

Low Mood Improvement for Thalidomide Survivors (LifTS) Study

Report from the 2018 Mood Survey

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Chapter 1 Introduction and Methods

Poor mental wellbeing, including low mood, depression and anxiety, is a growing concern within the Thalidomide community. The findings from the Health and Wellbeing survey conducted in 2015, suggested that half the beneficiaries who responded were currently or had recently experienced symptoms of depression or anxiety. Concerns about low mood and common mental health problems have also emerged from the new Holistic Assessments conducted with beneficiaries by Trust staff.

Clearly, Thalidomide survivors experiencing common mental health problems can and do seek help from their GPs and may be referred on to other psychological therapy services (e.g. counselling, CBT etc.). However, many choose not to seek help or have not found the treatments offered effective or acceptable. The Trust was therefore interested in exploring alternative ways to support Thalidomide survivors with low mood or mild to moderate depression and anxiety, and in particular, the scope for using peer support.

Recent research with older people and people with long-term health conditions has shown that a simple psychological approach called Behavioural Activation (BA), accompanied by telephone support, can reduce people's symptoms of low mood. It can also reduce the likelihood of people with low mood developing depression (Gilbody *et al* 2017). The Trust was interested in examining whether a similar BA approach with support, could help Thalidomide survivors. With this in mind, they commissioned the Mental Health and Addictions Research Group (MHARG) at the University of York to undertake a pilot study, to test a six-session BA programme, accompanied by peer support from specially trained beneficiaries. The study is called LIFTS or Low Mood Improvement for Thalidomide Survivors.

The first stage of the LIFTS study was a Mood Survey of all beneficiaries. The overall aim of the survey was to gather data that would provide a more detailed picture of the extent and severity of depression and anxiety amongst UK Thalidomide survivors. The results will be used to set the context for the whole LIFTS study and to help inform the Trust's work more generally. This report presents the findings from the Mood Survey. The next section of this chapter briefly sets out what is known, from recent research, about the mental wellbeing of Thalidomide survivors. Section 1.2 Methods, describes how the Mood survey was developed and conducted. Chapter 2 provides a profile of the survey respondents and summarises their responses to the open questions about the things in life that help people maintain a positive mood and mental wellbeing more generally. The following two chapters then present what the survey revealed about low mood, depression and anxiety, and health related quality of life. Finally Chapter 5 draws together the key findings and conclusions from the survey as a whole.

1.1 Background

The Health and Wellbeing survey provided information about the likely prevalence of common mental health problems amongst UK Thalidomide survivors. However, alongside the UK picture, there is limited but consistent international evidence that compared with their peers in the general population, Thalidomide survivors are more likely to experience common mental health problems, in particular depression (Newbrunner and Atkin 2017). A Japanese study (Imai *et al* 2014) used GHQ-28 to measure 'psychological distress and minor psychiatric disorders' amongst a small (and not necessarily representative) group of

22 Thalidomide survivors. Their results need to be treated with caution but they suggest that 59% had some kind of mental health disorder. A major study of 200 German Thalidomide survivors in North Rhine Westphalia (Peters *et al* 2015) assessed the prevalence of 'psychological morbidities' using structured clinical interviews. They found that almost half had one mental health disorder (compared to 27% in the general population), including a quarter with depressive disorders. Another German study (Kruse *et al* 2013) looked specifically at the prevalence of depression amongst 870 Thalidomide survivors (using the Major Depression Inventory), and again found a higher prevalence rate than the general population.

In terms of understanding why the mental wellbeing of Thalidomide survivors appears to be vulnerable, the interviews conducted as part of the initial monitoring of the 10 year Health Grant suggests that there are two main reasons: i) the cumulative impact of living with a rare disability, in particular the sense of 'being different' which this engenders and the pressures of coping with everyday life; and ii) the emotional impact of further loss of function, associated with secondary health problems. However, how these experiences affect people and how they make sense of them, is influenced by both individual circumstances (e.g. family responses or life events) and the wider societal context (such as access to care and support, in addition to access to social networks, labour markets, housing and financial resources).

The emotional impact of loss of function appears to be more significant when it leads to peoples' lives becoming more limited or results in them giving up activities they enjoy, and when it has knock on consequences for their family. Further, alongside the impact of current changes in people's lives, people often speculate about the implication of further change in their circumstances. There is a clear sense from some Thalidomide survivors that their current way of life is fragile and uncertain. This makes them feel vulnerable, which in turn has a corrosive effect on their mental wellbeing. However, improved financial support in recent years has had a very positive impact on many Thalidomide survivors mental wellbeing, by giving them a greater sense of security.

1.2 Methods

Below we briefly sets out how the mood survey was developed and conducted. We have included descriptions of the three questionnaires used in the survey. A copy of the survey form, showing all the questions, is included in Appendix A.

