AN EVALUATION OF A HEALTH CARE PROGRAMME APPROACH TO COMMISSIONING STROKE SERVICES IN GATESHEAD AND SOUTH TYNESIDE

Thesis submitted for the degree of
Doctor of Medicine (MD)
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Abstract

Introduction

The NHS emphasises programme approaches to commissioning (Health Improvement Programmes and National Service Frameworks) but research is limited. I evaluated the Health Care Programme Approach (HCPA) for stroke whose individual elements are: a co-ordinating group; a co-ordinator; a technical document; and agreement of priorities.

Methods

1 Four rounds of interviews with managers and clinicians; observation at meetings; analysis of documentary sources.

2 Quantitative indicators of progress measured at two time points.

3 Estimation of the Programme Budget and Transaction Costs from published sources and local data.

4 Interviews with Directors of Public Health from nine comparator districts.

Results

1 A structured process led to a set of priorities, which were widely accepted across all agencies, allowing the co-ordinating group to focus on facilitating change. This group took two years to reach a stage where it could change services. Most people supported the approach but were not always clear about the process.

2 The indicators showed improvements in some aspects of care.

3 The programme budget was £10m, mostly in long-term care (£5.5m) and hospital care (£3m). The transaction costs amounted to 0.25% of the programme budget.

4 All comparator districts reported changes to commissioning and improvements in stroke services, but I found more widespread change in the study district.

Discussion

The detailed description of process, and use of multiple methods, gives strength to the findings. A collaborative approach has developed across the NHS during the period of this study making the findings highly relevant. There were important lessons for multiagency groups including: the time needed to function effectively; the need for individuals to clarify whether they represent an organisation or their own perspective; the need to review the group remit and the group's routes of communication; and the ability to adapt to changes in national policy while focusing on improving the health of the patients who fall within the programme.

Keywords

Planning, Purchasing, Commissioning, Stroke Services, Health Care Programme Approach, Evidence-Based, Multiagency Collaboration, Triangulation, Evaluation, Case Study.

1 Description of my contribution

Health Services Research is a multidisciplinary undertaking so it is important to describe my role in the study. This has two purposes: to describe my contribution for this MD, and to make my perspective explicit to aid the interpretation of the findings. The Appendix contains full acknowledgements and details of funding, but I have listed the research and implementation teams below.

1.1 The research team

I was Principal Investigator for this study, wrote the grant application and project managed the implementation and research.

The project team came from the Departments of Epidemiology and Public Health and Primary Health Care in the School of Health Sciences at the University of Newcastle upon Tyne. We worked closely with colleagues in the NHS as listed in the Appendix. Apart from myself as Principal Investigator, the team consisted of:

Jackie Bailey (JB), Senior Research Associate (qualitative)
Conducted most of the interviews, observation and documentary analysis.

Emma Hutchinson (EH), Secretary
Administered both implementation and research sides of the study and did the referencing for the final report.

David Parkin (DP), Senior Lecturer in Health Economics
Advised on the health economics part of the study.

Angela Robinson (AR), Research Associate (economics)
Conducted the economic aspects of the study.

Helen Rodgers (HR), Senior Lecturer in Stroke Medicine and Services
Advised on and jointly supervised the clinical and quantitative aspects of the study.

Rosie Stacy (RS), Senior Lecturer in Medical Sociology
Advised on and jointly supervised the qualitative aspects of the study.

Lois Thomas (LT), Senior Research Associate (quantitative)
Conducted the quantitative aspects of the study and the two surveys.

Richard Thomson (RT), Professor of Epidemiology and Public Health
Advised on and jointly supervised the quantitative aspects of the study and was my supervisor for this MD.

Additionally, Graham Stacy (GS), Health and Social Care Researcher, was contracted to carry out the final round of interviews.

1.2 The implementation team

Apart from myself in my capacity as Honorary Senior Registrar in Public Health Medicine and lead for stroke services at Gateshead and South Tyneside Health Authority, the team consisted of:

Emma Hutchinson (EH), Secretary

Ruth Richardson (RR), District Stroke Co-ordinator (From May 1998)

Helen Rodgers (HR), Senior Lecturer in Stroke Medicine and Services

Barbara Scott (BS), District Stroke Co-ordinator (Until April 1998)

Richard Thomson (RT), Professor of Epidemiology and Public Health

1.3 Design and management

Most of this study was conducted while I was a Lecturer in Public Health Medicine. When I started in post on 1 April 1996 there had already been some discussions about applying the HCPA to stroke and to evaluating it. I was therefore able to take the lead in developing the research question and methods and writing research applications. This was mainly with Richard Thomson, Helen Rodgers and Michael O'Brien. Having successfully obtained funding (see Appendix) I recruited the three research associates. I had the main project management role for both the implementation and research sides of the study and jointly supervised the research associates. I was principal investigator for the study and therefore responsible for the budget, project management and co-ordination.

I was appointed Honorary Senior Registrar in Public Health Medicine at Gateshead and South Tyneside Health Authority in order to carry out this study and took a lead on stroke for the health authority. I directly supervised the stroke co-ordinators Barbara Scott and Ruth Richardson and managed most aspects of the implementation. I convened the District Stroke Group, taking responsibility for preparation of agendas and reports. Richard Thomson chaired the group.

1.4 Data collection and primary analysis

I worked with Lois Thomas and Richard Thomson to develop the set of indicators and the data collection methods. Lois Thomas collected data from the Contract Minimum Data Set (CMDS) and General Practices, and carried out the primary analysis together with Angela Robinson, which I defined jointly with them. I worked with the whole research team to develop the survey of Directors of Public Health (DsPH) and Lois Thomas conducted the survey. Under my supervision, Lois drafted the chapters of the final report on the indicators, detailed analysis of the CMDS and the two surveys. I have revised and summarised these for this thesis.

I developed the research question and methods for the qualitative part of the study with Jackie Bailey and Rosie Stacy. Jackie conducted three of the four rounds of interviews. She also observed meetings and collected and analysed the documents. She wrote the qualitative chapter of the final report with Rosie Stacy. The nature of this aspect of the study (I was observed and was also one of the interviewees) means I did not have access to the primary data (eg transcripts of interviews). I have summarised the findings for this thesis.

