



# Commissioning Services for People with Long Term Neurological Conditions

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# Commissioning Services for People with Long Term Neurological Conditions

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# Introduction

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1. This guide note is the product of regional workshops in which the roles of commissioners, practitioners and clinicians were examined with a view to improving commissioning practice and better outcomes for end users. It aims to support commissioners in their work to secure effective services for people who live with the effects of long term neurological conditions. It is part of the work arising from the National Service Framework (NSF) for long term neurological conditions<sup>1</sup>, and reflects the commitments outlined in the White Paper, *Our Health Our Care Our Say*.<sup>2</sup> It provides a checklist which commissioners may use to help assess their current practice and as a basis for local development and change.

2. It complements the advice and information available elsewhere on approaches to commissioning services (a summary of sources for general guidance appears at Appendix 1) in that it focuses on issues for commissioners that are particularly associated with services for people with long term neurological conditions. These issues are:

- Leading the development of complex patterns of service.
- Understanding the importance of commissioning partnerships between funders of services.
- Understanding long term neurological conditions and their effects.
- Finding sources of information about the need for services in a given population.
- Designing performance measures which match commissioning intentions.
- Challenging providers to match re-designed care pathways.
- Understanding the connection between services commissioned locally; by PCTs, practice based commissioners, local authorities and jointly; and specialised services commissioned on a regional or national basis.

- Understanding the impact of health service reforms on commissioning services.

- Embedding commissioning continuing health care services into mainstream commissioning practices, in accordance with DH policy guidance, due to be issued in the autumn of 2007.

3. The experience of commissioning services for people who live with long term medical conditions, or a mental illness, or a learning disability, will be relevant; but applying precisely similar approaches to commissioning such services will not be suitable for all neurological conditions.

4. The focus for this guide note is on a particular set of long term neurological conditions: those that arise suddenly, for example, from a brain or spinal cord injury; and those associated with progressive, intermittent or unpredictable and lifelong conditions such as Parkinson's Disease, Multiple Sclerosis, Huntington's Disease, Motor Neurone Disease and Cerebral Palsy. Although it does not refer specifically to the needs of people living with the effects of stroke or dementia, which are covered in the National Service Framework for Older People<sup>3</sup> and *Improving Stroke Services*,<sup>4</sup> these clients will, inevitably, need many of the same services.

5. Several developments of the past five years have contributed to the policy aim of providing people with the opportunity to choose health and social care services that best meet their needs and are effective in terms of both cost and impact. References 4, 8-10 and 14 at Appendix 1 describe the means by which this is intended to be achieved in some detail.

1. Department of Health (2005) National Service Framework for Long Term Conditions

2. *Our health, our care, our say: a new direction for community services*. London: Stationery Office, 2006

3. Department of Health (2004) *National Service Framework for Older People*

4. Department of Health (2006) *Improving Stroke Services: a guide for commissioners*

## Policy context

6. There are several definitions of communicating recently published by the Department of Health in the Health Reform, and Health and Well-being Commissioning Frameworks, published in July 06 and March 07 respectively (and appended at App 3). Familiar commissioning cycles, such as this example, which begins with the analysis of needs, services and resources and ends with assessing the outcome of services paid for with those resources (figure 1), applies to services associated with long term neurological conditions as it does to any other.

7. Evidence shows, however, that services for people living with the effects of long term neurological conditions may require more sophisticated commissioning arrangements than others, and the pace of their development will be different. The National Service Framework for long term neurological conditions, guidance on supporting people with long term conditions<sup>6</sup> and the recommendations of the Warner report on commissioning specialised services<sup>7</sup> reflect increased concern to provide the best possible support for a large group of people whose health and social care needs have not always had a high profile. In addition to its definition of commissioning, Health Reform in England: update and commissioning framework<sup>8</sup> provides information and guidance on developing best practice amongst commissioners of service. Further guidance, on the Commissioning Framework for Health and Well-being, published in March 2007 supports the requirement on commissioners to undertake strategic assessments of all joined-up population needs and to develop appropriate services to meet those needs.

8. Developments in services have been initiated and pursued in different ways. Some have been led by professionals and providers of service, others by primary care trusts as they exercise their service development role and still others by people who use services. Clinical champions, service re-design programmes, clinical pathway developments, stakeholder partnerships, and voluntary organisations have all secured better services for service users and carers. Effective commissioning

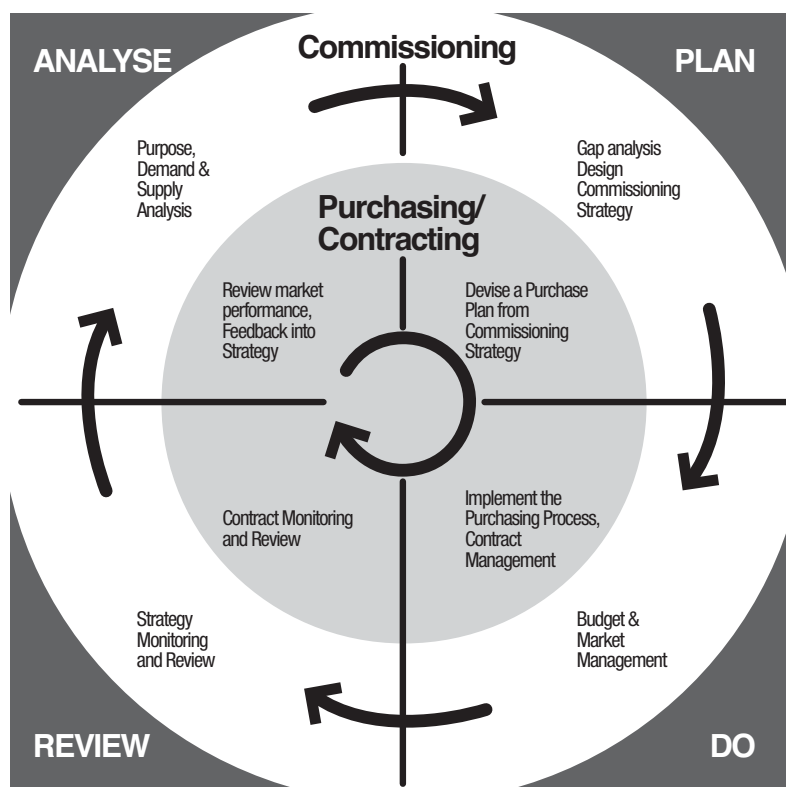


Figure 1 <sup>5</sup>

will make it much more likely that improvements are sustained, developed further, and are made available to all service users, wherever they live and whatever their circumstances.

