.g. dressing, using the toilet, washing hair, preparing and cutting up food etc.) was a major concern. It affected peoples’ identity and self-esteem; it limited their lives; and it had an impact on their family members. It



also had financial implications in terms of buying in help, topping up Personal Budgets, buying pre-prepared foods, or paying for services (e.g. a weekly hair wash at the hairdressers). As is noted in the next section, many more people were also buying in help to maintain homes (e.g. cleaning, gardening, decorating etc.).

*“It is limiting. It limits in the sense of things taking longer to do but its limiting in the sense that actually ‘I really can’t do this now’ – I’ve got to get somebody to help me out with it or stop completely.”* (Study Group ID 141)

As in the survey, a number of interviewees reported either giving up work or reducing their working hours because of health problem. Some could physically no longer do their jobs and had been given ill-health retirement or taken voluntary redundancy.

*“Partly depression – not depression – but I’d just had enough....I just couldn’t cope anymore. I’ve been working since I was 16 and the aches and pains had just got to the point where I couldn’t cope.”* (Study Group ID 127)

Others found that they no longer had the energy to work full time or felt that continuing to work was damaging their health. Conversely, people also talked about the improvement in their health and general well-being once they had given up work or changed their working hours. A few said that they wanted to continue working, at least part time as they enjoyed the stimulation and social contact that work gave them, and/or they needed to work financially.

Not surprisingly many people talked about the impact of their changing health on their families. There was concern about the burden being placed on partners and children. A few people said that their partners had given up work to look after the home and/or provide support to them. Several interviewees were supporting aging parents, and a few had a parent or parent-in-law living with them. Whilst people of a similar age in the general population are facing the same issue, there was a sense that the situation is often more difficult and more complex for Thalidomide-affected people:

*“I think mentally I’ve been under of lot of stress because of my parents for more than two years....I suppose what I’ve had is mental strain and I do wonder if that is a bit linked to my disability – feeling less able to cope sometimes than other people – I don’t know.”* (Study Group ID 106)

Further analysis of the interview will be undertaken in early 2015. It will be used to inform the next stage of the monitoring project, as well as supporting wider work within the Trust.

## Chapter 5

### Ten Year Health Grant – Current Use and Future Issues

Overall, whilst people continued to see their Health Grants as a fund to be used for their health and well-being, in practical terms it was increasingly part of their household income, and few people were managing it as a separate ‘pot’ of money. The 41 in depth interviewees were asked specifically about the main ways in which they had used their 2013/14 Health Grants (although many people also talked more broadly about their use of the Health Grant since its introduction). This is discussed further below. Both the survey and the interviews also gave Beneficiaries an opportunity to reflect on future health and well-being issues and how they might use their Health Grants to address these. The issues and concerns raised are briefly discussed at the end of the chapter.

#### 5.1 Use of the New Health Grant

People used their Health Grants in a wide variety of ways but there were seven broad areas of expenditure:

##### **Self-management of Health Problems**

The majority of the 41 in depth interviewees were using some part of their Health Grant to self-manage their health problems but how they did this varied. People were commonly funding therapies such as remedial, sports and general physiotherapy and/or massage to get relief from pain and stiffness and/or using complementary medicine, in particular acupuncture, chiropractic and osteopathy to treat or manage specific problems. Several people were paying for gym membership including advice from a personal trainer, or fitness training at home, and a number paid for regular yoga and Pilates sessions to maintain or improve their core strength and flexibility.

*“I’ve got on-going issues with my neck and upper spine....It results in a lot of muscular pain and like spasms. I do receive regular sort of fortnightly massage to help keep on top of that....if the pain isn’t sorted out with the massage I ask to be referred over to see one of the physios”. (Study Group ID 128)*

##### **Private Health and Dental Care**

A few interviewees had used their Health Grant to take out private health insurance or to pay directly for private health care treatment.

