

The **Thalidomide** Trust

Changing Lives – The Health and Wellbeing of
Thalidomide Survivors in Middle Age

Conducted by Firefly Research & Evaluation

Final Report from the 2015 Health and Wellbeing Survey

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Thalidomide and The Thalidomide Trust

Thalidomide is a sedative that was created by the German pharmaceutical company, Chemie Grunenthal, in 1954. It was promoted as a safe treatment for a range of conditions including headaches, insomnia and morning sickness in pregnant women. However, the drug caused serious damage to unborn babies when women who took it during the first three months of their pregnancy. The range of impairments caused by Thalidomide include shortening and absence of limbs, malformation of hands and digits, damage to ears and eyes, sensory impairment, facial disfigurement/palsy and damage to the brain, internal organs and skeletal structure.

The Thalidomide Trust was established in 1973 – originally as the Thalidomide Children’s Trust – as part of a legal settlement between Distillers Company Ltd and the disabled children whose mothers took Thalidomide (distributed in the UK under the brand name Distaval) during their pregnancy. It is a registered charity, which provides information, advocacy and advice on health and broader wellbeing issues to support its beneficiaries in maximising their health, independence and quality of life. Since 1973, the Thalidomide Trust has accepted 531 people as beneficiaries, though sadly 65 of them have since died. Currently the Trust supports 466 beneficiaries (467 at the time of the survey), aged between 51 and 57 years old.

The Thalidomide Trust is responsible for administering two funds - the annual compensation payments funded by Diageo (the company formed by a merger between Grand Metropolitan and Guinness - who took over Distillers in 1990) and the Health Grants funded by the four UK Health Departments. The distribution of both funds is based on the original damage cause by the drug. Each beneficiary has been assessed and given ‘points’ according to the severity of their impairment. The total number of points is referred to as their 6(iv) b figure and ranges from 3.5 to 75. The Trust groups these points into five impairment Bands: 0-19.5 points, Band 1; 20-29.5 points, Band 2; 30-39.5 points Band 3; 40-49.5 points, Band 4; and 50+ points, Band 5, with beneficiaries in Band 5 having the most severe impairments. Where appropriate, these bandings have been used in the analysis of the survey data.

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Foreword

This challenging report on the health and well-being of the thalidomide survivors in middle age only too clearly confirms that the deterioration in the health of the beneficiaries of the Thalidomide Trust, continues apace.

The survey upon which this 2016 report is based received a 75% response from the beneficiaries, thereby providing the Trust with a comprehensive picture of their health and well-being. It makes depressing reading.

Ninety three percent of the beneficiaries surveyed report musculoskeletal problems, particularly pain or loss of movement in their backs or shoulders or hands. The need for joint replacement has increased. These increasing physical problems frequently lead to pain; nearly half of all beneficiaries surveyed experienced pain on a regular basis

Progressive loss of function accompanied by disabling pain have also led to mental health problems, including depression and anxiety. Around a half of beneficiaries surveyed suffer from mental health problems compared with approximately a fifth of the general population. It is noteworthy that when those who have been able to work, become unable to do so, they suffer from poorer mental health. Some describe themselves as the 'newly disabled'. More than half of the respondents said that their emotional well-being was worse or much worse than it had been five years earlier.

These increasing physical and mental health problems affect daily lives: expensive adaptations are required for their homes when mobility and dexterity are decreased, some will have to move home; more cars have to be adapted; greater assistance in the home and more personal care is required; and life generally becomes more difficult. Many of those in work have had to give up employment or change jobs or reduce their hours. Our beneficiaries are only half as likely to be in full or part time work compared with the general population in their age group. It is probable that more beneficiaries will have to cease work in the next few years because of increasing disability.

It was a common view amongst the beneficiaries surveyed that their current way of life was vulnerable if not precarious. Some have lost confidence in their ability to cope with their increasing disability. They need more support, yet find access to knowledgeable health professionals difficult to obtain; they are making greater demands on their families at a time when changing family circumstances pose their own burden; they are worried about being unable to continue in work, and they are worried about further physical deterioration, reduced mobility, and pain. The resilience which has enabled many beneficiaries to overcome the grave disabilities they have faced, requiring them to deal with work and life at the upper limits of their energy and mental and physical strength at all times, can no longer be so readily called upon. It appears that some are beginning to doubt their ability to continue striving at the limit of their powers.

Sir Robert Nelson
Chair of Trustees

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Executive Summary

The report presents the results of the first health and wellbeing survey of the Thalidomide Trust's beneficiaries. The survey was sent to all 467 beneficiaries and the 75% who responded were highly representative of the beneficiary community as a whole. The overall aim of the survey was to provide the Trust with a comprehensive picture of the health and wellbeing of beneficiaries, which can inform its work going forward.

1. Self-Reported Health Problems

Beneficiaries were asked to record the health problems they were currently experiencing or had recently experienced.

Musculoskeletal problems:

- 93% of respondents were experiencing pain and/or loss of movement in one or more joint, with back problems being most commonly reported, closely followed by shoulder pain/loss of movement and problems with hands.
- Many respondents reported multiple musculoskeletal problems, with the mean number of problems being 4.5; over half of all respondents reported five or more problems.
- Beneficiaries with severe or moderate upper limb damage and those with upper and lower limb damage reported marginally more problems.

Generalised pain, neuropathy, fatigue and balance

- Nearly half the respondents said they had generalised pain, with 92 (26%) describing it as 'severe and/or continuous' and a further 81 (23%) as 'moderate and/or intermittent'. Respondents in Bands 5 were the most likely and those in band 2 the least likely to report experiencing generalised pain.
- 66% of respondents reported experiencing neurological symptoms, with tingling/pins and needles being the most common symptom
- 40% of respondents also said that they experienced severe tiredness/fatigue and nearly a third said they had problems with balance/falls
- The proportion of beneficiaries reporting fatigue was higher in impairment Bands 1 and 2, and balance was a particular issue for beneficiaries in Bands 3 and 4.

Mental health

- Half of all respondents said that they were currently experiencing or had recently experienced depression and/or anxiety.

- This prevalence rate is much higher than in the general population – the Mental Health Foundation estimates that each year 20% of adults aged between 50 and 54 experience a common mental health problem.
- The prevalence of mental health problems amongst beneficiaries is very similar to that reported in a 2015 German study of the health problems of 202 Thalidomide survivors (conducted for the Federal Health Centre North Rhine Westphalia, Cologne), which used face-to-face psychiatric assessment.

Hearing, sight, dental problems and other health problems

- 43% (150) respondents said they had deteriorating sight/eye problems and 38% (133) deteriorating hearing/other ear problems.
- Just over a third (120/34%) of beneficiaries reported dental health problems.
- Beneficiaries reported a range of other health problems, all of which are experienced by people in the general population. The prevalence rates reported by beneficiaries for some conditions (e.g. diabetes and stroke) appear to be similar or lower than the general population whilst for others (e.g. asthma/breathing problems and kidney problems) they appear to be higher.
- A high proportion of beneficiaries were experiencing multiple health problems with almost half (46%) were reporting between four and nine health problems.

2. Use of Health and Social Care Services

The survey provided an opportunity to examine how beneficiaries are using health and social care services, and to look more closely at whether beneficiaries were encountering problems with access to services or the quality of services.

Use of health services (in the past ten years):

- Physiotherapy and/or complementary therapies were the most commonly used treatments, with over two thirds of beneficiaries reporting using these.
- Overall, 17% of respondents said they had undergone joint or back surgery – 6% had undergone a hip replacement/hip surgery and 4% knee surgery in the last ten years, compared to 1% (for both procedures) for the general population aged 50 to 54.
- Half of the respondents said that they had either taken prescription pain medication and/or had received pain-relieving treatments in the past ten years; this was more common amongst beneficiaries in Bands 1 and 2.
- A quarter of beneficiaries had received treatment for anxiety and/or depression and a further 10% said they had received counselling for emotional issues.

Access to health services

Two thirds of beneficiaries said that (in the last five years) they had experienced one or more problems with the quality of and/or access to health services. Common problems included: a perceived lack of knowledge/understanding amongst health professionals of Thalidomide damage in general and/or specific impairments; difficulties/delays in seeing a suitably experienced health professional/specialist; and delays in getting treatment. We asked beneficiaries – ‘How well does your GP/GP surgery understand how your Thalidomide damage affects you?’ and over half said that their GP fully understood or partly understood. In addition, almost half thought that if they had a Thalidomide-related health problem their GP would be willing to seek advice from a specialist with knowledge of Thalidomide damage and/or from the Trust.

Use of social care services

Sixty-six beneficiaries (19%) were receiving local authority funded social care, with those living alone more likely to receive it. Of the beneficiaries getting local authority funded social care, just over half said the level of support they were getting was enough to meet their needs. However, almost two thirds of this group were paying for additional time or services from their own income, and three quarters thought they would need more support in the next five years. Of those not receiving local authority funded social care, almost two thirds were buying help with domestic tasks and/or personal care privately.

3. Health Related Quality of Life and Mental Wellbeing

To assess health related quality of life and mental wellbeing we used two validated questionnaires – SF12 Health Related Quality of Life questionnaire and the Warwick Edinburgh Mental Wellbeing Scale (WEMWBS) - and two bespoke questions. The SF12 results suggest that:

- Beneficiaries experience significantly poorer physical health related quality of life compared to the general population of a similar age; their mental health related quality of life is also worse, but the difference is far less marked.
- There was a strong correlation between poorer physical health related quality of life and higher levels of impairment.
- Beneficiaries with lower impairment levels, who said they were unable to work because of their disability or health problems, had poorer mental health related quality of life.

The WEMWBS results showed that beneficiaries had a lower mean score (43.6) than both the national mean for England of 50 and for Scotland of 48.7, for those aged 45 to 54. Lower wellbeing scores (i.e. the bottom 40% of beneficiaries) also appeared to be associated with living alone or with a family member (i.e. parent or sibling, not spouse or spouse and children).

Over half the respondents said their emotional wellbeing was worse or much worse than it was five years ago. Well over half said that their social life was good and they never or only occasionally felt lonely but there was a group (56/16%) who reported feeling lonely or isolated much of the time. Beneficiaries in this group were more likely to live alone and be unable to work because of their disability or health problems.

4. Housing, Adaptation and Mobility

The majority of beneficiaries (304/87%) owned their own house or flat, a higher proportion than the general UK population aged 50 to 64 (75%). Almost a third were planning adaptations to their home in the next year but a number of respondents (42/12%) said they could not afford to do so. Over 40% of respondents (143) anticipated that they would need to move house in the next five years, the most common reasons being that they needed a home with no stairs; needed a home that was fully adapted for their disability/health problems; and/or they needed a smaller house/garden. Beneficiaries in band 4 were most likely to give needing a home with no stairs as a reason for anticipating moving house.

Nearly half of the respondents (163) said that they had a car or van with adaptations. Several of those currently driving cars with no or minor adaptations said they anticipated needing (more) adaptations in the future. With regard to wheelchairs, 38 beneficiaries (10%) said that they used an electric wheelchair some or all of the time and 61 (18%) used a manual wheelchair some or all of the time (25 used both). Thirty-six respondents (10%) used prosthetic limbs some or all of the time and 73 beneficiaries (21%) used a hearing aid or aids and/or had hearing implants.

5. Work and Pensions

There is some evidence that, over the past decade, the work situation of beneficiaries has been changing more rapidly than might be expected for people of a similar age in the general population. Overall, 59% (208) of respondents said that their work situation had changed since 2000 – almost two thirds of these (130) had stopped working and the remainder had either changed jobs or reduced their working hours.

Just 37% of beneficiaries were working (full or part time) compared to 82% of the general population aged 50 to 54. The biggest group was those who were unable to work because of their disability or health problems (145/41%). Of those beneficiaries who were working full or part-time, over three quarters (118) thought that their Thalidomide-related disability/health problems would require them to change their work situation in the next five years, and of these 51 thought that they might have to stop working. Together, these findings suggest that many beneficiaries are facing difficult decisions about their working lives.

Thirty nine percent of respondents (137) said that they had contributed to a private or employers' pension.

6. Concerns for the Future

The survey had one question about future concerns but many respondents also added further comments, which reflected their concerns for the future. Physical health was the major area of concern for the vast majority of beneficiaries, including deterioration in general health; specific health problems; the implications of declining health for independence and family relationships; and wider fears about coping and loss of identity or self-esteem.

Mobility, personal assistance/help in the home and emotional health were the next three main areas of concern. In particular, deterioration in physical health and loss of independence were, for many beneficiaries, intertwined with their emotional health. Finally, whilst respondents' comments highlighted specific concerns for the future, running through many of them was a common thread, namely a sense that their current way of life was vulnerable, even precarious.

7. Conclusions

Overall, the results of the survey suggest that as Thalidomide survivors reach middle age, a number of factors are converging to adversely affect their wellbeing. A combination of (often multiple) physical and mental health problems, inadequate access to knowledgeable health professionals, the need for more practical and personal support, changing family circumstances, and a decline in the ability to work, are creating new challenges for beneficiaries. However, the area of life beneficiaries are most concerned about when they look ahead is their physical health.

Chapter 1

Introduction

This report presents the results of the first health and wellbeing survey of all the UK Thalidomide Trust’s beneficiaries. The survey was sent to all beneficiaries, including those living abroad and those who have a family member or guardian to act on their behalf. The response to the survey was excellent, with 75% of beneficiaries returning questionnaires. Moreover, the beneficiaries who responded to the survey were highly representative of the beneficiary community as a whole.

The survey was intended to build on previous work commissioned by the Trust, in particular the evaluation and monitoring of the Health Grant (see section 1.2 below). Its overall aim was to provide the Trust with a more comprehensive picture of the health and wellbeing of beneficiaries. In particular, the Trust wanted to use the survey to:

- Quantify how many beneficiaries were experiencing different types of health problems.
- Examine in some depth beneficiaries’ mental and emotional wellbeing.
- Explore if/how beneficiaries’ health and wellbeing were related to the nature or severity of their Thalidomide damage or their personal circumstances.
- Gather supporting information about the circumstances of beneficiaries (e.g. housing and employment situations).

The Thalidomide Trust commissioned Firefly Research & Evaluation to carry out the survey and this report has been prepared by them. In the following chapters, we discuss the key findings from the survey. Where possible we have looked at the relationships between levels and types of Thalidomide impairment and health and wellbeing, and examined whether beneficiaries’ impairments or personal circumstances appeared to have any bearing on their responses. We have also, where appropriate, made comparisons with the general population in the UK, or with evidence from research about the health and wellbeing of Thalidomide survivors in other countries.

1.1 Background to the Survey

During the early 2000s, as Thalidomide survivors entered their forties, evidence began to emerge that they were experiencing an increasing number of Thalidomide-related health problems. The findings from a UK study commissioned by the Thalidomide Society suggested that the health of Thalidomide survivors was deteriorating more quickly than that of people of a similar age in the general

population¹. A second UK study highlighted the issue of overuse injuries and secondary damage². Internationally, a few studies raised concerns about the health related quality of life of Thalidomide survivors^{3 4}.

In March 2010, acknowledging the growing evidence about the deteriorating health of Thalidomide survivors, the four UK Departments of Health agreed to provide a ‘pilot’ Health Grant of £26.4 million (over three years) to Thalidomide survivors in the UK. The Grant was intended to help them address their exceptional health and health related needs. In early 2013, the Grant was renewed for a further ten years.

The pilot Health Grant was evaluated and three reports were published over the life of the Grant^{5 6 7}. The main aim of the evaluation was to explore the impact of the Grant on the health and wellbeing of individual beneficiaries, in particular, how they used their Health Grants to address their health and support needs. It also provided wider insights into the health and wellbeing of beneficiaries at that time.

When the Health Grant was renewed in 2013, the Thalidomide Trust decided to continue monitoring the Grant in order to: inform future discussions about the renewal of the Grant; support the wider work of the Trust around health and wellbeing; and gather data which would complement the routine information the Trust already holds about the health of beneficiaries (e.g. gathered by the Trust’s health and wellbeing advice service – HealthLink). The first report⁸ from this monitoring focused on health, quality of life and employment and was presented to the Trust in early 2015.

Together these reports and the Trust’s own information provide a good picture of the health problems beneficiaries are facing and the wellbeing issues that concern them. However, much of the information is qualitative in nature or is limited in scope (e.g. HealthLink information inevitably only covers those beneficiaries who have chosen to contact the HealthLink team). The Trust wished to gain a comprehensive picture of

¹ Kennelly, C. Kelson, M. and Riesel, J. (2002). *Thalidomide-impaired People: Quality of Life*. The College of Health/Thalidomide Society.

² Bent, N. Tennant, A., Neumann, V. and Chamberlain, M. A. (2007). Living with thalidomide: health status and quality of life at 40 years. *Prosthetics & Orthotics International*, 31(2), 147-56.

³ Nippert, I. Edler, B and Schmidt-Herterich, C. (2002). 40 Years Later: The Health Related Quality of Life of Women Affected by Thalidomide. *Community Genetics* 2002;5:209-216.

⁴ Edworthy, S. M. Edworthy, S. and Wolbring, G. (1999). *Thalidomide Survivors: a questionnaire survey on musculoskeletal abnormalities, general health and quality of life*. Thalidomide Victims Association of Canada.

⁵ Newbronner *et al* (2011) *Taking the Pressure Off: Evaluation of the Health Grant to Thalidomide-Impaired People*. Firefly Research/The Thalidomide Trust.

⁶ Newbronner *et al* (2012). *Looking to the Future: Evaluation of the Health Grant to Thalidomide-Impaired People*. Firefly Research/The Thalidomide Trust.

⁷ Newbronner *et al* (2013). *A Securer Future - Evaluation of the Health Grant to Thalidomide-Impaired People*. Firefly Research/The Thalidomide Trust.

⁸ Newbronner, E. (2015) *Health, Quality of Life and Employment amongst Thalidomide-affected People – Evidence from the UK*. Firefly Research/The Thalidomide Trust.

the health and wellbeing of beneficiaries and so in 2015 it decided to conduct a health and wellbeing survey of all its beneficiaries.

