Healthcare for London

NHS

The shape of things to come

Whole pathway assurance paper
Stroke

Appendix 7f

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1 Introduction

The first phase of the Healthcare for London stroke project outlined the strategy for implementing new stroke services for London. While emergency and acute care have been the initial focus, the scope of the project covers the whole pathway from prevention to rehabilitation and life after stroke. The ongoing Healthcare for London work on the non-acute stages of the stroke pathway is the subject of this paper.

This paper is presented in two parts.

1) Part A outlines the description of any assurance affecting the Joint Committee of Primary Care Trusts' (JCPCT) decision.
2) Part B outlines the additional information relating to the proposed further development of work on the whole stroke pathway.

2 Executive summary

Part A

No factors have been identified within the proposed plans to further develop work on the whole stroke pathway that would impact on any decision made by the JCPCT so as to discount a particular decision or option.

No factors have been identified in relation to the plans for further whole pathway work that would influence any decision reached by the JCPCT.

Part B

2.1 Prevention

A significant amount of work has already been carried out on stroke prevention as part of the *National Stroke Strategy* and the *NHS Health Check*.

This preliminary work has identified that London is performing poorly against stroke prevention indictors.

Commissioner guidance on stroke prevention is planned for publishing in autumn 2009. Recommendations will be developed with clinical colleagues and will fall broadly into three categories: primary prevention, secondary prevention and public awareness.

2.2 Rehabilitation and life after stroke

Since the publication of the *Stroke strategy for London* in November 2008, further work on developing more comprehensive rehabilitation and community recommendations has taken place.

A directory of third sector services for stroke patients and carers will be available by 2 November 2009.

Further work on rehabilitation and life after stroke is planned for commissioning from specialists during the summer of 2009.

Commissioner guidance on rehabilitation and community stroke services is planned for publishing in autumn 2009.

2.3 Conclusion

The plans in place to continue work on the non-acute aspects of the stroke pathway allow assurance to be offered that a decision on the future of acute stroke services can be taken.

3 Scope

The purpose of this paper is to outline the planned outputs from the whole stroke pathway workstream and offer assurance that the work on the non-acute stages of the stroke pathway will not cause any disruption to the introduction of the proposed London-wide acute stroke services.

The paper provides assurance to the JCPCT in Part A before providing supplementary information in Part B. Part B outlines the work that has been carried out by Healthcare for London to date before setting out the further phase of work for both prevention, rehabilitation and life after stroke.

4 Context

4.1 Prevention

Prevention is the only part of the stroke pathway where it is possible to bring about a reduction in the overall number of strokes. In 2007, stroke accounted for well over 4,400 deaths in the capital; it is estimated that nearly 25% of these may have been prevented[1]. This amounts to around 1,100 lives a year that could be positively affected through primary prevention, in the general public, and secondary prevention, in those who have suffered from a previous stroke or transient ischaemic attack (TIA).

London is underperforming against the national average, as measured by a variety of stroke prevention indicators. While London's diverse population creates particular challenges such as the presence of language and social barriers, there is great potential to improve stroke prevention.

4.2 Rehabilitation and life after stroke

Currently there are over 6,000 people left with an impairment following a stroke in London[2]. Effective rehabilitation, initiated at the beginning of their treatment, can improve their opportunities to reengage with their lifestyle, family and friends.

[1] Healthcare for London, *Preliminary acute stroke strategy for London*, July 2008
[2] Healthcare for London, *Stroke Strategy for London*, November 2008

Across London, there is wide variation in the availability of rehabilitation and community stroke services between boroughs, with some areas having no dedicated community stroke service. In addition, there is wide variation in approaches to service provision. Because of this, it was judged inappropriate to identify a single central model of rehabilitation. Each Primary Care Trust (PCT) must commission locally appropriate services to meet best practice standards. The level of investment required will vary widely between PCTs so cannot be a shared investment decision: each PCT must determine its own investment locally (and work closely with borough social care). This investment is not included in the £23m already agreed for acute stroke care.

The introduction of hyper-acute stroke units (HASUs) and stroke units (SUs) as laid out in the consultation is expected to positively change the outcome of people who have had a stroke. It is expected that there will be an increased number of people who have had a stroke having mild disability or limited therapy needs and that there will be fewer people who die following a stroke. The impact of this decrease in mortality will mean that the number and profile of patients requiring rehabilitation and community stroke services may be expected to stay broadly similar. No study has prospectively looked at the issue of how hyper-acute care modifies therapy input; however, it is clear that thrombolysis increases the number of patients with a good outcome and very likely that hyper-acute care *per se* has a similar effect.

