

Institution: University of Leeds
Unit of Assessment: 2
Title of case study: Transforming stroke rehabilitation research and care
<p>1. Summary of the impact</p> <p>Forster, House and Young have played a leading role in establishing the importance of long-term psychological and social distress after stroke, shifting the clinical emphasis (and evidence base) in stroke care from a limited focus on physical recovery to acceptance of the importance of psychological and social factors. Evidence we have generated has informed the stroke care pathway in national and international clinical guidelines that influence stroke service delivery, by providing guidance to clinical teams on psychological treatments after stroke and information provision. In tandem we have developed the methodology of stroke rehabilitation research, involving clinical staff in delivery of multi-site studies and thereby enhancing evidenced-based stroke care.</p>
<p>2. Underpinning research</p> <p>Every year approximately 110,000 people in England have a stroke – the third largest cause of death and the commonest cause of severe disability in the community. It is estimated that stroke costs the NHS over £2.5 billion annually, accounting for 6% of total NHS and social services expenditure. A particular focus of our research has been to explore and address psychological and social recovery and their influences on the longer-term quality of life of stroke survivors.</p> <p>Improving stroke care</p> <p>Work published by staff at the University of Leeds since 1995 has highlighted the poor psychosocial outcome for stroke survivors and their families. Since then we have explored the difficulties faced by stroke survivors and their carers through a range of studies (all led by Forster, Young and /or House) including: systematic literature reviews; cohort studies of the course and impact on physical outcomes of depressive symptoms (1, 2) and the incidence of falls (an important cause of anxiety) (3, cited >190 times); qualitative work addressing adjustment after stroke; and surveys of unmet need in stroke survivors. Building on this research, which emphasises the need for stroke rehabilitation to address psychological and social problems as well as physical ones, we have developed interventions and led evaluations (randomised trials) addressing pre-discharge preparation in stroke units and post-discharge care. The following list gives such interventions (and where available, their effects):</p> <p>Pre-discharge:</p> <ul style="list-style-type: none"> • education and goal setting: gives significant reduction in patient anxiety (4) • caregiver training immediately post stroke: has no benefit (5). <p>Post-discharge:</p> <ul style="list-style-type: none"> • evaluation of home physiotherapy and day hospital care: the latter showed no benefit • physical therapy later after stroke: improves mobility, but has no long-term effect (6) • advice and guidance provided by a specialist nurse: showed there is no proved strategy addressing the psychosocial difficulties of stroke patients and their families (7, cited >110 times) • UK national policy of routine re-assessment of disabled patients and their carers at 6 months after stroke onset (the National Service Framework for Older People): showed no benefit (8) • counselling and peer support: on-going work • continuity of care in stroke services: on-going work • structured assessment by a stroke care co-ordinator: on-going work. <p>Our primary randomised trial work, specifically evaluation of input from a specialist nurse, contributed to the Cochrane Review of ‘stroke liaison workers’.</p> <p>Development of research approach – randomised trials of complex interventions.</p> <p>In this work we have shown that it is possible to include mixed methods (qualitative, process and realist evaluations) and health economic analysis in trials of complex interventions even in the frail elderly population that constitutes most stroke survivors. The trials have progressed from small single-centre studies to two-centre studies culminating recently with the implementation of two multicentre studies (36 and 32 centres) recruiting 900 and 800 patients respectively, making them the world’s largest completed randomised trials in stroke rehabilitation (Forster, Chief Investigator for both). The pioneering nature of this work is evidenced by the former of these studies, the</p>

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TRACS trial, being the first stroke rehabilitation trial funded by the MRC (6).

