

NATIONAL CLINICAL GUIDELINE FOR STROKE

for the United Kingdom and Ireland

2023 edition

Chapter 2

Organisation of stroke services

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2 Organisation of stroke services

2.0 Introduction

This chapter considers stroke management from a population perspective, addressing the means of organising services to deliver high quality stroke care. If services for people with stroke are poorly organised, outcomes will also be poor despite the evidence-based practice and best endeavours of individual clinicians. Furthermore, if clinical teams do not have sufficient knowledge and skills, and are not consistent in their clinical practice, many people will receive sub-optimal care. [2016]

The recommendations in this chapter affect the full range of services within a comprehensive acute and community stroke service, and many of them have a strong evidence base and are among the most important contained in this guideline. [2016]

2.1 Public awareness of stroke

In recent years mass media campaigns such as the Face Arm Speech Time (FAST) campaign, have been delivered with the aim of increasing public awareness of the symptoms and signs of stroke (available at <http://www.nhs.uk/actfast/Pages/know-the-signs.aspx>; <https://irishheart.ie/campaigns/fast/>; <https://www.thinkfast.org.uk/>). Public awareness of stroke prevention and treatment are also important. [2016]

2.1 Recommendation

A Public awareness campaigns of the symptoms of stroke should be recurrent, targeted at those most at risk of stroke, and formally evaluated. [2016]

2.1 Sources

A Lecouturier et al, 2010a,b; Working Party consensus

2.1 Evidence to recommendations

The available research indicates some trends with regard to mass media campaigns, for example: television may be more effective than posters and newspaper advertisements; campaigns need to be repeated rather than short-term and one-off, and there are methodological weaknesses in the research (Lecouturier et al, 2010a). The evidence for a direct link between awareness and recommended behaviour is weak, especially among older members of the population, minority ethnic groups and those with lower levels of education, all of which are population groups at greater risk of stroke (Jones et al, 2010). Campaigns aimed at both public and healthcare professionals may have more impact on professionals than the public (Lecouturier et al, 2010b). More research in the area of improving public awareness and appropriate action is needed. [2016]

2.2 Definitions of specialist stroke services

– A **specialist** is defined as a healthcare professional with the necessary knowledge and skills in managing people with stroke and conditions that mimic stroke, usually by having a relevant further qualification and keeping up to date through continuing professional development. This does not require the healthcare professional exclusively to manage people with stroke, but does require them to have specific knowledge and practical experience of stroke. [2016]

– A **specialist team or service** is defined as a group of specialists who work together regularly managing people with stroke and conditions that mimic stroke, and who between them have the knowledge and skills to assess and resolve the majority of problems. At a minimum, any specialist unit, team or service must be able to deliver all the relevant recommendations made in this guideline. This does not require the team exclusively to manage people with stroke, but the team should have specific knowledge and practical experience of stroke. Types of acute stroke service are described in [Section 2.4 Organisation of inpatient stroke services](#). [2016]

2.3 Transfer to acute stroke services

2.3 Recommendations

- A Community health services and ambulance services (including call handlers and primary care reception staff) should be trained to recognise people with symptoms indicating an acute stroke as an emergency requiring transfer to a hyperacute stroke centre with pre-alert notification to the stroke team. [2023]
- B People with an acute neurological presentation suspected to be a stroke should be admitted directly to a hyperacute stroke unit that cares predominantly for patients with stroke, with access to a designated thrombectomy centre 24 hours a day, 7 days a week for consideration of mechanical thrombectomy. [2023]
- C Acute hospitals receiving medical admissions that include people with suspected stroke should have arrangements to admit them directly to a hyperacute stroke unit on site or at a designated neighbouring hospital as soon as possible to monitor and regulate basic physiological functions such as neurological status, blood glucose, oxygenation, and blood pressure. [2016]
- D Acute hospitals that admit people with stroke should have prioritised access to a specialist stroke rehabilitation unit on site or at a neighbouring hospital. [2016]
- E Local health economies/health boards (geographic areas or populations covered by an integrated group of health commissioners/service planners and/or providers) should aim to have a specialist neurovascular service capable of assessing and treating people within 24 hours of transient cerebrovascular symptoms. [2016]
- F Public and professional education programmes should be run to increase awareness of stroke and the need for urgent diagnosis and treatment. [2016]

2.3 Sources

- A, B Follows from the evidence concerning the emergency diagnosis and treatment of stroke ([Section 3.4 Diagnosis and treatment of acute stroke – imaging](#), [Section 3.5 Management of ischaemic stroke](#), [Section 3.6 Management of intracerebral haemorrhage](#), [Section 3.7 Management of subarachnoid haemorrhage](#))
- C Follows from the evidence concerning acute stroke care ([Section 3.10 Acute stroke care](#))
- D Follows from the evidence concerning specialist stroke units ([Section 2.2 Definitions of specialist stroke services](#), [Section 2.4 Organisation of inpatient stroke services](#))
- E Follows from the evidence concerning TIA diagnosis and treatment ([Section 3.2 Management of TIA and minor stroke – assessment and diagnosis](#), [Section 3.3 Management of TIA and minor stroke – treatment and vascular prevention](#))
- F Follows from the evidence concerning the emergency diagnosis and treatment of stroke ([Section 3.4 Diagnosis and treatment of acute stroke – imaging](#), [Section 3.5 Management](#))

[of ischaemic stroke](#), [Section 3.6 Management of intracerebral haemorrhage](#), [Section 3.7 Management of subarachnoid haemorrhage](#))

2.3 Evidence to recommendations

Effective stroke care needs an organisational structure that facilitates best treatments at the right time. This section makes recommendations that follow from studies of treatment efficacy; e.g. intravenous thrombolysis can only be given within the eligible time window if people arrive in the appropriate setting within that time. Major urban reorganisations of stroke services have taken place in some parts of the UK and Ireland to improve access to hyperacute stroke unit care. Evidence from Manchester and London suggests that such care should be in hyperacute stroke centres available 24 hours a day, 7 days a week, and should be for all people with acute stroke, not just those who might be suitable for intravenous thrombolysis (Ramsay et al, 2015). **[2016]**

The RACECAT trial in Catalonia, Spain tested whether transporting people with acute stroke suspected to be due to large artery occlusion directly to a thrombectomy centre (ambulance redirection or bypass) improves outcomes compared with being taken to the patient's nearest acute stroke centre (Pérez de la Ossa et al, 2022). This multi-centre, cluster RCT did not demonstrate a clinical outcome advantage from redirection, but in many respects RACECAT is not directly applicable to many parts of the UK and Ireland. The strategy for adopting either a secondary transfer or an ambulance redirection service model for thrombectomy will depend upon local and regional services and the population served (Ford et al, 2022). There is an urgent need for research addressing this question that is directly applicable to the NHS and HSE. Processes of care are important for optimising patient outcomes and these apply at both the referring acute stroke centre and the receiving thrombectomy centre. If local acute stroke centre workflow cannot be optimised, then redirection to a thrombectomy centre may be better and should be considered regionally. For secondary transfers that are longer than one hour, helicopter-based transfer may improve speed of access to thrombectomy and associated patient outcomes (Coughlan et al, 2021). **[2023]**

Mobile stroke units (MSUs) are ambulances equipped with brain imaging equipment and specialist staff that are capable of delivering thrombolysis or identifying large artery occlusion when equipped with CT angiography. In data largely from non-randomised trials with a standard ambulance comparator group and blinded outcome assessments, after deployment of an MSU, patients with ischaemic stroke had a better clinical outcome, were more likely to receive thrombolysis and incur shorter onset to thrombolysis times (Turc et al, 2022). However, it is uncertain what the effects of MSUs are on an unselected stroke population, the cost-effectiveness of MSU care, how to integrate MSUs into pre-hospital pathways and how these might be applied across both rural and urban regions. Ongoing randomised trials may answer some of these questions, although modelling of costs and benefits applied across different regions and service models is likely to be required (Chen et al, 2022). **[2023]**

2.3 Implications

These recommendations have significant implications for the organisation of acute medical services within any 'health economy' (locality). At a regional or subregional level, those who commission and provide stroke services are required to configure these services to achieve the maximum benefit to the population from the delivery of time-sensitive treatments, and to consider issues relating to the co-location of other emergency services that are beyond the scope of this guideline. It is important that, with such reconfiguration of services, there is a robust governance infrastructure in place to monitor the quality of stroke services delivered. **[2023]**

2.4 Organisation of inpatient stroke services

There is strong evidence that specialised stroke unit care initiated as soon as possible after the onset of stroke provides effective treatments that reduce long-term brain damage, disability and healthcare costs. An acute stroke service consists of either: a) a comprehensive stroke centre (CSC) providing hyperacute, acute and inpatient rehabilitation including thrombectomy (thrombectomy centre) and neurosurgery; or b) an acute stroke centre (ASC) providing hyperacute, acute and inpatient rehabilitation. A stroke rehabilitation unit (SRU) provides inpatient rehabilitation only. All components of a specialist acute stroke service should be based in a hospital that can investigate and manage people with acute stroke and their medical and neurological complications, but this requirement does not apply to services designed to provide stroke care only in the rehabilitation phase. **[2023]**

2.4 Recommendations

- A People with the sudden onset of focal neurological symptoms seen by community-based clinicians (e.g. ambulance paramedics) should be screened for hypoglycaemia with a capillary blood glucose, and for stroke or TIA using a validated tool. Those people with persisting neurological symptoms who screen positive using a validated tool should be transferred to a hyperacute stroke unit as soon as possible with pre-alert notification to the admitting stroke team. **[2016]**
- B People with suspected acute stroke (including people already in hospital) should be admitted directly to a hyperacute stroke unit and be assessed for emergency stroke treatments by a specialist clinician without delay. **[2016]**
- C Acute stroke services should provide specialist multidisciplinary care for diagnosis, hyperacute and acute treatments, normalisation of homeostasis, early rehabilitation, prevention of complications and secondary prevention. **[2016]**
- D Acute stroke services should have management protocols for the admission pathway including links with the ambulance service, emergency stroke treatments, acute imaging, neurological and physiological monitoring, swallowing assessment, hydration and nutrition, vascular surgical referrals, rehabilitation, end-of-life (palliative) care, secondary prevention, the prevention and management of complications, communication with people with stroke and their family/carers and discharge planning. **[2016]**
- E Acute stroke services should have continuous (24/7) access to brain imaging including CT or MR angiography and perfusion when necessary and should be capable of undertaking immediate brain imaging when clinically indicated. **[2023]**
- F Acute stroke services should have protocols for the monitoring, referral and transfer of patients to thrombectomy centres for mechanical thrombectomy and regional neurosurgical centres where available for decompressive hemicraniectomy, surgical management of intracranial haemorrhage and the management of symptomatic hydrocephalus including external ventricular drain insertion. **[2016]**
- G Acute stroke services should ensure that people with conditions that mimic stroke are transferred without delay into a care pathway appropriate to their diagnosis. **[2016]**
- H People with a diagnosis of stroke that was not made on admission should be transferred without delay into that part of the stroke service most appropriate to their needs. **[2016]**
- I Patients with acute neurological symptoms that resolve completely within 24 hours of onset (i.e. suspected TIA) should be given aspirin 300 mg immediately, unless contraindicated, and be assessed urgently within 24 hours by a stroke specialist clinician in a neurovascular clinic or an acute stroke unit. **[2023]**
- J Acute stroke services should have an education programme for all staff providing acute stroke care (including ambulance services and the emergency department as appropriate)

- and should provide training for healthcare professionals in the specialty of stroke. [2016]
- K Acute stroke services should participate in national and local audit, multicentre research and quality improvement programmes. [2016]