I developed the question and methods for the two economic aspects of the study with Angela Robinson and David Parkin. The programme budget was mainly based on the Contract Minimum Data Set, which was obtained from the information department of Gateshead and South Tyneside Health Authority and analysed by Angela. This was combined with published data from a number of sources. The data for the transaction costs was derived from the locally collected data along with published costs. I have summarised the findings for this thesis.

1.5 Triangulation, interpretation and dissemination

As well as leadership of the various components of the research, I personally lead the triangulation of all the aspects of the study, and co-ordinated group meetings. Triangulation is an iterative process that involves all members of the research team. I also took the lead in writing, editing and disseminating the findings from the research.

1.6 An analysis of my role

From the foregoing, it is clear that I had a number of roles in both implementation and evaluation, so these are discussed in terms of my perspective in the research. I had some elements of a number of roles described in the methodological literature.

a Participant Observer

My position in Gateshead and South Tyneside Health Authority had elements of participant observation. As a Lecturer in Public Health Medicine I was appointed as Honorary Senior Registrar in Public Health Medicine at the district where the study took place. This meant I was appointed to a post where I could work on stroke commissioning as well as researching it. Whilst I am not a trained qualitative researcher, nor did I take regular field notes, it is clear from the literature that the position of participant observer can vary.

Murphy[*] describes Gold's typology of:

- **Complete participant**
- **Participant as observer**
- **Observer as participant**
- **Complete observer**

and Gan's typology of:

- **Total participant**

---

[*] Murphy E, Dingwall R, Greatbatch D, Parker S, Watson P. Qualitative research methods in health technology assessment: a review of the literature. *Health Technology Assessment* 1998;2(16):0-276.

- **Researcher participant**
- **Total researcher**

In these two classifications my position comes closest to *participant as observer* or *researcher participant.* The strength of this role lies in the enhanced data collection opportunities as interactions become normalised. The danger is of over-identification with one or more key informants. There is also the specific problem of being professionally qualified for the role and therefore identified as belonging to a specific professional group: for example I was seen as the 'medic' on the district multidisciplinary forum.

b Key Informant

In some qualitative research it is common to find one member of the group under study acting as a key informant to the researcher. I was interviewed by the qualitative researcher as member of the District Stroke Group but also had regular meetings with her. These allowed me to explain in more detail the situation as I saw it in Gateshead and South Tyneside Health Authority and in the wider NHS. However, as a principal investigator in the research I inevitably brought my own interpretation as well as a description of events.

c Reflective Practitioner

This term is generally used to suggest a characteristic of a 'good' practitioner[†] and has been less used in research settings. However, the research has allowed me to reflect with more rigour than is normally possible on my practice during this period. This has obviously influenced the triangulation and interpretation of the findings and has had direct effects on my 'clinical' (ie public health) practice.

Thus I had multiple roles in this research, to be borne in mind when reading and interpreting this thesis.

[†] Schön DA. The *reflective practitioner: how professionals think in action.* Aldershot: Arena, 1995.

2 Acknowledgements

I would like to thank all those who worked on this project, particularly Professor Richard Thomson who was my supervisor for my MD as well as for the implementation and research. A complete list of those who worked on and supported this study and their roles is given in the Appendix. However I would like specifically to mention a number of people whose contributions were critical to the success of this project.

- The research associates who did much of the data collection and analysis on the qualitative, quantitative and economic aspects: Jackie Bailey, Lois Thomas and Angela Robinson.
- The other principal investigators: Richard Thomson, Helen Rodgers, Rosie Stacy and David Parkin.
- The administrator, Emma Hutchinson.
- The stroke co-ordinators, Barbara Scott and Ruth Richardson.
- My sister-in-law, Jane Chappel, who was responsible for proof reading.
- My wife, Rachel Bailey and our two children, Lucy and Edmund, who put up with me trying to complete the thesis.

Thanks also to NHSE Northern and Yorkshire, Research and Development and the Stroke Association who funded this project.

All errors and omissions remain my own.

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1 Introduction

This study is about commissioning health services in the National Health Service (NHS). It aims to contribute to improving the health of the population by furthering knowledge of how best to organise health services. It starts from a number of assumptions:

- that planning health services is necessary;
- that co-operation between health professionals and agencies improves the quality of health care so should be pursued as an end in itself;
- that multidisciplinary research is necessary to understand multiagency and multidisciplinary practice.

This introduction covers the background to commissioning in the NHS and different strategies that are used to do this. The next section describes in detail a particular strategy called the Health Care Programme Approach (HCPA) that is the subject of this study. This is a complex intervention and there is a methodological review at the start of the Methods section. The Methods section then describes each of the components of the evaluation and the Results section bring together all the findings using the framework of the objectives set for the HCPA. The implications are picked up in the discussion.

1.1 Planning, purchasing and commissioning health services

Planning is a "...deliberate, systematic, and objective process of mobilizing information and organizing resources."[1] The formation of the NHS in the 1940s made it possible to plan for the whole country, although it was only in the 1960s that comprehensive health service planning systems were widely used internationally.[2] The focus of planning was predominantly on buildings and staff, with a primary aim being a more equitable geographical spread of resources.[3]

In the 1970s there was a move away from historical budgets, to those based on "need,"[4] although the ability to assess need was limited.[5] This included both a geographical reallocation (the Resource Allocation Working Party – RAWP – formula) and a shift between patient groups from "acute services" such as medicine and surgery to "priority services" such as the mentally ill, mentally handicapped, elderly and the chronically sick.[4]

In the late 1980s two important developments took place in the NHS: the separation of strategic planning from service provision, and "market" reforms to introduce competition. The former has allowed the strategic planners (now "purchasers" or "commissioners") to focus on health improvement.[1] Their aims now also include improving the quality and effectiveness of services, reducing inequalities, and restraining costs. This separation of roles, but not the market, seems to have become accepted across the political spectrum.[7 8]

Another focus for recent reform has been the desire to move from a demand or supply-led service, to one that is more focused on need. Need is usually defined in terms of capacity to benefit,[9] although different definitions exist.[10] Alongside this, an important development and influence has been the emergence of the concept of "consumerism" centred on ideas of patient choice and health service accountability.[11]

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[1] The political context has often determined the terminology, as much as the aims, of planning. Although good definitions exist,6. Ovretveit J. *Purchasing for health: a multidisciplinary introduction to the theory and practice of health purchasing*. Buckingham: Oxford University Press, 1995. and *commissioning* tends to encompass a broader range of activities than *planning*, their use in the literature is very variable. Therefore, I have not distinguished between the terms "planning", "purchasing" or

