The Research Gaps and Priorities Around the Psychological Consequences of Stroke

A Summary of What We Know, What We Don’t Know and What We Need To Know

1. Cognition

What we know:

Impaired cognitive functioning is common after stroke especially during the acute phase where without adequate identification, explanation and advice around compensatory strategies and tools, the individual and their family experience distress. Furthermore, without stroke team awareness of cognitive problems and corresponding adjustments to care, the individual’s participation in their rehabilitation is restricted, reducing the potential benefits of proven interventions (e.g. Stroke Unit care and Early Support Discharge).

Although cognitive functioning undoubtedly improves over time, difficulties persist for a significant proportion of people, as evidenced by the McKevitt/Stroke Association’s unmet needs survey for ‘life after stroke’ and the Pollock/James Lind Alliance priority-setting exercise. In the latter, stroke survivors and providers chose ‘what are the best ways to improve cognition after stroke?’ as the number 1 research priority.

Severity of impairment does not map neatly onto severity of impact e.g. being told they are within the ‘normal range’ on a test can be deeply upsetting for those who enjoyed fully exercising their cognitive abilities pre-stroke and younger stroke survivors. The fact that cognitive difficulties are hidden, their impact on mood, changes in confidence and identity and resulting social withdrawal are persisting issues that survivors feel should be addressed by current services.

What We Don’t Know:

We do not know the size of the problem in today’s NHS stroke services and the numbers likely to be recruited to research. Co-morbidity and changes over time (both recovery and decline).

Return to work after stroke

Research is needed to support people with a cognitive impairment to return to work. This should include factors that are not limited to disease or injury e.g. personal or environmental, as we know that contextual factors are fundamental to employment success. An intervention may involve a detailed assessment of cognition and may or may not involve some elements of remediation for those problems, but the primary focus will be on an assessment of the role, matching the stroke survivor’s abilities to the demands of the job and making changes to the environment such as modifying employers and others’ attitudes; addressing environmental, organisational and employer related barriers to return to work; and negotiating accommodations to a particular work role that enable the person to work.

This involves case coordination across a range of different service providers, there is a need for research which understands the service models and the effective components therein.
People who have a job to return to should be included in a definitive trial of vocational rehabilitation, with exploration of the contextual barriers to implementation success. We also need to know which approaches are appropriate for people unable to resume work with an existing employer and those with no job at the time of stroke.

There is a need to evaluate approaches that enable people to participate in their chosen activities or life roles (e.g. community activities, return to work) and to identify the contextual factors which might limit the success of any approach.

**Driving after stroke**

We need to better understand the relationship between severity of impairment and the impact on driving skills. Certainly, in the assessment of fitness to drive after stroke, some misclassifications are attributable to adaption/ the overlearned nature of the driving task.

The gaps in this area:

We have some evidence to suggest which tests have predictive validity for on road driving but these are not being routinely used in practice, thus there is a need for research at the implementation level. We need to further explore the implementation barriers to evidence based cognitive screening for fitness to drive. We need to further understand the value of cognitive screening/assessment apps in ‘fitness to drive’ clinical decision making.

**What We Need to Know:**

How do we operationally define specific interventions for each cognitive domain (e.g. attention, memory, spatial awareness) such that they could be delivered consistently across multiple sites and replicated within a multicentre research trial or a service evaluation?

What are the component interventions to make up a comprehensive cognitive rehabilitation programme that is acceptable to survivors and feasible for delivery within the NHS. How might these be integrated 1. with the intentions for mood and behaviour to achieve the comprehensive/holistic neuropsychological rehabilitation approach and, 2. with multidisciplinary stroke care rather than being seen only as the psychologists’ role?

What is the value of current screening given it may well stop after identifying the obvious (presence/absence)? What should the ideal screening look like and lead to? What is usual care across the pathway (need this information if future trials of screening, rehabilitation or service reorganisation wish to employ a usual care comparator). How do we capture outcomes that are meaningful to survivors (and carers) and commissioners alike?

What training and support is required to deliver a stepped care model involving the wider range of available staff, 3rd sector role and peer support? What is the role and ideal staffing ratio of the stroke psychologist and other mental health specialists in delivering stepped care?

