Chronic Illness Inclusion Project

Response to GSS consultation on use of the Harmonised Principle of impairment in social surveys

About the Chronic Illness Inclusion Project

The Chronic Illness Inclusion Project is an emancipatory research project led by people with chronic illness. It is part of the DRILL programme of disabled-led research, supported by Big Lottery.

We are investigating the lived experience of both impairment and disabling barriers among people with chronic illness. Our research will result in a manifesto in 2020 for changing perceptions and policies around chronic illness.

Introduction

One of the central aims of our research has been to develop a language and terminology for self-identification and self-advocacy. A survey of over 2K people (findings as yet unpublished) with chronic illness found that:

- Fatigue and energy limitation are the most activity-restricting feature for 45% of people with a broad range of long-term health conditions, followed by pain (27%). See Figure 1 for range and distribution of diagnoses included in survey responses.
- The terms “Energy-Limiting Chronic Illness” and “energy impairment” were the preferred terms for self-identification and description of impairment among this group. See Figure 3.

We are pleased to respond to this consultation about the use of harmonised questions on impairment. We would also welcome the opportunity to share further findings from survey of over 2K people with chronic illness with a view to informing and influencing the language and concepts of impairment to reflect our lived experience of chronic illness.

The Chronic Illness Inclusion Project (CIIP) is an organisation of chronically ill people and as such our energy is very limited. As such, due to the short time frame for a response and the fact that the project is still processing and writing up data, this response will not be as detailed, well-evidenced and in depth as we would like. The response will mainly focus on questions 1, 2 (applied to just the harmonised principle), 4 and 5.

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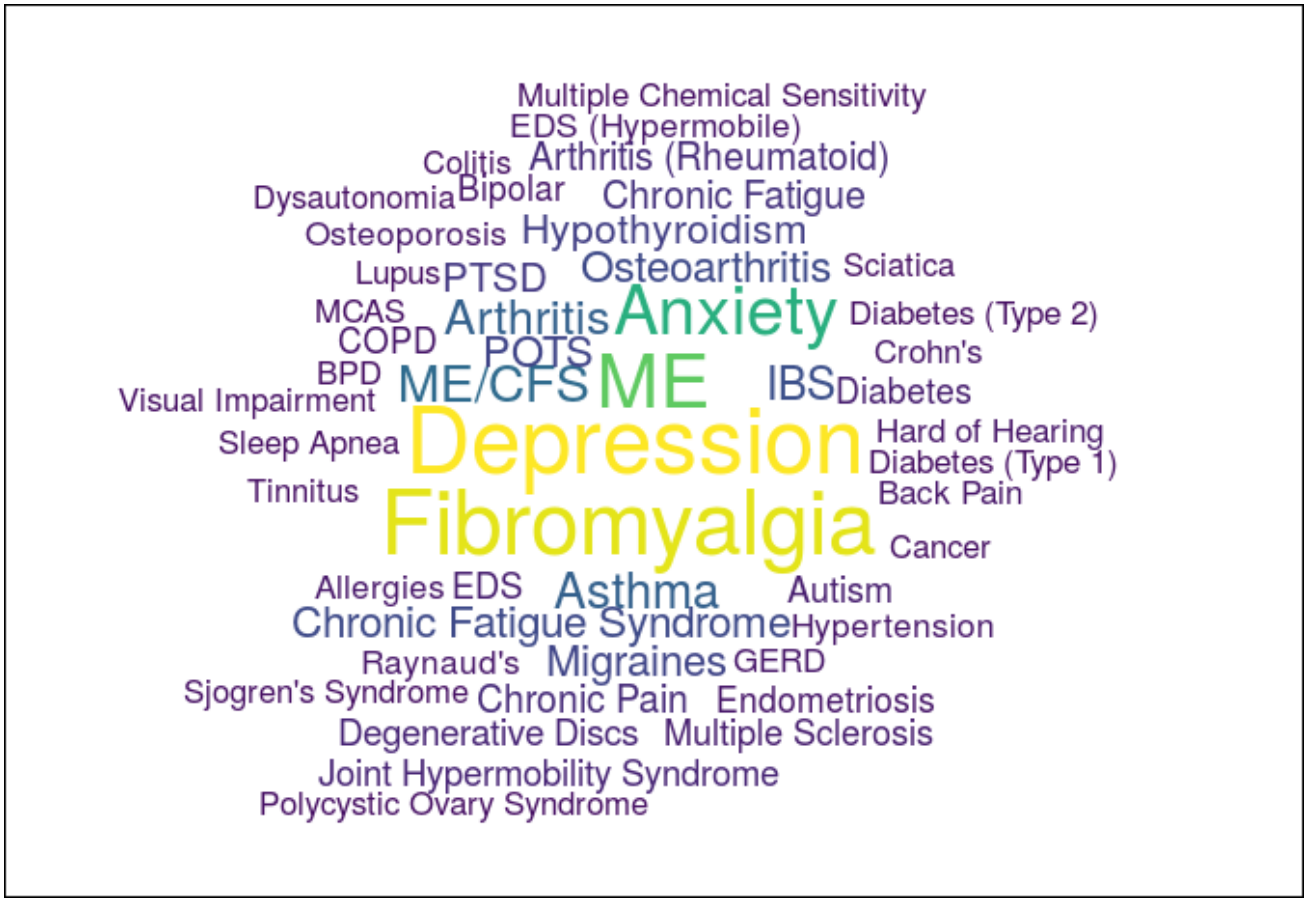

