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ADOPTION OF STROKE REHABILITATION TECHNOLOGIES BY THE USER COMMUNITY

A PROGRAMME OF ENGAGEMENT WORKSHOPS AND USER SURVEYS

SCOTTISH UNIVERSITIES INSIGHT INSTITUTE

Final report 21/10/2016

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Background

Stroke has been a priority for NHS Scotland for 15 years, in that time there has been a 21% decrease in the incidence and a 41% improvement in survival rates (1). These figures represent enormous success for public health and acute care but have created a new challenge; to provide the rehabilitation and care needed so that the increasing number of people living with the effects of a stroke (currently estimated at 117, 500 in Scotland(2)) are able to live meaningful lives. This challenge is not confined to Scotland, worldwide an estimated 15 million people suffer a stroke every year with a third left with persistent disability (3).

There is now good evidence that rehabilitation can improve recovery after a stroke (4), furthermore the recovery of functions such as walking, hand/arm functions and speech is better with high-intensity, repetitive task-specific practice with feedback on performance (4).Typically this practice is delivered by skilled healthcare professionals who are a naturally limited NHS resource, with little promise of this resource improving.

The inevitable rationing of rehabilitation services, while understandable in the context of budget constraints, is likely to limit individual recovery. Technology can be used to increase intensity and practice repetition (5, 6), enhance health professional's efficiency (7) and give objective feedback on progress (8). Technology can also support independent practice, which is critical to achieving sufficiently high levels of practice intensity. Technologies are developing rapidly and global developments in healthcare mean a greater reliance on technology is inevitable. This is compounded in Scotland by the drive to reduce length of hospital stay (9) which will, by necessity, require greater integration of care in the community and promotion of self-management (10). Technologies designed to promote patient centred functional recovery after a stroke can play a critical role, particularly those aspects prioritised by patients and healthcare professionals e.g. mobility, speech, cognition and confidence (11). At the moment few emerging technologies are being embedded into everyday practice and technologies are still rarely developed with user determined priorities as the main problem, the focus remains the problem and not the person (12).

In summary, rehabilitation technologies ranging from mobile phone apps to advanced robotics can support efficient and effective delivery of rehabilitation after a stroke. The integration of these technologies into mainstream practice is critical to achieving the levels of movement practice associated with improved functional outcomes; however, uptake by users (patients, carers, rehabilitation professionals) has been slow and variable. Resolving this disconnect between technology development and user uptake has the potential to benefit both technology developers and technology users.

Aim

Our aim in this project funded by the Scottish Universities Insight Institute (SUII) was to identify user priorities for rehabilitation technology, generate new thinking in this area and create a coherent network of stakeholders to continue the work.

We proposed the following objectives:

1. Identify user (patients, carers and healthcare professionals) priorities for rehabilitation technology.
2. Develop a user-perspective evaluation framework for current/future technologies.
3. Establish a network of users, developers and policy-makers to progress the rehabilitation agenda and influence practice.

To meet these objectives we planned three, one day seminars inviting local, national and international stakeholders, with the first two seminars preceded by a questionnaire of the wider community to ensure broad engagement and to prime the seminar discussions.

Objective 1

To identify user (patients, carers and healthcare professionals) priorities for rehabilitation technology.

Gaining consensus for priorities

Briefly, the consensus process consisted of a survey of 177 users (stroke survivors, carers and healthcare professionals) and a consensus meeting in April 2016 during which a long list of 24 priorities from the survey were reduced incrementally to a top ten.

Workshop 1

The workshop included presentations of different models of rehabilitation provision including; 1) community therapy delivered according to current NHS model 2) private rehabilitation delivered in the patient's home and 3) a third sector provided system based around a gym and activity centre that uses high amounts of technology. There were also presentations of rehabilitation technologies for mobility and communication impairments.

Participants

50 individuals from the three stakeholder groups (users, technology developers and policy makers) attended, with an equitable number from each group.