*“I’ve paid for two lots of private treatment to try and improve my health. This included surgery, physio and consultation.” (Study Group ID 151)*

Others saw the Health Grant as a ‘safety net’ if they had to pay for private treatment in the future. Many upper-limb affected Beneficiaries were also paying for additional dental treatment and regular care from a dental hygienist. The use of private physiotherapy also appeared to be increasing, as people chose not to use NHS physiotherapy, which is largely short term in nature and waiting times to be seen can be long. A number of Beneficiaries had found good private physiotherapist and either

used their Health Grants to pay for regularly treatment or were able to fund treatment if a problem flared up.

### **Off-setting Loss of Income/Higher Costs of Living**

It was very evident from the interviews that many Beneficiaries (almost half the interviewees) were using their Health Grants to off-set the income lost from reducing their working hours or giving up work completely. In-effect, the Health Grant had enabled them to make active decisions about their working lives, often with the aim of preserving their health and functioning for as long as possible. A Beneficiary who was struggling with both his job and commuting to work explained his situation:

*“So basically I thought to myself, well, I don’t want to put any more strain on my right leg. So I tried to stay [at work] but made the decision to give up on the basis that I just didn’t want to damage myself any more.... The Health Grant did kind of sway my decision because it boosted my income.”* (Study Group ID 131)

More generally, the Health Grant was helping people with the higher costs of living that their impairments created. These included paying for things like supermarket home deliveries and having their PA there to help unpack; having to buy more prepared foods or smaller packets; getting clothing altered because they could no longer do it themselves; and having to pay more for items such as beds and furniture in order to get what they needed.

### **Home Maintenance and Adaptations**

Whilst some people said that in the first three years of the Health Grant they had been able to do the major adaptation they had most needed, others said their houses still needed further adaptations and/or things that they had done over the past ten years now needed ‘up-grading’. Funding these often took up a significant proportion of their Health Grant in any one year or involved saving for more than one year.

Many people were also using their Health Grants to pay for more minor but important adaptations and improvements. The things people commonly mentioned were installing (or replacing old) Clos-o-Mat or similar toilets; replacing windows, doors and locks with ones that were easier to open; changing domestic appliances and/or repositioning them to make them more accessible; and improving heating systems and insulation to make their houses warmer. For example:

*“I tend to make one or two major house adaptations in the financial year. In this last year I took out all the secondary double glazing in the house and put in regular windows. They are all accessible for me now. It’s quite a rare blessing to be able to open a window”.* (Study Group ID 108)

The other major theme was the increasing need to pay for home maintenance tasks that people can no longer do themselves. This ranged over things like changing light bulbs and putting up shelves, to decorating and gardening.

### **Mobility**

The Health Grant was also important in helping people to maintain their mobility. In relation to driving, a few people (notably those in the impairment bands 1 and 2) who had driven ordinary automatic cars all their lives now found that they needed an adapted car if they were to continue driving comfortably and safely. Others needed

cars with more, and more costly, adaptations (e.g. moving from hand to foot steering). One Beneficiary explained:

*“I’ve got a car. It’s ok but for the next one I’ll go for one with a higher roof [to accommodate a wheelchair]. At the moment what I do is I get in the back and haul my chair in but I won’t be able to do that for the rest of my life”. (Study Group ID 104)*

The interviews suggest that without the Health Grant many Beneficiaries would struggle financially to maintain and replace their cars, and even with it, several people said that they were saving to replace cars that were now ten or more years old.

As was noted earlier, several people also talked about now needing to use an electric wheelchair, at least some of the time. Again many people were using their Health Grants to buy and maintain their wheelchairs, including buying spare wheelchairs and lightweight ones for traveling.

### **Domestic Help and Personal Care**

Almost two thirds of the interviewees were using their Health Grants to pay for regular domestic help because they were finding household tasks more difficult and tiring, or in some cases they simply could not do them anymore. Most commonly, people were buying help with cleaning, washing and ironing and gardening. As one Beneficiary put it:

*“Help in the house is the big one. I’ve got more help in, more time with the cleaner. I have a gardener who comes every fortnight and a man who puts my wheelie bins out and rakes my drive.... That’s made a big difference, a very big difference pain level wise”. (Study Group ID 118)*

Most interviewees who received funding for personal care from Social Services were using their Health Grants to top up their Personal Budgets or Direct Payments (to some degree), to create more flexibility or to give them more support at critical times (e.g. if they felt unwell). Those who currently had an Independent Living Fund award were concerned about its abolition in 2015 as they doubted that all the hours of support it funded would be picked up by their local social services department.