1.2.1 Ethical Approval and Beneficiary Involvement

The Department of Health Sciences Research Governance Committee (DHSRGC) approved the study on the 2nd July 2018. An Advisory Group for the study, comprised of three Beneficiaries, the Chair of the Research Committee and the Director of Health and Wellbeing was formed. It met for the first time in August 2018, to review the Mood Survey questionnaire and other key documents. Following that meeting, some documents were changed and so further approval from the Chair of the DHSRGC was obtained in late August.

1.2.2 Development of the Mood Survey

In developing the initial plans for the Mood Survey, we drew on current and previous research carried out by MHARG, about BA with support. We then discussed the draft survey form with colleagues from the Trust and the LIFTS Study Advisory Group. The final survey (see Appendix A) had five sections:

Section 1: Biographical Information

This section had just three questions about gender, home circumstances, and work situation. For the questions about home circumstances and work situation, we used the same wording as that used in the 2015 Health and Wellbeing survey. This was to facilitate comparisons with the Health and Wellbeing survey results and to help assess the representativeness of the Mood Survey respondents.

Section 2: Depression

To measure self-reported depression severity we used the Patient Health Questionnaire (PHQ-9) (Kroenke et al 2001). PHQ-9 is widely used in clinical trials and in a range of settings. It explores how the person has felt in the last two weeks and consists of nine questions with four possible responses to each question. For example, the first question asks:

Over the last 2 weeks, how often have you been bothered by any of the following problems?

1. *Little interest or pleasure in doing things*

With the four possible responses being: *Not at all; Several days; More than half the days; and Nearly every day*. The responses are scored from 0 to 3 giving an overall score range of 0-27. There are five scoring levels: 0 to 4 = no depression; 5 to 9 = mild depression; 10-14 = moderate depression; 15 to 19 = moderately severe depression; and 20 to 27 = severe depression. It is important to note however, that whilst this is a widely accepted measure of self-reported depression, it is not the same as clinical diagnosis of depression.

Section 3: Generalised Anxiety

Anxiety commonly occurs with low severity depression and previous studies have shown that interventions for depression can also reduce anxiety, and so we decided to measure generalised anxiety using the General Anxiety Disorder Scale (GAD-7) (Spitzer et al 2006). The questionnaire consists of seven questions with the same four possible responses to each question as the PHQ-9. The responses are scored from 0 to 3 giving an overall score range of 0-21. There are four scoring levels: 0 to 4 = no anxiety; 5 to 9 = mild anxiety; 10 to 14 = moderate anxiety; and 15 to 21 = severe anxiety.

Section 4: Health-related Quality of Life

EQ-5D is a standardised measure of health status, which was developed to provide a simple, generic measure of health. It is widely used in the clinical and economic evaluation of health care but also, as in this study, in population health surveys. It is designed for self-completion by respondents and works well in postal surveys and one to one interviews. We used the longer version of EQ-5D (EQ-5D-5L), which has the same 5 dimensions as the short version (i.e. mobility, self-care, usual activities, pain/discomfort, anxiety/depression) but each dimension has five levels: no problems, slight problems, moderate problems, severe problems, and extreme problems. Respondent are asked to indicate their health state by placing a tick in the box against the most appropriate statement in each of the 5 dimensions. We slightly altered the wording of some of the statements to ensure they were appropriate for Thalidomide survivors. For example, we changed '*I have no problems in walking about*' to '*I have no problems in walking/getting about*'.

EQ-5D-5L also includes a visual analogue scale (VAS) numbered from 0 to 100, where 100 is '*the best health you can imagine*' and 0 is '*the worst health you can imagine*'. This provides a quantitative measure of health as judged by the individual respondents on the day they complete the questionnaire.

Section 5: Open Questions

At the end of the survey we asked three open questions:

- What activities or pastimes do you enjoy?
- What things in your life help you to feel positive?
- Is there anything else you would like to tell us about your mental wellbeing?

These were partly intended to gather brief information about what helps beneficiaries to maintain a positive mood, and provide respondents with a space to tell us anything else about their mental wellbeing they felt was important. However, given the nature of the other questions in the survey, we also felt it was important to end the survey on a positive note.

1.2.3 Conducting the Survey

The survey was sent by the Trust to the majority of its beneficiaries (n=453). Those who lacked capacity, were currently being treated for serious mental health problems, or who had a terminal illness were excluded. Ideally, we would have given beneficiaries the option of completing the survey on-line. We did not do so because on-line use of the EQ-5D-5 measure involves a significant fee and an approval process, which would have meant extra cost and delay. We did offer the option of completing the survey on the telephone but it is possible that the not having the option of an on-line response reduced the response rate.

The survey was sent out by the Trust at the beginning of September, and it was then followed-up with an email reminder later that month. In addition, information publicising the survey was included on the Trust's website and the UK Thalidomide survivors Facebook page. The responses to the survey were returned directly to the research team in Freepost envelopes. The survey closed in mid-October, although a small number of responses were received after this date, which we were able to include. In total we received 182 completed survey forms, giving a response rate of 40%. However, a small number of the responses had some missing data.

