NIHR Dissemination Centre
THEMED REVIEW

ROADS TO RECOVERY
Organisation and Quality of Stroke Services
FOREWORD

During my professional career, stroke care has been transformed. At one time, it was a condition that was seen largely as untreatable, apart from rehabilitation usually delivered late in its course. Now, thanks to the kinds of evidence described here, many make a full recovery. And the incidence of stroke has fallen by over 50% in the last twenty years. This is due to better prevention, informed again by research, much of it done in the UK.

But there are still too many people having a stroke and not recovering adequately. This review highlights the areas where more work is needed, as well as celebrating some of the successes of recent years. Compared to other equally devastating diseases, stroke has been relatively underfunded. I hope this report will stimulate commissioners and clinicians to deliver better evidence-based services and remind funders and young researchers that research can make a difference to stroke care.

Professor Anthony Rudd
National Clinical Director for Stroke
NHS England
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Disclaimer:
This independent report by the NIHR Dissemination Centre presents a synthesis of NIHR and other research. The views and opinions expressed by the authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR or the Department of Health. Where verbatim quotes are included in this publication, the view and opinions expressed are those of the named individuals and do not necessarily reflect those of the authors, the NHS, the NIHR or the Department of Health.
Stroke services have been transformed in the last twenty years and research has played an important part in this. This review features over fifty published studies funded by the National Institute for Health Research which have made a difference to stroke care. Other ongoing research addresses areas of continued uncertainty. Together with research funded by others, this evidence shows us that investment in organised stroke services improves patient outcomes and saves overall costs for health and social care. Put another way, poor stroke care costs money and lives. Roads to Recovery should help those making decisions about stroke systems and services to deliver better care. Key findings from NIHR research featured in this report are summarised below.

**SERVICE CONFIGURATION**

» Best evidence shows that people receiving care in dedicated stroke units are more likely to be alive, independent and living at home one year after their stroke.

» In urban areas, a centralised model of stroke care accessible to all people with stroke leads to fewer deaths and better quality of care.

» Strong system and clinical leadership is essential to drive improvements in stroke care.

» Patients admitted to hospitals that score highly on organisational quality (staffing, facilities, level of service) are more likely to receive the right care and have a reduced risk of death.

» Higher ratios of trained nurses to beds throughout the week in stroke units are associated with better chances of survival for stroke patients.

» Modelling work can support commissioners and providers to make decisions about where to site stroke units and how to streamline pathways.

» Data shows some persistent inequalities in health and care – for instance, one study showed delays in people of black ethnicity presenting to hospital for stroke assessment and treatment.

**ACUTE MANAGEMENT**

» Evaluation showed the positive impact of the ActFAST campaign in increasing public awareness of stroke with a greater number of appropriate patients attending emergency departments and receiving rapid treatment.

» Stroke-specific training improved rates of recognition of stroke cases by emergency ambulance dispatchers.

» NIHR research has informed clinical guidelines and recommendations to implement cost-effective treatments like thrombolysis. More patients than ever are now receiving timely thrombolysis but more could benefit.

» A trial showed that use of intermittent compression leg sleeves in immobile stroke patients reduces risks of developing blood clots by a third – but less than a sixth of all patients receive them. Many more could benefit, given that around half of stroke patients are immobile.

» Unexplained variation still exists in rates of thrombolysis between clinicians. New research should help to improve consistency of decisions about which patients should get treatment.

**RECOVERY AND REHABILITATION**

» Stroke specific early supported discharge services can reduce a hospital stay by an average of seven days. Patients receiving this service are more likely to be alive and able to stay living at home longer.

» Research on stroke units shows that rehabilitation by specialist stroke multidisciplinary teams reduces dependency after stroke.

» A recent large trial suggested that very early and intense efforts to mobilise patients immediately after stroke may lead to poorer outcomes.
» A trial of early, enhanced speech and language therapy was not able to show added benefit over an equivalent amount of social support, but both were valued by patients.

**LIFE AFTER STROKE**

» Recovery can be long and difficult for those surviving strokes and their needs for health and social care support change over time. Research has produced reliable tools to support NICE-recommended six month reviews – but less than a third of people have had such a review.

» A trial of occupational therapy in very disabled stroke survivors living in care homes found no benefits over usual care in improving daily function.

» A large trial of post-discharge support for stroke survivors using care coordinators showed no improvement in outcomes.

» A trial of exercise for people with limited mobility after stroke found they had more journeys away from home but no improvement in quality of life.

» A review of research showed the benefits of exercise for people after a stroke, particularly walking, in improving mobility without increasing risk of falls.

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"I had a stroke over six years ago. Following my initial stabilisation in hospital, I received the support needed to have a good recovery from a specialised rehabilitation team. This consisted of regular therapy delivered by skilled staff structured to my personal requirements. Seeing the research laid out in this report, I realise how lucky I am that my stroke happened at that time and not twenty years earlier when treatment was not as advanced as it is now.

Philip Johnson, stroke survivor, Nottingham"
The evidence in this review raises questions that you and your organisation may want to consider to improve stroke services and care. Whether you are commissioning, planning, delivering or using services, you can identify areas for improvement arising from what we know.

**STROKE CONFIGURATION**

» How are stroke services organised in my area? In urban areas, are stroke services centralised?

» Do we share, discuss and act on audit results locally? What plans are in place for improvement and service redesign? How can we be involved?

» How do our units compare in terms of ratio of patients to stroke trained nurses and therapists with other units around the country?

» What are we doing to improve awareness of stroke symptoms and access for all, including ethnic minority groups?

**ACUTE MANAGEMENT**

» What kind of training do GP receptionists, 999 call handlers and other frontline staff get on stroke recognition and awareness by our local urgent and emergency care network?

» Do all people with a stroke go immediately to a dedicated stroke ward?

» What are our emergency stroke pathways and how could these be improved? Can specialists at the hub communicate urgently with all our local hospital emergency departments?

» What is our rate of rapid thrombolysis and how does this compare with national figures?

» What proportion of immobile hospital stroke patients here use inflatable sleeves, which have been shown to prevent leg clots?

**RECOVERY AND REHABILITATION**

» Is rehabilitation available from stroke trained teams every day, including weekends?

» Does our service include a stroke specific early supported discharge programme? Does this include a multidisciplinary team, continued at-home rehabilitation and strong links between the team and the acute service? How many people benefit from this?

**LIFE AFTER STROKE**

» Do our GPs and community nursing teams know which patients have had a stroke and who is looking after them?

» What tools do we use to review health and social care needs?

» What emotional and psychological support is available?

» What self-management support do we offer to people after stroke and to their families? Do we monitor how well they are doing?

» Do we promote the benefits of walking as a safe and effective way of keeping active?

» Having had a stroke, have we given people clear information about what steps to take and what checks and treatment will be given to reduce the risk of further strokes?

**STRENGTHENING THE EVIDENCE BASE**

» How many research studies is our organisation currently running? Could we do more?

» Do we have any ideas for new research around stroke care? (You can send your good idea for NHS-relevant research to http://www.nets.nihr.ac.uk/identifying-research/make-a-suggestion)
Roads to Recovery brings together recent evidence relevant to those planning and delivering stroke services, those delivering treatments to people with stroke and to those living with stroke. Together with other evidence, this review may be particularly useful for those developing stroke pathways and care across a system. This is not a comprehensive review of all evidence on stroke care; it focuses on studies funded by the National Institute for Health Research (NIHR). The NIHR was set up in 2006 as the research arm of the NHS to provide a health research system focused on the needs of patients and the public. Over the last ten years, it has funded a number of programmes, projects, research centres, workstreams and researchers working in stroke prevention, management and care. These different studies have not been brought together in this way before.

This review celebrates the range of recent studies on stroke care funded by NIHR in the last ten years. During this time we have seen a great increase in the volume of stroke studies and the numbers of patients, staff and organisations participating in stroke research. This has strengthened the base of what we know about how best to organise care.

We have looked through the portfolio of NIHR funded research and identified studies with implications for the organisation and quality of stroke services. This includes 44 published and 29 ongoing studies (Appendix 1). We have not included all NIHR clinical research on stroke. These studies – together with other research funded by government, charities and industry - have informed clinical guidelines on stroke, most recently from the Royal College of Physicians in October 2016. Research also informs NICE quality standards for stroke in adults updated in 2016 and other relevant clinical guidance. The implications of clinical research for treatment decisions are best made through careful deliberation and agreed processes of guideline development and so are not the main focus of this review. However, some relevant NIHR clinical studies with particular implications for staffing and delivery of care are highlighted in this report and a full list of NIHR clinical research on stroke is given in Appendix 2 for information.

Important resources are available from the UK-based Cochrane Stroke Group funded by the Chief Scientist Office in Scotland which has produced over 170 reviews of research on stroke care. In this report, we feature only those Cochrane reviews supported by specific NIHR project grants or related directly to NIHR organisational research. A complete and searchable database of all stroke trials and reviews is available at http://stroke.cochrane.org/doris.

The review covers research starting at the point of a stroke or suspected stroke, including services for transient ischaemic attacks (TIA). It does not cover research and services relating to primary prevention of stroke. It will however address secondary prevention, as part of the longer-term care for stroke survivors in hospital and the community.

Unless stated otherwise, all research featured in this report is funded entirely or substantively by NIHR through project, programme or infrastructure support. In the appendices, published research is numbered and ongoing studies are lettered. The review is focused mainly on the needs of those in England, Wales and Northern Ireland.

Pull-out statistics in this report come from the Sentinel Stroke National Audit Programme (SSNAP) clinical audit (2015-16) and organisational audit (2016) data.
A FEW STROKE TERMS USED IN THIS REPORT:

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aphasia</td>
<td>Problems with speech and language.</td>
</tr>
<tr>
<td>Early supported discharge</td>
<td>Rehabilitation provided by specialist teams at home rather than at hospital but to the same intensity.</td>
</tr>
<tr>
<td>Haemorrhagic stroke</td>
<td>Stroke due to blood vessel bursting causing bleeds into the brain.</td>
</tr>
<tr>
<td>Hyperacute services</td>
<td>Specialist centres to diagnose, treat and manage patients in first few days after onset of stroke.</td>
</tr>
<tr>
<td>Intermittent pneumatic compression (IPC) devices</td>
<td>Air pumps with plastic inflatable sleeves applied to legs to prevent deep vein thrombosis.</td>
</tr>
<tr>
<td>Ischaemic stroke</td>
<td>Stroke due to clots blocking supply of blood and oxygen to the brain.</td>
</tr>
<tr>
<td>Thrombectomy</td>
<td>Mechanical procedure to pull the blood clot out of the brain.</td>
</tr>
<tr>
<td>Thrombolysis</td>
<td>Treatment with drug to dissolve clot and restore flow of blood.</td>
</tr>
<tr>
<td>Transient ischaemic attack (TIA)</td>
<td>‘Mini-stroke’ where the effects normally wear off within 24 hours.</td>
</tr>
</tbody>
</table>
Through working to improve stroke services in our region, we’ve often found it difficult to get the right evidence to make strategic recommendations and to support quality improvement initiatives. Now the NIHR stroke themed review provides some of that evidence, easily accessible and thoroughly reviewed.

WHY DOES STROKE MATTER?

Stroke is a devastating disease affecting many people as well as being an area of substantial health and care spend. It represents around 5% of total NHS costs (Saka 2009) and is the fourth largest cause of death in the UK. There are around 1.2 million people who have survived a stroke in the UK and half of these will have a disability (Stroke Association 2017). These include problems with walking, talking, speech and continence. This has huge impact on people with stroke and their families. New estimates suggest that each person with a stroke costs the health and care system around £22,175 each year. (www.strokeaudit.org)

But much can be done about this. Recent years have seen huge improvements in the clinical management of people with stroke with early assessment, use of thrombolysis and better organisation of services into acute stroke units. Over the last twenty years, stroke mortality rates have halved. This is a big success story for the NHS. Yet providing the right care over many years to those living with stroke and their families remains a challenge.

STROKE – key facts

» Every year in the UK, over 100,000 people have a stroke
» Around 95,000 people in the UK admitted to hospital with acute stroke every year
» Fourth largest cause of death – but death rates halved in last 20 years
» Direct costs to the NHS of around £1.7 billion in England every year
» 1.2 million people in the UK live with a disability after stroke


The National Stroke Strategy in 2007 (Department of Health 2007) in England and the recently updated Stroke Delivery Plan in Wales (Welsh Government 2017) have set important policy direction. These national frameworks include standards for clinical treatment and services, including specialised rehabilitation.

Not all people receive the best care though. We know about variation in care through a high quality national stroke audit in England, Wales and Northern Ireland. Compared to other conditions, we know more about what care each patient with stroke receives and how well they are. This is probably the most comprehensive stroke audit in the world (www.strokeaudit.org). It is used widely by services to see how they are doing in relation to others and to improve quality. Some of the research featured in this review uses this audit information. We have also used latest data from 2016 organisational and clinical audits at the start of each section to highlight important issues of variation around quality and standards in stroke care.
This review should be of interest not just to staff working in specialist stroke units or part of specialist stroke rehabilitation teams, but to other general clinical staff. This might include paramedics, community physiotherapists, district nurses, general practitioners and all staff caring for older people. At a system level, it should be relevant to urgent and emergency networks and those leading stroke quality improvement initiatives of all kinds. People living with stroke and their carers may also be interested in research on how services are best organised and delivered to improve quality of care.

STRUCTURE OF THE REPORT AND STROKE PATHWAY

- **Configuration of Stroke Services - General organisation of care and staffing**
- **Identifying Stroke and Acute Management - From 999 response to first few days in hospital**
- **Recovery and Rehabilitation - Immediate recovery and support on leaving hospital**
- **Life After Stroke - Longer term support to stay well in the community**
CONFIGURATION OF STROKE SERVICES

We do not always have good quality evidence to support important decisions about the organisation of care. Decision-makers want to know how to provide the best stroke care to their population in the most cost-effective ways. This includes making the best use of skilled staff and ensuring rapid assessment and treatment for all people with suspected strokes. Each locality needs to make difficult decisions about how best to organise care. These include trade-offs between access to local care and quality at specialist centres and investment in different kinds of support along the stroke pathway. This section summarises some of the important NIHR research around planning, organisation and delivery of stroke care across the system.

PROPORTION OF PATIENTS WHO NEED A STROKE UNIT ADMITTED WITHIN 4 HOURS

Less than 2/3

STROKE UNITS THAT DO NOT MEET RECOMMENDED LEVELS OF SENIOR NURSE STAFFING

Just under half

HOSPITALS OFFERING EARLY SUPPORTED DISCHARGE

4/5 (compared with only 3/4 two years ago)
WHAT DID THE RESEARCH FIND?

An important early study funded by the NIHR Health Technology Assessment programme assessed new ways of organising acute stroke care. This trial compared outcomes and recovery for 457 stroke patients when cared for in specialist stroke units or by stroke teams on general wards or at home. The study published in 2000 found that patients in stroke units were more likely to be alive and living independently up to one year after having a stroke than those cared for by teams at home or on general hospital wards. Further analysis published in 2005 showed that stroke units were cost-effective. This was the largest UK stroke trial of its kind at that time.

Single studies cannot provide definitive answers. Findings from this study were brought together with other trials in a series of influential Cochrane reviews and meta-analyses on organising stroke care in the last twenty years. This was most recently updated in 2013 (SUTC 2013) combining data from 28 trials worldwide and showing that care in stroke units improves outcomes for people with all kinds and severity of stroke. Benefits were seen most clearly when care was delivered in dedicated stroke wards.

WHAT DIFFERENCE DID IT MAKE?

This evidence has directly influenced policy and practice. The 2007 national stroke strategy identified specialist stroke units as the single biggest factor in improving outcomes. This led to the development of dedicated stroke units across the country. In the year 2000, less than one in five people with stroke were admitted to stroke units. Latest audit figures show that now around four in five people after a stroke are cared for in stroke units.

CENTRALISING STROKE CARE

Research has shown the effectiveness of organised stroke care (see study 1, above). This could be due to greater staff expertise, better diagnostic procedures, better nursing care, early mobilisation, prevention of complications, more effective rehabilitation – or all of these factors combined. Some of these benefits have been taken further in a number of regions by centralising services into a smaller number of very specialist hyperacute stroke units. These have been set up to provide early assessment by stroke consultants, imaging, rapid thrombolysis and care by specialist multidisciplinary teams. Centralising services in this way is an important development but, until recently, we have not known what difference it makes to patient outcomes. Indeed, an NIHR review published in 2014 noted important gaps in high-quality evidence on the impact of centralising services for stroke, trauma and head injury.

In 2014, findings from a major NIHR evaluation of stroke service reconfiguration in London and Greater Manchester provided some important answers (see study 3, overleaf).