Commissioners and providers have been encouraged to seek and respond to the views of patients and public, and to incorporate those views into their strategies, service development and quality improvement.[12]

Commissioning includes assessing need,[13] setting priorities, allocating resources, influencing providers, involving patients and the public, minimising transaction costs, and managing financial risk. The task of commissioning is so large that it is often divided into manageable components. Two ways of doing this have been by division either into "localities" - eg by geography, general practice, or hospital - or into "programmes" - by condition (eg stroke), care group (eg children) or specialty (eg orthopaedics). A programme approach based on a condition or care group is likely to incorporate such approaches as "integrated care pathways"[14] and "disease management"[15] (although "managed care" has a number of different meanings.[16])

"Evidence-based commissioning" is a recent term that can have two meanings. The first focuses on the providers and is about *what* is commissioned.[17] [18] This is dependent upon the evidence base (for example in stroke, summaries of evidence are available from the Cochrane Library,[19] the Department of Health,[20] the Stroke Association,[21] and others), and the ability of commissioners to create,[22] access[23] and interpret[24] [25] that information. The second focuses on the commissioners and is about *how* commissioning is done. This is dependent upon structures and processes of commissioning and is the subject of this review.

1.1.1 Research

The methodology of research into commissioning is still being developed.[26] [27] Like most health services research it requires a multidisciplinary approach. De Wildt and colleagues have described some of the difficulties of this type of research, which include a lack of clarity about the meaning and goals of commissioning, the speed of change of reforms, and problems of access to information.[28] There is also a danger that valuable research is discarded with each reform, when findings may still be instructive.[29] [30]

"commissioning" in this report. I have used the term "commissioning" except in referring to other work where the terms "purchasing" and "planning" have been kept.

Below, I compare the locality and programme approaches and appraise the published research in these areas.

1.2 Locality commissioning

1.2.1 Theory

Locality commissioning is a geographical or general practice-based division of the health authority's work. The potential advantages include: responsiveness to local needs and demands, a clear primary care lead, and a focus to involve patients and the public. Potential disadvantages include: higher transaction costs than commissioning for a larger population, lack of a broad population perspective, and fragmentation of (secondary and tertiary care) services.

Primary Care Groups (PCGs) have been defined with populations of around 100,000.[8] But as they become Primary Care Trusts (PCTs) many long-standing questions remain. Is this the optimum size of population for commissioning all services, or should this vary with different conditions?[31] How are resources allocated fairly to each locality?[3 32] What is the role of health and local authorities?[33] How should patients be involved?[11 34]

1.2.2 Practice

The Dawson report in 1920 suggested that British health facilities should have a tiered administration system based on health centres.[35] While this was not implemented at the time, the NHS has (perhaps inevitably) always had a hierarchy of tiers of administration of varying shapes and sizes, for example, regions, areas, districts, and localities. The lowest tier at any one time is, arguably, where locality commissioning takes place. The decision on the size, responsibilities, and boundaries of these tiers seems always to have been based on political pragmatism rather than epidemiology.

In fact, there is little research on which to base these decisions. Kerr White described the "ecology" of medical care in similar terms to Dawson.[36] Later he and others compared the patterns of health systems in 12 areas in 7 countries and came to conclusions about appropriate population sizes for provision of care (2,000-30,000 for primary care, 200,000-500,000 for secondary care and 0.5-1.0 million for tertiary care).[37] McLachlan's study of planning in eight European health systems found broadly similar patterns but suggested that primary health care was organised on populations of 10,000 to 50,000 people.[2] However these studies relate to catchment populations for the provision and delivery of care rather than its planning or commissioning.

There are many reviews of locality commissioning.[7 38 39] However, the focus of most seems to be GP fundholding, and only Balogh's review[39] gives a broader, historical perspective. GP fundholding has been the most prominent example, but subsequent developments have seen a range of locality commissioning organisations (Figure 1). A wide range of sizes and structures is possible for locality commissioning groups,[40] seen for example in the total purchasing pilots.[41]

The 1997 changes to the NHS outlined in *The New NHS*,[8] led to larger, more uniform organisations with 481 PCGs each covering a population of approximately 100,000 people (range 46,000 - 257,000[42]). It looks as though the move from PCGs to PCTs, with added responsibilities for provision as well as commissioning of care will need a larger population. In some cases these PCTs will have similar populations to health authorities in 1991. There is no specific guidance in the 2000 reforms in *The NHS Plan*.[43]

Figure 1 Typology of locality focused commissioning in the NHS (adapted from references [7,41])

- *Health Authority Models*
  - Geographically Based
    - Conventional (centralised)
    - GP consultation schemes
    - Formal GP involvement with the health authority
    - Locality commissioning
  - GP Practice-based
    - GP commissioning
- *Fundholding models*
    - Fundholding multifunds
    - Fundholding consortia
    - Standard fundholding
    - Community fundholding
- *"Hybrids"*
    - GP total purchasing pilots
    - Extended fundholding pilots

1.2.3 Research

Most research into locality commissioning has addressed GP fundholding and its successors. There have been detailed descriptions of processes.[7,41] However, the more rigorous research (comparing fundholders and non-fundholders) has concentrated on the behaviour of GP fundholders as *providers*,[44] such as changes to patterns of prescribing[45,46] and referring[47] rather than as *commissioners* (although referral patterns may represent a mixture of both.[48]) This probably reflects the availability of data, rather than the pursuit of the key research questions. Fundholders appeared to restrain prescribing costs better than non-fundholders (although this was not always sustained), whilst patterns of referral were similar. There are some descriptions of improvements to the responsiveness of secondary care providers (for example to waiting times and outreach services) at the expense of equity.[49] Evaluation of Total Purchasing Pilots has also found greater change in primary than secondary care.[29]

The additional management costs for GP fundholders were about 4-5% of their budget with further administrative costs to the trusts.[50] Total Purchasing Pilots Results had transaction costs of about £115,000 per site which was about £2.83 per capita (range £1.42 to £4.18).[51] This is not easily comparable although in the TPP study, GP fundholder costs were in excess of £4.00 per capita.[51] Comparisons with other methods of commissioning are also difficult because of the different ways of expressing cost (absolute, per capita, proportion of budget, etc.) and will be discussed further under Transaction Costs pages 80, 233 and 315 on page. Evaluation of PCGs and PCTs is underway.[52]