What is the ideal complete pathway e.g. what are the needs, priorities and realistic models of service delivery specific to the different key points: acute in-patient care, transition to primary care, care home residents, vocational rehabilitation/return to work, 6 and 12 month reviews, living with stroke.
What impact do post-stroke cognitive problems have on informal carers and how can they be supported?

A greater understanding of the nature, course and impact of cognitive deficits after stroke is required, specifically:

- Improvements in differentiating between post-stroke cognitive impairment and post-stroke vascular dementia. Establishing the different presentations of this and development assessment protocols for ensuring more accurate diagnosis will allow for improvements in providing clear information for patients and families, targeting rehabilitation interventions appropriately and ensuring the most appropriate services are involved to support the patient / family.

- Establishing how cognitive deficits improve or remain stable over time and whether early assessment allows for predictions to be made about support / rehabilitation needs on discharge from hospital. For example, can we predict based on early cognitive assessment which patients are likely to need additional OT (occupational therapy) in the community, or may require longer input from Community Stroke Teams.

- Establishing which cognitive deficits have the greatest impact on functional recovery and emotional adjustment. Identifying the cognitive deficits which have the greatest negative impact on recovery will encourage greater research into rehabilitation interventions and will allow for prioritisation of rehabilitation needs.

Development of educational interventions to help patients and families understand cognitive impairments

- Could develop and trial a psycho-educational group intervention.

Development of effective cognitive rehabilitation interventions

Summary of recommendations from RCP guidelines:

**Attention**
“Adequately powered trials of Time Pressure Management and other interventions (eg Attention Process Training) would greatly improve the evidence base for these common, disabling impairments.

**Memory**
“Research is needed to establish both the clinical effectiveness (particularly at an activity level) and the patient acceptability of different memory rehabilitation approaches, recruiting larger, more representative, groups of stroke patients”

**Visual agnosia**
No rehab interventions has be adequately developed in this area

**Dyspraxia**
Future research needs to provide detailed descriptions of the interventions and measure the impact on everyday function.
Executive Functioning
An intervention was well described by Spikman et al 2010. This study provides promising evidence of efficacy but requires replication with a larger sample and one that is more representative of the stroke population, including older people.

In all areas of cognitive functioning except possibly visual inattention, there has been very limited development of rehab techniques at both a theoretical and practical level. Initial research should focus on developing practical, everyday techniques for a stroke population, for example anchoring, use of memory compensation aids, use of technology to compensate for attention / memory / executive functioning deficits. The strategies need to be focused on meaningful improvements for patients rather than deficit specific improvements for example we should be asking:

- What strategies can we use to help patients enjoy reading again?
- What strategies might help a person get their shopping done?

Group approaches to attention and executive function rehab might also be a way to meet need more effectively but need to be developed and tested out.

Research Questions Around Driving After Stroke:

1. Do driving assessment apps have predictive validity for on road driving?
2. What are the barriers to evidence based cognitive screening for fitness to drive?
3. Can cognitive rehabilitation using driving games or computer driving simulators improve on road driving performance?
4. Do we know whether tests with predictive validity for on road driving performance after stroke are valid for patients with stroke related dementia? (however: problems distinguishing stroke-related dementia from stroke-related cognitive impairment)

2. Mood and Adjustment

What We Know:

The emotional impact of stroke is important to survivors and those close to them, but under the surface of that observation there are challenging questions about what they actually think about causes and what they want done. We know quite a lot now about what patients think about depression associated with other physical disease, and also what their GPs think. We also know that QOF (Quality Outcomes Framework)-incentivised screening for depression in two other long term conditions has just been withdrawn for reasons not unrelated to what everybody thinks of it. What can we learn? The potential benefit of this is more patient-centred services.

It would be good to develop work in all of the key areas of epidemiology, drug management, traditional psychological therapies and patients’ life after stroke and their families’ perspectives on the support available to them.

We know that many stroke patients and carers (around 2/3) report a very wide range of clinical and sub-clinical psychological problems and issues. These problems and issues do not fit neatly into clinical diagnostic categories and include relationships, confidence, frustration, fear, stress, identity issues and isolation.
We know quite a lot about point prevalence of anxiety, depression and post-traumatic stress disorder, and something about the course and natural history of depression after stroke.

We know that survivors and carers report that their psychological needs are largely unmet, especially after discharge to the community. We know that community services are patchy and that non-specialist staff frequently deal with psychological issues and often feel insufficiently trained and supported in doing so.