Services for people with long term neurological conditions: bringing about change

9 The National Service Framework for long term neurological conditions sets out aspirations for, and expectations of, services for people living with these conditions. The framework describes a service in ways that are quite different from what has gone before. The quality requirements for the service are familiar, but not in the terms now expressed: these should now form the basis for services rather than ambitions for them.

5. Care Services Improvement Partnership, Institute of Public Care (November 2006) Key Activities for Social Care Commissioning, Lessons from Care Services Improvement Partnership Better Commissioning Learning Network Commissioning Exemplar Project

6. Department of Health (2005) Supporting people with long term conditions: An NHS and social care model to support local innovation and integration

7. Department of Health (2006) Review of Commissioning Arrangements for Specialised Services

8. Department of Health (2006) Health Reform in England: Update and commissioning framework and Department of Health (2007) Commissioning Framework for Health and Well-being

10. The National Service Framework is based on sound evidence as well as the views of people who live with long term neurological conditions, and those who care for them.

**The NHS should:**

- Diagnose the condition quickly.
- Provide access to whatever treatment is needed in the immediate term, to specialist and general rehabilitative care as required.
- Provide people with information about their condition and what it might mean for them.

**Health, social care and other agencies should work together to ensure that people**

- Continue to have the information they need to help them manage the effects of their condition.
- Have access to the full range of services they require, from accommodation improvements to transport and leisure facilities.

The NSF places an emphasis on the need for expert and specialist care when that is required, for example when the injury that might lead to a long term condition occurred or when a condition was diagnosed: and for those services to be closely connected to the rehabilitation and other services that followed on. People also want the NHS to respond effectively when their condition requires urgent care or when they are affected by an illness unrelated to their neurological condition.

The NSF makes the point that people are right to expect that service providers will understand their health and well being relies only in part on effective health care or, indeed, on services of any kind. Access to housing and transport that meet a person's needs, access to work and leisure activities and to financial and personal support will have a greater impact on most people's lives than their health care. The freedom to choose between options for care and support may have the greatest impact of all.

11. Various new models of service are being developed around the country in response

to the National Service Framework including:

- Clinical networks (where health care professionals come together, often with people who live with long-term neurological conditions, to streamline their work and communications and make the most of available resources).
- Commissioning partnerships between statutory organisations, and with individual payers.
- Better engagement with independent (for profit, not for profit and voluntary) sector services providers.

*There are several examples of these at Appendix 2.*

12. Aside from the acknowledged need to provide better support for people with long term neurological conditions, there is a sound business case for doing so. Poorly co-ordinated care, or care which stops outside the hospital walls, is costly for all involved. It leads to unplanned hospital admissions, extended hospital stays, and disruption of home and working lives. The cost to individuals is high – and so is the cost to the general economy.

## Securing change and improvement

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13. General guidance on commissioning (references given in Appendix 1) sets out the basis for a process that has the potential for bringing about large scale change and improvement in services. The paragraphs that follow outline the particular issues that should be taken into account when commissioning services for people living with long term neurological conditions. They arise in every part of the commissioning cycle and in the way the commissioning process itself operates. Specifically they are:

The commissioning process

- working with the complexity of needs and of potential service responses associated with long term neurological conditions
- providing leadership and co-ordination
- developing commissioning partnerships

Analysis

- understanding the conditions
- finding sources of information
- developing measures of performance

Planning

- understanding the effect of NHS reform
- developing partnerships with specialised commissioning groups

Implementation

- Achieving change management

Review and monitor

- monitoring outputs and outcomes

## The commissioning process and its governance

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14. Commissioning services for people living with long term neurological conditions is a complex matter. While the term 'long term neurological conditions' refers to several conditions that have diverse effects on the people who live with them, a feature they have in common is that the number of professionals and agencies that are involved in their care is very high, and the services they provide may be highly specialised and interdependent. Individuals' needs may be complex and change over time: they need tailored and timely services which have traditionally been provided by a number of different agencies, and may use their own resources (from; income, the benefits system, Direct Payments/individual budgets or insurance) to pay for aspects of their care. The 'service map' for an individual, or a group of clients, can be particularly complex. All this presents a serious challenge for commissioners. They should:

- Engage with people who use services and their carers in planning them and monitoring their quality and impact.
- Think widely about the range of services required, from preventive care (for example

immunisation) to critical care and from Extra Care to support for self management and independent living.

- Put technological developments at the service of people with long term neurological conditions.
- Determine whether service providers in both the statutory and independent sectors have the capacity to deliver the right services, both in terms of qualified and experienced staff, and the appropriate facilities.

Policy development on, for example, choice and funding, also tests commissioners: direct payment and individual budget schemes mean that people with long term neurological conditions will increasingly purchase some of their own services.<sup>9</sup>

15. Therefore it is important that primary care trusts and adult social care departments identify an individual with the necessary skills, experience and mandate to take a leading role in commissioning this type of service.

9. The experience of Individual Budget pilot sites will be of value to commissioners in the future. [www.individualbudgets.csip.org](http://www.individualbudgets.csip.org)

### Identify an individual to take a leading role

An individual with the necessary skills, experience and mandate can provide

- Effective support for practice-based commissioners
- Effective relationships with health care and other service providers
- Signposts to sources of information about long term neurological conditions and good practice in other locations
- Support for collaborative work with other funders
- Effective support for relationships with specialised commissioning groups

16. Commissioning services for people living with long term neurological conditions demands effective partnership amongst stakeholders. Funders and providers of services can, together, secure a clearer understanding about current and future needs for services, and the options for delivery and development, than they might working separately from each other.