The other small but important area of ‘personal care’ which the women in particular in the group used their Health Grants for, was personal grooming, ranging from having their hair washed at the hairdressers every week, to having a manicure or eyebrow shape – all things they were unable to do themselves but which were important for their general well-being.

### **Holidays and Social Activities**

Many interviewees used some of their Health Grants for holidays, short breaks and social activities. For some people it had enabled them to afford the type of holiday that they could manage with their impairments (e.g. cruises which did not involve flying) or which gave them privacy (e.g. self-contained villa). The benefits of sun and warmth during the winter were also a common theme. Others said that they were using their Health Grants to meet the higher costs of social activities (e.g. having to use taxis, PA time, staying overnight rather than travelling in one day).

## 5.2 Future Issues and Concerns

The comments added to the Health Related Quality of Life and Employment survey revealed that many people have significant worries about the future. Although care needs to be taken in the interpretation of the comments, as it is hard to judge how representative they are of the Thalidomide community as a whole, they suggest that people were concerned that their ability to work was declining at the same time as the cost of managing or coping with their Thalidomide-related health problems and disabilities was increasing. As two Beneficiaries put it:

*“I can’t believe the rate of decline in health since I retired. Thank god for the Health Grant. Pain is a major issue with me but there are now lots of other issues regarding deterioration in heath and joints....I’ve been medically retired and subsidising my pension heavily with my Trust income....because of the rate of deterioration I don’t think the Health Grant will be sufficient in years to come.”* (Survey Respondent 71)

*“Even with the ten year Government settlement [Health Grant] I worry for the future. As we reach our 60’s the risk that our income dips hugely when our needs will be further increased causes tension and anxiety.”* (Survey Respondent 9)

Linked to this was a sense that, despite the current Health Grant being confirmed for ten years, people have growing worries about how they will cope in the future, not just financially but also emotionally. In their comments, a number of people said that they had or were suffering from depression, whilst others talked about feeling emotional or frightened about the future. Two quotes illustrate this very powerfully:

*“I feel my physical health, my back, hips, knees and numbness in my hand and fingers is deteriorating rapidly year by year. This is very frightening and I fear for the future even though I am a very optimistic person.”* (Survey Respondent 52)

*“The older I get the more emotional I am and feel more and more inadequate due to being physically less able, and having to rely on others to do even the most basic of tasks really gets me down.... I now have to use a straw to drink because I can’t pick the cup up to my mouth. My neck, back, hips, collarbone, arms, knees are all giving me pain at some point in the day. I hate myself for putting on others and hate struggling all the time.”* (Survey Respondent 44)

The in depth interviews provided an opportunity to explore these issues in more depth. Perhaps not surprisingly (and as the quote above shows) one of the biggest concerns was that further deterioration in health and functioning would lead to increased dependence on family, paid care workers and/or equipment. A few noted that the combination of Thalidomide-affected peoples’ original impairments and those of old age would lead to many people having quite complex needs. However, they also felt that there was still time to develop specialist equipment and to build up sources of information and advice.

As was noted in the final Health Grant Evaluation report<sup>16</sup> there were also general concerns about changing family circumstances, in particular the wish to support ageing parent and adult children leaving home (and the loss of the help that both had previously provided). Several noted that their partners were a major source of help and support and they were worried that if their health declined they would not be able to do as much in the future.

A number of in depth interviewees were thinking about moving to a more manageable property but the cost of both buying and adapting a new home was a concern. Others felt they were unlikely to move because over the years they had adapted the current home to suit their needs, and/or they were reluctant to move away from the social networks they had established in their neighbourhood.

It was striking that despite the Health Grant being confirmed for ten years, people had real worries about the future, and in particular the fact that at the same time as the cost of living with their Thalidomide-related health problems and disabilities was increasing, their ability to work was declining.