2.4 Sources

- A, B Follows from the evidence concerning emergency stroke treatments ([Section 3.4 Diagnosis and treatment of acute stroke – imaging](#), [Section 3.5 Management of ischaemic stroke](#), [Section 3.6 Management of intracerebral haemorrhage](#), [Section 3.7 Management of subarachnoid haemorrhage](#))
- C Follows from the evidence concerning emergency treatments and monitoring ([Section 3.5 Management of ischaemic stroke](#), [Section 3.6 Management of intracerebral haemorrhage](#), [Section 3.7 Management of subarachnoid haemorrhage](#), [Section 3.10 Acute stroke care](#))
- D Follows from the evidence concerning specialist stroke units ([Section 2.5 Resources: inpatient stroke services](#))
- E Wardlaw et al, 2004; follows from the evidence concerning emergency stroke treatments ([Section 3.5 Management of ischaemic stroke](#))
- F Follows from the evidence concerning emergency stroke treatments ([Section 3.5 Management of ischaemic stroke](#), [Section 3.6 Management of intracerebral haemorrhage](#))
- G, H Working Party consensus
- I Follows from the evidence concerning TIA diagnosis and treatment ([Section 3.2 Management of TIA and minor stroke – assessment and diagnosis](#), [Section 3.3 Management of TIA and minor stroke – treatment and vascular prevention](#))
- J Follows from the evidence concerning specialist stroke units ([Section 2.5 Resources: inpatient stroke services](#))
- K Obligations under the NHS Standard Contract; Working Party consensus

2.4 Evidence to recommendations

Given that 1 in 20 strokes occur in people already in hospital (Intercollegiate Stroke Working Party, 2016), clinicians in high-risk clinical areas (e.g. cardiology or renal wards, cardiothoracic units) should have a high level of awareness of acute stroke and the time-critical nature of interventions to improve outcome, including how to contact a stroke specialist for advice, arrange imaging and transfer patients to a hyperacute stroke unit. [2023]

Any person with the acute onset of a focal neurological syndrome with persisting symptoms and signs (i.e. suspected stroke) needs urgent diagnostic assessment to differentiate between acute stroke and other causes. Progress in the medical management of acute stroke demands a corresponding increase in the availability of advanced imaging techniques, and all hyperacute stroke services will need immediate and timely access to multi-modal brain imaging including CT or MR angiography and perfusion when necessary. [2023]

2.4 Implications

These recommendations have significant implications for the organisation of clinical services within acute hospitals. Systems need to be adapted to ensure that people with acute stroke have rapid access to an acute stroke unit and to facilitate rapid transfer out of the unit once acute management is complete. [2016]

2.5 Resources – inpatient stroke services

Leadership and culture are important contributors to delivering high quality stroke care, and they should be evident at all levels, e.g. individual professionals, teams, units, trusts/hospitals and across networks. Culture and tone ‘from the top’ matters and are key enablers of joint working across professional and organisational boundaries and important to the provision of holistic and compassionate care to patients and their families (Francis, 2013; Getting it Right First Time, 2022). A well-led, appropriately staffed and skilled multidisciplinary stroke unit is the cornerstone of holistic and compassionate care for people with stroke. In parts of the UK, legislation is due to be implemented in 2024 to ensure ‘safe staffing’ for nurses and medical practitioners in health and social care settings (Scottish Government, 2019). **[2023]**

2.5 Recommendations

- A People with stroke should be treated in a specialist stroke unit throughout their hospital stay unless their stroke is not the predominant clinical problem. **[2016]**
- B A hyperacute, acute and rehabilitation stroke service should provide specialist medical, nursing, and rehabilitation staffing levels matching the recommendations in Table 2.5.

Table 2.5 Recommended levels of staffing for hyperacute, acute and rehabilitation units

	Physiotherapy	Occupational therapy	Speech and language therapy	Clinical psychology / neuropsychology	Dietetics	Nursing	Consultant stroke physician	Consultant-level practitioner-led ward rounds
Hyper-acute stroke unit	Whole-time equivalents (WTE) per 5 beds*					WTE per bed	24/7 availability; minimum 6.0 thrombolysis trained physicians on rota	Twice daily ward round
	1.02	0.95	0.48	0.28	0.21	2.9 (80:20 registered: unregistered)		
Acute stroke unit & stroke rehabilitation unit	1.18	1.13	0.56	0.28	0.21	1.35 (65:35 registered: unregistered)	Acute stroke unit: 7 day cover with adequate out of hours arrangements**	Acute stroke unit: daily ward round** Stroke rehabilitation unit: twice-weekly ward round**

* WTE figures are for 7-day working for registered staff and include non-clinical time (such as supervision and professional development) as well as non-face-to-face clinical activity. Registered staff should be augmented by support workers and rehabilitation assistants to achieve the intensity and dose of therapy recommended in [Section 4.2 Rehabilitation approach – intensity of therapy \(motor recovery and function\)](#).

** Consultant stroke physician input may need to be adjusted according to the acuity of the unit. All acute and rehabilitation units should have at least 2 ward rounds per week led by a consultant-level practitioner (physician, nurse or therapist; see Recommendation 2.5K). For recommendations regarding orthoptist staffing, see [Section 4.48 Vision](#).

[2023]

- C A hyperacute stroke unit should have immediate access to:

- specialist medical staff trained in the hyperacute and acute management of people with stroke, including the diagnostic and administrative procedures needed for the safe and timely delivery of emergency stroke treatments;
 - specialist nursing staff trained in the hyperacute and acute management of people with stroke, covering neurological, general medical and rehabilitation aspects;
 - stroke specialist rehabilitation staff;
 - diagnostic, imaging and cardiology services;
 - tertiary services for endovascular therapy, neurosurgery and vascular surgery. **[2016]**
- D A hyperacute stroke unit should have continuous access to a consultant physician with expertise in stroke medicine, with consultant review 7 days per week. **[2016]**
- E An acute stroke unit should provide:
- specialist medical staff trained in the acute management of people with stroke;
 - specialist nursing staff trained in the acute management of people with stroke, covering neurological, general medical and rehabilitation aspects;
 - stroke specialist rehabilitation staff;
 - access to diagnostic, imaging and cardiology services;
 - access to tertiary services for neurosurgery and vascular surgery. **[2016]**
- F An acute stroke unit should have continuous access to a consultant physician with expertise in stroke medicine, with consultant review 5 days per week. **[2016]**
- G Where telemedicine is used for the assessment of people with suspected stroke by a specialist physician, the system should enable the physician to discuss the case with the assessing clinician, talk to the patient and/or family/carers directly and review radiological investigations. Telemedicine should include a high quality video link to enable the remote physician to observe the clinical examination. **[2016]**
- H Staff providing care via telemedicine (at both ends of the system) should be appropriately trained in the hyperacute assessment of people with suspected acute stroke, in the delivery of thrombolysis and the use of this approach and technology. The quality of care and decision making using telemedicine should be regularly audited. **[2016]**
- I A stroke rehabilitation unit should predominantly care for people with stroke, and should maintain the staffing and skill levels required of a stroke unit regardless of size, location or mix of conditions of the patients being treated. **[2023]**
- J A stroke rehabilitation unit should have a single multidisciplinary team including specialists in:
- medicine;
 - nursing;
 - physiotherapy;
 - occupational therapy;
 - speech and language therapy;
 - dietetics;
 - clinical psychology/neuropsychology;
 - social work;
 - orthotics;
- with timely access to rehabilitation medicine, specialist pharmacy, orthotics, specialist seating, assistive technology and information, advice and support (including life after stroke services) for people with stroke and their family/carers. **[2023]**
- K A stroke rehabilitation unit should have access to a consultant specialising in stroke rehabilitation (medical or non-medical, i.e. nurse or therapist, where professional regulation permits) at least 5 days a week, with twice weekly consultant-led ward rounds. **[2023]**

- L Stroke rehabilitation units with non-medical consultant leadership should have daily medical cover (ward doctors, GPs), enabling admissions and discharges 7 days a week, with support available from stroke physicians as required. 24 hour on-site medical cover may not be required depending on patient admission criteria, with adequate out of hours arrangements. **[2023]**
- M A facility that provides treatment for inpatients with stroke should include:
- a geographically-defined unit;
 - a co-ordinated multidisciplinary team that meets at least once a week for the exchange of information about inpatients with stroke;
 - information, advice and support for people with stroke and their family/carers;
 - management protocols for common problems, based upon the best available evidence;
 - close links and protocols for the transfer of care with other inpatient stroke services, early supported discharge teams and community services;
 - training for healthcare professionals in the specialty of stroke. **[2016]**
- N Specialist inpatient stroke services should include sufficient administration and management (including data management) support. **[2023]**

2.5 Sources

- A Stroke Unit Trialists' Collaboration, 2013
- B Bray et al, 2014; Ramsay et al, 2015; Guideline Development Group consensus
- C-F Follows from the evidence and recommendations concerning emergency treatments and monitoring ([Section 3.5 Management of ischaemic stroke](#), [Section 3.6 Management of intracerebral haemorrhage](#), [Section 3.7 Management of subarachnoid haemorrhage](#), [Section 3.10 Acute stroke care](#))
- G, H Meyer et al, 2008; Working Party consensus
- I-L Stroke Unit Trialists' Collaboration, 2013; NICE, 2016d; Guideline Development Group consensus
- M Working Party consensus
- N Guideline Development Group consensus

2.5 Evidence to recommendations

The previous sections have been concerned with the organisational structure of stroke services. It is equally important to have appropriate resources available for the care of people with stroke: the workforce, buildings, and technological support required. Minimum staffing levels on stroke units were originally defined in hyperacute stroke service reconfigurations such as that in London, and are supported by observational evidence from UK registries about acute care processes that are associated with substantial benefits to patients, including those admitted outside office hours and at weekends (Ramsay et al, 2015; Turner et al, 2016). The evidence regarding the optimal size of a hyperacute stroke unit was similarly confined to observational studies, reflecting a level of institutional experience and competence in the provision of specialist hyperacute treatments such as intravenous thrombolysis (Bray et al, 2013) that corresponds with a volume of at least 500 acute stroke admissions per year. **[2023]**

The evidence supporting stroke unit care from the stroke unit trialists in the 1990s was updated in a 2013 Cochrane review, which found that people with stroke who receive organised inpatient care in a stroke unit are more likely to be alive, independent, and living at home one year after their stroke (Stroke Unit Trialists' Collaboration, 2013). The benefits were only apparent in units based in a discrete

ward. Increased access to stroke unit care has made a vital contribution to reducing stroke mortality and remains an imperative for all inpatients with stroke. [2023]

The Guideline Development Group endorses an updated recommendation regarding staffing levels of registered staff on inpatient stroke units expressed as whole-time equivalents (WTE) in Table 2.5. These recommendations take into account therapy delivered across seven days. Achieving the recommendations in [Section 4.2 Rehabilitation and recovery – intensity of therapy \(motor recovery and function\)](#) will also require unregistered support workers and rehabilitation assistants delivering rehabilitation under the supervision of registered staff. SSNAP reports 2021-22 (Sentinel Stroke National Audit Programme, 2022) indicate that for suitable patients, up to a third of physiotherapy and occupational therapy is currently being delivered by unregistered rehabilitation assistants. An understanding of the local context, together with these recommendations, will be required to inform more detailed service specifications (including banding/seniority), which may include increased staffing if deemed appropriate. [2023]

Staffing recommendations also include non-clinical time (such as supervision and professional development) as well as non-face-to-face clinical activity such as environmental visits, family contact and equipment ordering. Units with a small bed base may need to consider revisions to these staffing levels to ensure adequate registered staffing cover across the week, taking account of rotas and days off for weekend working. Recommendations for orthoptist staffing levels in hyperacute and acute stroke units are made in [Section 4.48 Vision](#). Sufficient administrative and management support (including data management) is essential to the efficiency and governance of the core stroke unit team and should also be included. [2023]

Telemedicine is used in some centres to support decision making in the hyperacute management of people with stroke because of significant practical or geographical obstacles. Observational evidence suggests that telemedicine is associated with more protocol violations and longer treatment times (Meyer et al, 2008; Dutta et al, 2015). Furthermore, unless telemedicine is used as part of an otherwise well-developed acute stroke service, outcomes may suffer (Heffner et al, 2015). [2016]

2.5 Implications

These recommendations will require a considerable increase in the provision of some specialties in stroke services, including clinical psychology/neuropsychology and social work. The Guideline Development Group is concerned by the findings from national registries indicating continued poor provision of these specialties for people with stroke. Patterns of work need to be reviewed to deliver sufficient direct therapy by removing some administrative duties and ensuring that time is not spent by registered therapists on tasks that could be done by unregistered staff. Restoring adequate social work provision will require close integration with social services. [2023]