17. Commissioning partnerships can be established in one of several forms; existing Partnership Boards commissioning services for children, for people with learning disabilities and with mental illnesses offer useful models. Some health and local authorities have entered into formal agreements which allow them to pool resources and risks and share accountability for commissioning services ('Section 31' agreements<sup>10</sup>). Others have a less formal arrangement that promotes access to the resources available for services, and to decision making that focuses on securing the best possible configuration of services. There are stakeholder groups that are, perhaps, 'semi-permanent' versions of Partnership Boards which do the work needed to set a new direction for services and reform: the task of bringing about change begins with a translation of that work into a commissioning strategy and, later, service specifications. The form that commissioning partnerships take may vary dependent on local history and interests. A collaborative approach to commissioning services is essential, however: funders who commission services in isolation from each other will not secure the most effective service for clients.

## Analysis

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18. The phrase 'long term neurological conditions' is short-hand for a range of conditions. The effect that any one of them will have on the wellbeing of the individual may:

- Fluctuate over a long period.
- Involve periods of acute illness.
- Involve a gradual reduction in capacity over an extended period.

The needs of a person who suffers brain injury in a road accident and those of a person with multiple sclerosis may be quite similar at some times – for swift diagnosis, initial care and information for example. It may be rather different at other times, for example, of remission for a person who has multiple sclerosis, for example.

19. It is important that commissioners of services secure access to the best possible advice about neurological conditions and their effects. There are several organisations<sup>11</sup> that have extensive experience of supporting people with long term neurological conditions and their carers, and which can provide information (from research findings to the real-life experience of their members) to support commissioners' decision-making. A number of them have a national presence and can point to developments in different parts of the country that may be of relevance and value.

10. Health Act 1999 Section 31: arrangements between NHS bodies and local authorities

11. Most such organisations are members of the Neurological Alliance: a full list is available on its website at <http://www.neural.org.uk/pages/about/members.asp>

## Understanding neurological conditions

Lead commissioners will find expert advice and support from

- National organisations such as the Parkinson's Disease Society, the Motor Neurone Disease Association and other members of the Neurological Alliance
- Royal Colleges, neurologists and neurosurgeons, rehabilitation other health and social care professionals working locally
- Services users, their families and carers who live locally
- Providers of general and specialised services
- Neuroscience leads for specialised commissioned groups
- Directors of Public Health

20. Professionals who care for those with long term neurological conditions offer important insights into the way services operate, and the way that research findings or other developments should affect services in the future. In some areas, such professionals may have little direct experience of the commissioning process but it is crucial to establish relationships with them.

Establish relationships with local clinicians

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*"We can't find the commissioners, and they can't find us"*

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Specialist and community rehabilitation professional

12. Department of Health (2005) Long-term conditions information strategy: Supporting the National Service Framework for Long-term Conditions

13. Unique Care is an approach to managing the care of patients who have complex needs.

Unique Care involves an intensive analysis of individuals' health and social care needs, and draws on primary, community and acute health services, social services, housing, the voluntary sector, and the patient him or herself, to meet those needs. The model features prominently in the Department of Health's Long-Term Conditions Framework. [www.improvementfoundation.org](http://www.improvementfoundation.org)

14. ISIP is designed to help NHS organisations achieve significant changes in services. It takes the form of a programme that includes several well tried ways of bringing about change. ISIP

- is commissioner-led, but fully involves people who use and provide services
- promotes involvement of people and organisations other than in health care ie local government (social care, housing, education), employers, voluntary sector organisations, and their combined resources
- emphasises the work needed to realise the benefits of making a change

15. [www.cat.csip.org.uk](http://www.cat.csip.org.uk)

16. [www.neural.org.uk](http://www.neural.org.uk)

## Sources of information about assessing and meeting needs

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21. Commissioners in different parts of the country report varying success in establishing a local profile for long term neurological conditions. Information about the prevalence and incidence of a particular condition is central to understanding whether services can meet the needs of those who need them now, or will need them in the future. The information strategy published alongside the National Service Framework<sup>12</sup> outlined commissioners' information requirements and a series of national and local actions designed to help meet those needs. The Framework also includes (at annex 4) information about UK prevalence rates for a range of long term neurological conditions. Commissioners can secure local development by working with acute health care and social care providers to examine the information that is presently available, and using it to improve contracting for services. For example, by contracting enhanced care services for people with multiple sclerosis from general practices, practice-based and PCT commissioners can build up local and

accessible information about people's needs and their experience of service.

Organisations that use the Unique Care methodology<sup>13</sup> or the Integrated Service Improvement Programme (ISIP) approach<sup>14</sup> establish information bases in similar ways. It is likely that early work will have much to do with revising coding and recording practices, but this should have a longer term, and general, benefit.

22. Members of the Better Commissioning Network<sup>15</sup> can offer access to public health and other information, and may be in a position to share analytical resources with colleagues engaged in parallel work. Public Health Observatories are useful reference points. National client-based organisations, like the Parkinson's Disease Society and Motor Neurone Disease Association are also sources for research and prevalence data, as can the umbrella organisation, the Neurological Alliance<sup>16</sup>.

23. Commissioners also report difficulty with finding information that is both authoritative

and sensitive to local circumstances about what people need by way of services and support. Commissioning services along a complex pathway for a relatively small number of people presents particular difficulties. A combination of information derived from national sources, as above, from measures of service outcome (see paragraph 27 below), and from local service user groups and voluntary organisations, could help fill that gap. Directors of Adult Social Services, and Directors of Public Health, have a formal responsibility to ensure this information is available to inform commissioning plans.

24. Information about current levels and types of service purchased from other than

statutory providers can also offer valuable material about the types of care needed by people with neurological conditions. An assessment of this information may help determine where there may be inappropriate provision (for example, in distant residential care or where there has been no reassessment of individuals' needs for some time), or where there are opportunities for purchasing more relevant care (for example, supported housing or domiciliary services).

25. Taken together, information from these sources will allow commissioners to use service mapping and other techniques to ensure that people have access to relevant and cost effective services.