There are other interesting findings from the evaluation of stroke configuration programmes. The team used clinical audit data to compare clinical processes in London and Manchester. They found that those in Manchester were less likely than those in London to receive optimal care, such as a brain scan within three hours. They also found that in Manchester only two thirds of patients who were eligible for hyperacute care were admitted to these centres (Ramsay 2015).

Qualitative research has provided insights on context and how changes were implemented (Fulop 2016). This underlined the benefits of a model in London which was more radical and simpler, with all potential stroke patients admitted to hyperacute units. By contrast, the model in Manchester was more complex and selective. Changes in London were launched on a single day, with support from networks. Another paper (Turner 2016) focused on the importance of clinical and strategic leadership in
Centralising stroke services in London saved 96 lives in one year compared to standard care (Morris 2014). Hospital stays were also reduced by around a day and a half. This study assessed the impact of reorganising services in London into eight hyperacute stroke centres for rapid assessment and treatment in specialist units from 2010. Some local hospitals in London stopped providing stroke care. This study also looked at less radical changes in Greater Manchester with a mix of three specialist stroke centres for stroke patients within a four hour window of symptoms developing and ten district stroke centres for others. No hospital stopped providing stroke services entirely.

This study was a controlled before-after assessment using data from 258,915 stroke admissions across England from 2008-2012, including 17,650 in Greater Manchester and 33,698 in London. Centralisation in London reduced death rates by 1.1% at 90 days after stroke after adjusting for confounding factors. The authors calculated that 96 fewer patients died over a one-year period after centralisation over and above the lives saved by improvements in stroke care in other urban areas in the rest of England. Greater Manchester, which made less radical changes, saw length of stay fall, but mortality did not improve significantly over and above improvements in other urban areas.

Based on calculations from this study, it was estimated that a fully centralised model could have saved an additional 50 lives in Manchester. Published findings from this study influenced decisions in Greater Manchester to further centralise acute stroke services in 2015.

This is an important study for those planning stroke services, especially in major conurbations. There may also be important lessons on system-wide changes for other acute services such as major trauma, vascular and cardiac surgery. But the relevance to more rural areas is not clear. There are important ongoing uncertainties given the time-critical nature of assessment and treatment in stroke and differences in geography and population. Decisions about centralising services are difficult and involve trade-offs which need to be explored and understood.

Most evidence of benefits from centralising services come from major towns and cities. A particular challenge in rural areas is getting access to brain scans and specialists quickly before starting thrombolytic treatment. Telestroke networks are starting to develop, with hub and spoke services providing specialist advice in local hospitals where stroke physicians or neurologists may not be available around the clock.

An NIHR study has supported and evaluated one telestroke network in the north west providing this kind of service. Emergency staff in local hospitals are connected by live video link to stroke specialists at centres who can see patients and review brain scans. The first phase of this work has resulted in an evidence-based telecare toolkit, including standardised assessments and checklists, which can be used by other services.
A research network in the south west has used computer simulation programmes to produce data that has driven improvements in stroke care. The Royal Devon and Exeter hospital modelled different approaches to how patients with suspected stroke were managed on arrival at hospital and speed of thrombolysis. It factored in the number of available staff at different times of day and the changes in volume of patients. From this work, two changes were identified to optimise care processes: referring patients to the acute stroke team at triage and paramedics phoning ahead to alert the team of imminent arrivals.

Further work has been done by this team to model trade-offs and options for concentrating services into fewer specialised centres in one region. This involved factoring in different scenarios for a mixed urban and rural population. The aim was to combine acceptable travel times for the greatest number of people while maximising the proportion of people attending a specialist stroke centre with at least 600 attendances a year.

The complex analysis suggested that centralising stroke services in a mixed urban and rural setting would lead to overall clinical benefit, but a significant minority of people would experience slower time to treatment because of distance from centres. Higher quality care in larger specialist centres might offset delays in treatment, but this was not certain. The study illustrates the complexity of decisions and how modelling can help.

Operational research has been used to help NHS decisions since the 1950s, from estimating bed occupancy rates to modelling flows through emergency departments. In stroke care, such approaches have been invaluable (see study 5, below).

**STAFFING AND SEVEN-DAY WORKING**

These major changes to how stroke services are organised have important implications for the workforce. These include availability of trained staff, access to brain scans and the challenges of providing round the clock specialist stroke services.

Many of these complex organisational questions cannot be answered by clinical trials. Some useful insights can be drawn from the rich and comprehensive national stroke audit data. This can help us to identify variation and trends in processes of care and potential relationships between organisational factors, care received and patient outcomes. Such research from observational studies cannot provide definitive answers. But careful analysis can identify emerging associations for discussion by decision-makers and, in some cases, further testing. Many of the audit-linked research studies in this section have not had direct NIHR project funding but research teams carrying out the work have had some NIHR support. Analysis of audit data shows that patients admitted to stroke services scoring highly on a measure of organisational quality were more likely to receive good care. This was defined by patients receiving all six care processes recommended in current standards, from admission to a stroke unit to being seen by a stroke doctor and receiving a brain scan within 24 hours. Organisational quality was
measured by a combination of staffing (numbers, type and training), facilities and service level (for instance, access to around the clock emergency scanning and thrombolysis). Patients receiving high quality care had a lower risk of death thirty days after a stroke.

Audit data also suggests an association between delay in assessment by a speech and language therapist and risk of stroke-associated pneumonia. This is one of the main causes of death after acute stroke (Bray 2017).

Also of interest to commissioners is a study which developed and validated models to predict stroke deaths.

Similarly, a review compared different prognostic models to see which performed best in predicting death and disability after stroke.

These studies are useful because it allows for better adjustment of case mix when comparing different service models or stroke care.

One way in which stroke audit data has been used is to examine patterns of care throughout the week. Recent analysis (Bray 2016) suggested no clear overall ‘weekend effect’, that is consistently poorer care or outcomes at the weekend. This was just one of a number of different patterns of weekly variation in quality identified in this study, such as time of day and day of week. For instance, patients admitted on Thursdays or Fridays tended to wait longer for a therapy assessment. Some indicators suggested marked patterns of care, for instance poorer door to needle time for thrombolysis at nights and weekends. But the authors cautioned against a simplified notion of a weekend effect. Some of the emerging findings will be explored further in ongoing NIHR funded research around seven-day stroke care (see below).

Another study focused on 24/7 care as a tracer condition to explore the relationship between quality of care, levels of staffing, patient outcomes and day or time of admission.

Using audit data, an NIHR study will examine variation in what stroke therapy and rehabilitation people receive during the week, how people access services and impact on outcomes.

**NURSE STAFFING**

Two observational studies have recently reported findings around nurse staffing which could stimulate further discussion. An NIHR study tracked patient outcomes for one year in hospitals in one region. They found that variation in many service characteristics of stroke services explained very little of the variation in outcomes. But a consistent finding was that a higher number of higher trained nurses (staff nurse or senior staff nurse level) was associated with better mortality outcomes up to a year after stroke, over and above other risk factors. Indeed, the authors suggested that increasing stroke unit staff by one full-time trained nurse for every ten beds could reduce one year mortality by 8-12%. However, the authors recognise the limitations of a study of this kind which can only provide partial information for decision-makers.

Similar associations were reported in an analysis of staffing and weekend working using national audit data from over a hundred stroke units. This study found no association between units not carrying out seven day ward rounds by specialist stroke doctors and higher risk of death. But it did find a strong relationship between the intensity of weekend staffing of registered nurses and patient outcomes. Patients admitted at a weekend to a stroke unit with 1.5 nurses to ten beds had an estimated adjusted 30 day mortality risk of 15.2% compared to 11.2% for patients admitted to a unit with 3 nurses to ten beds. This was equivalent to one excess death per 25 admissions. We cannot be certain that lower levels of nurse staffing cause a higher number of patient deaths, as this was an observational study. There may be confounding factors – that is, units with lower nurse staffing levels may have other features driving poor care which are not examined here. These
findings point to the need for more robust research on the cost-effectiveness of different staffing models in the stroke unit.

Another published study has examined how multidisciplinary teams work together in caring for people with stroke. Tracking five stroke teams at different points in the pathway using mixed methods, the study suggested the importance of clear leadership and the difficulties when teams were too large. One particular insight was that separate targets for each profession often prevented good collaboration and could be replaced by whole team performance metrics.

Nursing and the quality of nursing care is the focus of a small ongoing study which examines models of clinical supervision for stroke nurses working in both acute stroke units and rehabilitation.

Research underpins all important developments in stroke, from early studies showing that stroke units save lives to more recent evidence on thrombectomy for acute ischaemic stroke. We are also lucky in this country to have had reliable national audit data for nearly twenty years providing robust benchmarking data for NHS organisations delivering stroke care.

Pippa Tyrrell, Chair in Stroke Medicine, Manchester
MAKING A DIFFERENCE - Inequalities in health and care

WHAT DID THE RESEARCH FIND?

A five year programme of stroke research based on population data across south London provided valuable insights into variations in stroke care. We learned that people from more deprived backgrounds are less likely to survive after a stroke. And while new cases of stroke have gone down significantly over time, this was not true for younger people (under 45) or those of black ethnicity. Black people were also less likely to present to hospital within three hours of symptoms of stroke and receive thrombolysis.

WHAT DIFFERENCE DID IT MAKE?

In the last ten years, there has been a greater awareness of inequalities in health status, outcomes and access to services. However, the relation between population and services is complex, as centres of excellence for stroke care are often concentrated in major urban areas with higher concentrations of minority ethnic groups and economic deprivation. However, these findings can help managers in targeting awareness campaigns and planning services.

SUMMARY

IHR research has helped to show the benefits of organised inpatient stroke care. This work influenced the 2007 national stroke strategy and the development of specialist stroke units. More recently, analysis of stroke audit data has shown that organisations with better staffing, facilities and level of service are associated with better quality of care and outcomes. Observational data also shows strong associations between levels of trained nurses and outcomes for stroke patients.

Research has assessed the impact of centralising stroke care into fewer specialised services. Evaluation of major stroke changes in London and Manchester showed that more radical centralisation in London saved more lives. Both saw length of stay fall and improved quality of care after changes were introduced. Studying implementation showed the importance of system and clinical leadership to drive change.

Modelling research has helped decision-makers to optimise stroke pathways and improve the speed of thrombolysis in one region. These approaches have also helped to inform planning decisions about the number and location of specialist stroke centres in south west England and in Wales.
IDENTIFYING STROKE AND ACUTE MANAGEMENT

- Patients that arrive at hospital within four hours of stroke onset (when this is known): 60%
- Eligible patients who receive thrombolysis within 4 hours: 85%
- Hospital stroke patients using inflatable sleeves to prevent leg clots: 16.6%
Making a difference - improving recognition of stroke

What did the research find?

An NIHR programme of work has evaluated the effectiveness of “Act FAST”, a national campaign to improve public recognition of stroke. Unlike previous surveys and assessments, this evaluation looked at changes over a period of four years to account for the influence of the campaign over and above other developments in stroke services. Analysis of the campaign showed greater levels of public awareness of stroke symptoms and higher numbers of appropriate patients arriving at specialist centres and receiving thrombolysis within the stroke onset to treatment window. These increases were seen over and above general trends and can be attributed to the campaign.

What difference did it make?

Evaluation of ActFAST indicated its impact on behaviour, with more appropriate use of secondary care as fewer people contacted a primary care practitioner as the first response to stroke symptoms. Perhaps most importantly, the assessment showed significant increases in thrombolysis activity after the campaign. The FAST tool has been recommended as a screening tool of choice in NICE guidance and in recent RCP clinical stroke guidelines.

Recognising stroke

Early recognition that someone has had a stroke and needs urgent medical attention is essential to improve stroke outcome. Many people do not seek medical help immediately or do not know who to call. The national advertising campaign Stroke: Act FAST has helped to raise public awareness. This was based on early research funded by the Stroke Association to develop rapid protocols to improve paramedic recognition of stroke. The FAST tool focused on weakness in face, arm and speech problems. After initial validation, it became widely used for public awareness in successive campaigns from 2009. Initial metrics on the government public awareness campaign suggested a 24% increase in stroke-related 999 calls. Other evidence came from snapshot surveys, but the wider impact was not known until recently (see study 13).

Improving recognition by other frontline healthcare groups is also important. One study interviewing patients and GPs identified the need for better training of non-medical staff such as practice receptionists in recognising stroke symptoms. The study also found that less than one in ten high-risk patients with TIA or minor stroke attended a clinic within 24 hours of experiencing symptoms. Many were delayed by waiting for a second opinion from...
another professional. Findings suggested the need for emergency pathways allowing direct referral to specialist clinics from paramedics, optometrists and out of hour services.

READ MORE (Study 15)

GETTING THE RIGHT TREATMENT

Where patients are taken for treatment is important. Ideally this should be a dedicated acute stroke centre with well trained staff and the facilities to diagnose and treat strokes without delay. Some services have pathways in which ambulance staff take people with stroke symptoms straight to stroke units, bypassing emergency departments. Early brain scans are essential to give the right treatment, as people with bleeds to the brain should not be given clot-busting drugs (thrombolysis). But the vast majority of strokes – around 8 out of 9 – are ischaemic where, if indicated, rapid thrombolysis is critical to good outcomes (see study 16, overleaf).

One study has looked at the cost-effectiveness of increasing thrombolysis rates using a number of intervention strategies. They found that better recording of onset time gave the best potential benefit to patients while immediate CT scan on arrival in hospital gave the greatest cost saving.

READ MORE (Study 17)

Another study using stroke audit data found that hospitals with higher volumes were more likely to administer thrombolysis to patients faster.

READ MORE (Study 18)
MAKING A DIFFERENCE - NIHR research on clot-busting treatment

WHAT DID THE RESEARCH FIND?

The drug alteplase was first licensed in 2002 for use within 3 hours of symptom onset where a scan has ruled out bleeding in the brain. In 2012, the drug was approved by the licensing authority for extended use within 4.5 hours. An evidence appraisal and stakeholder exercise funded by NIHR contributed to the decision by NICE in 2012 to recommend its use as a cost-effective treatment in the extended time-frame. (https://www.nice.org.uk/guidance/ta264). The technology appraisal included five clinical trials and concluded that alteplase administered between 3 and 4.5 h after onset of stroke symptoms was effective and cost-effective in reducing risks of disability after acute ischaemic stroke.

WHAT DIFFERENCE DID IT MAKE?

NICE recommended in 2012 that thrombolysis start as soon as possible and within 4.5 hours of onset of symptoms. Since then, more patients than ever have been receiving this cost-effective treatment thanks to increased awareness and changes to service delivery. Latest audit results from 2016 show a marked improvement with 85% of eligible patients now receiving this treatment. This is an increase from 74% of eligible patients three years earlier in the first national audit. This is a success story for the NHS, with underpinning NIHR evidence on what works, at what cost.

ESTIMATED NHS COST SAVINGS OVER 5 YEARS PER EXTRA PATIENT THROMBOLYSED

£4,100
I have seen stroke care get better for patients over the years in the specialist centre where I work. Stroke nurses now have consolidated their skills and competences in many areas, from knowledge of thrombolysis to spotting deteriorating patients and stroke-related complications. It all makes for better outcomes for people recovering from a stroke.

Maria Fitzpatrick, Consultant Nurse in Stroke Management, London
MAKING A DIFFERENCE - Who to treat?

WHAT DID THE RESEARCH FIND?

Although recommended since 2007, thrombolysis is not given to all suitable patients. As services have become more organised, much of this variation is now due to differences between clinicians and their decisions about who would benefit from thrombolysis. Areas of uncertainty include factors such as age, stroke onset time to treatment and a patient who had had recent medical procedures. An NIHR study published in 2017 used scenario approaches to explore these differences between clinicians in the trade-offs between risks and benefits for certain groups of patients.

The findings showed considerable differences in decision making among the 138 clinicians taking part in the study. There were also distinct patterns. Respondents were significantly more likely to treat 85-year-old patients than patients aged 68 years. This may reflect acceptance of data from the Third International Stroke Trial (IST-3 Collaborative Group, 2012) that reports benefit for patients aged over 80 years. Respondents were also more likely to offer thrombolysis to patients with severe stroke than to patients with mild stroke; this may indicate uncertainty about the risk/benefit balance in treatment of minor stroke. Some differences in clinicians were also identified – those more experienced in administering thrombolysis were more likely to offer it.

WHAT DIFFERENCE DID IT MAKE?

The study highlighted marked differences between clinicians in who to treat. Findings from this study will be of value when training clinicians in patient selection and in reflecting on their decision making processes. A related study has developed a computerised decision aid to support better decisions about which patients can benefit from thrombolysis and to support involvement of patients and carers in shared decisions wherever possible (Flynn 2015).
MAKING A DIFFERENCE - Preventing leg clots in stroke patients

WHAT DID THE RESEARCH FIND?

