2019 surveillance of stroke rehabilitation in adults (NICE guideline CG162)

Surveillance report
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2019 surveillance of stroke rehabilitation in adults (NICE guideline CG162)

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Surveillance decision

We will update the guideline on stroke rehabilitation in adults.

NICE is engaging with the Royal College of Physicians Intercollegiate Stroke Working Party in the update of the guideline.

Reasons for the decision

The surveillance review identified that the evidence base for some aspects of stroke rehabilitation has progressed since the guideline was developed in 2013. Additionally, feedback from topic experts and stakeholders highlighted the following that impact on the relevance of the guideline to current practice:

- Limited implementation of some of the guideline recommendations.
- Lack of integration between the guideline and NICE’s guideline on stroke and transient ischaemic attack in over 16s (which focuses on the first 48 hours after symptom onset), which could make improving integration of acute care and rehabilitation services in practice difficult.
- Lack of alignment with the 2016 Royal College of Physicians Intercollegiate Stroke Working Party guidelines, which may be confusing for the health and social care setting.
- Changes in how stroke rehabilitation services are structured, therefore changing the context in which the guideline was developed.
- New policy imperatives for stroke as outlined in the NHS Long Term Plan (January 2019), which make the position of the current guideline uncertain.

The following table gives an overview of how evidence and intelligence identified in surveillance might affect each area of the guideline:

<table>
<thead>
<tr>
<th>Section of the guideline</th>
<th>New evidence identified to impact guideline</th>
<th>New intelligence identified to impact guideline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organising health and social care for people needing rehabilitation after stroke</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>-----</td>
<td>----</td>
</tr>
<tr>
<td>Planning and delivering stroke rehabilitation</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Providing support and information</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Cognitive functioning</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Emotional functioning</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Vision</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Swallowing</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Communication</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Movement</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Self-care</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Long-term health and social support</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

**Areas not currently covered in the guideline**

<table>
<thead>
<tr>
<th>Area</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transcutaneous electrical nerve stimulation (TENS) for spasticity</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Music therapy</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Mirror therapy</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Pharmacological therapies</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Other areas including peripheral magnetic stimulation; transcranial magnetic stimulation; transcranial electrical stimulation; telerehabilitation and active telephone support; rehabilitation for car driving; virtual reality; post-stroke fatigue; acupuncture; vibration therapy; art therapy and other pharmacological therapies</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

For further details and a summary of all evidence and intelligence identified in surveillance, see appendix A.
Overview of 2019 surveillance methods

NICE's surveillance team checked whether recommendations in the NICE guideline on stroke rehabilitation in adults remain up to date.

The surveillance process consisted of:

- Feedback from topic experts via a questionnaire.
- A search for new or updated Cochrane reviews.
- Examining related NICE guidance and quality standards and National Institute for Health Research (NIHR) signals.
- A search for ongoing research.
- Examining the NICE event tracker for relevant ongoing and published events.
- Literature searches to identify relevant evidence.
- Assessing the new evidence against current recommendations to determine whether or not to update sections of the guideline, or the whole guideline.
- Consulting on the decision with stakeholders.
- Considering comments received during consultation and making any necessary changes to the proposal.

For further details about the process and the possible update decisions that are available, see ensuring that published guidelines are current and accurate in developing NICE guidelines: the manual.

Evidence considered in surveillance

Search and selection strategy

We searched for new evidence related to the whole guideline.

We found 200 studies in a search for randomised controlled trials and systematic reviews published between 5 October 2012 and 23 October 2018.
We also included:

- 1 relevant study identified by topic experts
- 1 study identified through comments received after publication of the guideline
- 3 studies identified in comments received during consultation on the 2019 surveillance review.

From all sources, we considered 205 studies to be relevant to the guideline.

See appendix A: summary of evidence from surveillance for details of all evidence considered, and references.