It is useful to note that in the last few years a small number of other countries (notably Canada, Germany, Ireland, Japan and Sweden) have also started looking in some depth at the health and wellbeing of their Thalidomide survivors. In particular, a recent German study of the health problems of 202 Thalidomide survivors in North Rhine-Westphalia⁹ provides some potentially useful comparisons and so the findings from this study are referred to in this report where appropriate.

1.2 Summary of Methods

The survey questions were developed in conjunction with the Thalidomide Trust Research Committee, and other colleagues from the Trust and the Trust's National Advisory Council¹⁰ (NAC). The draft questionnaire was piloted online and on paper with ten beneficiaries. In early August 2015 a paper copy of the survey was sent to all beneficiaries (467 in total), together with an information sheet and a covering letter from the Trust's Director and the Chair of the NAC Health and Wellbeing Committee. Beneficiaries could complete the survey on paper, online or on the telephone with a member of the research team. A copy of the questionnaire, showing responses to each question (excluding the SF12 questions), is attached in Appendix A.

The survey closed at the end of September. In total 351 responses were received, giving a response rate of just over 75%. Beneficiaries were asked to provide their names when completing the survey, although they had the option to remain anonymous. Eighty seven percent of beneficiaries gave their name, which made it possible to take account of additional characteristics, such as level of impairment (6(iv) b figure¹¹) and country of residence, when analysing the data. It also confirmed that the beneficiaries who responded to the survey were highly representative of the beneficiary community as a whole in terms of gender, 6(iv) b figures, and country of residence.

Full details of the methods used in the survey are described in Appendix B.

1.3 Structure of the Report and Terminology

Chapter 2 provides a profile of beneficiaries who responded to the survey. In Chapter 3 we describe the health problems reported and, where possible, make comparisons

⁹ Peters *et al* (2015). *Damage to Health, Psychosocial Disorders and Care Requirements of Thalidomide Victims in North Rhine Westphalia from a Long Term Perspective*. Federal Health Centre North Rhine Westphalia, Cologne.

¹⁰ The National Advisory Council is comprised of 12 elected beneficiaries. It acts as an advisory body for the Trust and is the principal means by which the beneficiaries are able to influence the Trust's policies.

¹¹ 6(iv) b figures and Bands – see section 1.1.

with the general population and examine whether different groups of beneficiaries are more or less likely to report particular health problems. Chapter 4 looks at beneficiaries' use of health and social care services and Chapter 5 sets out the results of questions about health related quality of life and mental wellbeing, including two standardised measures. In Chapter 6 we report on housing, adaptations and mobility and in Chapter 7 on respondents' work situations. Chapter 8 focuses on beneficiaries' concerns for the future. Lastly, in Chapter 9 we discuss the overall findings and wider issues emerging from them.

Throughout the report, we used the words 'respondent' and 'beneficiary' to refer to those 351 beneficiaries who completed the survey. This is purely to make the report more readable and is not intended to imply that the results will necessarily apply to all 467 of the Trust's beneficiaries. However, we are confident that the results are highly representative of the beneficiary population as a whole.

Chapter 2

Profile of Beneficiaries in the Survey

This chapter presents a profile of the beneficiaries who responded to the survey. It shows that the survey respondents are highly representative of the Trust's beneficiaries as a whole. Some of the information presented here is used elsewhere in the report to help explore other issues.

2.1 Biographical Information

In terms of gender, 174 of the respondents were female and 174 were male, which matches the gender split of all UK beneficiaries. Three respondents did not give their gender. Almost two thirds of beneficiaries lived with their partner/spouse or with their partner/spouse and their children/another family member. Nearly a quarter (76/22%) lived alone. As a comparison, 17% of the general UK population aged 50-64 live alone¹². Just over 10% lived with another family member/s (e.g. parents or sibling). Nine beneficiaries said they lived at home with full-time paid carers or lived in residential care.

Full details of respondents' work situations are given in Chapter 7 but it is perhaps helpful to briefly note here that just over 15% of beneficiaries were working full time, 22% were working part time and 41% said that they were unable to work because of their disability or health problems. In terms of educational qualifications, the beneficiaries in the survey had a very similar pattern of qualifications to the general population of a similar age¹³.

2.2 Original Thalidomide Impairments

The survey asked beneficiaries to describe their original Thalidomide impairments. There were 25 categories covering limb damage, sensory impairments and damage to internal organs, plus a free text box where respondents could add other damage. There are inevitable limitations and issues of accuracy when self-classification is used. However, the aim of gathering this information was to enable us to look at any variations between groups of beneficiaries with different types of impairments (e.g. upper limb affected or hearing impaired beneficiaries), including those who

¹² Office of National Statistics (2014). Living Alone in England and Wales. See: <http://www.ons.gov.uk/ons/rel/census/2011-census-analysis/do-the-demographic-and-socio-economic-characteristics-of-those-living-alone-in-england-and-wales-differ-from-the-general-population-/sty-living-alone-in-the-uk.html>

¹³ Office for National Statistics (2011). *Highest levels of qualification across England and Wales*. See: <http://www.ons.gov.uk/ons/rel/census/2011-census-analysis/local-area-analysis-of-qualifications-across-england-and-wales/info-highest-qualifications.html>

completed the survey anonymously. It was not intended to provide a comprehensive clinical classification.

Full details of respondents’ self-reported original Thalidomide impairments are shown in Appendix A. However, for analysis purposes, the 25 categories have been collapsed into fourteen groupings. To check how representative the survey respondents were in terms of their original Thalidomide impairments, we compared the self-reported information from the survey with (anonymised) data held by the Trust on the number of beneficiaries with different impairments, based on the clinical information captured at the time they were accepted as beneficiaries by the Trust. There are some differences between the survey categories and the categories used by the Thalidomide Trust, and so it was not possible to make direct comparisons for all categories.

Tables 1 & 2 below show the self-reported information about impairments from the survey compared with information held by the Trust. It is important to note that many beneficiaries have multiple impairments and so will appear in both Table 1 and Table 2. For example:

- 73 beneficiaries had both upper limb damage and were deaf or partially deaf.
- 27 beneficiaries said they had both sight impairment and hearing loss.
- All except one of the beneficiaries who had damage to their internal organs also had another impairment/s.

Table 1 Self-reported Original Thalidomide Impairments – Limbs

| Impairment | Survey Number | Survey % (351) | Trust Number | Trust % (467) |
|----------------------------------|----------------------|-----------------------|---------------------|----------------------|
| Upper & Lower limb mild/moderate | 39 | 11% | | |
| Upper & Lower limb severe | 50 | 14% | | |
| Upper and Lower limb total | 89 | 25% | 157 | 34% |
| Upper limb mild | 23 | 7% | 55 | 12% |
| Upper limb moderate | 69 | 20% | 40 | 9% |
| Upper limb severe | 61 | 17% | 85 | 18% |
| Upper limb very severe | 52 | 15% | 73 | 16% |
| Upper limb only total | 205 | 58% | 253 | 54% |
| Lower limb only | 14 | 4% | 7 | 1.5% |
| No limb damage | 43 | 12% | 50 | 11% |
| Total Respondents/Beneficiaries | 351 | | 467 | |

Table 2 Self-reported Original Thalidomide Impairments – Other damage

| Impairment | Survey Number | Survey % (351) | Trust Number | Trust % (467) |
|---------------------------------|---------------|----------------|--------------|---------------|
| Scoliosis | 77 | 22% | | |
| Spinal damage | | | 151 | 32% |
| Totally Deaf | 28 | 8% | 147 | 31% |
| Partially deaf | 96 | 27% | | |
| Blind*/Partially sighted | 40 | 11% | 117 | 25% |
| Damage to face and/or outer ear | 65 | 19% | 218 | 47% |
| Damage to internal organs | 110 | 31% | 102 | 22% |
| Damage to nervous system | 52 | 15% | | |
| Learning needs | | | 27 | 6% |
| Epilepsy | | | 17 | 4% |

*NOTE: *Just one survey respondent was totally blind.*

There are a number of points to note in comparing the self-reported survey information and the clinical information held by the Trust:

- The proportions of beneficiaries who have no limb damage and those who have upper limb damage only, are broadly similar.
- There is a big difference between the proportion of beneficiaries in the survey group who have both upper and lower limb damage, and the proportion found in the Trust's records.
- The number of beneficiaries who have lower limb damage only is small but there is a marked difference between the proportion in the survey and the Trust's information.
- We think that there may be a number of beneficiaries that the Trust's records show have both upper and lower limb damage, who have not recorded the damage to their upper limbs in the survey, possibly because they regard this damage as minimal.
- Whilst the proportion of beneficiaries who are hearing impaired is similar in both the survey and the Trust's records, substantially fewer beneficiaries reported that they were blind or partially sighted, suggesting that beneficiaries with a visual impairment may be under represented in the survey.

- The number of beneficiaries who self-reported damage to their face and/or outer ear was also significantly lower but this may be because those with ear damage felt they had reported this by identifying as deaf or partially deaf.
- A far greater proportion of survey respondent reported that they had damage to their internal organs than the Trust’s information would suggest. However, some of this damage may not have been apparent at the time of their original assessment.

2.3 Representativeness of the Survey Beneficiaries

The spread of 6(iv) b impairment figures/Bands¹⁴ for the survey respondents almost exactly matched that of all beneficiaries. There were only minor differences, which can be seen in Figure 1.

Figure 1 Proportion of Survey Respondents and all Beneficiaries by Impairment Band

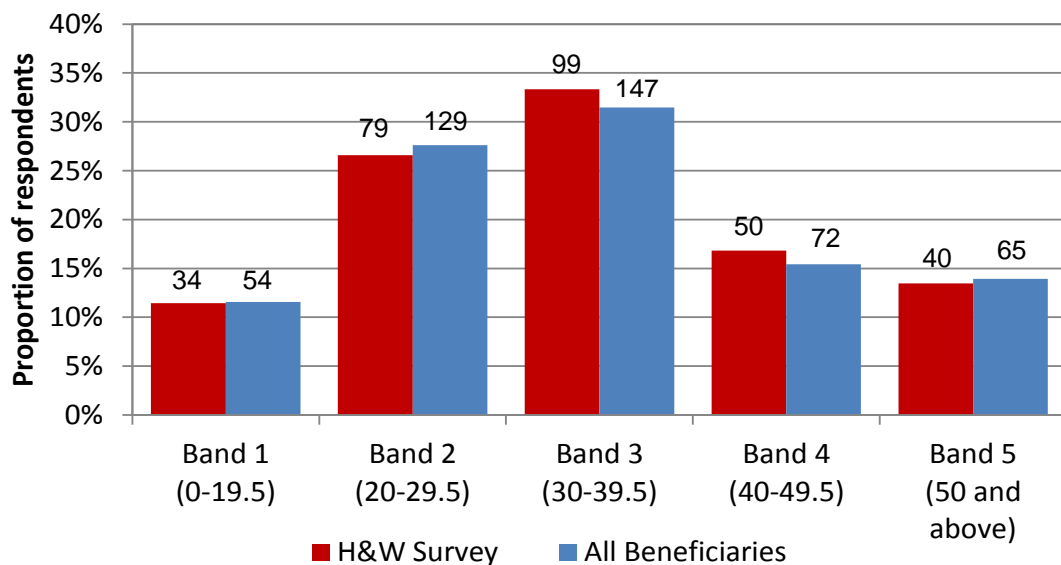


Table 3 below compares the country of residence of the survey respondents with that of all UK beneficiaries, and shows that the pattern is broadly the same.

¹⁴ Ibid - footnote 11

Table 3 Country of Residence

| Country of Residence | All UK Beneficiaries | Survey Beneficiaries |
|----------------------|----------------------|----------------------|
| England | 325 (69%) | 214 (71%) |
| Wales | 37 (8%) | 16 (5%) |
| Scotland | 55 (12%) | 38 (13%) |
| Northern Ireland | 19 (4%) | 14 (5%) |
| Non-UK resident | 31 (7%) | 20 (7%) |

NOTE: The total number of survey beneficiaries (responses) in Figure 1 and Table 3 is 302. This is because we were only able to identify impairment band and country of residence for those beneficiaries who provided their names.

Chapter 3

Self-Reported Health Problems

Key Findings

Overall, 93% of beneficiaries were experiencing pain and/or loss of movement in one or more joint; many reported multiple problems.

50% of respondents said that they were currently experiencing or had recently experienced depression and/or anxiety.

Over a quarter of beneficiaries said they had generalised pain which was 'severe and/or continuous'.

The survey asked beneficiaries to record the health problems they were currently experiencing or had recently experienced. There were 35 categories they could tick and a text box where they could describe other problems. Sixty-eight respondents provided additional information. In this chapter, we set out the main results for this question. We have split the health problems reported into five groups. Where possible, we have made comparisons with the prevalence of those health problems in the general population of a similar age. We have also examined whether different groups of beneficiaries were more or less likely to report particular health problems or types of health problems.

3.1 Musculoskeletal Problems

A study by Manchester University¹⁵ notes that the term 'musculoskeletal conditions' includes over 200 disorders affecting joints, bones, muscles and soft tissues. The Thalidomide Trust survey results suggest that overall, 93% of respondents were experiencing musculoskeletal problems (defined in the survey as pain and/or loss of movement in one or more joint, including their neck and/or back). As Table 4 shows, back problems were the most commonly reported musculoskeletal problem, closely followed by shoulder pain/loss of movement and problems with hands. Whilst comparisons with general population are not straightforward, the General Household Survey of 2007¹⁶ does provide some context. It found that 19.5% of adults aged 45-64 reported having a chronic musculoskeletal condition.

¹⁵ Parsons, S. Ingram, M. Clarke-Cornwell, A.M. and Symmons, D. P. M. (2011) *A Heavy Burden*. The University of Manchester.

¹⁶ Office for National Statistics. General Household Survey 2007. Available from: http://www.statistics.gov.uk/downloads/theme_compendia/GHS07GeneralHouseholdSurvey2007.pdf.

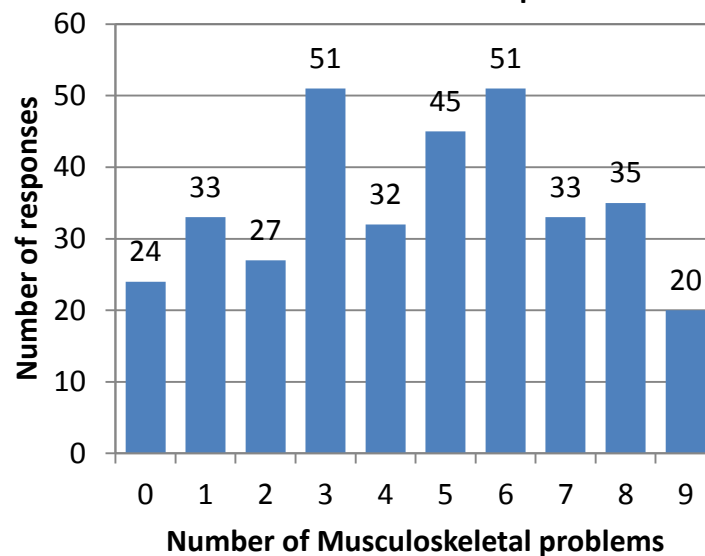
Table 4 Pattern of Musculoskeletal Problems

| Musculoskeletal Problem | Number | % |
|---|--------|-----|
| Back problems – prolapsed disc; damage to vertebrae; scoliosis and/or muscular pain | 254 | 72% |
| Shoulder – pain, loss of movement or deterioration of the joint | 211 | 60% |
| Hands – pain, loss of grip and/or dexterity | 210 | 59% |
| Arms and wrists – pain, loss of strength and/or movement | 197 | 56% |
| Neck pain and/or loss of movement | 195 | 55% |
| Knee – pain or deterioration of the joint | 168 | 48% |
| Hip – pain, loss of movement or deterioration of the joint | 164 | 46% |
| Ankles, feet and toes – pain and/or loss of movement | 100 | 28% |

The categories/groupings used in the recent German study¹⁷ of the health problems of Thalidomide survivors are slightly different and so full comparison is not possible. However, the proportion of beneficiaries reporting back, shoulder and hip problems was very similar, whilst in the German study hand problems were less common and neck problems were more common.

Many survey respondents reported multiple problems, with the mean number of problems being 4.5 and over half of all respondents reporting five or more musculoskeletal problems (see Figure 2 below).

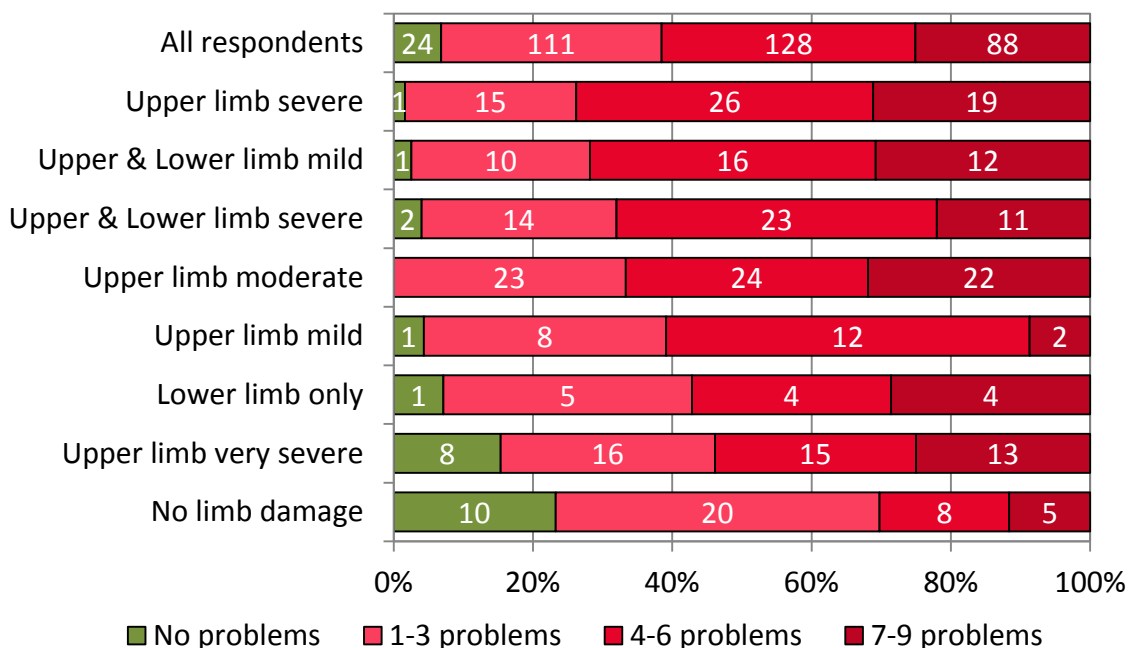
Figure 2 Number of Musculoskeletal Problems Reported



¹⁷ Ibid – footnote 9

We looked at whether there were any differences between beneficiaries with different types/severity of impairment. Our analysis suggests that beneficiaries with severe or moderate upper limb damage and those with upper and lower limb damage reported marginally more problems. Figure 3 below gives a breakdown of the number of problems reported by each impairment group.

