

Aspiring to excellence

Services for the long-term
support of Stroke Survivors

Guidance for Commissioners
A resource for Providers

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Executive Summary

'Stroke patients may spend several days or weeks in hospital, but it is the months and years after discharge that they, their families and carers experience the full impact of stroke'

National Audit Office, February 2010¹

Stroke remains the largest cause of adult disability in England. Whilst in recent years there have been significant improvements in acute care, the provision of high quality, integrated services for stroke survivors after they leave acute care is not as straight-forward.

When a stroke happens, the impact can be devastating both emotionally and physically. Many people survive a stroke but are left with a range of difficulties and impairments that are often still present on discharge from acute care. These impairments may include paralysis, problems with movement, balance and posture, weakness, spasticity and pain. Many stroke survivors also have emotional difficulties and a very real sense of both personal and physical loss. Physiotherapists and other allied health professionals, with their holistic, person centred approach to health and well-being are ideally placed to support individuals in working towards re-enablement and recovery.

One fundamental tenet of good quality services for those impacted upon by stroke is that stroke survival means living successfully with a long-term condition. Stroke survivors and their families and carers will potentially require the support of a range of health and well-being professionals for months and possibly years to come.

Commissioners have the responsibility to ensure services for stroke survivors are high quality, responsive, sustainable, clinically, fiscally and socially effective. To achieve this, commissioners need to appreciate the trajectory of the condition that is 'stroke' and the health and well-being needs of stroke survivors in order to specify the appropriate service. The service specification, tendering and letting the contract are key, but commissioners

must ensure that services delivered remain true to what is specified and that the service continues to develop whilst remaining embedded in evidence based practice.

Service providers have the responsibility of delivering services that are underpinned by evidence and are responsive to need, addressing the needs of the stroke survivor through:

- Fulfillment of agreed quality and standards of best practice
- Delivery by a workforce that has the knowledge and skills appropriate to their role within the stroke pathway
- Delivery in an appropriate environment that facilitates re-enablement and re-engagement with society on day-to-day and social levels
- Giving choice and personal control with engagement in decision making about their care and support
- Integrating services and delivering a seamless transition across boundaries
- Giving support and education for carers
- Enabling individuals to live successfully with the long-term consequences of stroke

Achieving the ambition of excellence in service delivery will require dialogue and co-operation between commissioners and providers; it is intended that this guidance for commissioners and resource for providers will assist in developing a shared approach in achieving an improved quality of life for stroke survivors.

Some aspects of the material contained within this publication will be familiar to the reader, however, as a resource it is designed to be 'dipped into' rather than read from cover to cover. The additional content setting out the political, social and economic context of health and well-being should enhance mutual understanding and appreciation of the different perspectives of both commissioner and provider. Where appropriate, examples of service redesign that have been successfully achieved have been included.

¹ Progress in improving stroke care. Report by the Comptroller and Auditor General. HC291 Session 2009-2010. London: The Stationery Office.

Aspiring to excellence: Services for long-term support of Stroke survivors: guidance for commissioners, a resource for providers

Introduction

'Stroke patients may spend several days or weeks in hospital, but it is the months and years after discharge that they, their families and carers experience the full impact of stroke'
NAO February 2010²

This guidance is aspirational. It is about whole system commissioning and recognises that achieving excellence across the whole service is challenging, will not be immediate and that one size does not fit all. World Class Commissioning is about expecting excellence and evidence suggests³ there are unacceptable variations in services for stroke survivors⁴. The guidance also recognises the potential within the system and that a courageous approach is needed to really make a difference, viewing the pathway as a 'year of care' to optimise opportunities for 'adding life to years, and years to life'⁵ of stroke survivors.

This is a resource to be 'dipped into' rather than read from cover to cover. It sets out the political, social and economic context of commissioning. Some aspects will be well known to the reader, other parts will provide useful information and learning so that commissioners and providers can work together to establish the services for patient benefit.

The current work on the roll out of the National Stroke Strategy⁶ maintains an acute interventionist perspective about stroke survival, but stroke is not a fixed pathology illness and with increasingly successful acute interventions, it is the long-term support for stroke survivors that needs review and transformation. This perspective is supported in 'Moving On' the recently published joint report from The Stroke Association and The Chartered Society of Physiotherapy.⁷

The quality of the services commissioned is directly related to the service specification constructed for the tendering process. Commissioners will want to understand the trajectory of the condition that is 'stroke' and the health and well-being needs of stroke survivors in order to develop an appropriate service specification. Services that are delivered must also uphold the aspirations set out in 'NHS 2010-2015: from good to great'.⁸ Working in partnership with local authorities to put health at the centre of joint targets set through the Local Area Agreement (LAA) and Local Strategic Partnerships (LSP) sets a sound foundation for tackling the issues of maintaining mobility and independence. There is also a clear commitment to ensuring that all patients receive the best treatment and that the NHS will further improve access to dedicated stroke units for all stroke patients.

² Progress in improving stroke care. Report by the Comptroller and Auditor General. HC291 Session 2009-2010. London: The Stationery Office

³ National Stroke Strategy www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_081062 accessed 15th October 2009

⁴ The guidance focuses on post acute services – early supported discharge and long-term service provision

⁵ NHS Next Stage Review, Department of Health, 2008

⁶ National Stroke Strategy www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_081062 accessed 15th October 2009

⁷ 'Moving On' A vision for community based physiotherapy after Stroke in England, The Stroke Association in partnership with The Chartered Society of Physiotherapy

⁸ NHS 2010-2015: from good to great, preventative, people-centred, productive, Department of Health, December 2009

Role of Commissioners

- The core responsibility for commissioners is to commission high quality safe services that are tailored to the needs of individual patients and to do so in a way that maximizes value for money.
- In essence this means buying healthcare services for their defined population from a range of providers.
- PCTs should do this in conjunction with practice based commissioners (PBCs) and commissioning colleagues from other sectors including local authorities and the voluntary sector.
- Ensuring access to other services, such as out of hours services and rapid response to maintain continuity of care, can support individual preferences and choice.
- Commissioners also have a key role in the performance management of service delivery in line with agreed outcome measures and are required to understand the roles, responsibilities and governance arrangements of existing structures for example, clinical networks.⁹
- The service specification, tendering and letting of the contract are key, but it is imperative that the true needs of the service user remain central; and that what is commissioned is actually implemented. Commissioners may wish to consider including a service review period within the specification and contracting process to ensure that services continue to evolve as the evidence base for practice evolves.
- Whilst this resource is aimed at services for stroke survivors, many aspects are equally applicable for other long-term conditions and end of life care.
- Commissioners will be aware of the increasing number of people now living with long-term conditions and could seek to integrate transition of services for long-term conditions with those commissioned

as services for end of life care.

- Commissioners need to specify clearly what needs to be in place to deliver good quality end of life care for their stroke populations.¹⁰

What is World Class Commissioning?

- World class commissioning is a statement of intent, aimed at delivering outstanding performance in the way we commission health and care services in the NHS.
- WCC will have a direct impact on the health and well-being of the population driving unprecedented improvements in patient outcomes.¹¹
- Commissioners have a legal duty to secure the best services, in terms of quality and productivity for the people they serve. This is to be achieved through robust contract management and benchmarking.
- Good management is absolutely critical to realising the vision of higher quality and more productive services. The challenge for WCC is to lead local change by working systematically to realise local visions for changing patient pathways
- By understanding local needs, reshaping the provider sector on a service by service basis to secure the most efficient services for their populations – commissioners are at the forefront of this change.¹²

⁹Information for commissioning end of life care; National End of Life Care Programme Department of Health, 2008

¹⁰National Stroke Strategy www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_081062 accessed 15th October 2009

¹¹World Class Commissioning: vision www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080956 accessed October 15th 2009

¹²NHS 2010-2015: from good to great, preventative, people-centred, productive. Department of Health, December 2009

The political, social and economic context of commissioning

In 2006, the Department of Health White Paper 'Our health, our care, our say'¹³ set out the direction for improving the health and well-being of the population in order to achieve:

- Better prevention and early intervention for improved health, independence and well-being
- More choice and a stronger voice for individuals and communities
- Tackling inequalities and improving access to services
- More support for people with long-term needs

This White Paper also identified the need for Directors of Public Health, Adult Social Services and Children's Services to undertake regular strategic needs assessments of the health and well-being status of their populations, enabling local services to plan, through Local Area Agreements, both short and medium term objectives. The subsequent Local Government and Public Involvement in Health Act 2007 places a duty on local authorities to prepare Local Area Agreements in consultation with others. Local Authorities and Primary Care Trusts (PCTs) also have to produce a Joint Strategic Needs Assessment (JSNA). The statutory guidance accompanying the Act positions JSNA as underpinning the Sustainable Community Strategy and, in turn, the Local Area Agreements.

