Institution:	University of Northumbria at Newcastle
Unit of Assessment:	3 - Allied Health Professions, Dentistry, Nursing and Pharmacy

Title of case study: Cueing people with Parkinson's to improve their walking: the RESCUE project

1. Summary of the impact

The part of the brain affected by Parkinson's disease (PD) is responsible for co-ordinating complex sequences of movement, such as walking, by generating internal cues for each stage of the movement. REhabilitation in Parkinson's Disease: Strategies for CUEing, RESCUE project, successfully tested a home-based physiotherapy programme to train people with PD to use externally delivered rhythmic cues in a randomised control trial, to see if cueing therapy made a difference to walking/walking-related activities. Evidence has been incorporated into the European Guidelines for Physiotherapy in PD. It has also been used in health and social care professionals' training programmes. The evidence-based cueing guidelines have been made available on CD-ROM and in patient and carer information leaflets. Information has been translated into Danish and adapted for use by patients with neuroleptic induced parkinsonism.

2. Underpinning research

The RESCUE project (2002-2005) was funded (£1 million) under the European Commission Framework Scientific Programme V, within the Quality of Life and Management of Living Resources Programme (1998-2002) key action – the ageing population and their disabilities. The working hypothesis for the cueing intervention was that delivering external cues by sound, light or vibration, which brain imaging techniques suggest bypass the area most affected in PD, would normalise walking by providing on-going individualised rhythmic cues which patients could use to match to their heel strike. This would help to overcome the classic symptoms of small, shuffling steps and complete cessation of steps, known as freezing, all of which predispose to falls.

RESCUE was a physiotherapy led project, involving leading clinical academics in neurological rehabilitation, co-ordinated by Northumbria University: Professor Rowena Plant (1990-2007); Dr Diana Jones, Principal Lecturer (1994-present); Dr Lynn Rochester, Reader (2002-2007); Dr Katherine Baker, Research Physiotherapist (2003-present, currently Senior Lecturer); Vicki Hetherington, Research Assistant (2002-2005), with partners at the Katholieke Universiteit, Leuven, Belgium, and the Vrije Universiteit Medisch Centrum, Amsterdam, The Netherlands. The project generated new scientific knowledge on the use of external rhythmic cues (auditory, visual, and somatosensory) in both the laboratory and the home; validated a test battery to assess gait and gait-related activities in people with PD in the home setting; developed an optimised, evidence-based therapeutic package of cueing strategies for rehabilitation (based on laboratory-based year 1 studies) and tested this in a community-based trial (in years 2 and 3) involving 153 participants with PD across three countries; and, in addition to peer review journal output, developed resources (CD-ROM of guidelines for cueing for gait and gait-related problems and patient and carer information sheets about cueing) to help communicate the intervention trialled widely to professionals, patients and carers, with details on a project website (http://hces-online.net/websites/rescue/overview/cueing.htm).

RESCUE was the first large scale randomised control trial to investigate the effects of a cueing training programme in the home and high quality evidence of its effectiveness was generated (Nieuwboer et al, 2007). In an editorial in the issue of the Journal of Neurology, Neurosurgery and Psychiatry in which the trial results were published (Hirsh & Hammond, 2007 JNNP 78:111 DOI: 10.1136/jnnp.2006.104794) the study was described as 'ground breaking' for four main reasons: its size; its strong adherence to reducing potential trial biases; the fact the intervention took place in the community; and the inclusion of a follow up period. RESCUE results showed that rhythmic cueing therapy significantly improves measures of gait and balance in people with PD. Improvements in fatigue and depression were found. Cues can be used to improve walking during functional activities and raise overall levels of activity. Auditory cueing was the most popular modality amongst trial participants and small metronome devices are able to deliver appropriate rhythmic auditory cues for rehabilitation purposes.