2.6 Location of service delivery

Stroke services should be organised to treat a sufficient number of patients to ensure that the specialist skills of the workforce are maintained. At the same time, the closer a rehabilitation service is to the person's home the more that family/carers can be engaged and the more targeted the rehabilitation can be. This section provides a recommendation on the location of delivery of services, aiming for an appropriate balance between care in hospital, on an outpatient basis and at home. [2016]

2.6 Recommendation

- A People with acute stroke who cannot be admitted to hospital should be seen by the specialist team at home or as an outpatient within 24 hours for diagnosis, treatment, rehabilitation, and risk factor management at a standard comparable to that for

inpatients. [2016]

2.6 Source

A Working Party consensus

2.7 Transfers of care – general principles

After stroke, many people will interact with several different services during their recovery: primary care, specialist acute stroke services, specialist rehabilitation services, social services, housing, generic community services etc. This section covers general principles around the transfers of care between these agencies. Transfers of care out of hospital are covered in [Section 2.8 Transfers of care from hospital to home – community stroke rehabilitation](#). [2016]

2.7 Recommendations

- A Transfers of care for people with stroke between different teams or organisations should:
- occur at the appropriate time, without delay;
 - not require the person to provide information already given;
 - ensure that all relevant information is transferred, especially concerning medication;
 - maintain a set of person-centred goals;
 - preserve any decisions about medical care made in the person’s best interests. [2016]
- B People with stroke should be:
- involved in decisions about transfers of their care if they are able;
 - offered copies of written communication between organisations and teams involved in their care. [2016]
- C Organisations and teams regularly involved in caring for people with stroke should use a common, agreed terminology and set of data collection measures, assessments and documentation. [2016]

2.7 Sources

- A Working Party consensus
B Asplund et al, 2009; Working Party consensus
C Working Party consensus

2.7 Implications

These recommendations require those who commission and provide services across health and social care to consider the current situation and how it might be redesigned to reduce transfers of care between organisations and improve continuity. The person recovering from stroke and their family should experience seamless care without artificial distinctions between service providers or between health and social care. [2016]

2.8 Transfers of care from hospital to home – community stroke rehabilitation

The most common transfer of care, and the most stressful for people with stroke and their family/carers, is that from in-hospital care to their home or to a care home. Many people report feeling afraid and unsupported, and carers report feelings of abandonment (Stroke Association, 2015). There is

much that services can do to support and reassure people with stroke and their family/carers regarding the smooth transfer of care into the community. [2016]

Community stroke rehabilitation services, including delivery of early supported discharge, are required to co-ordinate the transfer of care from hospital to home, working collaboratively with people with stroke and family members, stroke inpatient unit staff and informed by an assessment of the person's home environment (Drummond et al, 2013). Through a specialist multidisciplinary team structure, early, effective community specialist stroke rehabilitation and disability management needs to be provided to all people with stroke leaving hospital who need it. Stroke rehabilitation should be provided in the person's own home or place of residence, including residential or nursing homes (Fisher et al, 2011; Fisher et al, 2013; NHS England, 2022). [2023]

2.8 Recommendations

- A Hospital inpatients with stroke who have mild to moderate disability should be offered early supported discharge, with treatment at home beginning within 24 hours of discharge. [2023]
- B Patients undergoing rehabilitation after stroke who are not eligible for early supported discharge should be referred to community stroke rehabilitation if they have ongoing rehabilitation needs when transferred from hospital. [2023]
- C Early supported discharge and community stroke rehabilitation should be provided by a service predominantly treating people with stroke. [2023]
- D Therapy provided as part of early supported discharge should be at the same intensity as would be provided if the person were to remain on a stroke unit. [2023]
- E The intensity and duration of intervention provided by the community stroke rehabilitation team should be established between the stroke specialist, the person with stroke and their family/carers, and be based on clinical need tailored to goals and outcomes. [2023]
- F A multidisciplinary service providing early supported discharge and community stroke rehabilitation should adopt a minimum core team structure matching the recommendations in Table 2.8 and below.

Table 2.8 Recommended levels of staffing for multidisciplinary services providing early supported discharge and community stroke rehabilitation

Discipline	WTE per 100 referrals to service p.a.
Physiotherapy	1.0
Occupational therapy	1.0
Speech and language therapy	0.4
Social worker	Up to 0.5 and at least 0.5 WTE per team recommended locally
Rehabilitation assistant/assistant practitioners	1.0
Clinical psychology/neuropsychology	0.2-0.4*
Nursing	Up to 1.2 and at least 1 full time nurse per team
Medicine	0.1

*This reflects the time that a team member should be co-located within the MDT and could include additional skill mix, e.g. assistant psychologist.

The service should also include:

- Appropriate administration and management (including data management) support;
- Timely access to psychological and neuropsychological services (e.g. Improving Access

to Psychological Therapies [IAPT] and community mental health services with stroke-specific training and appropriate supervision, psychology or neuropsychology departments), return to work and vocational rehabilitation services, dietetics, pharmacy, orthotics, orthoptics, spasticity services, specialist seating, assistive technology and information, pain management, advice and support for people with stroke and their family/carers. **[2023]**

- G** Early supported discharge and community stroke rehabilitation services should include:
- a co-ordinated multidisciplinary team that meets at least once a week for the exchange of information about people with stroke in their care;
 - provision of needs-based stroke rehabilitation, support and any appropriate management plans, with the option for re-referral after discharge if stroke rehabilitation needs and goals are defined, and with access to support services on discharge;
 - information (aphasia-friendly), advice, and support for people with stroke and their family/carers;
 - management protocols for common problems, based upon the best available evidence;
 - collaboration, close links and protocols for the transfer of care with inpatient stroke services, primary care, community services and the voluntary sector;
 - training for healthcare professionals in the specialty of stroke. **[2023]**
- H** People with stroke and their family/carers should be involved in decisions about the transfer of their care out of hospital, and the care that will be provided. **[2023]**
- I** Members of the early supported discharge and community stroke rehabilitation services should be involved in hospital discharge planning and decision making by attending stroke unit multidisciplinary team meetings. **[2023]**
- J** Before the transfer of care for a person with stroke from hospital to home (including a care home) occurs:
- the person and their family/carers should be prepared, and have been involved in planning their transfer of care if they are able;
 - primary healthcare teams and social services should be informed before or at the time of the transfer of care;
 - all equipment and support services necessary for a safe transfer of care should be in place;
 - any continuing treatment the person requires should be provided without delay by a co-ordinated, specialist multidisciplinary service;
 - the person and their family/carers should be given information and offered contact with relevant statutory and voluntary agencies (e.g. stroke key worker). **[2023]**
- K** Before the transfer home of a person with stroke who is dependent in any activities, the person's home environment should be assessed by a visit with an occupational therapist. If a home visit is not considered appropriate, they should be offered an access visit or an interview about the home environment including viewing photographs or videos taken by family/carers. **[2023]**
- L** People with stroke who are dependent in personal activities (e.g., dressing, toileting) should be offered a transition package before being transferred home that includes:
- visits or leave at home prior to the final transfer of care;
 - training and education for their carers specific to their needs;
 - telephone advice and support for three months. **[2023]**
- M** Before the transfer of care for a person with stroke from hospital to home (including a

care home) they should be provided with:

- a named point of contact for information and advice;
- personalised written information in an appropriate format about their diagnosis, medication and management plan. **[2023]**

N People with stroke, including those living in care homes, should continue to have access to specialist services after leaving hospital, and should be provided with information about how to contact them, and supported to do so if necessary. **[2023]**

O Early supported discharge and community stroke rehabilitation services should participate in national and local audit, multicentre research, and quality improvement programmes. **[2023]**

2.8 Sources

A-I Fisher et al, 2011, 2013, 2016, 2020, 2021; Langhorne et al, 2017; NHS England, 2022

J Guideline Development Group consensus

K Drummond et al, 2013; Guideline Development Group consensus

L Grasel et al, 2006; Lannin et al, 2007a; Barras et al, 2010

M, N Guideline Development Group consensus

O Obligations under the NHS Standard Contract; Guideline Development Group consensus

2.8 Evidence to recommendations

Consensus studies and national policy guidance recommend that services are available to provide early supported discharge and community stroke rehabilitation in a timely way following hospital discharge. They also recommend that the duration and intensity of stroke rehabilitation provided needs to be based on clinical need and tailored to the person's goals and outcomes (Fisher et al, 2011; Fisher et al, 2013; NHS England, 2022). **[2023]**

There is strong evidence for the effectiveness of stroke specialist early supported discharge for those who experience mild to moderate disability after stroke. Trials and observational studies have demonstrated that early supported discharge can reduce long-term dependency and admission to institutional care and clinical trials demonstrated a reduction in length of hospital stay (Fisher et al, 2016; Langhorne et al, 2017). However, more recent evidence has found that the impact of early supported discharge on length of hospital stay in practice is less than was previously reported in clinical trials, likely due to the fact that the length of hospital stay for all inpatients with stroke is much shorter than when many of the trials were conducted (Fisher et al, 2021). It should be noted that evidence suggests that early supported discharge is only appropriate for a proportion of the stroke population (those with mild to moderate disability - up to 40% of patients) and is usually offered as a time-limited intervention (Fisher et al, 2011). **[2023]**

Consensus-based recommendations state that people with more severe disability following a stroke, those with rehabilitation needs beyond early supported discharge or those going into residential or nursing homes need access to community stroke rehabilitation. This should be available following discharge from hospital, immediately following early supported discharge, or at a later point if needs are identified within the community (Fisher et al, 2013; NHS England, 2022). People with complex stroke-related needs are likely to require rehabilitation in hospital and should be transferred into the community only when they can be supported in their place of residence, including care homes, by a community stroke rehabilitation service (Fisher et al, 2013; NHS England, 2022). **[2023]**

The greatest benefits of rehabilitation are associated with co-ordinated, multidisciplinary stroke specialist community services (Langhorne et al, 2017; Fisher et al, 2020). Stroke specialist care is

defined as that provided by healthcare professionals with the necessary knowledge, skills and experience in managing stroke, evidenced by a suitable qualification and training. A stroke specialist team or service is defined as a group of specialists who work together regularly to manage people with stroke, and who between them have the specific knowledge and skills to assess and manage most stroke-related problems (Fisher et al, 2013; Fisher et al, 2020; NHS England, 2022). While in some instances it may be appropriate for stroke and neurological rehabilitation to be delivered by the same integrated team, the service must be able to deliver all the relevant recommendations made in this guideline. **[2023]**

The importance of in-reach from the community and collaborative working across the stroke care pathway has also been emphasised. Members of early supported discharge and community stroke rehabilitation services should be involved in hospital discharge planning and decision making by attending stroke unit multidisciplinary team meetings (Fisher et al, 2013; Fisher et al, 2020). **[2023]**

Evidence also supports the need for at least a minimum multidisciplinary core team structure defined by recommended ratios of WTE staff per 100 patients treated annually. These ratios should be viewed as the minimum core team requirements and will require local review and modelling to ensure that services meet patients' needs and deliver the required intensity of therapy, recognising that appropriate resources will be required to support people with stroke with more complex disability and needs. To achieve this, existing services including early supported discharge teams and community stroke rehabilitation could be brought together into one integrated seamless service e.g. an Integrated Community Stroke Service (Fisher et al, 2011; Fisher et al, 2020; NHS England, 2022). A regular review of the number of patients seen and monitoring of the patients' characteristics and needs should be an integral process undertaken by community rehabilitation services. **[2023]**

Stroke services should routinely use standardised measures to monitor the person's recovery (Fisher et al, 2011; Fisher et al, 2013). Consensus and observational studies suggest that the carer's needs should also be assessed and appropriate training in care provided (Fisher et al, 2013; Fisher et al, 2016; NHS England, 2022) although a large cluster RCT of a structured training programme for caregivers of inpatients after stroke showed no benefit of the intervention over usual care (Forster et al, 2013), and further research is needed in this area. **[2023]**