People in hospital after a stroke are at greater risk of deep vein thrombosis (clots in the leg) because they cannot move around so well. This NIHR study tested whether squeezing the legs of immobile stroke patients with intermittent pneumatic compression (IPC) sleeves, a kind of inflatable stocking, reduced the risk of developing clots. These sleeves had been shown to be effective in patients having surgery. This was a large randomised trial, known as CLOTS 3, involving 2876 stroke patients in over 90 UK hospitals. It found that 8.5% of patients using the sleeve developed blood clots, compared with 12.1% of patients who were treated normally. The risk of developing a clot was reduced by about a third and patients using the device also had improved chance of survival. As the cost of the sleeve was £65, this was confirmed as an effective and inexpensive treatment.

WHAT DIFFERENCE DID IT MAKE?

This was seen as a landmark piece of research. Results were first published in 2013, with full findings in 2015. Since then, the use of IPC devices for immobile stroke patients has become widespread in stroke centres. It was recommended by NICE in 2015 (https://www.nice.org.uk/guidance/cg92) and is now measured as a national standard. Latest audit results show that, at an organisational level, 80% of hospitals now offer IPC devices as first line prevention for clots (SSNAP organisational audit 2016). However, audit data at a patient level shows that in 2015/2016 only 16.6% of all stroke patients received this treatment. (SSNAP clinical audit annual report 2016) As around half of stroke inpatients are immobile and could be eligible, this suggests that more can be done to get good evidence into practice.

READ MORE (Study 20)

There are other areas of medical management and clinical care for stroke patients which have drawn directly on NIHR evidence. For instance, one of the standards for national organisational audit is the use of inflatable sleeves to prevent leg clots in hospital stroke patients (see study 20, above).

Another development is the use of mechanical thrombectomy. This is where the clot is removed using an instrument guided under x ray to remove the clot using a stent or suction. Only some patients will benefit from this treatment but evidence now suggests that early thrombectomy can reduce disability (Goyal 2016). The effectiveness of this technology was confirmed by a recent UK trial funded in part by the NIHR (Muir 2016). This is an important advance in stroke care but raises questions for services around staffing, delivery and organisation. Mechanical thrombectomy is an area now under consideration for central support through specialised commissioning (NHS England 2016).

The CLOTS 3 trial has dramatically altered how patients are managed in stroke units to prevent deep vein thrombosis. IPC devices have now replaced compression stockings as the primary preventative measure in UK stroke units as a direct result of this trial.

Jatt Khaira, Consultant Physician in Stroke, Birmingham
E valuation has shown the effectiveness of the Act FAST campaign in raising public awareness and a greater number of appropriate people being taken to hospital and receiving evidence-based treatment, including timely thrombolysis. Analysis of stroke-related 999 calls has helped to develop and evaluate training for ambulance dispatchers for better recognition of stroke symptoms. Other research shows the need for further training in awareness and recognition of stroke symptoms by frontline staff such as GP receptionists. Mechanisms are also needed for direct referrals from paramedics, out of hour services and others to prevent delay in accessing clinics for people with minor stroke and TIA.

Many studies identify ways in which different parts of the service can work together better in the acute management of patients. This includes collaboration between general practice, ambulance services and stroke units. One study is reviewing whether an enhanced role for paramedics accompanying suspected stroke patients for early scans and treatment can improve outcomes.

Changes in treatment have implications for service delivery. New studies are looking at the implications of mechanical thrombectomy for the service, as a promising new development which could change stroke care in coming years. A trial showed the effectiveness of low cost intermittent pneumatic compression devices to prevent leg clots in immobile stroke patients, but uptake could be improved. Other research has looked at how clinicians make decisions about which patients receive thrombolysis and how decision-making could be improved. This complements other work developing computerised decision aids to make it more likely that the right patients get thrombolytic treatment.

An important programme of research is looking at better pre-hospital systems for speedier stroke treatment, looking at interactions between paramedics, GPs and hospital teams. This includes a trial of three ambulance services in England and Wales to test an enhanced protocol for paramedics to assess patients, pre-alert the hospital team and stay with stroke patients during brain scan and thrombolysis to reduce time to treatment. NIHR is funding further work around the implications of cost and use of thrombectomy. Modelling studies will provide more evidence on how many could benefit and more accurate information on risks and benefits.

READ MORE (Study E)
Recovery and Rehabilitation

After a stroke, patients may need a range of rehabilitation therapies as well as advice and support to prepare for leaving hospital and life at home. NICE and RCP guidance recommends that this care should be delivered on a dedicated stroke inpatient unit – see box for details of what this service should include. At the outset, there should be a full assessment of the patient’s abilities and needs and a clear plan for rehabilitation. This includes programmes known to be effective, such as therapy to help stroke survivors with activities of daily life such as washing, dressing and feeding (Legg 2007). NIHR research has explored different models of care, addressing questions of when, where and how best to support recovery and restore function in the stroke unit and leaving hospital.
Providing Rehabilitation Early After Stroke

It was generally thought that getting stroke patients up and out of bed as soon as possible contributed to their longer-term recovery. Until recently, though, there had only been a few small-scale trials, and there was not a clear definition of what was meant by ‘early mobilisation’. In a large international trial part supported by NIHR involving over 2,000 patients, those who were mobilised within 24 hours of stroke were less likely to have a favourable outcome than those who received usual care. However, the ‘early mobilisation’ delivered here was at a very early stage post-stroke and at a relatively high intensity.

Further analysis of the exact quantities and timing of activity in this trial have provided a more nuanced view: it appears that getting patients up and about for shorter, but more frequent, spells was associated with more favourable outcomes after three months. Longer periods out of bed did not improve outcomes and could even worsen them. Although further trials are needed to confirm this, it appears that ‘little and often’ may be the best approach to early mobilisation following stroke, confirmed by recent clinical guidelines (RCP 2016).

Another trial explored whether an early speech and language therapy intervention could help...
patients improve their ability to communicate. The intervention was started on average two weeks after stroke, and involved around 22 contacts mainly with a speech therapist, both in hospital and at home. This was compared with social support from a non-therapist. After six months, both groups of patients could communicate more clearly, but there was no evidence of added benefit from the early therapy over and above equivalent amount of social support from an employed visitor, but both were valued by patients. Taken in the context of wider evidence we know that some intervention is better than none, but further work is needed to identify the nature of the intervention, mode of delivery, optimal duration and intensity for different speech and language problems.

READ MORE (Study 22)

ONGOING RESEARCH

Current research is considering if different patients require different approaches to therapy for speech and language problems. Looking at patterns of recovery for over 3,000 stroke patients with language difficulties, it should provide insights into optimal timing, duration and frequency of therapy for different groups of patients.

READ MORE (Study F)

Two further studies are exploring the provision of stroke therapy in hospital and how this is experienced by stroke patients and their families. This includes research into how recommended levels of 45 minutes of therapy are delivered and particular therapy to support activities of daily living (washing, dressing and eating). New research is also testing how patients and carers can work with staff to re-design rehabilitation services in stroke units. The study will measure whether this approach provides benefits for patients over and above their scheduled therapy.

READ MORE (Study G, H & I)

USE OF NEW TECHNOLOGY

There is an increasing role for new technology to support recovery after stroke. These range from robots to help people move their arms to electrical stimulus to activate muscles. This forms part of rehabilitation started in stroke units.

One study used wearable devices to track range of movement in stroke survivors carrying out prescribed exercise. The system also gave individuals feedback on their progress in relation to their particular goals and recovery plan. Part of this programme has also developed an ‘intelligent shoe’, using hi-tech insoles to provide sensors around walking. The use of technology for this kind of personalised self-management is promising and an interesting area of new knowledge.

READ MORE (Study 23)

Another study tested the feasibility of a trial to assess a virtual glove to strengthen arm function after stroke.

READ MORE (Study 24)

ONGOING RESEARCH

One programme is surveying use and acceptability of assistive technologies in stroke units and will evaluate some of the most promising from use of robots to electrical stimulus to activate muscles.

READ MORE (Study J)

A five year clinical trial involving four stroke centres will test robot assisted rehabilitation to improve arm and hand function after stroke.

READ MORE (Study K)

Other studies include an early assessment of technology to strengthen facial expression in stroke survivors.

READ MORE (Study L)

A study is testing tailored apps for people with speech difficulties after stroke.

READ MORE (Study M)

A further NIHR trial is also evaluating the use of specialist speech and language software to deliver high doses of self managed language practice to people with aphasia after stroke.

READ MORE (Study N)
Communication and swallowing problems are a frequent and often distressing outcome of stroke. Speech and language therapists have a pivotal role in the assessment and management of communication and swallowing difficulties following stroke. The published and ongoing NIHR studies featured here will help us know how best to deliver these essential services through the week.

Kathryn Head, Principal Speech and Language Therapist, Cwm Taf

WHAT IS EARLY SUPPORTED DISCHARGE?

Early supported discharge (ESD) is now recommended for people with a safe environment to go home to and who have some mobility (for instance, can move from bed to a chair on their own or with some assistance). This involves support from a dedicated stroke-specific team of doctors, nurses and therapists who co-ordinate the discharge and provide ongoing specialist rehabilitation at home.
LEAVING HOSPITAL

A programme of implementation research in one region used expert consensus to identify what was most important, from the multidisciplinary nature of teams to strong links between the acute service and the early support discharge team. Evaluation of two local early supported discharge services with these features suggested shorter length of stay and faster recovery. The team also looked at barriers and enablers to effective early supported discharge, including the need for staff to work well across organisational boundaries.

READ MORE (Study 25)

Some patients ready to go home from hospital after a stroke may be offered a pre-discharge home visit by an occupational therapist. This is offered routinely in many regions, but it is not known how effective it is. Early research showed that a trial is feasible and compared costs of home visits with an in-hospital interview by occupational therapists. Preliminary findings suggested that home visits could be more expensive but also more effective, although this needs confirming in a definitive trial. Other work identified variation in scope and content of home visits and looked at how therapists decide which patients should get home visits.

READ MORE (Study 26)

Support from family members or other informal caregivers is often vital for people going home from hospital after a stroke. Many caregivers are not well-prepared for this role, and may experience negative effects on their own well-being. One training programme for caregivers had shown promise as a means of providing early support and caring skills for people caring for someone after stroke. When assessed in a large trial involving 36 stroke units and 900 pairs of patients and carers, participation in training did not appear to be associated with improvements in patients’ independence, or caregiver burden. However, the researchers suggested that the immediate post-stroke period as inpatients in stroke units – when caregivers are still coming to terms with their new role – may not be the optimum time to deliver structured training. A process evaluation alongside the trial also suggested the need for stroke unit staff to invest time in building strong relationships with carers for training to be effectively implemented, adopted and supported.

READ MORE (Study 27)

Making A DIFFERENCE – Early supported discharge

WHAT DID THE RESEARCH FIND?

More stroke services are now providing specialist therapy and support at home rather than at hospital, but the impact of this was not known. The most reliable form of evidence for these kinds of questions is a systematic review. The latest review of published research in 2012 combined data from 1957 patients in fourteen good quality trials, including four from the UK. This found that people receiving early supported discharge from specialist teams left hospital on average seven days earlier than others, and were subsequently less likely to be admitted to institutional care or experience long-term dependency. Seven of the trial included economic data which showed that the opportunity savings from fewer hospital bed days was greater or equal to the cost of the early supported discharge teams. Patients were satisfied with the service. Greatest benefits were seen in patients who had mild to moderate disability from teams who were well organised.

WHAT DIFFERENCE DID IT MAKE?

This review has informed policy and practice, with increased availability of services. NICE guidance in 2013 recommended that early supported discharge services be offered to suitable stroke patients [NICE CG 162]. This is also now recommended as a standard in national audit. An increasing number of places now offer this, with latest audit figures showing that 80% of stroke units now provide early supported discharge teams.

READ MORE (Study 25)
Much of the research on recovery in this report confirms many of my own common-sense conclusions as I grappled with the disabling consequences of my stroke. This includes the value of the early supported discharge team who looked after me and my wife in her new role as carer, in the first five weeks after leaving hospital. I left hospital in a wheelchair and it was the ESD team who got me walking and even climbing stairs. The words ‘it will be difficult, but you could try doing it this way’ completely re-programmed my negative thinking. The positive impact of the ESD team on my morale and well-being has been incalculable.

Stephen Hill, stroke survivor, Bristol
SUMMARY

Overall, there is good evidence around the value of specialist rehabilitation in stroke units from multidisciplinary teams. In the period after a stroke, new research found that early intense mobilisation does not benefit patients. Although analysis from this study suggested that shorter and more frequent spells of moving around may help, this needs further testing. Another trial found that starting speech therapy earlier did not improve outcomes compared with equivalent social support. Ongoing research will explore the duration and intensity of therapy to help people with speech problems, as well as the different therapies available in stroke units against recommended levels. New research will also explore the effectiveness of a range of technologies to support recovery after stroke. Work is also underway to co-design stroke rehabilitation services with input from stroke patients, carers and staff.

We know from a review of published evidence that early supported discharge teams can shorten length of stay and improve outcomes. Other work is examining the optimal features of this specialist team and also whether home visits or pre-discharge consultations from an occupational therapist are most helpful for patients recovering after leaving hospital.

Technology plays an increasing part in supporting people after a stroke. New research is testing effectiveness of devices, from robotic arms to electric impulses. Wearable technology with data sensors has also been used to provide feedback to stroke survivors on their mobility and progress against recovery goals.
LIFE AFTER STROKE

NUMBER OF STROKE SURVIVORS IN THE UK

STROKE PATIENTS LEAVEING HOSPITAL WITH A DISABILITY

STROKE PATIENTS THAT HAVE HAD 6 MONTH REVIEWS OF THEIR HEALTH ANDSOCIAL CARE NEEDS

1 in 50 people

2/3

Less than a third
Fewer people die after a stroke these days. But more people live with disability of different kinds. Many will need support from family, friends and paid carers to live at home or elsewhere in the community.

Recovery can take many years. Some people never regain all their brain function and have continued problems with speech, mobility or continence. But others make a full recovery over time. Some people may make good progress, but need help to carry out daily activities in their home. Whatever the level of disability, it is not easy to adjust to life after stroke. A quarter of people experience extreme tiredness, sometimes lasting for years after a stroke. As many as a third of people with stroke may suffer from depression (Stroke Association 2017).

To understand the long-term needs of people after a stroke and how these change over time, one study tracked patients for up to ten years. A key finding was the importance of social support to help overall health and wellbeing for people after a stroke. As part of the same study, a large survey suggested that many health and social care needs were not being met. These included help with problems such as mobility, falls, incontinence, fatigue, and emotional wellbeing.

To address this problem of unmet needs, one study developed a tool based on a register of stroke survivors in the community to identify the gap between need and service provision. The pilot study following patients for a year after discharge revealed some shortfall in services such as community rehabilitation, equipment and social support.

Evidence on life after stroke is welcome. Future research might address longer term reviews and the difficulty for people accessing services again some time after their stroke. We need to look outside the clinical perspective to explore both ‘hidden’ needs and the impact of stroke and aphasia on managing everyday life.

John Miles, community development worker with older people, London
MAKING A DIFFERENCE - Reviewing health and care needs

WHAT DID THE RESEARCH FIND?

Recent NICE quality standards emphasise the importance of regular review of patient needs at six and twelve months after a stroke and every year after. This includes how well the person can participate in daily activities and their role in their community, as well as secondary prevention and continuing rehabilitation. Researchers in Manchester worked with stroke survivors and their families as well as different kinds of staff to develop an evidence-based tool to review these needs. From research and work with stakeholders they identified thirty nine areas of potential post-stroke care needs, from medication management and secondary prevention, through to mood and fatigue. In the toolkit, they developed evidence-based algorithms, assessment tools and scales and service directories for staff carrying out reviews. There was also an easy-access version for people with aphasia (speech and communication difficulties). This tool was developed in 2010 and tested initially with over a hundred stroke survivors.

WHAT DIFFERENCE DID IT MAKE?

The Greater Manchester Stroke Assessment Tool (GM-SAT) is now used across the country. The Stroke Association have used the tool to carry out more than 12,500 reviews up to May 2015, with the number of reviews having grown year on year since its introduction. In addition, a 'snapshot audit' in 2016, found that the GM-SAT was used by providers in twelve of the fifteen authorities which commission six month post-stroke reviews in north west England. These findings are consistent with the findings of a national audit which showed GM-SAT to be the most commonly used six month post-stroke review assessment tool nationwide. In the latest quality standards for stroke in adults (NICE QS2, 2016) used GM-SAT as an example of a structured health and social are assessment.

