

# Health & Wellbeing Survey 2015 Initial Results

Liz Newbronner  
Firefly Research & Evaluation  
NACAC – October 2015

The Thalidomide Trust

**Firefly**  
ILLUMINATING RESEARCH

# Why the Trust did the Survey

The overall aim was to get a picture of beneficiaries' current situations and the challenges people are facing or think they will face over the next few years. This information will be used to:

- Help the Trust develop its services
- Enable us to demonstrate to the Departments of Health the sort of health-related issues beneficiaries are facing and so...
- Secure further funding when the current Health Grant comes to an end
- Support negotiations with Diageo about future funding

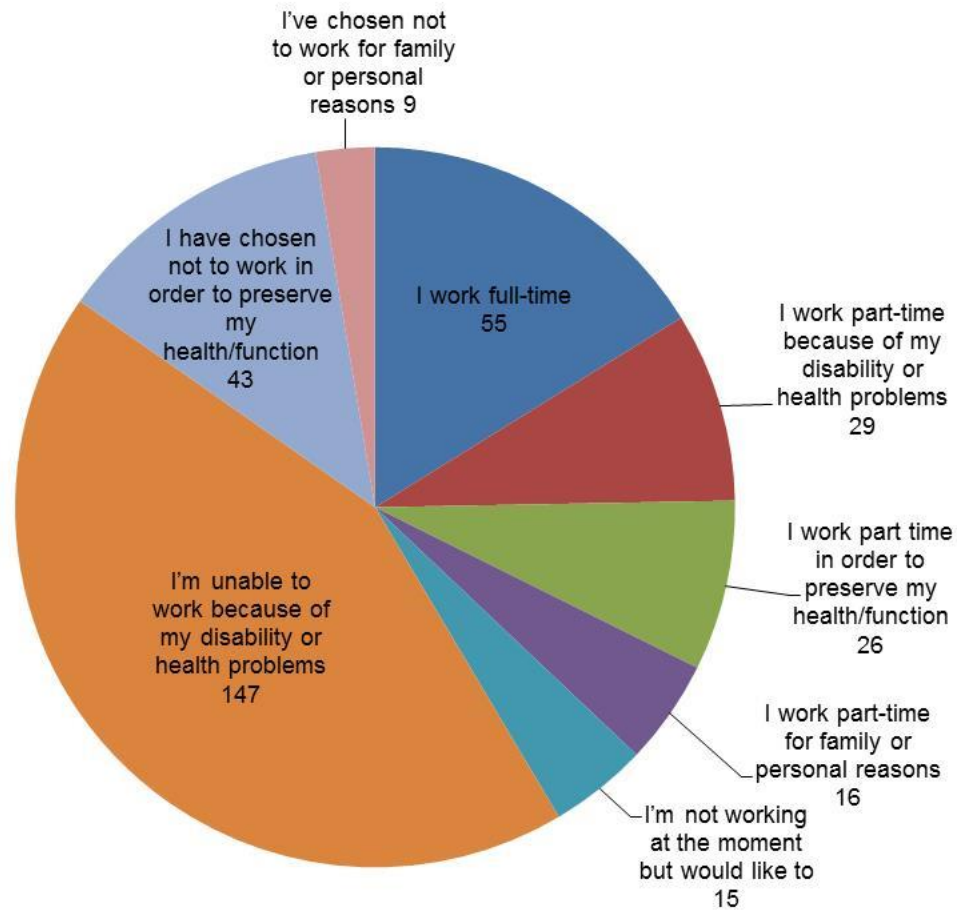
# Conducting the Survey & Response Rate

- Survey 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
- Sent by the Trust to all 467 beneficiaries,
- People could respond by post, on-line or complete it on the telephone with support
- 351 people completed the survey – a response rate of just over 75%
- 13% chose to complete the survey anonymously
- 169 of the respondents were female; 171 were male; and 11 did not give their gender

# Housing and Adaptations

- Majority of beneficiaries (85%) own their own house/flat
- Around a third were planning adaptations to their home in the next year (major - 83; minor - 23) but 42 people said they could not afford to do adaptations in the next year
- Almost half (45%/160) anticipated that they would need to move house in the next 5 years:
  - 19% (68) needed a home with no stairs
  - 15% (53) needed a home which was fully adapted for their disability/health problems
  - 11% (39) needed a smaller house/garden
- 14 people said that they needed a house with accommodation for a live-in personal assistant and a further 21 people said they needed a larger house

