A participatory model for co-creating accessible rehabilitation technology

Andrew Kerr, Madeleine Grealy, Milena Slachetka, Chioma Wodu, Gillian Sweeney, Fiona Boyd, Philip Rowe

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Table of Contents

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Andrew Kerr[1*] PhD; Madeleine Grealy[2*] PhD; Milena Slachetka[1*] BSc; Chioma Wodu[1*] BSc; Gillian Sweeney[1*] PhD; Fiona Boyd[1*] MENG; Philip Rowe[1*] PhD

[1]Department of Biomedical Engineering, University of Strathclyde Glasgow GB
[2]Department of Psychological Sciences & Health, University of Strathclyde Glasgow GB
[*]these authors contributed equally

Corresponding Author:
Andrew Kerr PhD
Department of Biomedical Engineering, University of Strathclyde
Wolfson Centre, 106 Rottenrow,
University of Strathclyde
Glasgow
GB

Abstract

Background: Globally, one in three people live with health conditions that could be improved with rehabilitation. Ideally this is provided by trained professionals delivering evidence based levels of dose, intensity and content, for optimal recovery. The inability of healthcare providers to deliver this, creates an opportunity for technological innovation. Design processes that lack close consideration of users' needs and healthcare budgets, however, mean that many rehabilitation technologies are neither useful, nor used.

Objective: To develop a model for designing accessible rehabilitation technology using a co-creation approach that is informed by users who have completed, or are completing, an eight-week technology based rehabilitation programme.

Methods: To address this problem our multi-disciplinary research group established a co-creation centre for rehabilitation technology that places the user at the centre of the innovation process. The core of this model is an eight-week holistic rehabilitation programme delivered exclusively through commercial and prototype technology so that users are able to provide truly informed feedback on technologies under development, as well as creating an observatory to better understand how patients interact with rehabilitation technologies. The process is supported by focus groups for product development and a translation group advising on broader issues of adoption. As the leading cause of global adult disability, the target population for the centre has been stroke, however the principles can be applied to any clinical population.

Results: Our model has been active for more than two years with 80/86 individuals completing the programme. Five new devices have emerged from the process with further ideas logged for future development. In addition, it has led to accessibility modifications to existing technology, including modifications to hand grips and the structure of rehabilitation games. Critically it has also produced a set of co-created protocols for technology enriched rehabilitation that has allowed us to replicate the model on an acute stroke ward.

Conclusions: Sub-optimal rehabilitation limits recovery from health conditions. Technology offers support to increase access to intensive and enriched rehabilitation, but needs to be designed to suit users and not just their impairment. Our co-creation model, built around participation in an intensive, technology-based programme, has produced new accessible technology and demonstrated the feasibility of our overall approach to providing the rehabilitation that people need, for as long as needed.

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A participatory model for co-creating accessible rehabilitation technology

Kerr, Grealy, Slachetka, Wodu, Sweeney, Boyd, Colville, Rowe
University of Strathclyde

Abstract

Background

Globally, one in three people live with health conditions that could be improved with rehabilitation. Ideally this is provided by trained professionals delivering evidence based levels of dose, intensity and content, for optimal recovery. The inability of healthcare providers to deliver this, creates an opportunity for technological innovation. Design processes that lack close consideration of users' needs and healthcare budgets, however, mean that many rehabilitation technologies are neither useful, nor used.

Model

To address this problem our multi-disciplinary research group established a co-creation centre for rehabilitation technology that places the user at the centre of the innovation process. The core of this model is an eight-week holistic rehabilitation programme delivered exclusively through commercial and prototype technology so that users are able to provide truly informed feedback on technologies under development, as well as creating an observatory to better understand how patients interact with rehabilitation technologies. The process is supported by focus groups for product development and a translation group advising on broader issues of adoption. As the leading cause of global adult disability, the target population for the centre has been stroke, however the principles can be applied to any clinical population.

Our model has been active for more than two years with 80/86 individuals completing the programme. Five new devices have emerged from the process with further ideas logged for future development. In addition, it has led to accessibility modifications to existing technology, including modifications to hand grips and the structure of rehabilitation games. Critically it has also produced a set of co-created protocols for technology enriched rehabilitation that has allowed us to replicate the model on an acute stroke ward.

Discussion

Sub-optimal rehabilitation limits recovery from health conditions. Technology offers support to increase access to intensive and enriched rehabilitation, but needs to be designed to suit users and not just their impairment. Our co-creation model, built around participation in an intensive, technology-based programme, has produced new accessible technology and demonstrated the feasibility of our overall approach to providing the rehabilitation that people need, for as long as needed.