Location: St, Mungos Museum of Religion, Glasgow

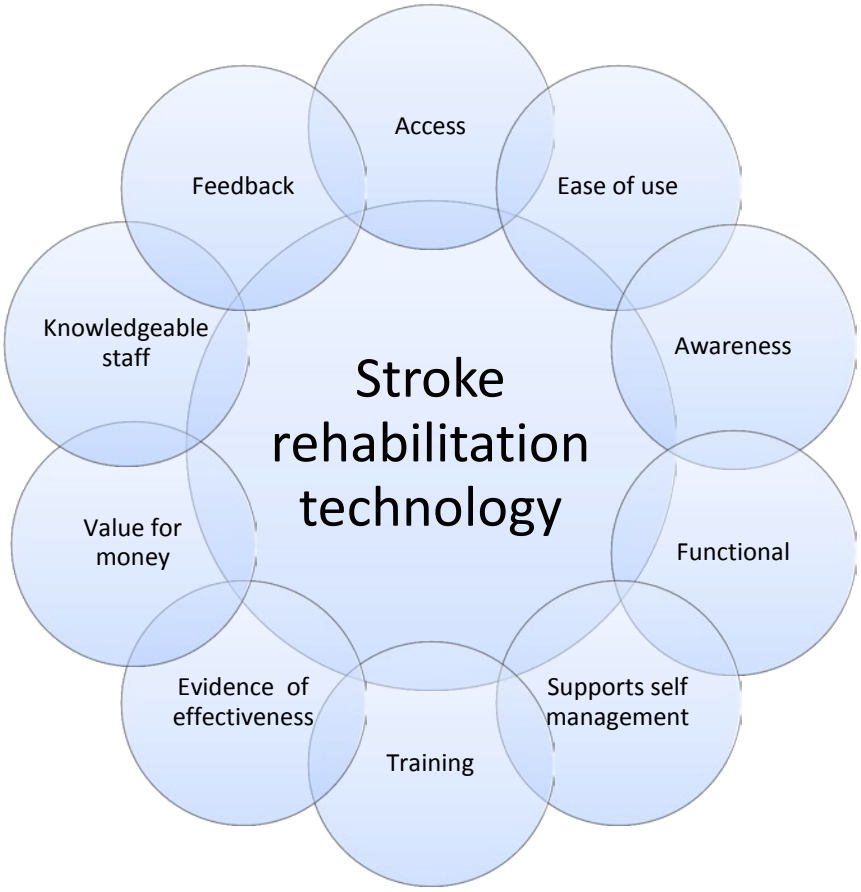
Discussions around priorities were facilitated by our third sector partners (Chest Heart & Stroke Scotland). Seven tables of 6/7 individuals (mix of stroke survivors, clinicians, technology developers, researchers and policy makers) were each supported by a facilitator in their discussions with regular 'whole group' discussions throughout the day as contentious issues were raised.

The following priorities were agreed at the end of the workshop. A short description is appended to each priority, the group felt this was important to avoid ambiguity. They were initially ranked (based on a group vote) in the order set below, however, the workshop delegates requested the list should not be ranked as level of priority may differ according to context and background/role of individual but they were happy that these were the ten most important priorities. The final list, therefore, was visualised as a circle (see figure 1).

Rehabilitation Technology Priorities

1. **Access to equipment:** This meant users being able to gain access to specific pieces of equipment without too much trouble and also being able to use them within NHS facilities, the latter particularly to healthcare professionals using digital equipment, (*e.g*. IPad apps) that challenge NHS IT systems.
2. **Ease of use:** this was considered to be self-explanatory but included one handed usage and was aimed at all end-users, healthcare staff, stroke survivors and their carers.
3. **Awareness:** This was awareness of what is actually available to users in their local area as well as where and how they could access it.
4. **Functional:** Technology should be clearly focussed on improving functional outcomes i.e. those that enhance activities of daily living whether this relates to mobility, speech or cognition/memory.
5. **Supports self-management:** This was a term which potentially covers different areas (access, ease of use *etc*.) but the group requested it should have its own position. So technologies should be designed with the ambition that they can be used to assist the user to manage their own condition by enabling them to practice rehabilitation activities.
6. **Training:** For all end users and should available in accessible formats.
7. **Evidence of effectiveness:** This was widely debated as it was felt definitive 'proof' is unlikely to be achieved for technologies in the near future. The group felt that while lack of definitive evidence should not pose a barrier to a technology being adopted the stakeholder community (users, researchers and technology developers) should work together to provide this evidence. Initially this may be collated experiential evidence but should progress toward definitive evidence suitable for inclusion in practice guidelines.
8. **Value for money:** The wording of this term was altered from 'cost' so that the benefit (individual and societal) of each technology was considered relative to it's cost.
9. **Knowledgeable staff:** Stroke survivor end users felt that a technology was more likely to be used and be effective if their healthcare professional was knowledgeable (practically and theoretical).
10. **Feedback:** Where possible technologies should provide information on general rehabilitation progress to users as well as detailed information on performance of the specific activity. It was recognised that this was not always possible for example when using resistance bands. That this information should be presented in an accessible format considering visual/cognitive/communication problems of the stroke users and should be also be available to the healthcare professional, provided this was agreed