Figure 3 Number of Musculoskeletal Problems by Impairment Group



3.2 Generalised Pain, Neuropathy, Fatigue and Balance

In addition to the very high proportion of beneficiaries reporting joint pain, 49% said they had generalised pain; 92 (26%) respondents said this was severe and/or continuous and a further 81 (23%) described it as moderate and/or intermittent. As Table 5 below shows, respondents in Bands 5 were the most likely and those in band 2 the least likely to report experiencing generalised pain.

Table 5 Experience of Generalised Pain by Impairment Band

| | Band 1 | Band 2 | Band 3 | Band 4 | Band 5 |
|-----------------------------|----------|----------|----------|----------|----------|
| Generalised pain - severe | 8 (24%) | 12 (15%) | 30 (30%) | 13 (26%) | 15 (38%) |
| Generalised pain - moderate | 9 (26%) | 19 (24%) | 21 (21%) | 13 (26%) | 10 (25%) |
| Generalised pain - either | 17 (50%) | 31 (39%) | 51 (51%) | 26 (52%) | 25 (63%) |

NOTE: Percentages apply to the proportion in the impairment Band

The comments added by respondents suggest that for some beneficiaries the cause of their pain was unclear and therefore treatment choices were limited or difficult.

“Chronic neuropathic pain in peroneal nerves - both legs, below knee. 5 years. No cause found. Does not respond to treatment/pain management medication.”
(Survey ID298)

“I have been suffering with regular bouts of pain in my side. I have had several tests done but I am told there is no conclusive reason for the pain.” (Survey ID104)

Overall, 66% (231) of respondents reported experiencing neurological symptoms, with tingling/pins and needles being the most common symptom (see Table 6 below). The causes of these symptoms may be varied but the impact on beneficiaries’ general wellbeing can be significant, especially where sleep is affected.

Table 6 Pattern of Neurological Symptoms

| Neurological Symptoms | Number | % |
|------------------------------------|--------|----|
| Tingling/pins and needles | 182 | 52 |
| Numbness/Loss of feeling | 130 | 37 |
| Sensations of extreme heat or cold | 127 | 36 |

A significant proportion of beneficiaries also said that they experienced severe tiredness/fatigue (139/40%) and nearly a third of all respondents said they had problems with balance/falls. However, as Table 7 shows, whilst the proportion of beneficiaries reporting neurological symptoms was consistent across all five impairment Bands, fatigue was more commonly reported by respondents in Bands 1 and 2. The survey also suggests that beneficiaries in Bands 3 and 4 were more likely to experience balance problems but these could have many different and/or multiple causes, including deteriorating sight and musculoskeletal problems.

Table 7 Number of Respondents Reporting Neurological Symptoms, Fatigue and Problems with Balance/Falls

| | Band 1 | Band 2 | Band 3 | Band 4 | Band 5 | Band not known |
|---------------|----------|----------|----------|----------|----------|----------------|
| Neurological | 22 (65%) | 50 (63%) | 66 (67%) | 34 (68%) | 28 (70%) | 31 (63%) |
| Fatigue | 15 (44%) | 34 (43%) | 36 (36%) | 21 (30%) | 15 (38%) | 18 (37%) |
| Balance/Falls | 5 (15%) | 15 (19%) | 37 (37%) | 24 (48%) | 10 (25%) | 18 (37%) |

NOTE: Percentages apply to the proportion in the impairment Band

3.3 Mental Health

Overall, 50% of respondents said that they were currently experiencing or had recently experienced depression and/or anxiety, and a further 19% said they had generally poor emotional health. Table 8 provides a more detailed breakdown of the problems reported.

The Mental Health Foundation estimates that in the UK, 20% of adults aged between 50 and 54 experience a common mental health problem (i.e. depression, anxiety or panic) and between 8% and 12% of the population (all ages) experience depression in any year. The self-reported prevalence of mental health problems amongst the beneficiaries is therefore significantly higher than in the same age group in the general population but it is very similar to the prevalence of mental health problems found in the recent German study¹⁸. Using face-to-face psychiatric assessment (rather than self-reporting), that study found that 47.7% of Thalidomide survivors had experienced a mental health problem in the preceding four weeks or were currently experiencing mental health problems.

Table 8 Pattern of Mental Health Problems

| Mental Health Problems | Number | % |
|------------------------------|--------|-----|
| Anxiety | 145 | 41% |
| Depression | 118 | 34% |
| Alcohol or drug misuse | 26 | 7% |
| Other mental health problems | 25 | 7% |

3.4 Hearing, Sight and Dental Problems

Deteriorating sight/eye problems were a concern for nearly half (see Table 9) of respondents and 38% (133) said that they had deteriorating hearing/other ear problems. However, these figures are likely to encompass both normal deterioration in sight/hearing due to ageing and more severe problems directly related to respondents' Thalidomide damage. Over a third (120/34%) of respondents reported dental health problems. The unusual and varied nature of the original damage to Thalidomide survivors' hearing, sight and teeth/jaws makes comparisons with the general population difficult. However, a Swedish study¹⁹ of the dental health of Thalidomide survivors found that they had higher levels of tooth wear and decayed, missing or filled teeth than the general population of a similar age. The study suggest

¹⁸ Ibid footnote 9

¹⁹ Ekfeldt, A. and Carlsson, G. E. (2008). Dental status and oral function in an adult group of subjects with thalidomide embryopathy - A clinical and questionnaire study. *Acta Odontologica Scandinavica*, 66(5), 300-306.

that these differences may be due to a combination of factors including difficulties with tooth brushing, using teeth as tools and regurgitation/acid reflux.

Table 9 Sight, Hearing and Dental Problems

| Hearing, Sight and Dental Problems | Number | % |
|--|--------|-----|
| Deteriorating sight/eye problems | 151 | 43% |
| Deteriorating hearing/other ear problems | 133 | 38% |
| Dental Health Problems | 120 | 34% |

3.5 Other Health Problems and Comorbidity

Weight management is a concern for many beneficiaries²⁰, and the survey confirmed this with 40% (141) identifying this as a health problem. Respondents reported a range of other health problems and a breakdown of these is shown in Table 10 below. In addition, eight people noted in the free text box that they had high blood pressure, or were being treated for hypertension.

Table 10 Other Health Problems

| Health Problem | Number | % |
|--------------------------------|--------|------|
| Bowel or digestive problems | 98 | 28% |
| Bladder or continence problems | 72 | 20% |
| Asthma or breathing problems | 54 | 15% |
| Diabetes | 32 | 9% |
| Kidney problems | 30 | 9% |
| Heart problems | 28 | 8% |
| Cancer | 17 | 5% |
| Stroke/TIA | 5 | 1.4% |

All of these health problems are experienced by people in the general population and the prevalence rates reported by beneficiaries for some conditions do appear to be similar or lower. For example:

²⁰ Ibid – footnote 8

- Information collated by Diabetes UK²¹ suggests that in the UK around 19% of people aged 50-59 have diabetes (Type 1 and 2) whereas 9% of the beneficiaries in the survey reported having diabetes.
- Five (1.5%) beneficiaries (all men) reported that they had had a stroke/TIA. This compares to a prevalence rate of between 0.8 to 2% in the UK population aged 45 to 54²² (with prevalence rates being higher for men).

However, some problems may be more prevalent amongst Thalidomide survivors. For example:

- In 2011, the national outcomes strategy for COPD and asthma²³ estimated that 13% of the population aged over 35 had COPD (both diagnosed and undiagnosed) and around 6% of the adult population had asthma, compared to 15% of survey respondents reporting asthma/breathing problems.
- NHS Kidney Care²⁴ defines chronic kidney disease as '*abnormal kidney function and/or structure*' and the Health Survey for England 2010²⁵ estimated the prevalence of doctor diagnosed chronic kidney disease to be under 2% in the 45 to 64 age group. This compares to 9% of respondents reporting kidney problems.

These comparisons need to be treated with caution, as there are differences in definitions, prevalence periods and age groups etc. What is clear, however, is that all these health problems may be made more difficult to manage, or be exacerbated by, beneficiaries' Thalidomide damage. For example, a recent Japanese study²⁶ of 'lifestyle' diseases amongst Thalidomide survivors suggests that hypertension is a particular area of concern because of the problems many Thalidomide survivors have in exercising and controlling their weight, and the potential inaccuracy of blood pressure measurement in people with limb difference.

Furthermore, the survey suggests that a high proportion of beneficiaries were experiencing multiple health problems. We examined the survey data to identify how many beneficiaries reported that they were currently or had recently experienced one or more of the following health problems – a musculoskeletal problem,

²¹ Diabetes UK (2015) *Facts and Stats*. See:

https://www.diabetes.org.uk/Documents/Position%20statements/Diabetes%20UK%20Facts%20and%20Stats_De%202015.pdf

²² Townsend N, Wickramasinghe K, Bhatnagar P, Smolina K, Nichols M, Leal J, Luengo-Fernandez R, Rayner M (2012). *Coronary heart disease statistics 2012 edition*. British Heart Foundation: London.

²³ Department of Health (2011) *An Outcomes Strategy for Chronic Obstructive Pulmonary Disease (COPD) and Asthma in England*. DH: London.

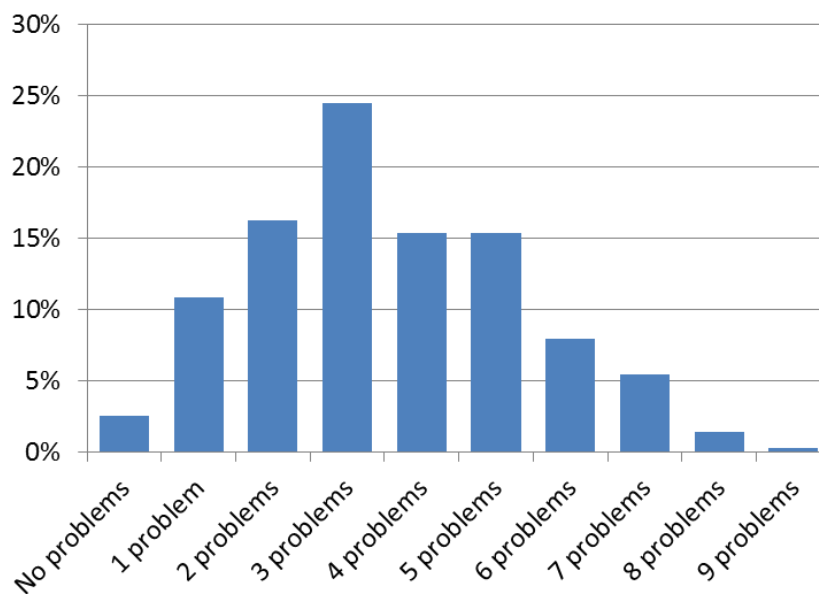
²⁴ East Midlands Public Health Observatory (2010) *Kidney Disease: Key Facts and Figures*. NHS Kidney Care.

²⁵ Health Survey for England 2010. See <http://www.hscic.gov.uk/catalogue/PUB03023/heal-surv-eng-2010-resp-heal-ch8-kidn.pdf>

²⁶ Shiga, T. Shimbo, T. and Yoshizwa, A. (2015). *Multicentre Investigation of Lifestyle-Related Diseases and Visceral Disorders in Thalidomide Embryopathy at around 50 years of age*. *Birth Defects Research (Part A)* 103:787-793, 2015.

generalised pain, neuropathic symptoms, a mental health problem, bowel or digestive problems, bladder or continence problems, asthma or breathing problems, diabetes, kidney problems, heart problems, cancer and stroke/TIA. Figure 4 shows that just 9 respondents (3%) had no health problems, and almost half (46%) reported between four and nine health problems.

Figure 4 Proportion of Respondents Reporting Multiple Health Problems



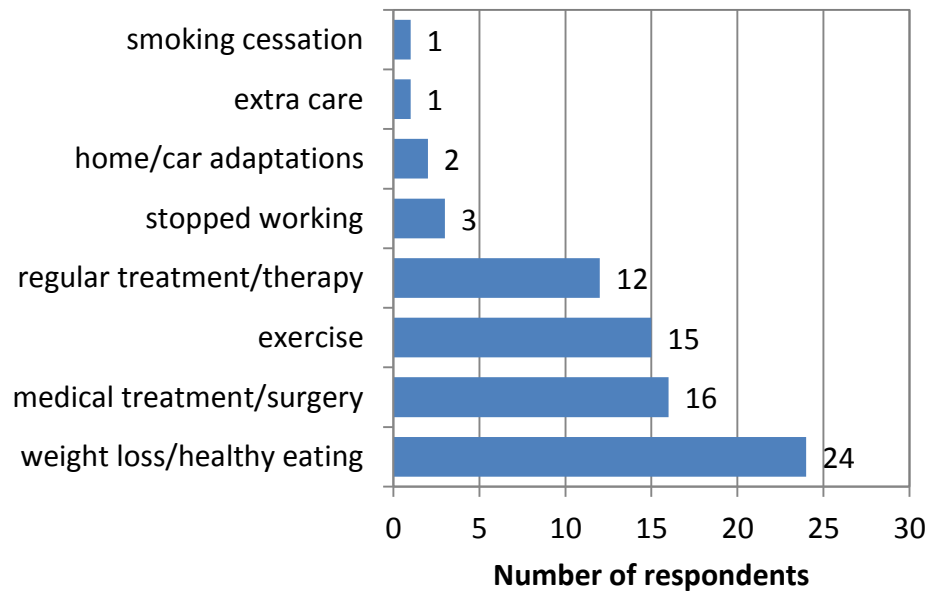
3.6 Improved Health and Well Being

Interestingly, 74 respondents (21%) said their health or wellbeing had improved recently. The things that had made the most difference were weight loss/healthy eating; medical treatment e.g. pain medication or surgery; exercise and regular treatment/therapy e.g. massage. Figure 5 shows all the responses to this question.

One respondent added a comment which described the difference which losing weight had made:

“I have enjoyed a huge improvement in my physical abilities and mobility from having lost a lot of weight. I have also experienced a reduction in my pain levels by exercising regularly and building lots of stretching exercises into my exercise regime. If I stop exercising for any period of time, there is a marked increase in my pain and increase in stiffening of my joints (back, neck, hips).”
(Survey ID275)

Figure 5 Reasons for Improved Health and Wellbeing



Chapter 4

Use of Health and Social Care Services

Key Findings

Half of the respondents had either taken prescription pain medication and/or had had pain-relieving treatment in the past ten years; beneficiaries with lower levels of impairment were more likely to have done so.

Two thirds of beneficiaries had experienced problems with access to or the quality of health services in the last five years.

Just 19% of beneficiaries currently received local authority funded social care services; two thirds of all respondents paid privately for support and care services.

The survey provided an opportunity to get a wider view of how beneficiaries were using health and social care services, and to find out whether beneficiaries were encountering problems with access to appropriate services or the quality of services.

4.1 Use of Health Services

We wanted to understand more about the health treatments beneficiaries have used in the past ten years, both NHS treatments and those purchased privately. The most commonly used treatments were physiotherapy (NHS or private) and/or complementary therapies (especially therapeutic massage), with over two thirds of beneficiaries ticking these categories. Table 11 below provides a more detailed breakdown.

Table 11 Use of Physiotherapy and Complementary Therapies

| Treatment | Number | % |
|-------------------------|--------|-----|
| Physiotherapy – NHS | 105 | 30% |
| Physiotherapy – private | 88 | 25% |
| Therapeutic massage | 89 | 25% |
| Chiropractic | 61 | 17% |
| Acupuncture | 53 | 15% |
| Osteopathy | 34 | 10% |

Overall, 17% of respondents (60) said they had undergone joint or back surgery. As Table 12 below shows, hip replacement/hip surgery was the most common procedure. Six percent of respondents reported that they had had a hip replacement/hip surgery in the last ten years, compared to 1% of the general population aged 50 to 54²⁷. Similarly, 4% of respondents had undergone knee surgery, compared to just under 1% of the general population aged 50 to 54²⁸. Similar comparisons with the general population for wrist/arm, shoulder and back surgery are less straightforward as these grouping cover a wider range of procedures. Furthermore, national data collection is less developed for these areas. However, data collected by the National Joint Register²⁹ suggests that there are only about 2000-3000 shoulder and elbow procedures performed each year (compared to around 85,000 hip replacements), so the proportion of beneficiaries who have had these procedures appears high.

Table 12 Joint and Back Surgery in the Past Ten Years

| Type of joint/back surgery | Number | % |
|------------------------------|--------|----|
| Hip replacement/hip surgery | 21 | 6% |
| Wrist/arm surgery | 18 | 5% |
| Knee replacement/surgery | 14 | 4% |
| Shoulder replacement/surgery | 12 | 3% |
| Back surgery | 6 | 2% |

The comments which respondents added to their questionnaires also revealed that some beneficiaries were facing difficult decisions about surgery:

“Need a shoulder replacement but surgery is not an option as it can only be done once and will wear out within 4-5 years potentially leaving me in a worse situation. Managing related pain using meds and will get surgery if/when the issue is no longer bearable”. (Survey ID43)

“Both knees are in need of replacement. Surgeon reluctant to do this due to flexibility after surgery.” (Survey ID257)

“Following surgery on my hand I now suffer from CRPS (Complex regional pain syndrome).” (Survey ID114)

²⁷ Access all Ages: Assessing the impact of age on access to surgical treatment. Age UK. See http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Health-and-wellbeing/access_all_ages_final_web.pdf?dtrk=true

²⁸ Ibid footnote 27

²⁹ <http://www.njrcentre.org.uk/njrcentre/NewsandEvents/Shoulderandelbowjointreplacements/tabid/240/Default.aspx>

The figures presented here may not be surprising given the number of beneficiaries identifying hip, knee and/or shoulder damage as one of their original Thalidomide impairments (158/45%) and the high proportion of beneficiaries reporting pain and/or loss of movement in one or more of their joints.