Introduction

One in three people, across the world, live with a health condition that could benefit from rehabilitation [1]. Delivering effective levels of rehabilitation to meet this global demand is beyond the reach of most, if not all, state run health services, not least because of the inadequate workforce [2, 3]. This means most people will either receive suboptimal rehabilitation or no rehabilitation at all. Consequently, recovery from disabling conditions like stroke is not simply a function of severity but will depend on an individual's capacity to access additional rehabilitation. Technology has reached the point of maturity where could it help address this large unmet need in an equitable manner. Rehabilitation technology, such as virtual reality and robotics, have been shown to improve function across a range of conditions; for example stroke [4] and Parkinson's [5] as well as age related disability [6]. Access to this technology, however, has been described as poor, or non-existent, in the

public sector of many countries, including the UK [7].

Besides the initial challenge of access, the subsequent abandonment of prescribed technology (rehabilitation and assistive) is common, for example Sugawara et al., (2018) [8] reported more than 50% of upper limb prostheses were not used after prescription. Many reasons are given for non-use of technology in rehabilitation. Sweeney et al., (2020) [7] found reasons from both therapists (e.g. lack of training) and patients (e.g. poor motivation). To overcome these barriers, and increase the use of technology in rehabilitation, a number of recommendations have been proposed; including improved usability, clinical evidence of effectiveness, value for money and conforming to self-management programmes [9].

These recommendations require the involvement of end users throughout the design process, for the people in need of rehabilitation to be co-creators of the technology and involve them at different stages in the development process both as determiners and evaluators of these technologies.

Irrespective of the field of study, co-creation is the practice of identifying and involving relevant stakeholders (user groups) in the process of finding a solution to a problem affecting the user group. Its application in healthcare has been described using different terms such as co-design and co-production [10]. The common idea behind co-creation is the involvement and partnership between the researcher and the end-users of the product, services, or intervention in generating concepts and evaluating products [11] .

While co-creation addresses some of the user-based issues identified with rehabilitation technology (usability, access, adherence) [12] a potential weakness is an imbalance in the knowledge and experience between designers and users that might affect outcomes. Users' knowledge of rehabilitation technology is likely to be very limited both in the range of available devices and experience using them as a part of a rehabilitation programme. For the users to make meaningful contributions to the design process it is therefore important that they have practical experience.

In 2021 our research group set up a co-creation centre for rehabilitation technology (CCRT) [13] aiming to develop accessible rehabilitation using a co-creation approach that is informed by users who have completed, or are completing, an eight-week technology based rehabilitation programme [13, 14]. This paper describes the formal and informal co-creation processes that evolved from our centre and presents two cases studies to demonstrate how specific devices have benefited from our approach.

Methods

Participants

Details of our research centre (participants, intervention and outcome measures) are provided in previous publications [13, 14]. In the interests of clarity they are described here briefly. Participants living with disability (mobility, communication, cognition) caused by stroke are invited to attend an eight-week programme rehabilitation programme at the University of Strathclyde. Participants are recruited through invitations distributed by Chest Heart and Stroke Scotland. Interested individuals attend an initial meeting to assess eligibility (more than a year since a stroke diagnosis, well enough and able to attend at least twice a week, have physical and/or communication/cognitive disability resulting from stroke) and record baseline measures.

Intervention

A goal setting interview and baseline measures assist our research therapists to structure and supervise an intensive rehabilitation programme delivered exclusively through technology (treadmills, power assisted exercise machines, tablet apps, virtual reality, upper limb robots, balance training systems and functional electrical stimulation). Each session is two hours long, participants can attend daily but must agree to attend at least two sessions a week for the eight-week period. We have called the programme TERG -Technology Enriched Rehabilitation Gym - to encapsulate training with technology designed for all impairments.

Outcome measures

Standard, validated measures of mobility (e.g. Berg Balance Scale and the Ten Metre Walk Test) and

global impact (Stroke Impact Scale) are recorded immediately before and after the programme.