Another small qualitative study found that few professionals looking after stroke survivors felt confident in raising or addressing sexual problems or were aware of existing information which could help. The authors suggested this element could be included where appropriate in routine reviews and legitimised as an area of wellbeing.

Around a tenth of people will move to a care home after a stroke. They will tend to be more disabled than those living at home. Although there is evidence of benefits of occupational therapy for people living at home, this is rarely available in care homes. An occupational therapy intervention had shown promise in a single centre study. But a recent large trial of more than two hundred care homes and over a thousand residents some time after a stroke found no improvement in outcomes following three months of personalised occupational therapy and staff training. It was noted that the participating residents in this study were more disabled than in the first smaller study and a third died during the course of the research. The authors concluded that many were incapable of engaging in therapy and alternative strategies would be needed to improve daily life for this frail and clinically complex population.

ONGOING RESEARCH

In terms of services to support longer term recovery, one study will test the effectiveness and cost-effectiveness of extending specialist care from the early supported discharge team for a further eighteen months. This trial will assess over five hundred patients in different parts of the UK.

Another programme of research is focused on longer term service for people nine months after stroke, using qualitative research with staff and carers as well as evidence on behaviour change to develop and test a new model of self-management and
An ongoing programme of work is reviewing evidence to identify and test new models of primary care and community health services for those living with stroke, including single point of contact for service users.

Another study focused on the need for better coordination of care for stroke survivors (many with multiple health problems) will develop and evaluate an integrated information system to bring together health records and other information across sectors.

Supporting carers is a critical part of stroke recovery and one trial is looking at new approaches to identifying their needs.

Other research addresses particular services or settings for people living with stroke. This includes studies to assess common forms of eye problems after stroke and how best to identify and manage these.

Another study is looking at the important longer term effects of stroke on cognitive problems and development of dementia and whether closer monitoring of risk factors delays cognitive decline. This is a growing area of interest and service need.

We know that ethnic minority groups can have higher risk of stroke and poorer outcomes. One review looked at effectiveness of awareness and health promotion interventions tailored for ethnic populations. They found little evidence, all from the US, and noted this was an under-researched area.

One important area which featured as one of the new NICE 2016 quality standards is active support for people to return to work after stroke, when needed. One study explored this and found access to vocational rehabilitation services variable. Those with milder or ‘hidden’ symptoms were sometimes missed. It also found that some people need ongoing support later in recovery, when it can be difficult for them to re-access services.

One programme of work has developed a six week individualised self-management support programme for stroke survivors to strengthen coping skills, such as problem solving. Early feasibility tests show promise and this is being tested in a definitive trial; a related study is also testing the intervention in...
MAKING A DIFFERENCE - Getting mobile

**WHAT DID THE RESEARCH FIND?**

Most stroke survivors have low levels of physical fitness. A recent NIHR funded Cochrane review of published evidence found almost sixty trials looking at fitness training after stroke. The trials involving 2797 stroke survivors tested different forms of fitness training, including cardiorespiratory ('endurance') training, resistance ('muscle strength') training and a combination of both. They found that exercise was safe and that it improved mobility, providing walking formed part of the exercise. Mixed training improved walking ability and balance. There was not enough evidence to assess the effectiveness of resistance training. Longer term benefits were not known or the impact on cognitive function and other benefits. Further research was needed to say what kind of activity for how long was most cost-effective for different kinds of stroke patient.

**WHAT DIFFERENCE DID IT MAKE?**

This review should give stroke survivors confidence in the benefits of walking and other appropriate exercise, without the fear of harm. This evidence has informed advice on fitness training in clinical guidelines and on national courses and curricula for rehabilitation teams.

[READ MORE (Study 39)]

a group setting to see if the same benefits can be achieved in a more cost-effective form.

[READ MORE (Study W)]

Another initiative will develop and test a group intervention targeted specifically at carers offering support and education.

[READ MORE (Study X)]

Several studies will assess emotional and psychological support for stroke survivors and families. This includes access to formal psychological support and impact of particular interventions, such as art and health groups.

[READ MORE (Study Y & Z)]

Another trial is testing a package to support the whole family, not just the stroke survivor, through use of resources like online talking therapies.

[READ MORE (Study AA)]

**KEEPING ACTIVE**

An important area of interest is physical activity after stroke. Many people suffer from reduced mobility after stroke, with varying degrees of recovery.

The challenge of gaining weight after stroke is explored in a study, noting drop in activity levels when recovering from a stroke. Advice and information around diet and exercise were sometimes fragmented and the study noted the particular needs of younger stroke survivors.

[READ MORE (Study 40)]

Many activity programmes struggle to get people to join classes or to stay involved. One qualitative study looked at the motivation of stroke survivors to exercise. Findings showed mixed beliefs about stroke recovery, the value of emphasising the psychological benefits of exercise and, for some, the benefits of programmes in non-clinical settings led by people other than health professionals. These results helped to inform the design of a particular exercise intervention for stroke survivors which is being piloted now.

[READ MORE (Study 41)]

**ONGOING RESEARCH**

An ongoing study is adapting a walking programme used for healthy but sedentary people to the particular needs of stroke survivors. This will test the acceptability of this intervention before further testing in a trial.

[READ MORE (Study AB)]
People who have had a stroke or TIA are at high risk of another stroke. An important part of good stroke care is not just recovery but preventing another attack – secondary prevention. Evidence suggests that people with risk factors like blood pressure are not always managed well after a stroke. One Cochrane review looked at research on what works in secondary prevention. The findings from studies outside the UK suggested mixed results of organisational interventions on different risk factors. But it seemed that educational and behavioural interventions without organisational support were not likely to be effective in preventing further strokes.

Interestingly, one study found that TIA patients had higher number of visits to general practice for fatigue, cognitive and emotional problems for some time after the event. This suggests that the ‘transient’ nature of TIA may be misunderstood and health professionals need to be aware of potential longer term effects similar to more serious forms of stroke.

One study on secondary prevention looked at the effectiveness of a nurse prescribing drugs to manage hypertension and other risk factors for further strokes. Early testing suggested that six months of monitoring and management by a nurse prescriber improved adherence and blood pressure control and could be tested further.

Some people after a TIA or minor stroke may experience delays in starting medication which could prevent further stroke. One pilot trial is assessing a new approach where a general practitioner starts medication before referral to a specialist in a TIA clinic.
SUMMARY

Research shows that the needs of people after a stroke change over time. These include social and emotional needs as well as support to achieve optimum function and physical health. NIHR funded research has developed and tested different tools to identify and monitor this range of needs and target support where needed.

We know that there is often a gap between needs and some of the longer-term recovery and rehabilitation services. Different NIHR funded studies have tested enhanced programmes, for instance whether it is cost-effective to extend the support from specialist teams for up to a year and a half after discharge. Other studies have looked at different models of support from primary and community care. A particular study found no benefit in targeted occupational therapist support for stroke survivors in care homes.

Several studies have developed and tested programmes to develop coping skills for people after stroke. These include self-management support delivered to individuals and in groups, which could be cheaper to deliver. Some interventions are targeted at carers and the whole family, recognising the demands placed on those looking after stroke survivors. A trial of exercise for housebound stroke survivors showed no improved quality in life.

Studies have also looked at secondary prevention, noting the impact in one initiative of nurse prescribers in managing hypertension after stroke. Education and behaviour change without some organisational support is unlikely to help prevent further strokes.

Activity is important and research has shown that exercise, particularly walking, is a good way of staying active. Research on what motivates stroke survivors to take exercise and stay active will be used to design new activity programmes.
NIHR infrastructure and research funding has supported much leading stroke research over the last ten years. Research projects of different kinds have helped to improve stroke care. These range from clinical trials, mixed-methods evaluations, qualitative research, quantitative analysis of routine audit data and computer simulation. NIHR has engaged frontline staff and patients to find the most important research questions. Different parts of the research system have been able to develop new interventions and services, test them and evaluate for everyday use. To do this, NIHR has funded fellowships and trainee posts as well as established teams and units to ensure that new research can be done. NIHR-funded networks have also helped research supported by other funders to be carried out in the NHS.

This review shows that NIHR funding is providing evidence on which to base and provide high quality stroke services that will save more lives and improve the quality of life of people who have a stroke.

Ade Adebajo, Consultant physician, Barnsley

PERCENTAGE OF NHS HOSPITALS IN ENGLAND TAKING PART IN NIHR STROKE RESEARCH STUDIES IN 2015/16

92%

NUMBER OF INDIVIDUALS RECRUITED INTO NIHR STROKE CLINICAL TRIALS IN 2015/2016

21,574

Source: NIHR Clinical Research Network
This review provides an overview of NIHR research around the management and organisation of stroke care. Much interesting research has been published and is underway.

But there are still many areas where research is needed. We know far more about the right care and treatment for the more common ischaemic type of strokes, caused by clots in the brain, than the rarer haemorrhagic stroke caused by bleeds into the brain. We also know a lot more about what works in the first few hours after a stroke than what is most effective when people return to the community. We know that rehabilitation is effective after stroke but not enough about which models of care are most cost-effective. New developments, such as mobile stroke units with prehospital thrombolysis, have shown promise in other countries but their application or cost-effectiveness here is unknown.

At times of financial constraint, we need research to help us make best use of skilled staff. We do not know how to provide equitable services in acute stroke across diverse geographic areas and for all days of the week. More work is needed to understand the cognitive and emotional impacts of stroke and how best to support those with long-term disabilities. This includes developing and testing interventions with and for families caring for stroke survivors. Roads to Recovery has highlighted some of the ongoing work funded by NIHR but there are other important uncertainties in this rapidly changing field.

A recent analysis showed that government funding on stroke research had increased since 2008 as a proportion of all spend on health research (Luengo-Fernandez 2014). Indeed, NIHR stroke projects represent a healthy 5% of the total NIHR portfolio comparing well with other government and charity stroke research funding (around 1.3% of total) and need in terms of total disability-adjusted life years (around 3.8% of total). But compared with areas like cancer and coronary heart disease, stroke research overall is still relatively underfunded. Yet the UK has punched well above its weight, coming second only to the US in terms of citation of published stroke research of all kinds from 2001-2011 (Asplund 2012). This review shows the ways in which research can make a difference and inform improvements in stroke and stroke care for all.
This report was written by the following members of the NIHR Dissemination Centre team: Tara Lamont - Deputy Director with Tansy Evans – Business Manager, Dr Vaughan Thomas – Clinical Lead and Dr Tannaze Tinati - Researcher

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Images courtesy of the Stroke Association and Public Health England
APPENDICES AND REFERENCES
and Manchester. The key processes in service redesign and implementation will be examined, including the provision of acute stroke care, availability of acute treatments, and management of mini-stroke and rehabilitation services. Methods will include documentary analysis of routinely collected data, interviews and focus groups with commissioners, patients and carers, and a decisions analytic model to evaluate cost-effectiveness. The first phase of the research is now completed, with further work evaluating organisation changes and cost effectiveness. Full results from the complete programme are expected 2018.

Key publications to date include:


This study examined whether centralisation of acute stroke services in London and Greater Manchester was associated with changes in mortality and length of hospital stay. In London, hyperacute stroke care was provided to all patients compared to Greater Manchester, where hyperacute stroke care was provided to patients presenting within four hours of developing stroke symptoms. The study included 258,915 patients with stroke admitted to hospital in 2008 to 2012. Overall, it was found that in London there was a significant decline in risk-adjusted mortality at 3, 30, and 90 days after admission. At 90 days the absolute reduction was −1.1% (95% confidence interval −2.1 to −0.1; relative reduction 5%), indicating 168 fewer deaths (95% confidence interval 19 to 316) during the 21 month period after reconfiguration in London. There was a significant decline in risk-adjusted length of hospital stay: −2.0 days in Greater Manchester (95% confidence interval −2.8 to −1.2; 9%) and −1.4 days in London (−2.3 to −0.5; 7%). The authors concluded that a centralised model of acute stroke care reduce length of time in hospital and mortality. Further research could assess the impact of centralised care on disability after stroke.

- BMU 2014; doi: https://doi.org/10.1136/bmj.g4757

- B. Lessons for major system change: centralization of stroke services in two metropolitan areas of England. Turner

This study involved analysing 316 documents and conducting 45 interviews with transformation leaders, commissioners, providers and service user organisations. The aim was to identify the factors influencing the selection of different models of acute stroke service centralisation in London and Greater Manchester. In London, system leadership was used to overcome resistance to centralization and facilitate a centralized service model, whereas in Greater Manchester, programme leaders relied on achieving change by consensus, leading to the implementation of a less radical transformation of services.

- Research & Policy 2016; 21 issue: 3, page(s): 156-165. DOI: https://doi.org/10.1177/1355819615626189

- C. Effects of Centralizing Acute Stroke Services on Stroke Care Provision in Two Large Metropolitan Areas in England. Ramsey

Early findings show that after acute stroke care was reconfigured into hyperacute units, the likelihood of receiving interventions increased in both London and Manchester. London patients were overall significantly more likely to receive interventions. The authors concluded that that centralised systems for stroke patients leads to better provision of evidence-based clinical interventions.

- Stroke, 2015 Doi: http://dx.doi.org/10.1161/STROKEAHA.115.009723

- D. Explaining outcomes in major system change: a qualitative study of implementing centralised acute stroke services in two large metropolitan regions in England. Fulop

As part of the evaluation, the team undertook a theoretically-driven qualitative study of implementation of the two cases of major system change to stroke services in Manchester and London. This included interviews with stakeholders at national, pan-regional, and service-levels (n = 125) and analysis of 653 documents. The study found that London and Manchester’s differing
Implementation outcomes were influenced by the different service models selected and implementation approaches used. Fidelity to the referral pathway was higher in London, where a ‘simpler’, more inclusive model was used, implemented with a ‘big bang’ launch and ‘hands-on’ facilitation by stroke clinical networks and close alignment of serice specifications to financial incentives. In contrast, a phased approach of a more complex pathway was used in Manchester, with less dedicated project management support.

**STUDY 4 PUBLISHED**

The challenges of implementing a telestroke network: a systematic review and case study

*Published, 2013 Watkins*

This programme of research developed and tested a Standardised Telemedicine Toolkit (STT) that included a training package, standardised assessments and a checklist to help doctors and nurses to use a telemedicine system in stroke care. The toolkit is freely available online.

Publication: French (2013)

*BMC Medical Informatics and Decision Making 2013*  
DOI: 10.1186/1472-6947-13-125

**STUDY 5 PUBLISHED**

Evaluating the impact of a simulation study in emergency stroke care

*Published, Stein and Allen, 2015*

The implementation of changes made to the emergency stroke pathway, following a computer simulation of modelled change, were evaluated (Monks 2015) in a large acute hospital in the UK. Stroke treatment rates and door-to-needle times before and after the changes were assessed, with an increase in thrombolysis rate of 6.8% and a reduction of over 26 minutes in mean door-to-needle time. In line with expectations, treatment rates had increased 2 years after the changes were implemented, with four times as many patients being treated in half the time.

*Operations Research for Health Care 2015*  
http://dx.doi.org/10.1016/j.orhc.2015.09.002

**STUDY 6 PUBLISHED**

Associations between the organisation of stroke services, process of care, and mortality in England: prospective cohort study

*Published, 2013, Bray*

This study examined the association between stroke services, process measures of care quality and 30 day mortality in patients admitted with acute ischaemic stroke. Process of care was measured using six individual measures of stroke care (e.g. brain scan within 24 hours of admission, seen by a stroke consultant/associate specialist within 24 hours of admission) and summarised into an overall quality score. 36,197 patients were admitted with acute ischaemic stroke and 71.6% were eligible to receive all six care processes. Patients admitted to stroke services with high organisational scores were more likely to receive most (5 or 6) of the six care processes. Three of the individual processes were associated with reduced mortality, including two care bundles: review by a stroke consultant within 24 hours of admission, nutrition screening and formal swallow assessment within 72 hours, and antiplatelet therapy and adequate fluid and nutrition for first the 72 hours. The authors concluded that these results have important implications for stroke services. Patients receiving high quality of care have reduced risk of mortality in the first 30 days, and those receiving more organised stroke services are more likely to have high care quality of care.

*BMJ 2013,* doi: http://dx.doi.org/10.1136/bmj.f2827

**STUDY 7 PUBLISHED**

Derivation and external validation of a case mix model for the standardized reporting of 30-day stroke mortality rates.

*Published, 2014, Bray*

This study developed and validated prediction models to compare 30-day post-stroke mortality outcomes using routine clinical data. Models were derived using data from the Sentinel Stroke National Audit Program and external validation (n=1470 patients) was performed in the South London Stroke Register. Two models were equally effective at predicting mortality in unselected patients with acute stroke. The models included information on age, clinical presentation, presence of atrial fibrillation on admission, and stroke type.