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<sup>16</sup> Newbronner E, Borthwick R, Chamberlain R and Baxter M (2013). *A Securer Future - Evaluation of the Health Grant to Thalidomide-affected People*. Firefly Research & Evaluation, York.

## Chapter 6

### Conclusions

This research has been able to build on earlier work carried out or commissioned by the Trust and the NAC, to provide a fuller picture of the health and financial circumstances of Thalidomide-affected people in the UK. In particular, it suggests that trends identified in the evaluation of the original three year pilot Health Grant are continuing, notably the deterioration in peoples' health, their declining ability to work (or work full-time), and the use of the Health Grant to help deal with these two major issues.

The survey of all UK Thalidomide Trust Beneficiaries showed the extent to which Beneficiaries feel their health related quality of life is being affected by the changes they are experiencing in their health and/or disabilities as they grow older. In particular, it highlights the fact that Thalidomide-affected people have significantly poorer physical health than their peers in the general population. Their scores for Physical Functioning and Pain were particularly low. The comments people added to their survey forms and the reflections provided by the in-depth interviewees, reinforced the sense that Thalidomide-affected people feel their physical function is declining, and highlighted just how much pain, neuropathy and other wellbeing problems such as fatigue and weight gain, are affecting peoples' day to day lives.

Although the SF12 results suggest that the mental health of Thalidomide-affected people is only marginally worse than that of the general population, there is clearly a group of Beneficiaries who do experience very poor mental health. Although care needs to be taken in interpreting the comments from the survey, together with the study group interviews, the information provided suggests that a small but significant minority of Beneficiaries were either suffering from depression or felt emotionally low. The interviews in particular suggest that for a number of Beneficiaries in the lower impairment bands, the decline in their day to day functioning and the associated loss of independence was affecting their emotional health. For some this was layered on top of long standing emotional issues.

The employment questions included in the survey also provide a useful insight into people's changing work situations and the extent to which deterioration in their health and disabilities are affecting their ability to work. Half of those who responded to the survey said that they were unable to work because of their disability or health problems. There were also marked increases, around 2001 and 2010, in the (cumulative) number of Beneficiaries who reported changing their working situation because of their disability or health problems (i.e. stopped working; began working part-time or changed their job). Again the comments people added to their survey forms and the in depth interviews provided a real insight in to the work-related problems they were experiencing and the difficult decisions they were having to make about their working lives.

The survey also showed just how important the income people receive from the Trust is in enabling them to meet the cost of the managing or living with their disability and health problems. Even amongst the Beneficiaries who were working, their Annual and Health Grants often represented a significant proportion of their household income. Furthermore, the majority of people felt that their current household income only

partially enabled them to meet their thalidomide related disability and health needs. The in depth interviews showed how Beneficiaries were using their Health Grants in a wide range of ways, to manage their health problems, maintain their independence and preserve their quality of life. Whilst people raised the issue of the need for more adaptations, equipment and paid help coinciding with a decline in Beneficiaries capacity to work, they also stressed the huge difference the Health Grant had made to their lives and their sense of financial security. It was also clear that many people were looking forward positively – finding (or looking for) new relationships, keeping active, travelling and replacing paid work with interesting voluntary work. In many respects the Health Grant was enabling them to do this.



## Appendix A – 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 pilot three year Health Grant was 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 were intended to guide Thalidomiders in their expenditure. Seven categories of 'health-related needs' were set out in a guidance note: independent mobility; home adaptations; communications technology; medical treatment costs; respite; personal assistance; and social activities.

The Thalidomide Trust has a well-established and well-accepted system for distributing its Annual Grants to Beneficiaries, which is based on each person's level of impairment. 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. At that time, Beneficiaries were placed into one of five impairment severity bands, although people can move between bands if their impairments change (e.g. if previously undetected problems emerge). It was agreed that the three year Health Grant should be distributed on the same basis.

In early 2013, all four Departments of Health agreed to continue the Health Grant for another ten years. The new ten year Health Grant is distributed in the same way as the three year grant. In 2013/14 the Health Grants received by the Beneficiaries taking part in the in-depth interviews ranged from £10,461.60 to £45,769.50. The table below provides a more detailed picture.