2.8 Implications

All of the recommendations about transfers of care require close collaboration between those who commission/sanction and provide care in hospital and in the community. Service redesign based around the needs of the person with stroke often requires a willingness to shift resources from one sector to another if that is where care is more appropriately and effectively provided. Service redesign or extra resources may be required to ensure equity of access for people living in care homes. **[2016]**

2.9 Remotely delivered therapy and telerehabilitation

Remotely delivered therapy is rehabilitation delivered using technology, with a remote therapist personalising a programme or tasks to specifically address identified impairments and goals. Technological innovations such as telerehabilitation may help address barriers to face-to-face rehabilitation, such as time and resource limitations, geographical isolation, and compliance with rehabilitation (Appleby et al, 2019). Remotely delivered therapy is discussed in more detail in [Section 4.5 Remotely delivered therapy and telerehabilitation](#). **[2023]**

2.10 Measuring rehabilitation outcomes

The measurement of function is central to the rehabilitation process. A review of the literature relating to assessment and measurement is beyond the scope of this guideline, and the Working Party does not specify which measures should be used beyond a small number of specific circumstances and examples. Many valid tools exist and it is important when considering the use of an assessment measure to understand which domain of the WHO ICF framework the instrument is measuring, and to ensure that the instrument is appropriate to the intervention in question (Wade, 1992). Clinicians should be trained in the use of measurement scales to ensure consistent use within the team and to provide an understanding of their properties and limitations. This section therefore only considers the general principles of measurement in stroke rehabilitation. **[2016]**

2.10 Recommendations

- A Assessment measures used in stroke rehabilitation should meet the following criteria as far as possible:
- they should collect relevant data across the required range (i.e. they are valid and fulfil a need);
 - they should have sufficient sensitivity to detect change within a person and differences between people;
 - their reliability should be known when used by different people on different occasions and in different settings;
 - they should be simple to use under a variety of circumstances;
 - they should provide scores that are easily understood. **[2016]**
- B A stroke service should agree on a standard set of assessment measures that should be collected and recorded routinely. **[2016]**
- C A stroke service should have protocols for determining the routine collection and use of data that:
- specify the reason for and proposed use of each assessment measure;
 - provide individual clinicians with a choice of assessment measures where no measure is obviously superior;
 - review the utility of each assessment measure regularly. **[2016]**
- D A stroke service should have protocols for the use of more complex assessment measures, describing:
- when it is appropriate or necessary to consider their use;
 - which assessment measure(s) should be used;
 - what specific training or experience is needed to use the assessment measure(s). **[2016]**

2.10 Sources

A–D Wade, 1992; Wikander et al, 1998; Working Party consensus

2.10 Implications

Services should consider the assessment measures that best serve their patients with stroke. These are likely to vary according to where they are in their treatment and recovery, but the preference should always be towards assessment measures that describe activities and participation, as opposed to impairments (see the WHO ICF framework in [Section 1.3 Models underpinning guideline development](#)). **[2016]**

2.11 Psychological care – organisation and delivery

Psychological care should be provided by stroke services across acute and community settings. National audits continue to highlight inadequate service provision, and surveys of the long term needs of people with stroke echo the need for service improvement. This section covers issues of service organisation and delivery, with recommendations for the rehabilitation of specific cognitive and mood difficulties contained in Chapter 4. **[2016]**

The three main models (collaborative care, matched care and stepped care) are summarised in NICE Clinical Guideline 91: Depression in adults with a chronic physical health problem (NICE, 2010). Stepped care involves starting all people at the lowest level intervention and stepping up to the next level if they do not adequately respond. Matched (or stratified) care includes an initial triage so that people start on the most appropriate step, which may be the highest level. Stepped or matched care can be part of collaborative care, a model for the management of chronic disease. Collaborative care has four components: collaborative identification of problems; goal-planning; self-management training and support to facilitate intervention plans, behaviour change and emotional coping; and active monitoring and follow-up. **[2016]**

A key feature of these models is to highlight the complementary roles played by specialists in neuropsychological provision (clinical neuropsychologist/clinical psychologist and assistants) and by other members of the stroke team. In these models the latter provide psychological support at the first and second levels whilst the clinical neuropsychologist/clinical psychologist's role is principally at level three/high-intensity provision and in training other service providers. **[2016]**

One further model of psychological care is comprehensive neuropsychological rehabilitation, based on a biopsychosocial model of illness. Comprehensive programmes integrate evaluation of cognition, behaviour and emotional needs to formulate the individual's difficulties. They assist in developing alternative or compensatory expectations and behaviours, leading towards independent self-management (see [Section 4.4 Self-management](#)). They acknowledge that people with stroke may have limited awareness of impairments or their impact, and that many therapies require motivation for engagement. **[2016]**

2.11 Recommendations

- A Services for people with stroke should have a comprehensive approach to delivering psychological care that includes specialist clinical psychology/neuropsychology input within the multidisciplinary team. **[2016]**
- B Services for people with stroke should offer psychological support to all patients regardless of whether they exhibit specific mental health or cognitive difficulties, and use a matched care model to select the level of support appropriate to the person's needs. **[2016]**
- C Services for people with stroke should provide training to ensure that clinical staff have an awareness of psychological problems following stroke and the skills to manage them. **[2016]**
- D Services for people with stroke should ensure that the psychological screening and assessment methods used are appropriate for use with people with aphasia and cognitive impairments. **[2016]**
- E Services for people with stroke should provide screening for mood and cognitive disturbance within six weeks of stroke (in the acute phase of rehabilitation and at the transfer of care into post-acute services) and at six and 12 months using validated tools and observations over time. **[2016]**

- F Services for people with stroke should include specialist clinical psychology/neuropsychology provision for severe or persistent symptoms of emotional disturbance, mood or cognition. **[2016]**
- G Services for people with stroke should consider a collaborative care model for the management of people with moderate to severe neuropsychological problems who have not responded to high-intensity psychological interventions or pharmacological treatments. This care model should involve collaboration between the GP, primary and secondary physical health services and case management, with supervision from a senior mental health professional and should include long-term follow-up. **[2016]**

2.11 Sources

- A Salazar et al, 2000; Cicerone et al, 2008; NICE, 2016d; Working Party consensus
- B, C Gillham and Clark, 2011; NICE, 2010b; Working Party consensus
- D Working Party consensus
- E NICE, 2016d; Working Party consensus
- F, G Working Party consensus

2.11 Evidence to recommendations

Both NICE (2011) and the former NHS Stroke Improvement Programme (Gillham & Clark, 2011) advocate a stepped-care model based on an initial awareness of need and which places individuals on an appropriate step, or quickly identifies those who need to be immediately stepped up. Essentially, this is matched care. No stroke-specific evidence was found for stepped care. The literature from general mental health includes one systematic review including non-controlled trials (Firth et al, 2015) and one meta-analysis (van Straten et al, 2015). These focused on stepped care for depression and there were no trials in anxiety. They conclude that stepped care is as effective as usual care, with some results favouring stepped care. Both papers noted that the evidence for stepped care was limited and further research was required comparing stepped care with other models such as matched care and collaborative care, both in terms of efficacy and cost-effectiveness. Additionally, what is considered to be stepped care is highly variable, including the quality of services provided and the use of mixed models of service delivery (Firth et al, 2015; van Straten et al, 2015). A Cochrane review (Archer et al, 2012) of the effectiveness of collaborative care for the treatment of depression and anxiety in mental health concluded that collaborative care is associated with greater improvement in depression and anxiety outcomes compared with usual care. **[2016]**

Most of the evidence for comprehensive and holistic rehabilitation programmes after acquired brain injury, including stroke, comes from case series or cohort studies. Two RCTs in acquired brain injury support the integration of cognitive, interpersonal and functional skills (Salazar et al, 2000; Cicerone et al, 2008). Evidence for long-term improvement is mixed. Methodological concerns were reported in two reviews of traumatic brain injury (Cicerone et al, 2009; Cattalani et al, 2010) suggesting a need for more well-designed trials. **[2016]**

2.11 Implications

Stroke services need to consider how to develop and maintain the knowledge and skills in all clinical staff to provide appropriate psychological support to people with stroke, and how to provide the high-intensity support needed by a minority of people with cognitive and mental health issues. Compared to historical levels of provision, this will require considerable investment which is likely to prove cost-effective in the longer term. Commissioners/planners of therapy services for people with stroke should bear in mind that many current arrangements do not include psychological provision, or it may be separately commissioned often from another provider. For instance the 2016 NICE Quality Standard

QS2 is clear that a clinical psychologist/neuropsychologist with expertise in stroke rehabilitation should be a core member of the multidisciplinary team. Those responsible for planning and providing stroke services should also provide for the long-term management of psychological difficulties of delayed onset (e.g. anxiety, depression). [2016]

2.12 Vocational rehabilitation

Returning to work is an important goal for many people after stroke, and comprehensive stroke services should include vocational rehabilitation provision to support people with stroke to return to work. Vocational rehabilitation is summarised as ‘a co-ordinated plan supported by all those working with the employee to optimise their work capability’ (British Society of Rehabilitation Medicine, 2021). The organisation and delivery of vocational rehabilitation is discussed in more detail in [Section 4.15 Return to work](#). [2023]

2.13 Follow-up review and longer term support

The course of recovery after stroke in any individual may fall outside expected time frames. The consensus of the Guideline Development Group is that a comprehensive, structured needs reassessment should be undertaken at 6 months and annually thereafter, depending on the individual’s needs. This review should consider physical, psychological and social needs (including relationships and work, where applicable) related to adjusting to life after stroke. Whilst limited, there is evidence to suggest that for some people improvements in communication, arm function, walking, physical fitness and ADL can be achieved with interventions more than 6 months after stroke (Palmer & Enderby, 2007; Duncan et al, 2011; Ferrarello et al, 2011; Lohse et al, 2014; Veerbeek et al, 2014; Ward et al, 2019). The provision and timing of appropriate, person-centred follow-up rehabilitation, holistic structured reviews and long-term support after stroke are discussed in more detail in [Sections 5.27 Further rehabilitation](#), and [5.28 Social integration and participation](#). [2023]

2.14 Stroke services for younger adults

Stroke occurs at all ages and about a quarter of people with stroke are aged under 65 years. Some younger adults feel that general stroke services, of which the majority of users are older adults, do not meet their needs. For example, younger adults are more likely to have an unusual cause for their stroke, rehabilitation may require specific attention to work and bringing up children, and social needs and expectations may be different. Thus, although all stroke services should respond to the particular needs of each individual regardless of age or other factors, it is appropriate to draw attention to this group of younger people with stroke. Guideline users should also refer to [Section 4.15 Return to work](#). A separate guideline covering stroke in children has been produced (Royal College of Paediatrics and Child Health, 2017). [2023]

2.14 Recommendations

- A All stroke care, including (hyper-) acute care for younger adults with stroke, should be based on an assessment of the person’s individual needs and priorities. [2023]
- B Acute stroke services should:
 - recognise and manage the particular physical, psychological and social needs of younger people with stroke (e.g. vocational rehabilitation, childcare);
 - liaise with the most appropriate specialist neurorehabilitation service. [2023]
- C People who have had a stroke in childhood and require ongoing healthcare into adulthood should have their care transferred in a planned manner to appropriate adult services. [2023]

2.14 Sources

- A, B Guideline Development Group consensus
- C Department of Health (UK), 2005; Guideline Development Group consensus

2.14 Implications

These recommendations can most readily be met by a specialist neurological rehabilitation service as such services generally, though not exclusively, focus on people of working age. Each locality (health economy) should have a specialist neurological rehabilitation service to comply with the National Service Framework for Long-term (Neurological) Conditions (Department of Health (UK), 2005). There also needs to be a close link between neurological and stroke rehabilitation services and a system in place to ensure that there is a seamless transition for younger people with stroke from paediatric to adult neurological services. **[2016]**