## Setting objectives for commissioning

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26. The commissioning cycle requires an early focus on the measures to be used to gauge performance, and a clear articulation of commissioning intentions. There are some relatively straightforward output measures from health services available to commissioners: reduced numbers of urgent or emergency admissions, effective lengths of stay (via reduced re-admission rates), improved access to services (via waiting times for, for example, diagnostic and rehabilitation services). These are important measures of performance and are valued both by people who use and who provide services. They are, however, only proxy indicators of the ultimate aim – improving the outcomes of care, which are themselves more difficult to measure.

27. The Better Metrics set of clinical indicators developed by the Healthcare Commission<sup>17</sup> provides a mix of (largely) process and outcome indicators that the Commission uses to assess services in as part of the annual health check and which it commends to NHS organisations. The National Service Framework itself offers the basis for a similar range of measures.

28. While there are no standard and universally applied measures of service outcome for people who live with long term neurological conditions, developments of the LTC NSF, the commissioning

frameworks and the Payment-by-Results initiative address exactly this issue. In the meantime, however, there are at least two possible routes to establishing relevant measures of outcome. The first is to judge the effect of commissioning intentions by seeking information from people who use services. Survey, personal enquiry in the course of routine contact, and 'viewer panels' are examples of ways in which information about the impact of service provision can be collected. Secondly, services commissioned on the basis that they meet the requirements of person centred plans can generate information about achievement of objectives for care for the individuals concerned. Many specialist rehabilitation units record global independence measures as part of the routine assessment of clinical practice, and some record outcomes in terms of societal participation and quality of life. Sharing this sort of information between service provider and commissioner is important, and means that performance measures can be drawn from an anonymised and aggregated form of the information and agreed upon. Commissioners might otherwise consider the use of a general quality of life measure (for example, the Manchester Short Assessment of Quality of Life<sup>18</sup>), supplemented by a few items that related to the particular condition with which the individual lives.

17. [www.healthcarecommission.org](http://www.healthcarecommission.org)

18. Priebe S, Huxley P, Knight S, Evans S. Application and results of the Manchester short assessment of quality of life (MANSA). *Int J Soc Psychiatry* 1999;45: 7-12

## Planning and market development

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29. The planning component of the commissioning cycle provides the basis for improving services. An effective service model, supported by a clear joint commissioning strategy, can provide people with options for high quality services that suit their needs. This is particularly the case when people who use services are actively engaged in designing them, as well as those who will commission and deliver them.

30. The National Service Framework describes the design principles that should guide the provision and development of services for people with a neurological condition. It proposes a care and support

pathway that moves from diagnosis and critical care, through information provision about the condition and treatment, rehabilitation and supportive health care, the provision of urgent care when the condition requires it and the individual's care when other clinical conditions require it. The pathway, very explicitly, includes securing access to education, supported living and work, and care towards the end of life. A significant task for commissioners is to use the information available about services, resources and forecast demand to identify gaps in services that can interrupt a person's journey along this pathway.

## Gaps in service

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*"We collected information about NHS-purchased services from a cluster of PCTs and were able to demonstrate that we were paying for some services that were not suitable, and that some, more effective, services were just not available. Two years on, there are far fewer unsuitable residential placements, more intermediate care and more domiciliary care are now available. We are using both NHS and social care funds to commission services. People like it, more care is commissioned for more people – and it's cheaper!"*

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PCT cluster project manager

31. The examples of good practice in Appendix 2 include some which focus on responses to those 'interruptions' along the care pathway. There are several examples of community or home-based services replacing in-patient or out-patient care, of the way that general practitioners with special interest in neurological conditions can provide expert support to service users and professionals and where the transition points between services for children, for those of working age and for older people are managed effectively. There are also examples of outreach teams from specialist services working in close collaboration with local teams in the community to support them in the long-term management of people with more complex needs, and of developments in assistive technology that support independent living. Most examples address more effective or intensive use of resources; new services being established on the basis of a persuasive business case. There are few examples, however, where people have returned to work, entered or re-entered the education system or made a successful transition from residential care to independent living at home or in supported housing. Could these be achieved with a joint approach to developing commissioning strategies?

32. A joint commissioning strategy can challenge service providers to match the care pathway designed by commissioners. In some cases, service provider networks have had a significant influence on the pathway design, based on their own work to reform and realign services. In others, new service provider coalitions may be needed to realise the care pathway, which

may, in turn, see the development of supply chains that involve providers with little previous experience of working together. In still others, a commissioning strategy that borrows from work on the 'Year of Care' concept<sup>19</sup> will test providers' capacity to develop new working relationships with each other and, crucially, with people living with long term neurological conditions.

## New service provider coalitions

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*“Local GPs wanted to make significant inroads into services for people with Parkinson’s disease. Establishing two specialist nurse posts was reasonably straightforward: everyone could see that this would reduce hospitalisation rates and streamline case management – but we wanted to provide some respite services and facilities for community-based rehabilitation. We are talking to a local supported housing provider who has the space for rehab professionals, and could provide respite care, although they had not considered hosting either sort of service in the past, or offering it to their current clients. It’s new for all of us, but we think it could work well. We’re working on the detail.*

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LIFToo Manager

33. Some components of the care pathway can be contracted for locally; others demand a greater population base:

- Practice-based commissioners are best placed to commission the diagnostic services that people with neurological conditions, in common with all others, will need to secure an accurate and timely diagnosis. They are also in a position to commission community-based rehabilitation services that are needed by this group, and other groups of clients.
- More specialised care for people with less common conditions or especially complex care needs may need to be contracted for on behalf of a larger general population; commissioning partnerships with social services departments, for example, may be easier to manage at local authority/PCT level, for example specialist neuro-rehabilitation.
- Specialised commissioning groups will be best placed to contract for services that are much less often required or are particularly costly, including critical care.

In essence, the joint commissioning strategy requires breadth, so that it covers services that extend across health and social care, and into the housing, benefits and education sectors; and depth, so that commissioning expertise and resources at both local and wider levels are used effectively.