The Department of Health envisages that the JSNA will not only identify areas for priority action through Local Area Agreements but will help commissioners to specify outcomes that encourage local innovation and help providers design services to address the priorities. WCC is achieved through an understanding of both the demand within the system and also the future population need as set against the aspirations of government (there are national, regional and local priorities with corresponding indicators i.e.

'Vital Signs'¹⁴) for the health of the population. Naturally, WCC does not operate in isolation; there are other key components of the system that must be considered. The commissioning assurance process, a nationally consistent system managed by the Strategic Health Authorities, holds PCTs to account. The purpose of commissioning assurance is specifically to understand whether PCTs are improving in commissioning services that will provide better health outcomes for the population.

World Class Commissioning will continue to develop with the introduction of a new efficiency competency into the assurance framework in 2009-10 as announced in the 2009 Budget. Commissioners will therefore need to drive transformations in both the quality of care and the efficiency of services. By placing greater emphasis on assessing local needs, and prioritising investments to deliver long-term improvements in health outcomes, WCC should be pivotal in reducing health inequalities, supporting the shift from treatment and diagnosis to prevention and the promotion of well-being.

The Department of Health has stated that it will 'look for evidence that commissioning decisions have been informed by the Joint Strategic Needs Assessment, to achieve improved health and well-being and reduced inequalities and best value for all'.¹⁵ Achieving optimal service provision that really is for service user benefit requires co-operation and conversation between providers and commissioners such that both really understand the conflicting demands and can establish a 'best fit' for their particular population demands.

The demands facing health and well-being services in the next decade are well rehearsed: ever higher patient expectations; an ageing

¹³ Our health, our care, our say, Department of Health, 2006

¹⁴ The NHS in England, Operating Framework 2008/9 Department of Health December 2007

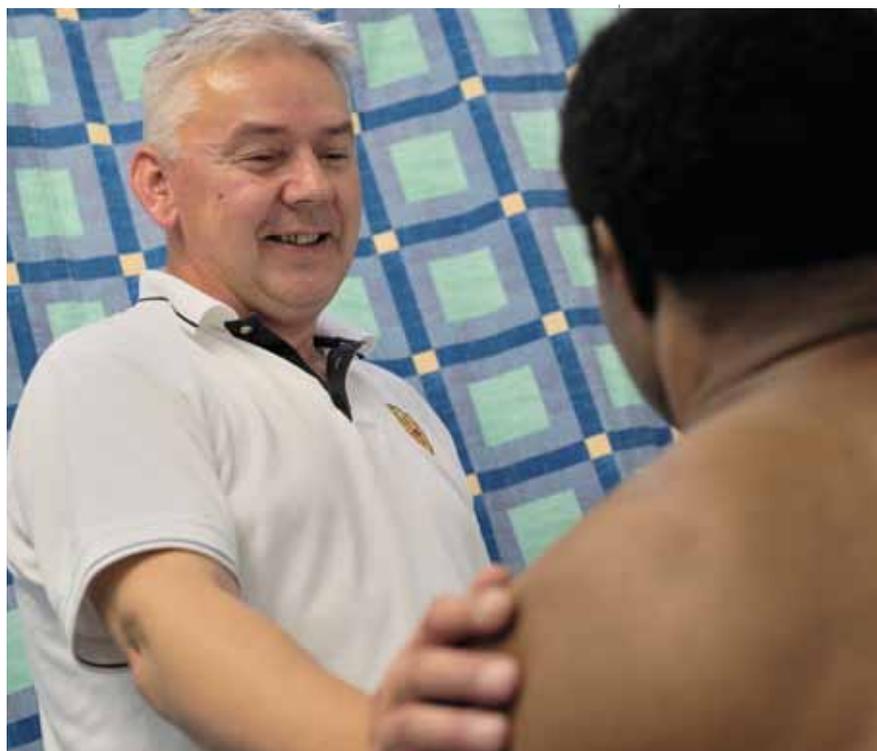
¹⁵ Commissioning Assurance Handbook, Department of Health, 2008

society; the dawn of the information age; the changing nature of disease; advances in treatments and a changing workforce.¹⁶ The predicted need to release £15 – £20 billion through efficiency savings from 2011 to 2014 whilst keeping quality as the organising principle presents a challenge to the NHS. Quality may be defined as becoming truly responsive to what patients, communities and staff want and putting them at the heart of what services do.¹⁷ In such a testing economic environment productivity is key and should be viewed in terms of using staff time and resources more effectively to improve quality, patient experience, individual efficiency and organisational efficiency. Success requires knowledge and understanding of the workforce, their skills and structure, what they are doing, where and why.

So commissioners will want to invest in what works best and transforms care, namely:

- Optimise pathway design, delivery & settings – for the user not the provider
- Encourage innovation and clinical leadership
- Enable cost-effective, safe co-production
- Invest to achieve the biggest returns in terms of health – this may not necessarily be in the health sector
- Understand the evidence of ‘what works’
 - Reduce clinical variation
 - Improve organisation and delivery of services
- Shift care to the clinically and economically most effective settings, then decommission and reallocate resources¹⁸

The Department of Health Transforming Community Services programme¹⁹ indicates that savings are to be made in this sector, but this is in a context of huge variability in pre-existing funding of community services, from under £100 to over £200 per head of population.²⁰ Securing the reduction of cost and improving patient experience by shifting care from reliance on hospital to a system where services are provided at, or nearer to home requires careful management and the development of integrated supply chains and new incentives



for providers. At the same time the ‘stranded costs’ from staffing and infrastructure will need to be removed and returned to commissioners to reinvest in care closer to home services.²¹ PCTs need to assertively commission high quality community based care and service users need to perceive that the quality and continuity of care provided in the community is at least equal to that provided in the acute hospital environment.

As the recent National Audit Office report²² indicates, improvements in acute care are not yet matched by progress in delivering more effective post-hospital support for stroke survivors, where there are barriers to joint working between the health service, social care and other services.

The recently published guidance on the assurance and approvals process for PCT-provided community services gives a clear steer to integration of provisions for maximum service user benefit, integrating services across disciplines and across agencies, not commissioning single professional provisions.

¹⁶ NHS 2010-2015: from good to great. Preventative, people-centred’ productive, Department of Health, December 2009

¹⁷ ‘Putting patients at the heart of care: the vision for patient and public engagement in health and social care’, Department of Health, September 2009

¹⁸ Our NHS, our future, NHS Next Stage Review, Leading Local Change, Department of Health, May 2008

¹⁹ Transforming Community Services: enabling new patterns of provision: www.dh.gov.uk/en/Publicationsandstatistics/publicationsPolicyAndGuidance/DH_093197 accessed on 24th January 2010

²⁰ Crump B ‘Variation shows NHS community services ripe for efficiencies’ Health Service Journal 13th August 2009

²¹ Harvey S Liddell A McMahon L; Windmill 2009 NHS response to the financial storm, The King’s Fund, London 2009

²² ‘Progress in improving stroke care. Report by the Comptroller and Auditor General. HC291 Session 2009-2010. London: The Stationery Office.

'By integration, we mean the single management of services to promote innovation, provide better quality and experience of care for individuals, and improve the efficiency of service delivery. This can include health and social care services, and hospital, community and primary care services, acting together to maintain and improve individuals' health and well-being.

It also means organising services around the needs of the individuals to reduce unnecessary hospital visits, or admissions to residential care, or reduce the length of time people spend in hospital by supporting people at home, ensuring that boundaries between different providers do not fragment care for the individual. Joining up commissioning and provision to provide individual care pathways ... can help improve outcomes. Providing this integration or co-ordination will be particularly important where people have multiple needs across different care pathways'²³

Achieving integration of services and releasing resources across the health and well-being environment will not be achieved by "tinkering around the edges". If stroke continues to be seen only as an acute condition with the continued 'front end' acute provider investment that has been favoured since the publication of the National Stroke Strategy for England²⁴ then there will continue to be a shortfall in the quality component of the quality and productivity challenge. Poor quality services for the stroke survivor result in a reduced quality of life patient reported outcome. The acute environment is governed by the ongoing demand for access to acute beds and consequently, when stable and by definition no longer acute, the stroke survivor is 'pushed out' into community care.