2.15 End-of-life (palliative) care

About one in 20 people with acute stroke will be receiving end-of-life care within 72 hours of onset, and one in seven people with acute stroke will die in hospital (Intercollegiate Stroke Working Party, 2016), making stroke one of the most lethal acute conditions in modern medicine. This means that providing high quality end-of-life care is a core activity for any multidisciplinary stroke team. Predicting the prognosis after acute stroke can be challenging and may account for the low proportion of people with stroke identified for end-of-life care in hospital and community settings. Stroke may cause a range of problems including pain and distress, depression, cognitive problems, confusion and agitation, and problems with nutrition and hydration. When these issues are appropriately and holistically managed, distress associated with the end of life for both the person and the family/carers can be alleviated. In particular, while there is the risk of aspiration and choking, rigid adherence to recommendations elsewhere in this guideline on access to oral food or fluids could, in palliative care, result in burdensome restrictions that may exacerbate suffering. The decision-making process to support people to eat and drink with acknowledged risks should be person-centred and involve the person and their family/carers, and other members of the multidisciplinary team and include a swallowing assessment and steps to minimise risk (Royal College of Physicians, 2021; Royal College of Speech and Language Therapists, 2021). The process can be supported by material such as the clinically-assisted nutrition and hydration guidance from the RCP (London)/BMA (2018) at <https://www.bma.org.uk/advice-and-support/ethics/adults-who-lack-capacity/clinically-assisted-nutrition-and-hydration>. **[2023]**

Advance care planning should take place for those people who may survive the acute stroke with limited life expectancy, to facilitate the timely involvement of specialist palliative care services. **[2023]**

2.15 Recommendations

- A Services providing acute and long-term care for people with stroke should provide high quality end-of-life care for those who need it. **[2016]**
- B Staff caring for people dying of stroke should be trained in the principles and practice of end-of-life care, including the recognition of people who are approaching the end of life. **[2016]**
- C Decisions to withhold or withdraw life-prolonging treatments after stroke including artificial nutrition and hydration should, whenever possible, take the person's prior expressed wishes and preferences into account and should be taken in the best interests of that person. When withdrawing artificial nutrition and hydration, a recognised nutrition and hydration decision-making process should be considered. **[2023]**
- D End-of-life (palliative) care for people with stroke should include an explicit decision not to

have burdensome restrictions that may exacerbate suffering. In particular, following assessment this may involve a decision, taken together with the person with stroke, their family/carers, and the multidisciplinary team, to allow oral food or fluids despite risks including aspiration and choking. [2023]

- E People with stroke with limited life expectancy, and their family where appropriate, should be offered advance care planning, with access to specialist inpatient and community palliative care services when needed. The multidisciplinary team should establish whether there is any existing documentation of the patient's wishes regarding management of risks associated with continued eating and drinking and whether it remains relevant, and agree with the patient and/or family/carers an advanced care plan where appropriate. [2023]
- F People dying of stroke should have access to specialist palliative care, including the timely transfer of care to their home or to a hospice or care home according to the wishes of the person and their family/carers. This should also include timely communication and involvement of the primary care team. [2016]

2.15 Sources

- A, B NICE, 2015a; Working Party consensus
- C-E Royal College of Physicians, 2021; Royal College of Speech and Language Therapists, 2021; Guideline Development Group consensus
- F Payne et al, 2010; NICE, 2015a; Working Party consensus

2.15 Evidence to recommendations

Much of the research in end-of-life care has come from the field of cancer, and there are few good quality end-of-life studies in stroke. A Cochrane review by Good et al (2014) reviewed medically assisted hydration in adults receiving palliative care, and concluded there was no clear evidence of benefit with assisted hydration as problems from side effects can be as distressing as symptoms associated with withholding fluids. Gardiner et al (2013) conducted a small qualitative study of focus groups and interviews with the multidisciplinary team, and concluded that more people with stroke should benefit from end-of-life care, and collaboration between palliative care and stroke teams at an earlier stage could improve patient care. [2016]

2.15 Implications

The main implication of these recommendations is that staff in stroke teams will need to increase their awareness and expertise in end-of-life/palliative care and recognise that this is a core part of the work of a comprehensive stroke service. This includes high quality liaison with palliative care and primary care teams. A systematic mortality audit can identify and encourage good practice in this important area of clinical care. [2016]

2.16 Carers

The term 'carers' can refer both to formal, paid carers (people with professional training) and to informal and unpaid carers such as family and friends who undertake care. This section is relevant to informal, unpaid carers: their role and involvement with the person with stroke is central from the outset and is likely to be a constant and continuing relationship with the person, long after other services have ended. [2016]

In the UK, the 2014 Care Act enshrines the legal duty of a Local Authority to assess any carer who requests an assessment or who appears to need support. The authority can use the assessment to

identify support needs, and to discuss how these could be met. This might mean providing help or putting the carer in touch with other organisations, such as local charities. There is no Irish equivalent of this Act but the Carer's Leave Act 2001 and the provision for a dedicated carer's allowance support carers in their role in Ireland. [2016]

2.16 Recommendations

- A The views of the person with stroke should be sought, to establish the extent to which they wish family/carers and others to be involved in the planning and delivery of their care. [2016]
- B If the person with stroke agrees, family/carers should be involved in significant decisions as an additional source of information about the person both clinically and socially. [2016]
- C The primary carer(s) of a person with stroke should be offered an educational programme which:
- explains the nature, consequences and prognosis of stroke and what to do in the event of a further stroke or other problems e.g. post-stroke epilepsy;
 - teaches them how to provide care and support;
 - gives them opportunities to practise giving care;
 - provides advice on secondary prevention, including lifestyle changes. [2016]
- D When care is transferred out of hospital to the home or care home setting, the carer of a person with stroke should be offered:
- an assessment of their own needs, separate to those of the person with stroke;
 - the practical or emotional support identified as necessary;
 - guidance on how to seek help if problems develop. [2016]
- E The primary carer(s) of a person with stroke should be provided with the contact details of a named healthcare professional (e.g. a stroke co-ordinator or key worker) who can provide further information and advice. [2016]
- F After a person with stroke has returned to the home or care home setting, their carer should:
- have their need for information and support reassessed whenever there is a significant change in circumstances (e.g. if the health of the carer or the person with stroke changes);
 - be shown how to seek further help and support. [2016]

2.16 Sources

- A, B Working Party consensus
- C Patel et al, 2004; Legg et al, 2011; Forster et al, 2012
- D Obligations under the 2014 Care Act; Working Party consensus
- E NICE, 2016d; Working Party consensus
- F Obligations under the 2014 Care Act; Working Party consensus

2.16 Evidence to recommendations

Two Cochrane reviews have addressed this issue: Legg et al (2011) and Forster et al (2012). Research into interventions that prepare carers for the role have focused on three main areas; support and information, procedural knowledge, and psycho-educational training (Legg et al, 2011). Whilst these systematic reviews are of high quality and support the provision of information and training for caregivers, information on implementation is lacking. With regard to long-term follow-up, only one Dutch trial (Fens et al, 2014) provided 18-month follow-up data but this was non-randomised and thus subject to bias. An earlier, single-site RCT found that a structured caregiver training programme,

delivered in an inpatient setting by stroke unit staff significantly reduced carer burden, anxiety and depression (Patel et al, 2004). However a much larger cluster RCT and economic evaluation did not reproduce these benefits when using a cascade training model i.e. training some staff to train all staff and then to train carers (Forster et al, 2013). A nested process evaluation indicated that many carers had not been trained to the necessary competency level (Clarke et al, 2013) and so the efficacy and generalizability of the cascade model for delivering caregiver training is still unproven, and recommendations remain largely based on consensus regarding best practice. [2016]

2.17 People with stroke in care homes

One in twelve people with stroke have to move into a care home because of their stroke (Intercollegiate Stroke Working Party, 2016). Conversely, about a quarter of care home residents have had a stroke, often in association with other significant co-morbidities. At present people in care homes in both the UK and Ireland rarely receive any ongoing rehabilitation or equipment provision by statutory stroke services despite this being their main domicile. Reducing dependency as far as possible and improving quality of life for people with stroke whatever their place of residence is an important and compassionate objective of community provision for people with stroke. [2016]

2.17 Recommendations

- A People with stroke living in care homes should be offered assessment and treatment from community stroke rehabilitation services to identify activities and adaptations that might improve quality of life. [2016]
- B Staff caring for people with stroke in care homes should have training in the physical, cognitive, communication, psychological and social effects of stroke and the management of common activity limitations. [2016]
- C People with stroke living in care homes with limited life expectancy, and their family where appropriate, should be offered advance care planning, with access to community palliative care services when needed. [2016]

2.17 Sources

- A Crocker et al, 2013; Working Party consensus
- B, C Working Party consensus

2.17 Evidence to recommendations

A Cochrane review (Crocker et al, 2013) examined the evidence for physical rehabilitation for older people in care homes with a range of co-morbidities that included stroke. The review identified small reductions in disability that may not be applicable to all residents, without adverse effects, and called for further trials. In a large cluster RCT of people with stroke living in care homes (1,042 participants in 228 care homes), Sackley et al (2015) found no benefits in disability, mood or quality of life from a 3-month person-centred goal setting intervention for residents and staff delivered by occupational therapists and assistants. This may be because the functional limitations in this group of people were so severe, and a third of all participants died over the course of the trial. On the strength of current evidence, the best means to reduce dependency and improve quality of life for people with stroke living in care homes is not known. [2016]

2.17 Implications

The extent of unmet need in people living in care homes is unknown, but resource implications are likely. The level of need may be considerable and not easily met within existing resources or with existing interventions. Presently, it will usually be more appropriate for staff from the stroke service to

visit the care home which has implications for travel and use of time. Furthermore in practice it would be difficult within a single home, both morally and practically, to restrict input to people with stroke when many other residents may also need and benefit from specialist rehabilitation assessment, advice and interventions. [2016]

2.18 Service governance and quality improvement

Stroke services should develop a culture of continuous quality improvement, and attention to good governance is mandatory. The obligation to seek and respond to information regarding service quality, safety and patient experience is another of the principal implications of the 2013 Francis report into the failings in hospital care at Mid-Staffordshire NHS Foundation Trust (Francis, 2013). The process of clinical governance should be embedded within all healthcare organisations, and this section only considers the stroke-specific aspects. People's perceptions of the quality of care they receive do not always match the clinicians' views of the care that they have delivered and these views need to be separately audited, in a manner that enables the participation of those with significant disabilities. The process of quality improvement includes collecting appropriate data in a timely manner, analysing the data and acting upon the findings. [2016]

2.18 Recommendations

- A Clinicians providing care for people with stroke should participate in national stroke audit to enable comparison of the clinical and organisational quality of their services, and use the findings to plan and deliver service improvements. [2016]
- B Services for people with stroke should take responsibility for all aspects of service quality by:
 - keeping a quality register of all people admitted to their organisation with a stroke;
 - regularly reviewing service provision against the evidence-based standards set out in relevant national clinical guidelines;
 - providing practical support and multidisciplinary leadership to the process of clinical audit;
 - encouraging patients to participate in research whenever possible;
 - participating actively in regional and national quality improvement initiatives such as Clinical Networks. [2016]
- C General practitioners should regularly audit the primary and secondary prevention of stroke within their practice, and maintain a register of people with stroke or TIA. [2016]
- D The views of people with stroke and their family/carers should be actively sought when evaluating service quality and safety, and when planning service developments. [2016]
- E People with stroke and their family/carers should be offered any practical support necessary to enable participation in service user consultations. [2016]

2.18 Sources

- A, B Obligations under the NHS Standard Contract; Working Party consensus
- C-E Working Party consensus

2.18 Implications

Data collection and quality control procedures require specific resources, including staff time and unfortunately these are often not made available, particularly for continuous audit. It also requires commitment to the process by the whole multidisciplinary team. Regulators and other organisations that monitor performance should use data that are collected routinely or through national audit, rather than demanding data that require additional resources to deliver. [2016]

Some resources need to be allocated to facilitate the involvement of service users who have limitations with mobility or communication. These recommendations require organisations to be supportive and listening in their attitude to the opinions of service users. **[2016]**