1.2.4 Analysis of the Survey Data

The data from the survey, including the responses to the open questions, was entered into an Excel spreadsheet. Each response was given an identification number. We then transferred the anonymized data to SPSS for analysis. We also undertook a simple content analysis of the responses to the open questions. This presented in Chapter 2 as a way of setting the scene for the quantitative results.

Chapter 2 Profile of Survey Respondents

This chapter describes the home circumstances and work situation of the beneficiaries who responded to the Mood Survey. Where appropriate, comparisons with the results of 2015 Health and Wellbeing survey have been made. The second part of the Chapter presents a brief analysis of the responses to the open questions included at the end of the Mood Survey.

2.1 Gender and Home Circumstances

Of the 182 survey respondents, 92 (53.5%) were women, 80 (46.5%) were men and 10 did not give their gender. In terms of living circumstance, (see Table 1) the Mood Survey respondents were very similar to the 2015 Health and Wellbeing survey with around two-thirds living with their partner/spouse or their partner/spouse and other family members, and almost a quarter living alone.

Table 1 Home Circumstances

Home Circumstances	2018 Mood Survey	2015 H&W Survey
I live alone	42 (23.5%)	76 (21.7%)
I live with my partner/spouse	71 (39.7%)	115 (32.8%)
I live with my partner/spouse and other family members (e.g. children)	46 (25.7%)	109 (31.1%)
I live with another family member (e.g. parent or sibling)	12 (6.7%)	38 (10.8%)
Other (including n=3 missing data)	8 (4.5%)	13 (3.6%)

2.2 Work Situation

Table 2 below shows the work situation of the Mood Survey respondents alongside that of the Health and Wellbeing survey respondents. Comparisons need to be made with caution but the results suggest that the work situation of the beneficiaries who responded to the Mood Survey was broadly similar to the Health and Wellbeing survey. A higher proportion of respondents to the Mood Survey stated that they are not working (all reasons), whilst the proportion working full or part time is also lower than in the Health and Wellbeing survey.

Table 2 Work Situation

Work Situation	2018 Mood Survey	2015 H&W Survey
I'm unable to work because of my disability or health problems	61 (34.1%)	145 (41.4%)
I have chosen not to work in order to preserve my health/functioning	40 (22.3%)	45 (12.9%)
I've chosen not to work for family or personal reasons	12 (6.8%)	8 (2.3%)
I work part-time because of my disability or health problems	4 (2.2%)	30 (8.6%)
I work part time in order to preserve my health/functioning	14 (7.8%)	29 (8.3%)
I work part-time for family or personal reasons	0	17 (4.9%)
I work full-time	22 (12.3%)	54 (15.4%)
I'm not working at the moment but would like to	6 (3.4%)	15 (4.3%)
Other	19 (10.9%)	7 (2.0%)

2.3 Summary of Responses to the Open Question

The open questions at the end of the survey were included partly so that the survey ended on a positive note. However, we also wanted to gather brief information about the activities or things in life that help beneficiaries to maintain a positive mood, and to provide a place where respondents could add anything else about their mental wellbeing that they felt was important. All except two respondents answered at least one of these questions, but the responses varied hugely in length from one word answers to quite long descriptions of the important things in peoples' lives or accounts how they were feeling.

2.3.1 Activities and Keeping Positive

In answer to the first question - *What activities or pastimes do you enjoy?* respondents not surprisingly, listed many of the things that a cross section of the population might include. Many highlighted how much they valued having time with their partner, children and wider family, simply saying things like: *"Meals out with my husband"*; *"Watching my son play football"*; *"Spending time with mother"*; *"Playing with my grandchildren"*; and *"Visiting my sister"*. However, a few people clearly wished they had more (or more positive) contact with their families:

"It would make me feel better if I had more support from my family".

"I have trouble telling people how I feel and saying no to family".

Socialising, seeing friends and meeting people was also important. Again, people described this very simply, for example saying: *"My friends"*; *"Going out with friends"*; and *"Socialising and meeting people"*. However, some peoples' comments reflected how they were struggling to maintain their social lives. Sometimes this appeared to be linked to giving up work or changing personal circumstances:

"I don't find it easy getting over the initial hurdles of meeting new people. And I have no 'role' anymore which used to make me do it... I feel lonely but don't know how to change it".

Another respondent highlighted the impact of declining health and mobility. He noted that the achievements of his children made him feel positive but then went on to say:

"My deteriorating health issues have severely curtailed many activities I once enjoyed, particularly over the past 10+ years...increasingly poor mobility - becoming far more restrictive in all aspects of day to day life...my social life's more or less none-existent - all bound to have a negative impact mentally".

Respondents also listed a huge range of activities that they enjoyed or made them feel positive. These included a wide variety of home based pastimes and hobbies such as reading, watching TV, cooking, puzzles, sewing, painting and generally repairing or making things but also social and cultural activities including bingo, cinema, theatre, going to museums, live music and sporting events. Many respondents clearly enjoyed outdoor activities, particularly gardening, walking/dog walking, birdwatching/nature and fishing. However, people also took part in a huge range of sport and exercise from swimming, yoga and going to the gym, to horse riding, scuba diving and cycling. Again a few respondents said that they could no longer do many of the things they enjoyed, often citing pain as the main reason: *"In past years I am unable to do activities due to pain"*.