The results pointed to the need for follow up therapy and the use of permanent cueing devices. The RESCUE project products (the CD-ROM of cueing guidelines for therapists and the patient and carer information sheets) were designed to help support therapists deliver evidence-based therapy in the home and support the patients and carers they work with to better understand the rationale for a treatment that has the potential to support self-management over the longer term if undertaken with regular therapy review. RESCUE data was included in the systematic review of physiotherapy for Parkinson's disease published in the British Medical Journal by the PDRehab trial team (Tomlinson et al. 2012).

3. References to the research

Nieuwboer A., Kwakkel G., Rochester L., Jones D., van Wegen E., Willems A-M., Chavret F, Hetherington V., Baker K. and Lim I. (2007) 'Cueing training in the home improves gait-related mobility in Parkinson's disease: the Rescue trial', *Journal of Neurology, Neurosurgery and Psychiatry*, 78, pp134-40. DOI:10.1136/jnnp.200X.097923.

Rochester L., Nieuwboer A., Baker K., Hetherington V., Willems A., Chavret F., Kwakkel G., van Wegen E., Lim I. and Jones D. (2007) 'The attentional cost of external rhythmical cues and their impact on gait in Parkinson's disease: Effect of cue modality and task complexity', *Journal of Neural Transmission*, 114, pp1243-8. DOI: 10.1007/s00702-007-0756-y.

Jones D., Rochester L., Birleson A., Nieuwboer A., Willems A-M., Kwakkel G., and van Wegen E. (2008) 'Everyday walking with Parkinson's disease: understanding personal challenges and strategies'. *Disability and Rehabilitation*, 30, pp1213-1221. DOI:10.1080/09638280701828955.

Lim I., van Wegen E., Rochester L., Nieuwboer A., Willems A., Jones D., Baker K., Hetherington V. and Kwakkel G. (2009) 'Does cueing training improve physical activity in patients with Parkinson's disease?', *Neurorehabilitation and Neural Repair*, 24, pp469-477. DOI: 10.1177/1545968309356294.

Nieuwboer A., Baker K., Willems A-M., Jones D., Lim I., Kwakkel G., Van Wegen E., and Rochester L. (2009) 'The short-term effects of different cueing modalities on turn speed in people with Parkinson's disease', *Neurorehabilitation and Neural Review*, 23, pp831-836. DOI: 10.1177/1545968309337136.

Rochester L., Baker K., Hetherington V., Jones D., Willems A-M., Kwakkel G., Van Wegen E., Lim I. and Nieuwboer A. (2010) 'Evidence for motor learning in Parkinson's disease: acquisition, automaticity and retention of cued gait performance after training with external rhythmical cues', *Brain Research*, 1319, pp103-111. DOI:10.1016/j.brainres.2010.01.001.

4. Details of the impact

Inclusion of RESCUE research data in guideline documents is important due to their influence on evidence-based commissioning, professional practice, on education and training and on patient expectations. While the RESCUE project reported outside of the timeframe for its research evidence to be included in the NICE national clinical guideline for diagnosis and management of PD in primary and secondary care, the importance of the project was noted in the full guideline document where it was acknowledged that its results on the effectiveness of cueing therapy could provide pilot data for the recommended research into the cost effectiveness of physiotherapy (PDRehab trial). RESCUE data will contribute to the planned update of the NICE guideline and has also recently been incorporated into the European guidelines for physiotherapy in PD (publication due Autumn 2013).

Translating RESCUE research results into practice has been a priority for Northumbria researchers, building on relationships with key stakeholders (e.g. national and international patient associations, professional networks such as those of Chartered Society of Physiotherapy i.e. AGILE - physiotherapists working with older people and ACPIN - physiotherapists working in neurology). Our CD-ROM of cueing guidelines designed for therapists, and the information sheets