Glossary

Activities of daily living	Refers to activities that people normally undertake (e.g. bathing, dressing, feeding themselves).
Acupuncture	A complementary medicine that involves inserting thin needles into the skin.
Acute stroke service	Consists of: a) a comprehensive stroke centre (CSC) providing hyperacute, acute and inpatient rehabilitation including thrombectomy (thrombectomy centre) and neurosurgery; or b) an acute stroke centre (ASC) providing hyperacute, acute and inpatient rehabilitation. All components of a specialist acute stroke service should be based in a hospital that can investigate and manage people with acute stroke and their medical and neurological complications.
Aerobic exercise	Low- to moderate-intensity exercise that can be sustained for long periods of time (e.g. cycling, swimming or walking).
Agnosia	The inability for a patient to recognise or make proper sense of sensory information.
Alteplase	A drug used for thrombolysis.
Aneurysm	A bulge in the wall of a blood vessel that is filled with blood. This can burst and cause a haemorrhage.
Angiography	A technique that uses X-ray technology to image blood vessels.
Anticoagulants	A group of drugs used to reduce the risk of clots by thinning the blood.
Antiphospholipid syndrome	Sometimes called 'sticky blood syndrome' because blood clots form too quickly; this is due to antibodies against the body's phospholipid part of every cell in the body.
Antiplatelets	A group of drugs used to prevent the formation of clots by stopping platelets in the blood sticking together.
Antithrombotics	The generic name for all drugs that prevent the formation of blood clots. This includes antiplatelets and anticoagulants.
Aphasia	Communication difficulties after a stroke which can affect a person's speech, processing, reading and writing.
Arterial dissection	This is caused as a result of a small tear forming in the lining of the arterial wall.
Atherosclerosis	Fatty deposits that harden on the inner wall of the arteries (atheroma) and roughen its surface; this makes the artery susceptible to blockage either by narrowing or by formation of a blood clot.
Atrial fibrillation	A heart condition that causes an irregular heartbeat, often faster than the normal heart rate.
Audit (clinical)	A method of evaluating the performance of a clinical service against a set of standards/criteria.
Bobath therapy	Treatment which aims to use facilitative handling which prioritises normal movement and muscle tone or inhibition of reflex activity rather than maximising practice and patient activity. Also known as neurophysiological or neurodevelopmental treatment.
Body mass index (BMI)	An index of body weight corrected for height.
Botulinum toxin	A toxin which when injected can relax muscles to reduce spasticity.

Cardiovascular disease	Disease of the heart and/or blood vessels.
Care pathway	A tool used by healthcare professionals to define the sequence and timings of a set of tasks or interventions that should be performed for a patient who enters a healthcare setting (e.g. a hospital) with a specific problem.
Carotid angioplasty	A surgical procedure that widens the internal diameter of the carotid artery, after it has been narrowed by atherosclerosis.
Carotid arteries	Main blood vessels in the neck, which supply oxygenated blood to the brain.
Carotid endarterectomy (CEA)	A surgical procedure used to clear the inside of the carotid artery of atheroma.
Carotid stenosis	The narrowing of the carotid arteries in the neck.
Carotid stenting	Insertion of a tube into the carotid artery in order to prop the artery open and reduce narrowing.
Caval filter	A device that is inserted into the veins to prevent a blood clot entering the lungs.
Cerebral venous thrombosis	A blood clot that forms within a vein inside the brain.
Clinician	A registered healthcare professional such as a doctor, nurse or therapist.
Cochrane review	A systematic review of research in health care and health policy that is published in the Cochrane Database of Systematic Reviews.
Commissioner (health services)	Person or organisation in some parts of the UK National Health Service (NHS) that decides how to allocate the health budget for a service.
Community stroke team, community stroke rehabilitation team	A stroke specialist multidisciplinary team that provides stroke rehabilitation for patients in their own home or other community setting (including care homes and nursing homes). This may be following hospital discharge, after a patient has been discharged from an early supported discharge team or at any point post stroke where rehabilitation needs are identified. The intensity and duration of this service should be determined by patient need.
Compensatory strategies	Learning an alternative way of completing a task.
Computed tomography (CT)	An X-ray technique used to examine the brain.
Confidence interval (CI)	When analysing a research study, this is the range ('interval') of possible results that statisticians are 95% confident the actual result lies between.
Constraint-induced movement therapy	Therapy that involves preventing the use of the unaffected side of the body thus forcing the use of the affected side.
Cost-effectiveness	The extent to which the benefits of a treatment outweigh the costs.
Decompressive hemicraniectomy	A surgical procedure for the treatment of raised pressure inside the brain from fluid, blood or swelling. A piece of skull is removed to allow the brain to swell.
Deep vein thrombosis (DVT)	A blood clot that develops in the large veins, usually in the legs.
Diabetes, diabetes mellitus	A metabolic disease in which a person has high blood sugar.
Diagnostic accuracy	The degree to which a diagnostic (or screening) tool or procedure is able to distinguish between cases and non-cases. See also 'sensitivity' or 'specificity'.
Doppler ultrasound	An imaging technique that measures blood flow and velocity through blood vessels.

Dysarthria	Difficulty producing clear speech, caused by muscle weakness.
Dyspepsia	Indigestion.
Dysphagia	Difficulty in swallowing.
Early supported discharge	An intervention delivered by a co-ordinated, stroke specialist, multidisciplinary team that facilitates the earlier transfer of care from hospital into the community and provides responsive (within 24 hours) and intensive stroke rehabilitation in the patient's place of residence (usually over a time-limited period).
Enderterectomy	The surgical removal of plaque from a blocked artery to restore blood flow.
Face Arms Speech Time (FAST) test	A test used to screen for the possibility of a stroke or a TIA.
Fatigue	Physical or mental exhaustion that does not get better through normal periods of rest.
Foot-drop	A condition in which the foot hangs limply whilst walking.
Gastrointestinal bleeding	Bleeding anywhere between the throat and the rectum.
Gastrostomy	A surgical opening into the stomach to enable feeding.
Gastrostomy feeding (also tube feeding)	Provision of nutrition and fluids via a tube directly into the gastrointestinal tract.
Goal attainment	Rehabilitation goals for particular tasks are set by the patient and therapists together.
Haemorrhage	Bleeding caused by blood escaping into the tissues.
Haemorrhagic stroke	A stroke that happens when a blood vessel bursts, leading to bleeding in the brain (also called a 'brain haemorrhage').
Healthcare professional	A professional involved in stroke care, such as a doctor, nurse, therapist, or care staff.
HEART UK	A cholesterol charity.
Hemianopia	Blindness or some loss of vision in one part of the visual field.
Homeostasis	Regulation of internal environment (e.g. body temperature regulated at 37°C).
Hydrocephalus	A build up of fluid within the skull.
Hyperacute stroke unit/centre/service	A stroke unit, centre or service that treats patients in the first 72 hours of symptom onset.
Hyperlipidaemia	Raised levels of lipids (cholesterol, triglycerides or both) in the blood serum.
Hypertension	Raised blood pressure.
Hypertensive encephalopathy	Brain damage caused by raised blood pressure.
Hypoglycaemia	Blood sugar levels lower than the normal range.
Hypoxia	Blood oxygen levels outside the normal range, e.g. below 95% saturation.
Incontinence	Inability to control passing of urine and/or faeces.
Infarct	An area of cell death due to a deprived blood supply.
Integrated community stroke service	An integrated service that provides early supported discharge and community stroke rehabilitation.

International Classification of Functioning, Disability and Health (ICF)	A classification of health used as a framework by the World Health Organization (WHO) to measure health and disability.
Ischaemic stroke	A stroke that happens when a blood clot blocks an artery that is carrying blood to the brain.
Lumbar puncture	A diagnostic or therapeutic procedure that involves collection of fluid from the base of the spine.
Magnetic resonance imaging (MRI)	A non-invasive imaging technique that allows for detailed examination of the brain.
Malnutrition Universal Screening Tool (MUST)	A screening tool consisting of five steps to help identify which adults are malnourished or at risk of malnourishment.
Meta-analysis	A statistical technique for combining the results of a number of studies that address the same question and report on the same outcomes to produce a summary result.
Mouth care	Also referred to as oral health care. Refers to the promotion and maintenance of a clean oral cavity including the teeth, gums, cheeks, tongue and palate. A clean mouth requires the removal of traces of food and debris and dental plaque.
MRI with diffusion-weighted imaging	This type of scan shows areas of recent ischaemic brain damage.
Musculoskeletal pain	Pain of the muscles and/or joints.
National Institute for Health and Care Excellence (NICE)	A special health authority set up within the NHS to develop appropriate and consistent advice on healthcare technologies, and to commission evidence-based guidelines. Its remit extends in most cases to England, Wales and Northern Ireland.
National Institute of Health Stroke Scale (NIHSS)	A score to assess the severity of a stroke.
Neuropathic pain	Pain caused by damage to nerves.
Orthosis	An appliance used to support or align an area of the body to facilitate movement, or prevent or correct damage.
Palliative care	Care that relieves rather than treats symptoms.
Pneumonia	An inflammatory condition of the lungs usually caused by infection.
Pulmonary embolism	A blood clot in the lungs.
Quality of life	Refers to the level of comfort, enjoyment, and ability to pursue daily activities.
Quality standard	A standard set (e.g. by NICE) that is used to define whether the quality of care is of a high standard.
Randomised controlled trial (RCT) (often 'randomised trial')	A trial in which people are randomly assigned to two (or more) groups: one (the experimental group) receiving the treatment that is being tested, and the other (the comparison or control group) receiving an alternative treatment, a placebo (dummy treatment) or no treatment. The two groups are followed up to compare differences in outcomes to see how effective the experimental treatment was. Such trial designs help minimise experimental bias.

Recognition of stroke in the emergency room (ROSIER)	A tool used to establish the diagnosis of stroke or TIA.
Rehabilitation	A set of treatments and activities to promote recovery and reduce disability. Rehabilitation treatments are provided by therapists and therapy assistants.
Saturated fat	A type of fat that is commonly found in meat and dairy products as opposed to fats found in plants and fish, which may be unsaturated.
Self-efficacy	A person's belief in their own competency.
Self-management	Actions and confidence of individuals to manage the medical and emotional aspects of their condition in order to maintain or create new life roles.
Sensitivity	The ability of a test to detect a problem.
Service planners	Those responsible for planning and sanctioning health services in Ireland.
Side effect	An adverse event that occurs because of a therapeutic intervention.
SIGN	Scottish Intercollegiate Guidelines Network, an organisation set up to develop evidence-based guidelines. It is part of Healthcare Improvement Scotland and its remit covers Scotland.
Spasticity	Increased stiffness of the muscles that occurs in the paralysed limbs after stroke.
Specialist	A healthcare professional with the necessary knowledge and skills in managing people with stroke and conditions that mimic stroke, usually by having a relevant further qualification and keeping up to date through continuing professional development. This does not require the healthcare professional exclusively to manage people with stroke, but does require them to have specific knowledge and practical experience of stroke.
Specialist team	A group of specialists who work together regularly managing people with stroke and conditions that mimic stroke, and who between them have the knowledge and skills to assess and resolve the majority of problems. At a minimum, any specialist unit, team or service must be able to deliver all the relevant recommendations made in this guideline. This does not require the team exclusively to manage people with stroke, but the team should have specific knowledge and practical experience of stroke.
Specificity	The ability of a test to detect the right problem.
Splint	A custom or ready-made external device to support a joint or limb in a certain position.
Stenosis	Abnormal narrowing of a blood vessel.
Stenting	A metal mesh tube is placed in an artery or blood vessel to increase blood flow to an area blocked by stenosis.
Stroke	A clinical syndrome, of presumed vascular origin, typified by rapidly developing signs of focal or global disturbance of cerebral functions lasting more than 24 hours or leading to death.
Subarachnoid haemorrhage (SAH)	A haemorrhage from a cerebral blood vessel, aneurysm or vascular malformation into the subarachnoid space (the space surrounding the brain where blood vessels lie between the arachnoid and pia mater).
Subluxation	An incomplete or partial dislocation of a joint.
Systematic review	A way of combining the findings from a variety of different research studies to better analyse whether the studies have provided a convincing answer to a research question.