Selecting relevant studies

Because of the large number of studies identified in the initial search, the following strategies were used to select studies for inclusion in the evidence summary.

**Systematic reviews**

- Only Cochrane systematic reviews were included (however, 1 non-Cochrane systematic review, felt to be topical and important because it was identified by the NIHR signals programme, was also included).

**Randomised controlled trials (RCTs)**

- Inclusion criteria: Over 50 participants; outcomes matching those in relevant review protocols (where possible) in the guideline.

- Exclusion criteria: Already taken into account in a Cochrane review; non-stroke populations (for example, head injury); pilot, feasibility, exploratory, preliminary, proof-of-concept studies; complementary and alternative medicine.

**Ongoing research**

We checked for relevant ongoing research; of the ongoing studies identified, 7 were assessed as having the potential to change recommendations. Therefore, we plan to regularly check whether these studies have published results, and evaluate the impact of the results on current recommendations as quickly as possible. These studies are:

- Non-invasive brain stimulation for dysphagia after acute stroke
• Home-training for hemianopia (partial blindness)

• Does arm training early after a stroke increase the contribution of the non-affected brain side to recovery

• Standing practice in rehabilitation early after stroke

• What is the impact of large-scale implementation of stroke early supported discharge?

• Return to work after stroke (RETAKE)

• RATULS: robot-assisted training for the upper limb after stroke

### Intelligence gathered during surveillance

#### Views of topic experts

We considered the views of topic experts, who completed a questionnaire about developments in evidence, policy and services related to the NICE guideline.

We sent questionnaires to 11 topic experts and received 6 responses. The topic experts were recruited to the NICE Centre for Guidelines Expert Advisers Panel to represent their specialty.

Several experts mentioned that differences between the NICE guideline and the Intercollegiate Stroke Working Party guideline need to be taken into account. Specific examples of differences raised by the experts that will be a focus of the update comprise:

• Increasing availability of rehabilitation therapy from a minimum of 5 days to 7-day standards.

• Including recommendations on a wider array of issues related to sex, relationships and emotions.

• Including a wider variety of post-stroke visual impairments requiring specialist assessment (not just double vision).

• Including greater detail on oral care.

Other concerns raised by topic experts that will be considered by the update include:

• The timing of vision assessment on admission to hospital with stroke.

• Interventions to improve upper limb function.
• Interventions for lower limb or walking impairments.

These areas for update highlighted by the topic experts, and the reason for update, are discussed in detail in the section on reasons for the decision.

Topic experts also raised concerns in the following areas:

**Adding orthoptics, pharmacy and dietetics to the core multidisciplinary stroke team**

No evidence in this area fulfilling the criteria of the current surveillance review was found, and the guideline already includes these aspects of care in a recommendation about ‘access to other services that may be needed’.

**Involvement of third sector organisations (such as the Stroke Association)**

No evidence in this area fulfilling the criteria of the current surveillance review was found, and the guideline already recommends facilitating participation in community activities, such as civic engagement, stroke support groups and volunteering. Additionally, rehabilitation in partnership with voluntary organisations, including the Stroke Association, is advocated within the **NHS Long Term Plan** (January 2019).

**Hyperacute stroke rehabilitation**

Mixed results from 2 heterogeneous RCTs on very early rehabilitation are unlikely to affect the guideline, which does not currently specify a timepoint after stroke within which to start rehabilitation. Additionally, recommendations on early mobilisation are made in the NICE guideline on **stroke and transient ischaemic attack in over 16s**.

**A more individualised 'rehabilitation prescription'**

The guideline already includes a section on setting goals for rehabilitation, which allows for personalised rehabilitation planning, and recommends that documentation about the person’s stroke rehabilitation should be individualised.