Half of the respondents (174/50%) said that they had either taken prescription pain medication and/or had received pain-relieving treatment such as injections in the past ten years. Nearly half (168/48%) had used prescription pain medication and nearly a quarter (79/23%) had received other treatment to relieve pain. The comments respondents added to their questionnaires bring to life the issues beneficiaries are facing, as this quote illustrates:

“Recently diagnosed with congenital fusion of two coccygeal segments for which I undergo an annual steroid injection into the joint. This is effective for three to four months but can only be repeated annually”. (Survey ID3)

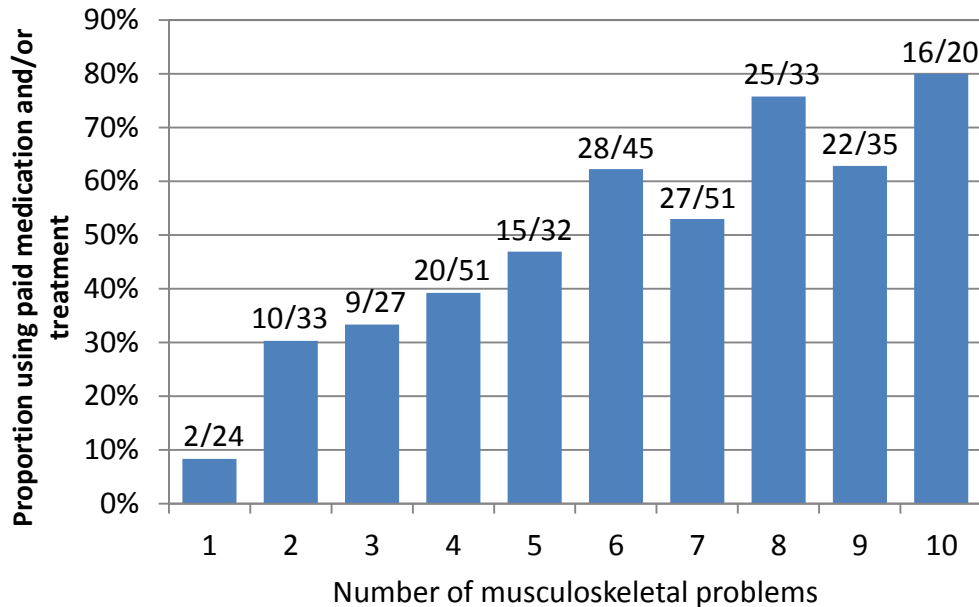
The use of pain medication/treatment was more common amongst beneficiaries in Bands 1 and 2, as Table 13 below shows.

Table 13 Use of Pain Medication/Treatment by Band

| Band | Number | % |
|-------------|---------------|----------|
| Band 1 | 21 | 62% |
| Band 2 | 46 | 58% |
| Band 3 | 42 | 42% |
| Band 4 | 27 | 54% |
| Band 5 | 18 | 45% |

Not surprisingly, the more musculoskeletal problems respondents reported, the more likely they were to report that they had had prescription pain medication/treatment. Figure 6 below provides a more detailed picture.

Figure 6 Use of Pain Medication/Treatment and Number of Musculoskeletal Problems



Given that 93% (327) of beneficiaries reported pain or loss of movement in one or more joints, these figures suggest that a significant proportion of beneficiaries were self-managing their pain through the use of other treatments, non-prescription medication and/or changes to their lifestyle, living or working situations. One respondent described the changes they had made in order to manage their pain:

“[Some] years ago I had real health issues and things got so bad I had to take dramatic action...sell [my] business and change lifestyle. So I had to learn to be less independent - to actually be dependent...I refused all help but I had to change my mind-set. I've gone from excessive painkillers every single day to rarely touching one now.” (Survey ID94)

With regard to mental health, a quarter of beneficiaries (87) had had treatment for anxiety and/or depression and 35 (10%) had had counselling for emotional issues (22 respondents had had both). Given that 50% of beneficiaries reported anxiety and/or depression, it is clear that a significant proportion of beneficiaries who have experienced mental health problems have not had any professional treatment.

4.2 Access to Health Services

In the Health Grant evaluation study (see section 1.2), beneficiaries talked about the problems they had experienced with either obtaining access to appropriate health services or the perceived quality of care they received. Specifically, many

beneficiaries reported that healthcare professionals often had a poor understanding of their particular impairments and/or Thalidomide damage in general. The survey provided an opportunity to explore this issue further, both for health services in general and general practitioner (GP) care in particular.

Nearly two thirds (215/61%) of beneficiaries said that (in the last five years) they had experienced one or more problems with the quality of and/or access to health services. The main areas of concern were:

- Perceived lack of knowledge/understanding of Thalidomide damage in general amongst health professionals (170/48%).
- Perceived lack of knowledge/understanding of their impairments amongst health professionals (127/36%).
- Difficulties/delays in seeing a suitably experienced health professional/specialist (81/23%).
- Delays in getting treatment (82/23%).

A number of respondents added comments about their experiences of health care services. The quotations below highlight the difficulties beneficiaries can experience in getting the knowledgeable, skilled care they need and the knock-on consequences that poor care can have for mental wellbeing:

“I have not enjoyed my usual robust general health for three years now. I have recently struggled with depression/isolation. I am awaiting the results of blood tests as I complete this form. I delayed the tests because of the difficulty in getting a needle into me to take blood. An angiogram ordered by a specialist had to be abandoned after s/he had tried unsuccessfully three times to insert a drip.” (Survey ID265)

“Could not get bloods done as nurses could not do it – took 2 years to get doctors to do it. Having a nervous breakdown due to stress and worry. It is hard to admit all about your illnesses, when it is your bowels and bladder. You feel ashamed when it is not your fault. The last thing you want is strangers knowing.” (Survey ID212)

Importantly, a small number had experienced misdiagnoses or delayed diagnoses (48/14%) and a similar number reported being given incorrect or inappropriate treatment (47/13%). From the survey data we were unable to determine whether these experiences concerned respondents’ Thalidomide related health problems or general health problems. However, as the following quotation illustrates, some beneficiaries perceived that the misdiagnosis of their problems was related to being a Thalidomide survivor:

“There is a lack of understanding of depression/psychological issues and Thalidomide amongst general health professionals. Living a life of being

stared at and fighting against barriers and perceptions has taken its toll. My depression was misdiagnosed by general health professionals originally. Thanks to the Trust's assistance I was able to access a specialist.” (Survey ID345)

We also asked beneficiaries, ‘How well does your GP/GP surgery understand how your Thalidomide damage affects you?’ Encouragingly, over half said that their GP fully understood or partly understood how their Thalidomide damage affected them. Just 20% said their GP did not understand and the remainder were not sure (see Table 14 below).

Table 14 How well does your GP/GP surgery understand how your Thalidomide damage affects you?

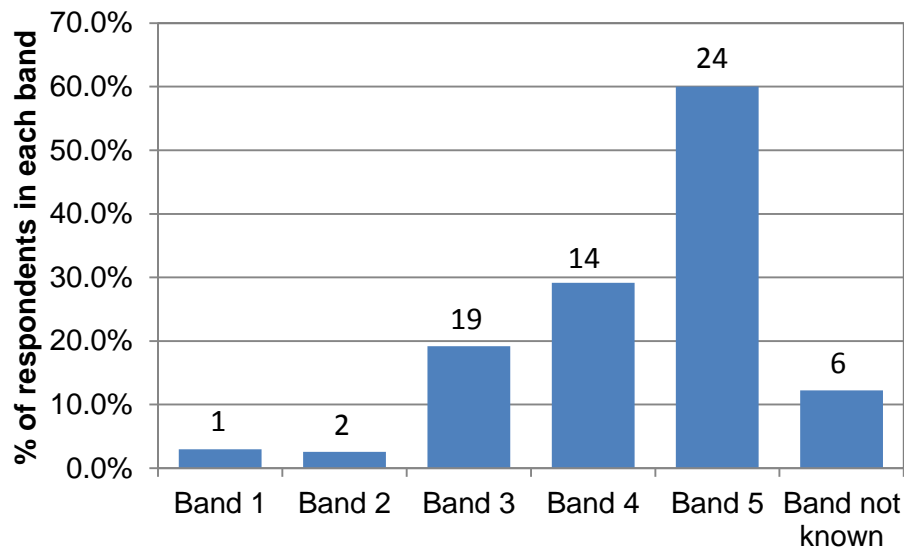
| Response | Number | % |
|---------------------|--------|-----|
| Fully understands | 57 | 16% |
| Partly understands | 136 | 39% |
| Doesn't understand | 72 | 21% |
| Not sure/don't know | 81 | 23% |

Almost half (45%) thought that if they had a Thalidomide-related health problem their GP would be willing to seek advice from a specialist with knowledge of Thalidomide damage and/or from the Trust. However, a similar number said they were not sure/did not know and 23 respondents (7%) felt that their GP would not be willing to seek advice.

4.3 Use of Social Care Services

Sixty-six beneficiaries (19%) were receiving local authority funded social care at the time of the survey. When we looked at this group in more depth we found that beneficiaries who lived alone, and therefore may have had less day to day help from family members, were more likely to be getting social care (25%) than those who lived with a partner or other family member (16%). We also expected that the number of beneficiaries using social care services would increase with the severity of their impairment and this was the case (see Figure 7).

Figure 7 Use of Local Authority Social Care by Impairment Band



Of those beneficiaries receiving local authority funded social care, just over half (34/52%) said that the level of support they were getting was enough to meet their needs. However, 20 beneficiaries (30%) said their care package had been reduced in the last five years and of these 14 felt that their package was not enough to meet their needs. In addition, almost two thirds of beneficiaries (40/60%) who received local authority funded social care were also paying for additional time or services from their own income, and three quarters (49/74%) thought they would need more support in the next five years.

Eighteen respondents made additional comments about their local authority social care support. Their main concerns related to the inflexibility in terms of how beneficiaries wanted to live their lives and/or a lack of understanding of their particular needs (sometimes linked to poor staff continuity).

“My social care officers seem unsure of how to assess my needs, I've had a lot of staff changes (high staff turnover) and they very rarely answer my questions on their SDS/DP [Self Direct Support/Direct Payment] system, so I've had to find help and advice from other sources or 'made it up' as best I can. I've found setting up as a full employer of PAs [Personal Assistants] quite onerous, and wish it could be simpler and explained more clearly in the guidance.” (Survey ID346)

Whilst the majority of beneficiaries (282/81%) were not receiving local authority funded social care, almost two thirds of this group (181/64%) were buying support privately (e.g. personal assistance, help in the home, gardening, DIY). Nearly 20% (54) thought that they would need to apply for local authority funded social care in the next five years but most felt that they would not (124/44%) or were unsure (83/29%).

Chapter 5

Health Related Quality of Life and Mental Wellbeing

Key Findings

Beneficiaries' physical health related quality of life was significantly lower than people of a similar age in the general population.

Beneficiaries in the lower 6(iv) b impairment Bands, especially those who were unable to work, had poorer mental health related quality of life than the group as a whole.

16% (54) of beneficiaries felt lonely or isolated much of the time; they were much more likely to live alone and be unable to work because of their disability/health problems.

The Trust was keen to find out more about beneficiaries' health related quality of life and mental wellbeing, and in particular to explore whether beneficiaries' health and wellbeing were related to the nature or severity of their Thalidomide damage or to other personal circumstances. To do this, we used two validated questionnaires – SF12 Health Related Quality of Life questionnaire and the Warwick Edinburgh Mental Wellbeing Scale (WEMWBS). Both these measures are 'snapshots' of how a person is feeling at a particular moment in time. SF12 looks specifically at health related quality of life and WEMWBS was designed to monitor mental wellbeing and investigate the determinants of mental wellbeing. Neither are designed to identify whether a person has currently or recently had a mental health problem.

In addition to these measures, we also included two questions about changes in beneficiaries' emotional wellbeing over the past five years and the quality of their social life.

5.1 SF12 Health Related Quality of Life

The SF12 Health Survey³⁰ is a tool for measuring health status which is widely used in health research in the UK and internationally. SF12 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 related quality of life and mental health related quality of life. Here we present the finding for both the physical health and mental

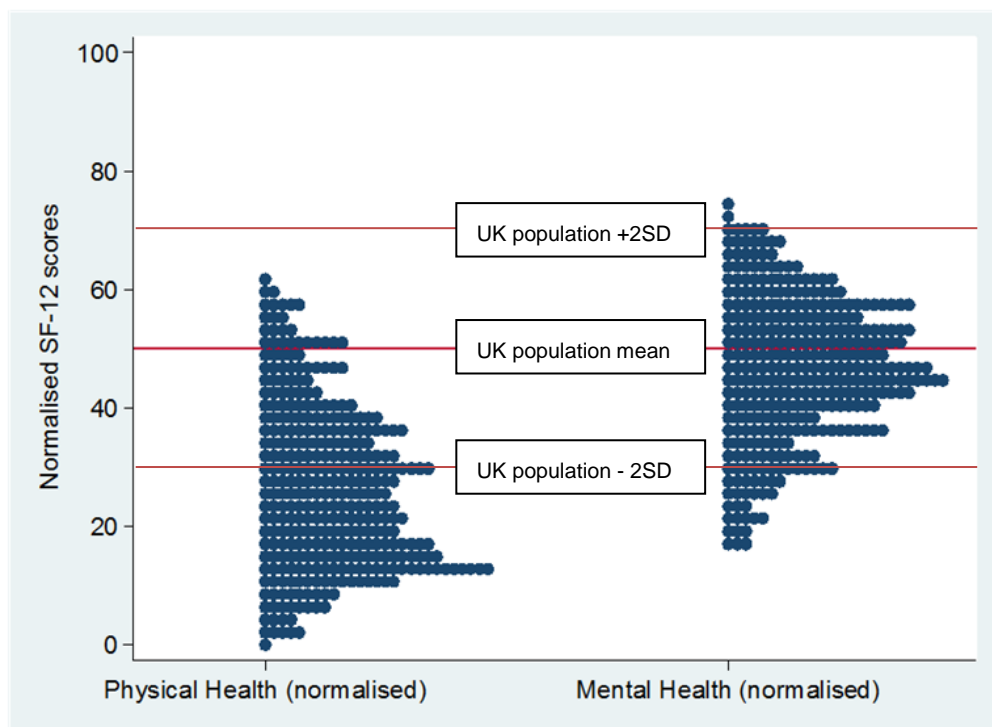
³⁰ SF12 was developed from the Short Form (36) Health Survey which has 36 questions and which has been used in studies with Thalidomide survivors in Australia, Germany, Japan and Sweden. The scores from SF12 can be compared with those from SF36.

health domains. Of the 351 survey respondents, 335 returned SF12 questionnaires that were useable for the analysis³¹ and for 285 of these we were able to link SF12 scores to 6(iv) b figures.

All the results are presented in '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 specific sub-groups and the general population.

Figure 8 shows the results for the survey respondents compared to the general population aged 45-54 (based on responses to the Central England Healthy Life Survey³²).

Figure 8 Normalised SF-12 physical and mental health scores for survey group



In the physical health domain:

- Beneficiaries had a significantly lower average aggregate score than people of a similar age (45 to 54 years) in the general population (i.e. a mean of 26.7)

³¹ Questionnaires which had not been completed in full could not be used in the analysis.

³² 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.

compared to 50) indicating that their physical health related quality of life is significantly poorer.

- 59.7% (n=200) of the beneficiaries had a score below 30 i.e. the same as or worse than the 2% of the general population group with the poorest physical health related quality of life, and only 7.5% (n=25) of the beneficiaries had a score above the average for the general population group.
- In the four sections which make up the physical domain (see Table 15), beneficiaries had the lowest scores for Physical Functioning (20.9), followed by Pain (33.6) and General Health (33.7).

In the mental health domain:

- The average aggregate score for beneficiaries was 46.5, which is lower than the general population (score 50), indicating that beneficiaries' mental health related quality of life is poorer on average than their peers in the general population.
- 40.9% of the beneficiaries (n=137) had a score above the average for the general population. However, 10.7% (n=36) of beneficiaries had a score below 30 i.e. the same as or worse than the 2% of the general population with the poorest mental health related quality of life.
- Of the four sections which make up the mental health domain (see Table 15), beneficiaries had the lowest score for Social Functioning (34.6).

Table 15 SF12 Component Scores

| Component | Mean | Min | Max |
|----------------------------------|-------------|-------------|-------------|
| Physical Functioning (PF) | 20.9 | 1.7 | 57.6 |
| Role Limitation Physical (RP) | 36.4 | 21.9 | 55 |
| Pain (BP) | 33.6 | 14.2 | 59.2 |
| General Health (GH) | 33.7 | 13.7 | 63.7 |
| Aggregate physical health | 26.7 | 0.5 | 61.7 |
| Vitality (VT) | 40.4 | 21.3 | 68.2 |
| Role Limitation Emotional (RE) | 43.5 | 23.7 | 55.3 |
| Social Functioning (SF) | 34.6 | 2.0 | 55.5 |
| Mental Health (MH) | 40.7 | 7.4 | 64.5 |
| Aggregate mental health | 46.5 | 16.8 | 74.9 |

The findings from this SF12 survey confirmed that beneficiaries experience significantly poorer physical health related quality of life compared to the general population. Their mental health related quality of life was also worse than the general population but the difference was far less marked. There was no substantial difference between men and women, although overall men had a higher mean score for physical health (28.6 compared to 24.7) and women had a higher mental health score (47.8 compared to 45.1). However, Figure 8 and Table 15 together show that for all beneficiaries, the range of both the aggregate and component scores is very wide.

