# TOWARDS A STROKE STRATEGY: CONSULTATION RESPONSE PROFORMA

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You comments **must** reach us by that date

**Respondent Details** (Please provide the details of a single point of co-ordination for your response)



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If you are replying on behalf of a group of respondents or a number of organisations, please complete the following information:

| Organisations represented within this response | |
|---|---|

Note: We would also welcome any anonymous responses.

**Date of response: Thursday 11 October 2007**

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**EXECUTIVE SUMMARY**

- Stroke is the largest single cause of severe disability in adults in England
- Over one third of acute stroke survivors are left dependent or moderately disabled. This number will continue to increase as the stroke mortality continues to fall
- One in three people who have a stroke will have persisting speech, language or communication problems
- A quarter of people who have a stroke are of working age

The stroke strategy document contains many new initiatives which we welcome, however we wish to draw attention to the following important points which must be addressed if the stroke strategy is to meet the growing and diverse needs of stroke survivors. No mention is made of the following:

- It is crucial to screen all people who have had a stroke for swallowing problems (dysphagia) within 24 hours post stroke. Those with complications must receive a full assessment by a speech and language therapist within 72 hours. The risk is to people who have had a stroke is very high if this is not carried
- Speech and language therapists provide an essential communication lifeline between people who have had a stroke and hospital staff in the first hours and days post stroke. One in three people will suffer from cognitive and perceptual difficulties in this acute stage, and this lifeline allows the individual to communicate their needs.
- In both the acute and the community setting, speech and language therapists have a key role in training professional staff, carers and family members to learn communication skills, which will enable them to understand the stroke survivor and also the help the stroke survivor to understand them. In this way, health professionals, family and carers are able to meet the needs of stroke survivors. The survivor is therefore able to make sense of what is happening around them and become involved in decisions around their own care.

**Chapter 1: Time Is Brain**

1. Are the recommendations from the project groups the right ones?

Yes ❑ **No** ✓ Don’t know ❑

(If ‘No’ please state why below)

Comments:

**The strategy does not state that all people who have had a stroke must be screened for the presence of swallowing problems within 24 hours. Following the screen those who are identified as having swallowing**

**difficulties must receive a full assessment from a speech and language therapist within 72 hours.**

Data from 2006[1] showed that over one third of people who had a stroke and who had difficulty swallowing were not assessed within 72 hours of admission. The failure to undertake timely screening and assessment of swallowing problems leads to increased patient complications and therefore increased inpatient times.

Swallowing problems (dysphagia) are a frequent and serious complication of stroke[2 3], over half of people who have a stroke will experience swallowing problems within the first 72 hours (8) [4]. This can result in aspiration[5] or reduced oral intake resulting in malnutrition and dehydration. Aspiration is the leading cause of pneumonia in intensive acute care and contributes significantly to the overall morbidity and mortality of the person who has had a stroke[6].

2. Will these recommendations deliver improved services for people who experience TIA?

Yes ❑ **No** ✓ Don't know ❑

(If 'No' please state why below)

Comments:

The RCSLT is concerned that there are inadequate resources available to meet the expectations within this strategy. Access to specialist multi disciplinary teams is limited. Access to professional expertise should be determined by patients' needs, not service availability.

There is current evidence that some patients who have had a TIA, but whose symptoms present as confusion, loss of cognition or visual difficulties, are not picked up by staff with appropriate knowledge or through the usual routes of a GP or A&E. Work needs to be done to raise knowledge and skills across all health and social care providers to ensure minimal distress and referral to appropriately skilled professionals and AHPs.

