

Firefly [Liz Newbronner]

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LN: Thank you very much Rowland for finding those for me. Just to say, thanks also very much for inviting me to come and speak today. It's a real pleasure. It's particularly nice to see some old friends and also to put faces to names of people I've just communicated with by email, including Mark from Australia. So that's really great.

As Simone said, today my purpose is just to give a very quick overview of some of the findings that are coming out of the health and wellbeing survey that we did recently. We're right in the middle of the analysis so you'll have to bear with me and accept that these are just very sort of headlines really. But hopefully we'll have a lot of details by Christmas, so ... well, before that actually, in November.

So I thought it might help just to refresh everybody's memories about why the Trust wanted to do the health and wellbeing survey. So the overall aim was very much to get a better picture of the current situations and circumstances of Beneficiaries and, particularly, the challenges that people were facing or that people felt they would face in the coming years. And the purpose of that was to sort of help the Trust think about how it might want to develop its services but also enable the Trust to demonstrate to the Departments of Health the sort of health related issues that people were facing and hopefully therefore make a case for the continuation of the Health Grant when that comes into review at the end of the ten year period.

And lastly, I know in 2016 there are negotiations with Diageo so hopefully the information from the survey will contribute to that as well.

So I won't go into lots of methodological boring details but just to briefly say what we did. The survey had ten main sections which you can see there and I won't go into all of the things today because some of the things we're still doing the analysis on but I'll just touch on some of the main areas.

The survey went out to all 467 Beneficiaries including Beneficiaries living abroad and those Beneficiaries who perhaps have a solicitor or a family member acting for them. So it was absolutely everybody. And people could respond by post, online, or I could complete it over the telephone with people if they preferred to do that. And all three methods were used although the post was the main one.

We had an absolutely fantastic response – over 75% of you responding to the survey. And a big thanks to Michelle-Jane and the team at the Thalidomide Trust office who, I think, reminded everybody and also to Beneficiaries like Roland. I think you put things on Facebook and encouraged responses so that's really super.

And we asked if people would be willing to put their names on the survey so that we could, you know, get back to people or track things back but obviously we appreciated that some of the information we were asking for was quite sensitive and so people had the option to complete it anonymously but only 13% of people did so I think that's really nice that people felt there was sufficient trust to give their names. And just to say it was a pretty even split: 169 women and 171 men. And for some

reason 11 people didn't give me their gender but I don't know why. I'm not going to go into that. So we did have a really good response.

So just the first area I wanted to cover was just a little bit about housing and adaptations because I know, as Anne, was saying, that's quite a hot topic and it's going to be a hot topic in the coming years. Interestingly, the majority of Beneficiaries, 85% of you, live in your own house or flat so that's the security that I think is great for people. But around a third of people were planning adaptations to their home in the coming year; 80 odd people were looking at major adaptations and a smaller number, minor adaptations. But also, interestingly, there were a proportion of people who just felt they couldn't afford to do the adaptations that they'd like to in the coming year so there still lots of people feeling that they couldn't do everything they needed to do.

I think it's also interesting that around half of the people that responded to the survey thought it was likely that they might need to move house in the coming five years and the biggest reasons for that were to have a home without stairs or to have a home that was more fully adapted to their needs. But also, in some cases, just having a smaller or more manageable house and garden. Interestingly, although it was a minority, there were fourteen people who said that they felt that they would need to move home so that they would have accommodation for a live-in personal assistant and a number of people needed a bigger home, perhaps to accommodate a wheelchair or to live with other family members. So whilst the numbers are small, I think for those people that's a really big issue. So it was useful to sort of get that detail from people.

We also asked about work and pensions and I know there's a group particularly looking at this at the moment. So just to give you a sense here. There were around 40% of people were currently not working because of their disability or health problems and another sort of 12% had reduced their working hours because of their disability or health problems. And I think that contrasts with the ... what Carolyn was presenting this morning from the German study. The proportion of people from this country who are not working because of their health problems was much greater. But, interestingly, around two thirds of the people who responded said that they'd changed their working situation since the year 2000, either they did not work or they'd changed their working hours or they'd changed their jobs. So I think, you know, the last ten / fifteen years has seen a lot of changes for people.

And, we just asked one question about pensions which was just whether people had contributed to a private pension or an employers' pension over and above their normal state pension and only a third of people said that they had any sort of private pension arrangements. So I think that's quite significant.

So just moving onto current and recent health problems and, again, I think this echoes some of the things that Carolyn was touching on this morning. The survey showed that 93% of the people who responded to the survey, so the overwhelming majority of people, were experiencing pain and / or loss of movement in one or more joint and lots of people ticked multiple areas. So it wasn't it's just my knee, or just my hip, or, you know, people often ticked several areas so that's a really big issue for people.

We also asked people about generalised pain and, again, nearly half of you said you are experiencing generalised pain. Sometimes that was severe and continuous and sometimes it was, you know, it was more intermittent but nevertheless it was a big feature for a lot of people. And nearly three quarters of people experienced some

sort of neurological symptoms so what we were talking about earlier about the tingling loss of feeling and the heat and cold. So, again, that was a common feature for folks.