We examined whether there was any relationship between the SF12 physical and mental health aggregate scores and other characteristics of the survey respondents. Figure 9 below shows that, not surprisingly, there was a strong correlation (which was statistically significant³³) between lower SF12 physical health scores and higher 6(iv) b figures (i.e. more severe Thalidomide damage). By contrast, there was a weak association between lower SF12 mental health scores and lower 6(iv) b figures. However, for the group of beneficiaries who said they were unable to work because of their disability or health problems, this correlation was much stronger (see Figure 10) and statistically significant³⁴. There was no marked difference between men and women. This suggests that for beneficiaries with lower impairment levels (i.e. a 6(iv) b figure below 40), being unable to work (as opposed to choosing not to work) was having a detrimental effect on their mental health related quality of life.

³³ Pearson's Coefficient of Correlation $r = -0.255$, and P value <0.01

³⁴ Pearson's Coefficient of Correlation $r = 0.269$, and P value <0.01

Figure 9 SF12 Physical and Mental Health Scores against 6(iv) b Figure – all Beneficiaries

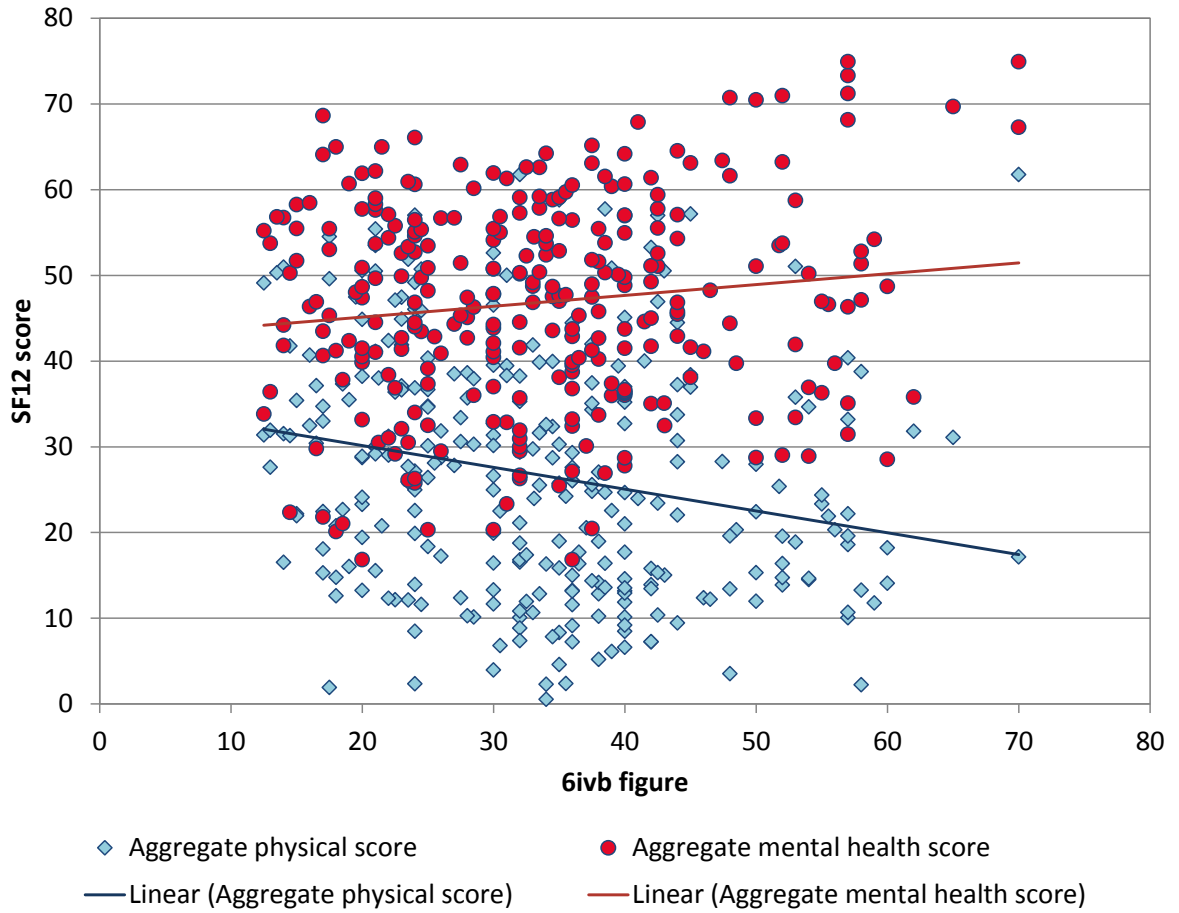
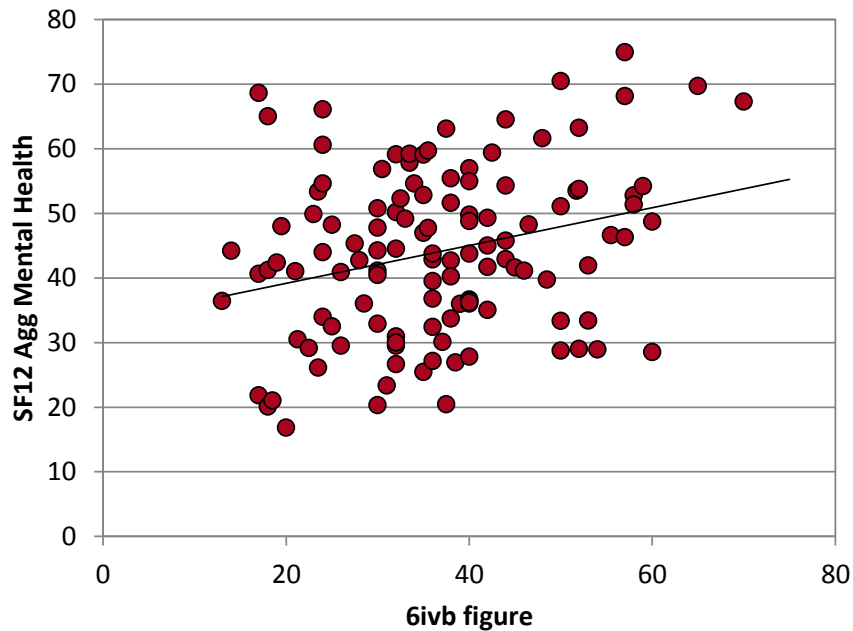


Figure 10 SF12 Mental Health Score against 6(iv) b Figure for Beneficiaries Unable to Work



Finally, we looked at whether those beneficiaries who reported that they were currently experiencing or had recently experienced depression and/or anxiety had lower mental health related quality of life scores. The analysis showed that this group did have a lower mean score than those who had not experienced anxiety and/or depression – 40 compared to 53.

5.2 Mental and Emotional Wellbeing

Gaining a better picture of the mental and emotional wellbeing of beneficiaries was one of the key aims of the survey. To do this we used a standard measure of mental wellbeing, the Warwick Edinburgh Mental Wellbeing Scale which enables comparisons with the general population to be made, plus two additional questions:

- Thinking about your emotional well-being, compared to five years ago how well do you feel you are coping now with the demands of everyday life?
- Thinking about your social life, including social activities and relationships with family, friends and neighbours, which of the following statements best describes your current situation?

5.2.1 Warwick Edinburgh Mental Wellbeing Scale

WEMWBS is validated for use in the UK and has been used in the National Scottish Survey of Public Attitudes to Mental Wellbeing and Mental Health Problems³⁵ since 2008 and the Health Survey for England³⁶ since 2011. It has a long form with 14 questions and a short form (SWEMWBS) with seven, which is the one we used. Respondents were asked to rate each of seven statements against a five-point scale – ‘None of the time’, ‘Rarely’, ‘Some of the time’, ‘Often’, ‘All of the time’ – where ‘None of the time’ = 1 and ‘All of the time’ = 5. So for SWEMWBS the minimum score is seven and the maximum score is 35. The seven statements are:

- I’ve been feeling optimistic about the future.
- I’ve been feeling useful.
- I’ve been feeling relaxed.
- I’ve been dealing with problems well.
- I’ve been thinking clearly.
- I’ve been feeling close to other people.
- I’ve been able to make up my own mind about things.

³⁵ Davidson S. *et al* (2009) *Well, What Do You Think? The Fourth National Scottish Survey of Public Attitudes to Mental Wellbeing and Mental Health Problems*. Scottish Government Social Research, Edinburgh.

³⁶ Department of Health (2013) *No Health without Mental Health: Mental Health Dashboard*. DH, London.

Within the survey group, the lowest ratings were for ‘I’ve been feeling relaxed’, ‘I’ve been feeling useful’ and ‘I’ve been feeling optimistic about the future’, with over a quarter of respondents ticking ‘none of the time’ or ‘rarely’ against these statements. The highest rating was for ‘I’ve been able to make up my own mind about things’, with three quarters of respondents ticking ‘often’ or ‘all of the time’.

To compare SWEMWBS results with WEMWBS data from the national surveys mentioned above, the scores have to be ‘transformed’ (i.e. weighted) and then doubled. This comparison showed that beneficiaries had a lower mean score (43.6) than both the national mean for England³⁷ of 50 and for Scotland³⁸ of 48.7, for those aged 45 to 54. There were no major differences between men and women and there did not appear to be any obvious relationship between mental wellbeing score and impairment band. However, beneficiaries in band 3 had a slightly lower mean score (42) than those in the other Bands. Lower wellbeing scores (i.e. the bottom 40% of beneficiaries) also appeared to be associated with living alone or with a family member (i.e. parent or sibling, not spouse or spouse and children).

We also looked at whether those beneficiaries who reported that they had currently or recently experienced depression and/or anxiety had lower WEMWBS scores. The analysis showed that this group did have a lower mean score than those who had not experienced anxiety and/or depression – 39 compared to 48.

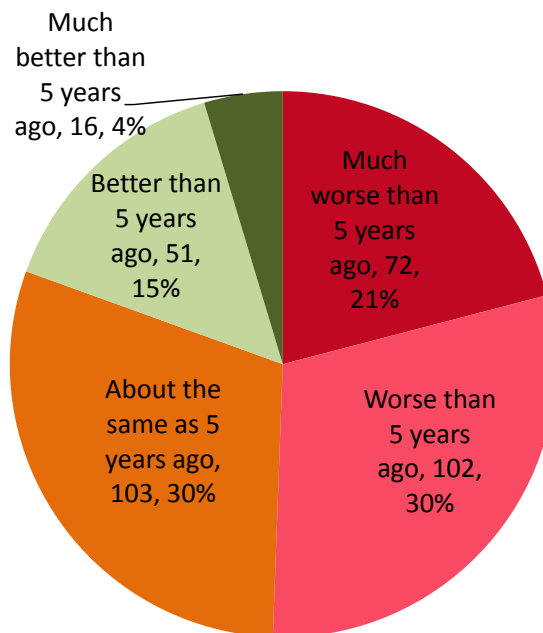
5.2.2 Emotional Wellbeing

As part of the survey we wanted to gauge how beneficiaries’ emotional wellbeing had changed in the past five years and if any changes were related to their Thalidomide damage or personal circumstances. They were asked the question: *‘Thinking about your emotional well-being, compared to five years ago how well do you feel you are coping now with the demands of everyday life?’* There were five possible responses and Figure 11 shows the result for all beneficiaries.

³⁷ Ibid – footnote 36

³⁸ Ibid – footnote 35

Figure 11 Emotional Wellbeing Compared to Five Years Ago



Just over half the respondents said that their emotional wellbeing was worse or much worse than it was five years ago. We looked in more detail at the 72 beneficiaries who said their emotional wellbeing was much worse than five years ago but found few distinguishing characteristics. The pattern of their work and home situations were broadly similar to that of all respondents. However, beneficiaries with higher levels of impairment (i.e. those in Bands 4 and 5) were over represented.

Anecdotally, the Trust believes that many beneficiaries feel they have to ‘put a brave face on’ and find it difficult to be completely honest about how they are feeling. We therefore decided to add a question at the end of the WEMWBS about this.

Beneficiaries were asked to choose one of five responses to the statement: ‘I’ve been able to be honest about how I am feeling/coping’. The results suggested that almost half the beneficiaries in the survey (154/44%) are able to be honest about how they are feeling/coping ‘often’ or ‘all of the time’. However, over a quarter (103) only felt able to be honest ‘some of the time’ and nearly a quarter (81) said they were ‘rarely’ or ‘never’ able to be honest about how they were feeling/coping. The majority of this group of respondents (73/90%) were in the bottom half of the mental wellbeing (WEMWBS) scores.

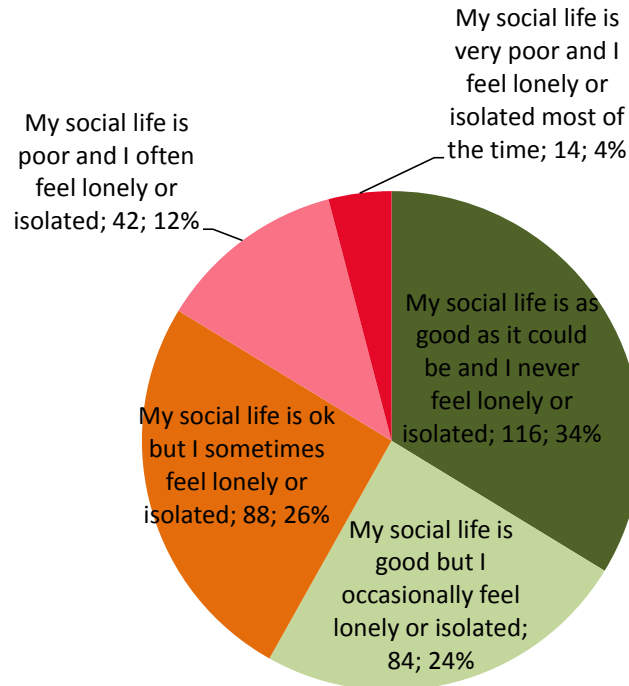
5.2.3 Social Life

The interviews conducted in 2014 for the Health Grant monitoring³⁹ suggested that social isolation may be becoming an issue for some beneficiaries. To explore this issue further we asked the question: ‘Thinking about your social life, including social

³⁹ Ibid – footnote 8

activities and relationships with family, friends and neighbours, which of the following statements best describes your current situation?’ Figure 12 shows the results for all beneficiaries.

Figure 12 Social Life



Encouragingly, well over half the respondents said that their social life was good and they never or only occasionally felt lonely. However, as the graph shows, there was a small group (56/16%) who reported feeling lonely or isolated much of the time. We examined this group more closely and found that whilst the number of women and men was the same (28), the beneficiaries in this group were far more likely to live alone – 39% lived alone compared to 22% of all respondents. A much greater proportion of them also said that they were unable to work because of their disability or health problems, or were not working but would like to – 71% compared to 45% for the whole group.

Chapter 6

Housing, Adaptations and Mobility

Key Findings

Over 40% of respondents anticipated that they would need to move house in the next five years; moving to a home with no stairs and/or one that was fully adapted for their disability/health problems were the most common reasons given.

A number of beneficiaries reported beginning to need cars with adaptations or needing more adaptations.

The cost and quality/availability of wheelchairs, prosthetic limbs and hearing aids continued to be a concern for many beneficiaries.

Housing, adaptations and mobility have always been important concerns for beneficiaries but they have come into sharper focus in recent years as beneficiaries reach their fifties and their circumstances and needs have changed⁴⁰. The survey sought to gather some new information around these issues, in particular related to housing and mobility needs. The results are presented in this chapter.

6.1 Housing and Adaptations

The majority of beneficiaries (304/87%) owned their own house or flat, which is a higher proportion than the general UK population aged 50 to 64 (75%)⁴¹. Twenty one (6%) lived in a private rented house or flat; 15 (4%) in a housing association/local authority house or flat; just six lived in a residential care home or supported housing and five did not answer this question. We looked at the 36 beneficiaries who lived in rented accommodation and found that a significantly higher proportion lived alone (43% compared to 22% for all respondents) and they were also more likely to be unable to work due to their disability or health problems. Beneficiaries in Band 2 were over-represented in this group (31% compared to 23% for all respondents).

When asked whether they were planning any adaptations to their homes in the next year, 30% (106) of respondents said that they were. Eighty-three were planning major adaptations such as an extension or a new kitchen and 23 intended to do minor adaptations such as fitting new door handles or repositioning sockets and switches. Just 62 respondents said they had done all the adaptations required to

⁴⁰ Ibid – footnote 6

⁴¹ Office of National Statistics (2013). *Home ownership and renting in England and Wales – detailed characteristics*. See: <http://www.ons.gov.uk/ons/rel/census/2011-census/detailed-characteristics-on-housing-for-local-authorities-in-england-and-wales/short-story-on-detailed-characteristics.html>

meet their current needs and 42 (12%) respondents said that, despite needing some, they could not afford to do any adaptations in the next year.

Nearly two thirds of respondents (219/62%) had lived in their current home for more than ten years. Beneficiaries who had lived in their current home for less than ten years were more likely to say that either they were planning major adaptations (27% compared to 21% for those who had lived in their current home for ten years or more) or could not afford to do any adaptations in the next year (16% compared to 10%).

Over 41% of respondents (144) anticipated that they would need to move house in the next five years. Table 16 gives a breakdown of the main reasons.

Table 16 Reasons for Needing to Move House

| Reason | Number | % (of those needing to move) |
|--|--------|------------------------------|
| I need a home with no stairs e.g. bungalow or flat | 70 | 48% |
| I need a home which is fully adapted for my disabilities/health problems | 53 | 37% |
| I need a smaller house/garden | 38 | 26% |
| I need to move nearer to shops and services | 28 | 19% |
| I need a larger house | 21 | 15% |
| I need to release some capital from the value of my home | 15 | 10% |
| I need to move nearer to a family member | 16 | 11% |
| I need a house with accommodation for a live-in personal assistant | 14 | 10% |

NOTE: Respondents could tick more than one reason

Table 16 shows that the most common reasons were that the beneficiary needed a home with no stairs; needed a home that was fully adapted for their disability/health problems and/or needed a smaller house/garden. Interestingly, 14 respondents said that they needed a house with accommodation for a live-in personal assistant and a further 21 said they needed a larger house (e.g. to make adaptations possible; create space to use a wheelchair or to share with another family member). The characteristics of those beneficiaries who anticipated needing to move house were broadly similar to those of all respondents, however, beneficiaries in Band 3 were slightly over represented. Beneficiaries in band 4 were most likely to give needing a home with no stairs as a reason for anticipating moving house.