*Stroke 2014* doi: 10.1161/STROKEAHA.114.006451

**STUDY 8 PUBLISHED**

Reviewing and testing prognostic models in stroke

*Published, 2012, 2013 Teale*

A systematic review of published evidence compared a range of validated prognostic models in stroke (Teale 2012). It identified seventeen models from 43 papers which included factors from stroke severity, pre-stroke health and co-morbidities. The UK-developed Six Simple Variables model performed well in predicting death and dependency after stroke. In a related study (Teale 2013), the team tested the Six Simple Variables model on a cohort of 176 patients from three hospitals in Yorkshire and confirmed it as a useful tool.


**STUDY 9 PUBLISHED**

Important factors in predicting mortality outcome from stroke: findings from the Anglia Stroke Clinical Network Evaluation Study.

*Published, 2016, Myint*

This study examined stroke service provision and outcomes in relation to mortality rates. Data was obtained prospectively from eight acute NHS trusts to assess patient-related factors and service characteristics on stroke outcome at seven, 30 and 365 days post stroke, and time to death within 1 year. Overall, 2,388 acute stroke patients were included in the study. One year mortality was predicted by increasing age, haemorrhagic stroke, total anterior circulation stroke type, higher pre-stroke frailty, history of hypertension and ischaemic heart disease and admission hyperglycaemia. Variation in stroke services explained very little of the variation in stroke mortality. There was a considerable benefit of higher nursing levels on mortality: an increase in one trained nurse per 10 beds was associated with significant reductions in 30-day mortality of 11–28% (P < 0.0001) and in 1-year mortality of 8–12% (P < 0.001). Trained nurses were NHS bands 5-7. The authors concluded that trained nursing staff and higher nursing:beds ratio are vital in providing stroke care.


**STUDY 10 PUBLISHED**

Associations between Stroke Mortality and Weekend Working by Stroke Specialist Physicians and Registered Nurses: Prospective Multicentre Cohort Study

*Published, 2014, Bray*

The aim of this study was to determine whether there was a "weekend effect" for patients admitted for stroke. This study utilised a prospective cohort of 103 stroke units, involving 56,666 patients who were admitted with stroke between June 2011 and
December 2012. After adjusting for confounders, there was no significant difference in mortality risk for patients admitted to a stroke service with stroke specialist physician rounds fewer than 7 days per week compared to patients admitted to a service with rounds 7 days per week. Patients admitted on a weekend to a stroke unit with 1.5 nurses/ten beds had an estimated adjusted 30 day mortality risk of 15.2% compared to 11.2% for patients admitted to a unit with 3 nurses/ten beds. This was equivalent to one excess death per 25 admissions. The authors concluded that stroke outcomes are affected by the level of registered nurses available at the weekend, rather than 7 day ward rounds by physicians.

PloS Med 2014 doi:10.1371/journal.pmed.1001705

**STUDY 11 PUBLISHED**

Interprofessional teamwork across stroke care pathways: outcomes and patient and carer experience.

Published, 2013, Harris

This study aimed to explore the impact and effectiveness of teamwork for survivors of stroke and their carers. Data was collected from five stroke unit teams, including two acute, one inpatient rehabilitation and two community teams. Multiple interviews were conducted with staff, patients and carers along the care pathway. Staff questionnaires on team characteristics and quality of life at work were also completed. The results indicated that open communication, collaboration and pooling of resources within a team led to better patient outcomes. Smaller teams, or subgroups within larger ones, were preferred. Leadership appeared to be a complex issue, with staff in rehab and acute settings finding it difficult to identify a clear leader. Patients and carers do not specifically notice interprofessional team working. The authors concluded that team working in stroke care is a complex process, and clear leadership is often essential for good patient outcomes.


**STUDY 12 PUBLISHED**

Modelling, evaluating and implementing cost effective services to reduce the impact of stroke

Published, 2014, Wolfe

This programme of research used the South London Stroke Register (SLSR) to answer a series of questions. A focus was on the risks and underlying causes of stroke, the management of stroke, and the long-term implications for patients and carers in a multi-ethnic population. This grant has led to a range of important findings. For example, there is a significant relationship between socio-economic deprivation and reduced survival after stroke (Chen et al. 2014). Further, between 1995 and 2010 total stroke incidence decreased significantly, but this was not reflected in younger age groups (under 45 years) or in black populations (Wang et al. 2013). Another study found that the median time to hospital following suspected stroke was 4.73 hours. Patients of black ethnicity has increased odds of a delay in presentation whereas those with more severe strokes had reduced odds of delay. (Addo et al. 2012). The study also found that there was no difference in the proportion of patients who arrived within 3 hours in the period immediately before and after the FAST campaign.


Further publications:


Wang Y, Rudd AG, Wolfe CD. Age and ethnic disparities in incidence of stroke over time: the South London Stroke Register. Stroke 2013;44(12):3298-3304. DOI: 10.1161/STROKEAHA.113.002604

**ONGOING STUDIES**

**STUDY A ONGOING**

Mixed methods analysis of the London Hyperacute Stroke System: identifying lessons on 24/7 working (METRO-24/7).

Simister, Due to publish 2017

This study will investigate the extent to which care received by stroke patients differs between normal work hours and out of hours in all London Hyperacute Stroke Units (HASUs). The HASUs were designed to provide comprehensive stroke care in the first 72 hours, and 24/7 access to thrombolysis and stroke nursing care. However, they do not provide the same level of access to therapists, consultants or diagnostic investigations out of working hours compared to within working hours. The study will examine the care received by patients and clinical outcomes. Both quantitative and qualitative methods will be adopted to analyse organisation and provision of 24/7 care in all eight London HASUs. Staff and patient experiences will also be investigated. The research will also look at how services are organised and provided and a cost analysis will be conducted.

https://www.journalslibrary.nihr.ac.uk/projects/1212841/#/

**STUDY B ONGOING**

The future of 24/7 care: investigating the links between staffing levels, patient access and inequalities in health outcomes (focus on stroke amongst other conditions).

Doran, Due to publish 2017

This programme of research is developing a linked data set of patient records for those admitted to Salford Royal Foundation Trust. Salford Royal was chosen because it has implemented extended hours (7am to 11pm) 7 days a week, since 2012, with full provision during this time. Amongst other factors, the data set will be used to look at staffing levels, clinical outcomes and quality of care. The research will also look at whether quality of care and patient outcomes varies with time of admission for all acute hospital trusts in NW England. Stroke care will be examined in one hospital and compared to Salford Royal.

https://www.journalslibrary.nihr.ac.uk/projects/1212848/#/

**STUDY C ONGOING**

Stroke Sentinel Audit Programme: Investigating and Evaluating Stroke Therapy (SSNAPIEST).

Tyson, Due to publish 2018

Using data from the Sentinel Stroke National Audit Programme (SSNAP), this research will examine the provision of stroke services and clinical outcomes to determine differences in the availability of services. A better understanding of this data may lead to a more effective care pathway for stroke patients, as well as greater cost savings. Another aspect of the research will look at the influence of disabilities caused through stroke and the impact on therapy and recovery.

https://www.journalslibrary.nihr.ac.uk/projects/1419809/#/

**STUDY D ONGOING**
Clinical supervision in stroke care pathway.
Ryan, due to publish 2017

This six year programme of research (2010-2016) has developed working relationships with the South Yorkshire stroke network, providers, commissioners, patients and carers. The research has been examining a range of factors including awareness and prevention of stroke, the provision of stroke units, rehabilitation and long-term support.

http://www.clahrcprojects.co.uk/impact/projects/clinical-supervision-stroke-care-pathway

IDENTIFYING STROKE AND ACUTE MANAGEMENT
PUBLISHED

STUDY 13 PUBLISHED
Ford, 2012

This programme of research aimed to improve access to acute treatment for individuals suspected of having a stroke. Interviews with patients, families and health care staff were undertaken to inform the development of education programmes to improve the awareness of stroke symptoms, types of treatment including the use of thrombolysis, and reduce transfer time to hospital. The “Act FAST” (Face, Arm, Speech, and Time) campaign was also evaluated, as well a review of emergency stroke services to determine which designs provided better access to care (McMeekin et al, 2013).

There are multiple outputs from this work – a few of the most relevant include:

This project involved the development of a computerised decision aid for to support patient-specific decision making on the use of thrombolysis in acute care. The COMputerised decision Aid for Stroke thrombolysis (COMPASS) was tested with simulated situations, and with 25 real patients by clinicians. Clinicians input the details of a stroke patient, which provides numerical and graphical presentations of the predicted likelihood of functional independence and death with or without thrombolysis. No adverse effects were reported when used in practice. Clinicians valued the aid in terms of both the patient-specific predictions for thrombolysis use, and the ability to communicate risk with patients and families.


In 2009, the Department of Health in England launched Act FAST mass media campaign. This report is an evaluation of the impact of three consecutive phases of FAST in England. Overall, a statistically significant benefit for each of the three phases of Act Fast was found. Results indicated that before the campaign, emergency admissions and thrombolysis activity was increasing significantly over time whereas emergency admissions via general practitioners were decreasing significantly. After phase one of the campaign, there were significant increases in overall emergency admissions and patients admitted via A&E Significantly fewer monthly emergency admissions via GPs were reported after phase three. Thrombolysis activity per month significantly increased after phases one and three. The authors concluded that the campaign led to a significant impact on information seeking behaviour (such as Stroke Association website hits and views, information materials dispatched by the Stroke Association, and calls to their helpline) and emergency admissions.


STUDY 14 PUBLISHED
Emergency Stroke Calls: Obtaining Rapid Telephone Triage (ESCORTT) - a programme of research to facilitate recognition of stroke by emergency medical dispatchers
Published, 2014, Watkins

This programme of research examined the factors around the recognition of stroke by emergency medical dispatchers (EMDs) and evaluated an intervention designed to improve recognition rates. The research included eight phases, including understanding the stroke diagnosis, interviews with EMDs, content analysis of emergency calls, and the implementation of a stroke-specific online training package. The setting was one ambulance service and four hospitals in the north-west of England. This intervention was designed to improve recognition of stroke for EMDs. The intervention appeared to be beneficial, showing a significant difference (p=0.003) in proportions correctly dispatched as stroke – before the training was implemented 58 out of 92; during implementation of training 42 out of 48; and after training implemented 47 out of 59. An analysis of the calls found that the mention of ‘stroke’ or one or more Face Arm Speech Test (FAST) items was much more common in stroke compared with non-stroke calls. The authors concluded that the effectiveness of the training package should now be assessed across other emergency medical services across England.

Appl Res 2014 DOI: http://dx.doi.org/10.3310/pgfar02010

STUDY 15 PUBLISHED
Barriers to early assessment of TIA and stroke (BEATS)
Wilson

This project aimed to understand the barriers and facilitators to the diagnosis of TIA and stroke, and provide recommendations to reduce delays to receiving appropriate treatment.

Several publications have been produced:
Wilson, 2016

This study aimed to investigate the service factors leading to delays in rapid treatment following stroke and TIA. Interviews were conducted with patients diagnosed with TIA or stroke (n=42), and their GPs if they had been involved in their care (n=18). Using constant comparative analysis, three themes were identified around different types of delay. The themes included (i) delays in assessment in general practice; (ii) delays in diagnosis by the health care professional first consulted; and (iii) delays in referral after a suspected diagnosis. The authors recommend better training of non-medical staff, such as receptionists, to identify symptoms as well as a mechanism in place to allow a direct referral to TIA clinics when patients present to other agencies.

BMJ Open 2016;6:e011654. doi:10.1136/bmjopen-2016-011654

B. Delay between symptom onset and clinic attendance following TIA and minor stroke: the BEATS study. Wilson, 2014

This was a retrospective cohort study examining rapid access to TIA clinics. Interviews were conducted with 278 patients newly diagnosed with TIA or minor stroke. Eight percent of high-risk TIA patients attended a clinic within 24 hours of experiencing symptoms and 53% of low-risk TIA patients attended within 7 days. Median delay between symptom onset and seeking help from a
healthcare professional was 4 hours. 56% of patients contacted a GP first, compared to 17% who called an ambulance or attended the emergency department. Over a third of patients had a second consultation with a healthcare professional before attending a clinic. A delay in attending the clinic was reduced if an emergency pathway was used and increased if patients were seen by a second professional. The authors concluded delays could be reduced through direct referrals from paramedics, optometrists, and out-of-hours services.


**STUDY 16 PUBLISHED**

Alteplase for acute ischaemic stroke

Published, 2012, Davis

Alteplase was originally licensed in 2002 to treat acute ischemic stroke when used within 3 hours of onset of stroke symptoms. In 2012 the licensed was extended to cover those treated within 4.5 hours. This study evaluated the evidence for the clinical and cost effectiveness of alteplase in this extended timeframe. The evidence for clinical effectiveness was obtained from five trials, with death or disability as the main outcomes. In the 3–4.5 hour treatment window, based on evidence from a single study, alteplase did not show a statistically significant treatment effect on death or dependency at three months follow-up but did show a statistically significant reduction in dependency. For the 4–4.5 hour treatment window, data from a meta-analysis of three trials indicated that the reduction of death and dependency was statistically significant. The NICE committee concluded that Alteplase administered within 4.5 hours was cost-effective compared with standard treatment and clinically effective in decreasing the probability of death or dependence. The report of this (Davis 2012) also included a stakeholder exercise. A pharmacoeconomic summary (Holmes 2015) was published subsequently.

PharmacoEconomics 2015, doi:10.1007/s40273-014-0233-z (Holmes 2015)

**STUDY 17 PUBLISHED**

Cost effectiveness of optimising acute stroke care services for thrombolysis.

Published, 2014, Penaloza –Ramos

This study aimed to establish the cost-effectiveness of increasing thrombolysis rates through a series of hypothetical change strategies designed to optimize the acute care pathway for stroke. Using a decision-tree model, current practice relating to acute management was assessed and compared with seven change strategies designed to facilitate wider eligibility for thrombolysis. The cost of the strategy per quality-adjusted life year (QALY) gained was estimated. All intervention strategies were found to be cost-effective because of a reduction in dependency after stroke and long-term care costs. The strategy of better recording of onset time was the change strategy with the largest potential benefit, with 3.3 additional quality-adjusted life years and a cost saving of US $46 000 per 100 000 population. The strategy of immediate CT scan upon arrival, with a saving of US$75,000 and an additional 5.4 QALYs per 100,000 population, provided the largest cost reduction. The authors concluded that since any strategy increased thrombolysis rates, they should be actively considered to improve both patient outcomes and cost of care.

Stroke. 2014; doi: http://dx.doi.org/10.1161/STROKEAHA.113.003216

**STUDY 18 PUBLISHED**

Bigger, faster? Associations between hospital thrombolysis volume and speed of thrombolysis administration in acute ischemic stroke.

Published, 2013, Bray

This paper examined possible associations between the volume of hospital thrombolysis performed and speed of thrombolysis (tissue-type plasminogen activator (tPA)) administration in patients with ischemic stroke. Data from 80 hospitals was obtained from two audits. Hospitals were categorised into 3 groups based on the annualized volume of thrombolysis: 0 to 24, 25 to 49, and ≥50 cases per annum. 42024 patients were admitted with acute ischemic stroke and 10.3% received tPA. Patients admitted to hospitals with an annual thrombolysis volume of ≥50 cases per annum had median arrival-tPA times that were 28 and 22 minutes shorter than patients admitted to hospitals with volumes of 0 to 24 and 25 to 49, respectively. Multivariable analysis showed that patients admitted to hospitals with a volume of ≥50 cases per annum had 4.33 the odds of receiving tPA within 60 minutes of arrival. There were similar 30-day mortality and complication rates across the groups. Authors concluded that hospitals with higher volumes achieve statistically and clinically significant shorter delays in administering tPA to patients after arrival.

Stroke. 2013, Doi: http://dx.doi.org/10.1161/STROKEAHA.113.001981

**STUDY 19 PUBLISHED**

Understanding clinicians’ decisions to offer intravenous thrombolytic treatment to patients with acute ischaemic stroke: a discrete choice experiment.