An innovative commissioner may consider how much better might such a key transition point be, if it was community care who 'pulled' (i.e. facilitated) the stroke survivor through the transition, towards 'early' supported discharge,

bringing people into community care at the most appropriate time clinically and socially. When advocating a courageous approach to commissioning, why not use the system levers that currently exist to encourage 'pull through', perhaps using a local tariff based on best practice, or more courageously still, giving the whole pathway contract to the community provider with a view to 'sub-contracting' the acute provision, truly transforming community service and enabling the community to establish itself as a pathway driver. Consideration might be given to integration of supply chains and partnership with other providers. Alternatively perhaps patient experience measures could be linked with service payment for this group?²⁵

Stroke is an enduring condition, not a fixed pathology illness. There are 110,000 strokes and 20,000 mini strokes each year in England, and 25% of these are within the working age population (under 65 years). Approximately one third of stroke survivors are left with disabilities and rehabilitation needs. To achieve WCC of services for people who are post acute stroke survivors, the innovative commissioner should be familiar with the characteristics of high performing systems for service provision in long-term conditions.

One such model for a service is the Model for Chronic Care that sets out basic changes that will support delivery of care that is evidence based, population based and person centred. This model has been used to re-orientate from acute to chronic care. Key actions required include^{26 27}:

- Greater attention to supporting people with long-term conditions to care for themselves
- Increased emphasis on multi-disciplinary teams delivering high quality primary care
- Achieving effective integration of primary care and specialist care
- Action to address modifiable risk factors
- Facilitation for return to work, voluntary or leisure pursuits, re-enablement for active contribution to society

²³ Transforming Community Services: The assurance and approvals process for PCT provided community services, Department of Health, 2010

²⁴ National Stroke Strategy www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_081062 accessed 15th October 2009

²⁵ A 'Best Practice Tariff' guidance for rehabilitation services is expected in 2011/12. This should complement the best practice tariff published in the 2010/11 NHS Operating Framework for England.

²⁶ Wagner E 'Chronic Disease management: what will it take to improve care for chronic illness? Effective Clinical Practice 1; 2-4, 1998

²⁷ Ham C The ten characteristics of the high performing chronic care system, Health Economics, Policy and Law 5, 71-90, 2010

The Stroke Strategy

The National Stroke Strategy for England²⁸ was published by the Department of Health on 5th December 2007 and identified 20 quality markers for what a good stroke service should look like.

For each of these the strategy identifies action that commissioners should take to meet the standard set out in the quality marker.

Commissioners are advised to begin by establishing a baseline to determine where they already have plans in place and where work is needed?

Key features in the quality markers include:

- Members of the public and health and social care staff will be able to recognise the main symptoms of stroke and know that it needs to be treated as a medical emergency
- Those at risk of stroke and those who have had a stroke are assessed for and given



information about risk factors and lifestyle management issues (exercise, smoking, diet, weight and alcohol)

- High-risk TIA (mini-stroke) patients to be assessed by experts and, wherever possible, scanned using magnetic resonance imaging (MRI) within 24 hours of experiencing symptoms; lower-risk groups to be seen within seven days and given follow-up care
- Immediate transfer of those with suspected stroke to a specialist centre offering immediate clinical assessment, scans and clot-busting drugs through out the 24 hour period.
- Those patients with stroke requiring urgent brain imaging scanned within the next scan slot during normal working hours, and within 60 minutes out of hours.
- All individuals with stroke spend the majority of their time on a stroke unit.
- People affected by stroke and their carers should have immediate access to high quality rehabilitation and support from stroke-skilled services in hospital, immediately after transfer from hospital and for as long as they need it
- Stroke patients must receive a clear discharge plan developed by health and social services that has involved the individual (and their family where appropriate) and responded to their particular circumstances and aspirations, to ensure a smooth transition from hospital to home.
- A range of services need to be available locally, to support the long-term individual needs of people who have had a stroke and their carers. This includes communication, psychological, occupational health and physiotherapy services
- Stroke survivors need to be offered a review of their health, social care and secondary prevention needs, typically within six weeks of leaving hospital, before six months have passed, and then annually
- People who have had a stroke should have access to practical advice, emotional support, advocacy and information throughout their care.

²⁸ National Stroke Strategy www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_081062 accessed 15th October 2009

- Networks (involving all the organisations involved in stroke care) are established covering populations of 0.5 to 2 million to review and organise delivery of stroke services across the care pathway.

Voluntary sector involvement

Commissioners are encouraged to engage a wide range of service provision, including that from the voluntary sector.

The stroke strategy goes on to describe the comprehensive package of support services that the voluntary sector can provide including:

- Family and carer support intervening soon after the event and providing
 - Information, advocacy and support
 - Day care

- Services for people of working age
- Primary and secondary prevention
- Dysphasia and aphasia support groups
- Activity and rehabilitation programmes
- Stroke clubs.

The strategy explains that these services are supported by volunteers and provide opportunities for individuals recovering from stroke to contribute their experience and encouragement to those at an earlier stage of the stroke journey.

The strategy also recognises that support from the stroke specialist voluntary sector is becoming increasingly important.

One fundamental tenet of good quality services for those impacted by stroke is that stroke survival means living successfully with a long-term condition. This philosophy needs to be embedded within any discussion around service specification.

The ten characteristics of high performing chronic care systems (see panel) map successfully to the delivery of stroke services, and also map to the delivery of integrated services for the support of all those living with long-term neurological conditions. The key element in an integrated neurology service being to ensure that access to specialist support is available in recognition that different neurological conditions have different requirements for management as a result of differing prognoses.

Commissioners may wish to look at what strategies providers have in place for achieving re-orientation of health care services from acute to long-term care. Elements such as effective clinical leadership by those best placed to understand the needs of those accessing stroke services; the use of measurement of patient outcomes, both clinical and patient reported in developing a culture of continuous improvement; alignment of incentives and community stakeholder engagement in the transition, are all agreed to be good indicators of paradigm shift.

The ten characteristics of the high performing chronic care system have been identified as:

- 1 Ensuring universal coverage
- 2 Care that is free at the point of use, or at least provided at a cost that does not deter access
- 3 Delivery system should focus on prevention not just treatment of illness
- 4 Priority given to people self-managing with support from family and carers
- 5 Priority given to primary health care
- 6 Emphasis on population management
- 7 Care is integrated to enable primary health care teams to access specialist advice and support when needed
- 8 Exploits the potential benefits of information technology
- 9 Care is effectively co-ordinated
- 10 All the previous 9 characteristics are linked together as a coherent whole and part of a strategic approach to change²⁹

²⁹Ham C, The ten characteristics of the high performing chronic care system, Health Economics, Policy and Law 5, 71-90, 2010

Stroke in context³⁰

The evidence for the need for increased prevention of stroke is robust. Each year in England and Wales:

- Over 130,000 people have a stroke or mini-stroke.
- There are 87,700 first strokes and 53,700 recurrent strokes.
- This is equivalent to someone having a stroke every five minutes.
- 25% of strokes occur in people aged under 65 years.
- 35 people out of every 100,000 each year have a TIA.
- 10-20% of those who have had a TIA will go on to have a stroke within a month. The greatest risk is within the first 72 hours.
- The risk of a recurrent stroke is 30-43% within five years
- People aged 75 years or older have a nine-fold higher risk of stroke and from recurrent stroke when compared to people aged 45 to 64 years.
- The incidence of stroke increases with decreasing socio-economic conditions^{31 32 33}
- Stroke causes over 60,000 deaths each year in the UK
- Of all people who have a stroke, about a third are likely to die within the first ten days, about a third are likely to make a recovery within one month and about a third are likely to be left with disabilities and needing rehabilitation.
- There are more than 900,000 people who have had a stroke living in England. Approximately half of these people are left dependent on others for everyday activities.
- Up to one third of these people are depressed at whatever time point mood is assessed³⁴

One year after a stroke, approximately:

- 80% of people are at home
- 12% live in a residential or nursing home
- 66% regain the ability to walk
- 45–60% are independent

- 5-9% are totally dependent
- 44% are unable to transfer independently, which means they will never again be able to go to the toilet unaided
- 30% are depressed³⁵

People have a range of everyday living needs that are frequently unmet, including:

- physical needs
- emotional and well-being needs
- social needs
- communication and cognition needs
- financial, legal and care needs
- re-enablement needs
- carer needs

Services that address secondary prevention issues are imperative in establishing multi-level services in stroke that support individuals from the post acute stage throughout the lifetime of the condition.

This guidance offers advice shaped around establishing services that are grounded in evidenced local need and address the four broad themes identified within the Next Stage Review³⁶. These being:

- Access
- Dignity and the patient as a person
- Integrating care and partnership
- Choice and personal control

Access:

Direct access/self-referral to services such as physiotherapy can considerably reduce waiting times, improve patient satisfaction with a reduction in the 'referral merry go-round' and better assist patients to manage their conditions thereby reducing the development of co-morbidities. Commissioners working alongside providers must enable system change to provide ongoing availability of the right services at the right time by the right provider.