Figure 1: Top ten priority circle



Objective 2

To develop a user-perspective evaluation framework for current/future technologies.

The results of the first workshop directly influenced the structure of the second workshop to the extent that we included a new perspective informed through discussions with the Hunter Centre for Entrepreneurship who have been involved in establishing frameworks for other (non-health) technologies. As developers of technology we (University of Strathclyde and Heriot Watt) were keen to work towards a framework that could be used to directly guide technology developers, in other technologies this is known as a road map and we were interested to see if this could be used in rehabilitation technology, again to bring a new perspective.

Pre-workshop survey results (desirable attributes of stroke rehabilitation technology)

An electronic survey was distributed by Chest Heart & Stroke Scotland, the Scottish Stroke Allied Health Professionals Forum and through the organising committees own network. We received 136 responses, 81 from rehabilitation professionals, 22 from stroke survivors, 22 from University staff (academics and researchers), 7 from industry and 4 carers. The survey simply asked individuals to

rate (1-5) the importance of 5 factors (cost, ease of use, evidence that it works, technical support and portability) determined as priority from workshop 1

Table 1: Importance of factors rated 1-5

Importance (1-5*)	Cost	Ease of Use	Evidence that it works	Technical support	Portability
1	15	1	2	4	8
2	20	3	7	18	13
3	41	13	17	36	41
4	36	40	32	53	49
5	20	74	72	22	21

*5=highest importance

The order of importance was therefore;

1) Ease of use, with 114 responses ranked 4 & 5.

2) Evidence that it works, with 104 ranked 4 & 5.

3) Technical support, with 75 responses ranked 4 & 5.

4) Portability, with 70 responses ranked 4 & 5.

5) Cost, with 56 responses ranked 4 & 5.

This broadly confirmed the findings of the first survey and subsequent consensus meeting.

Workshop 2

The second workshop was organised for early June 2016, it was planned along the same structure as workshop 1 i.e. a mix of discussions facilitated by CHSS facilitators at tables consisting of technology users, developers and policy makers and key presentations.

Participants

50 individuals from the three stakeholder groups (users, technology developers and policy makers) attended, with an equitable number from each group.

Location

Biomedical Engineering Dept, University of Strathclyde, Glasgow

The workshop coincided with an “engage Strathclyde” event to maximise the number of participants able to try out the technologies under development.

Presentations included an overview of the role of the Digital Health Institute (Joanne Boyle), a personal experience of delivering rehabilitation with technology (Tricia Mitchell) and an introduction to the idea of a road map (Annabelle McLaren-Thomson).

Group discussions

1) An exercise to develop a detailed analysis of the user benefits of technology: Production of a ranked grid/matrix of user benefits.

2) Group consensus on how we should move this agenda forward.

There was also a two hour exhibition of stroke rehabilitation technologies under development (mix of University based projects and commercial partners), this was organised in collaboration with Engage Strathclyde and was aimed at stimulating participants to think about the possibilities for future rehabilitation technology.

To enable discussions we made the decision before the workshop to focus on technologies designed to support the recovery of walking. This was to reduce the diversity of discussions and gain more in-depth discussions. If progress was made in this area then we would extend to other areas such as communication.

The discussion activities were facilitated by a researcher from the Hunter Centre for Entrepreneurship. The output of these activities was a list of potentially deliverable user benefits for walking technology separated into three themes: 1) Facilitating movement 2) Increasing independence and 3) motivation

Customer needs for facilitating walking included a) increasing number of steps, b) increasing length of walking duration and c) increasing joint flexibility.