6.2 Mobility – Cars

A high proportion (147/42%) of beneficiaries had cars with no adaptations but a number of them noted that they now needed an automatic car and/or a more expensive model with extra features (e.g. a highly adjustable driving position) in order to be able to drive safely and comfortably. A few added comments to say that whilst they had driven a car without adaptations all their lives, they were finding this increasingly difficult:

“Over the last 25 years I have been 'fortunate' enough not to have had any adaptations to my cars. In recent years though the constant bending to my left to change gears is causing me to have aches and pains in my left hip and all up the left side of my torso.” (Survey ID283)

Nearly half of all respondents (163/46%) said that they had a car or van with adaptations (94 with minor adaptations and 69 with major adaptations). Here again beneficiaries indicated that their needs were changing, with several of those currently driving cars with minor adaptations saying that they anticipated needing more adaptations in the future:

“Choosing a vehicle often limits me as I must try to select a vehicle which either needs minor adaptations or none if I'm lucky. I don't believe this will continue...I am sure I will need more adaptations as time progresses”. (Survey ID195)

Many respondents also added comments about the high cost of adaptations, giving examples ranging from £2,000 for an extended steering wheel column and gear stick to over £25,000 for foot steering. Cost and the difficulties associated with finding and adapting the right vehicle often deterred respondents from changing their cars and several noted that as a consequence they were driving old cars that were becoming unreliable.

6.3 Mobility – Wheelchairs

Thirty-eight beneficiaries (11%) said that they used an electric wheelchair some or all of the time and 61 (18%) used a manual wheelchair some or all of the time (25 respondents used both). Just 19 respondents used a mobility scooter. A few expressed frustration with the quality of NHS wheelchairs and concern about the cost of buying wheelchairs privately, especially electric wheelchairs.

6.4 Prostheses and Hearing Aids

Thirty-six respondents (10%) used prosthetic limbs some or all of the time. A few of these provided additional information, with three noting that they were finding it increasingly difficult to walk due to pain/discomfort and one commenting that they

would like to buy a prosthetic limb privately but at a cost of £70,000 could not afford to do so.

Seventy three beneficiaries (21%) used a hearing aid or aids and/or had hearing implants. Again a few respondents made further comments, in particular highlighting the problem of finding a suitable hearing aid given their Thalidomide damage:

"I've been advised to wear [hearing aids] but they are very big and ugly. I have no ear to 'hide' the device behind and I like short hair. Waiting for critical need and miniaturisation." (Survey ID94)

"My health issues are linked to [my] ability to manage my deafness via the right type & quality of technology. Also managing my personal appearance ...when I am beginning the usual process of age related hair loss my concerns about the visibility of prosthetic ears are increasing." (Survey ID320)

Chapter 7

Work and Pensions

Key Findings

Just 37% of beneficiaries were working (full or part time) compared to 82% of the general population aged 50 to 54.

Of those currently working full or part-time, over three quarters thought that disability/health problems would require them to change their work situation in the next five years.

Over 60% of beneficiaries appeared to have no pension provision over and above their state pension.

There is some evidence⁴² that, over the past decade, the work situation of beneficiaries has been changing more rapidly than might be expected for people of a similar age in the general population. The survey provided an opportunity to examine this further and to explore whether changes in beneficiaries' work situation had wider implications for their health and wellbeing.

7.1 Current Work Situation

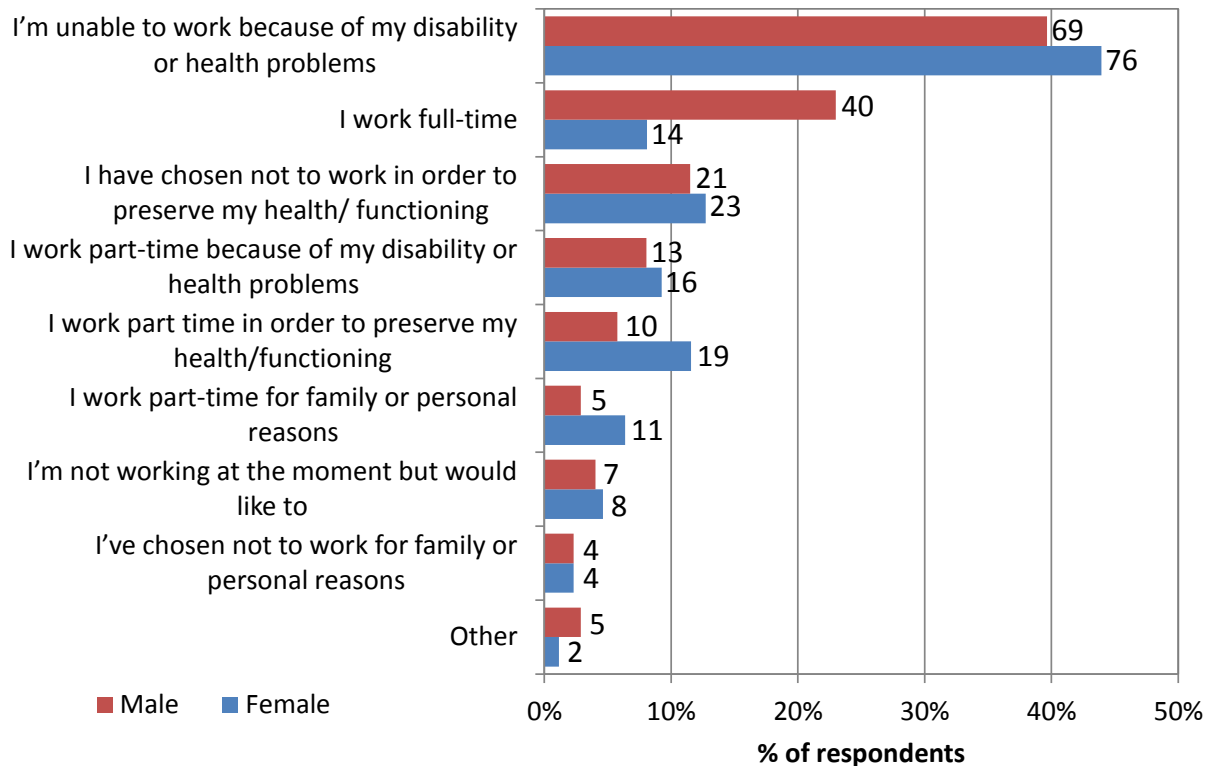
The survey asked respondents to describe their current work situation by ticking one of ten statements. Table 17 provides an overview for all respondents and Figure 13 below shows the breakdown of responses for men and women.

Table 17 Work Situation

| Work Situation – all respondents | Number | % |
|--|--------|-------|
| I'm unable to work because of my disability or health problems | 145 | 41.4% |
| I work full-time | 54 | 15.4% |
| I have chosen not to work in order to preserve my health/functioning | 45 | 12.9% |
| I work part-time because of my disability or health problems | 30 | 8.6% |
| I work part time in order to preserve my health/functioning | 29 | 8.3% |
| I work part-time for family or personal reasons | 17 | 4.9% |
| I'm not working at the moment but would like to | 15 | 4.3% |
| I've chosen not to work for family or personal reasons | 8 | 2.3% |
| Other (e.g. in education) | 7 | 2.0% |

⁴² Ibid – footnote 8

Figure 13 Work Situation of Men and Women



Overall, 15.4% (54) of beneficiaries were working full time but, as Figure 13 shows, there are some significant differences between men and women with only 8% of women working full time. Perhaps not surprisingly, beneficiaries in the lower impairment Bands (1 and 2) and those with no limb damage or mild upper limb damage were more likely to be in full time work. However, around a quarter of beneficiaries in these groups (28%) also said they were unable to work because of their disability or health problems.

Seventeen percent of all respondents (59) were working part time either because of their disability/health problems or because they had chosen to do so to preserve their health/functioning, and a few (17/4.9%) had chosen to work part time for family or personal reasons. A small number (15/4%) said they were not working at the moment but would like to. By far the biggest group were those who were unable to work because of their disability or health problems (145/41%). Here again there was some difference between women and men, with 44% of women compared to 40% of men saying they were unable to work.

Comparisons with the general population, and/or with people with disabilities as a whole are difficult, as different sources use different terminology, definitions and age

groupings. Furthermore, Thalidomide survivors themselves are a diverse group in terms of the severity of their impairments. So the comparisons set out here should be treated with some caution. Data from the Department of Work and Pensions show that in 2015, the employment rate for people aged 50 to 54 in the general population was 82% (78% for women and 86% for men)⁴³. This suggests that 18% of this age group were 'economically inactive', compared to 63% of the survey respondents. However, data collated by the Papworth Trust suggest that disabled people were four times as likely as their non-disabled peers to be unemployed or involuntarily out of work⁴⁴.

We were also interested in exploring how many beneficiaries had changed their work situation since 2000. That year was chosen because in the last 15 years:

- More evidence about the health problems Thalidomide survivors are experiencing as they age has emerged and both research (see section 1.1) and anecdotal evidence suggest that as a result many beneficiaries are finding it hard to work or to work full time, or to do the type of work they had done for much of their lives.
- The exemption from taxation and an uplift in annual Grants⁴⁵ has resulted in some improvement in the general financial position of UK Thalidomide survivors.
- The first Health Grant was introduced in 2010 and renewed for ten years in 2013. The evaluation of the Grant⁴⁶ suggested that for some beneficiaries whose deteriorating health was affecting their ability to work, and others who felt, or were advised that working was having a detrimental effect on their health, the Grant enabled them to change their work situation.

Overall 59% (208) of respondents said that their work situation had changed since 2000 – almost two thirds of these (130) had stopped working and the remainder had either changed jobs or reduced their working hours. Figure 14 below shows, in five-year bands, when respondents' work situations changed.

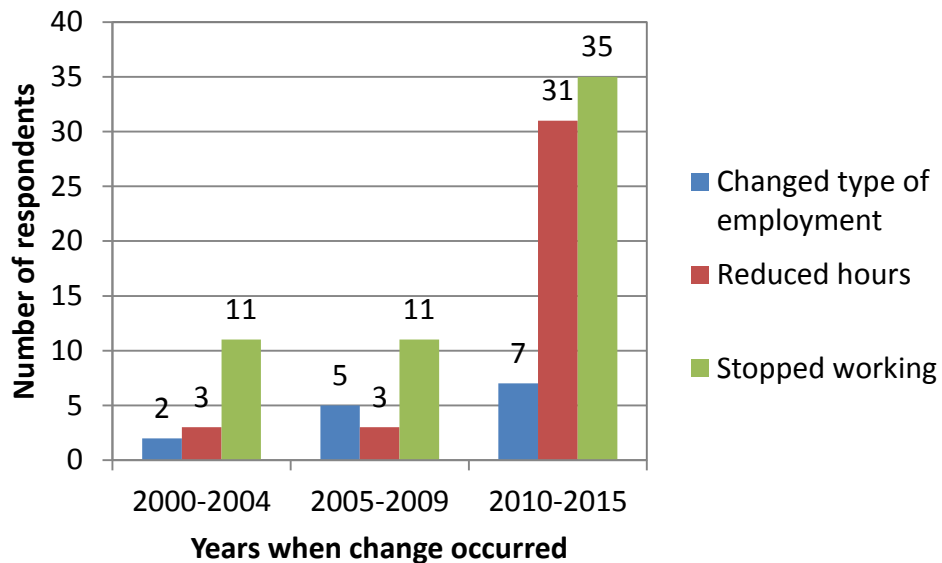
⁴³ Department of Work and Pensions (2015). *Employment statistics for workers aged 50 and over, by 5-year age bands and gender: From 1984 to 2015*. DWP, London.

⁴⁴ Papworth Trust (2104). *Disability in the United Kingdom 2014: Facts and Figures*. Cambridge.

⁴⁵ The compensation payments to beneficiaries of the Thalidomide Trust take the form of Annual Grant.

⁴⁶ Ibid – footnote 6

Figure 14 Changes in Work Situation since 2000



There did not appear to be any obvious relationship between impairment band and changes in work situation, except that beneficiaries in Band 5 were least likely to have changed their work situation. However, this may be because, due to the severity of their impairment, fewer of them were working in 2000.

Of the respondents whose work situation had changed since 2000, 91 volunteered additional comments. For many of these respondents the change in their work situation was progressive, often moving from full to part time employment, or reducing working hours or changing jobs, and then giving up work completely.

“Increasingly from 2002 onwards, at which time I was a Director of a limited company working in excess of 50 hours per week. I now struggle to manage 18 hours per week. I have now reached the point where stopping work altogether is imminent.” (Survey ID2)

Whilst a few respondents noted that the uplift in the annual Grant had enabled them to change their work situation, others still felt under financial pressure:

“Injury to hand, equivalent of RSI – my physio told me I needed to retire, cannot afford to, but cut down.” (Survey ID89)

“I left work for a bit due to ill health but could not survive on benefit money and had to go back to full time work.” (Survey ID166)

Others had reluctantly given up work, sometime because their employer could not accommodate their needs:

“2011 I was forced to make a difficult decision to stop working due to continued failing health.” (Survey ID183)

“In 2009 I had to reduce my hours in line with medical advice. In 2010 I had further problems... and in 2011 I was medically retired (not at my request) as my employer had no role for me.” (Survey ID276)

Of those beneficiaries who were working full or part-time, over three quarters (118) thought that their Thalidomide-related disability/health problems would require them to change their work situation in the next five years, and of these 51 thought that they might have to stop working.

Together, the findings from the employment section of the survey suggest that many beneficiaries are facing difficult decisions about their working lives. Compared to their peers in the general population, health problems appear more likely to affect beneficiaries' ability to work or to work full time and, for some beneficiaries, changing their work situation is an important means of preserving their health.

7.2 Pension Provision

There was just one question in the survey about pension provision. We asked, *‘If you have paid into an employers’/company or private pension (in addition to your state pension), approximately how many years of contributions do you have?’* Thirty nine percent of respondents (137) said that they had contributed to a private or employers' pension, which suggests that over 60% of beneficiaries had no pension provision over and above their state pension. This is a much higher figure than the pre-retirement group in the general population. The Office of National Statistics estimates that 35% of men aged 50 to 64 and 39% of women aged 50 to 59 do not have any private pension savings.⁴⁷ These percentages vary with educational qualifications but as was noted in Chapter 2, the beneficiaries in the survey had a very similar pattern of qualifications to the general population of a similar age, so this does not account for the difference. The number of years of contributions ranged from one to 39 years and the mean was 19.1 years⁴⁸. More generally, the data from this question need to be treated with caution as respondents may have had difficulty recalling how many years of contributions they had.

⁴⁷ Office for National Statistics (2014) Statistical Bulletin: Characteristics of People and Households without Private Pension. ONS London.

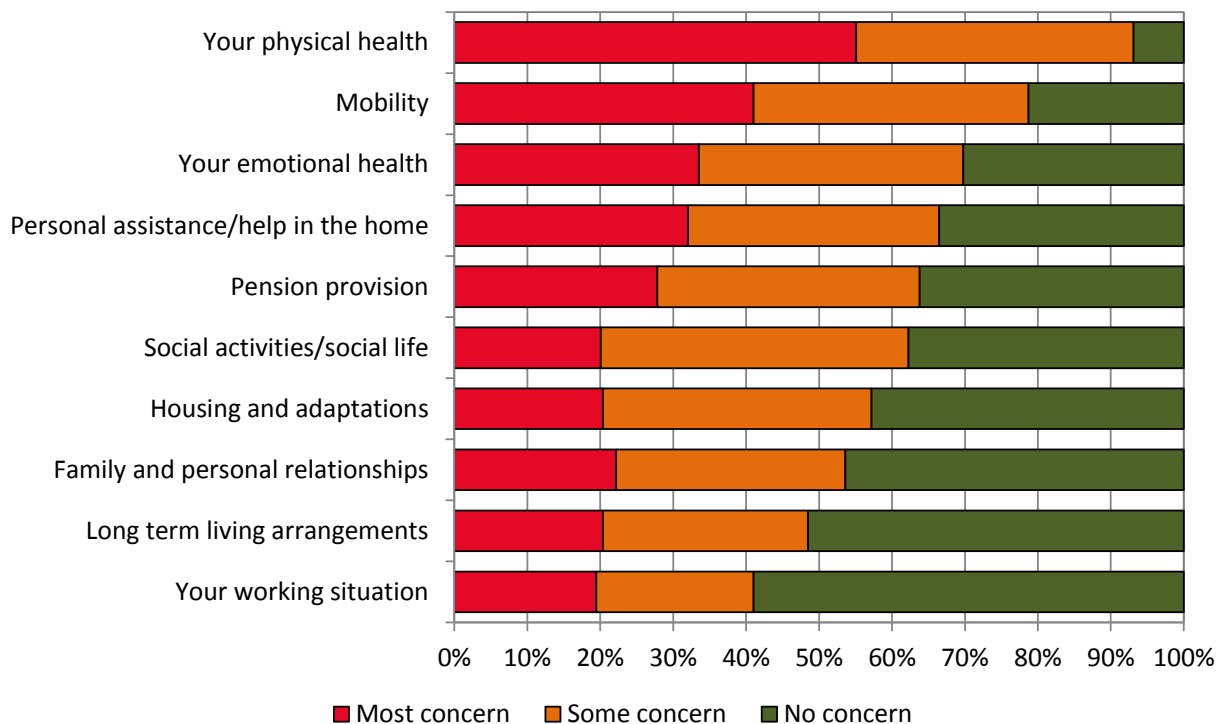
⁴⁸ One anonymous respondent said they had 45 years of contributions which, given the age range of beneficiaries, would be impossible unless they had made additional contributions. As we were unable to check this response, we have not included it in the mean.