1.3 Programme commissioning

1.3.1 Theory

In programme-focused commissioning the cake is sliced differently: by condition, care group or, less commonly, by specialty. A potential advantage is the involvement of commissioners, providers and clinical professionals (from primary and secondary care) leading to better co-ordination of services and a more explicit and shared acknowledgement of cost restraints.[53] Condition-specific programmes are a logical approach to the use of evidence of clinical effectiveness and facilitate the development of clinical outcomes with the integration of clinical audit into commissioning. Potential disadvantages include: high transaction costs, unintentionally emphasising one condition over another with patients outside the programme being disadvantaged, and domination by secondary care. Furthermore, different organisations may work with different types of programme (eg Health Authority by disease, Local Authority by disability) inhibiting partnership working. Whether programmes are best defined by condition, care group or (less likely) specialty is unresolved.

1.3.2 Practice

The use of programmes has a long history. The district (health care) planning teams in the NHS in the 1970s represent an early programme focus based upon consensus management. "[They] were set up to plan either for a specific client group eg the elderly or children, or for specific services, eg maternity services ..."[54] They contained clinical professionals, administrators, community physicians, local authority representatives (mostly social services), and others such as the community health council, with variable success in developing and improving health services.

More recently the Calman-Hine report[55] on cancer services describes another programme approach. *The New NHS* suggests that "... service agreements will generally be organised around a particular care group (such as children) or disease area (such as heart disease) ...".[8] *The New NHS* also prepared for the development of Health Improvement Programmes (HImPs), which are described in more detail in this study, and "evidence-based National Service Frameworks (NSFs) to set out what patients can expect from the health service in major care areas or disease groups."[56]

At the time of writing three NSFs had been published: for Mental Health, Coronary Heart Disease and older people. In many districts these have led to multiagency local implementation teams with a remit similar to the Health Care Programme Approach described by the Academy of Medical Royal Colleges.[57]

The Health Care Programme Approach (HCPA) is a clinically led programme approach to commissioning usually based around a specific disease. The HCPA is the model used for this project and so will be described in more detail in the next chapter.

The financial aspect of any plan or strategy is its budget. Interestingly, the use of programme budgeting and marginal analysis (PBMA), led by health economists,[58] seems to have been more common than (clinical) health care programmes. The aim is to achieve maximum health gain from the (fixed) overall budget, by explicitly assessing the benefits and costs of changes from the current position (marginal analysis). PBMA aims to focus resources where there is the largest potential health gain, whereas the HCPA may have a "burden of illness approach" focusing resources where there is most need.[59] [60]

There are two approaches to programme budgeting: the "macro" approach initially divides the whole budget into programmes.[61] The "micro" approach assumes that the programme has the right budget and changes within programmes are tackled first. There have been a number of descriptions of the application of these methods.[62] [63]

1.3.3 Research

Most research on programme approaches has been in the form of pilot and demonstration projects. It is unclear if programme approach leads to improved decision making, better services, and better patient outcomes. There is also a need to quantify transaction costs and the knock-on effects on other programmes. Furthermore, there has been no comparison of condition-specific or care group-specific approaches. Condition-specific programmes seem better demarcated and more relevant to searching for evidence of effectiveness and efficiency. Care group-specific programmes may be better for facilitating working between different agencies.

1.4 Compatibility of localities and programmes

The different methods of commissioning described are not, in theory, incompatible.[8 64] A programme approach could be "primary care led." A locality group could have programmes of work, or engage with a wider programme strategy.[65] However, both cannot hold budgets and the transaction costs may be higher if both approaches exist. Some choice will have to be made. Although *The New NHS*[8] re-emphasises locality commissioning through PCGs, it also gives impetus to NSFs which are programme-based. Programmes are likely to be the better framework for collaborative planning and development of evidence-based practice. However, they will require locality intelligence to be most effective.

1.4.1 Power and influence

The different approaches could also be seen as representing a struggle for influence on health strategy. Both locality and programme commissioning may focus on clinical issues,[66] giving more influence to professionals than managers, compared to the current broad contracts between commissioners and providers. In contrast, choosing between localities or programmes may shift power between different professional groups. In the NHS, expert power[67] is important. Locality-focused commissioning is likely to favour GPs who have a greater knowledge about the practice populations. Programme-focused commissioning may shift more power to the specialists who have a greater knowledge about specific conditions and treatments. This could be balanced by those with a public health perspective "holding the ring" between competing interests.

The difference between localities and programmes at a commissioner level mirrors a tension at provider level between generalists and specialists. There are good examples of improved patient outcomes with increased professional specialisation, such as stroke units[68 69] or vascular surgical units.[70] However, it is more difficult to address whether the associated shift of resources will disadvantage patients elsewhere in the service.

There is also an echo of the debates between "vertically integrated" services (managing conditions through a centrally organised programme, such as a malaria control programme) and "horizontally integrated" services (having services to meet all needs organised together, such as a village health worker) seen particularly in developing countries.[71-73] This may represent an extreme, ideological form of the debate. However, it is important to be aware that a programme approach could appear to succeed on its own terms without improving the health of the population. For example, a stroke programme could reduce mortality and morbidity from stroke, but if the resources used came from reducing care to other groups, there may not be an overall benefit to the population.

There is increasing emphasis on the influence of patient and consumer views on commissioning.[11] The locality focus has shown itself able to bring in consumer perspectives,[34] although in theory the programme approach might engage specific patient groups, such as the Stroke Association, who have important perspectives to contribute to particular programmes.

1.4.2 Research

Governments are usually reluctant to encourage research on structural change. But research is needed to describe the processes of different models, their effectiveness and cost-effectiveness, to measure change, and to evaluate the role of the intervention in this. Initial studies on the commissioning process are by necessity descriptive, usually case-studies or uncontrolled before-and-after studies (see pages 47 to 52 for further discussion of methods).

It is important that new models of commissioning are clearly described and do not become "black box" interventions, partly to allow others to apply them, but also so that hypotheses about the effective components of the complex interventions can be developed and tested. This can be illustrated by the studies that demonstrated the effectiveness of stroke units,[70] where key aspects of the intervention are only now becoming clear. Combining both qualitative and quantitative methods is particularly valuable for this.[74]

Nevertheless, describing the process is of limited value without measurement of resulting change. One major difficulty is that the ultimate aim - improved patient outcomes, including prevention of disease - is at the end of a cascade of change.