Published, 2017, Thomson

This study investigated factors influencing clinicians’ decisions on the use of intravenous thrombolysis. Factors that affect decision-making include both patient and clinician characteristics (e.g. age, attributes, setting, experience of thrombolysis, experience of patient having a bleed in the brain due to thrombolysis). A robustly developed on-line discrete choice experiment (DCE) was conducted to allow for exploration of the relative importance of different factors within a decision making model (separate journal output referenced below). Clinicians were presented with a range of hypothetical patient vignettes, focusing around grey areas of decision making and asked to state their decision. There was considerable heterogeneity among respondents in thrombolysis decision-making, indicating that clinicians differ in their thresholds for treatment across a number of patient-related factors. Respondents were significantly more likely to treat 85-year-old patients than patients aged 68 years and this probably reflects acceptance of data from the Third International Stroke Trial that report benefit for patients aged > 80 years. That respondents were more likely to offer thrombolysis to patients with severe stroke than to patients with mild stroke may indicate uncertainty/concern about the risk/benefit balance in treatment of minor stroke.

NIHR Service Delivery and Organisation Programme 2017, https://www.journalslibrary.nihr.ac.uk/hsdr/hsdr05040#abstract

**STUDY 20 PUBLISHED**

The CLOTS 3 trial: a randomised controlled trial to determine whether intermittent pneumatic compression reduces the risk of post stroke deep vein thrombosis.

Published, 2015 Dennis

This study aimed to assess whether the application of intermittent pneumatic compression (IPC) to the legs of immobile stroke patients reduced their risk of deep vein thrombosis (DVT). Between 2008-2012, 2876 patients in 94 UK hospitals were recruited. The patients were admitted to hospital within 3 days of acute stroke and were immobile on the day of admission to day 3. Participants were randomly allocated to routine care or routine care plus IPC.
for 30 days, or until earlier discharge or walking independently. The primary outcome was DVT within 30 days of randomisation. Patients were followed up for 6 months. It was found that IPC was an effective and inexpensive method of reducing the risk of DVT and improving survival in immobile stroke patients. DVT occurred in 8.5% of patients allocated to IPC and 12.1% patients allocated to no IPC. Patients who were treated with IPC showed a significant improvement in survival to 6 months, but no improvement in disability. The direct cost of preventing a DVT was £1282 per event. The authors indicated that research is needed to improve adherence to IPC, which could lead to further benefits for stroke patients.

Lancet 2013, DOI: http://dx.doi.org/10.1016/S0140-6736(13)6050-8

Health Technol Assess 2015 DOI: 10.3310/hta19760

ONGOING

STUDY E ONGOING

Promoting Effective And Rapid Stroke care (PEARS) [Better working between ambulance and hospitals including enhanced paramedic role and pathways for delivering new clot-busting treatments at specialist centres.]

Ford, Due to publish 2019

This programme of research aims to achieve more rapid delivery of intravenous thrombolysis and define the role of intra-arterial thrombectomy for serious stroke. To address this, research will focus on understanding and integrating pre-hospital services (ambulance paramedics, GPs) and hospital teams (emergency department, acute stroke, radiology, and neuroradiology). An enhanced protocol for paramedics will be developed and evaluated by a clinical trial in three ambulance trusts in England and Wales in its use to rapid assess potential stroke patients and pre-alert the hospital team. Alongside the RCT, cost-effectiveness and qualitative analysis with patients and professionals will be conducted. A second aspect of the research will be the clinical and cost effectiveness of delivering intra-arterial therapy (IAT) for acute ischaemic stroke patients in England. Using mathematical modelling, it is hoped that this will provide a mapping of the stroke care pathway to provide potential cost-savings to the NHS and improve patient outcomes.

http://www.ncl.ac.uk/ion/research/neurodegenerative/ncpdpred/

RECOVERY AND REHABILITATION

PUBLISHED

STUDY 21 PUBLISHED

Published, Langhorne, 2015

AVERT is a large RCT (with several funders, including the NIHR) comparing very early mobilisation plus usual care or usual stroke care alone, with acute stroke patients. Very early mobilisation (VEM) focuses on task specific mobility training (for example sitting out of bed, standing, and walking) commenced within 24 hours after a stroke. Such activities continue on a frequent basis for up to 14 days until discharge. Intensity can range for 4 to 16 times a day depending on the severity of the stroke. The primary outcome is the proportion of patients dead or disabled at 3 months post stroke.

A Efficacy and safety of very early mobilisation within 24 h of stroke onset (AVERT): a randomised controlled trial. The AVERT Trial Collaboration group

2014 patients, from five countries, were recruited. 965 (92%) patients were mobilised within 24 hours in the VEM group compared with 623 (59%) patients in the usual care group. Fewer patients in the VEM group had a favourable outcome than those in the usual care group (n=480 [46%] versus n=525 [50%]; adjusted odds ratio [OR] 0.73, 95% CI 0.59–0.90; p=0.004). 88 (8%) patients died in the very early mobilisation group compared with 72 (7%) patients in the usual care group (OR 1.34, 95% CI 0.93–1.93, p=0.113). The authors concluded that their results suggest an early, lower dose activity regimen is preferable to very early, frequent, higher dose intervention. However, they cations that clinical recommendations should be informed by future analyses of dose–response associations.

Lancet, 2015, doi.org/10.1016/S0140-6736(15)60690-0

B Prespecified dose-response analysis for A Very Early Rehabilitation Trial (AVERT). Bernhardt.

The prespecified dose-response analyses of AVERT aim to provide practical guidance for clinicians on the timing, frequency, and amount of mobilization following acute stroke. Eligible patients were aged 18 years, had confirmed first (or recurrent) stroke, and were admitted to a stroke unit within 24 hours of stroke onset. Patients were randomized to receive very early and frequent mobilization, commencing within 24 hours, or usual care. 2,104 patients were enrolled, and 99% were followed up at 3 months. A consistent pattern of improved odds of favourable outcome in efficacy and safety outcomes with increased daily frequency of out-of-bed sessions was found, keeping time to first mobilization and mobilization amount constant. Increased amount (minutes per day) of mobilization reduced the odds of a good outcome. The authors concluded that shorter, more frequent mobilization early after acute stroke is associated with greater odds of favourable outcome at 3 months when controlling for age and stroke severity. This is a sub-analysis of the main trial, and will need further definitive research before becoming definitive.


STUDY 22 PUBLISHED

Clinical effectiveness, cost-effectiveness and service users perceptions of early, well-resourced communication therapy following a stroke: a randomised controlled trial (the ACT NoW Study)

Published, 2012, Bowen

The ACT NoW Study (Assessing Communication Therapy in the North West) is an RCT of communication therapy for stroke survivors. The target group was adults with dysarthria or aphasia, seen early after admission to hospital with a stroke. One hundred and seventy participants (mean age 70 years) were randomised to receive either early speech and language (S&L) therapy or visits by a non-therapist (attention control – unstructured social contact). The primary outcome was functional communicative ability 6 months post randomisation on the Therapy Outcome Measure (TOM). The intervention generally began after 2 weeks, providing an average of 22 contacts over 13 weeks. Both groups improved on the TOM. The estimated 6 months’ group difference [95% confidence interval (CI)] was 0.25 [-0.19 to 0.69] points in favour of S&L therapy. The intervention had no added benefit in terms of the secondary outcome measures (such as participant and carer perceptions). Qualitative analysis indicated that participants in both groups had improved mood and confidence. The cost-effective analysis was unclear. The authors argued there is no real added benefit of having S&L therapy over and above social support but what may be important is early and regular communication practice with a professional (therapist/visitor).

Health Technol Assess 2012 DOI: http://dx.doi.org/10.3310/hta16260

STUDY 23 PUBLISHED

Stroke patients’ utilisation of extrinsic feedback from computer-
This review aimed to establish the effects and costs of early supported discharge (ESD) services compared with conventional services. The review included 14 good quality RCTs (1957 patients) including four from the UK. The ESD group showed significant reductions (P < 0.0001) in the length of hospital stay equivalent to approximately seven days. The odds ratios (95% confidence interval (CI)) for death, death or institutionalisation, death or dependency at the end of scheduled follow-up were OR 0.91 (95% CI 0.67 to 1.25, P = 0.58), OR 0.78 (95% CI 0.61 to 1.00, P = 0.05) and OR 0.80 (95% CI 0.67 to 0.97, P = 0.02) respectively. A well-organised ESD team had the greatest benefits, as did patients with less severe strokes. There were no differences in carers’ subjective health status, mood or satisfaction with services. At five-year follow-up the benefits were no longer statistically significant.

Cochrane Database of Systematic Reviews 2012, DOI: 10.1002/14651858.CD000443.pub3.

STUDY 26 PUBLISHED
Linked studies 2011-2016 on implementing best practice on early supported discharge
Published, 2016, Fisher
A Consensus on Stroke Early Supported Discharge
Published, 2011, Fisher

This study used consensus methods to get agreement on Early Supported Discharge (ESD). Ten ESD trialists were consulted and a modified Delphi approach was used to get consensus of opinion. Over 75% agreement was obtained on 47 of the 56 statements. Multidisciplinary, specialist stroke ESD teams should plan and coordinate both discharge from hospital and provide rehabilitation in the community.

Stroke 2011, doi: 10.1161/STROKEAHA.110.606285
Published, 2016, Fisher

The aim of this study was to evaluate the effectiveness of ESD services operating in a ‘real world’ setting. 293 stroke survivors were recruited from two acute stroke units: ‘ESD’ n=135 and ‘Non ESD’ n=158 and 84 caregivers. The ESD group had a significantly shorter length of hospital stay (p=0.029) and reported significantly higher levels of satisfaction with services received (p<0.01). Carers of patients accessing ESD services showed significant improvement in mental health scores (p<0.01).

Implementing evidence-based Stroke Early Supported Discharge services: a qualitative study of challenges, facilitators and impact.
Published, 2014, Chouliara

This study explored the perspectives of 35 healthcare professionals and commissioners working with a stroke Early Supported Discharge service. The identified facilitators to the implementation of evidence-based services were: (1) the adaptability of the intervention to the healthcare context, (2) the role of rehabilitation assistants and (3) cross-service working arrangements.

A qualitative study exploring patients’ and carers’ experiences of Early Supported Discharge services after stroke.
Published, 2013, Cobley

Themes specific to patients and carers receiving Early Supported Discharge services were: the home-based form of rehabilitation; speed of response; intensity and duration of therapy; respite time for the carer; rehabilitation exercises and provision of technical equipment; disjointed transition between Early Supported Discharge and ongoing rehabilitation services.
showed that implementation of training was affected by (Forster 2013). More people are now being offered a visit at home before leaving hospital to check the suitability of the home environment after stroke. This represents substantive input from occupational therapists yet there has been little effectiveness data. A feasibility study was carried out, partly to test the acceptability of randomising patients to not receiving a home visit. Those in the control received an interview in hospital by an occupational therapist, but no home visit. Ninety three patients were recruited successfully to the feasibility trial and the appropriateness and completeness of data for the primary outcome was confirmed. There were no significant differences in the primary outcome at one month between intervention and control. The average cost of a home visit in this study was £208. A health economic analysis in this study (Sampson 2014) found that the mean total cost of a home visit was £183, compared with £75 for a hospital interview. Home visits were slightly more effective, resulting in a cost per quality-adjusted life year of just over £20,000. The authors noted that this was not a definitive trial and results needed further confirmation by other research. Other work has included a survey of current practice in home visits, with responses from 85 stroke units showing variation in what was included (Drummond 2012). Another qualitative study of decision-making using interviews with 20 occupational therapists identified how therapists selecting patients for home visits, highlighting presence of a cognitive impairment as a particularly important factor (Whitehead 2014).


A cluster randomised controlled trial and economic evaluation of a structured training programme for caregivers of inpatients after stroke: the TRACS trial

Published, 2013, Forster

The study was a randomised trial of a competency-based training programme (the London Stroke Carer Training Course, LSCTC) for caregivers of stroke survivors. The programme included a checklist of important information, practical advice and skills training for the caregiver whilst the patient was in hospital, with a follow-up session after discharge (Forster). The control group provided care as per national guidelines. A total of 930 stroke patient and carer dyads were recruited from 36 hospital stroke units. Outcomes included both physiological and psychological measures for caregivers and patients, at 6 and 12 months after recruitment. Results indicated that there was no difference between the intervention and usual care with respect to improving stroke patients’ recovery, reducing caregivers’ burden, or improving other physical and psychological outcomes. The programme was not cost-effective. The authors concluded that the timing of the training, give immediately after a stroke, might not have been appropriate (Forster 2013).

A process evaluation funded separately alongside the trial showed that implementation of training was affected by organisational history and team relationships, external policy, and service development initiatives. The authors argued that sufficient time needs to be invested by stroke unit staff in developing strong relationships with key stakeholders for training to be effectively implemented, adopted and supported (Clarke 2013).


Why do patients with stroke not receive the recommended amount of active therapy (ReAct)? Study protocol for a multisite case study investigation.

Clare

The ReACT study is a multisite ethnographic case study to provide an in-depth understanding of stroke therapy provision. This is particularly in relation to how the guideline of 45 minutes a day of each relevant active therapy, for 5 days a week, is implemented by therapists, given that there is some concern that this is not always achieved. The views of stroke survivors and their families will also be explored. A minimum of six stroke units will be recruited, and will include analysis of process, observations of service organisation, therapy delivery and documentary analysis. A series of semi-structured interviews will be conducted with therapists, service managers, patients and informal carers. Results should lead to a set of recommendations for managers, therapists and clinical guideline developers.


Research to Implement Evidence Based In-hospital stroke rehabilitation (REVIHR)

Walker

The delivery of in-hospital stroke rehabilitation services in England varies greatly in both quality and quantity but little is known as to why these differences occur. This study aims to uncover the mechanisms that enable or inhibit the implementation of evidence based rehabilitation within "real life" clinical contexts with the view to informing improvement strategies. A realist evaluation approach has guided the collection of mixed methods data from four stroke units in the East Midlands region. Structured observations have been conducted with 144 patients, within one month post stroke, focusing on their activity levels and the time spent practicing activities of daily living. A total of 219 activity logs of therapists and nurses have been collected, investigating how they divided their time between direct patient contact and other patient and stroke unit related activities. Forty interviews with staff members and 24 with patients have also been conducted and analysed using realist evaluation concepts. Observational mapping
and qualitative data are currently being triangulated to identify key “Context-Mechanism-Outcome” configurations related to evidence based rehabilitation practice. Findings will provide a framework for developing and evaluating quality improvement initiatives designed to enhance the quality and intensity of stroke rehabilitation in hospitals.


STUDY I ONGOING
Using co-production to improve patient carer and staff experiences in health care organizations: a multi-centre, mixed methods evaluation in inpatient stroke units (CREATE).

Jones, Due to publish 2019

This study will utilise the Experienced Based Co-Design (EBCD) method to explore how stroke rehabilitation services are provided, particularly bringing together the experiences of staff, patients, families and carers to redesign and implement best practice. EBCD is a structured process for developing services based on the input of a range of individuals and groups, and this co-design method has been used before in health care. Phase 1 will include an evidence synthesis of available evidence on co-production approaches in healthcare. Phase 2 will use EBCD in 2 stroke units to design interventions to increase supervised and independent therapeutic activity, and evaluate their impact. Finally, this new way of working will be tested in 2 additional stroke units to determine whether the EBCD process brings about successful change. Interviews and observations will be conducted and the Normalisation Process Theory (NPT) will be used to understand the process of development, implementation and embedding of interventions.

https://www.journalslibrary.nihr.ac.uk/projects/1311495/#/

STUDY J ONGOING
Development of an integrated service model incorporating innovative technology for the rehabilitation of the upper limb following stroke

Swain

The aim of this programme of research is to improve rehabilitation of the upper limb following a stroke with technology to maximise function. Recently a greater number of Assistive Technologies (ATs) have been developed for upper limb rehabilitation. These include the use of robots to move the arm, electrical impulses to activate muscles, and botulinum toxin to reduce tightness in paralysed muscles. To understand the current treatments available, a detailed survey of Stroke Units in England and a comprehensive literature review will be conducted. Stroke survivors, carers and health professionals will also be consulted, as well as commissioners to understand barriers to implementing these technologies in the NHS. A trial of the most promising technologies will then be conducted to analyse their effectiveness before providing recommendations to the NHS on a suitable care pathway.

Recent publications (below) have examined the use of ATs through focus groups and surveys with patients, carers and healthcare professionals. From their sample, 41% of healthcare professionals and 64% of patients and carers had never used ATs. The most frequently used AT was functional electrical stimulation. The authors concluded that better knowledge and awareness of AT was needed, as well as good clinical evaluation and improvements in AT design.


