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CIHR Research into Practice Seminar Series 27/03/08

**Collaborating to  
advocate for patients  
through research**

Dr Cathy Bulley, Queen  
Margaret University



Queen Margaret University  
EDINBURGH

[www.qmu.ac.uk](http://www.qmu.ac.uk)

# This seminar aims to:

- Describe the journey of a collaborative project from idea to dissemination
- Describe the journey of a research team in relation to capacity and capability
- Provide time for questions and discussion, particularly about ways of facilitating such journeys



# Capacity & Capability



Dictionary definitions:

- **CAPACITY**: the maximum amount that something can contain or produce; the ability or power to do something
- **CAPABILITY**: the power or ability to do something

[Compact Oxford English Dictionary]



# Advocating for patients through research



- The value of research is now integrated into much of NMAHP training and into promotion structures
  - Evidence based practice
  - Service evaluation
  - Service development



# Case Study:

- Patient and carer experiences of functional electrical stimulation (FES) for dropped foot after stroke
- Pump-priming project funded by the CIHR



# Project Team

## Clinically-based

(Astley Ainslie  
Hospital)

- Caroline McGuire
- Jane Shiels
- Katie Wilkie

## Academically-based

- Cathy Bulley  
(QMU)
- Lisa Salisbury  
(Edinburgh  
University: CIHR)
- 0.5 Research  
Assistant



# Starting point: the clinical need

- Clinical physiotherapists
  - Sought and received one-year's non-recurrent funding for a pilot FES clinic
  - Recognised the need for rigorous research focusing on user experiences
  - Approached academically-based physios
- Successful collaborative application for funding





# Capacity & Capability

## Clinically-based

- Very experienced clinically
- Less research experience— some quantitative
- Involvement in other research projects

## Academically-based

- Less clinical experience
- 2 PhDs, several previous grant applications
- P.I.: no previous experience of managing a grant



# Study rationale

- Stroke incidence: 174-216 / 100,000 UK p.a. (Royal College of Physicians, 2004)
- Up to 20% develop dropped foot and altered gait (Burridge et al, 1997)
- Impacts of dropped foot: greater risk of trips and falls, fatigue
- Standard management: rigid ankle foot orthoses (AFOs), callipers, and FES



# AFO

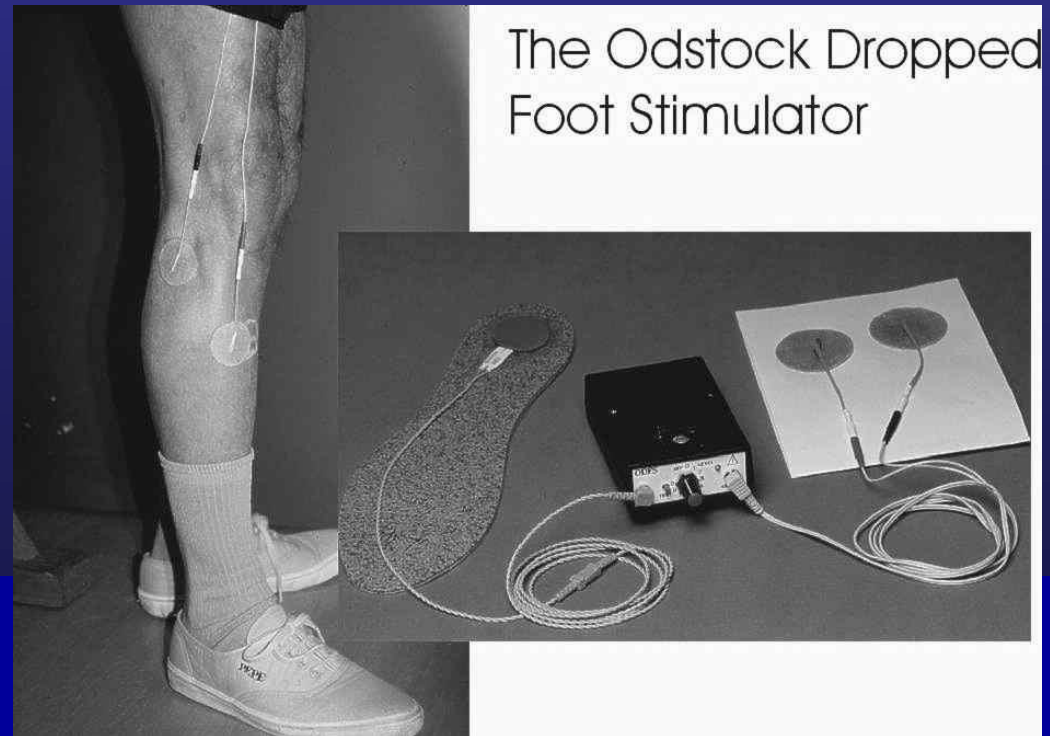
- Evidence of improved walking ability, confidence, speed, and reduced energy expenditure
- BUT also evidence of muscle wasting and poor patient compliance due to appearance, impracticality, discomfort