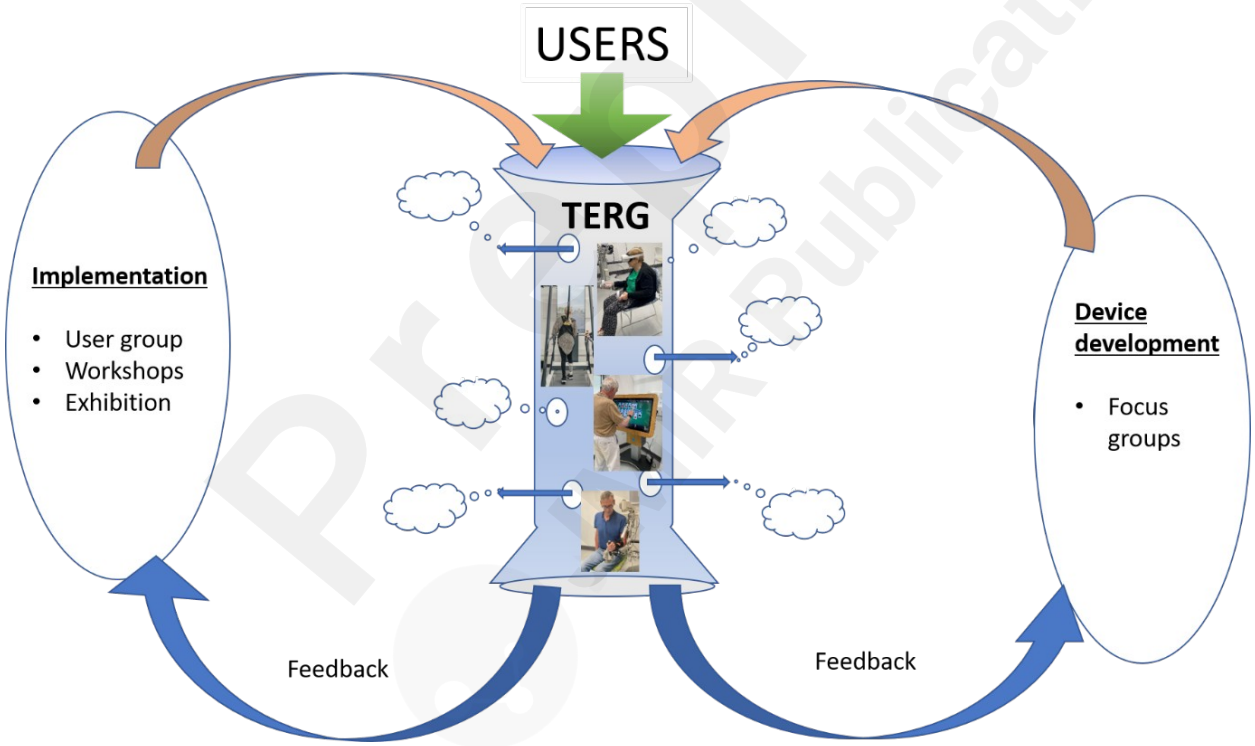
Co-creation activities

Our co-creation activities are aimed at either specific device development or informing the implementation of our TERG model into practice. For device development, short term, purposively selected, focus groups are formed from individuals (n=5 to 8) currently attending the TERG to provide focussed user feedback on the device. The number of focus groups varies (typically 3-5) and may extend into future groups, in which case individuals are invited to continue participating.

Translating, and integrating, our TERG model into everyday rehabilitation practice, is the long term aim of our centre. To achieve this we have formed a User Advisory Group that meets formally three times a year and provides feedback on specific plans and ideas around implementation in community and hospital settings.

The activities described, so far, represent formal methods of co-creation. The opportunity to observe and work closely with users as they carry out their rehabilitation provides our multi-disciplinary research group (therapists, engineers and scientists) with a rich experience and opportunity to acquire informal feedback on specific technology and the way it integrates with other systems. This more informal mechanism has arguably provided a greater volume of feedback on devices and led to several new ideas that are currently being explored. A graphical overview of the whole co-creation model is presented in figure 1.

Figure 1: Overview of the participatory co-creation process showing the core 8 week and related focus and user groups



To illustrate how the model functions practically we have provide two case studies.

Case Study 1: Design of a low-cost hand device for people with hemiplegia

The aim was to design a technology that could improve the hand flexibility, and function, of people with moderate to high levels of spasticity that was accessible in community settings (low-cost, easy to use and did not require professional supervision) including low income countries, comfortable and supported self-management.

The design process followed the UK Design Council's Double Diamond model [15] which promotes divergent (creating a range of solutions) and convergent (narrowing solutions down through a set of

criteria) thinking. The model supports a co-creation approach with users (in this case rehabilitation professionals and stroke survivors) contributing to the discovery and delivery phases of this iterative design model through observations of technology interactions, focus groups and interviews.