**Table A1 Health Grant by Impairment Band for the Beneficiaries involved in the in-depth interviews**

<b>For Band:</b>	Band 1	Band 2	Band 3	Band 4	Band 5
<b>Max</b>	£11,442.38	£18,307.80	£25,173.23	£31,005.57	£45,769.50
<b>Min</b>	£10,461.60	£15,692.40	£19,615.50	£26,154.00	£32,692.50
<b>Average</b>	£11,115.45	£17,000.10	£22,884.75	£28,154.78	£36,437.10

## Appendix B – Health Related Quality of Life Survey



### **Ten Year Health Grant Monitoring Project Health Related Quality of Life Questionnaire**

Dear Beneficiary

This questionnaire is part of the monitoring arrangements for the new ten year Health Grant. Every beneficiary is being asked to provide this information, which will be used by the Thalidomide Trust and the NAC to help present a case to the UK Departments of Health for the Health Grant to be renewed in 10 years-time.

#### **About the questionnaire**

There are two parts to the questionnaire. Part A looks at health related quality of life and asks for your views about your physical and emotional health. In particular, we are interested in how your general health and any Thalidomide-related health problems (as opposed to your original impairments), are affecting your ability to do things and/or how you are feeling. The questions are standard ones which are used all over the world and with lots of different groups of people, so you may find that the wording of some of the questions doesn't completely fit your situation. However, by using them it means we can compare the health-related quality of life of Thalidomide-impaired people, to people of a similar age in the general UK population.

Part B looks at whether people are able to meet the cost of living with Thalidomide-related disabilities and health problems, and whether they are affecting your ability to work. These questions have been designed by the NAC as they are particularly keen to understand how important the Health Grant is in enabling people to meet their changing health needs.

#### **Completing the questionnaire**

There are three ways to complete the questionnaire:

1. You can fill this paper copy and return it in the Freepost envelope to Firefly Research
2. You can go to <http://surveys.firefly-research.co.uk/s/97485FXTBT> and fill it in on-line
3. You can ring Liz Newbronner or Martin Baxter on 01653 691351 and answer the questions on the phone

The questionnaire is completely anonymous – there is no need to put your name on it (if you complete it by phone we will not put your name on it), so no one will know how you have answered the questions. However, when you have completed the questionnaire, it would be extremely helpful if you could let Sue or Louise at the Trust know (01480 474074 or [sue.brooks@thalidomidetrust.org](mailto:sue.brooks@thalidomidetrust.org)) so that we don't trouble you again if we send out reminders.

#### **More information**

If you have any questions about the questionnaire or the Health Grant monitoring project, please feel free to ring or email me on 01653 691351 / [liz@firefly-research.co.uk](mailto:liz@firefly-research.co.uk). Many thanks for helping us with this survey.

Liz Newbronner

**Part A - Health Related Quality of Life Questions**

For each of the following questions, please circle the word or phrase (in the unshaded boxes) that best describes how your health is now or how you are feeling now.

1) In general, would you say your health is:				
Excellent	Very good	Good	Fair	Poor
2) The following questions are about activities you might do during a typical day. Does <u>your health now limit</u> you in these activities? If so, how much?				
a. <u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner or light gardening				
Yes, limited a lot	Yes, limited little	No, not limited at all		
b. More strenuous activity such as carrying heavy shopping, washing the car or mowing the lawn.				
Yes, limited a lot	Yes, limited little	No, not limited at all		
3) During the <u>past 4 weeks</u> , how much of the time have you had any of the following problems with your work or other regular daily activities <u>as a result of your physical health</u> ?				
a. <u>Accomplished less</u> than you would like				
All of the time	Most of the time	Some of the time	A little of the time	None of the time
b. Were limited in the <u>kind</u> of work or other activities you are able to do				
All of the time	Most of the time	Some of the time	A little of the time	None of the time
4) During the <u>past 4 weeks</u> , how much of the time have you had any of the following problems with your work or other regular daily activities <u>as a result of any emotional problems</u> (such as feeling depressed or anxious)?				
a. <u>Accomplished less</u> than you would like				
All of the time	Most of the time	Some of the time	A little of the time	None of the time
b. Did work or activities <u>less carefully than usual</u>				
All of the time	Most of the time	Some of the time	A little of the time	None of the time