The second question - *What things in your life help you to feel positive?* elicited both practical and philosophical answers. Many respondents said that the activities and pastimes they had listed against question 1 made them feel good but it was relationships with family and friends that dominated the responses. Almost half of those who answered the question listed some type of family relationship or friendship as one of the things that helped them to feel positive. For example: *"Love from my wife"*; *"Being married"*; and *"Good friends"*. A few people specifically mentioned the importance of intimate relationships. For some respondents, the relationship with their animals, particularly dogs and horses, was also significant.

Several respondents were still working and many of them said that their job or working made them feel positive. However, it was clear that some were finding it hard: *"Work but only when I have a good day which are getting less every day"*. Others mentioned that they had given up work and whilst this was mostly a positive step, it appeared to have had a negative impact on others: *"I used to enjoy working and knowing that life had a purpose to it. I now connect with few people because I have few activities I share with people"*. Voluntary work and generally helping other people was also important to many respondents, as was learning and studying.

A number of people highlighted the importance of their faith or their church, whilst others talked about the positive effect of things in the natural world like good weather, seasons changing, or being out in the countryside. Feeling healthy or having less pain or sleeping well as also highlighted. Several respondents added comments which suggested that feeling positive was more broadly about their outlook on life, saying things like: *"Generally upbeat attitude"* and *"Waking up and still being alive!"*. Others talked about having a lifestyle that was right for them and the impact of being financially secure: *"Being involved (friends, family, interest groups). The sense of being wanted/needed by people. Being outside - close to nature etc. Using my brain and body."*; and *"Getting out and about. Having secure finances"*.

2.3.2 Comments on Mental Wellbeing

Just half the respondents answered the final question - *Is there anything else you would like to tell us about your mental wellbeing?* but those who did often provided a lot of information. Furthermore of the 98 responses, 48 were 'negative' in that people described the problems they were experiencing with common mental health problems (particularly low mood, depression and/or anxiety, phobias and OCD), or the impact on their mental wellbeing of physical problems. Clearly, some people had been experiencing problems for many years and a few had reached a very low point:

"I do wait to die to be released from my life. I feel I should never have been born, as my life has been and continues to be a struggle that is now not worth doing".

"Been in depression since my late teens. Chronic pain for the last seven years. I'm having to stop work because of my need to preserve my health. I feel I have rolled over and given up after 40 years in employment".

Some were receiving 'talking treatments' such as CBT and group or individual counselling, whilst others mentioned taking anti-depressants, as the quotation below illustrates:

"I have been on and off anti-depressants for years. At the moment off them for a month to see if I can cope with anxiety [and] mood swings".

For others low mood appeared to be strongly associated with physical problems, in particular pain and reduced mobility and function.

"Getting up, washed and dressed now feels a marathon, takes much longer and drags me down".

"Living with pain every day can be so draining especially when nobody understands what it is like to live with chronic pain. Put on a brave face and try to focus on what I can do rather than what I can't".

A few people reflected on how their physical and mental health was changing as they got older, and the difficulty they were having coming to terms with this:

"After years of being relatively fit and active I feel that I am getting older. I seem to be deteriorating both mentally and physically".

"I just don't understand why I have lost that get up and go feeling. I used to love to go to work, now I just can't seem to hold a job down and would rather not go to work now. I feel I have work since I was 16 yrs old and I have just had enough. I don't know how long I have left to live and want to be with my children and grandchildren".

However, there were positive comments too and so for balance, it is perhaps appropriate to close this chapter with one of them:

"I think I am very fortunate in being a naturally positive and happy person who knows how to preserve my mental and emotional wellbeing. I am lucky to enjoy good support from my husband and close family members. Not having to worry about money or employment makes things much easier".

Chapter 3 Depression and Anxiety

Set out below are the results of the PHQ-9 and GAD-7 questionnaires. Together they present a picture of level depression and anxiety amongst Thalidomide survivors. Where possible, comparisons with the general population (either of a similar age or of all ages, depending on availability) have been made.

3.1 Depression

The Patient Health Questionnaire (PHQ-9) was used to measure self-reported depression severity amongst Thalidomide survivors. It explores how the person has felt in the last two weeks. The overall score range is 0-27, and the results are presented against five 'levels' of depression severity. Of the 182 responses to the survey, 173 completed the PHQ-9 questions in full and so the results shown below are based on this number.

