Empathetic design research and development in practice; co-development of an innovative head and neck support for people with Motor Neurone Disease

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250 WORD VERSION

Sheffield Hallam University Project team – Heath Reed, Andrew Stanton, Joe Langley

P138 **Empathetic design research and development in practice; co-development of an innovative head and neck support for people with Motor Neurone Disease**

People with Motor Neuron Disease (MND) experience muscle weakness. The human head can weigh 5kg so when this happens in the muscles around the neck it can become very difficult to hold the head up and result in the head falling forward.

The situation can lead to extreme pain, restricted movement, problems with eating, drinking, swallowing, breathing and importantly adversely affect face to face communication. Ideally, a neck collar would help alleviate these important quality of life (QoL) issues. Current neck collar provision can be of limited use for people with MND and are regularly rejected by users as often they are designed to immobilise the head and neck, and can be socially stigmatising.

A fundamental reappraisal of the way these physical products are configured and used was undertaken. The project explored the use of open and empathic approaches to the co-design of solutions and further product designs role as developer and explorer of complex multidisciplinary, social and QoL issues. It demonstrates experts working openly together using a range of 'live' research practice methods to arrive at holistically considered optimum outcomes.

The project was funded by the NIHR i4i program. The team consisted of clinicians, engineers and designers working with partners including people experiencing MND and their carers. Processes included a range of research through design methods at the heart of which was a series of ten, iterative, co-design workshops. The team developed mutual empathies between project participants. These played a key role in the motivation to reach appropriate solutions.

Project representative will bring one artefact. Can you supply a single plinth / stand approximately 1 meter high and with a flat top surface area of not less than 12 inches (300mm) square).

Submit a camera-ready abstract no more than 250 words for the conference abstract book (with an ISBN). Please send the plain text with your abstract reference number, and specifications on display to artefact@cumulus.hkdihongkong2016.org **by 5 August 2016 (Friday)**. It should include size of exhibit(s), technical and logistical requirements, images, sketches or drafts of display for arranging exhibtion area.

Submitted text

People with Motor Neuron Disease (MND) experience muscle weakness. The human head can weigh 5kg so when this happens in the muscles around the neck it can become very difficult to hold the head up and result in the head falling forward coming to rest on the upper chest or shoulder.

Figure 1.

The condition can lead to extreme pain, restricted movement, problems with eating/drinking/swallowing, breathing and importantly adversely affect personal, face to face, communications. Ideally, a neck collar would help alleviate these important quality of life (QoL) issues. Current neck collar provision can be of limited use for people with MND and are regularly rejected by users for reasons of head movement restriction (being designed to immobilise the head

and neck), a lack of overall support, general discomfort and social stigmatisation. It was felt that a fundamental reappraisal of the way these physical products are configured and used was needed.

This project explored the use of open and empathic approaches to the co-design of solutions for the user group. This report reflects on and illustrates product designs role as developer and explorer of various levels of insight needed to be built to tackle complex multidisciplinary, social and QoL issues.

The project spanned two years and was funded by the (X) program. The project aimed to provide high quality designs that were appropriate in terms of function, were desirable, cost effective and to bring designs as close to volume production as possible. The team consisted of clinicians (X), engineers (X) and designers (X) working with partners including people experiencing MND and their carers. It demonstrated experts working openly together using a range of 'live' research practice methods to arrive at optimum outcomes. Of the wide range of human technical (ergonomic and anthropometric), fabrication process/cost, form/function issues the team also developed mutual empathies between project participants. These played a key role in the motivation to reach appropriate solutions.

Processes included a range of research through design methods; at the heart of the strategy was a series of ten, iterative, co-design workshops. All participants were considered experts in either life experience, as product users or in their specialism. Physical making was used as part of an in-depth multi-disciplinary, participatory, co-design process. Given the complex and often conflicting nature of the issues raised and diversity of specialist knowledge, the designers developed ways of not necessarily solving problems but making objects that encapsulated them. This was an attempt to 'level the playing field' between the experts, to realise their creativity and to synthesise and impart collective knowledge. The authors argue that this democratised the innovation process.

Figure 2.

An example revolved around the term 'support with movement'. The design team suggested that any provision of 'support', by virtue of the fact that it offered support, would inevitably limit an aspect movement. The device shown in Figure 2. was a result of patient-designer conversation on the topic. It emerged that that the removal of any movement provision in the vertical ('nodding') plane in favour of full movement provision from side to side (horizontally) could be acceptable. At the next workshop a model was tabled exhibiting these technical characteristics. It enabled all participants to see and understand one idea of 'support with movement' and, whereas it was deemed an acceptable idea in conversation, the device enabled all partners to empathise with the reality of that kind of solution. In this sense the physical models purposes were provocative and 'sacrificial'.

A third adopted approach involved the design and clinical partners wearing and evaluating existing collar products to provide greater empathetic understanding of the inadequacies of current provision. The McGill pain questionnaire was completed by each designer and emotional reactions resulting from collar use and impact on Activities of Daily Living were recorded.

Figure 3.

In this these ways the design team were able to more deeply explore human centred requirements alongside technical/clinical ones, develop insight and empathies and apply/embody knowledge in sacrificial models and invent new product concepts. Further methods included technical testing of existing and proposed designs.

Figure 4. Design listening compassionately to users (YouTube)

"…the designers… were very interested in our reflections and they really wanted to know, you could tell they were really, really interested and they were really keen to design and appropriate product." (X)

Outcomes of the study include a rationalised neck orthosis design to pre-production level, a CE marked product and granted IP. The product has been subject to further user and technical evaluations. In the later the design was deemed to offer comparable levels of support as existing provision, in the former user acceptance of the design was much improved because the design offers low visual profile, is more comfortable and, emerging from the research, facilitated customisable support to meet individual needs. The design is currently undergoing further user evaluations, manufacture and commercialisation strategy reviews.

Although empathy as a factor influencing design directions was not explicitly recorded during the course of the study it became clear that it was a key driver in reaching appropriate solutions for end users. Empathy was not one way - from designer to end user for example. In the same spirit as co-designing, 'co-empathies' emerged - from patient to designer, in terms of developing deeper understandings of design limitations. From health-care practitioner to end users, in building insights as to what it was like to use and wear a product that is not fit for purpose. And, from patients at earlier stages of disease progression to those who exhibited advanced symptoms. In that sense the team identified a requirement for a system that could evolve as the needs of the user changed. Design outcomes were more holistically balanced as they took on board, and embodied, a broader range of desirable and functional requirements that may have not been evident in an outcome driven by a more conventional design brief driven enquiry. The design team were able build human level tacit insight providing the basis for inventing new, acceptable solutions.

Figure 5.