3. Will these recommendations help ensure stroke is treated quickly and effectively?

Yes ❑ **No** ✓ Don't know ❑

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[1] National Sentinel Audit for Stroke, 2006
[2] D.G. Smithard, N.C.Smetton, C.D.A. Wolfe, Long-term outcome after stroke: does dysphagia matter? 2006
[3] Mann G, Hankey GJ, Cameron D. Swallowing disorders following acute stroke; prevalence and diagnostic accuracy. Cerebrovasc Dis 2000; 10: 380-6.
[4] Mann G, Hankey GJ, Cameron D. Stroke, Swallowing functions after stroke: prognosis and prognostic factors at 6 months, 1999; 30 (4): 744-8.
[5] Smithard et al, 1996
[6] McClave SA, DeMeo MT, DeLegge MH, et al, North American summit on Aspiration in the critically ill patient: consensus statement, 2002, Journal of parenteral and enteral nutrition, 26(6): S80-86

(If ‘No’ please state why below)

Comments:

**The strategy in the acute stage (Chapter one) does not mention communication difficulties. Over one in three people who have had a stroke will have problems with their speech, language or communication[7].**

Communication difficulties can be characterised by confusion, difficulty in expressing ones needs or understanding other people. The ability to speak coherently may temporarily be completely lost. Speech and language therapists are able to create an immediate communication life-line between the stroke survivor and other professionals to enable the stroke survivor to understand what is happening and for the staff to understand what the survivor is trying to communicate.

The national stroke strategy does not highlight the importance of screening for and assessing eating, drinking and swallowing problems following an acute stroke. If swallow problems are not detected this can result in malnutrition and dehydration, chest infections, pneumonia and even death.

Minor swallowing problems occur in nearly all patients with acute stroke[8] [9]. One in five stroke survivors will still experience swallowing problems one week after their stroke (2). At six months after a stroke swallowing problems may persist in around 11% of individuals and a third of stroke survivors may experience problems with normal eating[10].

Quick and effective treatment can only be achieved if there are adequate resources to deliver the services alongside staff with the specialist skills and experience in stroke care. Alternative strategies should be available for patients, who cannot, for whatever reason, follow the usual care pathway e.g. because their communication difficulties make it difficult to explain the procedure or gain their agreement to it. Speech and language therapists have an ongoing role in facilitating communication between the stroke survivor and the rest of the health team to ensure that the individual understands and is able to consent to the necessary procedures.

4. Are these the right recommendations to feed into an imaging strategy for TIA and stroke?

Yes ❑ No ❑ **Do not know✓**

[7] Communicating Quality 3, RCSLT guidelines, RCSLT, 2006
[8] Mann G, Hankey GJ, Cameron D. Swallowing disorders following acute stroke; prevalence and diagnostic accuracy. Cerebrovasc Dis 2000; 10: 380-6.
[9] Mann G, Hankey GJ, Cameron D. Stroke, Swallowing functions after stroke: prognosis and prognostic factors at 6 months, 1999; 30 (4): 744-8.
[10] Wright D (2002) Medication administration in nursing homes, Nursing Standards 16:33-38

(if ‘No’ please state why below)

Comments:

5. Will this approach support continuing improvements to stroke unit care?

Yes ❑ No ❑ **Don’t know** ✓

(If ‘No’ please state why below)

Comments:

Improvements in stroke care will be dependent on having a qualified specialist workforce to deliver high quality stroke care to people who have had a stroke.

The multi disciplinary team includes assessment and treatment given by skilled AHPs. Further, it is important that quality indicators (p23) are sufficiently comprehensive and inclusive.

6. Do these recommendations adequately address the need for close working across first contact services, ambulance services and hospitals?

Yes ❑ No ❑ **Don’t know** ✓

(if ‘No’ please state why below)

Comments:

7. Is there anything that has been missed?

**YES, the three main issues that are missing are:**
**1. Assessment for and managing swallowing problems**
**2. Providing communication lifelines to stroke survivors**
**3. The contribution of SLTs to the multi disciplinary stroke care team**

1. Management of swallowing complications
**It is essential that a stronger emphasis is placed on the importance of carrying out and managing swallowing problems in people who have had a stroke.**

As the complications associated with swallowing problems are avoidable or reversible all people who have had a stroke must be screened for swallowing problems within 24 hours to identify those individuals at risk of swallowing difficulties. Only healthcare professionals trained in the procedure should carry out a screening test.