Table 3 PHQ-9 Results for Thalidomide survivors and comparator group

Level of Depression	Thalidomide Survivors		*Combined % for SCI, MS and MD
	Number	Percentage	
None (0-4)	75	43.4%	44%
Mild (5-9)	47	27.2%	32%
Moderate (10-14)	23	13.3%	15%
Moderately Severe (15-19)	16	9.2%	6%
Severe (20-27)	12	6.9%	3%
Total	173	100%	
Missing	9		

* SCI=Spinal Cord Injury; MS=Multiple Sclerosis; MD=Muscular Dystrophy

As Table 3 shows, 43.4% (n=75) respondents had no depression. Just over a quarter (27.2%/n=47) had mild depression (i.e. low mood). Almost a third had moderate to very severe depression: 23 respondents (13.3%) had moderate depression; 16 (9.2%) had severe depression; and 12 (6.9%) very severe depression. On average, male respondents had higher PHQ-9 scores (more depressive symptoms) than female respondents but this difference was not statistically significant. It is of some concern that in response to the final question - *'Over the last 2 weeks, how often have you been bothered by thoughts that you would be better off dead, or of hurting yourself in some way'* - almost a fifth of respondents (n=32/18%) said that they had experiences such thoughts. However, this should be interpreted with caution, and does not imply that people were actively suicidal.

Previously, the analysis of the 2015 Health and Wellbeing survey had suggested that being unable to work was having a negative impact on the mental wellbeing of Thalidomide survivors. So, we examined (using a Pearson Correlation) whether being unable to work was associated with higher depression (PHQ-9) and anxiety (GAD-7) scores, and this was

the case (PHQ-9: Pearson Correlation = $-.463/p = .000$. GAD-7: Pearson Correlation = $-.348/p = .000$.). The findings from the Health Grant Monitoring project suggested that there may be two aspects to the relationship between being unable to work and depression or low mood. Not working may lead to some Thalidomide survivors feeling more socially isolated and/or losing a sense of purpose or a clear role in life. However, it is likely that Thalidomide survivors who are unable to work also have significant secondary health problems and it may be this that is affecting their mood. There was no association between living alone and higher depression and anxiety scores.

PHQ-9 was originally designed for use in primary care but a few studies have looked at its validity in general population surveys and have made estimates of the prevalence of depressive symptoms in the general population. One study (Martin *et al* 2005), based on data from the representative sample of 2060 Germans, indicated a prevalence rate for depressive disorder of 9.2% (3.8%, major depression and 5.4% mild or subthreshold depressive disorder). This study also consistently found a strong positive association between depression and disability. A second German study (Kocalevent *et al* 2013) had similar results, concluding that 5.6% of the general population have moderate to high severity of depressive symptoms. This suggest that the prevalence of all levels of self-reported depression is likely to be much higher amongst the Thalidomide survivors than the general UK population.

It was difficult to find comparative data on PHQ-9 scores for other groups of people with lifelong impairment. However, an American study (Jensen *et al* 2014) used PHQ-9 to measure depression amongst people with Spinal Cord Injury (SCI), Multiple Sclerosis (MS) and Muscular Dystrophy (MD). Whilst this study included adults of all ages, the mean age for their participants was 52.6 i.e. relatively close to the mean age of Thalidomide survivors. The right hand column in Table 3 above shows the results from this study. The pattern is broadly similar to the Mood Survey, although the proportion of Thalidomide survivors in the 'Moderately Severe' and 'Severe' groups is almost double.

3.2 Anxiety

The General Anxiety Disorder Scale (GAD-7) was used to measure self-reported anxiety severity. It explores how the person has felt in the last two weeks. The overall score range is 0-21 and the results are presented against four 'levels' of anxiety severity. Of the 182 responses to the survey, 176 completed the GAD-7 questions in full and so the results shown below are based on this number. Table 4 below shows the results.

Table 4 GAD-7 Results

Level of Anxiety	Number	Percentage
None (0-4)	91	51.7%
Mild (5-9)	41	23.3%
Moderate (10-14)	26	14.8%
Severe (15-21)	18	10.2%
Total	176	100%
Missing	6	

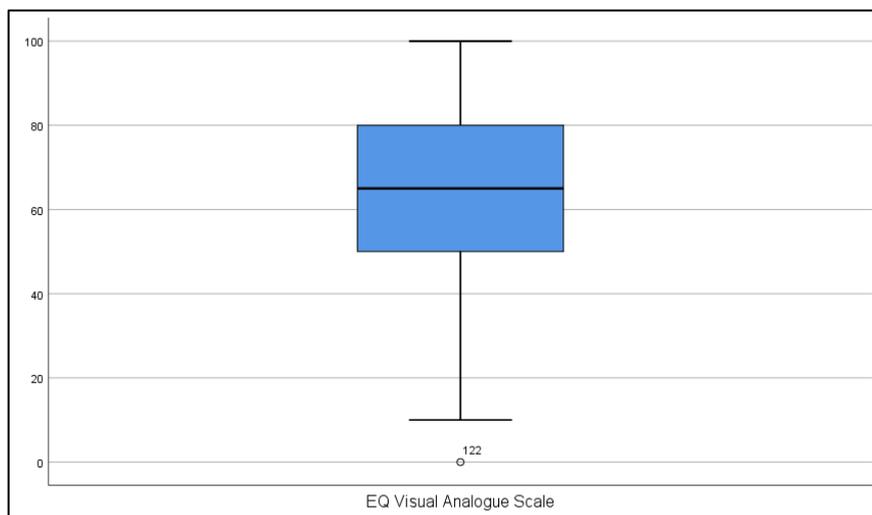
Three quarters of respondents had no anxiety (n=91/51.7%) or mild anxiety (n=41/23.3%). The remaining quarter had moderate to severe anxiety: 26 respondents (14.8%) had moderate anxiety and 18 (10.2%) had severe anxiety. This compares to estimates of 5% and 1% respectively for the general population (Lowe *et al* 2008). On average, male respondents had higher GAD-7 scores (more anxiety symptoms) than female respondents but this difference was not statistically significant. As is noted above in section 3.1, there was also a significant association between being unable to work was and higher anxiety (GAD-7) scores.