Research presented here was led by: John Young Consultant Physician/ Professor of Elderly Care 2005-present; Allan House, Professor of Liaison Psychiatry, 1999-present; Anne Forster, Research Physiotherapist/ Professor in Stroke Rehabilitation 1997-present

3. References to the research

1. **House A**, Knapp P, Bamford J, Vail A. Mortality at 12 and 24 months after stroke may be associated with depressive symptoms at one month. *Stroke* 2001;32:696-701. *Showed early distress predicts 12 month mortality independently of disability.*
2. **West R**, Hill K, **Hewison J**, Knapp P, **House A**. Psychological disorders after stroke are an important influence on functional outcomes: A prospective cohort study. *Stroke* 2010;41:1723-7. *Showed distress predicts rehabilitation outcomes independently of disability*
3. **Forster A**, **Young J**. Incidence and consequences of falls due to stroke: a systematic inquiry. *Brit Med J* 1995;311:83-6. *Demonstrated high rate of falls and their social and emotional impact.*
4. Smith J, **Forster A**, **Young J**. A randomised trial to evaluate an education programme for patients and carers after stroke. *Clinical Rehabilitation* 2004;18:726-736. *Demonstrated education reduces anxiety without increasing knowledge.*
5. **Forster A**, Dickerson J, **Young J**, Patel A, Kalra L, **Nixon J**, Smithard D, Knapp M, Holloway I, Anwar S, **Farrin A**. A structured training programme for caregivers of inpatients after stroke (TRACS): a cluster randomised controlled trial and cost-effectiveness analysis. *The Lancet*. Online Sep 18, 2013: [http://dx.doi.org/10.1016/S0140-6736\(13\)61603-7](http://dx.doi.org/10.1016/S0140-6736(13)61603-7). *Showed early training of caregivers does not improve outcomes.*
6. Green J, **Forster A**, Bogle S, **Young J**. Physiotherapy for patients with mobility problems more than 1 year after stroke: a randomised controlled trial. *The Lancet* 2002; 359: 199-203. *Showed late physiotherapy improves mobility but benefits are not sustained when treatment stops.*
7. **Forster A**, **Young J**. Specialist nurse support for patients with stroke in the community: a randomised trial. *BMJ* 1996;312:1642-6. *Showed using specialist nurses did not improve outcomes*
8. **Forster A**, **Young J**, Green J, Patterson C, Wanklyn P, Smith J, Murray J, Wild H, Bogle S, Lowson K. Structured re-assessment system at six months after a disabling stroke: a randomised controlled trial with resource use and cost study. *Age and Ageing* 2009;38:576-83. *Showed that structured secondary care based 6 month assessment did not improve 12 month outcomes.*

Grants:

- **Forster A**, **Young J**, Bhakta B, **Farrin A**, Murray J, Knapp M, Patel A, **House A**, **Hewison J**, Bhakta B, Powell J, Steele V, Brady T. Improving patient and carer centred outcomes in longer-term stroke care. £1.9 million *NIHR Programme Grant* October 2007 for 60 months.
- **Forster A**, **Young J**, **Farrin A**, Kalra L, Knapp M, **Nixon J**, Patel A, Smithard D. A cluster randomised controlled trial of a structured training programme for caregivers of in-patients after stroke. £2,029,049 *MRC Clinical Trials Grant* April 2007, 53 months. The first ever MRC funded trial in stroke rehabilitation.

4. Details of the impact

The UK Stroke Association used our work to inform development of their nationally provided community support services. Specific changes based on our work include a significant move away from input primarily from a stroke liaison worker to a more focused patient-centred approach; and an increased focus on identifying and addressing, on an individual basis, the long-term problems faced by each stroke survivor and his/her carers. This impact has had wide reach: the Stroke Association currently provides 340 commissioned services with a contract income of £12.3 million and many thousands of clients: e.g. in 2011/12 Stroke Association staff saw 35,940 new clients.