5 Part A – Assurance

This section will outline the description of assurance affecting the decision to be taken by the JCPCT:

1) Any factors that determine whether a particular decision or option should be discounted

   There have been no factors identified to suggest that the plans to further develop work on the whole stroke pathway would impact on any decision made by the JCPCT so as to discount a particular decision or option.

2) Any factors that influence a decision and should be considered 'in the round'

   No factors have been identified in relation to the plans for further whole pathway work that would influence any decision reached by the JCPCT.

6 Part B – Supplementary information relating to workstream implementation

6.1 Work to date

6.1.1 Prevention

National context
The early prevention work by the Healthcare for London stroke project recognises that a significant amount of work has already been carried out as part of the *National Stroke Strategy* and the *NHS Health Check*. This preliminary work has identified that London is performing poorly against stroke prevention indicators.

The Stroke strategy for London
The London strategy outlines a number of patient expectations from prevention services that were developed and tested with a range of patient representatives and patient organisations:

a) Public understanding what risk factors make a stroke more likely;
b) Increasing awareness amongst the public and healthcare professionals of the signs and symptoms of stroke;
c) Reacting quickly to reduce the chance of lasting impact on the lives of stroke survivors and their families.

The strategy outlines the biggest prevention concerns highlighted by stakeholders; these were a lack of:

a) Campaigns tailored for hard-to-reach and at-risk groups;
b) Education amongst healthcare professionals in recognising risk factors and symptoms;
c) Knowledge sharing and co-ordinated stroke prevention across London.

TIA services
The proposals for the reconfiguration of acute stroke services in London contain plans for transient ischaemic attack (TIA) services that will provide rapid assessment and access to a specialist within 24 hours (for high-risk patients) or within seven days (for low risk patients). These TIA services will form part of London's secondary prevention landscape as the access to expertise and further investigation provided in these units will reduce the likelihood that patients will go on to have a full stroke.

Draft prevention guidance for commissioners
Work has begun to develop draft guidance for commissioners to address these expectations and concerns. In developing the guidance, current performance and best practice examples have been considered alongside input from experts in the field. Following consultation with directors of public health, commissioners, general practitioners and acute experts, Healthcare for London has:

a) Identified key challenges to implementing the prevention agenda;
b) Developed high level solutions to address these;
c) Developed prevention standards for stroke to give assurance that the stroke prevention agenda is being delivered.

The Qualities and Outcomes Framework
The need to measure success of stroke prevention services in the capital was highlighted during this early work; standards for prevention were therefore developed from existing QOF (Quality and Outcomes Framework) data. QOF is a payment schedule for primary care based on targets for patient activity. QOF was chosen because it is currently the best and most comprehensive data source of preventative interventions. The indicators that were selected give assurance that both primary and secondary prevention interventions are in place.

The high level of exception reporting in QOF gives it limitations as a health indicator. GPs can choose to report patients as exceptions and these patients will not appear in QOF data and little may be known as to why patients are reported as exceptions. Looking at QOF data in isolation does not therefore provide an accurate view of the health of the population. Healthcare for London therefore also looked at the data that were excluded from QOF. Metrics were then developed from both of these approaches. Stroke awareness is not covered in QOF so non-QOF based standards were also created to ensure that stroke awareness is delivered in London.

Gaps in services
Areas have been identified where there are gaps in prevention services. These include a lack of emphasis on the maintenance of the stroke registers that allow the follow-up of stroke patients to be co-ordinated and assured.

In addition, some groups may be excluded from prevention services. For example, the exclusion from the *NHS Health Check* screening programme of those over 74 years of age means that individuals with stroke risk factors may fall through the prevention net. In addition, QOF measures the process of prevention rather than the outcomes. As such, patients may be on treatment to control their blood pressure but this may not necessarily mean that their blood pressure is under control. The stroke prevention guidance for London commissioners will address such gaps in services.

6.1.2 Rehabilitation and life after stroke services

The *Stroke strategy for London*
Support for the development of non-acute services for stroke survivors has been identified as a priority by the JCPCT. Early work by the Healthcare for London stroke project on rehabilitation and life after stroke developed recommendations and performance standards for inpatient rehabilitation, initial access to community rehabilitation, and the review of patients in the first year following a stroke.