We know that we need new, creative, affordable service delivery methods to address the needs, such as those already being employed in mental health around the UK.

Stroke isn’t unique in terms of its psychological impact. We know many of the causes of depression in stroke are shared with other conditions and not necessarily stroke specific. We must not forget that much of what occurs with mood disorder and stroke also occurs in other conditions with sudden onset acute coronary syndrome, nervous system involvement (e.g. Multiple Sclerosis) or long-term disabling consequences (e.g. rheumatoid arthritis).

It is common to assume that any mood disorder associated with stroke must be attributable to the stroke. Many people have physical co-morbidities that are causally associated (diabetes, heart disease) or not (arthritis, Alzheimer’s disease) and these co-morbidities are independently associated with mood disorders. They may also have psychiatric co-morbidities that predate stroke – for common states like anxiety and for rarer states like bipolar disorder and other psychotic illness.

A potential benefit of this: it broadens the remit of services to respond, but requires cross-service co-ordination (another challenge for 6 month checks). Another potential benefit is that we can learn from elsewhere what does and doesn’t work rather than viewing stroke-specific work in this area in isolation.

**What We Don’t Know:**

Supporting adjustment to life after stroke is a key gap in current service provision, and in previous and ongoing research, which mostly focusses on identification and management of problems. There is a shortage of knowledge about the effectiveness, affordability and practicability of psychological approaches after stroke, not just with regard to therapies, but also regarding service models with which to deliver them.

We require an understanding of how adjustment can be supported through individualised approaches and within care pathways that can be delivered in a model of care that is achievable in the NHS. There are of course some promising approaches to supporting adjustment and preventing depression, but these need definitively testing in an appropriate model of psychological support and care.

We need to aim for a better understanding of:
- what constitutes normal and problematic emotional responses to stroke,
- how these can be captured meaningfully in a way that is patient centred and acceptable to patients
- how this informs development of appropriate support strategies and / or referral to specialist services through a stepped model in order to promote better recovery and life satisfaction as rated by family and patient.

We need better organisation of services to provide psychological care. We need to understand how to organise services to deliver psychological care systematically and
effectively. Who can/should deliver services, and at the different points of the stroke pathway? We need to consider staff training needs, competencies and supervision. We also need to consider the role of group and individual interventions. Another issue is access to services for psychological care in the longer-term, in particular once patients are no longer receiving rehabilitation. Many of the points raised that apply to services will apply to support carers too.

Currently, there is too much fragmentation between specialist services and primary care, and a model where there is a co-ordinated approach would be very attractive. In that regard, self-help tools that can be delivered to the patient in primary care would be a potentially important area of study.

We should explore the potential role of the voluntary sector, e.g. peer support, volunteers, online support groups/forums accessed by stroke survivors.

Research has predominantly been medically-oriented and problem-based. Consequently we know relatively little about what promotes well-being and a good life after stroke, and how to encourage growth and positive adjustment. We should look further at interventions that enhance peer support, social networking, etc. as well as group-based psycho-educational/therapeutic approaches.

As well as interventions for patients with depression, studies should address causes of distress and poor coping in those who do not fit the criteria for a depression diagnoses, and that we may need to address more studies towards prevention of distress/depression later in the course of stroke rather than how to treat it. Psychological treatments that have been shown to have any success so far have been in the area of prevention.

We should study psychological coping resources after stroke. We should address what results in wellbeing, including what psychological resources, attributes and attitudes are needed for successful physical and emotional rehabilitation as studied in other chronic conditions, e.g. hope, optimism, gratitude etc. Nahal Maddavat is currently completing a study looking at psychological factors contributing to perceptions of excellent recovery in stroke survivors. It suggests that those who do well have specific psychological coping resources that we may be able to draw on to potentially design interventions that could work for others.

In line with the above, as well as designing interventions to reduce negative affect, we should include further study of interventions to increase psychological coping resources that may counteract effects of stressors and negative affect on stroke survivors; for example, positive psychology interventions such as mindfulness, meditation, relaxation therapy, resilience training, gratitude journals etc.

Of course we don’t know much about what works in drug treatment and brief psychological therapies, but what grounds do we have for thinking that the answers will be very different for the common mood disorders associated with stroke from what they are in other contexts?

