The STROKE Association

Caring for today
Researching for tomorrow
Working for change

A cluster trial evaluation of a patient and carer-centred system of longer-term stroke care

Who's who?

LoTS care
Stroke system of care trial

- **Chief investigator:**
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- **Co-investigators:**
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NHS Foundation Trust

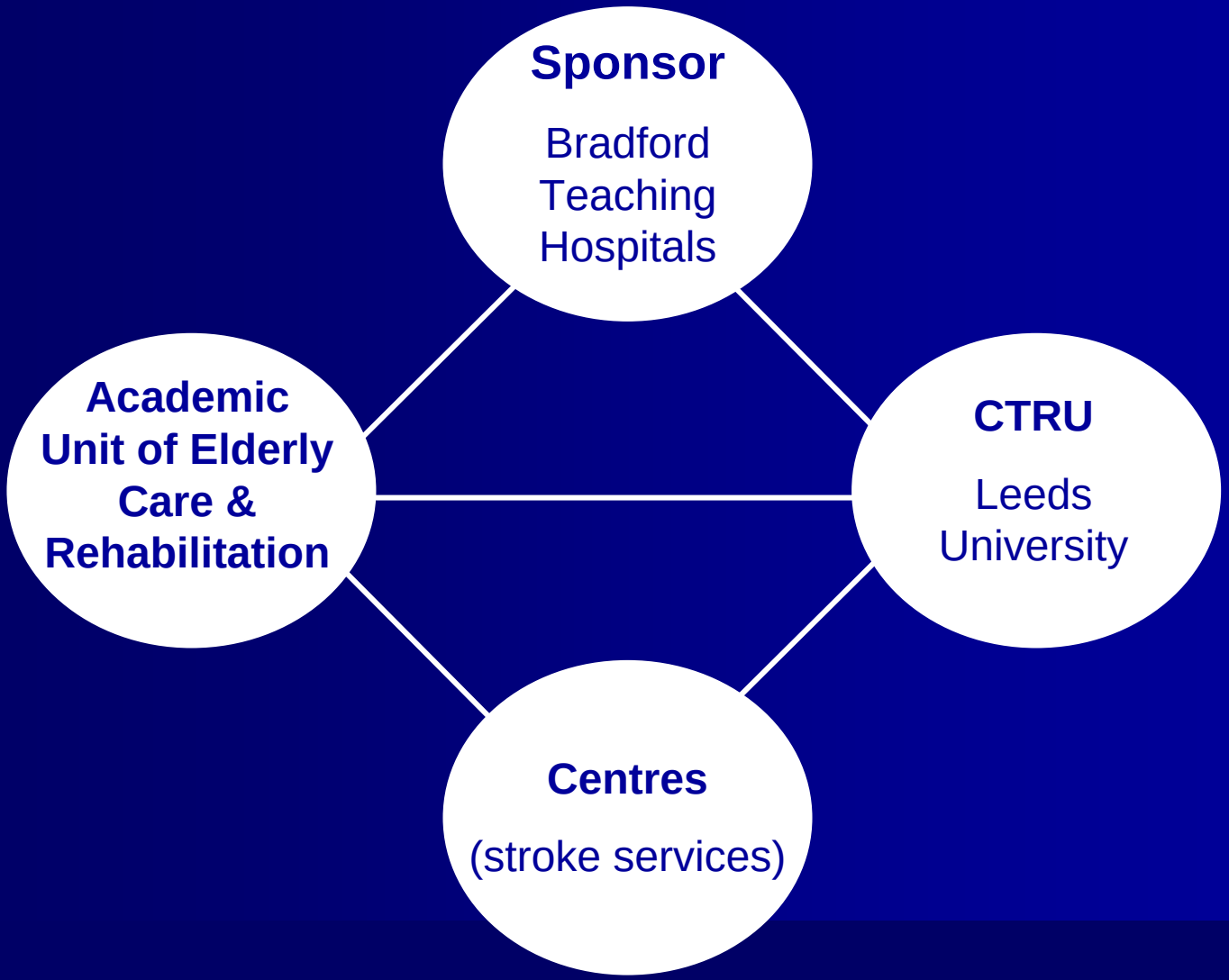
ctru
University of Leeds

KING'S College LONDON
University of London

Who is involved?

- Funders: NIHR Programme Grant & TSA
- First NIHR stroke rehabilitation programme grant to be awarded
- The trial is part of a programme of research to improve longer-term outcomes of stroke patients living in the community
- A very exciting & prestigious study to be involved with!

Who is involved?