**Predictive modelling to give better information to patients and carers about eventual outcome**

No evidence in this area fulfilling the criteria of the current surveillance review was found.
**Executive functioning**

Evidence found in this area by the current surveillance review was not deemed sufficient to impact the guideline. A Cochrane review found insufficient high-quality evidence to reach any generalised conclusions, and 6 individual studies provided evidence of benefit, but the interventions were heterogeneous, and most did not examine outcomes specific to executive function.

**Therapy apps for more self-directed rehabilitation**

No evidence in this area fulfilling the criteria of the current surveillance review was found.

**Activities of daily living are not limited to dressing**

The guideline gives examples of occupational therapy strategies that include dressing, but the overarching recommendation covers any relevant occupational therapy and any difficulties with activities of daily living, not just dressing.

**Return to driving**

Evidence on driving rehabilitation was found by the current surveillance review, but not deemed sufficient to impact the guideline (which does not include driving rehabilitation, but does cross-refer to the Driver and Vehicle Licensing Agency [DVLA] about requirements for driving after stroke). Additionally, recommendation 1.11.3 contains an outdated link to a web page of DVLA requirements, which will be amended.

**Stem cell therapy**

No evidence in this area fulfilling the criteria of the current surveillance review was found.

**Implementation of the guideline**

Some topic experts felt that the NICE guideline was superseded by the 2016 Intercollegiate Stroke Working Party guideline, and that the NICE guideline was not now widely used by clinicians.

Data on measuring the use of the NICE guideline is provided in the uptake of this guidance page. In areas where measurements have been made across 2 timepoints, the data suggest increased uptake of the guideline since its publication. However, for some areas, the proportion of patients receiving the recommended intervention remains below 50%, indicating variable implementation across the guideline recommendations. Additionally, overlap of recommendations in the NICE guideline and the Intercollegiate Stroke Working Party guideline mean the basis of these effects is
unclear.

**Views of stakeholders**

Stakeholders are consulted on all surveillance reviews except if the whole guideline will be updated and replaced. Because this surveillance proposal was to update part of the guideline, we consulted with stakeholders.

Overall, 9 stakeholders commented: 3 professional associations, 2 manufacturers, NHS England, a royal college, a charity, and a provider of healthcare services. Seven stakeholders agreed with the decision to update the guideline and 2 did not give a firm response. The following issues were raised by stakeholders:

**New evidence and information**

Several stakeholders referred to the [NHS Long Term Plan](https://www.nhs.org.uk/) (2019), and the Royal College of Physicians Intercollegiate Stroke Working Party (2016) [National clinical guideline for stroke](https://www.nice.org.uk/). These documents were considered by the surveillance review and are referred to at relevant points in **appendix A**: evidence summary. Additionally, NICE is planning to explore engaging with the Intercollegiate Stroke Working Party on any update of the guideline.

A stakeholder highlighted 2 publications stemming from the Spasticity in Stroke-Randomised Study (SISTERS) of the effects of intrathecal baclofen versus conventional medical management on post-stroke spasticity, pain and quality of life. These publications were not identified in the searches performed for the surveillance review and we have added them to the surveillance evidence summary. We acknowledge that the results show benefits of intrathecal baclofen, and we will add these publications to the surveillance evidence summary and consider their impact on the guideline as part of the update. The licence for intrathecal baclofen (Aguettant brand) states it is ‘...indicated in patients with severe chronic spasticity resulting from trauma […] who are unresponsive to oral baclofen or other orally administered antispastic agents and/or those patients who experience unacceptable side effects at effective oral doses. Baclofen Aguettant is effective in adult patients with severe chronic spasticity of cerebral origin, resulting e.g. from […] cerebrovascular accident; however, clinical experience is limited’.

Several stakeholders supplied other evidence not identified by the surveillance review. However, it was not suitable for inclusion in the review for various reasons (unpublished research, unsuitable evidence type, not in scope and outside search dates).

**Merging the NICE guidelines on stroke and transient ischaemic attack in over 16s and**
stroke rehabilitation

We have no current plans to merge these guidelines, but the NICE Pathway on stroke brings together everything NICE has said on a topic in an interactive flowchart, and includes all the recommendations from both guidelines.