These recommendations and performance standards, published in the *Stroke strategy for London*, were developed through a process of clinical and patient engagement at large workshops, working groups and through the Healthcare for London stroke project governance panels. The stroke project team also engaged with stroke survivors, carers and their representatives. Six stroke engagement events were held, including one focussed specifically on rehabilitation and community care. Each event was attended by up to 200 people including staff from inpatient and community stroke services, social care and the voluntary sector and a number of patients and carers. In addition, presentations were made to specific groups including directors of social services and intermediate care managers.

The *Stroke strategy for London* states that:

> 'Rehabilitation and care services should be delivered around the needs of the individual and their family. These include aspects of care related to clinical issues and residual impairments (including communication problems), but also to the person's functional and activity-based goals and ongoing social participation. The psychosocial needs of the individual and their family, and their re-engagement back into society, also need to be addressed.' (p32)

The strategy outlines recommendations based on feedback from service users, London commissioners and providers, examples of good practice and the *National Stroke Strategy*. The *Stroke strategy for London* continues: (p32-33)

> 'The recommendations aim to help PCT commissioners develop user-friendly rehabilitation services which respond to the needs of stroke patients and their carers. The stroke project will complete further work on long-term care and the links with primary and social care.
>
> 'The following are overarching recommendations that all London PCTs should adopt in commissioning stroke rehabilitation services. Specific performance standards for these services are set out for inpatient and community rehabilitation, GPs and the voluntary sector.
>
> 1. Inpatient rehabilitation should be available for all stroke patients. Rehabilitation starts as soon as possible and continues for as long as required. This must meet all of the performance standards.
> 2. Every PCT should commission a community rehabilitation service for stroke patients that includes staff with specialist stroke skills. The configuration of this service is for local determination but it must meet all of the performance standards.
> 3. Every PCT should commission an early supported discharge service that includes staff with specialist stroke skills. This service must meet all of the performance standards.
> 4. Everyone who has had a stroke, and their carers, should have:
>   i) A key support worker such as a family support worker or community matron to provide:
>   - longer-tern support;
>   - navigation and advocacy; and
>   - a link with the inpatient and community rehabilitation teams and other care providers.
>
>   ii) A designated person from health or social care who is the key contact for the patient and carer whilst in each setting, such as a therapist, social worker, or healthcare assistant.
> 5. For the first 12 months following a stroke, all individuals and carers will have a regular review and assessment of ongoing medical, social and emotional needs as both an inpatient and in the community.
>
> 'The recommendations aim to greatly improve current rehabilitation services in London, reducing inequalities in provision that exist between different localities. The recommendations also aim to improve communication between different care settings and with the patient.'

Post *Stroke strategy for London*

Since the publication of the *Stroke strategy for London* in November 2008, follow up work has been completed with a working party consisting of representatives from health, social care and the voluntary sector. Other interested individuals and groups such as GPs and community rehabilitation teams were also engaged. This work

clarified some of the services currently available across London. A number of service gaps and examples of good practice were identified that informed the further development of Healthcare for London's recommendations. Evidence from a range of national strategies and guidelines was also drawn upon.

This work has developed more comprehensive rehabilitation and community recommendations, including commissioning guidance and recommendations for the longer-term provision of services in the community setting (life after stroke). A third sector working group and a grassroots user group have been established to support the workstream in the development of life after stroke recommendations. The work of these groups has focused around the care model described in the *National Stroke Strategy* and any areas that were identified as not being represented within this care model.

Network level

In addition, work has been carried out at the local level with London cardiac and stroke networks comparing the services being provided for stroke patients with the quality markers defined in the *National Stroke Strategy*. This process identified where services meet the quality markers, such as the established early supported discharge teams in some boroughs and vocational rehabilitation services in others. The process also identified where there are gaps, outlined some recommendations for meeting the quality markers and provided a high-level project plan for the implementation of those recommendations for the networks.

Third sector

In addition, the Stroke Association has been commissioned to map third sector services across London and produce an accessible directory of services for use by health and social care professionals, service users, third sector organisations, PCTs and the general public.