**What We Need To Know:**

Research should adopt an activity/participation perspective (or we risk doing more medically-oriented and problem-based research) and consider the personal and environmental contextual factors which can ultimately determine the success of any isolated or complex intervention (particularly where little if any change at an impairment level is anticipated).
How can we best understand the emotional responses to stroke at different stages of the recovery? Emotional responses to stroke are wide ranging, complex and more subtle than just “depression” or “anxiety.” There has been no development of measures designed to fully encapsulate the emotional experiences of people with stroke. Existing measures that have been validated within a stroke population do not allow for understanding of an individual’s emotional support needs and the full range of responses that people experience.

What factors promote resilience to or coping with the negative emotional impact of a stroke? People will adjust to a stroke in lots of different ways. People who adjust well may have some factors in common and those who don't may similarly have some factors in common. We don’t know what those factors are and understanding these would help develop ways of helping those who don't, this includes individual, environmental and systemic factors.

How can we improve service provision to promote resilience? Being able to better understand and describe experiences will allow for appropriate support being provided in a timely manner by the most suitable services.

There is a need to explore how mood and sense of identity are linked. There are metasyntheses of peoples’ experiences post stroke highlighting that sense of identity change is an important issue for people. It is possible and quite likely that the degree of identity change is associated with the degree of mood change. Preliminary findings from Kathryn Radford’s group in stroke and Traumatic Brain Injury in this area suggest that people who are working are less depressed. Depression is also greater in those who cannot resume driving, so there’s a complex relationship between mood, conditions, comorbidities and importantly activity and participation. So there is a need to explore how mood and sense of identity are linked and we do need to know more about what promotes well-being and a good life after stroke, and how to encourage growth and positive adjustment.

Approaches should be tested e.g. rehabilitation services, individual or group interventions, which prevent the onset of mood problems (e.g. depression, anxiety).

More work is needed to identify the processes, approaches and specifics of service delivery which would support positive transition following a stroke. Service provision needs to be considered in the widest sense; involving formal psychological services, training for other formal service providers, voluntary services, wider community services and peer support. This would ‘spread the load’ in terms of support post-stroke and also recognise that different people and families will gain most benefit from various types of support.

Can interventions from other branches of mental health be applied to stroke without the need to re-evaluate? In particular, we need to consider those stroke patients with aphasia or severe cognitive difficulties and the accessibility of (assessments and) interventions to these groups. Outcome measures are often questionnaires which need people to have relatively intact communication to be able to complete them.

The priority now is to increase knowledge about what works for stroke patients and carers in terms of psychological interventions, and about the service models to deliver them. This may require preliminary work to develop suitable service models and select their component therapies. Picking the best and most appropriate from the different IAPT (Improving Access to Psychological Therapies) developments in England, Scotland and Wales could inform this.

This initial stage will require consultation with service-based psychologists, GPs, and other relevant staff (including the Stroke Association’s own service arm), as well as survivors and carers. Once that is done therapy components could be trialled with small-scale RCTs.
The evaluation of the overall service model is necessary, but would require larger-scale funding, probably from NIHR.

We also need to know more about the effectiveness of social network or other interpersonal interventions.

Q: What is the influence of common mood problems on secondary prevention? (e.g. smoking cessation, alcohol, physical activity, adherence to medication) and what is the role of integrated care?
Q: What makes good psychological coping skills in stroke survivors and how can we promote psychological and other coping resources to prevent distress and depression?
Q: What is really specific to stroke in cause or treatment?
Q: Does every treatment from every other branch of mental health work need to be re-run as an RCT in stroke?
Q: When can we generalise from other long term conditions?
Q: How do we evaluate specific symptoms and outcomes that are stroke-attributable, versus those attributable to co-morbidities or other pre-existing or co-existing medical conditions?

From a Primary Care Perspective:

From a primary care perspective, any potential future research should include the following considerations:

- The applicability of the research on both diagnostic aids and treatments for people with prevalent (i.e previous) stroke, as these will be the people who will be presenting to their GP.
- The deliverability of any diagnostic aid in a primary care setting e.g. what training is required? Are the treatments deliverable by a generalist, or do they require a specialist, or is it a partnership between generalist and specialist that is required?
- The scalability (epidemiological evidence suggests these problems are common), so the NHS needs to be able to provide any treatments for large numbers of people).