Customer needs for increasing independence included a) ability to walk without support b) able to use on own and c) can be used anywhere.

Customer needs around motivation is that the technology should a) monitor progress b) provide visual feedback and c) set goals.

In the general discussions the group felt there was an opportunity to develop an on-line resource for rehab technology customers which detailed:

a) Evidence of efficacy, b) usability and c) user feedback (as per “TripAdvisor”).

Such a resource would greatly assist users when deciding which technologies to purchase

Objective 3: Develop a user network which can:

a) Disseminate outcomes from objectives 1 and 2 to a wider audience and make appropriate revisions to the priority list and evaluation framework.
b) Explore ways of using the priority list (objective 1) and evaluation framework (objective 2) to influence technology development, for example through product endorsement.
c) Work with Scottish government policy makers regarding the implementation of outcomes.
d) Influence education providers to ensure rehabilitation technology is addressed in health professionals’ education.

e) Establish a potentially fundable European collaborative group e.g. the Innovative Training Networks (ITN).

Preceding workshop 3 Annabelle McLaren-Thomson (Hunter Centre for Entrepreneurship) analysed the data from workshop 2, in particular she focussed on extracting desirable attributes for walking technologies, considering their potential to be exploited by technology developers. These were categorised into three themes (movement, independence and motivation), see table 2 for details.

Table 2 Desirable attributes for walking technologies

Customer needs: Improve movement	***Customer needs: Increase independence:***	***Customer needs: Sustain motivation:***
Increase number of steps walked	Ability to walk without support	Ability to set goals
Increase walking pace	Ability to use device without help	Monitor progress
Increase length of time walked	Device can be put on with one hand	Provides visual feedback
Increase range of movement	Device can be used anywhere	
Increase muscle strength	Device is portable/wearable	
Increase joint strength	Ability to use device at home	
	Reduce time required to put on device	
	Minimal maintenance of devices	
	Low cost of device/reduction of care package	

Workshop 3

Location

Heriot Watt University was chosen to allow other users (therapists and stroke survivors) to attend. The use of the new sports facility (Oriam) was deliberately chosen to engender a new perspective on rehabilitation which is a big part of elite sport. This was also behind the speaker selection (Macaluso and Gibson).

Participants

60 participants representing users, policy makers, academics and technology developers. In particular we wanted to ensure a good representation from stroke survivors. As with the previous workshops this contribution was organised by the third sector partners (Chest Heart & Stroke Scotland). Previous participants were invited and invites were also sent to NHS Lothian therapists.

This final workshop was structured along similar lines to the previous two. A mixture of invited talks to stimulate discussions, a small exhibition of rehabilitation technology and a tour of the high performance rehabilitation rooms and the Oriam centre itself.

Talks

An initial presentation on progress to date was provided by Andy Kerr and Annabelle McLaren-Thomson (Hunter Centre for Entrepreneurship). This was intended to bring all participants up to date on what we had achieved and remind everyone on the aim of the final workshop.

This was followed by talks from Macaluso who provided an overview of his work using technology in rehabilitation (sport and older adults) from a physiological perspective and Neil Gibson who talked about his experiences of rehabilitation in elite sport.

Jon Fogarty talked about his own personal experience of stroke

The morning session was completed by Dr. Sarah Mitchell who was able to provide an insight on the Scottish Government's policy development in relation to management of long term conditions, such as stroke through the Active and Independent Living Improvement Programme (AILIP).

The afternoon coffee break included an opportunity to try out some rehabilitation technology under development.

The afternoon consisted of a couple of talks but the main focus was the workshop activity.

Workshop activity:

Participants were organised into 7 tables of ~8 individuals with a mix of backgrounds (users/academics/industry/3rd sector) to discuss the following questions

1. What activities can we continue?
2. What proposals for projects can we envision?
3. Do you want a network in stroke rehabilitation technologies to continue and if so in what format?

Afternoon talks

Chris Sawyer gave a talk on the network that Innovate UK set up and run on assistive technologies which has clear overlaps with our focus of rehabilitation technologies.

Erwin van Wegen gave an outline of his work developing technology for rehabilitation in Netherlands, most of this related to stroke and there were clear areas for collaboration.