on cueing designed for patients and carers, have been key products to aid implementation and impact. Parkinson's UK evidence-based materials on gait related symptoms include RESCUE resources in their reference lists. The RESCUE project website and linked resources are referenced in Parkinson's UK training sessions (69 such sessions were delivered in 2012 in the NE region of Parkinson's UK, reaching 692 health and social care staff). The RESCUE project has given permission for incorporation of CD-ROM material into a new Parkinson's UK credit rated learning programme entitled 'Understanding Parkinson's for Health and Social Care Staff' being piloted in Scotland during 2013 with planned roll out to the UK in 2014. Parkinson's UK branches and health service organisations in the UK regularly contact Northumbria researchers for workshops and we have presented the project internationally at the request of Parkinson's specialist nurses, neurologists and physiotherapists (e.g. New Zealand 2008). Our work has been extensively presented at non-academic conferences attended by people with PD, carers and professionals (e.g. those organised by the European Parkinson's Disease Association) raising awareness of the research and resources available.

[text removed for publication] Dr Baker has provided cueing workshops and generated information on the range of cues used in practice settings for use by this group. As a result of increased awareness, Dr Baker has responded to queries about the purchase of metronomes to deliver auditory cues.

Dr Diana Jones of Northumbria is a founding member and sits on the Board of the Association of Physiotherapists in Parkinson's Disease Europe. This European link increased awareness and understanding of the research. This facilitated a request from the Danish Parkinson's Disease Association to translate the patient and carer information sheets into Danish.

The RESCUE project website provides links to information sheets for people with PD and carers on cueing, web resources and the CD-ROM. More than 200 copies have been sold since 2008 to therapists in the UK, Europe, the Middle East, North and South America and Australasia. The initial purchase of the CD-ROM by staff in the physiotherapy programme at the University of British Columbia resulted in a request to embed videos from the CD-ROM within a virtual case study of a patient with Parkinson's disease. The University produced a series of computer based virtual patients to support their internationally educated physiotherapists prepare for their national licensing exams.

Research insights from the RESCUE project have also supported the management of mental health patients who develop parkinsonism as a result of neuroleptic medication taken to treat serious behavioural difficulties. Northumberland Tyne and Wear NHS Trust used the project's patient information sheets to assist treatment. Feedback from patients indicated that they were upset by the reference to Parkinson's disease. As a result of this feedback, the RESCUE team made minor changes to the wording, tailoring the information to make it more appropriate, usable and acceptable to this new patient group.

5. Sources to corroborate the impact

Reports, reviews and web links or other documented sources in the public domain

The NICE national clinical guideline for diagnosis and management of PD in primary and secondary care full guideline document acknowledgement can be viewed via this link: http://www.nice.org.uk/nicemedia/pdf/cg035fullguideline.pdf

RESCUE data has been incorporated into the European physiotherapy specific guidelines for physiotherapy. See this via the following link:

http://www.appde.eu/european-physiotherapy-guidelines.asp

Parkinson's UK evidence-based materials on gait related symptoms include RESCUE resources in their reference lists. See this via the following link:

http://www.parkinsons.org.uk/content/freezing-parkinsons-information-sheet

The Association of Physiotherapists in Parkinson's Disease Europe link to the RESCUE project resources from their website

http://www.appde.eu/external-resources.asp

Information on the CD-ROM and information sheets can be viewed on the RESCUE project website: http://hces-online.net/websites/rescue/overview/cueing.htm

Individual users/beneficiaries who can be contacted to corroborate claims

Clinical Associate Professor and Virtual Patient Project Physiotherapy Lead at the University of British Columbia can corroborate claims concerning the virtual case study

Education and Training Officer at North East Parkinson's UK can corroborate claims concerning training

Associate Professor in Neurorehabilitation, Radboud University Nijmegen Medical School can corroborate claims concerning the European Guidelines for Physiotherapy in Parkinson's Disease

Danish Parkinson Disease Association can corroborate claims concerning the translation of information sheets into Danish

Senior Physiotherapist at Northumberland Tyne and Wear NHS Foundation Trust can corroborate claims concerning the adaptation of information sheets for neuroleptic induced parkinsonism