These effects may be both long-term and confounded by many other coincident changes, particularly in the rapidly shifting field of service development.

Very few direct comparisons of different methods of commissioning have been attempted. These are unlikely to provide such a clear cut indication of "best practice", as can be achieved with clinical research. But they will be valuable in informing the subsequent implementation of commissioning models, including the choice of models best suited to local circumstances.

A critical element of any comparison of different models will be the quantification of transaction costs - costs associated with the process of commissioning which therefore cannot be used for direct patient care.[75] These include the costs of contract negotiation and monitoring, development of service specifications, and provision of necessary information and IT support. This needs to be a focus of future research since these costs may outweigh any benefit obtained, although evaluation will itself be an additional cost.

1.4.3 Summary points

- The NHS has always used a mixture of locality and programme commissioning to plan and develop services. The balance between the two has varied but locality methods have been more prominent until recently.
- *The New NHS*[8] emphasises both locality commissioning with Primary Care Groups and Trusts (PCGs and PCTs) and the strategic framework of health improvement programmes (HImPs) and National Service Frameworks (NSFs).
- It is suggested that these strategic frameworks must drive locality commissioning if this model is to be effective.[76]
- Programmes provide a framework for partnership between sectors potentially leading to more integrated care.
- Programmes may also lead to better uptake of effective and cost-effective interventions, thus to better quality services. Additionally, a programme approach should support the broader public health perspective including disease prevention and health promotion.

- There will always be a political dimension to planning health services to balance with evidence of effectiveness and cost-effectiveness. However, there is clearly a need for research in this area to help practitioners to improve services.

2 The Health Care Programme Approach

2.1 Background

2.1.1 Development

The creation of the NHS internal market in 1991 led to concerns that contracting was entirely financially driven and did not incorporate clinical issues. The Academy of Medical Royal Colleges Purchasing Development Project was set up in 1993 to develop methods to improve the contracting process and came up with the health care programme approach (HCPA).[53 57] The pilot project using an ischaemic heart disease (IHD) programme was based in Oxfordshire and Gloucestershire.[77] The details can be found in the reports, but the objectives, key features and potential benefits are summarised below.[57]

(a) Objectives

The Academy of Medical Royal Colleges Purchasing Development Project was seeking to develop a method to: make appropriate judgements about the balance within and between prevention, treatment and rehabilitation; base contracts on local burdens of disease; use information on the effectiveness of interventions; involve the clinical professions.

In discussions about the application of the HCPA to stroke it was further stated that the method should be flexible enough to continue through any reorganisation of services or management – in the words of one team member it should be

'Reform-Proof.'

Furthermore, the method needed to be robust such that in any district where organisations were using the HCPA its continuation was not dependent on one individual (and could not be derailed by one individual). In other words, it should be

'Individual-Proof.'

(b) The key features

The key features of HCPA are:

- The programme for the condition encompasses all levels of prevention, treatment and care;
- A group to develop the programme is created from all the key local players including commissioners and providers;
- A "technical document" is drawn up summarising the evidence base, and local epidemiology and services;
- A comprehensive service specification is developed from which contracts with a range of providers can be arranged.

(c) Potential benefits

The HCPA was piloted for patients with IHD in Oxfordshire and Gloucestershire. There was no research evaluation but the implementers of the project felt that this type of approach: has the potential to improve health; provides a balanced programme of care spanning primary prevention to rehabilitation and provide co-ordination between different organisations; focuses on health rather than simply on health care services; actively involves the clinical professions; relates more clearly to identified need than previously; aids the development and use of clinical outcomes; uses evidence of effectiveness; integrates clinical audit into the commissioning process.

2.1.2 Underpinning theories

The Academy's original project was a common sense and empirical approach not based upon any articulated theories (JMO'B, personal communication). However, the concept reflects a number of theoretical discussions that were contemporary with the work. The development of the HCPA for this study is described in section 2.2.2 on page 27.

(a) Network management

Ferlie describes three possible structures to be found in most organisations: **hierarchies, markets and networks.**[78] The predominant mode in the NHS has been hierarchical organisation. In the 1980s the emphasis in the NHS was on the strengthening of the general management function thus enhancing the hierarchical structure. By the early 1990s there was a shift to a market model: it was this that led to the development HCPA. By the late 1990s the policy had shifted again with a number of initiatives that fit the network management model. Examples include: *Health of the Nation*[79] and *Our Healthier Nation*,[80] the expansion of *GP Fundholding*, *Total Purchasing Pilots* and subsequently *PCGs* in partnership with health authorities, interagency initiatives such as *City Challenge* and *Health Action Zones*.[81] Network organisations emphasise the importance of patterns of social relationships within organisational relationships and informal ties rather than formal structure and policy. Concepts of trust, reciprocity and reputation are seen as more important than market processes.

Ferlie and Pettigrew[78] describe the drivers towards networks as: the need for flexibility and learning; reducing market uncertainty; managing joint production; a high-tech base; and managing cultural diversity. These factors are all at work in the NHS at present, so there is likely to be a move in this direction.

(b) Change management

The promotion and management of change in health services has been a topic of major consideration in the past few years, particularly with the rise of 'evidence-based medicine'.[82] Three characteristics of innovation which influence their adoption are: *Relative advantage* — though the advantages and disadvantages of innovations may be perceived differently by professionals and patients; *Compatibility* — with current philosophies, beliefs or practices; *Complexity* — more complex changes involving many groups of people are more difficult to achieve, although they may also be more likely to be maintained because so many have had to be involved. Two further characteristics *Observability* (can you see the innovation in operation?) and *Trialability* (can you try it out on a limited basis?) can be useful although they are not essential and can occasionally be counter-productive.

A different way of looking at change is to look at the characteristics of the individuals who need to change. Five categories have been defined (mainly on the basis of research in farmers) in order of the likelihood and speed at which new ideas are adopted:

- *Innovators* — 'venturesome'
- *Early adopters* — 'respected'

- *Early majority* — 'deliberate'
- *Late majority* — 'sceptical'
- *Laggards* — 'traditional'

These concepts are useful in analysing the situation before making changes and selecting appropriate strategies for change such as: *Providing information* — about the results of research and feedback on individual practice; *Education* — vocational and continuing; *Peer review* and audit methods; *Person to person contact* — by respected peers or opinion leaders, patients, drug representatives; and *Financial incentives.*

These perspectives have all been used in developing the HCPA.