³⁰ The Stroke Association at www.stroke.org.uk accessed September 2009

³¹ Mant J, Wade D, Winner S, Health care needs assessment: stroke. In: Stevens A, Raftery J, Mant J, Simpson S (eds) Health Care Needs Assessment: the Epidemiology Based Needs Assessment Reviews. 2nd Edition. Radcliffe Medical Press, Oxford 2004.

³² Smithard DG Management of stroke: acute, rehabilitation and long-term care. In: White R (ed) Stroke: Therapy and Rehabilitation. Quay Books, London, 2005

³³ Boussier MG et al, Cerebral venous thrombosis: an update. *Lancet Neurology* 6(2):162-170, 2007

³⁴ Hackett M et al, Frequency of depression after stroke: a systematic review of observational studies *Stroke*; American Stroke Association 2005

³⁵ 'Progress in improving stroke care. Report by the Comptroller and Auditor General. HC291 Session 2009-2010. London: The Stationery Office.

³⁶ Our NHS, Our Future, Interim Report, October 2007

Dignity and the patient as a person:

In services where the focus is strongly on capability and potential there is a positive and enabling impact on service users. It is important that services for working age stroke survivors link with 'Fit for Work' initiatives and are underpinned by the recent work on 'Work, Health and Well-being'³⁷. The long-term management of stroke survivors is less about being a stroke survivor and more about what a person can do in terms of making a positive contribution to society. An holistic, person centred approach to health and well-being with the provision of timely information and appropriate aftercare and rehabilitation improves patient outcomes significantly. Services must address personalization, individualised care and respect for the individual and quality of life issues.

An illustration of how effective this can be is seen in the integrated services in the South of Tyne and Wear. This service has a community integration approach to rehabilitation, supporting individuals to return to work or meaningful occupation. The Stroke Association and Momentum are working together to undertake joint home visits to facilitate a 'Life after Stroke' approach and improve understanding of stroke, its impact and most importantly how the service will continue and help their rehabilitation³⁸

Integrating care and partnership:

Necessarily, the NHS is increasingly focused around individual responsibility for personal health and well-being. Enablement and empowerment of service users to manage their own situation and condition more effectively is key. Effectively led multi-professional rehabilitation programmes produce long-term cost effectiveness and help to ensure a seamless transition from one stage to the next along a care pathway, addressing both physical and psychological impacts, with an improved service user outcome.

Choice and personal control:

By working closely with service users, appropriately lead services can act as key 'sign posters'. Social inclusion is a fundamental tenet of well-being and services must include access to ways of engagement with community group activities to promote inclusion. This has recognised benefits for the demand on health services. The use of personal health budgets are a key element of personalization, empowering individuals to select their own personal support packages. This promotes choice, independence and well-being.

Stroke survival, a long-term condition and quality of life

Surviving a stroke is a long-term and lifetime condition that has an impact upon future health, well-being, personal productivity and quality of life. Commissioners need to be aware of the experience of living with a long-term condition such as stroke and establish services that have the capacity to account for the different challenges that may arise for stroke survivors and all those affected by stroke, at various times.

The World Health Organization (WHO)³⁹ defines quality of life as an individual's perception of his or her position in life in specific cultural, social, and environmental context. Quality of life consists of the following main areas: objective environment, environment, behavioural competence (including health), perceived quality of life, and psychological well-being (including life satisfaction). Quality of life is influenced by subjective perception and assessment of physical, material, social, and emotional well-being, personal development, and purposeful activity; all are influenced by an individual's personal value system⁴⁰

Local commissioners have the opportunity to make a real difference by focusing on the outcomes that people want for themselves and for their communities.

Commissioning for health and well-being means involving local communities to provide services

³⁷ Working for a healthier tomorrow, Dame Carol Black, Department of Work & Pensions 2008

³⁸ Contact peter.moore@stroke.org.uk

³⁹ 'The WHO needs to reconsider their definition of health', Education and Debate, BMJ, 314, 1409 1997

⁴⁰ Lovorka Brajkovi, Ana Godan, and Ljiljana Godan, Quality of Life After Stroke in Old Age: Comparison of Persons Living in Nursing Home and Those Living in Their Own Home Croat Med J. 2009 April; 50(2): 182-188.

⁴¹ Commissioning Framework for health and well-being, Department of Health 2007

⁴² Not a model of care as care denotes passive response, in living with a long-term condition there is an implicit requirement to take personal control and responsibility and services need to engender and enable this until such time as it is no longer a feasible option

The Department of Health framework for commissioning for health and well-being⁴¹ offers eight steps:

- 1 Putting people at the centre of commissioning
- 2 Understanding the needs of populations and individuals
- 3 Sharing and using information effectively
- 4 Assuring high quality providers for all services
- 5 Recognising the inter-dependence between work (useful activity), health and well-being
- 6 Developing incentives for commissioning for health and well-being
- 7 Making it happen – local accountability
- 8 Making it happen – capability and leadership

that meet their needs, beyond just treating them but also keeping them (and enabling them to keep themselves), healthy and independent.

Using the eight steps above as the philosophical foundation for decisions made, grounded in the knowledge of the pathway of stroke survival as a long-term condition, then services commissioned for this important group will be improved.

People with long-term conditions move between primary and secondary care at different times throughout the trajectory of their condition, the frequency and complexity of need increasing with increasing age. Management of this increased complexity will likely require involvement of social and voluntary services as well as those more traditionally health based services. All such services must work together to better meet the needs of people with long-term conditions throughout their lifetime. An integrated model of health and well-being service⁴² provision is without doubt the best model for the future.

The advantages of the integrated model include better communication and educational exchange,⁴³ improved patient satisfaction,⁴⁴ greater efficiency and improved health outcomes⁴⁵. Effective commissioning needs to provide the mechanism to facilitate this integration. A jointly commissioned model of integrated service provision provided by primary and secondary care would be more sensitive to the wider health and well-being needs of the local population, and maintain a more holistic and preventative focus.⁴⁶ While this guidance is focusing on services for those surviving a stroke, there is a substantial role for secondary prevention and health promotion that must be addressed within services established for this group.

The Elements of Pathway Based Commissioning:

- Patient outcomes
- Service improvement and pathway redesign
- Demand, capacity and activity
- Pathway performance
- Planned versus unplanned care

are mapped against the **Functions of Commissioning**

- Assessment and planning
- Relationship management
- Contracting and procurement
- Performance management, settlement and review⁴⁷

Planning Personalised Care for People with Long-term Conditions

In November 2009 NHS Primary Care Commissioning published an outline service specification for personalized care planning for people with long-term conditions⁴⁸. This aimed to assist commissioners to put in place appropriate arrangements to ensure people with long-term conditions have informed choice of and access to, services that best enable them to manage their condition. The NHS Operating

⁴³ Bowling A et al Evaluation of specialists outreach clinical in general practice in England: process and acceptability to patients, specialists and general practitioners. *J Epidemiology and Community Health* 1997,51:52-61

⁴⁴ Bond M et al Evaluation of outreach clinics held by specialists in general practice in England, *J Epidemiology and Community Health*, 2000, 54:149-156

⁴⁵ Gruen RL et al Specialist outreach clinics in primary care and rural hospital settings. *Cochrane Database of systematic reviews* 2004, Issue 1 Art. No: CD003798

⁴⁶ 'Teams without walls', Report of the working party of the RCP, RCGP and RCPCH 2008

⁴⁷ NHS Institute for Innovation and Improvement: Commissioning for Patient Pathways 2007

⁴⁸ Outline Service Specification: personalised care planning for people with long-term conditions; accessible at www.pcc.nhs.uk published 3rd November 2009

Framework 2009/10⁴⁹ also requires help for self management and personalised care plans and reflects other policy commitments around integrated care plans, i.e. NHS Choices⁵⁰ website providing information around local choices available, Information Prescriptions for quality assured information and support⁵¹, the NHS Constitution⁵² explaining the rights and responsibilities of service users and staff, and the use of personal budgets to enable choice and personal control.

Choosing a model as a basis for service delivery

A wide variety of models are presented for the delivery of services for long-term conditions. In this context, stroke will be considered synonymous with other long-term conditions. A key requirement to any model chosen is that it takes a personalised approach to care planning and that the commissioning is sufficiently flexible to meet the wide-ranging needs of stroke survivors. Those with complex needs (for whom planning of services is likely to be co-ordinated by one lead professional) may need frequent planning reviews. Care planning for stroke survivors with moderate and low needs will include information about how stroke survival will impact upon their lives and support for self care.