Chapter 8 Concerns for the Future

Whilst the survey was primarily designed to document the health and wellbeing issues beneficiaries were currently experiencing, we did ask one specific question about their concerns for the future. In addition, at the end of the questionnaire there was a free text box where respondents could make comments or provide more information on any topic. Ninety-eight beneficiaries added comments and many of these reflected their concerns for the future. In this chapter we begin by presenting the results of the standard question. We then draw together the main themes and issues emerging from beneficiaries' comments. We have purposefully included a number of quotations, as these bring to life the issues beneficiaries are facing.

Question 47 asked – ‘When you think about your future which of the following areas of your life are of most concern to you?’. There were ten areas of life listed and for each one respondents had three answer choices – ‘Most Concern’, ‘Some Concern’ and ‘No Concern’. Figure 15 shows the overall results for the question.

Figure 15 Areas of Life of Most Concern



It is clear that physical health is the major area of concern for the vast majority of beneficiaries, and this was reflected in the comments respondents added. These

ranged from concerns about deterioration in their general health, either now or in the future, to specific health problems:

“Health-wise, I feel at the moment I am in between feeling quite well and potentially deteriorating quite quickly. I could stay at this level of health for the next 20 years or so but equally all it would take is for a few physical problems to occur and my health and way of life both domestically and socially would change forever.” (Survey ID70)

“As a result of doing everything with my only arm I have multiple RSIs, trapped nerves in my neck and shoulder and have lost some dexterity and experience numbness in my hand. I have been told that this won't improve and have had to stop doing a lot of everyday general activities about the house. There is the possibility that I will completely lose the use of my arm but there's no way to predict when.” (Survey ID276)

Many of the health problems beneficiaries mentioned were causing progressive loss of function and the implications of this for their independence and family relationships caused concern:

“My only normal hand is deteriorating badly. I've had 3 operations on it, they can't do anything more. I'm in pain with it nearly all the time. I can't do hardly anything for myself now. I'm terrified. I'm only 55 – how much worse is it going to get? Having one hand I was never disabled but I am now. Luckily I have fantastic children who all automatically do everything for me that's needed. They cut my food up, do up my buttons, zips, and laces, and are amazing but I don't want to be a burden to them. Losing your independence is soul destroying.” (Survey ID307)

A number of beneficiaries described their wider fears about coping and loss of self-esteem if their health declined further:

“This past few years my health has declined, my anxiety is more and I worry about coping. I physically struggle more with daily life. I don't like talking about not being able to cope or asking for help. Hate having to rely on people. Simple things I used to do I can no longer do. It makes me feel a burden and useless at times.” (Survey ID126)

Mobility was the second major area of concern. For some beneficiaries it was linked to specific injuries (e.g. a misdiagnosed fracture) or problems with prosthetic limbs or wheelchairs, but others described a more general decline:

“I am an optimistic person sustained by a fantastic family and faith. However, my mobility and independence have reduced over the past couple of years. I need more help than did to get dressed etc. and I drop things and find stairs difficult at times. It concerns me that my body is wearing out and this does worry me.” (Survey ID308)

As the data presented in previous chapters have shown, deterioration in physical health and loss of independence were, for many beneficiaries, intertwined with their emotional health, and their comments highlighted this. For some, worries about emotional health resulted from a lifetime of dealing with physical impairment, whilst for others it arose from recent problems or events:

“Everything in life is and always has been a compromise from the type of property I live in to what I may prefer in clothes, social activities, holidays, or helping with grandchildren. All aspects of life are a compromise between what I would like and what my disability allows. Emotionally, psychologically, physically this is impacting far more as I age. A combination of deteriorating health/ability and [the] realisation of the freedom of choice my peers have.” (Survey ID132)

“In the last few years I have noticed a huge deterioration in my everyday needs and emotional wellbeing. This has made me suffer with deep anxiety and panic attacks. I do feel safe and secure when in my own home [but] cannot cope with busy environments at all these days... [since] I had a serious fall...which left me with very little confidence and scared of falling again.” (Survey ID80)

A number of respondents highlighted their growing need for personal assistance and help in the home. Some beneficiaries found it hard to come to terms with this in relation to their independence and personal privacy, and looking ahead were unsure how to manage their need for support. Others had concerns about paying for the level of help they anticipated needing.

“I am very independent...but I find it harder to manage. The big dilemma is how to maintain independence or how to manage help or minimize it because I don't mind one-off visits e.g. for garden or handyman jobs but regular cleaning etc. I don't like. It feels like an interference and I like my space.” (Survey ID192)

“I feel lucky to have the support of my husband who has given up work to care and support me. Also, I have the backup of my Mum...who can help and support me. Without this support I don't know how I would afford to live this way, as the extra help I would have to pay for could not be covered with my allocation alone.” (Survey ID59)

Respondents' comments about personal assistance and help in the home often overlapped with comments about support from family members and fears about this changing in the future.

“Because I live with my partner, I feel relatively secure. This year he had a cancer scare and though his results were negative I came face to face with the precariousness of my living arrangement. I would be in a disastrous situation if anything happened to him. I rely on him 100%.” (Survey ID85)

“I have concerns about my health and the impact it will have on my wife, as well as [my] deteriorating independence.” (Survey ID104)

“What happens to me when my parents are no longer alive?” (Survey ID133)

A small number of respondents commented on their housing or living circumstances, including the future cost of living or being able to afford to move house. However, worryingly, a few beneficiaries highlighted fears about safety in their home, as the two quotations below illustrate:

“Housing – I feel unsafe where I live. I'm 53 and several men have tried to assault me.” (Survey ID156)

“I think one area that's not covered here is a feeling of vulnerability. I do feel this as I'm getting older, in particular when I'm in the home alone. Not just in case something happened about the house but also from the potential threat of 'break ins' and what could I do to defend myself!” (Survey ID283)

Whilst respondents' comments highlighted specific concerns for the future, running through many of them was a common thread, namely a sense that their current way of life was vulnerable, even precarious.

Lastly, a few beneficiaries added comments that both reflected how much they valued the support they had had from the Thalidomide Trust but also highlighted areas where more help may be needed in the future, including:

- Advice about social care services.
- Support for emotional and mental health problems.
- More research into the types of aids and adaptations that Thalidomide survivors will need as they grow older.
- Facilitating beneficiaries coming together to reduce isolation and improve peer support.

A comment from one beneficiary reinforced this final point:

“As a late beneficiary (only had more severe problems in the last 10 years), I feel an outsider to the Thalidomide Trust and Thalidomide family. I also feel that I have no idea what is 'out there' to help me. I want more out of my life but don't know how to get it or who to talk to for advice.” (Survey ID194)

Chapter 9

Conclusion

The 2015 survey was the first comprehensive investigation of the health and wellbeing of all beneficiaries to be conducted by the Trust and the response from beneficiaries was excellent, with over 75% of them completing it. The high response rate, coupled with the representativeness of the beneficiaries in the survey group in terms of gender and level of impairment, mean that the data gathered are robust and we can have a high degree of confidence in the results.

Overall, the survey results show that beneficiaries are experiencing a wide range of health problems. A number of these health problems appear to be more common amongst Thalidomide survivors than in the general population of a similar age (e.g. musculoskeletal problems, anxiety and depression and chronic kidney disease), whilst the prevalence rate for other conditions (e.g. diabetes and stroke/TIA) appears to be similar. What is clear, however, is that all these health problems may be made more difficult to manage, or be exacerbated by beneficiaries' Thalidomide damage; international evidence supports this conclusion (e.g. osteoarthritis⁴⁹, depression and anxiety⁵⁰, diabetes⁵¹). Furthermore, a high proportion of beneficiaries were experiencing multiple health problems, the disabling consequences of which may be substantial.

Many beneficiaries appear to be self-managing some of their health problems, using complementary therapies, diet and exercise, making changes to their working lives and adapting their homes. However, a very high proportion had used or were using prescription pain medication or pain relieving treatments. Joint surgery appears to be more common amongst Thalidomide survivors than in the general population of a similar age. The survey also showed that half the respondents were currently experiencing or had recently experienced depression and/or anxiety. Again, this is a far higher proportion than the general population. Importantly, only a quarter of beneficiaries had actually had treatment for anxiety and/or depression, which suggests that many beneficiaries have not had any support from health professionals for their mental health problems.

The findings in relation to health related quality of life and mental wellbeing are particularly interesting. The SF12 results suggest that beneficiaries with lower levels of impairment, who are now unable to work because of their disability or health problems, have poorer mental health related quality of life than their peers with

⁴⁹ Ghassemi, S. A. Danielsson, B Karlsson, J. Danielsson, A. J. (2014). Long term follow-up of thalidomide embryopathy: malformations and development of osteoarthritis in the lower extremities and evaluation of upper extremity function. *Journal of Child Orthopaedics* 2014; 8:423-433.

⁵⁰ Ibid – footnote 9

⁵¹ Ibid – footnote 18

more severe impairments. Many of these beneficiaries may have coped well for much of their lives – working, being active and perhaps using few adaptations/aids – but they are now experiencing a loss of function. In some ways, they may feel ‘newly disabled’ and this is having a detrimental effect on their mental health related quality of life.

Beneficiaries who lived alone and/or were unable to work because of disability or health problems were more likely to experience lower mental wellbeing (as assessed by SWEMWBS) and to report that they felt lonely or isolated most of the time. Whilst these ‘risk factors’ are not unique to Thalidomide survivors, it is clear that a far higher proportion of them felt unable to work because of their disability or health problems than might be expected amongst their peers in the general population. Furthermore, the survey suggested that this proportion is likely to increase over the next five years.

This decline in the ability to work, or work full time, has been occurring at a time when many beneficiaries have been contemplating other changes in their home and support arrangements, many of which have financial implications. In particular, the survey suggests that a significant proportion of beneficiaries anticipate needing to move home in the next five years because they need a home with no stairs, one that is fully adapted for their needs or one that is simply more manageable. It also highlighted that, in the future, more beneficiaries expected to need an adapted car or more adaptations, whilst others anticipated making greater use of electric wheelchairs. Lastly, whilst only a minority of beneficiaries were currently using local authority social care services, a similar proportion thought they would need to apply for local authority funded social care in the next five years and two thirds of all respondents were already paying privately for their support and care services.

Overall, the results of the survey suggest that as Thalidomide survivors reach late middle age, a number of factors are converging to adversely affect their wellbeing. A combination of (often multiple) physical and mental health problems, inadequate access to knowledgeable health professionals, the need for more practical and personal support, changing family circumstances, and a decline in the ability to work, is creating new challenges for beneficiaries. However, as the final question in the survey showed, and the quotation below vividly illustrates, the area of life beneficiaries are most concerned about when they look ahead is their physical health.

“From being a fully employed, independent active and optimistic person, I am becoming isolated and cut off from work and family... Any serious health concerns – diabetes, cancers etc. – will be both difficult and painful to manage. Perhaps more than anything I dread the prospect of going blind. While I am endeavouring to remain active and positive and have received huge support from family, friends and Thalidomiders (social media is invaluable) at times, I feel my sense of myself as a person is under siege.”
(Survey ID265)

Appendix A Health & Wellbeing Questionnaire with Responses



The Thalidomide Trust

Health and Wellbeing Survey 2015

Note: unless otherwise stated all percentages are out of 351; percentages are not shown for the individual WEMWBS statements; numbers and percentages are not shown for the individual SF12 questions.

About You

At the end of the survey we will ask you for your name. It would be extremely helpful to us if you could give your name but if you would prefer to complete the survey anonymously, that's fine.

| | | | | | | |
|----------|------|-----|--------|-----|------------|---|
| Are you? | Male | 174 | Female | 174 | Not stated | 3 |
|----------|------|-----|--------|-----|------------|---|

| What is the highest level of education qualification you have obtained (please tick one box)? | | | |
|---|-------------|--|-------------|
| Degree or higher degree (e.g. MA, PhD) | 70 (20%) | ONC/BTEC or NVQ Level 3 | 15 (4%) |
| Diploma or professional qualification (e.g. Registered Nurse) | 30 (9%) | O Level or GCSE equivalent (Grade A-C) | 65 (19%) |
| A Levels or Highers | 37 (11%) | O Level or GCSE equivalent (Grade D-G) | 17 (5%) |
| HNC/HND or NVQ Level 4 | 15 (4%) | No formal qualifications | 77 (22%) |
| Other | 18 (5%) | Not stated | 7 (2%) |

Family and Housing

Q1 Which of the following best describes your home circumstances (please tick)?

| | |
|--|-----------|
| I live alone | 76 (22%) |
| I live with my partner/spouse | 115 (32%) |
| I live with my partner/spouse and other family members (e.g. children) | 109 (31%) |
| I live with another family member (e.g. parent or sibling) | 38 (11%) |
| Other (please describe): | 10 (3%) |
| Not stated | 3 (1%) |

Q2 Which of the following best describes your housing situation (please tick)?

| | |
|---|-----------|
| I live in a house/flat which I (or my partner/family) own | 300 (85%) |
| I live in a private rented house/flat | 22 (6%) |
| I live in a housing association or local authority house/flat | 15 (4%) |
| I live in a residential care home | 3 (1%) |
| Other (please describe): | 4 (1%) |
| Not stated | 7 (2%) |

Q3 How many years have you lived in your current home?

Q4 Are you planning any adaptations to your home *in the next year*?

| | |
|---|----------|
| Question is not applicable to me | 71 (20%) |
| No, I have done all the adaptations required to meet my current needs | 62 (18%) |
| No, I can't afford to do any adaptations in the next year | 44 (13%) |
| Yes, major adaptations e.g. new kitchen, an extension, other structural changes | 83 (24%) |
| Yes, minor adaptations e.g. new door handles, repositioning electrical sockets | 23 (7%) |
| Not sure/don't know | 61 (17%) |
| Other | 2 (1%) |
| Not stated | 5 (1%) |

Q5 If you think you will need to move home *in the next 5 years* what are the main reasons for this (please select all that apply)?

| | |
|---|-----------|
| Question is not applicable to me - I don't think I will need to move home | 207 (59%) |
| I need a home which is fully adapted for my disabilities/health problems | 53 (15%) |
| I need a smaller house/garden | 38 (11%) |
| I need a home with no stairs e.g. bungalow or flat | 70 (20%) |
| I need a larger house | 21 (6%) |
| I need a house with accommodation for a live-in personal assistant | 14 (4%) |
| I need to release some capital from the value of my home | 15 (4%) |
| I need to move nearer to a family member | 16 (5%) |
| I need to move nearer to shops and services | 28 (8%) |
| Other | 39 (11%) |

Q6 Which, if any, of the following difficulties might affect your ability to move home (please tick all that apply)?

| | |
|---|-----------|
| Question is not applicable to me - I don't think I will need to move home | 183 (52%) |
| The cost of buying <i>and</i> adapting a new home | 91 (26%) |
| Getting a mortgage/increasing your existing mortgage | 52 (15%) |
| Finding the right property | 81 (23%) |
| Selling your existing home | 25 (7%) |
| Finding a suitable property to rent | 9 (3%) |
| My local authority/housing association accepting that my needs are not being met in my current home | 3 (1%) |
| Not sure/don't know | 7 (2%) |
| Other | 13 (4%) |

Work and Pensions

Q7 Which of the following best describes your work situation (please tick one)?

| | |
|--|-----------|
| I work full-time | 54 (15%) |
| I work part-time because of my disability or health problems | 30 (9%) |
| I work part time in order to preserve my health/functioning | 29 (8%) |
| I work part-time for family or personal reasons | 17 (5%) |
| I'm not working at the moment but would like to | 15 (4%) |
| I'm unable to work because of my disability or health problems | 145 (41%) |
| I have chosen not to work in order to preserve my health/functioning | 45 (13%) |
| I've chosen not to work for family or personal reasons | 8 (2%) |
| I'm in full or part-time education | 1 (<1%) |
| Other | 6 (2%) |
| Not stated | 1 (<1%) |

Q8 **Since the year 2000**, has your work situation changed in any of the following ways because of your Thalidomide-related disability and/or health problems?

| | |
|--------------------------------------|-----------|
| My working situation has not changed | 139 (39%) |
| I have reduced my working hours | 63 (18%) |
| I have changed the type of work I do | 36 (10%) |
| I have stopped working | 128 (36%) |
| None stated | 5 (1%) |

If your working situation has changed please tell us in what year(s) this occurred.

Q9 If you currently work full or part time, **in the next 5 years** do you think your Thalidomide-related disabilities and/or health problems will require you to change your work situation in any of the following ways?

| | |
|--|-----------|
| Question does not apply to me as I am not currently working | 201 (57%) |
| Reduce my working hours? | 42 (12%) |
| Change the type of work I do? | 25 (7%) |
| Stop working? | 50 (14%) |
| I don't expect my work situation to change because of my Thalidomide-related disabilities and/or health problems | 50 (14%) |

Q10 If you have paid, or are currently paying into an employer/company or private pension (i.e. additional to the normal state pension) approximately how many years of contributions do you have?

Q11 Is there anything else you would like to tell us about your work or pension situation?

Original Thalidomide impairments

We would like to understand how the health and wellbeing of beneficiaries with different types of impairments is changing. The categories in the table below are just intended to provide us with a simple picture and are not comprehensive.