(c) Ethical Priority Setting

Prioritisation and rationing have been much discussed at a national level over the last decade.[83] There has been a move away from the view that there is a technical solution to rationing by marshalling all the available evidence and calculating the best solution.[84] There is recognition that this is "inescapably a political process"[85] and a developing interest in defining that process. There has been much less discussion about how prioritisation is done at a local level, but a view that there should be more central guidance and reduced scope for local differences.[83]

However, there will always be a need for local prioritisation as national priorities can only be broad.[80] National decisions can only be made on a relatively small number of specific treatments,[86] usually expensive ones, and so may have relatively little impact on the totality of care locally. They need to be operationalised locally. Studies of local priority setting have been limited and have, as in the national situation, focused more on evidence-based solutions[87] or on the mechanism for gaining public input[88] rather than on the whole process leading to decisions. They have also focused on ways to deal with new problems rather than on prioritising within the current service.[89]

There are a number of tensions to acknowledge at both national and local levels. Firstly, those between the evidence base and the views of stakeholders: health and other professionals, the public and patients, managers and administrators.

Secondly, the appropriate involvement of professionals: many view the input of professionals as important,[84] but others believe that there is an ethical incompatibility between fidelity (caring for patients) and stewardship (optimising the use of resources).[90]

Thirdly, the appropriate involvement of users (patients and carers) and the public: whilst most agree that this is important,[11] there are concerns that the framing of questions, and the amount of information and time given, can substantially alter the views expressed.[91]

2.1.3 Distinction from other concepts

It is important to be clear what the HCPA is and what it is not. I describe below some related terms and suggest how they differ from the HCPA. Two aspects of UK context are important in making the distinctions, particularly between 'managed care' and 'health programmes'. In the UK there are organisations whose purpose is to commission services for a defined geographic population (such as health authorities) and within the totality of services there are many agencies involved in delivering care (NHS, local authorities, voluntary and private sector organisations). In the USA, for example, there is no comprehensive system; so targeted 'programmes' have been developed in many areas to provide services, usually for a disadvantaged group.

(a) Social and Health Programmes

Most European countries have comprehensive health systems that try to make health care available for everyone so discussions of programmes are mainly written from a North American perspective. There are a wide range of health, social and educational programmes usually targeted at more deprived sections of society (such as those who are uninsured or underinsured) or specific problems (such as drugs). There is extensive US literature on Programme Evaluation dating back to the 1960s.[92-94] Programme in this context implies the provision (rather than commissioning) of services and a more focused area of work (rather than breadth of approach).

(b) Managed Care

There is no agreed definition of Managed Care.[16 95] Its origins are in the US which has a fragmented health care system with high costs:

> *"Managed care ... seeks to control costs by the efficient management of health care resources. Some of the ways it does this are utilization review ("second opinion" panels), the use of primary-care ("gatekeeper") physicians to limit access to higher-paid specialists, financial incentives that reward doctors for holding down costs, and in general offering patients fewer services than they would get in a fee-for-service setting."*[96]

However, a European definition:

> *"a process to maximise the health gain of a community within limited resources by ensuring an appropriate range and level of services are provided and by monitoring on a case by case basis to ensure continuous improvement to meet national targets for health and individual health needs"*[95]

is much closer to the ideas of the HCPA but still focuses on disease management (see below) of individual cases.

(c) Disease management

Disease management is an approach to patient care that co-ordinates medical resources for patients across the entire health system.[97] Although it has similarities to HCPA its origins are very different, mostly driven by the need to cut costs in North America. It requires a knowledge base, co-ordinated care and quality improvement measures.[98] It is also focused on the individual rather than the population and may tend to focus on treatment, ignoring the 'ends' of the programme — health promotion and long-term support.

(d) Integrated Care Pathways

> *"Integrated care pathways (ICPs) are structured multidisciplinary care plans which detail essential steps in the care of patients with a specific clinical problem."*[14]

Like guidelines and protocols, ICPs may be a way of implementing some aspects of the HCPA, particularly around secondary care.

(e) Healthcare Resource Groups

> *'HRGs, Healthcare Resource Groups, are a UK-specific method of aggregating healthcare information. Aggregation is a means by which similar groups of individuals or subjects are "lumped" together. This enables like-for-like comparisons to be made. HRGs were developed during the late 1980s by the National Casemix Office (NCMO) in Winchester. They are loosely based on Diagnostic Related Groups (DRGs) - an American method of aggregating healthcare which is used as a means of reimbursing hospitals for care provided. However, it was soon discovered that original DRGs were not applicable in the UK because of different coding norms and clinical practices'.*[99]

DRGs, Diagnosis-Related Groups, are a US system used by Medicare (publicly funded health care for older people) as a method of prospective payment (determining in advance what the payment will be for medical services). It was developed originally by the Yale School of Organization and Management and became law for hospitals in the state of New Jersey before Congress made it nation-wide for Medicare.

HRGs may be used as a tool in understanding and developing the budget for the HCPA.

(f) The Care Programme Approach

This (unfortunately very similar) term from the UK mental health services describes a clinical process. The Care Programme Approach[100] (CPA) was introduced in 1991 to provide a framework for effective mental health care.[101] Its four main elements are:

- systematic arrangements for assessing the health and social needs of people accepted into specialist mental health services;
- the formation of a care plan which identifies the health and social care required from a variety of providers;
- the appointment of a key worker to keep in close touch with the service user and to monitor and co-ordinate care; and
- regular review and, where necessary, agreed changes to the care plan.

In recent years there has been a process of integrating this with Care Management — a tool used by Social Service Departments.

(g) Whole Systems Approach

The Systems or Whole Systems Approach (WSA) is an increasingly used method of tackling 'intractable' problems that involve many individuals and organisations.[102] [103] It uses the analogy of organisations as living organisms, rather than mechanical structures, with complex informal relationships. Characteristic features include: *Meaning*: the system has a common shared purpose; *A system that knows itself* and acts to conserve its identity; *Many perspectives* which are all valuable: and the lay perspective is a critical part; *Participation* by all groups is essential; *Trusting local resourcefulness* rather than a top down approach; *Web* of connections and communication; *Passion*: requires and releases energy; *Here and Now*: the approach makes particular use of Whole System Events to develop sustainable solutions.