Services need to continually change: involving stroke survivors and their families on an ongoing basis in the planning and design of the service. No single model will meet all needs so the service needs to have the capacity to be responsive, with robust feedback loops built in to ensure commissioners and providers gain a clear understanding about what is and is not wanted within a service.⁵³

Commissioners (and providers) need to put in place a communications strategy that engages all those affected by stroke and

raises their awareness of services available and how they may be personalised. Governance arrangements for the service must be proportionate and integrated to include all current quality requirements, and all aspects of user and public involvement, safeguarding, safety, professional competency, information management, education and training needs, equality and diversity issues, monitoring, audit and continuous improvement strategies. The service must be able to demonstrate value for money in respect of quality and effective, efficient use of all human and physical resources.

The wellness of the population may be viewed by a staged disease continuum of:

- Well
- At risk
- Established condition
- Controlled long-term condition

This guidance has its focus on the established and controlled long-term condition stage of lifespan. However, there is an implicit need to deliver services that offer primary prevention to limit movement from the 'well' to the 'at risk' stage, from 'at risk' to 'established condition' and to prevent progression to complications and re-admission in the later stages⁵⁴.

In focussing on the established and controlled long-term condition stages, commissioners need to ensure services offer high quality treatment and immediate post-acute discharge care along with complications prevention and/or management and access to specialist services and primary care if required. This should integrate with continuing care, rehabilitation, maintenance and self-management provision with easy access to ongoing services. All aspects of both stages should be underpinned by health promotion/secondary prevention health and well-being support.

⁴⁹ The NHS in England Operating Framework 2009/10, Department of Health, 2008

⁵⁰ High quality care for all, NHS Next Stage Review, Department of Health, 2008

⁵¹ Our health, our care, our say, Department of Health 2006

⁵² NHS Constitution, Department of Health, 2009

⁵³ NHS Institute for Innovation and Improvement: Commissioning for Patient Pathways 2007

⁵⁴ Preventing chronic disease: a strategic framework, background paper, Melbourne: National Public Health Partnership 2001

Key elements of a High Quality Stroke Service

In 2006, two years before the National Stroke Strategy, and as a result of Standard 5 in the National Service Framework for Long-term Conditions⁵⁵, the Department of Health published 'Improving Stroke Services: a guide for commissioners'. This identified that two of the key elements of a high quality stroke service appropriate to this work, are:

- Provide stroke specialist multi-disciplinary rehabilitation within the hospital sector and the community
- Ensure people using services and their families are informed and empowered to take control of their care⁵⁶

This is further defined as:

Rehabilitation

- As early and intensive as tolerated
- An ongoing process
- May involve dedicated rehabilitation unit or intermediate care facility

Stroke recovery is complex and non-linear with an initial rapid functional improvement that slows and is seen to end in about 6 months post stroke event. Until recently this plateau in recovery represented the end of potential recovery – and therapy services are withdrawn once plateau occurs. Recent research⁵⁷ challenges the notion of plateau and its implications for service providers.

While stopping therapy at plateau has short term gains in re-allocation of resources, in the longer term there is impact upon the stroke survivor's physical recovery, which in turn may lead to learned helplessness and depression. Managed care programmes often reinforce that recovery ceases at six months with restricted access to therapy and rehabilitation. Research suggests that such people benefit from motor

rehabilitation programmes that apply different strategies.⁵⁸ Services could reconsider how they might maximize potential for service users after the six months perceived plateau. Evidence also suggests that there is substantial physical and functional benefit for individuals with stroke from long-term engagement with a range of physical activities⁵⁹.

Transfer of care

- Early supported discharge
- Close working across health and social care

Research indicates that early supported discharge when combined with stroke unit care is a cost effective service⁶⁰. However it is clear that success is derived only where there is a co-ordinated stroke multi-disciplinary, multi-agency team delivering the service. It is most effective for those stroke survivors with mild or moderate disability⁶¹. Such co-ordination is most effective when undertaken by a stroke specialist. Northumbria Healthcare NHS Foundation Trust established early supported discharge, offering a service seven days a week, with up to three visits per day. This has resulted in the average length of stay being reduced to half of the national average. The trust is now performing in the top 5% of the Sentinel Audit⁶² and some £500k has been saved by commissioners as a result of replacing inpatient beds with early support discharge and a more efficient model of care.⁶³

Commissioners will want to deliver optimum outcomes. Watered down early supported discharge reduces effectiveness of teams to be able to provide comprehensive rehabilitation at home. A poorly structured or incomplete multi-disciplinary team may struggle to provide a comprehensive quality service that addresses adjustment and reintegration into society,

⁵⁵ National Service Framework for Long-term Conditions, Department of Health, 2006

⁵⁶ www.dhcarenetworks.org.uk/ accessed November 2009

⁵⁷ Demail S, Wiles R, Roberts L, McPherson K 2006 Recovery plateau following stroke: Fact or fiction? *Disability and Rehabilitation* 28, (13-14) 815-821

⁵⁸ Page SJ, Gater DR, Bach-y-Rita P 2004 Reconsidering the Motor Recovery Plateau in Stroke Rehabilitation, *Arch Phys Med Rehabil* Vol 85, 1377-1381

⁵⁹ Morris JH, Williams B 2009 Optimising long-term participation in physical activities after stroke: Exploring new ways of working for physiotherapists *Physiotherapy* 95, 227-233

⁶⁰ Saka O, Serra V et al 2009 Cost effective stroke unit care followed by early supported discharge; *Stroke* 40,(1) 24-29

⁶¹ Langhorne P, Taylor G, Murray G et al, 2005 Early Supported Discharge Service: a meta-analysis of individual patients' data, *Lancet* Feb5-11, 365(9458), 502-506

⁶² Stroke Sentinel Audit 2009, www.nelm.nhs.uk/en/NeLM-Area/organisational-audit-2008 accessed February 2010



continence rehabilitation and access to equipment. This, at the same time as managing to administer the service, collect data, ensure access within the mandated time frame and derive satisfactory patient reported outcomes on satisfaction and experience adds further to the likelihood of failure.

An example of a well performing multi-disciplinary team is seen in Nottingham. The early supported discharge team for CitiHealth, NHS Nottingham City⁶⁴, consists of:

- 1 Team Manager Band 7
- 1 Clinical Specialist Physiotherapist Band 8a
- 0.4 Physiotherapist Band 7
- 0.5 Occupational Therapist Band 7
- 0.6 Specialist Mental Health Nurse Band 7
- 0.2 Community Matron Band 7
- 1 session per week from a Stroke Consultant
- 0.5 Speech and Language Therapist Band 7
- Social Worker
- Physiotherapist Band 6
- Occupational Therapist Band 6
- Stroke Nurse Band 6

- 2 Assistant Practitioners Band 4

- 5.5 Rehabilitation Support Workers Band 3
- This team gives an 8am-8pm service, seven days per week with up to four visits per day.

The economic basis for early supported discharge is evident through health technology assessment⁶⁵ that has demonstrated that poor outcomes for patients were reduced from 21.7% to 14% and those referred to nursing homes fell from 11.3% to 6%. At the same time the average length of hospital stay reduced by 10 days to 22 days. Ensuring that the right team structure is in place to deliver the optimal outcomes means that quality aspirations can be maintained, as well as a focus on productivity for immediate and longer term health and well-being resource gains and longer term personal productivity gain for the stroke survivor.

Early supported discharge can reduce long-term dependency and admission to institutional care as well as releasing hospital beds by reducing length

⁶³ Contact Anne-Marie Lavery, Lavery@northumbria-healthcare.nhs.uk

⁶⁴ Contact Julia Pollard, Programme Manager, Community Neurology, CitiHealth, NHS Nottingham City

⁶⁵ Larsen T, Olsen TS, Sorenson J, 2006 Early home supported discharge of a stroke patient: a health technology assessment, *International Journal of Technology Assessment in HealthCare*, 22(3), 313-320

⁶⁶ "Progress in improving stroke care. Report by the Comptroller and Auditor General. HC291 Session 2009-2010. London: The Stationery Office.

⁶⁷ Framing the contribution of the Allied Health Professions, Department of Health 2008, N.B date for mandated data collection changed from 2010 to 2011

⁶⁸ David Roberts ADASS 16th July 2009 presentation entitles: Rehabilitation & Transfer of Care – Peer Support Meeting; accessing and using social care data

of stays. Economic modelling carried out by the National Audit Office suggests that increasing the availability of early supported discharge from the current 20% to around 43% of stroke survivors would be cost effective over a ten year period, costing about £5,800 per QALY gained.⁶⁶

While there is published research on the economic benefits of service structures, there remain complexities around local data collection to provide evidence for cost benefits realization for multi-disciplinary teams who manage complex pathways and people with co-morbidities. Data collection around waiting times for allied health professional services will be collected from April 2011⁶⁷. While such data will latterly help shape evidence for local service structures, until available commissioners will need to draw on best practice initiatives, data from national data indicator sets, or provided by the public health observatories, and the NHS information centre. Key to success has to be in making the data in the joint strategic needs assessment and commissioning strategies relevant to all parties⁶⁸, integrating the data to develop an integrated service.