5) During the <u>past 4 weeks</u> , how much did <u>pain</u> interfere with your normal work (including both work outside the home and housework)?				
Not at all	A little bit	Moderately	Quite a bit	Extremely
6) These questions are about how you feel and how things have been with you <u>during the past 4 weeks</u> . For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the <u>past 4 weeks</u> ...				
a. Have you felt calm and peaceful?				
All of the time	Most of the time	Some of the time	A little of the time	None of the time
b. Did you have a lot of energy?				
All of the time	Most of the time	Some of the time	A little of the time	None of the time
c. Have you felt downhearted and depressed?				
All of the time	Most of the time	Some of the time	A little of the time	None of the time
7) During the <u>past 4 weeks</u> , how much of the time has your <u>physical health or emotional problems</u> interfered with your social activities (like meeting friends, visiting relatives etc.)?				
All of the time	Most of the time	Some of the time	A little of the time	None of the time

**Part B – The Cost of living with Thalidomide-related Disabilities and Health Problems**

1. Which of the following best describes your work situation?	Please tick one
I work full-time	<input type="checkbox"/>
I work part-time	<input type="checkbox"/>
I am unemployed but would like to work	<input type="checkbox"/>
I'm unable to work because of my disability or health problems	<input type="checkbox"/>
I've chosen not to work for family or personal reasons	<input type="checkbox"/>
Other/Comments	

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2. If you are currently working (full time or part time), do you:		Please tick									
Feel you have to work to maintain your standard of living?		Yes		No							
Feel that working is having a negative effect on your health?		Yes		No							
3. If you work part-time, have you:		Please tick									
a) Always worked part time because of your disability or health problems?		Yes		No							
b) Reduced your hours because of your disability or health problems?		Yes		No							
If you answered 'yes' to b), when did you reduce your hours of work?		Year:									
4. If you are not currently working, have you worked in the past? (please tick)		Yes		No							
If Yes, when did you stop working?		Year:									
5. Have you ever had to change your job or the type of work you do because of your disability or health problems? (please tick)		Yes		No							
If Yes, when did you change jobs/type of work?		Year:									
6. Approximately what proportion of your current household income comes from the Thalidomide Trust i.e. Annual Grant and Health Grant together? (please tick)											
Less than 20%											
Between 20% and 40%											
Between 40% and 60%											
Between 60% and 80%											
More than 80%											
7. Is your current household income enough to meet your thalidomide related disability and health needs i.e. for practical/personal assistance at home and away from home, equipment, home or car adaptations etc. (please circle)?											
I can't afford <i>any</i> of the things I need when I need them	1	2	3	4	5	6	7	8	9	10	I can afford <i>all</i> the things I need when I need them
8. Is there anything else you would like to tell us about your health or financial situation?											

## Appendix C – SF12 Detailed 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 Beneficiaries of the Thalidomide Trust living in the UK were invited to participate in the survey. 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 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’<sup>17</sup>, using the age group from that survey (45-54 year olds) which was closest to those of the Thalidomiders.

The Beneficiaries were also compared with a three other groups with conditions that might be expected to have similar implications for health related quality of life:

- 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
- A group of post stroke patients in the US (age 18-64)

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

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<sup>17</sup> Jenkinson C, Wright L, Coulter A. Quality of Life measurement in health care. A review of measures, and population norms for the UKSF-36. Oxford: Health Services Research Unit, 1993.

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, post stroke or Beneficiary groups to have a normal distribution.

Table 1 below shows the figures for each of the groups in the two main domains.