34. The problems associated with achieving this end are recognised and acknowledged. The Payment-by-Results initiative has yet to focus on services for people with neurological conditions. The independent

19. The Year of Care Model helps people to self-manage their care over an appropriate length of time and within limits appropriate to the stage of disease progression, with the goal of maximising their wellbeing, quality of life, and the efficient use of healthcare resources. It takes the form of a written statement, which incorporates the views of patients, clinicians and managers, and specifies the events in self care and clinical care within primary and community settings whose occurrence or non occurrence will significantly affect quality, cost and outcomes. <http://www.dur.ac.uk/ccmd/yoc>

review of commissioning arrangements for specialised services, the Carter review, reported in May 2006<sup>20</sup>. Ministers have accepted the review as the blueprint for a programme of change. An implementation plan is in place to address the recommendations<sup>21</sup> and the headline priorities were included in the first

Commissioning Framework document. Commissioners can also discuss and reach local agreements among themselves about which services should be commissioned by whom. The essential responsibilities of commissioners – securing comprehensive options for high quality services – are best fulfilled in this way.

## Implementation

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35. Sound relationships between commissioning partners and with service providers will promote service, and market, development. A common understanding of the effect of national policies and developments, for example Payment-by-Results, contestability and choice of services for people with neurological conditions will allow stakeholders to use the principles behind these initiatives to good effect, and help with the process of reviewing and refining those policies.

### The tariff

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*The potentially perverse effects of the tariff for services exercised our stakeholder group for some time! But we hammered out an agreement with our main providers that meant the service was provided at reasonable cost. We passed our experience of the discussion, and its outcome, to the Department – and hope it will influence the next version of the tariff.*

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PCT service development director

36. Commissioners should bring all their experience of securing change in services to bear on work to implement the NSF, and draw on the work and experience of Local

Implementation Teams. Discussions about what makes for a successful change programme that involve both commissioners and providers of service can be very productive. People working together to understand the risk factors involved in bringing about change are more likely to avoid problems. Those risk factors include:

- Achievable timetables for change among providers.
- The lead time for securing market developments (additions to existing providers' portfolios, or new providers entirely).
- Assuring stability and transitional support for providers (and those using their services) during service development.

It is important to consider whether increasing capacity in one area of service will mean increases in other areas (for example for tertiary or community based services, and whether this will mean, in turn, that services must be de-commissioned in another area, with possible consequences for services for other groups of people.

37. The examples outlined in Appendix 2 include some local experiences of addressing service shortages, workforce shortages and financial constraints. Service providers have shifted investment from activities that are known to have less effect into effective service re-designing service teams and shared teams across geographical areas. Services have been commissioned from organisations where there is capacity; and devised contracting arrangements that are better suited to continuing and complex requirements than the standard spot or block contract for

20. Department of Health (2006) Review of Commissioning Arrangements for Specialised Services

21. [http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/Commissioning/CommissioningSpecialisedServices/CommissioningSpecialisedArticle/fs/en?CONTENT\\_ID=4141589&chk=W4n/sp](http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/Commissioning/CommissioningSpecialisedServices/CommissioningSpecialisedArticle/fs/en?CONTENT_ID=4141589&chk=W4n/sp)

services, and offer considerable economies. In line with current proposals being considered by the Department of Health for development for weighted tariffs to reflect treatment of patients with more complex

needs, some services have started to explore the use of weighted contracting currencies to provide more transparent and accurate information on treatment costs for people with different levels of need.

## Review and performance

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38. The review process – determining whether the strategy is achieving the intended effect – is a critical component of the commissioning cycle. The performance measures that commissioners use will provide the foundation for review. Some measures will focus on outputs, such as: access to service, speed of service,

completion of portions of the journey to a defined standard, reduced reliance on benefits, missed schooling, unemployment. Other measures need to focus on the planned outcomes for which the above outputs are proxy indicators, for example, measures of independence, freedom from pain, mobility.

## Conclusion

39. This guide note recognises the complexity of commissioning and contracting for people with long term neurological conditions. People with such conditions may have complex health and care needs that require complex packages of health and care services if a good quality of life is to be enjoyed. As has been argued above, it is important that good local commissioning and contracting frameworks are put in place, which will work well for the range of conditions, and have good quality outcomes for service users and their carers at its heart.

## Summary

40. The following page summarises key features of effective practice in commissioning services for people with long term neurological conditions and may be used to inform structures, processes and implementation plans to improve commissioning effectiveness in this essential area of work

ICSIP March 2007

# Commissioning Services for People with Long Term Neurological Conditions

## Summary

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PCTs need to ensure that there is appropriate capacity and capability to effectively commission services for people with long term neurological conditions. This may be delivered by adopting a variety of measures:

- Designating a specific person to co-ordinate the commissioning activities for this client group
- Where current commissioning arrangements require improvement, PCTs may wish to consider utilising the Framework for Providing External Support for Commissioning (FESC)
- Undertake needs assessments of local populations in line with the duties proposed in the Commissioning Framework for Health and Well-being (March 2007)
- Agree budgets and align finances between stakeholders with commissioning responsibility, establishing controls in accordance with financial regulations and entering the right balance is reached on health, local authority and joint finance
- Establish commissioning alliances between health and social care and with service users.
- Know the conditions – take advice from service users, professionals and other experts.
- Know your population: track down information about incidence and prevalence and compare numbers known to numbers that need to be known.
- Know your service users – draw on local people and service providers for information about what service users need and how they would prefer those needs to be met.
- Use the National Service Framework as the basis for clearly articulated commissioning intentions.
- Test the full range of services – from critical care and specialist rehabilitation to preventive care, home adaptation, supported housing, and assistive technology.
- Understand commissioning mechanisms (such as Payment-by-Results and Practice-based Commissioning), and their limitations for long term neurological conditions. Take what advantage you can of them, and look for variations that would work better.
- Agree local performance measures for services, including measures of both outputs and outcomes, and report on them. Explore how service user and carers can contribute to monitoring.
- Foster good relationships with providers.
- Secure agreements between Practice-based Commissioners, Primary Care Trusts and Specialised Commissioning Groups about who will commission what health services.
- Seek out effective contracting methods.
- Embed commissioning continuing care as part of mainstream activity based on assessment of need within agreed funding stream.