STUDY K ONGOING
RATULS: Robot Assisted Training for the Upper Limb after Stroke

Rodgers, due to publish 2017/18

This study aims to recruit patients with acute or chronic stroke who have moderate to severe upper limb functional limitation to evaluate whether robot assisted training with the InMotion robotic gym system improves upper limb function post stroke. The study aims to recruit 720 patients from 4 NHS stroke services centres, and randomise them to receive either the robot assisted training, enhanced upper limb therapy or usual care. A process evaluation will also be conducted, included interviews with participants and health professionals. The robot assisted intervention consists of training up to 45 minutes per day, 3 days per week for 12 weeks, in addition to usual care.

https://www.journalslibrary.nihr.ac.uk/programmes/hta/112605/#/

STUDY L ONGOING
Face to Face

Breeden

This study is developing a system for patients experiencing facial weakness after stroke. It is a partnership between Nottingham CityCare Partnership, University of Nottingham, Maddison Product Design, patients, clinicians, engineers and researchers. The prototype uses a 3D camera with a depth sensor, a small form factor PC and a monitor to recognise and track facial expressions. The system records the improvements made by a patient to provide valuable feedback on progress. Early work indicated this system improves adherence to exercises and improves patient recovery times.

http://www4.ntu.ac.uk/strategy/case_studies/face_to_face/

STUDY M
ReaDySpeech for people with dysarthria after stroke

Mitchell, due for publication 2017

This study will evaluate the feasibility and acceptability of a new speech rehabilitation technology, ReaDySpeech, developed for patients with dysarthria (slurred speech) after stroke. This study will assess its acceptability with clinicians and patients. Researchers aim to recruit 36 patients, 1 week post stroke, who present with dysarthria and able to participate in communication therapy. ReaDySpeech is a specially designed computer programme that provides patients with greater access to personalised speech rehabilitation. Results will be used to inform a larger trial.

http://www.isrctn.com/ISRCTN84996500?q=&filters=conditionCategory:Circulatory%20Sys%5Cn&trialStatus:Ongoing&sort=&offset=9&totalResults=190&page=1&pageSize=50&searchType=basic-search

STUDY N ONGOING
Clinical and cost effectiveness of aphasia computer therapy compared with usual stimulation or attention control long term post stroke (CACTUS)

Palmer, due for publication 2018

This study aims to evaluate a self-managed computerised therapy exercise practice for persistent aphasia. The intervention will be tailored by speech and language therapists and supported by volunteers or assistants. This large trial is based on positive findings from a small pilot study with 34 individuals with aphasia. The study aims to recruit 285 patients, who have had aphasia for 4 months or more post stroke. Patients will be randomly assigned to receive the computer therapy, usual care, or puzzle books for regular purposeful activity. The intervention will last 6 months, with tailored therapy accessed individually on a computer for 20-30 minutes a day. Usual care will also be continued in addition to any intervention. Speech and language ability will be assessed at recruitment, and after 6 months, 9 months and 12 months.

https://www.journalslibrary.nihr.ac.uk/programmes/hta/122101/#/
LIFE AFTER STROKE

PUBLISHED

STUDY 29 PUBLISHED

A Identifying the long-term needs of stroke survivors and developing an innovative model of care
Published, 2011, McKevitt

This programme of research explored the long-term needs (10 years post stroke) of stroke survivors. The South London Stroke Register was used to analyse patterns of care and needs provision. Interviews were held with long-term stroke survivors and their families/carers. To understand the provision of services interviews were held with health, social and voluntary care workers. One study looked at the long-term needs of stroke survivors through a survey of individuals 1 to 5 years post stroke. Approximately half of the respondents reported no unmet needs; among the remainder, the median number of unmet needs was 3 (range, 1 to 13). Fifty-four percent reported an unmet need for stroke information. In multivariable analysis, ethnicity and disability were associated with total number of unmet needs. Both clinical and social needs were identified, which were greater in areas of social deprivation, amongst people with disabilities and those from ethnic minority groups. The authors concluded that novel methods must be developed to meet these unmet needs of stroke survivors.

Stroke. 2011 DOI: 10.1161/STROKEAHA.110.598839

B Identifying the long-term needs of stroke survivors using the International Classification of Functioning, Disability and Health.
Sumathipala 2012

Another study explored the long-term impact of stroke through a series of interviews with 35 stroke survivors between 1 and 11 years after stroke. The International Classification of Functioning, Disability and Health framework (ICF) was used to contextualise the needs. Long-term needs included activities of daily living, housing, mobility, social participation, financial support, information, rehabilitation and transport. A key facilitator for functioning was social support. Patients often experience health problems not related to stroke as well. The authors concluded that in order to meet long-term needs a range of personal, contextual and environmental factors should be taken into consideration.

Chronic Illness 2012, doi: 10.1177/1742395311423848

STUDY 30 PUBLISHED

Turner-Stokes
Evaluation of Community Rehabilitation Service Delivery in Long-Term Neurological Conditions
Published, 2013, Siegert

The aim of this study was to pilot the Long-Term Neurological Conditions (LTNC) register as a means to identify and monitor patients who have unmet needs and examine the rehabilitation services. The study evaluated a new tool - the Needs and Provision Complexity Scale (NPCS) - and followed patients for 12 months after discharge. Over 90% of patients required on-going community rehabilitation. At six months post discharge, the NPCS demonstrated significant gaps between needs and service provision. For example, needs for medical, nursing care and basic personal care were met or exceeded in over 70% of cases, but needs for a personal enabler to assist with more extended community-based activities were met less often (53%). Half of patients had unmet need for therapy. Vocational needs were met for approximately two-thirds of the sample. Accommodation needs were met in 78% of the sample but 61% had unmet equipment needs. The average cost of formal care was £10,486 in the first six months, increasing to £28,352 when informal care costs were included. Costs-analysis of met and unmet needs demonstrated a relative under spend on rehabilitation, social care and equipment at 6 months, compared with predicted needs. The authors concluded that detailed analysis is now needed outside of London services to identify areas for service development and investment.


STUDY 31 PUBLISHED

Development and evaluation of tools and an intervention to improve patient- and carer-centred outcomes in Longer-Term Stroke care and exploration of adjustment post stroke: the LoTS care research programme
Published, 2014, Forster

This programme of research focused on the needs of patients and carers after hospital discharge and consisted of 4 interlinked projects. A review (project 1) of the evidence around patient care was undertaken. A Cochrane review was also conducted in one area. From this evidence, a system of care manual and a series of questions were designed for use with patients to identify their needs and develop a care plan. An RCT evaluated the clinical and cost effectiveness of this system of care in 29 community-based UK stroke care co-ordinator services (project 2). A total of 800 patients and 208 carers were recruited. There was no evidence of statistically significant differences in primary or secondary endpoints or adverse events between the two groups, nor evidence of cost-effectiveness. A 22-item Longer-term Unmet Needs after Stroke (LUNS) questionnaire was developed and tested (project 3). A pack including the LUNS questionnaire was posted to participants 3 or 6 months after stroke. 850 patients were recruited and acceptability, validity and test–retest reliability of the LUNS questionnaire as a screening tool for post-stroke unmet need were confirmed. This tool is now available for clinical use. An in-depth qualitative investigation was undertaken with 22 patients (and carers) at least 1 year after stroke (project 4) to gain further insights into the experience of adjustment. This included semi-structured interviews with a follow-up 3–4 months after the initial interview and highlighted a range of different trajectories for post-stroke recovery.


STUDY 32 PUBLISHED

Evaluation of the use and uptake of the Greater Manchester Stroke Assessment Tool (GM-SAT)
Published, 2013, Tyrrell and Boaden

The Greater Manchester Stroke Assessment Tool (GM-SAT) was developed with stroke survivors, carers, and professionals. This evidence-based assessment tool was developed as a comprehensive six-month post-stroke review to identify unmet needs for people after stroke in four key areas: health, physical, social and emotional. It is being developed for use in the community and care homes. This review evaluated the GM-SAT uptake across the UK, 18 months after dissemination activities finished. The tool was successfully piloted and its use disseminated widely. The present evaluation contacted 47 users of the tool, with a 59% response rate. Most responses came from clinical nurse specialists and stroke co-ordinators, but also from speech and language therapist, occupational and physical therapists, and local and regional managers. Results indicate that the Stroke Association are using the tool in 24 services across England (they are responsible for 362 services across the UK). Although the reorganisation and redistribution of providers in the English NHS makes estimating the GM-SAT’s use problematic, most respondents indicated that were about to introduce the tool in their workplace. Feedback from those who used the tool indicated that they found it is easy to use,
and it could be administered by non-clinical staff.

**STUDY 33 PUBLISHED**
Developing stroke rehabilitation and community services: a meta-synthesis of qualitative literature
Published, 2012, Reed, Wood

A meta-synthesis of qualitative research was conducted to identify key factors in planning and developing rehabilitation and community services for stroke survivors. 18 papers were included that met the inclusion criteria and published between 1998-2008. All were appraised as being of high quality and eight were based in the UK. The main themes about the impact of stroke related to the person, close social relationships and the social environment (such as physical, economic and social barriers). The experience and consequences of stroke is dependent on the individual’s identity. When support was delivered in line with how an individual understood and interacted with their social world, it was seen to be more effective. The authors concluded that studies that address the needs of stroke survivors at different stages post stroke are required.

**STUDY 34 PUBLISHED**
Health Care Professionals’ Views on Discussing Sexual Wellbeing with Patients Who Have Had a Stroke: A Qualitative Study
Published, 2013, Mellor

The aim of this study was to determine whether sex was a ‘taboo’ subject for staff caring for stroke patients. In-depth interviews with staff found that sexual wellbeing was not raised by the professional and was infrequently raised by patients. Several barriers to discussing the topic were identified: worry that it would embarrass the patient and harm the patient-staff relationship, belief that it was not a priority topic, and not seeing it as part of the care pathway or within their staff role. The authors concluded that staff often lacked confidence and motivation to discuss sexual wellbeing after stroke and normalisation of this sensitive topic is needed.
PloS One. 2013 Doi: http://doi.org/10.1371/journal.pone.0078802

**STUDY 35 PUBLISHED**
An Occupational Therapy intervention for residents with stroke-related disabilities in UK Care Homes (OTCH): cluster randomised controlled trial with economic evaluation
Published, 2016, Sackley

This RCT evaluated the clinical and cost-effectiveness of targeted occupational therapy (OT) in maintaining functional activity and reducing further health risks from inactivity for care home residents living with stroke-related disabilities. The intervention consisted of a personalised 3-month course of OT delivered by therapists. The control condition was usual care. The primary outcome was the Barthel Index of Activities of Daily Living score at 3 months. 568 residents from 114 care homes were allocated to the intervention arm and 474 residents from another 114 care homes were allocated to the control arm (mean age 82.9 years, 64% female). Of the 1042 participants, 870 were included in the analysis of the primary outcome (intervention, n=479; control, n=391). The primary outcome showed no significant differences between groups. Secondary outcome measures showed no significant differences at all time points. Mean incremental cost of the intervention was £438.78 (95% CI –£3360.89 to £1238.46) and the incremental QALY gain was 0.009 (95% CI –0.030 to 0.048). One limitation of the study was that many of the residents had severe physical and cognitive impairments that may have reduced therapy engagement.

Health Technol Assess 2016 DOI: http://dx.doi.org/10.3310/hta20150

**STUDY 36 PUBLISHED**
Rehabilitation aimed at improving outdoor mobility for people after stroke: a multi-centre randomised controlled study (the Getting out of the House Study).
Published, 2014, Logan

The aim of this RCT was to assess the clinical and cost-effectiveness of an outdoor mobility rehabilitation intervention for stroke patients. 568 stroke patients (mean age 71), who were motivated to leave the house more often were recruited. All participants received routine care (verbal advice and outdoor mobility leaflets) prior to randomisation. The intervention consisted of a targeted outdoor mobility rehabilitation programme delivered by NHS therapists to 287 randomly chosen participants for up to 12 sessions over 4 months. After the intervention, there was a significant difference in travel journeys; the intervention group were 42% more likely to make a journey compared with the control group (rate ratio 1.42, 95% CI 1.14 to 1.67) at 6 months and 76% more likely (rate ratio 1.76, 95% CI 1.36 to 1.95) at 12 months. There was no significant difference between the groups on social function, or in functional ability, psychological well-being or satisfaction with outdoor mobility at 6- or 12-month follow-ups. The mean incremental cost (total NHS and personal social services cost) of the intervention was £3413.75 (95% CI –£448.43 to £7121.00). The authors concluded that the intervention was not clinically or cost effective.

Health Technol Assess 2014, DOI: http://dx.doi.org/10.3310/hta18290

**STUDY 37 PUBLISHED**
Health promotion interventions for increasing stroke awareness in ethnic minorities: a systematic review of the literature
Published, 2014, Gardois

This review looked at health promotion interventions for increasing stroke awareness in ethnic minorities. Eighteen studies were included, consisting of 15 interventions conducted in the US for African-American or Hispanic groups. There were many types of interventions, but they were mainly carried out in the community setting and delivered by health professionals or volunteers. Qualitative analysis of intervention implementation was generally lacking. More research is needed with other ethnic minorities and in other countries.


**STUDY 38 PUBLISHED**
Vocational stroke rehabilitation
Published, 2014, Sinclair

Following a stroke, it is important to support a positive return to work where possible. One project in 2012 found that access to Vocational Rehabilitation (VR) services varied considerably. After a stroke, those with more visible symptoms receive most support, whilst those with milder symptoms or visual and cognitive problems often receive less. Another mixed methods study in 2014 in another region assessed stroke-specific vocational rehabilitation provided by health, social care, Department of Work and Pensions and the voluntary and private sectors were assessed for their provision of supporting return to work after stroke. They found that the lack of a sanctioned vocational rehabilitation pathway meant access to support relied on brokered provision and tacit knowledge. There was an unmet need for mild stroke patients and often given seen as ‘non-essential’ due to competing commissioning priorities. The authors identified the need for integrated, cross-sector multi-disciplinary teams and that service providers from all sectors should receive better training on the complex needs of stroke survivors.
Study 39 Published

Physical fitness training for stroke patients

Published, 2016, Saunders

The aim of this review was to determine whether fitness training after stroke reduced death, dependence, and disability as well as a range of other outcomes. The review included 58 trials, involving 2797 participants, which comprised cardiorespiratory interventions (28 trials), resistance interventions (13 trials), and mixed training interventions (17 trials). Cardiorespiratory fitness training, especially walking, improved exercise ability and walking after stroke. Global indices of disability show moderate improvement after cardiorespiratory training (standardised mean difference (SMD) 0.52, 95% confidence interval (CI) 0.19 to 0.84; P value = 0.002) and by a small amount after mixed training (SMD 0.26, 95% CI 0.04 to 0.49; P value = 0.02). Long-term benefits were unclear. There was insufficient evidence to support the use of resistance training. The authors concluded that further well-designed randomised trials are needed to determine the optimal exercise prescription and identify long-term benefits. The effects on cognitive function also needs attention.

Cochrane Database of Systematic Reviews 2016, DOI: 10.1002/14651858.CD003316.pub6

Study 40 Published

Weight gain following stroke in younger age (below 70 years) in men and women: challenges and opportunities for prevention and action

Published, 2015, Homer

This study explored the incidence of weight gain in those under 70 following a stroke. In-depth interviews were conducted with patients and stroke service professionals in Sheffield. Weight gain was a significant issue for many individuals, and a reduction in activity levels was a main driving factor. Whilst short-term support was available, long-term support was harder to access. Support networks provided by health services and friends/families were vital to recovery and preventing weight gain. Not all staff provided health promotion advice, but they highlighted the importance of family engagement in the rehabilitation process. Communication between health professionals across the whole stroke pathway was also important but could often be limited.

Collaboration for Leadership in applied Health Research and Care http://shura.shu.ac.uk/10293/1/09062015_Weight_Gain_after_Stroke_Final_Report_April_2015.pdf

Study 41 Published

ReTrain: Community-based rehabilitation and exercise programme for people with stroke

Dean, 2016, Published

Range of outputs around a programme of work to develop and test a complex intervention of a community-based rehabilitation programme.


This research aimed to identify factors that motivate long-term stroke survivors to engage in exercise programmes. Focus groups and individual interviews were conducted with stroke survivors around exercise and participating in exercise programmes. Thematic analysis revealed that several factors influenced motivation, including the psychological benefits of exercise, a desire to de-medicalise exercise, beliefs about stroke recovery, and on-going support to sustain commitment. The authors concluded that these themes have implications for the design of exercise programmes in order to increase engagement.

Disability and Rehabilitation 2015, DOI: 10.3109/09638288.2014.946154

Study 42 Published

Interventions for improving modifiable risk factor control in the secondary prevention of stroke.