**Table 1 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 46.8	34.2	21.4	43.2	25.0
	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
Post stroke Patients		406	18-64	39.7	15	45.5	15
Beneficiaries	Aggregate	234		23.7	13.1	43.2	13.4

It is clear that the mean value of the aggregate physical health for the study group (23.7) is much lower than either the population average (50), MS comparison groups (34-50.4) or Post stroke patients (39.7) 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 most of 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 is identical to 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 6 (this also appears as Figure 1 in section 2). 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 mean 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 160 members of the study group (68%) have a physical health domain score below 30 i.e. outside the 96% normal range of the general population group, and only 15 have a score above the average for the 'average' group. The mental health scores are much higher with only 38 (16%) of the study group below the 96% range and 71 (30%) above the mean for the general population group.

Table 1 and Figure 6 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 6 Aggregate physical health and mental health for the study group**

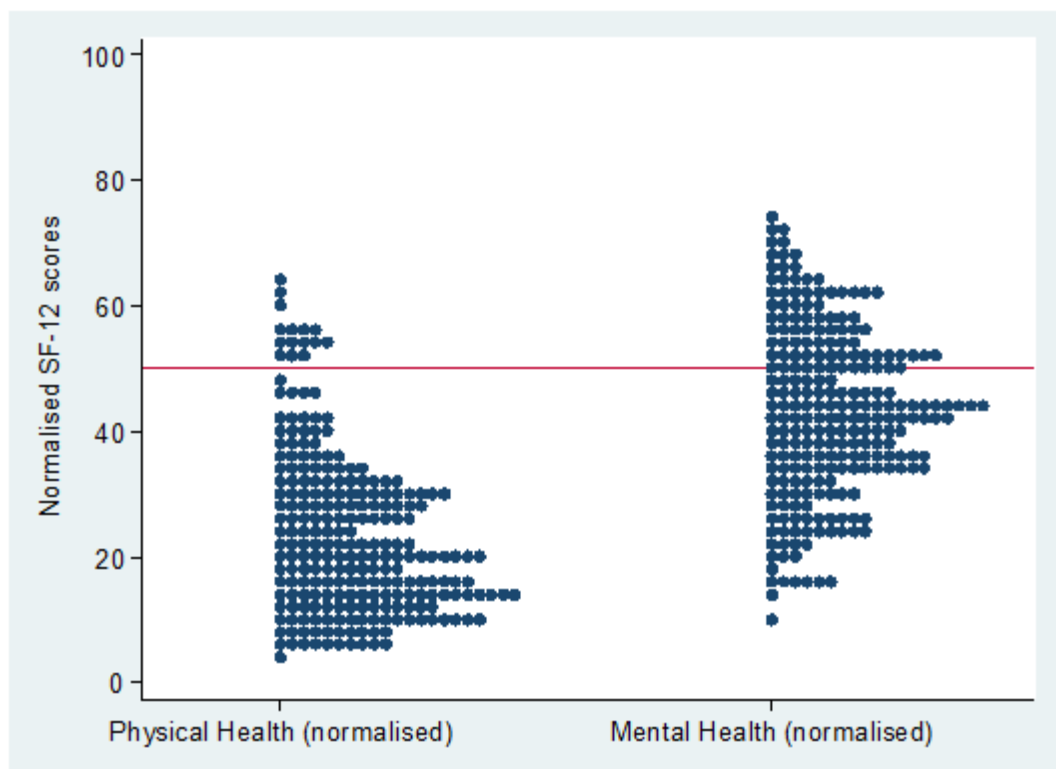


Table 2 shows the mean and standard deviation for each of the 8 sections in the survey. It clearly shows that all the physical domain scores for the study group are much lower than those of the general population group (mean 50), in particular those for physical functioning and pain, though the former has a very high sd indicating a



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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 2 SF12 normalised domain results for study group**

	Component	mean	sd	Min	Max
Physical domain	Physical Functioning (PF)	15.4	16.8	1.7	57.6
	Role Limitation Physical (RP)	33.9	8.7	21.9	55.0
	Pain (BP)	31.2	14.2	14.2	59.2
	General Health (GH)	31.8	13.1	13.7	63.7
Mental health domain	Vitality (VT)	38.0	11.4	21.3	68.2
	Role Limitation Emotional (RE)	41.0	9.3	23.7	55.3
	Social Functioning (SF)	29.9	16.3	2.0	55.5
	Mental Health (MH)	36.2	14.3	7.4	64.5



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