# Work and Pensions



# Current or Recent Health Problems

- 93% were experiencing pain and/or loss of movement in one or more joint (including their neck and/or spine)
- 48% had generalised pain
- 73% reported experiencing neurological symptoms (tingling; loss of feeling; heat/cold)
- 50% had one or more mental health problems
- 74 people said their health or wellbeing had improved recently. Things which made the most difference were:
  - Weight loss/healthy eating (24)
  - Medical treatment e.g. pain medication or surgery (16)
  - Exercise (15)
  - Regular treatment/therapy e.g. massage (12)

# Use of Health Services

Health treatments - Grouped	n=	%
Joint and/or back surgery	59	17%
Prescription pain medication and/or treatment to relieve pain	175	50%
Physiotherapy or complementary therapies	242	69%
Treatment for mental health problems (including counselling)	102	29%

Two thirds of beneficiaries had experienced one or more problems with the quality of or access to health services, especially:

- Lack of knowledge/understanding of Thalidomide damage in general amongst health professionals (48%)
- Lack of knowledge/understanding of my impairments amongst health professionals (36%)
- Difficulties/delays in seeing a suitably experienced health professional/specialist (23%)
- Delays in getting treatment (23%)

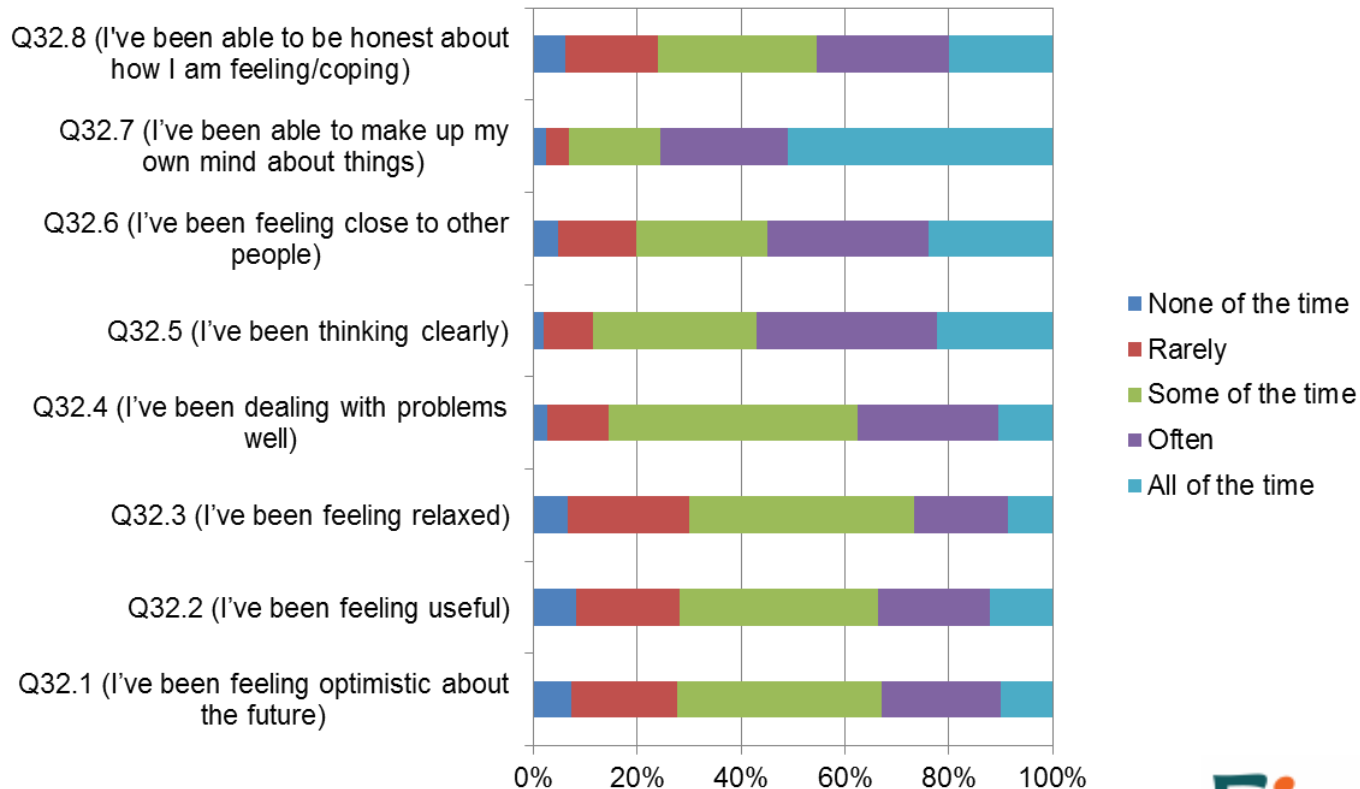
# Social Care

- 19% (65) of respondents were getting local authority funded social care
- Of these half felt that the level of support they got was enough to meet their needs
- 39 people were paying for additional time/services from their own income
- Of the 282 beneficiaries who were *not* getting local authority funded social care:
  - 179 were buying support (e.g. personal assistance, help in the home, gardening, DIY etc.) privately
  - 54 thought they would need apply for local authority funded social care in the next 5 years (83 were not sure)



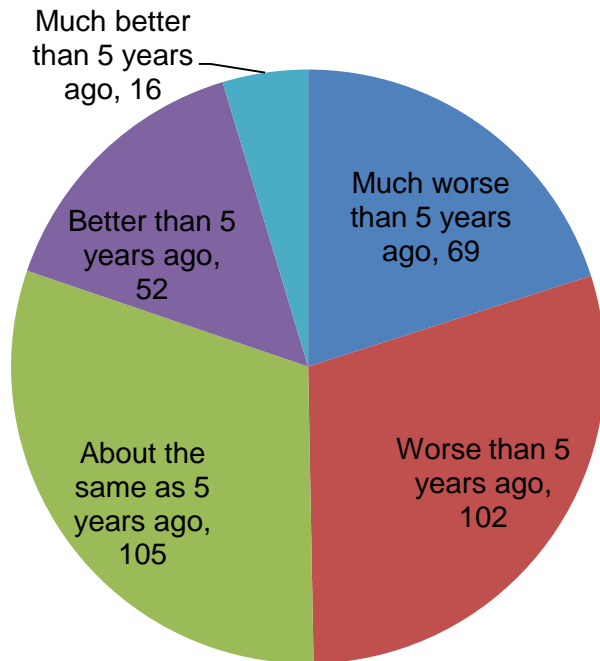
# Mental Wellbeing & Quality of Life

Two 'validated' questionnaires – a health related QOL scale (not shown) and a mental wellbeing scale which showed:

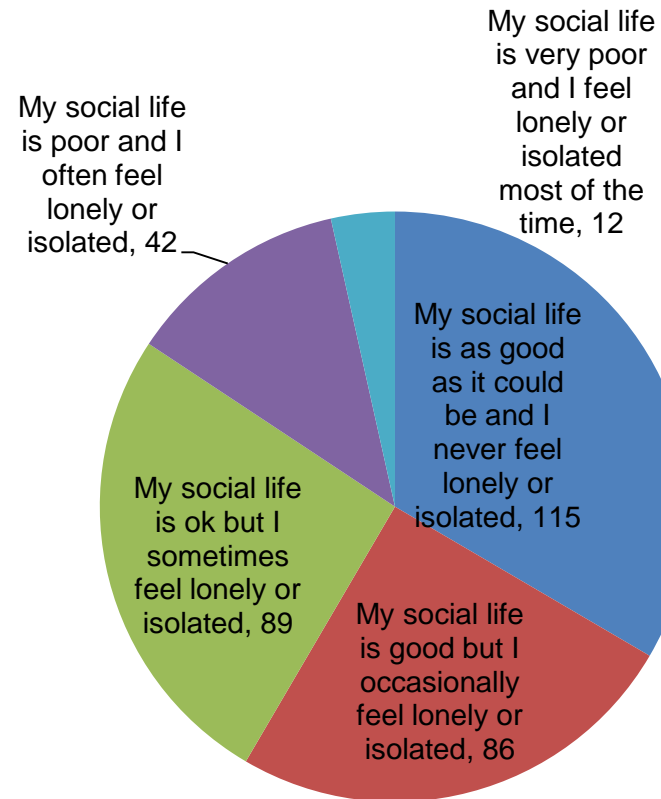


# Emotional Wellbeing and Social Life

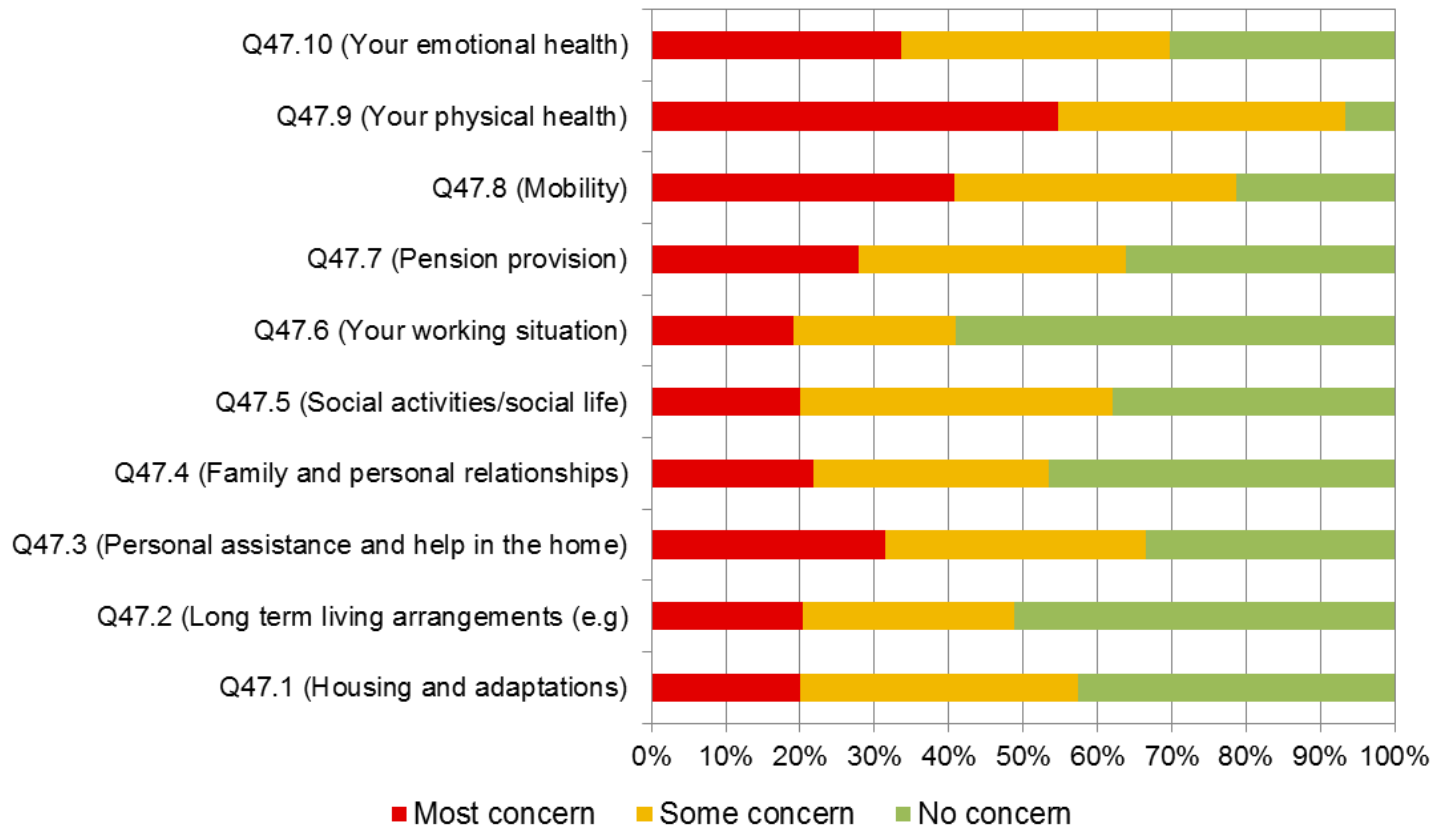
## Emotional Wellbeing



## Social Life



# Future Concerns



# Next Steps

- Currently analysing the survey data
- Would welcome ideas/suggestions for specific issues to look at
- First draft report will go to the Research Committee in November
- Second draft will go to Trustees in January
- Final report – February 2016