Q12 Original Thalidomide impairments - damage to limbs (please tick all the categories below that you feel apply to you):

| | Left side of body | Right side of body | Both sides |
|-------------------------------|-------------------|--------------------|------------|
| Minimal or no arm | 70 (20%) | 68 (19%) | 63 (18%) |
| Arm shorter than elbow length | 85 (24%) | 71 (20%) | 64 (18%) |
| Arm longer than elbow length | 70 (20%) | 80 (23%) | 50 (14%) |
| Arm normal length | 118 (34%) | 127 (36%) | 104 (30%) |
| Misshapen hand/missing digits | 213 (61%) | 202 (58%) | 188 (54%) |
| Misshapen shoulder joint | 109 (31%) | 101 (29%) | 87 (25%) |
| Minimal or no leg | 31 (9%) | 38 (11%) | 26 (8%) |
| Leg shorter than knee length | 22 (6%) | 17 (5%) | 14 (4%) |

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| | | | |
|-----------------------------|-----------|-----------|-----------|
| Leg longer than knee length | 18 (5%) | 18 (5%) | 11 (3%) |
| Leg normal length | 271 (77%) | 270 (77%) | 266 (76%) |
| Misshapen foot | 45 (13%) | 40 (11%) | 34 (10%) |
| Misshapen hip | 46 (13%) | 49 (14%) | 38 (11%) |
| Misshapen knee | 35 (10%) | 24 (7%) | 22 (6%) |

Q13 Original Thalidomide impairments - other damage (please tick all the categories below that you feel apply to you):

| | |
|--|----------|
| Scoliosis (curved spine) | 77 (22%) |
| Damage to face and/or outer ear (including facial palsy) | 65 (19%) |
| Totally deaf | 28 (8%) |
| Partially deaf | 96 (27%) |
| Totally blind | 1 (<1%) |
| Partially sighted | 39 (11%) |
| Damage to heart | 34 (10%) |
| Missing or damaged kidneys | 44 (13%) |
| Damage to digestive system/bowels | 42 (12%) |
| Damage to reproductive organs | 42 (12%) |
| Damage to nervous system | 52 (15%) |
| No 'other damage' | 91 (26%) |
| <i>Other impairments/damage (please describe if you wish):</i> | |
| | |

Mobility and Equipment

Q14 Do you use any of the following to help you with your mobility? (please tick)

| | All of the time | Some of the time | None of the time |
|--|-----------------|------------------|------------------|
| Manual wheelchair | 22 (6%) | 39 (11%) | 286 (82%) |
| Electric wheelchair | 14 (4%) | 24 (7%) | 309 (88%) |
| Mobility scooter | 3 (1%) | 16 (5%) | 328 (93%) |
| Prosthetic limbs | 29 (8%) | 7 (2%) | 311 (89%) |
| Q15 Do you use a hearing aid/s and/or have hearing implants? | | | 73 (21%) |

Q16 Do you have a car or van? (please tick all that apply)

| | |
|---|-----------|
| I don't have a car or van | 46 (13%) |
| I have a car/van with no adaptations | 147 (42%) |
| I have a car/van with minor adaptations | 94 (27%) |
| I have a car/van with major adaptations | 69 (20%) |

Q17 Is there anything else you would like to tell us about your mobility or the equipment/vehicles you use e.g. quality of wheelchairs, cost of adapting a car?

Health Problems

Q18 Are you currently experiencing, or have you recently had, any of the following health problems (please tick all that apply to you):

| | | | |
|---|-----------|---|-----------|
| Back problems - prolapsed disc; damage to vertebrae; scoliosis | 108 (31%) | Anxiety | 145 (41%) |
| Back problems – muscular pain and/or spasms | 237 (68%) | Alcohol or drug misuse | 26 (7%) |
| Neck pain and/or loss of movement | 195 (56%) | Other mental health problems | 25 (7%) |
| Shoulder - pain, loss of movement or deterioration of the joint | 211 (60%) | Generally poor emotional health | 68 (19%) |
| Arms and wrists - pain, loss of strength and/or movement | 197 (56%) | Generalised pain – severe and/or continuous | 92 (26%) |
| Hands - pain, loss of grip and/or dexterity | 210 (60%) | Generalised pain – moderate and/or intermittent | 81 (23%) |
| Hip - pain, loss of movement or deterioration of the joint | 164 (47%) | Severe tiredness/fatigue | 139 (40%) |
| Knee - pain or deterioration of the joint | 168 (48%) | Tingling/pins and needles | 182 (52%) |
| Ankles, feet and toes - pain and/or loss of movement | 100 (28%) | Numbness/Loss of feeling | 130 (37%) |
| Problems with the fit or use of prosthetic limbs | 25 (7%) | Sensations of extreme heat or cold | 127 (36%) |
| Deteriorating sight/eye problems | 151 (43%) | Heart problems | 28 (8%) |
| Deteriorating hearing/other ear problems | 133 (38%) | Kidney problems | 30 (9%) |
| Problems with balance/falls | 109 (31%) | Bladder or continence problems | 72 (21%) |
| Dental health problems | 120 (34%) | Asthma or breathing problems | 54 (15%) |
| Weight management problems | 141 (40%) | Diabetes | 32 (9%) |
| Bowel or digestive problems | 98 (28%) | Stroke/TIA | 5 (1%) |

| | | | |
|--|-----------|---------------------------|--------|
| Cancer | 17 (5%) | I have no health problems | 6 (2%) |
| Depression | 118 (34%) | | |
| Are there any other health problems you would like to tell us about? | | | |

Q19 If your health or wellbeing has improved recently what has made the difference e.g. weight loss, successful treatment.

| |
|--|
| |
|--|

Use of Health Services

Q20 Which, if any of the following health treatments have you had in the **past 10 years**:

| | | | |
|--|-----------|--|----------|
| Shoulder replacement/surgery | 12 (3%) | Physiotherapy - Private | 88 (25%) |
| Wrist/arm surgery | 18 (5%) | Acupuncture | 53 (15%) |
| Hip replacement/hip surgery | 21 (6%) | Osteopathy | 34 (10%) |
| Knee replacement/surgery | 14 (4%) | Chiropractic | 61 (17%) |
| Bariatric surgery for weight problems | 5 (1%) | Therapeutic Massage | 89 (25%) |
| Treatment to relieve pain e.g. injections | 79 (23%) | Treatment for depression and/or anxiety, including counselling | 87 (25%) |
| Prescription pain medication | 168 (48%) | Counselling for other emotional issues | 35 (10%) |
| Back surgery | 6 (2%) | Treatment for alcohol or drug dependence | 8 (2%) |
| Physiotherapy - NHS | 105 (30%) | No health treatments | 64 (18%) |
| Are there any other health treatments you would like to tell us about? | | | |

Q21 How well does your GP/GP surgery understand your Thalidomide damage and how it affects you?

| | | | |
|-------------------|--------------------|--------------------|---------------------|
| Fully understands | Partly understands | Doesn't understand | Not sure/don't know |
| 57 (16%) | 136 (39%) | 72 (21%) | 81 (23%) |

Q22 If you had a Thalidomide-related health problem do you think your GP would be willing to seek advice from a specialist with knowledge of Thalidomide damage and/or from the Thalidomide Trust?

| | | |
|-----------|---------|---------------------|
| Yes | No | Not sure/don't know |
| 158 (45%) | 23 (7%) | 169 (48%) |

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Q23 **In the past 5 years** have you experienced any of the following problems with healthcare services (please select all that apply):

| | |
|--|-----------|
| Lack of knowledge/understanding of Thalidomide damage in general amongst health professionals | 170 (48%) |
| Lack of knowledge/understanding of my impairments amongst health professionals | 127 (36%) |
| Lack of involvement/choice in decisions made about my care and treatment | 50 (14%) |
| Difficulties/delays in seeing a suitably experienced health professional/specialist | 81 (23%) |
| Misdiagnosis or delayed diagnosis | 48 (14%) |
| Delays in getting treatment | 82 (23%) |
| Incorrect or inappropriate treatment | 47 (13%) |
| Inflexible care or treatment (e.g. blocks of physiotherapy treatments rather than on-going care) | 62 (18%) |
| Problems with the quality or choice of equipment (e.g. wheelchairs, hearing aids, prosthetics) available through the NHS | 51 (15%) |
| I have not experienced any problems with healthcare services | 132 (38%) |
| Other (please describe) | |

Social Care Support

| | | Yes | No |
|-----|---|----------|-----|
| Q24 | Do you get local authority funded social care (i.e. personal budget, direct payment or home care services)? | 66 (19%) | 282 |

*If you answered 'Yes' to Q24 please continue with Q25, if 'No' go to Q30:
(Note: for Qs 25 to 28 incl. percentages are out of 66. However, some respondents who said 'Yes' to Q24 did not then respond to Qs 25 to 28)*

| | | | |
|-----|--|----------|--------|
| Q25 | Do you feel the level of local authority funded support you get is enough to meet your needs? | 34 (52%) | 27 |
| Q26 | Has your local authority funded care package or personal budget/direct payment been reduced in the last 5 years? | 20 (30%) | 39 |
| Q27 | Do you pay for additional time/services from your own income? | 40 (60%) | 22 |
| Q28 | Do you think you will need more support in the next 5 years? | 49 (74%) | 6 (9%) |

Q29 Is there anything you would like to tell us about the quality and/or availability of the social care services you get?

*If you answered 'No' to Q24 continue with Q30, if 'Yes' go to Q32:
(Note: for Qs 30 and 31 percentages are out of 282. However, some respondents who said 'No' to Q24 did not then respond to Qs 30 and 31)*

| | | Yes | Not sure | No |
|-----|---|-----------|----------|-----|
| Q30 | Do you buy support (e.g. personal assistance, help in the home, gardening/DIY) privately? | 181 (64%) | | 89 |
| Q31 | Do you think you will need to apply for local authority funded social care in the next 5 years? | 54 (19%) | 83 (29%) | 124 |

Mental Well-being

We know that many beneficiaries feel they have to 'put a brave face on'. So, the next few questions are designed to help us get a better picture of how people are really feeling/coping emotionally.

Q32 For each of the following statements **please circle** the number that best reflects how you feel now:

| Statements | None of the time | Rarely | Some of the time | Often | All of the time |
|---|------------------|--------|------------------|-------|-----------------|
| I've been feeling optimistic about the future | 25 | 69 | 134 | 77 | 35 |
| I've been feeling useful | 28 | 66 | 129 | 71 | 42 |
| I've been feeling relaxed | 22 | 80 | 145 | 61 | 29 |
| I've been dealing with problems well | 9 | 40 | 162 | 91 | 36 |
| I've been thinking clearly | 7 | 31 | 107 | 116 | 76 |
| I've been feeling close to other people | 16 | 51 | 84 | 105 | 81 |
| I've been able to make up my own mind about things | 7 | 12 | 51 | 118 | 148 |
| I've been able to be honest about how I am feeling/coping | 21 | 60 | 103 | 86 | 68 |

Q33 Thinking about your emotional well-being, **compared to five years ago** how well do you feel you are coping now with the demands of everyday life (please tick)?

| | |
|-------------------------------|-----------|
| Much worse than 5 years ago | 72 (21%) |
| Worse than 5 years ago | 102 (29%) |
| About the same as 5 years ago | 33 (9%) |
| Better than 5 years ago | 51 (15%) |
| Much better than 5 years ago | 16 (5%) |
| No response | 7 (2%) |

Q34 Thinking about your social life, including social activities and relationships with family, friends and neighbours, which of the following statements best describes your current situation (please tick):

| | |
|--|-----------|
| My social life is as good as it could be and I never feel lonely or isolated | 117 (32%) |
| My social life is good but I occasionally feel lonely or isolated | 84 (24%) |
| My social life is ok but I sometimes feel lonely or isolated | 88 (25%) |
| My social life is poor and I often feel lonely or isolated | 42 (12%) |
| My social life is very poor and I feel lonely or isolated most of the time | 14 (4%) |
| No response | 6 (2%) |

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. (Please try to complete all the questions in this section even if some of the wording does not completely fit your situation, because they are standard questions used internationally to measure health related quality of life.

| | | | | |
|--|---------------------|------------------------|----------------------|------------------|
| Q35 In general, would you say your health is: | | | | |
| Excellent | Very good | Good | Fair | Poor |
| The following two questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? | | | | |
| Q36 Moderate activities , such as moving a table, pushing a vacuum cleaner or light gardening | | | | |
| Yes, limited a lot | Yes, limited little | No, not limited at all | | |
| Q37 More strenuous activity such as briskly propelling your wheelchair, climbing several flights of stairs or mowing the lawn. | | | | |
| Yes, limited a lot | Yes, limited little | No, not limited at all | | |
| During the past 4 weeks , how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health ? | | | | |
| Q38 Accomplished less 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 |
| Q39 Were limited in the kind 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 |
| During the past 4 weeks , how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? | | | | |

| | | | | |
|--|------------------|------------------|----------------------|------------------|
| Q40 <i>Accomplished less</i> 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 |
| Q41 Did work or activities <i>less carefully than usual</i> | | | | |
| All of the time | Most of the time | Some of the time | A little of the time | None of the time |
| Q42 During the <i>past 4 weeks</i> , how much did <i>pain</i> interfere with your normal work (including both work outside the home and housework)? | | | | |
| Not at all | A little bit | Moderately | Quite a bit | Extremely |
| These three questions are about how you feel and how things have been with you <i>during the past 4 weeks</i> . 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 <i>past 4 weeks</i> : | | | | |
| Q43 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 |
| Q44 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 |
| Q45 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 |
| Q46 During the <i>past 4 weeks</i> , how much of the time has your <i>physical health or emotional problems</i> 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 |

Q47 When you think about your future which of the following areas of your life are of *most concern* to you?

| | Most concern | Some concern | No concern |
|---|--------------|--------------|------------|
| Housing and adaptations | 68 (20%) | 123 (37%) | 143 (43%) |
| Long term living arrangements (e.g. residential care) | 68 (20%) | 94 (28%) | 172 (51%) |
| Personal assistance and help in the home | 107 (32%) | 115 (34%) | 112 (34%) |
| Family and personal relationships | 74 (22%) | 105 (31%) | 155 (46%) |

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| | | | |
|---|-----------|-----------|-----------|
| Social activities/social life | 67 (20%) | 141 (42%) | 126 (38%) |
| Your working situation | 65 (19%) | 72 (22%) | 197 (59%) |
| Pension provision | 93 (28%) | 120 (36%) | 121 (36%) |
| Mobility | 137 (41%) | 126 (38%) | 71 (21%) |
| Your physical health | 184 (55%) | 127 (38%) | 23 (7%) |
| Your emotional health | 112 (34%) | 121 (36%) | 101 (30%) |
| <i>Note: Q47 was completed by 334 respondents</i> | | | |

Q51 Is there anything else you would like to tell us about your health and well-being or any issues/concerns you would like to highlight?

Q52 Would you be willing to answer a few more questions about the topics covered in this questionnaire, either on the telephone or in an informal discussion? Yes | No

It would be enormously helpful if you could give your name as it will make it easier for us to explore how the needs and experiences of beneficiaries vary and enable Firefly Research to get in touch with you to follow up this survey (if you said 'Yes' to Q52). It also means that we won't bother you with unnecessary reminders.

*If you do give your name your answers will still be **completely confidential** and will only be seen by Firefly Research.*

| | |
|-------|--|
| Name: | |
|-------|--|

Thank you again for helping us with this survey.

Appendix B Methods

Survey Content

The questions for the survey were developed in conjunction with the Thalidomide Trust’s Research Committee and other colleagues from the Trust and the National Advisory Council⁵² (NAC). We also drew on previous Health Grant evaluation and monitoring reports (see Section 1.1) and the knowledge of the HealthLink⁵³ team. Inevitably some trade-offs had to be made between the desire to collect more data and the need to avoid making the survey too onerous to complete. Most of the questions were ‘bespoke’ but we did include two validated questionnaires – the Warwick Edinburgh Mental Wellbeing Scale (WEMWBS) and the SF12 Health Related Quality of Life Questionnaire (SF12). These are briefly described in the relevant sections of this report.

The draft questionnaire was piloted online and on paper with ten beneficiaries – five (one from each of the 6(iv) b impairment Bands⁵⁴) involved in the Health Grant monitoring work and five who were actively involved in the NAC or other Trust committees. Their comments and suggestions were hugely helpful. The final questionnaire had ten sections:

- About You
- Family and Housing
- Work and Pensions
- Original Thalidomide Impairments
- Mobility and Equipment
- Health Problems
- Use of Health Services
- Social Care Support
- Mental Wellbeing
- Health Related Quality of Life

⁵² The National Advisory Council is comprised of 12 elected beneficiaries. It acts as an advisory body for the Trust and is the principal means by which the beneficiaries are able to influence the Trust’s policies.

⁵³ HealthLink is the Thalidomide Trust’s health and wellbeing advice service.

⁵⁴ 6(iv) b figures – Following the legal settlement in the 1970s, Distillers (now Diageo) set up a trust fund, which pays an Annual Grant to Thalidomide survivors in the UK. To establish the level of their Grant, each person was assessed and given ‘points’ according to the severity of their impairment. The total number of points is referred to as their 6(iv) b figure. Beneficiaries’ 6(iv) b figure can change if there is a significant loss of their functional ability.

Survey Distribution

A paper copy of the survey was sent to all beneficiaries (467 in total) in early August 2015, together with an information sheet and a covering letter from the Trust's Director and the Chair of the NAC Health and Wellbeing Committee. Those beneficiaries who had previously informed the Trust that they were happy to be contacted by email were also sent an email, which included a live link to the online survey. Both the information sheet and the covering letter also offered beneficiaries a further option to complete the survey on the telephone with a member of the research team. By early September around 270 beneficiaries had completed the survey. With the aim of improving the response rate further, a reminder letter and email were sent to all beneficiaries for whom no response was recorded, either because they had not responded or they had chosen not to give their name.

The survey closed at the end of September, although seven late responses were included. In total, 351 responses were received – 232 on paper, 116 online and three completed on the telephone with support - giving a response rate of just over 75%. Four survey forms were filled in by a family member or guardian because the beneficiary was unable to complete it themselves. Thirteen percent of beneficiaries (49) chose to complete the survey anonymously.

Analysis

All the survey responses were brought together in an Excel spreadsheet for analysis, which included initial counts and descriptive statistics. For those beneficiaries who had provided their name, we were able to obtain their 6(iv) b figure/Band and country of residence from the Trust. This enabled us to assess the representativeness of the survey group, and to look in more depth at the relationships between levels and types of Thalidomide impairment and health and wellbeing. For some questions we also examined whether the nature of beneficiaries' impairments or personal circumstances appeared to have any bearing on responses.

The quantitative data were also up-loaded into SPSS for further statistical analysis. Some of the results of this analysis are included in this report, especially where they shed extra light on a specific issue.

The comments and additional information provided in the free text boxes were analysed thematically.

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