Patient and family involvement

- Accessible support at all stages of the pathway

Carers need to be supported in taking on the role of carer and stroke services should offer education as part of the stroke service. The Occupational Therapy service at Somerset Community Hospital offers such a service⁶⁹ that enables carers to increase their understanding and the consequences of stroke. Alongside supporting carers there is the need to support the stroke survivor as they embark on self care. A common core set of principles to support self care highlights seven outcomes that are to be used to structure goal setting for health, social care and related activity in Local Authority Agreements⁷⁰.

Northumbria Healthcare NHS Foundation

Trust have instigated a service structure that supports engagement of all stakeholders. Part of this is a Stroke Practice Development Programme that features people with stroke and their carers. This work has helped understand the service user perspective and strengthened the links across the stroke family and their partnership.⁷¹

Ongoing care

- Support for physical and communication disabilities
- Equipment and adaptations
- Carer support and respite
- Mental health
- Vocational rehabilitation

There are examples of services already working across both internal and external boundaries for the benefit of service users. In Liverpool for the last 5 years, Crossroads Care has been running a stroke re-enablement and early supported discharge project in partnership with the University of Central Lancashire and The Royal Liverpool & Broadgreen NHS Trust. This scheme offers carer breaks and the re-enablement team is part of an inter-agency stroke pathway that provides an integrated service from referral to recovery.^{72 73}

Within 'Our health, our care, our say'⁷⁴ seven outcomes for social care were set out that set a new direction for community services. One element of enabling achievement of improved health, emotional well-being and personal dignity is having choice and control. The use of personal budgets in social care is well tried, their introduction into health is novel. Personal budgets are a key element in personalization of health and well-being services and enable individuals to have a real say in how their needs are met. A collaborative post supported by the Stroke Association and Portsmouth City Council⁷⁵ has been successful in guiding people to identify their needs and access chosen support pathways, enabling re-integration into the community.

⁶⁹ Contact Sue Glanfield Occupational Therapy at NHS Somerset Community Health

⁷⁰ Seven outcomes of social care as set out in 'Our health, our care, our say' Department of Health, 2006

⁷¹ Contact Anne-Marie Laverty Laverty@northumbria-healthcare.nhs.uk

⁷² Contact Penelope Fell CEO Crossroads Care; pennyfell@crossroadscareliverpool.co.uk

⁷³ Dickens J, McAdam J, Leathley M, Jack C, Crighton M, Watkins C, Rehabilitation Support: improving outcome after discharge following an acute stroke – a pilot study. *Clinical Rehabilitation* 2005, 19: 576

⁷⁴ Our Health, our care, our say, Department of Health 2006

⁷⁵ Angela Dryer & Debby Lewis, Portsmouth City Council, Presentation entitled Personal Budget Support Co-ordinator, 13th October 2009

When considering service structures, commissioners need to be aware of the benefits of personal budgets, but more especially the positive rewards associated with people having responsibility and ownership of decisions about their own health and well-being needs.⁷⁶

Secondary prevention

- Detection and management of Atrial Fibrillation
- Smoking cessation
- Cholesterol reduction
- Blood pressure lowering
- Healthy diet
- Exercise
- Regular reviews

Setting up access to regular reviews is required under Quality Marker 14 in the National Stroke Strategy but is often seen as problematic. It has been successfully piloted by Bournemouth & Poole Community Health Services⁷⁷ who offered physical reassessment, assessment of adjustment, medication review, help,

support and signposting as required. Evidence suggests that some 53% of attendees were offered general clinical advice that enabled them to self care more effectively. However accessing the review clinic proved challenging for some. Care closer to home, timely access to services, and the evidence identifying that improvement happens after 6 months⁷⁸ require that commissioners review routes of access to services for stroke survivors. A number of studies indicate that open access models could considerably reduce reliance on secondary care. Evidence suggests that open access clinics use fewer acute sector resources, result in the same quality of life for patients and are preferred by service users and GPs.⁷⁹

In 2009, guidance was published to support commissioners in commissioning personalised care planning.⁸⁰ Personalised Care Planning is also included in the Operating Framework for the NHS in England in 2008⁸¹. It is recognised across the health and social care sectors as a means of standardising excellent management of long-term conditions.



⁷⁶ 'Putting people first', Department of Health, 2008

⁷⁷ Naomi Gibson, Senior Physiotherapist, presentation entitled: Setting up a stroke review clinic within a community rehabilitation team, 2009 Woodlands Rehabilitation Team Poole Dorset

⁷⁸ Demain S, Wiles R, Roberts L, McPherson K 2006 Recovery plateau following stroke: Fact or fiction? *Disability and Rehabilitation* 28, (13-14) 815-821

⁷⁹ Williams JG, Cheung WY et al cited in *Rehabilitation Services: evidence for transforming community services*; 2009 University of Birmingham

⁸⁰ Supporting People with Long-term Conditions: Commissioning Personalised Care Planning, Department of Health, 2009

⁸¹ The NHS in England Operating Framework 2008/9 Department of Health December 2007

The Commissioning Cycle – step-by-step

The elements of the commissioning cycle have been conflated here with the Ambitions, Actions and Achievements laid down in the 6 transformational guides for Transforming Community Services⁸² to provide specific guidance for those commissioning post acute stroke services.

Assessing Need & Demand – strategic planning

Action:

- Know about local health needs and plan services accordingly
- Work with the public health observatory⁸³ to access information on the health needs of your population; identifying those who may be disadvantaged or marginalised in society: target identified need
- Use a proven tool like the combined predictive model to risk stratify your local population, e.g. King's Fund tool⁸⁴

Learn about:

- Current demand?
- Demographic profile of population and the evidence base for impact on incidence and prevalence of stroke?
- Social capital i.e. what active connections exist between people and communities that result in time and resources available for social networking, support and engagement in daily and wider social activity?
- Age mix?
- Gender mix?
- Ethnicity: existing, accounting for immigration demand, cross border workforce mobility, traveller population?
- Cardiovascular profiles of population – as a precursor to stroke prevention strategies and as a predisposing factor to incidence of stroke?
- Obesity incidence and prevalence data?

- Smoking and COPD incidence and prevalence?
- Projected impact of prevention strategies?
- Projected improvements in technological intervention?⁸⁵

Deciding Priorities – strategic planning

Action:

- Know your local (SHA) Vision, key priorities
- Know the national perspective

Learn about:

- Examples of good practice in stroke service provision; the who, what, when, where and how of these exemplar services
- What makes these services good?
- What can be translated into your services?
- Can the existing services be remodelled in the same way?
- Can the services work in a mutually beneficial manner for service user benefit?

Reviewing Service Provision – strategic planning

Action:

- Work with service providers to agree outcome data that needs to be collected for a specific service area to demonstrate effective intervention.
- Ensure robust systems are put in place to collect this data.
- Link this to the quality framework and if appropriate contracts including payment framework for commissioning, quality and innovation (CQUIN).
- Develop systems and processes to encourage constant patient, service user and carer feedback, audit changes made as a result of feedback on user experience.

⁸² Transforming Community Services, Transforming Rehabilitation Services, Transforming Services for people with Long-term Conditions, TCS guides, Department of Health, 2009

⁸³ www.qualityobservatory.nhs.uk accessed November 2009

⁸⁴ Combined Predictive Model, Kings Fund, accessible at www.networks.nhs.uk/uploads/06/12/combined_predictive_model_final_report.pdf accessed November 2009

⁸⁵ Intelligent Commissioning; Report by the Association of Public Health Observatories June 2009

Learn about:

- What services are currently available for stroke survivors post acute discharge and who provides them?
- Variability in services; are teams using up to date and appropriate evidence and tools to ensure effective working?
- What support is available for family, carers and all those affected by stroke?
- What do these services cost?
- What is the return on investment?
- Primary care, independent sector, 3rd sector support?
- Waiting times?
- Knowledge of and access to services?
- Geographical location?
- Family support systems?
- Does what is in place meet current requirements specified in the National Stroke Strategy?
- What is required to make the current service provision fit for purpose?
- Will what is currently in place meet projected demands?
- What will be needed to meet projected demands based on incidence and prevalence data?
- What skills and workforce shape will be required to deliver to meet the current and projected need?
- What education and training is available, what will be needed in the future, how will it be provided?
- Is training endorsed by the UK Forum for Stroke Training and compliant with the Stroke Specific Education Framework?
- Are all staff trained at the appropriate level relevant to their role in the care pathway?
- How is evidence informed practice demonstrated?
- Are personalised care plans provided, what about joint planning or integrated assessments, SAP or CAF
- Do patients have a named key worker or case manager?
- Is there a local carers strategy – what does it offer?