I think the other statistic which kind of really struck me because I know in the North Rhine-Westphalia study they had estimated that over 50% of their study responders had mental health problems and ... were currently experiencing mental health problems or had done recently. And that seemed an awfully high figure for me. When I read it I thought that can't be right. But actually from what you reported to me from this survey, 50% of the Beneficiary community have recently ... have currently had some mental health problems like depression or anxiety. So I think that's going to be a really important ... as we get into the analysis, I think that's going to be a really important area to look at in more detail, look at people's circumstances and so on.

I think, on the positive side, 74 people said their health and wellbeing had actually improved in recent years and the big reasons for that were weight loss or healthier eating and so on. Medical treatments, which included things like pain medication and, in some instances, surgery, but also exercise and people making choices about going for treatments with things like massage. I think the Health Grant has certainly enabled people to do that.

We also asked people a little bit about their use of health services and some of the experiences they've had of using health services and, again, I think this is something we'll be able to look at in more detail but just to give you a flavour of it. There were a relatively small but significant number of people who have had some form of back surgery and I know from the qualitative work that we've done previously around the Health Grant that people faced some really difficult decisions about whether surgery was a good option for them or not. So I think there are some really hard choices to make there.

Half of you told us that you were using prescription pain medication or had had pain-relieving treatments like injections and so on. Physiotherapy or complementary therapies were a very common service that people were using, a great majority, 69%. But, interestingly as well, nearly a third of people had had some kind of treatment for mental health problems, including counselling. And I think it's interesting the number of people reporting they've got mental health problems or had them recently and the number of people seeking treatment is a bit adrift and maybe that's because people don't feel comfortable seeking treatment and receiving help.

I think ... the other thing that we asked about was whether people had had any problems with the quality or access to health services and, as you can see from there, the two big issues I think were generally health professionals not really understanding the nature of thalidomide damage or not understanding the very specific nature of people's impairments. So they were the big concerns for people. But also people reported not being able to see a suitably qualified or experienced clinician and, associated with that, delays in getting treatment. And, again, this is something we will look at in a little bit more depth because hopefully that will be helpful to Dee and colleagues in the HealthLink team.

So I'm just going to touch very briefly on social care because we need to look in a little bit more detail at this. But, to me, I was actually quite surprised at the number of respondents who actually reported that they were getting local authority funded social care and there may be a variety of issues we need to look at. But whether there was perhaps some reluctance to seek help from social care services because of the bureaucracy of it and so on. But ... and of those that were getting help ... were

getting local authority social care, it was about 50/50 of people said they felt they were getting enough help and 50% said they felt they could really do with more. And a small proportion of people were, in any case, topping up what they were getting. And of the number of Beneficiaries who were not getting any local authority social care, a high proportion, two thirds, were buying in their own support which ranged from personal assistants to help in the home, DIY, gardening etc. So a big proportion of people were spending the Health Grant or other money on that kind of thing. And a fair number thought that they might need to seek additional support in the future or get the ... right. I'm nearly there.

So just homing in on some of the mental wellbeing issues briefly. In the survey we used what were called two validated questionnaires. So basically they're standard questionnaires that mean we can compare the results for thalidomiders with the general population or with people with other conditions. I think some of you will know we've previously compared to people with stroke or MS. So one of the surveys we're using, which is called SF12, which is the really horrible complicated one that you have to fill in. We haven't done the analysis of that yet so we're still working on it. But we also use something, another survey which is the one that you see here, which is one that's been used quite a lot in the National Census and things like that. You can see where people are scoring badly on those things. But the three sort of least good areas, if you like, were people feeling relaxed, people feeling useful and people feeling optimistic about the future. And I think there are really important messages there which again link to the issues around mental health and so on.

I'll keep whizzing on. So just keeping with the emotional wellbeing theme and people's social lives, it's interesting. We asked people about their emotional wellbeing and how it was compared to five years ago and nearly half the people responding to the survey felt it was worse or much worse than it was five years ago. So I think, again, that's quite an important finding. But on the up side, a lot of you have got a good social life so most people felt their social lives were very good. Having said that, I think what's important is not the majority who have got a good social network, as Mark was talking about earlier, but rather the people who do feel socially isolated and, you know, I think part of the analysis is going to be looking at that in a little bit more detail and understanding what's happening for that group of Beneficiaries who are struggling and who are finding it difficult.

So, nearly there, nearly there. So just two last slides. So quickly just to say, we asked people just a very broad question about what their future concerns were and, I mean I suppose in some way there's no surprises. But the three main concerns that people had were people's emotional health, physical health and mobility. But also, you know, beginning to have to use personal assistants was another issue. And I think ... really what we think is valuable about this question is really to give some pointers to the different topics and hopefully for those of you who said you'd be willing to contribute to further work, come back to you and talk to you about some of these things in more depth.

So just one more last slide. This is just to let you know what is happening next with it all. So, as I said, we're currently analysing the data at the moment, there's lots more to do but I'm obviously working with colleagues at the Trust about that but also I know that from the NAC and from the Research Committee and so on, I know that some of you have got particular topics that you're interested in so Craig and I have been talking about mental wellbeing and Liz and I have been talking about pensions and work. So if anyone does have a particular interest in something and you want to make suggestions and ideas to say can we look at a particular thing, then please do,

you know, do feel free to say that because we want the survey to be useful, that's its whole point really.

So the first draft of the report will go to the Research Committee in November and then the second draft will go to the Trustees in January and then hopefully we're aiming for the report to be finalised and hopefully available to people in about February time. So that's the sort of rough timeline that we're working to. So thanks very much folks.

[Applause]

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