Chapter 4 Overall Health Status

Alongside the specific measures of depression and anxiety, we also wanted to get a snapshot of beneficiaries' overall health status, as this is one of the things we will look at for those beneficiaries who take part in the BA programme. To do this we used EQ-5D-5L, a generic measure of health that is widely used in research. It has five dimensions (i.e. mobility, self-care, usual activities, pain/discomfort, and anxiety/depression) and each dimension has five possible responses. EQ-5D-5L also includes a visual analogue scale (VAS) numbered from 0 to 100, where 100 is *'the best health you can imagine'* and 0 is *'the worst health you can imagine'*. This provides a simple quantitative measure of health as judged by the individual respondents on the day they complete the questionnaire.

Figure 1 below provides a picture of the responses to the VAS questions, which asked people to rate how good or bad their health was (on that day). The range of responses (from the 177 who completed the question) was huge, with one person rating their health as 0 (shown as a small circle or 'outlier' at the bottom of the chart) and seven rating it as 100. In Figure 1, the thick line within the box indicates the median (or middle number) for all responses. The blue box is the interquartile range where the middle 50% of the respondents fall. The range of responses is indicated by the black line 'T' line. The mean score for beneficiaries was 63 which compares to 81.7 for the UK population aged 55-64 (Janssen and Szende, 2013).

Figure 1 EQ-5D-5 Health Rating Results



The responses to the questions about mobility, self-care, usual activities, pain/discomfort, and anxiety/depression, provide a more detailed picture of how respondents rated aspects of their health status. Figure 2 simply splits responses into two groups – No Problems/ Problems. For all the dimensions, there were more respondents in the 'Problems' group than in the 'No Problems' group but the difference is most striking for Pain/Discomfort and Usual Activities. Furthermore, the responses to the open questions at the end of Mood Survey suggest that for some Thalidomide survivors, chronic pain may be contributing to low mood or depressive symptoms. To some extent, this reinforces what we already know about Thalidomide survivors experiences of pain and their increasing problems with usual activities. There is also research evidence of a strong association between disabling chronic

pain and major depressive disorder (Arnow *et al* 2006). We anticipate that the BA programme could have some positive impact on pain and usual activity but this remains to be tested.

Figure 3 shows the same information for the UK population as a whole (all ages). It is striking that for every dimension, the picture is the reverse of that for Thalidomide survivors. However, the UK data is for adults of all ages, not just people in their late 50's and so it might reasonably be expected that the picture would be more positive. Nevertheless, it does provide a quite stark comparison.

Figure 2 Responses to EQ-5D-5 Questions – Thalidomide Survivor

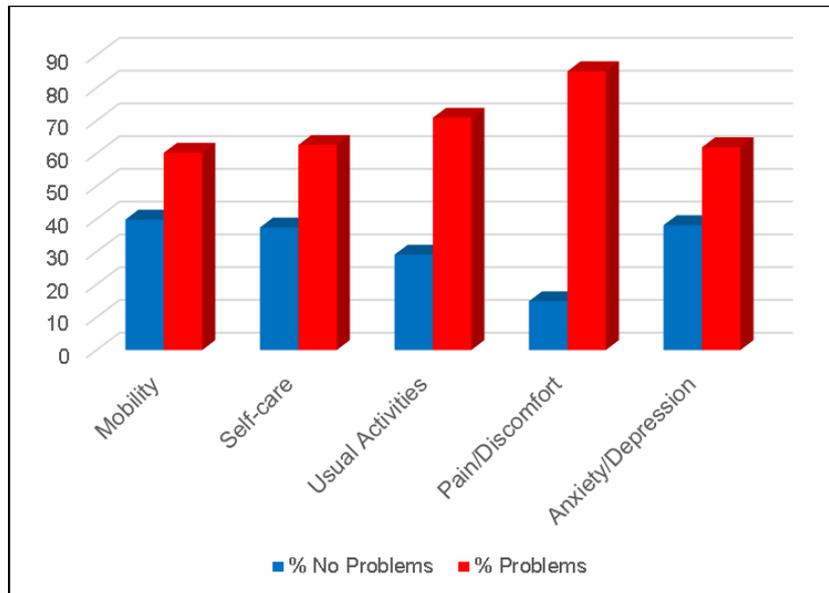


Figure 3 Responses to EQ-5D Question – UK Population (all ages)