Individuals with swallow problems must then be referred onto a full assessment by a speech and language therapist[11] within 72 hours. The failure to undertake timely assessments leads to poor patient outcomes and increased inpatient times.

2. Communication
One in three people who have had a stroke have communication problems. Therefore all people who have had a stroke must be assessed for communication, cognitive and perceptual difficulties and fine and gross motor skills within the first 72 hours.

3. MDT
Within the stroke strategy the specialist contribution of SLTs lacks emphasis. SLTs are core members of the stroke care team. SLTs have a key role in training nurses and other healthcare professionals in identifying swallowing difficulties and in how to perform a swallow screen to ensure that swallowing problems are managed as soon as they arise. SLTs also work with physiotherapists to establish postural positioning especially during feeding to prevent the stroke survivor from choking and aspirating.

Stroke patients should have an eye assessment during the acute phase of their stroke because many visual symptoms are very disabling and even at this early stage.

**Chapter 2: Life After Stroke**

1. Are the recommendations from the project groups the right ones?

Yes ❑ **No** ✓ Don't know ❑

(If 'No' please state why below)

Comments:

**At present we are concerned that this section is weak and requires substantial strengthening.**

Access to high quality long-term rehabilitation and support is essential to enable a stroke survivor to return home, remain independent within their community, return to work and to have their long term needs met. However access to rehabilitation and therapy is limited. Without timely access to rehabilitation the aims of the stroke strategy cannot be realised and the needs of people who have had a stroke will be left unmet.

Although there is some emphasis on improving health and well-being, it is disappointing to note that there is a strong medical focus, particularly around the first 10 days post stroke.

[11] SIGN reference

Rehabilitation on stroke units (p.36) is extensively referred to. However our members are concerned that there is no clear definition on what constitutes a stroke unit.

2. Will the recommendations help improve transitions from hospital to home?

Yes ❑ **No** ✓ Don't know ❑

(if 'No' please state why below)

Comments:

**Access to long term support and rehabilitation is essential for people who have had a stroke as soon as possible after their stroke. One in three stroke survivors have difficulty speaking and communicating, however access to speech and language therapy is patchy and inadequate even though such access has been shown to result in fewer delayed discharges[12].**

Less than half of stroke patients receive rehabilitation that meet their needs in the first six months following discharge. This falls to less than one in five stroke survivors receive appropriate rehabilitation in the six to twelve months after discharge. In South London data shows that only 14 per cent of people in need received speech and language therapy 3 to 12 months after discharge. (12)

A third of acute stroke patients are left dependent or moderately disabled. Rehabilitation is crucial and must be available to stroke survivors for longer periods of time. The amount of therapy must be determined by what the individual requires and not dictated by the resources, or the lack thereof, that are available.

3. Do the recommendations adequately address the needs of carers?

Yes ❑ No ❑ Don't know ✓

(if 'No' please state why below)

Comments:

The inclusion of carers' needs in the strategy is essential however more detail is required. An awareness campaign is required to highlight the help and support available to carers for example that their needs should be fully assessed before the stroke survivor is discharged from hospital.

4. Do the recommendations adequately address the needs of younger stroke survivors, who may face additional challenges?

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[12] NAO report

Yes ❑ **No** ✓ Don't know ❑

(If 'No' please state why below)

Comments:

**There is a particular lack of emphasis on the needs of younger people who have a stroke. One quarter of people who have a stroke are actually under the age of 65 years (NAO).**

These recommendations do not sufficiently address the needs of younger stroke survivors. In particular younger people may require support to access higher education, employment as well as information on self care and the longer-term health implications for themselves and their family following their stroke.

The provision of social care and vocational rehabilitation to aid return home and to employment are essential to meet the long term needs and health and well-being of those who have had stroke. This approach also has financial benefits and helps to meet other government policies in relation to 'Our health, our care, our say' (DH 2006) and 'Health, work and well-being' (DWP, DH & HSE 2005).