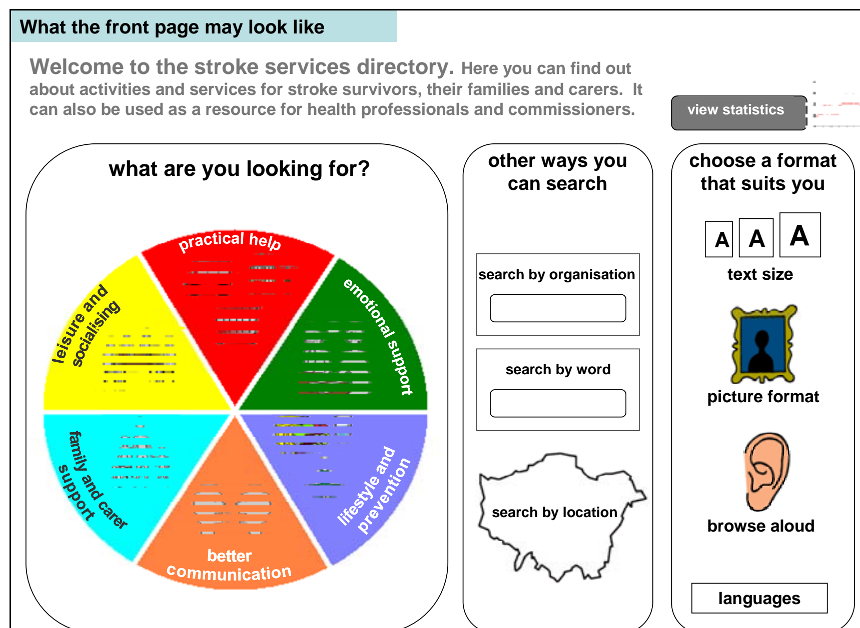
This resource will assist stroke survivors and carers in continuing to access services in the months and years following their stroke. Some services are provided across London and others at a very local level and it is difficult for patients to know exactly what services are available, how they are accessed and how they are funded. Moreover, many statutory organisations providing services to stroke patients may benefit from a repository of the details of all of the third sector services available.

The first stage of the project involved the mapping of the voluntary sector organisations providing services to stroke survivors across London. Information was collected through a variety of means including a postal survey, work with localised mapping co-ordinators (for example, at Hillingdon and Kingston PCTs), and by meeting with members of other voluntary sector organisations already known to Healthcare for London and the Stroke Association.

Research was conducted across all 31 London PCTs and organisational data was collected from 728 voluntary sector organisations. It is anticipated, however, that data gathering will continue into the second stage as new organisations emerge and information changes.

As well as the mapping exercise, the preliminary work for stage two has been completed. This stage will produce a directory of mapped services in an accessible format and a proposal for the maintenance of this directory. This has involved developing a structure on which to base the navigation of the online directory so that it is accessible for all of those within the stroke pathway.

The following visualisation gives an indication as to what the final directory could look like.



6.2 Further development phase

The further phase of whole pathway development is led by the conclusions of the work completed to this point. The current schedule runs until end of December 2009 and will encompass the development of:

1. Commissioner guidance on stroke prevention
2. Commissioner guidance on rehabilitation and community stroke services
3. A directory of third sector stroke services

6.2.1 Commissioner guidance on stroke prevention

Guidance for PCTs in the commissioning of prevention services will be further developed. Recommendations will be developed with clinical colleagues and will fall broadly into three categories: primary prevention, secondary prevention (including the development of the TIA pathway) and public awareness.

This commissioner guidance will provide direction on stroke prevention to PCTs in order that:

a) They can understand the prevention needs in their area;
b) They can assess the suitability of forming partnerships with other organisations to improve stroke prevention;
c) The London population and the wider stroke community have confidence that stroke prevention is being delivered throughout London.

Drawing upon the material already collated by the Healthcare for London stroke project, coupled with emerging work from across London, the following elements will form part of the prevention guidance:

a) Existing prevention initiatives and guidance on the methods that PCTs can use to support the wider prevention and healthy lifestyles agenda;

b) The identification of service gaps within the current prevention services as derived from the *National Stroke Strategy* and the *NHS Health Checks* programme;
c) The description and analysis of current prevention performance indicators (QOF);
d) Links between prevention services and community based urgent care providers;
e) The development of the TIA pathway and secondary prevention services.

Proposed timescale
Publication of commissioner guidance on stroke prevention is planned for autumn 2009 following development with clinical stakeholders.

6.2.2 Commissioner guidance on rehabilitation and community stroke services

The aim of this guidance is to assist PCTs in commissioning services that:

a) Are easy to navigate and that respond to patient and carer needs;
b) Improve the quality and effectiveness of the rehabilitation and community stroke care that is delivered across London;
c) Improve support for people who have had a stroke and carers to access the right services in a timely manner;
d) Reduce the inequity of access to rehabilitation and community stroke services across London;
e) Improve links between acute, community stroke services and social services.
f) Make best use of investment in post-acute care.