Our findings also have reach beyond the UK. Based on our work, Clinical Guidelines for Stroke in several countries (including the UK, Scotland, Canada, New Zealand and Australia) now provide guidance to health and social care workers on the importance of providing information combined with educational sessions, rather than information alone. Lack of appropriate information is one of the commonest concerns of patients and their families (up to 50% report lack of information) and can hinder compliance with secondary prevention and access to relevant community services. We reported that information combined with educational sessions improved knowledge and patient mood and was more effective than providing information only. Our findings are cited in all these

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Clinical Guidelines for Stroke (**A-D**), among others. Provision of information about diagnosis and prognosis is a component of the National Sentinel Audit for Stroke, which assesses compliance with guidelines. The latest audit (**G**) reported some improvement in communication with patients.

Clinical Guidelines for Stroke have significant influence on service provision: for example, on development of services in London (**E**). This development work, which references our underpinning research, is part of a major initiative to redesign stroke services across London, where 6,000 people are left with impairments following stroke each year.

Assessment six months post stroke is a component of the National Stroke Strategy, and the development of assessment procedures is informed by our finding that outcomes following *secondary care*- based assessment six months post-stroke were no different from those following usual care (generally no formal assessment). Our trial on which this finding is based (**8**) is highlighted by the UK Stroke Improvement Programme (**F**), an NHS initiative set up to provide national support for local improvement of stroke services and the implementation of the National Stroke Strategy. and is informing UK stroke services as they develop methods to implement the six month assessment component of the National Stroke Strategy.

Addressing psychological need is now included in the UK National Stroke Strategy, and in the annual National Sentinel Audit for Stroke (**G**) that underpins its implementation, as an important component of stroke care, based on our work highlighting the importance of psychological outcomes after stroke, which raised the profile of this previously neglected area. House contributed to the development of the stepped care model for psychological interventions after stroke (**A**) which has been developed by the Stroke Improvement Programme for national implementation.

Forster, House and Young are authors of five stroke-related reviews within the Cochrane Library, the premier resource for the synthesis of evidence-based health care, which are used across the world as the foundation stone for clinical guidelines: these reviews provide the evidence for and are cited in Clinical Guidelines for stroke in the UK, Scotland, Australia and Canada (**A-D**) and elsewhere. These guidelines are the national templates for stroke service provision.

Our research was supported by (among others) the NIHR HTA and SDO programmes, MRC and The Stroke Association, further testifying to its direct clinical relevance, and underpinned by the development of a nationwide stroke research network and comprehensive research network. Forster is founding clinical director of the regional stroke network and House was founding clinical director of the regional comprehensive research network – so that development and implementation of our research has been intimately integrated with NIHR policy.

Research approach

In our leading roles in the stroke research network, we have directly evidenced the potential of research networks for stroke rehabilitation research. This potential has been realised in our TRACS trial in which 36 participating centres recruited 900 patient and caregiver dyads, making it the world's largest completed stroke rehabilitation trial (5). This approach, novel in stroke research, has been further strengthened by tandem economic and process evaluations. TRACS has demonstrated that large rehabilitation trials are feasible and provides a template for large pragmatic trials in rehabilitation. The study acted as an important vehicle to engage clinical teams from across the UK in implementation and delivery of research. Enhancing research methodology is a policy of charity funders, for example AgeUK and The Stroke Association. The importance of TRACS in the stroke rehabilitation research landscape is evidenced by a public statement made by a former National Clinical Lead for the NHS Stroke Improvement Programme. "TRACS has been a very significant study for two reasons. Firstly, the results of TRACS should help provide important clarity on how stroke carers can best be supported. Secondly, the engagement of front-line clinical staff in the running of the [TRACS] trial has been hugely successful. Both these factors will help raise the quality of care and support for people who have had a stroke and their carers." (**H**).