It is disappointing to note the lack of awareness of the role of AHPs in assisting younger people who have had a stroke. The role of AHPs is recognised in other government documents for example in Pathways to Work it is recognised that allied health professionals have a key role in supporting vocational goals as a key part of effective healthcare for people of working age.

5. How can services best improve access to psychological support?

Evidence shows that depression is still a problem for people at six months post stroke. In July 2007 eleven additional talking therapy projects were confirmed to help people with depression. However people with communication problems are unable to access these programmes due to their language and communication difficulties.

Speech and language therapists assist people with communication problems to be able to access talking therapy programmes, thereby directly affecting the quality of life of the stroke survivor.

Diagnosis of depression and other abnormal moods is difficult in the presence of speech problems. Talking therapies are successful in helping individuals to gain (quick) access to psychological therapy services. These services are designed to reduce the time that stroke survivors have ill health and allow them to regain their independence, particularly in returning to work and finding new jobs.

Clinical evidenceshows that better access to cognitive behavioural therapy (CBT) can help cure depression and reduce time off work due to ill-health. Improving access to talking therapies has the potential to save the economy a significant amount of money by helping people with mild to moderate depression get back into employment.

It is essential that the timescale for reviews (p39) should be revised to ensure that psychological problems are picked up in a timely fashion.

6. Is there more that can be done to improve joint working across services?

There should be easy referral routes to other professionals, regardless of employer. Some AHPs who work within contracted services, report difficulties in doing this due to the contracted nature of their services.

Improved communication and knowledge amongst health and social care professionals is paramount. SLTs already actively share their expertise with other professionals and would recommend increased sharing of information across all health and social care boundaries.

7. Is there anything that has been missed?

**YES**

**Greater emphasise must be placed on the importance of rehabilitation. Commissioners must be encouraged to commission long-term rehabilitation services to support stroke survivors within the community.**

Each stroke survivor should have their needs assessed before they leave hospital.

Communication is vital to achieving independence. Many of the skills essential for communication are directly linked with everyday life and activities and are adversely affected following a stroke, for example sequencing of words, initiation of speech, processing thoughts and planning. Without the ability to communicate with and be understood by others, we are unable to make choices, have our needs met or participate in community life. RCSLT recommends that there must be at least one SLT in every community stroke team so that stroke survivors receive prompt communication support to enable them to achieve the best possible quality of life.

Too few of the ‘specialist stroke teams’ are truly multidisciplinary. Every community stroke team should comprise of specialist / expert professionals in stroke to ensure for high quality care and support for people who have had a stroke. Specialist multi disciplinary rehabilitation stroke teams are essential in every community to provide timely rehabilitation for as long as stroke survivors need it.

Evidence shows that early supported discharge teams are effective both in terms of clinical benefit and resource use and yet only 22% of trusts have one.

All patients with communication problems should be assessed by a speech and language therapist for their suitability for access to intensive speech and language therapy[13].

**Chapter 3: Working Together**

1. Are the recommendations from the project groups the right ones?

Yes ❑ **No** ✓ Don't know ❑

(if 'No' please state why below)

Comments:

**Without investment in the training of the stroke workforce the aspirations of the stroke strategy cannot be delivered. More resources are required to ensure that sufficient levels of speech and language therapy can be delivered to people who have had a stroke.**

Speech and language therapists have a key role in indirect work with the family, carers and staff to enable the person who has had a stroke to make full use of the communication skills that they have to enable the individual to remain active in the community.

For all services to be truly multidisciplinary and patient focussed, commissioners must be made aware of the vital contribution SLTs make to the recovery and long-term support of the stroke survivor and their family.

**SLTs contribution to the multidisciplinary team is vital. SLTs work in the following ways:**

With professionals

1. SLTs train nurses to be able to identify people at risk of swallowing problems.
2. SLTs train nurses to be able to ensure safe feeding for people who have had a stroke by modifying the diet through liquidising the food or cutting the food into small mouthfuls.
3. SLTs providing training to medical staff including nurses and student nurses in basic communication skills including understanding how to communicate with a person who has had a stroke.
4. SLTs work with and train family members, carers, other members of the multidisciplinary team, health care assistants and residential staff on verbal and non-verbal strategies to improve communication interactions and conversations[14].