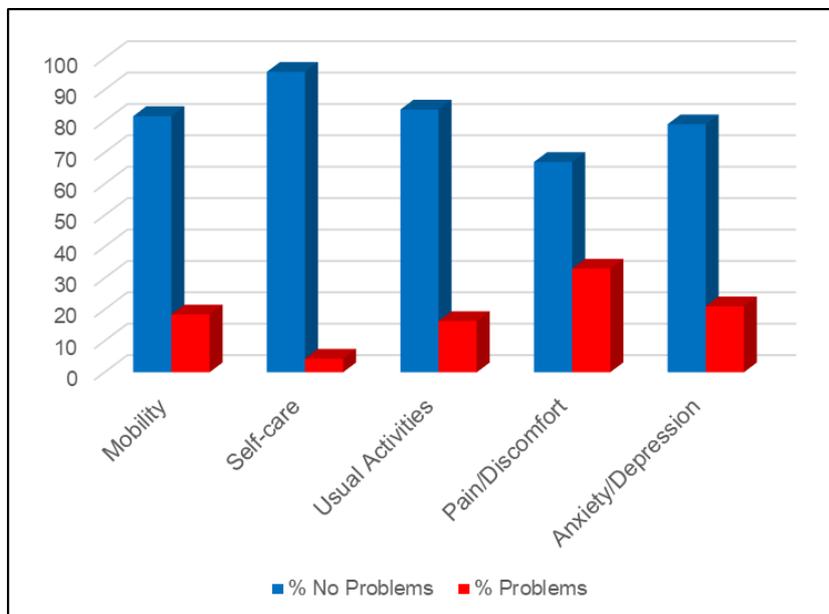


Table 5 below gives a more detailed breakdown of the severity of problems for all the dimensions.

Table 5 EQ-5D-5 Results

EQ-5D Dimension		Number	Percentage
Mobility	No problems	72	39.6
	Slight problems	45	24.7
	Moderate problems	33	18.1
	Severe problems	21	11.5
	Unable to...	11	6.0
Self-care	No problems	68	37.4
	Slight problems	47	25.8
	Moderate problems	39	21.4
	Severe problems	17	9.3
	Unable to...	11	6.0
Usual activities	No problems	53	29.1
	Slight problems	58	31.9
	Moderate problems	48	26.4
	Severe problems	19	10.4
	Unable to...	4	2.2
Pain/discomfort	No problems	27	14.9
	Slight problems	51	28.2
	Moderate problems	55	30.4
	Severe problems	35	19.3
	Extreme...	13	7.2
Anxiety/depression	No problems	69	38.1
	Slight problems	56	30.9
	Moderate problems	43	23.8
	Severe problems	10	5.5
	Extremely...	3	1.7

Chapter 5 Conclusions

The Mood Survey has provided a much more detailed picture of depression, anxiety and health status amongst UK Thalidomide survivors than was previously available. There are three key findings:

- **High prevalence of depression and anxiety** - The PHQ-9 results suggest that all levels of depression are far more prevalent amongst Thalidomide survivors, than the general population, with almost a third reporting moderate to severe symptoms of depression. The picture is similar for anxiety, with the GAD-7 results showing that a quarter of beneficiaries were experiencing moderate to severe anxiety – a far higher proportion than in the general population.
- **Small group of beneficiaries with very poor mental wellbeing** - The results from these two questionnaires, together with the responses to the open questions, suggest that there is a group of beneficiaries, perhaps 10% to 15%, with very poor mental wellbeing. This accords with the results of the SF12 (health related quality of life) questionnaire used in the 2015 Health and Wellbeing survey, which found that around 10% of respondents had mental health related quality of life scores equivalent to the bottom 2% of the general population of a similar age.
- **Impact of physical health problems on mental wellbeing** - The open questions confirmed some of what was already known about the effect that declining health, pain, and loss of function is having on beneficiaries' mental wellbeing. However, they also revealed the wide range of experiences, attitudes and circumstances within the Thalidomide community. This reinforces the need for an approach to tackling poor mental wellbeing that is both flexible and targeted, and could include addressing physical problems such as disabling chronic pain, which increase the risk of low mood and depression.

The LiFTS study is currently testing a six-session Behavioural Activation programme, accompanied by peer support from specially trained beneficiaries, to see if this approach can help Thalidomide survivors with low mood and mild to moderate depression. A report from the whole study, including the impact (if any) of the BA programme and the findings from a process evaluation, will be available in January 2020.

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Appendix A Mood Survey

The Thalidomide Trust

UNIVERSITY *of* York
The Department of Health Sciences

Low Mood Improvement for Thalidomide Survivors (LIFTS) Study

Mood Survey 2018

Please read this information before completing the questionnaire.

Thank you for helping us with this survey.

The following pages ask a range of questions about you and your mental wellbeing. The responses you provide will help us get a clearer picture of the mental wellbeing of UK Thalidomide survivors.