(Leung et al, 2003; DeWit et al, 2004; Geboers et al, 2001)



# FES:

- Quantitative evidence of improved walking ability and speed, fewer falls, improved quality of life (Glanz et al, 1996; Granat et al, 1996; Taylor et al, 1999)
- Recommended by RCP (2004)



# Research Question & Aims

- What are patient and carer experiences of stroke-related dropped foot and its management using Functional Electrical Stimulation?

Aims: \_

- to explore the impact of dropped foot
- to explore patients' and carers' experiences of a pilot FES Clinic
- to promote the use of research findings in service funding and development



# Study Design



- Study focus: lived experiences of individuals
  - PARADIGM: Qualitative
  - APPROACH: Phenomenological
  - TOOL: One-to-one semi-structured interviews using a topic guide



# Sampling and Recruitment

- Via FES User's group (database n = 50)
- Number: 13 patients, 9 carers, 19 interviews
- Purposive sampling based on fast/slow 10-metre walking speeds at baseline (13-72 sec), and time since stroke (2-9 years)
- Exclude patients with difficulty communicating
- Include carers of patients with difficulty communicating



# Procedure

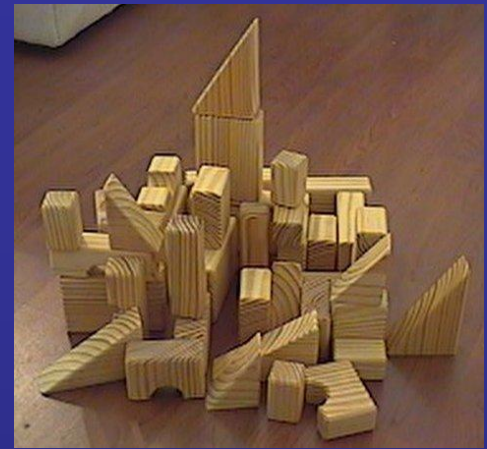
- Interviews in place of choice:
  - Participant's home (18)
  - Quiet room at the Astley Ainslie Hospital (1)
- Safe lone working practices
- Topic guide – flexible focus on study aims





# Analysis

- Systematic, thematic analysis
- Initial thematic analysis by principal investigator
- Cross check of all text units supporting each theme by a second research assistant
- Discussion of theme structure within the team (back-fill included in the grant for clinical time)



# Main Results:

- Several theme areas resulted, not all expected. Important areas were:
  - Patient and carer journeys
  - Impacts of stroke
  - Experiences of Ankle Foot Orthoses (AFOs)
  - Experiences of FES Clinic
  - AFOs (splints) versus FES



# Impacts of FES of patients

- *“It gives you the action of walking as a normal person.”*
- *“...I’m back to what I was doing [occupationally]. But... 75% of the reason for getting back, or allowing myself to get back is this [FES]”*
- *“I used to have to take her to the toilet but now you can only take her to the door. ... and that has triggered... her respect for herself.”*



# Impacts of FES on carers

- *“Well it gives me the confidence to go out for a wee while and know that he can manage...”*
- *“I think it’s lessened my workload... The kitchen was always his domain, nobody could clean the kitchen like my husband. So now, he’s got that job back.”*



# Impacts of FES Clinic & User's Group

- *“Just nice to have somebody to contact if I have any concerns about it... if it breaks or... the calibrated settings on it need attention... he does drift into maybe not putting it on as well and needs reminded where to position it ...they can very quickly isolate a problem. If we didn't have the ability to phone up and say could we come and see you this week, ...you know, my husband wouldn't be going out for a walk.”*



# Advocating for patients

- Among service managers & funders:
  - Managed Clinical Network for Stroke
  - NHS QIS Stakeholder meeting for AFO and Stroke → discussion of developing an evidence note regarding FES
- Among people with a special interest:
  - Conferences (three presentations completed)
  - Articles (to be submitted)



# Capacity & Capability:

## Clinically-based

- Increased specialist knowledge
- Increased knowledge of qualitative research
- Value placed on the process
- Ability to disseminate findings

## Academically-based

- Increased experience in project management,
- Importance of communicating motives, strengths, skill-sets



# To Summarise



- This project was successful in giving a voice to patients and carers in a rigorous manner
- This information has been, and will continue to be used to advocate for service development
- It was important for the development of research capacity and capability





# Time for questions & discussion

- Discussion topic:

How do you think that journeys like this can best be initiated and supported?