5. Sources to corroborate the impact**A-D: national clinical guidelines**

A. Royal College of Physicians, National Clinical Guidelines for Stroke, Fourth edition, London

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2012, ISBN 978-1-86016-493-4. <http://www.rcplondon.ac.uk/publications/national-clinical-guidelines-stroke>. Five papers cited:

- 1) Long Term Management in respect of moderately disabled patients or carers from a structured reassessment system at 6 months post-stroke (page 125)
 - 2) Information provision for stroke patients and their carers (page 130)
 - 3) Depression and anxiety which may be associated with mortality at 12 and 24 months after stroke (page 113)
 - 4) Interventions for treating depression after stroke (page 114)
 - 5) Pharmaceutical interventions for emotionalism after stroke (page 115)
- B. Canadian Best Practice Recommendations for Stroke Care: Ottawa 2006. The Canadian Stroke Strategy CMAJ JAMC, December 2 2008, Volume 179 (12) http://www.strokecenter.org/wp-content/uploads/2011/08/CSSManualENG_WEB_Sept07.pdf. Three papers cited:
- 1) Information provision for stroke patients and their caregivers (page E14)
 - 2) Reference to the Bradford Community stroke trial (page E60)
 - 3) Interventions for treating depression after stroke (page E67)
- C. Clinical Guidelines for Stroke Management (2010). National Stroke Foundation Australia. http://strokefoundation.com.au/site/media/Clinical_Guidelines_Acute_Management_Recommendations_2010.pdf. 13 papers cited, including:
- 1) Specialist nurse support for patients with stroke in the community (page 42)
 - 2) Structure re-assessment system at 6 months after a disabling stroke (page 42)
 - 3) Information provision for stroke patients and their caregivers (pages 46-7)
 - 4) Carer support during the recovery process (page 117)
 - 5) Review of longer-term problems after a disabling stroke – behavioural change (p 108)
 - 6) Physiotherapy for patients with mobility problems more than 1 year after stroke – falls (p 110)
 - 7) A comparative cost-effectiveness study – community rehabilitation (page 122)
 - 8) Mood disorders in the year after first stroke (page 107)
 - 9) Interventions for preventing depression after stroke (pages 27 & 107)
 - 10) Pharmaceutical interventions for emotionalism after stroke (pages 27 & 107)
- D. Scottish Intercollegiate Guidelines Network. Management of patients with stroke: rehabilitation, prevention and management of complications, and discharge planning: a national clinical guideline. June 2010. <http://www.sign.ac.uk/pdf/sign118.pdf>. Five papers cited:
- (1) Reference to the Bradford Community stroke trial – results at 6 months (page 51)
 - (2) Information provision for stroke patients and their caregivers (page 64)
 - (3) Interventions for preventing depression after stroke (pages 43 & 45)
 - (4) Management of depression after stroke – pharmacological therapies (page 43)
 - (5) Pharmaceutical interventions for emotionalism after stroke – emotional ability (pages 43-4)

E-F: impact on local service developments

- E. Stroke rehabilitation guide: supporting London commissioners to commission quality services in 2010/11 NHS Healthcare for London. November 2009. Three papers cited (pages 11, 27, 40, 45). <http://www.londonprogrammes.nhs.uk/wp-content/uploads/2011/03/Acute-Stroke-Rehabilitation-Guide.pdf>
- F. Department of Health Stroke Improvement Plan
<http://www.improvement.nhs.uk/stroke/Reviewsforstrokepatients/Reviewsevidence/tabid/173/Default.aspx>
<http://www.improvement.nhs.uk/stroke/Psychologicalcareafterstroke/tabid/177/Default.aspx>
<http://www.improvement.nhs.uk/stroke/Psychologicalcareafterstroke/Stepped.aspx>
- G. Intercollegiate Stroke Working Party. 2011. Public Report of National Sentinel Stroke Audit 2010. Royal College of Physicians, London.

Impact of Research Methodology

- H. Statement by a former National Clinical Lead for the NHS Stroke Improvement confirming the importance of TRACS in the stroke rehabilitation research landscape. Available at <http://www.crnc.nihr.ac.uk/NR/rdoonlyres/F7881FF8-5E53-476D-83F9-FD8B3FB54811/0/SRNTACSEBNFTNWFE2011.pdf> which should be accessed via http://www.crnc.nihr.ac.uk/about_us/stroke_research_network/health_professionals/impact_on_clinical_practice/index