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[13] National Clinical Guidelines for Stroke, 2nd Edition, 2004 Royal College of Physicians of London

[14] Booth S & Swabey D (1999)

In the community
5. SLTs provide training to staff in the community for example social services, day care staff and volunteers in basic communication skills.
6. SLTs train volunteers and other agencies who work with people with communication problems in the longer term[15]. Volunteers increase the individual's knowledge of communication techniques to facilitate communication and support people in conversation.
7. Communication difficulties can be a long-term condition. SLTs work in close partnership with other agencies such as voluntary organisations and adult education services as well as public and professional groups.

It is important to note that attention must be given to enable effective, tariffs to be developed that include SLT services that can easily be 'unbundled'. These need to take account of the social model of working using practices including training and non face-to-face contact (working with and through others)/

More focus must be given to the long-term needs of stroke survivor's especially younger people who have had a stroke and their needs across organisational boundaries.

2. Will clinical networks drive the changes needed?

Yes ❑ No ❑ **Do not know** ✓

(if 'No' please state why below)

Comments:

'Clinical networks', by their very names, have a medical focus. However, these networks should not be solely 'clinical', but must include allied health professionals, the social care sector, voluntary sector representatives and people who have had a stroke.

More support needs to be given to the development of local partnerships that include PCTs, acute health care providers, local authorities and social care providers, return to work organisations and stroke survivors and their carers.

'Networks' should communicate effectively with each other to share and disseminate good practice in local regions and ensure equality of services across the country. The composition of the northwest network which is used as an example in the consultation document is not necessarily replicated elsewhere.

3. What are the benefits and concerns about expanding the cardiac network infrastructure?

Yes ❑ No ❑ **Don't know** ✓

[15] Kagan A, Black S, Duchan J, Simmons Mackie N, Square P, Training volunteers as conversation partners using supported conversation for adults with aphasia, Journal of speech language and hearing research, 2001; 44: 624-38

(if ‘No’ please state why below)

Comments:

4. Will the recommendations support more effective local workforce planning for stroke?

Yes ❑ **No** ✓ Don’t know ❑

(if ‘No’ please state why below)

Comments:

**More emphasis must be placed on the longer-term needs of people who have had a stroke. Stroke mortality is falling and more people are living for longer after their stroke. Local workforce planning must reflect this increased future demand if we are to see an improvement in community services delivered to people who have had a stroke**.

Access to speech and language therapy in the community is patchy and inconsistent. The RCSLT surveyed best practice speech and language stroke units at the end of 2006[16]. The results showed that the shortage of speech and language therapists directly impacts upon the level and quality of service that therapists are able to provide to people with communication problems. As a result stroke survivors have frequently unmet communication needs as there are too few therapists in the community to deliver the quality of therapy that is required. This situation will deteriorate as the numbers of people living with communication problems after their stroke increases.

In August 2007, the RCSLT conducted a national survey of SLT managers[17]. The results showed that due to recent financial restrictions speech and language therapy managers are being asked to cut back on services. Two out of five stated that they face financial cuts for this coming year and one quarter have had posts frozen. This reduced workforce directly impacts on access to therapy and the quantity of therapy provided resulting in delays to vital communication support for people who have had a stroke.

Standards should be introduced to tackle this lottery of provision. Stroke survivors should receive the amount of speech and language therapy that meets their specific needs both in the short and longer term. The stroke strategy should be more explicit about the level of therapies required thus giving commissioners a clearer steer as to the staffing requirements.

[16] Please contact the Royal College of Speech and Language Therapists for further information
[17] Please contact the Royal College of Speech and Language Therapists for further information

5. Are there any key gaps in research activity that need to be addressed to support implementation of this strategy?

**Yes**

The Royal College of Speech and Language Therapists would like to see more research in the following areas:
1. The cost benefits of minimising disabilities and maximising the individual's potential.
2. The extent of the need for effective cognitive interventions and their impact on outcomes and quality of life.