## Appendix 1

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Guidance on commissioning health and social care services

1 Department of Health (2003)

Independence matters: an overview of the performance of social care services for physically and sensory disabled people

2 Department of Health (1998) The New NHS

3 Department of Health (2004) Practice based commissioning: engaging practices in commissioning

4 Department of Health (2004) Practice based commissioning: promoting clinical engagement

5 Department of Health (2005) Making practice based commissioning a reality: technical guidance

6 Department of Health (2005) Supporting people with long term conditions: An NHS and social care model to support local innovation and integration

7 Department of Health (2005) National Service Framework for Long Term Conditions

8 Department of Health (2005) Long-term conditions information strategy: Supporting the National Service Framework for Long-term Conditions

9 Department of Health (2005) Commissioning a patient-led NHS

10 Department of Health (2005) Health Reform in England: Update and next steps

11 Department of Health (2006) The NHS in England: The operating framework for 2006/7

12 London: Stationery Office (2006) Our health, our care, our say : a new direction for community services

13 Department of Health (2006) Effective practice-based commissioning: engaging with local people

14 Department of Health (2006) Practice based commissioning: achieving universal coverage

15 Department of Health (2006) Practice based commissioning: early wins and top tips

16 Department of Health (2006) Review of Commissioning Arrangements for Specialised Services

17 London: King's Fund (2006) Briefing paper, Practice-based commissioning

18 Audit Commission (2006) Early lessons in implementing practice based commissioning: key areas to focus on for success and key questions for primary care trusts' boards to consider

19 Department of Health (2006) Health Reform in England: Update and commissioning framework

20 Commission for Social Care Inspection (2006) Relentless Optimism: creative commissioning for personalised care

21 Care Services Improvement Partnership, Institute of Public Care (November 2006) Key Activities for Social Care Commissioning, Lessons from Care Services Improvement Partnership Better Commissioning Learning Network Commissioning Exemplar Project

22 Care Service Improvement Partnership (December 2005) Guide to Fairer Contracting Part One

23 Department of Health (2007) Commissioning Framework for Health and Well-being

## Appendix 2

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Examples of practice in developing services for people with long term neurological conditions

### Leeds

A community rehabilitation unit incorporates a young adult team and the head injury community team. The service provides effective, community based support for young people who live severely disabled lives and supports a smooth transition to adult services at the appropriate time.

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Contact Prof Anne Chamberlain  
(Professor of Rehabilitation Medicine)  
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### Suffolk

A Brain Injury Co-ordinator post has been established at Ipswich Hospital to fulfil the role described in the NSF. The experience of the postholder will inform a plan for a network of co-ordinators throughout the eastern region, covering every acute hospital.

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Tel: 01473 232425 Fax: 01473 230505

### Suffolk

Optua UK has established a case management co-ordinator post to reinforce its 'move on', outreach support, and supported housing services for people with a brain injury.

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William Challis, Head of Services, Optua UK,  
Optua House, Unit 12, Hillview Business Park,  
Claydon, Suffolk, IP6 0AJ  
Tel: 01473 836720 Fax: 01473 836778

### Torfaen

The Torfaen Social Services Physical Disability Team supports clients of working age with a diagnosed physical disability. Team members identified service gaps when working with clients who had been diagnosed with Huntington's Disease, MS, MND and epilepsy. They initiated

discussions with the Local Health Board about developing a pathway for clients with a neurological condition. The aim is to develop a pathway from 'diagnosis to death', in order to ensure that clients and their families have the opportunity to access to all relevant services.

Early discussions included specialist nurses for MS, MND and Huntington's Disease, social services planners, service users, social workers, mental health staff from the LHB and Social Services. A local GP with an interest in Huntington's Disease is supporting the project. Work has identified huge variations in individuals' experience of support from particular agencies: it is hoped that the development of a pathway in Torfaen will provide a model of good practice for service delivery that could be adopted throughout Wales.

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Andrea Cook, Senior Practitioner Physical Disability Team, Torfaen Social Services,  
Tel: 01633 648740 Fax: 01633 873203

### Somerset

The Primary Care Trust has led work on a Somerset health community analysis and action plan on long term neurological conditions. Stakeholders from all parts of the health and social care economy have worked together on gathering information to inform service re-design.

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Annabelle Legg, Deputy Director of Service Improvement, Taunton Deane Primary Care Trust,  
Wellsprings Road, Taunton, TA2 7PQ  
Tel: 01823 344402

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## Sheffield

The Sheffield Parkinson's Disease initiative has drawn stakeholders together to work on improved information about clients' needs and service development. Among the developments emerging from the work are a dedicated PD clinic, enhanced skills and awareness among primary and secondary care practitioners, and revised care protocols and pathways.

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## East Staffs PCT

### Adult Ability Team

The Adult Ability Team is a multi-organisational (primary and secondary health/health and social care/voluntary sector), multidisciplinary professional care team and effectively offers 'case management' to people affected by a long term neurological condition. The emphasis of the team is on 'self management'. It offers access to a specialist neurological community rehabilitation team which provides packages of rehabilitation to maintain and maximise functional abilities. The team offers planned episodes of rehabilitative respite care in a local cottage hospital.

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Pam Bostock  
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## Brain Injury Rehabilitation Trust

The Brain Injury Rehabilitation Trust (BIRT), a division of The Disabilities Trust, is a leading European provider of specialist brain injury rehabilitation, helping people regain lost skills, recover social independence and rebuild their lives following acquired brain injury.

In order to develop and improve working practices BIRT regularly holds "Commissioners' Lunch" events. These are held at our residential units and attended by Commissioners from local PCTs and Social Services Departments, BIRT Unit General Managers and members of BIRT's Clinical Team.

At the lunch, Commissioners are invited to discuss with BIRT how we can help them in their work in relation to cost effectiveness, value for money and other funding related topics.

Common issues are shared (ie common between Commissioners and common between BIRT and Commissioners), brainstormed suggestions discussed, debates held on how best to move forward.