The design process started by observing stroke survivors participating in the TERG model and engaging them in discussions related to hand rehabilitation. This early discovery phase provided general design criteria (comfort/ease of use) and important features which were further refined by a focus group of rehabilitation engineers (n=8) to ensure feasibility in terms of manufacturing. A range of three potential designs were then presented to two user groups; 1) rehabilitation professionals (physiotherapists and occupational therapists, n=9) experienced in this area and 2) stroke survivors (n=6) to reduce this list to a which was most appropriate to solving the problem.

A semi-structured interview (choice of in-person or virtual) was conducted by the researcher (Wodu) for each participant during which a 3D model of the three concepts was presented to generate opinions on key attributes (usability, comfort and effectiveness). The interviews were recorded, transcribed and anonymised. Thematic analysis was then used to identify common themes in the resulting data and used to reduce the list of devices to a single preferred device that would be built for further hands on evaluation.

A prototype of the final choice has been tested for feasibility and acceptability by a new group of stroke survivor attending the centre. The device is currently going through further refinement as part of a process to prepare it for commercialisation.

Case study 2: Design of a rehabilitation dosage and intensity monitoring system

This case study aimed to develop a system for monitoring rehabilitation dosage and intensity to allow stroke survivors and clinicians to gauge activity against the National Clinical Guidelines for Stroke [16]. The system tracks and logs the dosage and intensity of rehabilitation activities users partake in throughout their time at the CCRT, thereby supporting users in their recovery process. Central to its foundation was a co-design process, meticulously planned over a year through four focus groups. This methodological approach ensured the inclusion of direct feedback from participants, fostering a rapport that enriched the design process with iterative refinements and consistent insights.

Analysis from these sessions revealed a notable gap in the transition from prescribed to self-managed rehabilitation, often leading to reduced engagement. Yet, it also highlighted a persistent motivation among individuals to pursue adequate rehabilitation, particularly when supported by peers. This insight steered the development towards leveraging peer support to bolster self-rehabilitation motivation. Consequently, the project led to the collaborative design of a system that should not only facilitate home and community-based stroke rehabilitation but also improve the engagement and motivation of a person to complete their rehabilitation exercises.

Utilising these insights, the project embarked on the development of a mobile application with accompanying hardware to support home and community-based stroke rehabilitation. This development process also employed gamification principles to make said rehabilitation activities more engaging, with a strong emphasis on social involvement and accessible peer support. Further on in the design and development process, involving stakeholders from the stroke community, participants of the co-creation model, healthcare professionals, and researchers, ensured that the device not only met the unique needs of its users but also aligned with evidence-based rehabilitation principles.

Discussion/conclusion

We have described our user participatory approach to the co-creation of rehabilitation technology and presented two case studies to illustrate the process and highlight the potential benefits of this approach. Our model stretches the concept of co-creation beyond surveys, questionnaires and interviews/focus groups [17]. Contributions from end users are enriched by their participation in an eight-week, technology-based rehabilitation programme. Feedback is is highly informed, detailed and based on intensive, prolonged technology use with the opportunity to compare with other

technology, this in-depth feedback is critical for designing technology that is fit for the “real world” [18].

The participatory nature of our model also creates an ideal observatory for engineers (biomedical and design) to collect data on the interactions between stroke survivors and rehabilitation technology. This has led to a number of new device concepts being drafted and adjustments to commercial technology, for example alterations to hand grips and equipment portability which have been accepted by our industrial partners. A surprising outcome from these observations, and informal discussions with participants, has been the desire to integrate technology, for example balance and speech therapy training, and track these activities on a common platform, this is now a focussed area of our activity.

Case study 1 demonstrates that our co-creation method can complement standard design models like the UK Design Councils double diamond [19]. Similarly case study 2 followed the MRC framework for the design of complex medical interventions and devices [20]. Our model ensures the user voice strongly influences each phase of these innovation frameworks and guidelines and fulfils explicit requirements to engage stakeholders (MRC framework) and involve users [19].

Limitations

In presenting this model we recognise there are some limitations. Firstly the volunteers attending our centre may be more motivated and generally more positive towards rehabilitation than the average stroke survivor, since they have actively sought the opportunity for more rehabilitation. Their opinions may therefore be biased and not entirely generalisable. To address this potential bias we have recently started a version of our centre in a hospital setting where all appropriate stroke patients are offered the opportunity to experience technology enriched rehabilitation.

The process may also raise issues around intellectual property since a number of people contribute to technology development. This requires the involvement of an experienced research office and a legal framework that recognises and protects different contributions.

Finally, we recognise that our model is not be implementable in most engineering depts and industrial settings due to a lack of resource (equipment and therapy staff). This places greater importance on the need for collaboration across the rehabilitation engineering sector.

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Supplementary Files