There are a number of similarities with HCPA, including: an acknowledgement of the existence of a system where changes in one area potentially have consequences in other parts of the system; a realisation of the need to involve everyone to develop sustainable solutions; the inclusion of everyone in discussions about any aspect of the system; a focus on a client group with a shared aim of improving the care of that group.

Differences include: the predominance of professionals in HCPA; the more formal group structure in the HCPA; the lack of Whole System Events as a mechanism for working.

2.2 The HCPA in this study

2.2.1 Choice of condition and district

This research project was developed to help fill some of the gaps in knowledge evident for the Academy of Medical Royal Colleges Project.[57] When the project began in 1996 most purchasing research was on GP Fundholding with the early research into Total Purchasing Pilots underway. There had been little investigation of health authority commissioning or the use of programmes.

At this time the group who had developed the HCPA in Oxfordshire and Gloucestershire using IHD wished to develop the work into other geographical areas and other use conditions and to evaluate the concept more formally. This led to two members of the original HCPA co-ordinating team (JMO'B, JH) jointly developing the project with the Newcastle University purchasing research group (RT, DC) and others with expertise in stroke (HR), economics (DP) and sociology (RS).

Stroke was chosen as a condition for a number of reasons. Stroke accounts for 10-12% of deaths in the UK,[80] and is a major cause of impairment and disability. Morbidity and mortality from stroke are particularly high in the North East of England although that gap is narrowing in Tyneside.[104] About 4-5% of the health budget is spent on stroke and in addition there are other significant costs, such as to social services and to the patients and carers themselves. Strokes are a major cause of impairment, disability, and handicap especially in the elderly.[21]

There is potential for significant health gain from the application of a growing evidence base.[19] There is a wealth of evidence on effective primary prevention, principally in the detection and treatment of hypertension, the single most important risk factor for stroke,[105] and for patients with non-valvular atrial fibrillation, where treatment with anticoagulants has been shown to be effective in reducing the risk of stroke by 68%.[106] Other modifiable risk factors include smoking, diet and physical inactivity. The actuarial risk of recurrent stroke after a first stroke is about 30% over five years, [107] again there is strong research evidence of the benefits of antiplatelet therapy in secondary prevention.[108]

The pattern of care differs from IHD with considerable need for long-term support but very little need for tertiary care such as revascularisation procedures. This means that the local authority (especially social services) and independent sector (such as charities like the Stroke Association and private providers such as nursing homes) have a very large role.

The location of the research team and the importance of stroke in the North East led to a decision to use a district in Northern and Yorkshire Region.

Gateshead and South Tyneside Health Authority had a track record in evidence-based purchasing. It was a pilot district for a King's Fund Promoting Action on Clinical Effectiveness (PACE) project for angina, and had its own clinical effectiveness resource centre with an information specialist. The national project manager for the Academy of Medical Royal Colleges project (JH) was employed locally as a consultant in public health medicine and was involved with the King's Fund PACE[109] angina project in South Tyneside. Additionally, I could be placed as an Honorary Senior Registrar in Public Health Medicine at the health authority for the duration of the project.

These factors led to the decision to apply and evaluate the HCPA for stroke in Gateshead and South Tyneside.

(a) Changes from the Oxfordshire & Gloucestershire pilots

The details of implementation of an approach like HCPA need to adapt to local circumstances. However there were a number of small changes to the method that were decided beforehand on the basis of experience in Oxfordshire and Gloucestershire

The condition was stroke rather than IHD for the reasons described above. This led to early involvement of local authorities (social services) in setting up the project and substantial input subsequently from the voluntary sector. There was no direct involvement from tertiary care (neurosurgery);

The technical document was written within the district group rather than externally to ensure local ownership. This was because of experience within Oxfordshire where there was suspicion of an external review. Peer review was therefore by local professionals. This also led to a slightly different organisation of evidence and subsequent work into: Prevention, Treatment, Rehabilitation and Long Term Support rather than primary, secondary and tertiary prevention;[110]

There was less of a focus on contracts as levers for making change to practice were expected to be broader, such as guidelines and audit. This occurred, partly as a result a shift in NHS mechanisms and partly because of the multiagency approach being used.

Further modifications as a result of local experience and national reforms are described in the evaluation.

2.2.2 Study definitions

As the application of the HCPA in this case was going to be a part of a research study it was necessary to have a clear, tight definition of the intervention so that subsequent changes could be properly identified.

The health care programme approach is

> *a complex process of collaborative development of a "technical document" and subsequent identification of priorities with a view to creating change in the development and balance of services for stroke in order to improve the health and healthcare of the population of Gateshead and South Tyneside Health Authority.*

The intervention can be considered as consisting of an initial major intervention, and an on-going intervention, as defined below.

(a) Structures

The key structural elements of the intervention are the:

- creation of a district stroke group;
- appointment of a co-ordinator;
- development of a technical document;
- agreement of initial priorities.

Evaluation of the impact incorporates a description of the above activities and of their subsequent effects in terms of activity relevant to change in the health and healthcare of the population of Gateshead and South Tyneside.

(b) Initial major intervention

The time scale of the intervention is from the creation of the District Stroke Group (December 1996) to completion of agreement on the first stage of priorities (April 1998).

(c) Continuation

There will be an on-going intervention in the form of the District Stroke Group and the co-ordinator, and implementation of work related to specific priorities identified in the first stage.

(d) Evaluation

The time scale of the overall evaluation therefore required a baseline assessment prior to the initial priority setting (April 1998). Funded evaluation of the impact continued until June 2000. Specific components of the evaluation of the continuation phase (eg work on the identified priority of hypertension) will have their own baselines and time scales within the overall evaluation.

(e) Transaction costs

The transaction costs have two components. The initiation costs (the structural components described above) and maintenance costs which would be required to keep the process going year on year (stroke group and co-ordinator).

(f) Stroke group

The District Stroke Group (DSG) was formed in December 1996 following two 'set-up' meetings with senior officers of organisations involved. The next section provides the detail of this process and membership lists can be found in the Appendices. The group was funded by the research study and evaluated until March 2000. It continues to exist, as a health authority Health Improvement Group responsible for strategy, resource allocation and the HImP. However it has recently become a subgroup of the Elderly Strategy Group in anticipation of the National Service Framework.