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Catherine Portman, Business Support Manager,  
Brain Injury Rehabilitation Trust, 60 Queen Street,  
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Tel: 01924 896100  
www.birt.co.uk

## Leeds

Recent work on a detailed service specification for the Transient Ischaemic Attack pathway will ensure only those people who need it are admitted to hospital. Commissioners will be in a position to negotiate a reduced / tiered trim point and re-direct resources support access to other types of specialist services as out patients, when clinically safe to do so. Options for home medication and monitoring are also under consideration.

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Joanna Powell, Service Redesign Manager, Leeds North East PCT, Sycamore Lodge,  
7a Woodhouse Cliffe, LS7 2HF  
Tel: 0113 3059852 (team Secretary)

## London – Hammersmith and Fulham

A dedicated multidisciplinary clinic for people with Multiple Sclerosis was set up in direct response to a discussion at patient and public forum. People have access to clinicians with special expertise in MS, a social worker and a volunteer from the MS Society.

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Caroline Kelsall, Commissioning Manager Physical Disabilities and Sensory Loss,  
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London W6 9XY  
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Email: Caroline.Kelsall@lbhf.gov.uk

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## London – Wandsworth

The MND Association is testing out a joint commissioning approach to services for people with Motor Neurone Disease who live in the London Borough of Wandsworth. The aim is to develop a care pathway that reflects the NSF and MND care standards and to test this out with commissioners, providers and service users by January 2007

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Tricia Holmes, Head of Care Development, MND Association, PO Box 246, Northampton NN1 2PR  
Tel: 01604 250505

## Shropshire

The Shropshire Enablement Team provides services for people who live with the full range of neurological conditions. The joint commissioning team (Telford and Wrekin PCT and Borough of Telford and Wrekin) reviewed the service in 2005, collating information about clients, their needs and use of services. Recommendations arising from the review include extending some services, and improving coordination among practitioners.

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Julia Meakin, Joint Commissioning Manager (Physical & Sensory Disabilities), Telford & Wrekin Joint Commissioning Team, c/o 1st Floor The Wrekin Housing Trust, Colliers Way Old Park, Telford, TF3 4AW

## London – north west

### **Collaborative contracting for NHS care purchased from without the NHS.**

Intensive data collection and the appointment of a care placement service has led to the review of many placements, much improved information about client needs and a potential £10m reduction in costs.

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Michael Young, NHS  
London, Tel: 020 7756 2500

## Macclesfield

Community-based care provided by MS specialist nurses, avoiding unplanned admission and inappropriate lengths of stay and discharge arrangements, commissioned through EGMS arrangements.

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Dr Graham Duce  
Email: graham.duce@nhs.net

## London

NW Thames specialist rehabilitation network is a coordinated network of specialist rehabilitation services of people with complex disabilities is coordinated from the regional Rehabilitation unit at Northwick Park Hospital. The Specialist Outreach Rehabilitation and support Team (SORT) from the RRU provides support to local rehabilitation teams and specialist nursing homes to assist in providing ongoing management for people with very complex neurological needs, either in their own home or as near to their families as possible

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Lynne Turner-Stokes, RRU, Northwick Park Hospital, Watford Road, Harrow, Middx HA1 3UJ  
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## London

Pan London specialised commissioning for specialised rehabilitation services following acquired brain injury The Neuro-rehabilitation Group of the London Neuroscience Modernisation Team has assembled a combined service specification for specialised rehabilitation services providing rehabilitation for people with complex rehabilitation needs following acquired brain injury. At the request of the London Specialist Commissioning group, commissioners and service providers are currently working together to explore the feasibility of pan London collaborative commissioning of these services.

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## London

The Royal Hospital for Neuro-disability (RHN) is a registered charity and an independent organisation that provides a wide range of services for adults with neuro-disability.

Services range from post-acute rehabilitation through to challenging behaviour rehabilitation (often required as part of brain injury recovery), cognitive retraining and community reintegration,

continued overleaf ...

disability management and long-term placements for adults with Profound Brain Injury or degenerative disease. Services are provided via in-patient or day attendances. The 'catchment' is therefore national for the specialist in-patient neuro-rehabilitation, yet also local for the long-term care and day attendances. The Royal Hospital for Neuro-disability partners include health, social service, local authorities and other agencies involved with community living across the UK.

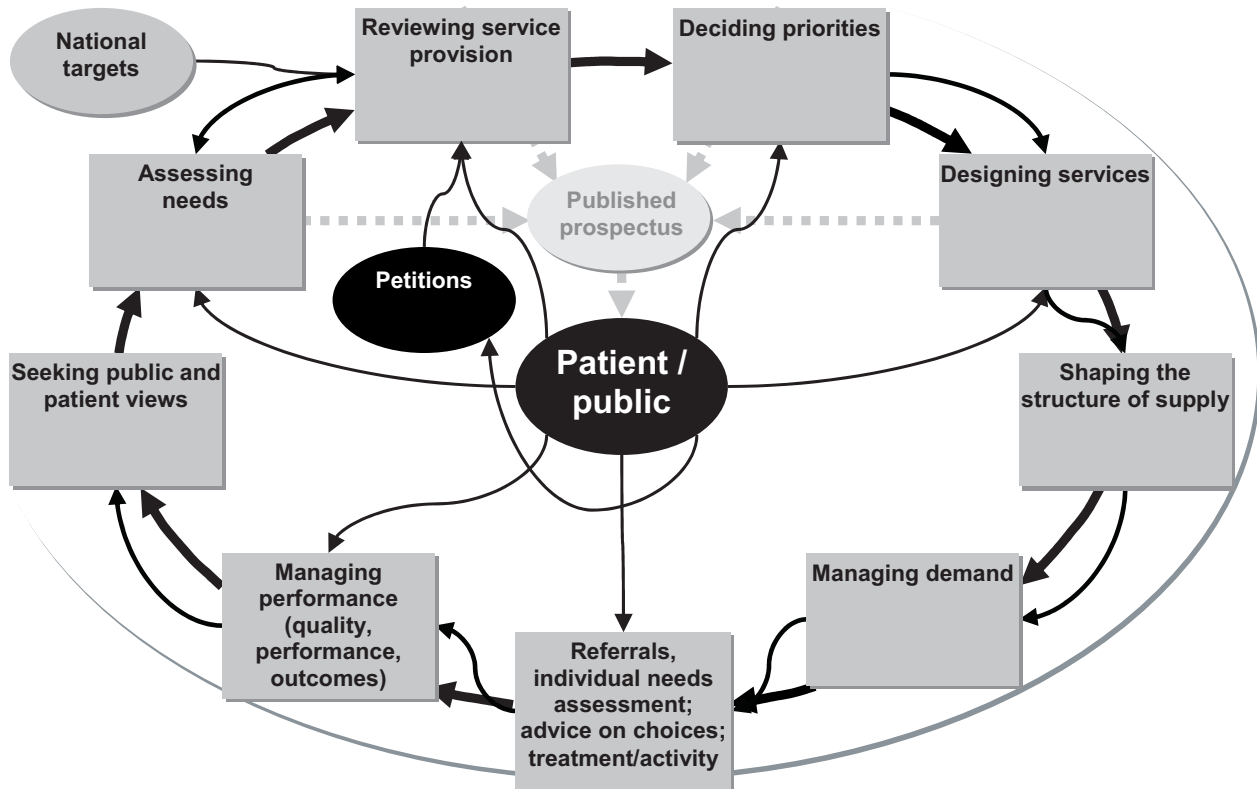
Senior staff are currently involved in the London Specialist In-patient Neuro-Rehabilitation Commissioning forums, local provider forums co-ordinated by joint commissioning arrangements, local and national neurological community rehabilitation teams and client based organisations such as the Huntington's disease Association. Through an understanding of the needs of those with complex and profound disability, developed through empirical and evidenced research and an active user representation as part of its integrated governance framework, RHN has developed its client services based upon unmet need and provides advice on management to other health providers on a formal and informal basis.