- Is there appropriate IT resource so that clinical pathways can be interlinked using shared records and joint care plans?
- If there is an example locally of something that is good, understand what it is that makes it good. Is that then transferable to other area, can it be built upon and how do you guarantee it is not lost in the formation of a new services?

Improving Services

Consider:

- The shape and structure of supply – how will 'form' ensure 'function' required?
- How will demand for services be managed so that it is equitable and addresses inequalities?
- How will services be evaluated and ensure an ethos of continuous improvement?



Designing the Service

Consider:

- Stages of the journey for the stroke survivor from the post acute phase to potentially end of life care, e.g.
 - Immediate post acute phase, discharged home
 - Immediate rehabilitation period
 - Vocational/occupation related rehabilitation & return to work
 - On-going rehabilitation
 - Secondary prevention of subsequent stroke
 - Management of co-morbidities/concomitant illness/problems
 - Entry into appropriate subsequent pathways e.g. end of life care
- How can points of transition between elements of the service be guaranteed fail-safe?
- How will the requirements for the stroke survivor be similar to those of others with long-term conditions?
- How will the requirements for the stroke survivor differ from those of others with long-term conditions?
- Are the needs of hard to reach groups considered and addressed, e.g. black and minority ethnic groups, people with complex co-morbidity for whom stroke is a complication not a primary condition.
- Provision of services for others impacted upon by stroke e.g. carers, partners, children, employers

Consider the issues key to making the provision of these services high quality:

Access: is direct access/self-referral to the service available? There is substantial evidence to support self-referral as being effective in reduction of waiting times for access to services, improving patient satisfaction with a reduction in the 'referral merry go-round' and better assisting patients to manage their conditions thereby reducing the development of co-morbidities and having a positive impact in secondary prevention. Does the service provide ongoing availability of

the right services at the right time by the right provider, providing specialist stroke services and potentially simultaneously meeting the needs of other people with long-term conditions.

- Is the service geographically convenient, advice available by telephone with extended hours to suit return to work or engagement with other useful occupation?
- How are the needs of stroke survivors resident in care homes met?

Dignity and the patient as a person: how does the service offer personalized and individualized care? How is respect for the individual evidenced and are quality of life issues at the centre of the planning? Are the needs of black and minority ethnic groups accommodated?

Integrated care and partnership: is there evidence of partnership in decision making between the service user and the practitioner? Are services focussed around the needs of the stroke survivor – what evidence is there for this? How does the service engage and empower the stroke survivor in taking responsibility for secondary prevention and for maximising the outcome of interventions? Is the model of care multi-professional? Is there seamless transition from one stage to the next? Are all elements of need including co-morbidities addressed? The Dudley Collaborative is an excellent example of seamless care. This is a collaboration between Dudley NHS PCT, the Dudley Group of Hospitals NHS Trust, Dudley Metropolitan Borough Council and The Stroke Association working together to provide a gold standard, equitable, accessible service for all stroke survivors and their carers, from presentation to end of life. This work has prioritised improving communication between primary and secondary rehabilitation teams and improving staffing levels within the community stroke rehabilitation team⁸⁶.

Choice and personal control: is there evidence of close working with service users, advocacy for service users and all those affected by stroke? Is decision making a user-led clear and supported

⁸⁶ Contact Dr Liz Pope, Stroke and TIA service lead, Dudley, liz0pope@hotmail.com

process? How does the service promote and enable social inclusion, where and how is choice offered and does the information offered meet quality standards? How are satisfaction and experience incorporated into service evaluation and ongoing development?

Stroke survival, a long-term condition and quality of life: does the service acknowledge stroke survivors as people living with a long-term condition that has an impact upon future health, well-being and quality of life? How does the service work across the boundaries to ensure that the service is integrated and provides what is needed to enable as far as possible, an individual to develop the capacity to live successfully with a long-term condition such as stroke.

Achievement – what data do you need to tell you if the service is improving?

- Service user feedback is positive about key issues of concern such as access, continuity of care, experience of health and well-being services
- How will public and patient views be sought?
- Evidence on access, referral, assessment of individual need, advice on choices, treatment and other activities
- Clinical and multi-agency teamwork enables all practitioners to deliver high quality care, achieve agreed outcomes, maximise productivity, promote and measure service user experience.
- Variability is reduced
- Seamless model of service provision
- Practitioners have confidence that the systems will support and empower them to deliver and time spent with individuals and families is maximised

Managing performance – how will you evaluate the service?

Within the service how is quality of life for the stroke survivor determined? As far as possible:

- Does the service meet the needs of stroke survivors?
- Do stroke survivors live their own lives to the full, maintaining their independence and managing their own condition?
- Are stroke survivors less dependent on services?
- Where carers are involved are they able to balance their role and maintain an acceptable quality of life?
- Do stroke survivors receive the support they require to be independent and only go into hospital or care when they have a need?
- Are people put in control of the services they receive?
- Do service users feel respected, safe and secure, that services are sensitive to their needs and respect their right to privacy?
- Do people have a genuine choice in how and when services are provided and know how to access the support they need?
- Do people know what is available to them locally, what they are entitled to and who to contact when they need help?
- Are people able to engage socially as much as they wish, avoiding loneliness and isolation?
- Do people feel that they are treated fairly and equally by services?
- As appropriate, are people able to be financially secure, find employment or access to benefits and allowances?
- Do people feel able to contribute to community life if they wish to and are able to access information when they need it?⁸⁷

While data suggests some 25% of stroke survivors are younger than 65 years and could be considered able to return in some way to paid employment, many stroke survivors will not achieve this. It must be recognized that being able to make a positive contribution to society in its broadest sense contributes significantly to perception of quality of life. This in turn enhances personal empowerment, perceived control and subsequently reduces potential burden on support services and carers.

⁸⁷ Making Policy Count: developing performance indicators for health and social care partnerships, Simon Medcalf, Local Performance Strategy Department of Health, presented 29th September 2009

Workforce

In promoting a shift toward primary care, and with innovative and courageous commissioning, innovative providers will need to meet a number of needs.

Multi-disciplinary teams improve rehabilitation and there is evidence that multi-disciplinary follow up after discharge can reduce reliance on hospital care helping shift care closer to home⁸⁸. To achieve this for stroke survivors, providers will need a workforce that delivers both transferable and specialist specific care – a ‘basket of skills’ that enable staff to deliver services addressing stroke survivor needs across a broad spectrum of environments, ‘moving around the community patch’.

Another model of early supported discharge that utilizes a flexible workforce structure is seen in CitiHealth, NHS Nottingham City. This is a seven-day service, 8am to 8pm with up to four visits per day, in a community setting

and offering a rapid same-day response where required. The service is supported by Rehabilitation Support Workers at Band 3 who provide a seven day service on an 8am-4pm, 12pm-8pm shift pattern.⁸⁹

Within community teams members will want to learn how to empower service users and how to educate carers to manage their role. Effective commissioning will need to account for the learning and development needs of the changing workforce within the service specification. Account will also need to be taken of the resource requirements to enable succession planning, the education of new members of the professions and the education of students. The National Stroke Strategy identifies that all staff involved in stroke care and patient education should demonstrate the relevant skills and competencies for effective communication/ information provision.



⁸⁸ Transforming Staff in Rehabilitation Services: evidence for transforming community services, University of Birmingham 2009

⁸⁹ Contact Julia Pollard, Programme Manager, Community Neurology, CitiHealth, NHS Nottingham City Julia.pollard@nottingham-pct.nhs.uk

A UK Forum for Stroke Training (UKFST), hosted by the Stroke Association, has been established to support development of mechanisms to review and endorse training that is compliant with the Stroke Specific Education Framework, and to define career pathways⁹⁰. Commissioners should work with employers to undertake a review of the current workforce and develop a plan supporting development and delivery of UK FST endorsed training to create a stroke skilled workforce.

Using a workforce planning tool such as that produced by the Department of Health⁹¹ enables comparison of actual staffing structures with recommended staffing levels to meet the standards set out for the delivery of stroke care. Blackburn with Darwen PCT undertook such a process and their experience over the last 3 years has indicated that for a population of 162,000, they accepted some 260 stroke survivors for rehabilitation. Areas of good practice identified within this service include:

- Widespread appraisal, supervision and peer support
- Multi-disciplinary working and joint goal setting
- Staff access to specialist stroke training
- Low staff turnover rates
- Community teams working well with other core rehabilitation teams
- Active involvement in research and development
- Training provision to other agencies in supporting stroke survivors

The same team provided insights in to the challenges for such services, which will not be unique. These include but are not limited to:

- Ongoing specialist skills development
- Increasing awareness of the stroke pathway across other wards and departments
- Workload and waiting list management
- Access to neuro-psychology support
- Access to family/carer support

- Access to education/secondary prevention
- Access to counselling services
- Equity of service provision across the health economy⁹²

Within the service, do the service providers demonstrate the transformational attributes of the workforce?