Invited speakers, Andrea Macaluso, Italian University of Sport and Movement, Italy.

John Fogarty, Stroke Survivor, Scotland, Neil Gibson, Oriam Director of Sport, Performance and Health, Heriot Watt., Sarah Mitchell, Policy maker NHS Scotland, Programme Director - Active and

Independent Living Improvement Programme (AILIP), Chris Sawyer, Policy Maker, Innovate UK.
Erwin van Wegen, Researcher, Amsterdam, the Netherlands.

Discussions

Consistent with previous workshops the discussions were lively and informative. Each table presented their views and the whole group discussed them in the final session of the day with a view to condense the views into a strategy for the future.

Participants expressed the need for a regular technology fair/exhibition to increase awareness of what exists and to influence design of new technologies. Including industry in this was thought to be useful. Furthermore such an exhibition could have a theme e.g. communication technologies and should be moved around the country.
Participants were interested in developing an online resource (portal) which could function in a similar way to other consumer rating websites such as trip advisor or "rotten tomatoes".
Participants were also enthusiastic about a user-network which could be linked to the previous initiatives.

Key outcomes and recommendations from whole programme

1. A top ten list of priorities for increasing the use of technology in stroke rehabilitation was agreed (see pages 6 and 7) by users, academics and technology developers. This will be a valuable list for technology developers, the organising committee have agreed to submit it for publication.
2. The potential for a technology road map in stroke rehabilitation was explored and initial steps taken for technologies that support recovery of walking function. The group considered this development valuable and worth future attention.
3. A regular (annual) technology fair was recommended by the group to 1) increase awareness among users of what technologies exist and are under development 2) allow users to influence technology development 3) allow developers to get informal feedback on ideas and 4) provide opportunity for users to put forward new ideas for technology.
4. An on-line resource modelled on consumer-rater websites such as trip advisor was considered to be an innovative way of promoting use of technology and creating a platform to inspire new technologies or re-development of existing ones.
5. Establishing a network of users, technology developers and policy makers would be critical to advancing the aforementioned initiatives. There was considerable enthusiasm for such as network with some caution around how this could work practically.

These outcomes and recommendations will be considered by the organising committee and an action plan put in place around implementation. Early discussions in this regard suggest an annual technology fair could be organised tied in with a first meeting of a network which will focus on developing the on line resource and road map.

Dissemination of results

Findings from the first workshop were presented orally at the June 2016 (Perth) meeting of the Scottish Stroke Allied Health Professionals Forum.

Findings from the whole programme will be presented as an oral presentation at the European Physiotherapy conference, Liverpool 2016 as well as the SUII event on 28th of November.

There are also plans to submit key findings to:

1) The UK Stroke Forum.

2) The European Stroke Conference.

2) A scientific journal.

Appendix A

List of contributors

Workshop 1

Andy Kerr, Academic, University of Strathclyde, Glasgow.

Linda Gibson, Occupational Therapist, NHS, Edinburgh.

Frans Steenbrink, Technology developer, MotekForcelink, Amsterdam, The Netherlands.

Wendy Edge, Service provider, Brain and Spinal Injury Centre, Salford.

Sylvia Moss, Physiotherapist, Brain and Spinal Injury Centre, Salford.

Kenny Thoms, Physiotherapist, Private Practice, Glasgow.

Workshop 2

Joanne Boyle (Digital Health Institute) (Confirmed)

Tricia Mitchell, Speech and Language Therapist, Borders.

Annabelle McLaren-Thomson, Hunter Centre for Entrepreneurship, University of Strathclyde.

Lynne Baillie (Heriot-Watt University) Talk on future possibilities for rehab technology.

Workshop 3

Andy Kerr, Academic, University of Strathclyde, Glasgow.

Andrea Macaluso, Academic, Italian University of Sport and Movement, Rome, Italy.

John Fogarty, Stroke Survivor, Scotland

Neil Gibson, Oriam Director of Sport, Performance and Health, Heriot Watt.

Sarah Mitchell, Policy maker NHS Scotland, Programme Director - Active and Independent Living Improvement Programme (AILIP)

Chris Sawyer, Policy Maker, Innovate UK.