Figure 1 ***Range and distribution of medical diagnoses among survey respondents. Survey respondents listed a mean of 3.5 (median of 3) diagnoses each.***

Question 1 – If you aren't using the GSS Harmonised Principle for your work, is it out of lack of awareness or does the Principle not meet your needs?

We were aware of the GSS Harmonised Principle. We used the impairment classification system required by the DRILL programme of disability research to record impairment type among research participants. However, we felt that DRILL's categories fail to capture the impairment experience of most our participants. In particular, the category "Long Term Health Condition" is insufficiently descriptive of impairment type. Therefore we added the category "Stamina, breathing, fatigue" to the DRILL categories. See Figure 2 for the results of this question.

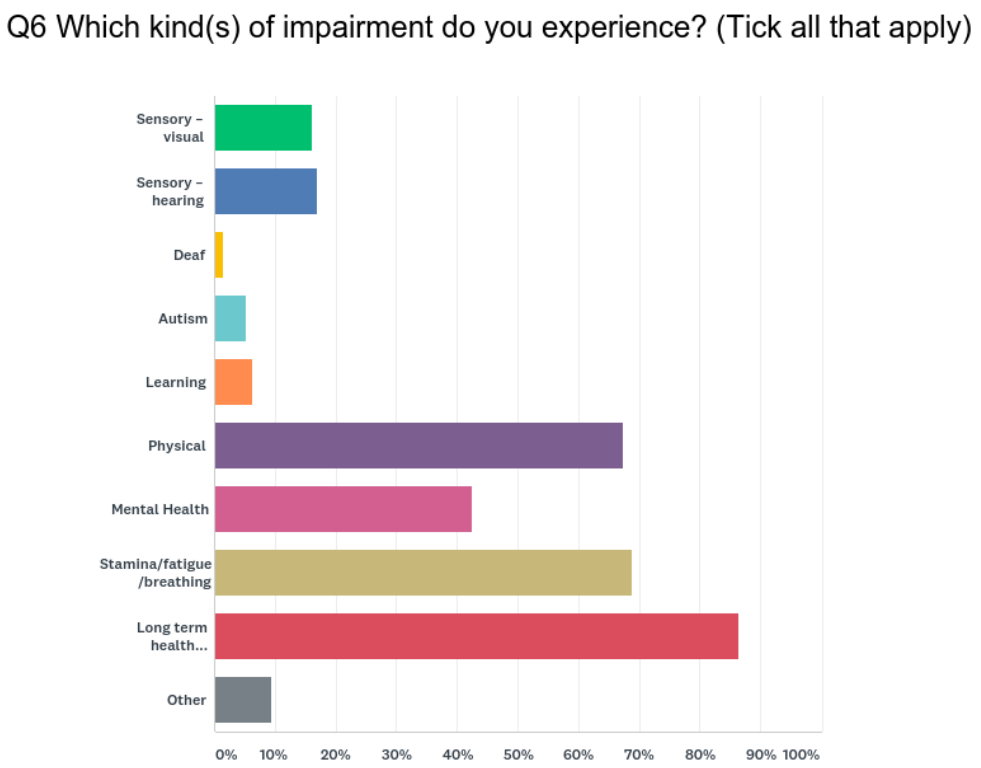

Figure 2 Impairment types reported by survey participants, using DRILL impairment categories supplemented by "Stamina, breathing, fatigue". N=2,135

Questions 2, 4 and 5 – **these questions focussed on the pros and cons of the current Harmonised Principle, and suggestions for future developments to the principle. Question 3 was omitted; it asked meeting participants to consider various scenarios and decide which type of impairment classification they'd find most useful for that scenario. As the results from the CIIP research are still being written up and given the time frame in which we had to generate a response, it wasn't possible to answer this question in the time available.**

From our perspective, the Harmonised Principle is very welcome because it acknowledges that stamina impairment and fatigue are impairments in their own right. This recognition is normally missing in most surveys on disability and impairment. Recognition of stamina impairment and fatigue is crucial because our survey found that the dismissal of fatigue as a "common health problem" and the stereotype that "everyone gets tired" are one of the main disabling barriers preventing people with chronic illness from adjusting to, and living as fully possible with, disability as well as accessing their right to reasonable adjustments under the Equality Act and their entitlement to financial support with the extra costs of living with a disability.

However, based on extensive focus groups and our large survey of people's understandings and preferences with regard to impairment language, we propose the category of "stamina, breathing, fatigue" be replaced with "energy impairment" or "energy limitation".

- The term "energy-impairment" emerged as strongly preferred by a large majority of respondents (72% agreed that this term described their health conditions affect them with an additional 15% saying that this term sometimes described how their condition affected them). See figure 3.
- The term "Fatigue", whilst widely used, was believed to diminish and dismiss the extent of impairment among focus group participants. It was thought that lay understandings of "fatigue" attribute it to universal human experience, not to impairment or disabililty.
- The term "stamina" also evoked negative connotations (see forthcoming report) among many survey respondents. Lack of stamina was associated with laziness and lack of moral fibre.