Telemedicine	The use of telecommunication and information technologies in order to provide clinical healthcare at a distance.
Tenecteplase	A drug used for thrombolysis.
Therapist	In the context of the guideline this includes the allied health professionals (UK) and health and social care professionals (Ireland) involved in stroke care. The main ones are dietitians, occupational therapists, orthoptists, orthotists, physiotherapists, and speech and language therapists.
Thrombectomy	The excision of a blood clot from a blood vessel.
Thrombectomy centre	A centre providing thrombectomies without providing acute stroke care.
Thrombolysis	The use of drugs to break up a blood clot. An example of a thrombolysis drug is alteplase, also sometimes called tPA.
Thrombosis	A formation of a blood clot.
Transient ischaemic attack (TIA)	An acute loss of focal cerebral or ocular function with symptoms lasting less than 24 hours and which is thought to be due to inadequate cerebral or ocular blood supply as a result of low blood flow, thrombosis or embolism associated with diseases of the blood vessels, heart, or blood.
Tube feeding (also gastrostomy feeding)	Provision of nutrition and fluids via a tube directly into the gastrointestinal tract.
Venography	An X-ray test that provides an image of the leg veins after a contrast dye is injected into a vein in the patient's foot.
Videofluoroscopy	A test for assessing the integrity of the oral and pharyngeal stages of the swallowing process. It involves videotaping X-ray images as the patient swallows a bolus of barium.
Vocational rehabilitation	A co-ordinated plan to optimise a person's ability to participate in paid or voluntary work.
Work	Different forms of occupation, including paid employment, vocational training, sheltered, therapeutic or voluntary work, and adult education.
Xanthochromia	The yellowish appearance of cerebrospinal fluid that occurs after bleeding into the fluid, usually after subarachnoid haemorrhage.

Abbreviations and acronyms

ABCD2	Age, blood pressure, clinical features, duration of TIA, and presence of diabetes
ADL	Activities of daily living
AF	Atrial fibrillation
APS	Antiphospholipid syndrome
ASC	Acute stroke centre
ASPECTS	Alberta Stroke Program Early Computed Tomography Score
ASA	Atrial septal aneurysm
BADS	Behavioural Assessment of the Dysexecutive Syndrome
BMI	Body mass index
BOA	Behavioural Outcomes of Anxiety
BP	Blood pressure
BPPV	Benign paroxysmal positional vertigo
CAA	Cerebral amyloid angiopathy
CADASIL	Cerebral autosomal dominant arteriopathy with subcortical infarcts and leucoencephalopathy
CI	Confidence interval
CIMT	Constraint-induced movement therapy
COC	Combined oral contraceptive
COVID-19	Coronavirus disease
CPAP	Continuous positive airways pressure
CPSP	Central post-stroke pain
CSC	Comprehensive stroke centre
CT	Computed tomography
CTA	Computed tomography angiography
CVT	Cerebral venous thrombosis
DISCs	Depression Intensity Scale Circles
DOAC	Direct oral anticoagulant
DVA	Driver and Vehicle Agency (Northern Ireland)
DVLA	Driver and Vehicle Licencing Agency (England, Scotland, Wales)
DVT	Deep vein thrombosis
DWI	Diffusion-weighted imaging
EADL	Extended activities of daily living
ECG	Electrocardiogram
ELISA	Enzyme-linked immunosorbent assay
EMA	European Medicines Agency
FAST test	Face Arm Speech Time test
FEES	Fibre-optic endoscopic evaluation of swallowing
FLAIR	Fluid attenuated inversion recovery
GDG	Guideline Development Group
GP	General practitioner
HAS-BLED	Hypertension, Abnormal score renal and liver function, Stroke, Bleeding, Labile INRs, Elderly, Drugs or alcohol score
HDL	High density lipoprotein
HIIT	High intensity interval training
HR	Hazard ratio
HRT	Hormone replacement therapy
HSE	Health Service Executive (Ireland)

IAPT	Improving Access to Psychological Therapies
ICF	International Classification of Functioning, Disability and Health
ICH	Intracerebral haemorrhage
ILR	Implantable loop recorder
INR	International normalised ratio (for blood clotting time)
IQR	Interquartile range
LDL	Low density lipoprotein
MCA	Middle cerebral artery
mCIMT	Modified constraint-induced movement therapy
MDT	Multidisciplinary team
MHRA	Medicines and Healthcare Products Regulatory Agency
MI	Myocardial infarction
MICON	Microbleeds International Collaborative Network
MR	Magnetic resonance
MRA	Magnetic resonance angiography
MRI	Magnetic resonance imaging
mRS	Modified Rankin Scale score
MSU	Mobile stroke unit
MUST	Malnutrition Universal Screening Tool
NASCET	North American Symptomatic Carotid Endarterectomy Trial
NDLS	National Driver Licence Service (Ireland)
NHS	National Health Service (UK)
NICE	National Institute for Health and Care Excellence
NIHSS	National Institutes of Health Stroke Scale
NIMAST	Northern Ireland Multidisciplinary Association of Stroke Teams
NMES	Neuromuscular electrical stimulation
NNT	Number needed to treat
NOAC	Non-vitamin K anticoagulant
NSAID	Non-steroidal anti-inflammatory drug
OR	Odds ratio
OSA	Obstructive sleep apnoea
PADL	Personal activities of daily living
PAF	Paroxysmal atrial fibrillation
PC-ASPECTS	Posterior circulation – Alberta Stroke Program Early Computed Tomography Score
PCC	Prothrombin complex concentrate
PE	Pulmonary embolism
PES	Pharyngeal electrical stimulation
PFO	Patent foramen ovale
POC	Progestin only contraceptive
RBMT	Rivermead Behavioural Memory Test
RCP	Royal College of Physicians of London
RCT	Randomised controlled trial
ROSIER	Recognition of Stroke in the Emergency Room
RR	Relative risk
SAH	Sub arachnoid haemorrhage
SARA	Scale for the Assessment and Rating of Ataxia
SBP	Systolic blood pressure
SIGN	Scottish Intercollegiate Guidelines Network
SLT	Speech and language therapy
SMC	Scottish Medicines Consortium
SRU	Stroke rehabilitation unit
SSNAP	Sentinel Stroke National Audit Programme

SSRI	Selective serotonin reuptake inhibitor
SWI	Susceptibility-weighted imaging
tDCS	Transcranial direct current stimulation
TENS	Transcutaneous electrical nerve stimulation
TIA	Transient ischaemic attack
TMS	Transcranial magnetic stimulation
TOE	Transoesophageal echocardiogram
TTE	Transthoracic echocardiogram
TULIA	Test of Upper Limb Apraxia
VA	Vertebral artery
VKA	Vitamin K antagonist
VNS	Vagus nerve stimulation
VOSP	Visual Object and Space Perception battery
VR	Vocational rehabilitation
VTE	Venous thromboembolism
WHO	World Health Organization
WTE	Whole time equivalent

Bibliography

- Appleby, E., Gill, S. T., Hayes, L. K., Walker, T. L., Walsh, M., & Kumar, S. (2019). Effectiveness of telerehabilitation in the management of adults with stroke: A systematic review *PLoS One*, *14*(11), e0225150.
- Archer, J., Bower, P., Gilbody, S., Lovell, K., Richards, D., Gask, L., et al. (2012). Collaborative care for depression and anxiety problems *The Cochrane Database of Systematic Reviews*, *10*, CD006525.
- Asplund, K., Jonsson, F., Eriksson, M., Stegmayr, B., Appelros, P., Norrving, B., et al. (2009). Patient dissatisfaction with acute stroke care *Stroke*, *40*(12), 3851-3856.
- Barras, S., Grimmer-Somers, K., & May, E. (2010). Consensus on 'core/essential' and 'ideal world' criteria of a pre-discharge occupational therapy home assessment *Journal of Evaluation in Clinical Practice*, *16*(6), 1295-1300.
- Bray, B. D., Campbell, J., Cloud, G. C., Hoffman, A., Tyrrell, P. J., Wolfe, C. D., et al. (2013). Bigger, faster? Associations between hospital thrombolysis volume and speed of thrombolysis administration in acute ischemic stroke *Stroke*, *44*(11), 3129-3135.
- Bray, B. D., Ayis, S., Campbell, J., Cloud, G. C., James, M., Hoffman, A., et al. (2014). Associations between Stroke Mortality and Weekend Working by Stroke Specialist Physicians and Registered Nurses: Prospective Multicentre Cohort Study *PLOS Medicine*, *11*(8), e1001705.
- British Society of Rehabilitation Medicine. (2021). *Specialist Standards for Community Rehabilitation* <https://www.bsrm.org.uk/downloads/2021-v9.3-22-3-21-speccommunitystandards-summary-fortheweb-clean.pdf>
- Cattalani, R., Zettin, M., & Zoccolotti, P. (2010). Rehabilitation Treatments for Adults with Behavioral and Psychosocial Disorders Following Acquired Brain Injury: A Systematic Review. *Neuropsychological Reviews*, *20*(1), 52-85.
- Chen, J., Lin, X., Cai, Y., Huang, R., Yang, S., & Zhang, G. (2022). A Systematic Review of Mobile Stroke Unit Among Acute Stroke Patients: Time Metrics, Adverse Events, Functional Result and Cost-Effectiveness *Frontiers in Neurology*, *13*, Article 803162.
- Cicerone, K., Mott, T., Azulay, J., Sharlow-Galella, M. A., Ellmo, W. J., Paradise, S., et al. (2008). A Randomized Controlled Trial of Holistic Neuropsychologic Rehabilitation After Traumatic Brain Injury *Archives of Physical Medicine and Rehabilitation*, *89*(12), 2239-2249.
- Cicerone, K., Azulay, J., & Trott, C. (2009). Methodological Quality of Research on Cognitive Rehabilitation After Traumatic Brain Injury *Medical Rehabilitation*, *90*, S52-S59.
- Clarke, D. J., Godfrey, M., Hawkins, R., Sadler, E., Harding, G., Forster, A., et al. (2013). Implementing a training intervention to support caregivers after stroke: a process evaluation examining the initiation and embedding of programme change *Implementation Science* *8*(96).
- Coughlan, D., McMeekin, P., Flynn, D., Ford, G. A., Lumley, H., Burgess, D., et al. (2021). Secondary transfer of emergency stroke patients eligible for mechanical thrombectomy by air in rural England: economic evaluation and considerations *Emerg Med J*, *38*(1), 33-39.
- Crocker, T., Forster, A., Young, J., Brown, L., Ozer, S., Smith, J., et al. (2013). Physical rehabilitation for older people in long-term care *Cochrane Database of Systematic Reviews*(2), CD004294.
- Department of Health (UK). (2005). *National service framework for long term conditions*. <https://www.gov.uk/government/publications/quality-standards-for-supporting-people-with-long-term-conditions>
- Drummond, A. E., Whitehead, P., Fellows, K., Sprigg, N., Sampson, C. J., Edwards, C., et al. (2013). Occupational therapy pre-discharge home visits for patients with a stroke (HOVIS): results of a feasibility randomized controlled trial *Clinical Rehabilitation*, *27*(5), 387-397.
- Duncan, P. W., Sullivan, K. J., Behrman, A. L., Azen, S. P., Wu, S. S., Nadeau, S. E., et al. (2011). Body-Weight Supported Treadmill Rehabilitation after Stroke *New England Journal of Medicine*, *364*(21), 2026-2036.