Two high level components of this deliverable have been identified for further investigation: a life after stroke model and investment priorities.

Development of life after stroke care model as identified in the *National Stroke Strategy*
Working with the Healthcare for London stroke project's expert panels and other members (professional and non-professional) of the London stroke community, the following additional priorities have been identified to ensure that the Healthcare for London commissioning guidance is comprehensive and is appropriately focussed:

a) Carers and family
b) Re-enablement
c) Communication
d) Practical help
e) Care and support
f) Adult protection
g) Local engagement

Investment priorities
An analysis of south London services providing stroke rehabilitation in the community with the *Stroke Strategy for London* suggested a very considerable gap between current and proposed standards in some PCTs. Financial analysis indicates that the scale of this gap is such that achieving the standards would be unaffordable for some PCTs under present NHS funding assumptions.

Further work is therefore needed to:

a) Seek more efficient approaches to provision of care, where necessary reviewing the performance standards;
b) Identify the potential for funding investment in community rehabilitation from disinvestment elsewhere in the pathway (e.g. split tariff arrangements for early supported discharge, reduced reliance on medium and long-term bed based care);
c) Identify which investments give the greatest return in terms of patient benefit and in terms of savings elsewhere in the pathway.

Proposed timescale

Further work on rehabilitation and life after stroke, commissioned from specialists, is planned for the summer of 2009. The full guidance for commissioning rehabilitation and community stroke services is planned for publishing in autumn 2009.

6.2.3 Directory of third sector services

The stroke project team has commissioned the Stroke Association to develop a directory of third sector services. The project team will continue to manage the development of this work. This resource is essential to assist stroke survivors and carers in continuing to access services in the months and years following their stroke. Many of these services are provided by voluntary sector organisations – some through statutory funding and others on a charitable basis.

Some services are provided across London and others at a very local level. It is difficult to obtain a clear map of what these services provide, how they are accessed and how they are funded. Moreover, many statutory organisations providing services to stroke patients may not know that some third sector services exist and therefore stroke survivors may miss out on services from which they may benefit.

Proposed timescale

Stage one was completed on 12 June 2009. This stage comprised of the mapping and documenting of all of the third sector organisations providing services to stroke survivors and carers across all 31 London PCTs and the provision of a stage one report.

Stage two is expected for completion by 2 November 2009. This stage will produce a directory of mapped services in an accessible format and a proposal for the maintenance of this directory.

6.2.4 Links to other work

A number of the aspects outlined link to other Commissioning Support for London (CSL) or NHS London initiatives.

1. The continuing professional development (CPD) framework for stroke. This project is being developed to establish a CPD framework for professionals working with stroke patients throughout recovery and rehabilitation. The intention is to identify the skills required and map these to Skills for Health and the *Knowledge and Skills Framework* to assist with workforce establishment and development.

2. The Healthcare for London major trauma project. There is some congruence between the rehabilitation services required for stroke patients and those who have sustained traumatic injuries. The parallels will be explored and links will be forged as appropriate. The CPD framework development is being run as a project in conjunction with the major trauma project and this will therefore contribute to this process.

3. The Healthcare for London long-term conditions project (Diabetes). Many of the prevention messages being developed by Healthcare for London are generic and will be strengthened if worked on collaboratively, rather than on a disease specific basis.

4. The long term conditions community – London region. This is a Department of Health (DH) initiative to help anyone with an interest in improving delivery of services for long-term conditions. Stroke is considered to be a long-term condition when services are delivered within the community setting and a member of the regional team is part of the life after stroke working group.

5. London local authorities – implementation of the *National Stroke Strategy* (Service Improvement Funding). The DH has provided financial support to deliver stroke care for adults in the community for each local authority with adult social services responsibilities.

6. The DH/Stroke Association FAST campaign. This is a three-year national campaign, launched on 9 February 2009, which aims to increase public awareness of stroke. Any pan-London awareness initiatives should be consistent with the national campaign.

7 Conclusion

Both prevention and post-acute stroke services in London can be improved. Healthcare for London will build on the work to date to produce a framework to enable this to happen. Commissioner guidance on stroke prevention is planned for publishing in autumn 2009. Commissioner guidance on rehabilitation and community stroke services is planned for publishing in autumn 2009. A directory of third sector services to assist stroke survivors and carers will be available from November 2009.

The plans in place to continue work on the non-acute aspects of the stroke pathway support the commissioning of the whole stroke pathway of care and provide assurance to the JCPCT that all elements of prevention and care are being considered.