Third sector organisations

No evidence in this area fulfilling the criteria of the current surveillance review was found. However, the guideline already makes several recommendations of relevance to the third sector, and rehabilitation in partnership with voluntary organisations is advocated within the NHS Long Term Plan.

Assessment and management of disorders of oral feeding

Two stakeholders noted that the International Dysphagia Diet Standardisation Initiative has been updated and should be included in the guideline.

Recommendations on people with dysphagia after stroke who are having modified food and liquid, and nutrition support for people with dysphagia, are covered by the NICE guidelines on nutrition support for adults and stroke and transient ischaemic attack in over 16s (which are linked to from the NICE guideline on stroke rehabilitation). The stakeholder comments will be added to the issue log for these guidelines for consideration at their next surveillance review.

Medicines management

We asked stakeholders for feedback on whether medicines management issues that may arise in stroke rehabilitation are suitably covered by other NICE guidance such as the NICE guidelines on medicines adherence and medicines optimisation. One stakeholder responded with concerns about patients with stroke and their carers being confused about medicines (for example, patients on warfarin previously, when given a new anticoagulant may not appreciate these must not be taken together; similar confusion may exist about aspirin). They noted the need to provide written plans for patients and GPs at discharge with reference to high-risk medications. These issues are covered by the NICE guidelines on medicines adherence and medicines optimisation. The NICE guideline on stroke rehabilitation already links to the medicines adherence one, but we will add links to the medicines optimisation guideline.
Neuromuscular electrical stimulation

A stakeholder noted that neuromuscular electrical stimulation (NMES) should be included in the guideline. The evidence searches performed for the surveillance review identified several studies of electrical stimulation, including NMES for various aspects of stroke rehabilitation (swallowing therapy, shoulder pain and lower limb problems). The findings are presented in detail in appendix A: evidence summary. We do not anticipate any impact of the new evidence on the guideline at the present time.

Digital interventions

A stakeholder asked that emerging large-scale trials of digital interventions be reviewed. Any studies of digital interventions that were within the scope of the surveillance review and identified by surveillance review searches and intelligence gathering were included in the surveillance evidence summary. Some studies of computer-based interventions were included; however, the evidence either supported or was not sufficient to impact the guideline. We also track important ongoing studies, which includes an RCT of computer therapy identified by the stakeholder.

Acupuncture

A stakeholder queried why acupuncture was not included in the guideline update proposal. The surveillance review is based on protocols used by the original guideline (in which no review questions or studies were included for acupuncture or any other complementary and alternative medicine). Therefore, studies of complementary and alternative medicine were excluded from the surveillance review. However, we included the Cochrane review by Yang et al. (2016) on acupuncture for stroke rehabilitation in the surveillance review as an overview of the best available current evidence on this subject. The authors concluded that 'most included trials were of inadequate quality and size. There is, therefore, inadequate evidence to draw any conclusions about its routine use'. This thus remains an area where not enough evidence of good quality is available to consider making recommendations.

Economic deprivation, ethnic minorities, and younger stroke survivors

Two stakeholders noted particular issues among these groups, for example, increased stroke risk, and worse outcomes and access to care. However, these issues are mainly related to stroke prevention (the scope of the NICE guideline specifically excludes primary and secondary prevention of stroke), and implementation issues. We will pass on issues regarding implementation of the guideline to the relevant team within NICE.
**Providing 7-day stroke services**

A stakeholder noted that many stroke units have significant workforce challenges (specialist staff in rehabilitation are often in short supply) and even if commissioned, the service may not be able to deliver sufficient staff to provide 7-day services. NICE guidance recommendations reflect best practice that services should aspire to. The final decision on new recommendation wording lies with the guideline committee who will develop the update. The committee may require more robust evidence on the effectiveness and cost effectiveness of recommendations that are expected to have a substantial impact on resources. This is defined as 'implementing a single guideline recommendation in England costing more than £1 million per year, or implementing the whole guideline in England costing more than £5 million per year' in NICE's process and methods guide, developing NICE guidelines: the manual, chapter 7 on incorporating economic evaluation. We will pass on concerns about the availability of specialist staff to the developers of the guideline update.