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## Appendix 3

### Commissioning Definitions.

(a) The commissioning cycle for health services (reprinted from Health Reform Commissioning Framework July 06)



#### Assessing needs

This will increasingly be based on more rigorous analytical approaches involving population segmentation and risk stratification and will involve public health professionals, local authorities, GPs and patients and the local community.

#### Reviewing service provision

Practices will identify gaps and the potential for improvements in existing services. PCTs will use the aggregated intelligence of their practices and their local needs assessment to identify gaps or inadequacies in provision, as well as broader requirements for service development.

#### Deciding priorities

The PCT should produce a strategic plan for the health community based on data on needs assessment collated from practices and on the clear choices patients are making. Practices and PCTs should work collectively to reinvest resources that have

been released through service redesign where these would achieve greater impact. PCTs should ensure patients and the local community, as well as local government and other partners, are properly involved in the process of deciding priorities.

#### Designing services

Practices will work individually, or in groups, to develop strategies and service models to improve healthcare services and address the priorities of the public.

#### PCT prospectus

The PCT prospectus will signal the strategic direction for local services, highlighting commissioning priorities, needs and opportunities to service providers, offering a focus for discussion with patients and local community and an opportunity to open dialogues with potential providers.

#### Shaping the structure of supply

PCTs will be clear about the services and

service specifications they and their practices and patients want to see developed and will give strategic support to proposals where necessary. They will seek to develop new services and will work with NHS Trusts and Foundation Trusts, expanding GP practices, neighbouring PCTs and private and third sector providers to ensure the best services for local people.

Where appropriate, PCTs will encourage practices to offer services locally and also attract private sector and third sector providers to offer services in line with identified needs and priorities. Incentives and levers will be available to PCTs to stimulate the supply of services.

PCTs will agree contracts with local secondary care providers within a new national contracting framework, with the involvement of practice-based commissioners. For a few very specialised services, contracts will be held at national level. For other specialised services, PCTs will group together to set contracts.

#### Managing demand and ensuring appropriate access to care

Practices and PCTs will establish strategies for care and resource utilisation to ensure that patients receive the most appropriate care in the right setting, ensuring that healthcare resource is maximised.

#### Clinical decision making

Individual practices and clinicians undertake individual needs assessments, make referrals and advise patients on choices and the treatments available to them – each referral is effectively a micro commissioning decision. Practices will work with social services and other agencies where appropriate to assess the needs of their patients. It will be important to facilitate the opportunity for patients to make their choices with the benefit of good advice from their GP. PCTs and local authorities should work together to develop this environment in which integrated working between practices and social services is the norm.

#### Managing performance

Practices will seek to manage their indicative budget to maximise the benefits from the resources available to them. To help them, PCTs will provide a support programmes including training and

development, and will develop systems to allow practices to monitor the services their patients receive through accurate, relevant and timely data. PCTs will be responsible for the aggregated financial position and for ensuring financial balance overall.

#### Patient and public feedback

PCTs will be responsible for measuring and reporting on patients' experience. Practices will also want to monitor patients' satisfaction. Robust mechanisms for collecting and understanding patients' views will need to be developed by PCTs and made available to practices. Throughout, PCTs will ensure that the public voice is heard in the development of priorities and shaping services

(b) An outcomes-based approach to commissioning (reprinted from Commissioning Framework for Health and Well-being March 2007).

### Key outcomes of, and requirements for, good local commissioning

Commissioning is the means to secure the best value for local citizens. It is the process of translating aspirations and need, by specifying and procuring services for the local population, into services for users which:

- deliver the best possible health and well-being outcomes, including promoting equality
- provide the best possible health and social care provision
- achieve this within the best use of available resources.

Commissioning for the health and well-being of individuals means helping local citizens to:

- look after themselves, and stay healthy and independent
- participate fully as active members of their communities
- choose and easily access the type of help they need, when they need it.

Commissioning for the health and well-being of a local population means:

- understanding and anticipating future need
- promoting health and inclusion and supporting independence
- identifying the groups or areas that are getting a raw deal and giving them a voice to influence improvements
- delivering the best and safest possible quality of care.

The essential principles and processes for good quality commissioning are set out in *Health reform in England: update and commissioning framework* (July 2006) and in *Joint planning and commissioning framework for children, young people and maternity services* (Annex C).