- Dutta, D., Kendall, J., Holmes, C., Murphy, P., Black, T., Whiting, R., et al. (2015). Evaluation of a telephone advice system for remote intravenous thrombolysis in ischemic stroke: data from a United Kingdom network *Stroke*, *46*(3), 867-869.
- Fens, M., van Heugten, C. M., Beusmans, G., Metsemakers, J., Kester, A., & Limburg, M. (2014). Effect of a stroke-specific follow-up care model on the quality of life of stroke patients and caregivers: A controlled trial *Journal of Rehabilitation Medicine*, *46*(1), 7-15.
- Ferrarello, F., Baccini, M., Rinaldi, L. A., Cavallini, M. C., Mossello, E., Masotti, G., et al. (2011). Efficacy of physiotherapy interventions late after stroke: a meta-analysis *Journal of Neurology, Neurosurgery & Psychiatry*, *82*(2), 136-143.
- Firth, N., Barkham, M., & Kellett, S. (2015). The clinical effectiveness of stepped care systems for depression in working age adults: a systematic review *Journal of Affective Disorders*, *170*, 119-130.
- Fisher, R. J., Gaynor, C., Kerr, M., Langhorne, P., Anderson, C., Bautz-Holter, E., et al. (2011). A consensus on stroke: early supported discharge *Stroke*, *42*(5), 1392-1397.
- Fisher, R. J., Walker, M. F., Golton, I., & Jenkinson, D. (2013). The implementation of evidence-based rehabilitation services for stroke survivors living in the community: the results of a Delphi consensus process *Clin Rehabil*, *27*(8), 741-749.
- Fisher, R. J., Cobley, C. S., Potgieter, I., Moody, A., Nouri, F., Gaynor, C., et al. (2016). Is Stroke Early Supported Discharge still effective in practice? A prospective comparative study *Clinical Rehabilitation*, *30*(3), 268-276.
- Fisher, R. J., Byrne, A., Chouliara, N., Lewis, S., Paley, L., Hoffman, A., et al. (2020). Effectiveness of Stroke Early Supported Discharge *Circulation: Cardiovascular Quality and Outcomes*, *13*(8), e006395.
- Fisher, R. J., Byrne, A., Chouliara, N., Lewis, S., Paley, L., Hoffman, A., et al. (2021). Effect of stroke early supported discharge on length of hospital stay: Analysis from a national stroke registry *BMJ Open*, *11*(1), e043480.
- Ford, G., James, M., & White, P. (2022). *Mechanical thrombectomy for acute ischaemic stroke: an implementation guide for the UK. Second Edition*. Oxford AHSN.
<https://www.oxfordahsn.org/our-work/our-programmes/adopting-innovation/cardiovascular-disease/mt-guide/>
- Forster, A., Brown, L., Smith, J., House, A., Knapp, P., Wright, J. J., et al. (2012). Information provision for stroke patients and their caregivers *Cochrane Database of Systematic Reviews*, *11*, CD001919.
- Forster, A., Dickerson, J., Young, J., Patel, A., Kalra, L., Nixon, J., et al. (2013). A structured training programme for caregivers of inpatients after stroke (TRACS): a cluster randomised controlled trial and cost-effectiveness analysis *Lancet*, *382*(9910), 2069-2076.
- Francis, R. (2013). In *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*. The Stationery Office.
- Gardiner, C., Harrison, M., Ryan, T., & Jones, A. (2013). Provision of palliative and end-of-life care in stroke units: a qualitative study *Palliative Medicine*, *27*(9), 855-860.
- Getting it Right First Time. (2022). *Stroke GIRFT Report*.
<https://future.nhs.uk/GIRFTNational/view?objectId=130558949>
- Gillham, S., & Clark, L. (2011). *Psychological care after stroke - Improving stroke services for people with cognitive and mood disorders*, NHS Improvement - Stroke.
- Good, P., Richard, R., Syrmis, W., Jenkins-Marsh, S., & Stephens, J. (2014). Medically assisted hydration for adult palliative care patients *Cochrane Database of Systematic Reviews*(4), CD006273.
- Grasel, E., Schmidt, R., Biehler, J., & Schupp, W. (2006). Long-term effects of the intensification of the transition between inpatient neurological rehabilitation and home care of stroke patients *Clinical Rehabilitation*, *20*(7), 577-583.
- Heffner, D. L., Thirumala, P. D., Pokharna, P., Chang, Y. F., & Wechsler, L. (2015). Outcomes of Spoke-Retained Telestroke Patients Versus Hub-Treated Patients After Intravenous Thrombolysis: Telestroke Patient Outcomes After Thrombolysis *Stroke; a journal of cerebral circulation*, *46*(11), 3161-3167.

- Intercollegiate Stroke Working Party. (2016). *Sentinel Stroke National Audit Programme Annual Results Portfolio*.
<https://www.strokeaudit.org/Documents/Results/National/Apr2015Mar2016/Apr2015Mar2016-AnnualResultsPortfolio.aspx>
- Jones, S. P., Jenkinson, A. J., Leathley, M. J., & Watkins, C. L. (2010). Stroke knowledge and awareness: an integrative review of the evidence *Age & Ageing*, 39(1), 11-22.
- Langhorne, P., Baylan, S., & Trialists, E. S. D. (2017). Early supported discharge services for people with acute stroke *Cochrane Database of Systematic Reviews*, 2017(7), CD000443.
- Lannin, N. A., Novak, I., & Cusick, A. (2007). A systematic review of upper extremity casting for children and adults with central nervous system motor disorders *Clinical Rehabilitation*, 21(11), 963-976.
- Lecouturier, J., Murtagh, M. J., Thomson, R. G., Ford, G., White, M., & Rodgers, H. (2010a). Response to symptoms of stroke in the UK: a systematic review *BMC Health Services Research*, 10(157).
- Lecouturier, J., Rodgers, H., Murtagh, M. J., White, M., Ford, G., & Thomson, R. G. (2010b). Systematic review of mass media interventions designed to improve public recognition of stroke symptoms, emergency response and early treatment *BMC Public Health*, 10(784).
- Legg, L. A., Quinn, T. J., Mahmood, F., Weir, C. J., Tierney, J., Stott, D. J., et al. (2011). Non-pharmacological interventions for caregivers of stroke survivors *Cochrane Database of Systematic Reviews*(10), CD008179.
- Lohse, K. R., Lang, C. E., & Boyd, L. A. (2014). Is more better? Using metadata to explore dose-response relationships in stroke rehabilitation *Stroke*, 45(7), 2053-2058.
- Meyer, B. C., Raman, R., Hemmen, T., Obler, R., Zivin, J. A., Rao, R., et al. (2008). Efficacy of site-independent telemedicine in the STRoKE DOC trial: a randomised, blinded, prospective study *Lancet Neurology*, 7(9), 787-795.
- NHS England. (2022). *National Service Model for an Integrated Community Stroke Service*.
<https://www.england.nhs.uk/wp-content/uploads/2022/02/stroke-integrated-community-service-february-2022.pdf>
- NICE. (2010). *Clinical guideline [CG91] Depression in Adults with a Chronic Physical Health Problem: Treatment and Management*. <https://www.nice.org.uk/guidance/cg91>
- NICE. (2011). *Clinical guideline [CG123] Common mental health problems: identification and pathways to care*. <https://www.nice.org.uk/guidance/cg123>
- NICE. (2015). *NICE guideline [NG31] Care of Dying Adults in the Last Days of Life*.
<https://www.nice.org.uk/guidance/ng31>
- NICE. (2016). *Quality Standard 2: Stroke in adults*. <https://www.nice.org.uk/guidance/QS2>
- Palmer, R., & Enderby, P. (2007). Methods of speech therapy treatment for stable dysarthria: a review *Advances in Speech Language Pathology*, 9(2), 140-153.
- Patel, A., Knapp, M., Evans, A., Perez, I., & Kalra, L. (2004). Training care givers of stroke patients: economic evaluation *BMJ*, 328(7448), 1102.
- Payne, S., Burton, C., AddingtonHall, J., & Jones, A. (2010). End-of-life issues in acute stroke care: A qualitative study of the experiences and preferences of patients and families *Palliative Medicine*, 24(2), 146-153.
- Pérez de la Ossa, N., Abilleira, S., Jovin, T. G., García-Tornel, Á., Jimenez, X., Urra, X., et al. (2022). Effect of Direct Transportation to Thrombectomy-Capable Center vs Local Stroke Center on Neurological Outcomes in Patients With Suspected Large-Vessel Occlusion Stroke in Nonurban Areas: The RACECAT Randomized Clinical Trial *JAMA*, 327(18), 1782-1794.
- Ramsay, A. I., Morris, S., Hoffman, A., Hunter, R. M., Boaden, R., McKeivitt, C., et al. (2015). Effects of Centralizing Acute Stroke Services on Stroke Care Provision in Two Large Metropolitan Areas in England *Stroke*, 46(8), 2244-2251.
- Royal College of Paediatrics and Child Health. (2017). *Stroke in Childhood: Clinical Guideline for Diagnosis, Management, and Rehabilitation*. Royal College of Paediatrics and Child Health.
<https://www.rcpch.ac.uk/resources/stroke-in-childhood-clinical-guideline>
- Royal College of Physicians, & British Medical Association. (2018). *Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent. Guidance for decision-making in*

- England and Wales. RCP. <https://www.bma.org.uk/media/1161/bma-clinically-assisted-nutrition-hydration-canh-full-guidance.pdf>
- Royal College of Physicians. (2021). *Supporting people who have eating and drinking difficulties*. <https://www.rcplondon.ac.uk/projects/outputs/supporting-people-who-have-eating-and-drinking-difficulties>
- Royal College of Speech and Language Therapists. (2021). *Eating and drinking with acknowledged risks: Multidisciplinary team guidance for the shared decision-making process (adults)* <https://www.rcslt.org/members/clinical-guidance/eating-and-drinking-with-acknowledged-risks-risk-feeding/#section-2>
- Sackley, C. M., Walker, M. F., Burton, C. R., Watkins, C. L., Mant, J., Roalfe, A. K., et al. (2015). An occupational therapy intervention for residents with stroke related disabilities in UK care homes (OTCH): cluster randomised controlled trial *BMJ*, 350, h468.
- Salazar, A. M., Warden, D. L., Schwab, K., Spector, J., Braverman, S., Walter, J., et al. (2000). Cognitive Rehabilitation for Traumatic Brain Injury *JAMA*, 283(23), 3075-3081.
- Scottish Government. (2019). *Health and Care (Staffing) (Scotland) Act 2019*. <https://www.legislation.gov.uk/asp/2019/6/enacted>
- Sentinel Stroke National Audit Programme. (2022). *Sentinel Stroke National Audit Programme 9th Annual Report: Road to recovery*. <https://www.strokeaudit.org/Documents/National/Clinical/Apr2021Mar2022/Apr2021Mar2022-AnnualReport.aspx>
- Stroke Association. (2015). *Struggling to recover*. <https://www.stroke.org.uk/resources/struggling-recover>
- Stroke Unit Trialists' Collaboration. (2013). Organised inpatient (stroke unit) care for stroke *Cochrane Database of Systematic Reviews*, 9, CD000197.
- Turc, G., Hadziahmetovic, M., Walter, S., Churilov, L., Larsen, K., Grotta, J. C., et al. (2022). Comparison of Mobile Stroke Unit With Usual Care for Acute Ischemic Stroke Management: A Systematic Review and Meta-analysis *JAMA Neurol*, 79(3), 281-290.
- Turner, M., Barber, M., Dodds, H., Dennis, M., Langhorne, P., Macleod, M. J., et al. (2016). Stroke patients admitted within normal working hours are more likely to achieve process standards and to have better outcomes *Journal of Neurology, Neurosurgery & Psychiatry*, 87(2), 138-143.
- van Straten, A., Hill, J., Richards, D. A., & Cuijpers, P. (2015). Stepped care treatment delivery for depression: a systematic review and meta-analysis *Psychol Med*, 45(2), 231-246.
- Veerbeek, J. M., van Wegen, E., van Peppen, R., van der Wees, P. J., Hendriks, E., Rietberg, M., et al. (2014). What is the evidence for physical therapy poststroke? A systematic review and meta-analysis *PLoS One*, 9(2), e87987.
- Wade, D. T. (1992). Measurement in neurological rehabilitation *Current Opinion in Neurology & Neurosurgery*, 5(5), 682-686.
- Ward, N. S., Brander, F., & Kelly, K. (2019). Intensive upper limb neurorehabilitation in chronic stroke: outcomes from the Queen Square programme *Journal of Neurology, Neurosurgery & Psychiatry*, 90(5), 498.
- Wardlaw, J. M., Seymour, J., Cairns, J., Keir, S., Lewis, S., & Sandercock, P. (2004). Immediate computed tomography scanning of acute stroke is cost-effective and improves quality of life *Stroke*, 35(11), 2477-2483.
- Wikander, B., Ekelund, P., & Milsom, I. (1998). An evaluation of multidisciplinary intervention governed by functional independence measure (FIMSM) in incontinent stroke patients *Scandinavian Journal of Rehabilitation Medicine*, 30(1), 15-21.