**Occupational therapy in care homes**

A stakeholder queried why the update in this area relates only to care home residents (whereas frailty may be a more appropriate distinction) and only to occupational therapy (whereas there may be concerns around inequitable access to NHS care in general in care homes).

The proposed update in this area was based on a large RCT specifically of occupational therapy in care homes, therefore the surveillance proposal was based around this intervention and population. However, we additionally noted that expert comments within an NIHR signal about this trial stated that patients in the study were very frail and cognitively impaired, therefore it may be that any changes to recommendations in this area could be centred on physical attributes such as frailty rather than place of residence. We will ensure the developers for the update are aware of the comments from the stakeholder and the NIHR signal.

Regarding people in care homes receiving inequitable access to NHS care, recommendation 1.1.14 states ‘Ensure that people with stroke who are transferred from hospital to care homes receive assessment and treatment from stroke rehabilitation and social care services to the same standards as they would receive in their own homes’. This therefore relates to an implementation issue and we will pass this information on to the relevant team within NICE.

See appendix B for full details of stakeholders’ comments and our responses.

See ensuring that published guidelines are current and accurate in developing NICE guidelines: the manual for more details on our consultation processes.
Equalities

A stakeholder stated that ethnic minorities are at greater risk of having a stroke, and more likely to report a greater number of unmet needs following a stroke. However, the scope of the NICE guideline specifically excludes primary and secondary prevention of stroke (which is more relevant to the NICE guidelines on cardiovascular disease: identifying and supporting people most at risk of dying early and cardiovascular disease prevention). Issues with unmet needs (highlighted by the stakeholder as stroke information; reduction in or loss of work activities; loss in income and increase in expenses) are largely covered by the guideline. In particular, the guideline makes specific recommendations on information provision (including identifying the patient’s information needs and how to deliver them, and a link to the NICE guideline on patient experience in adult NHS services – which is focused on tailoring care to the specific needs of individual patients), and identifying and managing issues around returning to work. The evidence therefore more likely reflects implementation issues and we will pass this information on to the relevant team within NICE.

Editorial amendments

During surveillance of the guideline, we identified the following points that should be amended.

Recommendation 1.9.22 cross-refers to the NICE guideline on neuropathic pain in adults, which has now been updated. The cross-referral link will be updated.

Recommendation 1.9.31 cross-refers to the NICE interventional procedures guidance on functional electrical stimulation for drop foot of central neurological origin. The current link is broken and will be fixed.

To clarify the meaning of the term neglect in recommendation 1.10.1 in the context of this guideline, a hyperlink to the definition of neglect in the terms used in this guideline section will be added.

Recommendation 1.10.6 cross-refers to the NICE guideline on workplace health. The current link is broken and will be fixed.

Recommendation 1.11.3 refers to a web page for DVLA requirements. This link is outdated and will be updated to the stroke (cerebrovascular accident) and driving page.

Recommendation 1.11.6 cross-refers to the NICE guidelines atrial fibrillation, lipid modification and type 2 diabetes (which have now been updated and replaced). The cross-referral links will be
updated.

**Editorial amendments by committee**

It is proposed that the committee developing the updated guideline will consider a refresh of recommendation 1.2.1, to potentially include vision in the issues to be immediately screened for on admission to hospital to ensure immediate safety and comfort (vision assessment is currently covered by recommendation 1.2.2, which concerns the full medical assessment of the person with stroke).

**Overall decision**

After considering all evidence and other intelligence and the impact on current recommendations, we decided that an update is necessary.

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