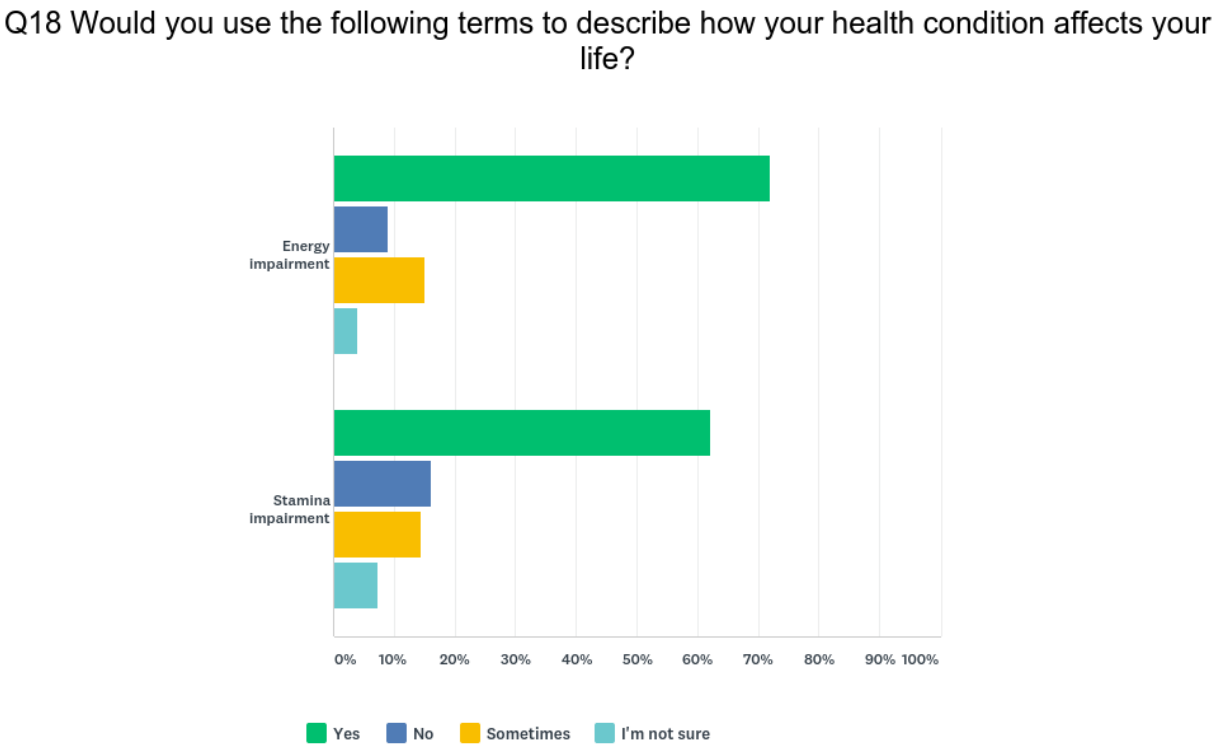

Figure 3 Preferred language to describe impairment. N=1,903

We have some additional concerns with the Harmonised Principle based on the results of our two focus groups and survey.

- Asking users to self-identify their areas of impairment risks under-reporting because it relies on the user having a good accessible mental model of the capabilities of a normal healthy

person. This is particularly a problem in the case of chronic illness where users may have acclimatised to their symptoms over several years (so the symptoms become their new normal) and are likely be socially isolated and/or housebound/bedbound (so they aren't exposed to many examples of healthy normal). We would reinforce the comments from the harmonising principle project development documents provided which state that benchmarks are very important for helping users frame questions correctly. For example, despite the fact that 86% of survey respondents with chronic illness said that 'energy impairment' described how their health condition affected them at least some of the time (72% all the time), only 69% of respondents checked the Stamina/fatigue/breathing option on the question about what kind of impairment types they experienced.

- Chronic illness generally involves multiple symptoms of different levels of impact and severity. What often happens is that 1-2 major symptoms overwhelm the rest in terms of their impact. We are concerned that presenting the list as a whole may lead to under-reporting due to the fact that users may select the 1-2 most impactful areas of impairment and forget to include all areas of impairment unless prompted.

- The other major symptom reported by the vast majority of the group is pain (27% of survey respondents listed pain as their most limiting symptom). We would like to see pain recognised as something that impairs a person's ability to function.

- We understand that the 'Stamina, Breathing and Fatigue' category is derived from analyses of the impact of diseases on disability and function in the WHO's *International Classification of Function, Health and Disability* (ICF). In the ICF it appears that impairment of stamina and fatigue is listed solely under cardio-respiratory disease. As the work of the CIIP shows, energy-limitation (fatigue) is a commonly experienced symptom by those with a much broader array of medical diagnoses (see Figure 1) and is often the most serious and limiting symptom. It is vital and this lived experience of chronic illness is understood and recorded by government in order to design policies and address the needs of disabled people living with energy impairment.