These being:

- 1 Health promoting practitioners, focused on health, well-being and addressing health inequalities
- 2 Clinical innovators and expert practitioners enabling increasingly complex care to be provided at home
- 3 Professional partners in expert-to-expert relationship with patients and in building teams across organisations
- 4 Entrepreneurial practitioners exploring business opportunities including social enterprises and other innovative approaches
- 5 Leaders of service transformation: individual, organisational and across systems
- 6 Champions of clinical quality using new techniques and methodologies to embrace continuous improvement⁹³

Within the service is it clear how quality of the service is achieved?

- What does high quality care post-acute care for stroke survivors look like?
- Is there a quality measurement framework for the service?
- Is the data available to staff, patients and the public?
- Is there a mechanism for recognising and rewarding quality?⁹⁴
- Are practitioners empowered to improve quality?
- How is quality in the workforce safeguarded: regulation, CPD, UK FST endorsed training and education?
- How is innovation supported and enabled?⁹⁵

⁹⁰ Stroke Specific Education Framework, Department of Health 2009

⁹¹ Workforce Planning Resource for Stroke available at www.dh.gov.uk/en/Healthcare/Stroke/DH_081389

⁹² Contact Tracy Walker, Intermediate care, Tracy.Walker@bwdpct.nhs.uk

⁹³ Ambition, action, achievement: how to deliver quality care closer to home, HSJ Supplement 9 July 2009, Department of Health

⁹⁴ The Good Indicators Guide: Understanding how to use and choose indicators; NHS Institute for Innovation and Improvement 2008

⁹⁵ 'Looking Good' in Ambition, Action Achievement, HSJ supplement 9 July 2009, Department of Health

Conclusion

What is presented here is a conflation of various guidance and information. This text has brought together different types of information and presented a series of suggestions and questions that may be appropriate to ask to inform decision making around provision of services for stroke survivors post discharge from acute care.

What to look for to transform services

NHS 2010-2015: from good to great⁹⁶ gives clear authority to commissioners to drive local change to systematically realise the local visions for changing pathways agreed during the NHS Next Stage Review. Understanding local needs and working with the providers to reshape services can lead to quality improvements and efficiencies can be made.

Recent research published by the University of Birmingham Health Services Management Centre identifies ten important top level issues that may transform rehabilitation services in the community are:

- 1 Using rehabilitation with multiple components
- 2 Providing rehabilitation in community venues
- 3 Testing home-based rehabilitation
- 4 Working in multi-disciplinary teams
- 5 Encouraging self referral to services when needed
- 6 Teaching self care
- 7 Providing extra support for carers
- 8 Working with care homes
- 9 Ensuring community ownership of services
- 10 Using alert systems and other monitoring⁹⁷



⁹⁶ NHS 2010-2015: from good to great, preventative, people-centred, productive, Department of Health December 2009

⁹⁷ Rehabilitation Services – evidence for transforming community services, University of Birmingham HSMC, Nov 2009

There are 3 components to successful transformation that need to be addressed separately. These are:

- 1 The services
- 2 The staff
- 3 The systems⁹⁸

Transforming the Services

What: service delivery

- Provide rehabilitation in community venues
- Multi-faceted rehabilitation works best
- Cognitive rehabilitation has mixed results, but stroke survivors with cognitive

problems can teach others with similar problems how to cope

- Monitor well-being and use tele-care initiatives and alert systems
- Use self-referral to services

Where: location

- Rehabilitation at home may improve outcomes

The Portsmouth Model of early supported transfer from hospital to home enables most stroke survivors to leave hospital as soon as possible, not just those with mild strokes. This team of stroke specialists who have core stroke skills and competencies are stroke survivor

Key factors to remember about surviving stroke:

- Stroke survival should be about re-ablement
- Stroke survivors want to rejoin society
- Stroke is not a fixed pathology illness, it becomes a long-term condition
- Six months post stroke is often a 'tipping point' for both survivor and carer/partner – is this it?
- Progress post stroke continues beyond the first 6 months.
- Pattern of recovery is variable.
- Individuals achieve greater levels of independence with ongoing, (not necessarily continuous) access to a variety of rehabilitation services.
- Services for stroke survivors have similarities with services for those with other long-term conditions so there may be economies of scale.
- Commissioning neurological services as a whole requires acknowledgment and incorporation of the specific needs of stroke survivors.
- Stroke survivors are an effective resource for supporting new survivors to establish coping mechanisms.
- Needs of stroke survivors cross health and social care boundaries, therefore whole system commissioning based on Joint Strategic Needs Assessment is a must.
- The points of transition between agencies or sectors are a source of stress for stroke survivors and a source of fear for carers.
- Stroke survivors benefit substantially from secondary prevention strategies and engagement and empowerment in their own health and well-being.
- The direction of travel for health and well-being services 2010-15 is focussed on prevention (primary and secondary), people-centred services, personalisation, choice and value for money from public funds.
- The use of technological support, telemedicine and robotics will need to be considered.

⁹⁸ Rehabilitation Services – evidence for transforming community services, University of Birmingham HSMC, Nov 2009

focussed and highly flexible. There is a small team of staff that addresses all stroke survivor needs, the team works intensively dealing with real problems in real time. Visits to stroke survivors are arranged to support and develop their independence, encourage risk taking and letting the stroke survivor take the lead. Planning from day one is about transfer out into community. The return on investment of this service has seen a reduction in length of stay both inpatient and outpatient rehabilitation, savings to social services in terms of number and intensity of support required in conjunction with good service user satisfaction responses⁹⁹.

Transforming the Staff

- Multi-disciplinary teams improve rehabilitation
- The formation of the team must fit the functions and delivery required:
 - Does the team as a whole have all the skills and abilities required to deliver care as detailed in the stroke specific education framework?
 - Does the team have the knowledge and understanding as detailed in the stroke specific education framework with which to deliver the required quality of service?
 - If not, what additions to the workforce are required, how may they be achieved, what education and training is required?
- Self-care can support rehabilitation
- Supporting carers is essential
- Staff need to learn and develop the skills associated with the new ways of working across professional and agency boundaries
- Staff need to learn how to best facilitate empowerment in stroke survivors and self – care abilities
- Staff should have stroke specialist knowledge and skills appropriate to their role in the care pathway, and receive relevant UK FST endorsed learning and development

Key factors to remember about services for stroke survivors:

Stroke survivors should have:

- Access to personalised and individualized services when they are required that:
 - Are evidenced based
 - Fulfill agreed quality and standards of best practice^{100 101 102}
 - Are delivered by a workforce that has the knowledge and skills appropriate to their role within the stroke pathway
 - Are delivered in an appropriate environment that facilitates re-enablement and re-engagement with society on day-to-day and social levels
 - Give choice and personal control with engagement in decision making about their care and support
 - Are responsive to need
 - Integrate services and delivers a seamless transition across boundaries
 - Give support and education for carers
 - Enable them to live successfully with the long-term consequences of stroke.

Transforming the System

- Ensure every service has a clear vision
- Local ownership of services is beneficial
- Work with care homes – partnership working between community and hospital services and between health and social care is important in providing seamless and robust rehabilitation. A care home might be a useful venue from which to provide rehabilitation services.
- Ensure existing tools such as tariffs are used innovatively

⁹⁹ Contact Sarah Easton, Team Leader Portsmouth CSRT sarah.Easton@porthosp.nhs.uk

¹⁰⁰ National Stroke Strategy www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_081062 accessed 15th October 2009

¹⁰¹ Rehabilitation after stroke, consultation, www.nice.org.uk/guidance accessed 7th February 2010, due for publication April 2012

¹⁰² At a local level some Heart and Stroke Networks are pulling together Core Standards for Stroke Rehabilitation. These will likely contain a number of quality markers drawn from for example, The National Stroke Strategy, NICE, The Royal College of Physicians guidelines as well as staffing guidance from the Department of Health and professional bodies. These could impact significantly on commissioning as they are likely to form the basis of strategic health authority performance indicators

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The Stroke Association is the only UK wide charity dealing with stroke in people of all ages. To find out more about our work, visit www.stroke.org.uk.
Stroke Helpline 0303 3033 100

The Chartered Society of Physiotherapy is the professional, educational and trade union body for the United Kingdom's 49,000 chartered physiotherapists, physiotherapy students and assistants



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