Erwin van Wegen, Researcher, VU University Medical Center, Amsterdam, the Netherlands.

Appendix B Workshop outlines

Stroke Rehabilitation Technology

User workshop 1

0930-10:00 *Registration with tea and coffee.*

10:00-10:40: "*Introduction and scene setting".*

1) Results of a national survey on the use of technology by stroke rehabilitation professionals and people living with stroke.

Presenter: Andy Kerr and Siu Ho-Fan, (Strathclyde)

2) Real life experiences of using technology in stroke rehabilitation

Presenter: Linda Gibson, Occupational Therapy, Community Stroke. (Edin)

3) Computer Assisted Rehabilitation Environments

Presenter: Frans Steenbrink, MotekForcelink (The Netherlands).

10:40-11:40: "***Priority setting around tables*"**

Participants to discuss results of survey and begin assembling long list of priorities.

11:40-12:10: *"Future possibilities for rehab technology"*

1) An alternative approach for providing technology based rehab.

Presenter: Wendy Edge & Sylvia Moss (Brain and Spinal Injury Centre, Salford)

2) User Centred approach to designing rehab technology.

Presenter: Lynne Baillie (Heriot Watt University).

12:10- 1:00pm: Lunch

*Technology demos and show and tell of good/bad technology.

1:00-1.15 Real life experiences of using technology in stroke rehabilitation

Presenter: Kenny Thoms, Physiotherapist, Neuro Physio Scotland.

1.15-2:10: "Final Priority setting around tables"

Groups to complete their final top 10.

2:10-3:00 Presentation of top ten lists from each group.

3:00-3:20 Break

3:20-3:50 Final selection of top ten priorities: All workshop participants to vote on list of priorities.

3:50 - 4:00 Summing up: advanced warning of future meetings

Workshop 2

Outline of workshop 2 (3rd May)

Location: Wolfson centre, University of Strathclyde

Theme

Developing a framework to evaluate stroke rehabilitation technologies

09:30 - 10:00am Registration (Teas and Coffee)

10:00 - 11:00am

Talk 1: Introduction and results of 2nd survey

Talk 2: How are healthcare technologies evaluated?

Joanne Boyle (Digital Health Institute) (Confirmed)

Talk 3: Personal experience: ?Tricia Mitchell (SALT, Borders TBC)

11:00 - 11:45am Activity

Exercise to develop a detailed analysis of the user benefits of technology: A ranked grid/matrix of user benefits

Delivered by Professor Levie (Strathclyde Business School)

11:45 - 12:00 noon Introduction to idea of a technology road map

12:00 noon Lunch and chance to try out some technologies. This will include demonstrations in the ground floor of Wolfson.

2pm Talk 4: NHS procurement person (Lynne?)

2:15 - 3:00pm Activity

Developing the benefits grid from morning

3.00 - 3:30pm Break

3:30 - 4:00pm Group consensus on how we should move this agenda forward.

4:00pm Summing up and advanced warning of final meeting

Workshop 3

Workshop 3:
Investigating Stroke Rehabilitation Technologies with the User Community

Schedule

9.30-10.00: Registration with coffee/Tea

10.00-10.25: Andy Kerr and Annabelle McLaren-Thomson “Update on work to date”

10.30-10.50: Andrea Macaluso, Italian University of Sport and Movement, “Views from Exercise Physiology”

10.55-11.15: Paul Hodson “A Stroke Survivors Experience of Technology”

11.20-11.40: Neil Gibson, Oriam Director of Sport, Performance and Health

11.40-11.50: Sarah Mitchell, Programme Director - Active and Independent Living Improvement Programme (AILIP) ‘Overview of programme’

12-13.00 Lunch

13.00-13.30: Tours

13.30-13.50: Chris Sawyer, Innovate UK, “Opportunities and Networks”

14.00-14.20: Erwin van Wegen, VU University Medical Center, Amsterdam, “perspective from the Netherlands”

14.30-15.10: Road map Ahead (split into groups):

1. What activities can we continue?
2. What proposals for projects can we envision?
3. Do you want a network in stroke rehabilitation technologies to continue and if so in what format?

15.10-15.50: Coffee and Posters/Demos

15.50-16.20: Feedback from groups approx 5 mins each and discussion of next steps

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