Published, 2014, Lager, Khunti

This review assessed the effects of stroke service interventions for implementing secondary stroke prevention strategies on modifiable risk factor control, including patient adherence to prescribed medications. Twenty-six studies involving 8021 participants were included. Studies were based in USA, Canada, Europe, Asia and Australia. Fifteen studies evaluated organisational interventions (such as integrated care services, knowledge management systems, collaboration between multidisciplinary teams) and 11 studies evaluated educational and behavioural interventions for patients. The majority of interventions lasted between 3 and 12 months. The estimated effects of organisational interventions were compatible with improvements and no differences in the modifiable risk factors mean systolic blood pressure (mean difference (MD) -2.57 mmHg; 95% confidence interval (CI) -5.46 to 0.31), mean diastolic blood pressure (MD -0.90 mmHg; 95% CI -2.49 to 0.68), blood pressure target achievement (OR 1.24; 95% CI 0.94 to 1.64) and mean body mass index (MD -0.68 kg/m2; 95% CI -1.46 to 0.11). There were no significant effects of organisational interventions on lipid profile, HbA1c, medication adherence or recurrent cardiovascular events. Educational interventions were not associated with clear differences in any of the review outcomes.


Study 43 Published

Ongoing impairments following transient ischaemic attack: retrospective cohort study

Published, 2016, Turner

This study used the Health Improvement Network database, which covers approximately 6% of the UK population to examine life after a transient ischaemic attack (TIA). A total of 9419 TIA patients and 46 511 controls were included, who were matched for age, sex and general practice. Results showed that compared with controls, TIA patients had an increased risk of 43% for consulting for fatigue, 26% for psychological impairment and 45% for cognitive impairment. For example, 25% of TIA patients consulted for psychological impairment within 7.1 months, compared with...
This programme of research is looking at the longer-term care needs of individuals who have had a stroke as well as the impact on carers. This will provide an assessment of a longer-term (nine-month post-stroke) service delivery care strategies. Interviews with a subsample of participants will provide qualitative insights.

https://www.journalslibrary.nihr.ac.uk/projects/103701/#/

This programme of research is looking at the longer-term care needs of individuals who have had a stroke as well as the impact on carers. This will provide an assessment of a longer-term (nine-month post-stroke) service delivery care strategies. Interviews and focus groups will be conducted with a range of health care professionals to discuss their views on supporting patients and their carers in terms of needs, opportunities and challenges. Intervention mapping will be used to develop ways of providing long-term care and support based on evidence and behaviour change theories. This will inform a feasibility RCT to compare an evidence-based intervention with routine care.

Note: (presentation only): http://www.joiningforces.org.uk/files/aqua/uploads/M%20J%20IMPROVE-Stroke%20Results_1.pdf

This randomised controlled pilot trial of nurse prescriber-led care pathway based on risk factor management after stroke or TIA. 40 patients from Exeter or East Devon with minor stroke or TIA and clinic systolic BP above 140 mmHg will be recruited within one month of their event. They will receive usual care or care led by a Nurse Independent Prescriber, who will manage risk factors according to an incremental care pathway for 6 months. Outcomes will include risk factor targets achieved at 6 and 12 months. A sub set of participants will also be interviewed to discuss the acceptability of the intervention.

http://www.phpc.cam.ac.uk/pcu/research/research-projects-list/other-projects/pcpas/

The Improving Primary Care After Stroke (IPCAS) programme of research aims to develop a primary care based model to optimise post-discharge care for stroke survivors and develop a ‘Managing life after stroke’ programme for individuals living with stroke. This intervention is likely to include better communication between primary care and specialist services; structured review of patient needs; re-referral to specialist care where indicated; information on how to access local services; a single point of contact for health services for stroke survivors and carers; and training for primary care staff. The effectiveness and cost effectiveness of this approach will be tested by a trial in the East of England and Leicester and compared with usual care. Health professionals, stroke survivors and carers will be involved in the development of the programme content and materials.

http://www.clahrc-southlondon.nihr.ac.uk/stroke/better-care-stroke-survivors

This randomised trial will evaluate the Carer Support Needs Assessment Tool (CSNAT), which is a carer-led approach to individualised assessment of need and tailoring of support. It consists of a needs assessment tool; assessment review; action plan; plus guidance for how these should be implemented in practice. Participating Stroke Association services will be randomly allocated to the intervention or control (standard services). The aim is to determine the effectiveness of the tool on caregiver outcomes. Carers will receive support from the Stroke Association, and both groups will be followed up 3 and 6 months after study entry. Qualitative telephone interviews will take place with a sub-sample of carers.

https://www.isrctn.com/ISRCTN58414120?q=&filters=&sort=&offset=1&totalResults=15358&page=1&pageSize=10&searchType=basic-search

23.5 months for controls. The authors argued that TIA is associated with subsequent GP consultation for three major impairments. This has implications for long-term care and treatment.


STUDY 44 PUBLISHED

IMPROVE-Stroke: IImproving the PRevention Of Vascular Events after Stroke or TIA – a randomised controlled pilot trial of nurse independent prescriber-led care pathway-based risk factor management.

James, 2013

This is a cluster randomised controlled pilot trial of nurse prescriber-led care pathway based on risk factor management after stroke or TIA. 40 patients from Exeter or East Devon with minor stroke or TIA and clinic systolic BP above 140 mmHg will be recruited within one month of their event. They will receive usual care or care led by a Nurse Independent Prescriber, who will manage risk factors according to an incremental care pathway for 6 months. Outcomes will include risk factor targets achieved at 6 and 12 months. A sub set of participants will also be interviewed to discuss the acceptability of the intervention.

Note: (presentation only): http://www.joiningforces.org.uk/files/aqua/uploads/M%20J%20IMPROVE-Stroke%20Results_1.pdf

STUDY Q ONGOING

Offering better care to stroke survivors who have different health problems

Wolfe, due to publish 2019

The research team is developing a prototype of an advanced information system that will bring together medical records and other information collected about stroke survivors to be used for research, to help plan services and to inform healthcare professionals’ decisions for better care. This prototype will use information about stroke survivors who live in a defined area of South London. Their pseudomised information from the Lambeth Datant will be linked with records from the South London Stroke Register. The work is inspired by the concept of a ‘learning healthcare system’ developed in the USA. It is hoped that this integrated information system will improve the care offered to stroke survivors through better information access, management and clinical decision support by healthcare professionals.

http://www.clahrc-southlondon.nihr.ac.uk/stroke/better-care-stroke-survivors

STUDY S ONGOING

Organising Support for Carers of Stroke Survivors (OSCARSS): A Cluster Randomised Controlled Trial with embedded Process Evaluation

Bowen, Due for publication 2019

This randomised trial will evaluate the Carer Support Needs Assessment Tool (CSNAT), which is a carer-led approach to individualised assessment of need and tailoring of support. It consists of a needs assessment tool; assessment review; action plan; plus guidance for how these should be implemented in practice. Participating Stroke Association services will be randomly allocated to the intervention or control (standard services). The aim is to determine the effectiveness of the tool on caregiver outcomes. Carers will receive support from the Stroke Association, and both groups will be followed up 3 and 6 months after study entry. Qualitative telephone interviews will take place with a sub-sample of carers.

https://www.isrctn.com/ISRCTN58414120?q=&filters=&sort=&offset=1&totalResults=15358&page=1&pageSize=10&searchType=basic-search
Impact of Visual Impairment after Stroke. The IVIS Study

Rowe, due to complete 2018

This programme of research has been investigating the effects of eye movement disorders following stroke. Publications include:


This review provided an overview of the tools available to screen for post-stroke visual impairment. 25 articles (n = 2924) were included. The majority of tools screened for visual perception including visual neglect (VN), with few screening for visual acuity (VA), visual field (VF) loss or ocular motility (OM) defects. The authors concluded that there was no standardised tool to assess the full range of post stroke visual impairments and future research should address this gap.

Disability and Rehabilitation 2016, DOI: 10.1080/09638288.2016.1231846


This review investigated the impact on quality of life from stroke related visual impairment. Eleven studies involving 5646 participants were included. All studies reported a reduction in quality of life in stroke survivors with visual impairment. Visual field loss was the most common issue. The authors concluded that all aspects of visual impairment need to be assessed, and a standardised tool needs to be designed.

Ophthalmology Research 2016 http://sciencedomain.org/abstract/12864

STUDY U ONGOING

SERVER Memory: Feasibility study of Screening & Enhanced Risk management for Vascular Event related Decline in Memory

Potter, due for publication 2018

This is a feasibility study to assess cognitive changes following TIA or mild stroke. The feasibility of targeting and treating cardiovascular risk factors in general practice more intensively through closer monitoring and feedback to patients’ GPs will be evaluated. 100 participants who have a confirmed stroke/TIA and mild-moderate cognitive impairment will be randomised to either the intervention or usual care. Another 100 participants will be recruited for an observational study who have normal cognition. The intervention includes individualised targets and closer monitoring (at 3, 6, and 9 months) of risk factors including blood pressure, cholesterol level, atrial fibrillation and diabetes. Cognitive testing will be carried out again at 6 months for both intervention and control with a final follow up at 1 year. The study is due to report in 2018.


STUDY V ONGOING

Support for stroke survivors in care homes

Boven

An ongoing study is extending the use of the GM-SAT (Greater Manchester Stroke Assessment Tool) to use in care homes with stroke survivors. The study will evaluate the usefulness, acceptability and feasibility of a modified GM-SAT for use with stroke survivors living in care homes. This will explore the content, value and implementation of the modified GM-SAT.

http://clahr-gm.nihr.ac.uk/our-work/stroke/stroke-care-homes/

STUDY W ONGOING

BRIDGES self-management programme

Feasibility study of an integrated stroke self-management programme: a cluster-randomised controlled trial.

Published, 2016, Jones

BRIDGES was developed as a stroke-specific self-management programme integrated into rehabilitation services http://www. bridgesselfmanagement.org.uk. There are various research projects associated with this initiative (http://www.kingston.ac.uk/research/ research-showcase/research-case-studies/building-bridges/) and some of the NIHR funded initiatives are described here.

The results of a feasibility trial was published in 2016. Community stroke rehabilitation teams were recruited from the London area. Seventy-eight patients were randomised to receive either the intervention or usual care. The intervention consisted of an individualised self-management approach based on self-efficacy. The sessions were guided by self-management principles such as problem solving, goal setting and knowledge, and supported by a stroke workbook that included activities, success stories and space for reflection and recording goals. Measures of mood, self-efficacy, quality of life, functional capacity and health and social care utilisation were taken at baseline, 6 and 12 weeks. There was no significant difference in any of the outcomes between the two groups, but measures of functional capacity and self-efficacy showed responsiveness to the intervention, although not significant (p = 0.14 and 0.3 respectively). The authors concluded it was feasible to integrate a stroke self-management programme into community rehabilitation and a definitive trial is now needed.


A related project (Ward) reporting in 2018 is testing the feasibility of delivering the Bridges self-management initiative in a group session. The intention is to recruit 60 stroke survivors to test the acceptability of the group-based intervention.


Research is also underway to adapt the self-management training and handbook to make it suitable for stroke survivors with communication and cognitive difficulties. Ways to support health care staff will also be explored.

http://www.clahr-southlondon.nihr.ac.uk/stroke/making-bridges-accessible-to-all

STUDY X ONGOING

Behavioural Intervention for Stroke Carers (BISC). Nottingham University Hospitals NHS Trust 2015-2017

Walker, due to publish 2017

This programme of research will develop a group intervention offering support and education based on biopsychosocial principles to improve adjustment and mood outcomes in carers of stroke survivors. (Biopsychosocial Intervention for Stroke Carers - BISC study). A manual is being developed with input from carers of stroke patients and health care professionals. Carers will be invited to take part in the study when the person they are caring for is discharged from Nottinghamshire Hospitals. The study aims to randomise 40 carers into either the intervention group or usual care. The intervention will run for 6 weeks. Health-related outcome measures will be completed with patients and carers at baseline, 2 and 4 months post randomisation.

https://www.nottingham.ac.uk/research/groups/strokerehabilitation/projects/bisc.aspx

STUDY Y ONGOING

Psychological support services

Watkins

The aim of the research is to determine if existing psychological support services (Improving Access to Psychological Therapies (IAPT)) can be adapted for stroke survivors. Interviews will be carried out with stroke survivors, carers and stroke services
to find out about experiences and provision of psychological support. This will be used to develop an implementation package of psychological care and provide training to staff to increase knowledge. Training will be provided to different staff groups (e.g. in hospital, rehabilitation, community) so they can provide basic psychological support. IAPT staff will also be trained to support stroke survivors. A before and after design will be used, with measures taken 6 months after intervention implementation.

http://www.clahrc-nwc.nihr.ac.uk/our-work/improving-mental-health/IAPT.php

**STUDY Z ONGOING**

‘HeART of Stroke (HoS)’, a community-based Arts for Health group intervention to support self-confidence and psychological well-being following a stroke: protocol for a randomised controlled feasibility study.

Ellis-Hill, due to complete in 2017

This trial will evaluate the acceptability and feasibility of delivering a community Arts for Health group intervention (‘HeART of Stroke’ (HoS) for people following stroke and will test its clinical and cost-effectiveness in a future definitive RCT. The intervention consists of ten 2-hour group sessions each led by an artist over 14 weeks. It offers a non-judgemental, supportive environment for people to explore sense of self, potentially enhancing well-being and confidence. The study will recruit and randomise 64 individuals, up to 2 years after stroke, to either HoS plus usual care or usual care alone. A range of outcomes will be measured at baseline and 5 months follow up, including stroke rehabilitation, well-being, mood, self-esteem, and quality of life. Feasibility of running the trial will also be assessed to inform the design of a subsequent RCT.


**STUDY AA ONGOING**

A depression recognition and treatment package for families living with Stroke (DepReT-Stroke): Study protocol for a randomised controlled trial

Campbell, Gray due to publish 2017

This RCT will evaluate whether families who are treated with the Depression Recognition and Treatment package (DepReT-Stroke) in addition to treatment as usual will show improved mental wellbeing compared to those families who receive only treatment as usual. The study aims to recruit one hundred and twenty-six families where a family member has experienced stroke. The intervention is designed to help families to consider treatment options for depression, support them in the use of self-help therapies (e.g. computerised Cognitive Behavioural Therapy or exercise) and help them adhere to their chosen treatment(s). The primary outcome will be the mental health quality of life assessed at baseline and again six months post intervention. An economic evaluation will also be conducted.

Trials 2011, DOI: http://eprints.uwe.ac.uk/17737 [protocol]

**STUDY AB ONGOING**

Developing and piloting a behavioural, community-based intervention to increase walking among people with stroke.

Wright, due to publish 2017

The aim of the project is to adapt a behavioural walking intervention, of proven efficacy in healthy, sedentary people, to increase stroke survivors' walking and social participation. Interviews will be held with stroke survivors to discuss their views on walking and how a walking programme could meet their needs. A pilot trial will then be run to assess the feasibility and acceptability of the adapted walking programme. Walking and social participation will be evaluated. Outcomes will be measured post-intervention and at 6 months. The results will be used to inform a full trial, and if proven effective it has the potential to become part of routine NHS care for stroke survivors who are able to engage in walking outside.

https://europepmc.org/grantfinder/grantdetails?query=pi:%22Wright+AJ%22+gid:%22PB-PG-1208-18164%22

**STUDY AC, ONGOING**

RAPid Primary care Initiation of Drug treatment for Transient Ischaemic Attack (RAPID-TIA): study protocol for a pilot randomised controlled trial.

Published, 2013, Mant, Edwards

This feasibility trial aims to determine the best methods of early treatment for individuals suspected of having a TIA. GPs will be randomised to either initiate secondary preventative measures (blood-pressure lowering protocol, simvastatin 40 mg and dipyridamole 200 mg m/r bd) in addition to aspirin, or they will only give aspirin as usual and refer the patient to a specialist who will initiate the secondary treatment after confirming the diagnosis (1-7 day delay). The trial will look at the feasibility of recruiting GPs and patients, with the aim of recruiting 100 patients from 30 GP practices. The primary outcome is stroke at 90 days. Cost-effectiveness will also be estimated.


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### APPENDIX 2: WIDER NIHR PORTFOLIO – STROKE CARE

This report focuses on the organisation and quality of stroke care. We have not featured all NIHR clinical studies around effective treatments for stroke in this review. Some of these are listed here for information, and published outputs can be found at [https://www.journalslibrary.nihr.ac.uk](https://www.journalslibrary.nihr.ac.uk). Information about the full range of NIHR funded work on stroke can be found at [www.nihr.ac.uk](http://www.nihr.ac.uk).

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<td>Pilot studies to develop and evaluate a muscle strengthening programme to reduce the risk of aspiration and improve outcome in dysphagic stroke patients. King’s College Hospital NHS Foundation Trust 2011-2014 Prof Lalit Kalra <a href="https://europepmc.org/grantfinder/grantdetails?query=pi:%22Kalra+L%22+gid:%22PB-PG-0909-19113%22">Link</a></td>
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