Please answer ALL the questions, even if some of the questions may not seem relevant to you. They are all important to the survey and do give us valuable information.

Unless otherwise stated please choose only ONE response from the options available. If you are unsure of which response to give, please choose the response that best describes your feelings or experience. Please answer all of the questions honestly and to the best of your ability - there are no right or wrong answers.

Please follow the instructions for each section carefully and then indicate your responses by putting a cross in the box.

If you have any questions or problems completing this questionnaire, please contact the LIFTS study team:

Study Manager: Liz Newbronner

Telephone: 01904 321630

Email: liz.newbronner@vork.ac.uk

Thank you again for taking the time to complete the survey.

<i>Office use only</i>	Post:		Telephone:	
Participant ID				
Date Received				

LIFTS Mood Survey FINAL (21-8-18)

SECTION 1: This section asks you a few questions about your work and home circumstances

1. Are you?

Male Female

2. Which of the following best describes your home circumstances?

Home Circumstances	Please Tick One
I live alone	
I live with my partner/spouse	
I live with my partner/spouse and other family members (e.g. children)	
I live with another family member (e.g. parent or sibling)	
Other (please describe):	

3. Which of the following best describes your work situation?

Work Situation	Please Tick One
I'm unable to work because of my disability or health problems	
I have chosen not to work in order to preserve my health/functioning	
I've chosen not to work for family or personal reasons	
I work part-time because of my disability or health problems	
I work part time in order to preserve my health/functioning	
I work part-time for family or personal reasons	
I work full-time	
I'm not working at the moment but would like to	
Other (please describe):	

SECTION 2: This section asks you questions about how you have been feeling over the last two weeks. Answer each question by placing a cross in the box that best describes your answer

Over the last 2 weeks, how often have you been bothered by any of the following problems?

1. Little interest or pleasure in doing things
Not at all Several days More than half the days Nearly every day
2. Feeling down, depressed, or hopeless
Not at all Several days More than half the days Nearly every day
3. Trouble falling or staying asleep, or sleeping too much
Not at all Several days More than half the days Nearly every day
4. Feeling tired or having little energy
Not at all Several days More than half the days Nearly every day
5. Poor appetite or overeating
Not at all Several days More than half the days Nearly every day
6. Feeling bad about yourself – or that you are a failure or have let yourself or your family down
Not at all Several days More than half the days Nearly every day
7. Trouble concentrating on things, such as reading the newspaper or watching television
Not at all Several days More than half the days Nearly every day
8. Moving or speaking so slowly that other people could have noticed. Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual
Not at all Several days More than half the days Nearly every day
9. Thoughts that you would be better off dead, or of hurting yourself in some way
Not at all Several days More than half the days Nearly every day

SECTION 3: This section asks about how your health is today

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

MOBILITY

I have no problems in walking/getting about

I have slight problems in walking/getting about

I have moderate problems in walking/getting about

I have severe problems in walking/getting about

I am unable to walk/get about

SELF-CARE (with your usual aids and equipment)

I have no problems washing or dressing myself

I have slight problems washing or dressing myself

I have moderate problems washing or dressing myself

I have severe problems washing or dressing myself

I am unable to wash or dress myself

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

I have no problems doing my usual activities

I have slight problems doing my usual activities

I have moderate problems doing my usual activities

I have severe problems doing my usual activities

I am unable to do my usual activities

LIFTS Mood Survey FINAL (21-8-18)

PAIN / DISCOMFORT

I have no pain or discomfort

I have slight pain or discomfort

I have moderate pain or discomfort

I have severe pain or discomfort

I have extreme pain or discomfort

ANXIETY / DEPRESSION

I am not anxious or depressed

I am slightly anxious or depressed

I am moderately anxious or depressed

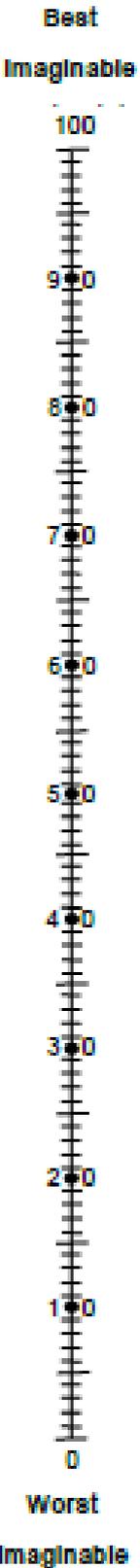
I am severely anxious or depressed

I am extremely anxious or depressed

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

**Your own
health state
today**



LIFTS Mood Survey FINAL (21-8-18)

SECTION 4: This section asks about the activities or things in life that help you feel positive.

1. What activities or pastimes do you enjoy?

--

2. What things in your life help you to feel positive?

--

3. Is there anything else you would like to tell us about your mental wellbeing?

--

If you are interested in taking part in the next stage of the LIFTS study, please put your name below **AND** complete the enclosed Permission to Contact Form

Name:	
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Thank you very much for taking the time to help us
with this survey

LIFTS Mood Survey FINAL (21-8-18)