Research must include qualitative as well as quantitative data and include all professional groups including SLTs.

There is a strong emphasis on medical research for stroke, which currently means that therapeutic research provided by AHPs goes unfunded. However research into rehabilitation is needed and this is of great relevance to patient care. Effective rehabilitation and social care interventions support stroke survivors and their families and produce cost benefits and savings but these have yet to be fully evaluated.

6. Is there anything that has been missed?

**Yes**

**The strategy omits to acknowledge that stroke is a life long condition. Therefore access to relevant therapy and support should continue for as long as the person requires it. The work of the voluntary sector is important to supporting the everyday lives of thousands of people with communication and/or emotional difficulties as a result of stroke.**

Funding must be made available for continuing professional development (CPD) opportunities and training for SLTs. SLTs are reporting cuts to funding for CPD training and to research budgets.

The 2006 RCSLT stroke survey[18] identified that speech and language therapists are not allocated any time or funding for research, which prevents the development of evidence-based practice, which has a detrimental impact upon patient care.

## Chapter 4: Everyone's Challenge

1. Are the recommendations from the project groups the right ones?

**Yes** ✓ No ❑ Don't know ❑

(If 'No' please state why below)

[18] Please contact the Royal College of Speech and Language Therapists for further information

Comments:

2. Will these recommendations improve public awareness?

Yes ❑ No ❑ **Do not know**✓

(If 'No' please state why below)

Comments:

**The final strategy must include proposals for stroke specific prevention campaigns for high-risk groups of people.**

The recommendations to improve public awareness need to be ongoing, widespread and involve extensive media coverage.

More also needs to be done to inform stroke survivors and their carers about how they can access services once they have been discharged from acute hospitals.

See question six prevention campaigns.

3. Will these recommendations improve professional awareness?

Yes ❑ **No** ✓ Don't know ❑

(if 'No' please state why below)

Comments:

The recommendations may improve professional awareness about risk factors but they will do little to improve professional awareness about ongoing stroke management.

Undergraduate training should be targeted to include recognition of the role of all professional groups in the care of stroke survivors.

Professional bodies can play a key role to ensure that there is maximum involvement of all relevant professions in the acute and long-term care of stroke survivors.

See question six prevention campaigns.

4. Is this the right approach to improve information and advice for people at risk or a stroke or who have experienced a stroke?

Yes ❑ No ❑ Don't know ❑

(if 'No' please state why below)

Comments:

5. What more could be done to support primary care in recognising and reducing people's risk of stroke?

6. Is there anything that has been missed?

**Yes**

Following a stroke people one in five people will have aphasia, which affects their use of language including speaking, reading, writing or understanding the spoken word. Therefore it is essential that information in a format that is accessible to the individual regardless of impairments, difficulties, disabilities and language.

The final strategy must include proposals for stroke specific prevention campaigns that target the following high-risk groups:

- Young people - A quarter of people who have a stroke are of working age.
- African Caribbean and South Asian communities - at higher risk of stroke. Death rates for stroke among those aged under 65 years of people born in Caribbean and West / South Africa is nearly twice as great as that of England and Wales.
- Females between 45 and 54 – who are more than twice as likely as males of the same age to have a stroke.
- Men nearing the end of middle age – men aged 55 to 64 are three times more likely than those aged 45 to 54 to have had a stroke.

There is a lack of information about the consequences of visual impairment following stroke. Without detection, accurate diagnosis and appropriate management, many patients have difficulty responding to other interventions. Delays such as these have cost effects to services and a negative impact on the quality of life for the individual.

Please return completed forms by **12 October 2007**:

By email to MB-strokeideas@dh.gsi.gov.uk

Or send to:

The Stroke Team

c/o Pasha Mondal
Department of Health
Room 403
Wellington House
133-155 Waterloo Road
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Please see Annex A of the main consultation document for further information about the consultation process.