Background

- Longer-term recovery is poor for many stroke patients
- Patients depressed and housebound
- Carers stressed and anxious

Development work

Review of qualitative research

Review of quantitative research

Interviews with patients and carers

Identification of patient and carer longer term problems (16)

System of Care

System of Care

Structured Assessment

(focussed on patient and carer centred problems following a stroke)

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highlights patients' and carers' problems

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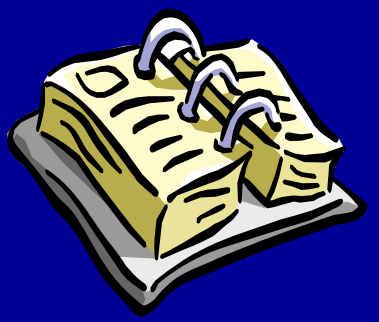
Reference Guides
(Treatment algorithms)



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Action Plans

Feasibility Study

- 47 patients/ 21 carers were recruited
- Professionals found it easy to use and helpful
- Feedback further refined system

Murray et al., (2006) British Journal of General Practice 56 (531) pp 775-780

Study Aim

- To evaluate the clinical and cost effectiveness of our new system of care, on psychological and functional outcomes of stroke patients living in the community.

Objectives

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- Primary Objective:
  - Improved psychological outcomes for patients
- Secondary Objectives:
  - Improved functional outcomes for patients
  - Improved psychological and functional outcomes for carers
  - Assess if the system of care is cost-effective

Methods

- Multi-centre, cluster randomised controlled trial of 800 stroke patients and their carers

- The system of care will be delivered by stroke care co-ordinators (SCCs)

Stroke Care Co-ordinators

Are you a stroke care co-ordinator (SCC)?

We have defined an SCC as follows, however other titles may be in use.

- A registered health profession with documented experience in stroke care
- Undertakes a community based liaison or co-ordinating role for stroke patients
- In regular contact with patients and co-ordinate a range of longer-term care inputs on their and their carers' behalf (e.g. signposting, carrying out assessments etc)
- Works within a stroke service

Service Eligibility

- Encompass primary and secondary care over a geographical area within the UK
- A stroke service must have a stroke unit, defined (at least 4 out of 5) as follows:
  - Consultant physician with responsibility for stroke
  - Formal links with patient and carer organisations
  - Multidisciplinary meetings at least weekly to plan patient care
  - Provision of information to patients about stroke
  - Continuing education programmes for staff

Service Randomisation

- This is a CLUSTER randomised trial, so the service will be randomised not the individual patients

- Services will be randomised to either:

Intervention

SCCs will deliver our new system of care to assess patients

OR

Control

SCCs will deliver their usual care

What will it involve?

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What will happen to my working practice if...

I'm randomised to the INTERVENTION

- You will deliver our new system of care to ALL your patients

I'm randomised to the CONTROL?

- You will continue to deliver your usual assessments

Your patients will be approached by a researcher to take part in the study i.e. to complete questionnaires

SCC Training

If randomised to the INTERVENTION:

- SCCs will need to attend 2 national training days:
  1. Training in delivering the system of care
  2. Training in the research procedures

If randomised to the CONTROL:

- SCCs will need to attend 1 national training day:
  1. Training in the research procedures

Travel expenses will be provided

Patient Recruitment

- Carried out by independent researchers

- Research nurse will:
  - Assess patients
  - Explain the trial to patients
  - Take informed consent
  - Collect baseline data

Outcomes

- Outcomes of the trial will be evaluated by a questionnaire pack:
  - at baseline
  - posted to patients and carers after 6 months
  - posted to patients and carers after 12 months
- Postal questionnaire packs will be co-ordinated centrally by the CTRU

Outcomes

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- Patient questionnaire pack contains:
  - General health questionnaire (GHQ12)
  - Frenchay activities index (social activities)
  - Barthel index (activities of daily living)
  - EQ-5D (health state)
  - Stroke Impact Scale
  - Longer-term unmet needs in stroke (LUNS)
  - Costs based on Client Service Receipt Inventory
- Carer questionnaire pack contains:
  - Caregivers burden scale
  - General health questionnaire (GHQ12)
  - Satisfaction

Patient Eligibility

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Inclusion criteria:

- Have a confirmed primary diagnosis of stroke
- Are referred to a SCC on discharge home from hospital or within 6 weeks of stroke
- Are still waiting for their first SCC assessment visit
- Provide written informed consent or carer assent

Exclusion criteria:

- Unlikely to survive for more than 3 months
- Are being discharged to a residential or nursing home
- Have been previously registered to the trial

Carer Eligibility

Inclusion criteria:

- Identified by the patient as the informal carer who provides them with practical support on at least a weekly basis

Exclusion criteria:

- If their patient does not consent to the trial

Methods

- Multi-centre: we aim to recruit 40 SCC from around the UK
- Approx. 20 patients/carers per service
- Recruitment over 12 months: approx. 1-2 patients per month per service