(g) Co-ordinator

The co-ordinator was appointed for two years funded by the research study and evaluated from February 1998 until March 2000. The first co-ordinator, Barbara Scott, was in post February 1998 to April 1998 and the second, Ruth Richardson was in post May 1998 to March 2000. Both were appointed as an 'I' Grade nurse, seconded from South Tyneside Health Care Trust. The co-ordinator worked about 22.5 hours a week in the first year reducing to about 15 hours per week by the end of the project. A copy of the job description is in the appendix.

(h) Technical document

The Technical Document was eventually a 70-page document describing local epidemiology and services, and summarising the evidence-base for stroke.[111] This was to ensure not only that evidence was used, but also that the stakeholders agreed on it.

The District Stroke Group defined four broad areas:

Prevention: This includes primary prevention (that is, interventions to prevent stroke) and secondary prevention (interventions to prevent further strokes following a first stroke or transient ischaemic attack) since many of the activities are similar in both areas.

Treatment: This includes the diagnosis and initial treatment for patients with stroke in the acute stage, including acute nursing care and the prevention of complications.

Rehabilitation: This includes early and long-term rehabilitation (and its organisation), particularly therapies such as physiotherapy, occupational therapy and speech therapy.

Long Term Support: This includes the work of carers, the voluntary sector (for example support groups) and the private sector (for example accommodation), as well as the work of the statutory sector (local authority and NHS).

A description of the development process can be found appended to this thesis.[111]

(i) Priority setting process

There were six stages of priority setting that are summarised in Table 1. Members of the DSG were asked to prioritise the large number of recommendations from the evidence review using a questionnaire that listed potential recommendations (Table 2).

The local stroke co-ordinator conducted structured interviews with stakeholders outside the DSG to validate the provisional priorities, help order the secondary priorities, and seek important areas not previously identified. The data from the postal survey and interviews were discussed at DSG meetings held in early 1998. The priority areas were agreed and the group started to develop them into clear action plans. Two user and carer consultation days were undertaken to get public input into the priorities.

Table 1 Priority setting process

Action	Date	Method
1 Formation of District Stroke Group (DSG)	Dec 96	A stroke group was formed, initially consisting of professionals from primary and secondary care together with health authority and social services staff. It has subsequently grown to encompass the voluntary sector, although membership does not include users or carers or the private sector (eg nursing homes).
2 Review of Evidence	Feb – July 1997	One member of the DSG reviewed and summarised the evidence base around stroke, the local epidemiology, and current services. Each draft was discussed and debated in the DSG and finally summarised in a "Technical Document". This listed forty-three potential recommendations, linked to the evidence in the technical document, in four areas: prevention, acute treatment, rehabilitation and long-term support.
3 Postal Survey of DSG members	Dec 1997	Members of the DSG were sent a questionnaire which listed the forty-three recommendations in the technical document. They were asked to score (1-5) the importance of each recommendation. An extract of the questionnaire is shown in Table 2. They were also asked to select the three areas most important for their particular sectors. As not all respondents gave a score for every recommendation, the average score for each recommendation was used, expressed as a percentage. Some related recommendations were combined. Four areas scored over 90% and became provisional priorities: hypertension in primary care, multidisciplinary teams in secondary care, long term care and support, and information and audit. A number of secondary priorities were listed scoring 70-80%. (Table 44)
4 Survey of other key professionals and managers	Feb – Mar 1998	A co-ordinator took up post in February 1998. She conducted structured interviews with twenty-nine people including patient representatives (two Community Health Councils and two voluntary groups), managers and professionals, again not directly with patients or carers.
5 Consensus within DSG	March 1998	The data from the postal survey and interviews were discussed at DSG meetings. The priority areas were validated and the group started to develop them into clear action plans.
6 Consultation with local users and carers	Nov 1998	Two user and carer consultation days were undertaken in November 1998. This was after the initial priorities had been set, because the time scale for the Health Improvement Programme was too short to organise them before. Invitations to patients and carers were sent to all people with a known stroke in contact with services and to all local stroke groups, and posters were put up in local libraries, and hospital wards. At each event the users were put into groups of about eight. Facilitators and note-takers were used to find out about the issues that concerned people.

Table 2 Extract from questionnaire with examples of recommendations

Recommendation	*Importance*	*Urgency*	*Year*	*Lead Sector*	*Group*	*Comments*
(number and page reference)*	*1–5*	*1–5*	*1,2,3†*	*see notes‡*	*see notes‡*	
1The quality of routine information (contract minimum data set) needs to be better if it is to be used to monitor the stroke programme. Although some improvement is already occurring, the stroke group should work with providers to improve the quality. P13						
2 More use should be made of existing data to highlight deficiencies and encourage improvements. The stroke group should work with purchasers to improve the dissemination of information. P13						
3 The information obtained from ad hoc audits should be made available to add detail to, and to help validate, routine information provided by the minimum data set. It may also be appropriate to try to make such audits compatible between providers. P15						
...						
6 Local guidelines for the diagnosis and treatment of hypertension in primary care are needed. There are many available eg British Hypertension Society, New Zealand guidelines so local consensus as to which to use or adapt is required Case finding and treatment of hypertension is traditionally undertaken in general practice. Case finding has also been undertaken elsewhere eg in the work place. P24						
...						
25 Hospitals should have a designated multi–disciplinary stroke team and, if possible, a designated stroke ward. P37						
...						
42 There is a need for a broad review of long term support facilities and access for stroke patients, including addressing co–ordination of services. P48						
43 A local strategy is required to ensure that professionals, patients and carers have an appropriate level of understanding about stroke and its effects are aware of services available for patients and their carers. P49						
...						

* Pages refer to Technical Document

† Year refers to the Health Improvement Programme

‡ Notes gave suggestions for these columns

2.2.3 Development of the HCPA during this study

Despite a tight study definition (page 27) it is important to set out, how the implementation actually occurred. A chronology of the development of the programme approach to commissioning stroke services in Gateshead and South Tyneside is given in Table 3 on page 35.

The proposal for a programme approach to commissioning stroke services in Gateshead and South Tyneside was discussed at a meeting held in June 1996. Chairs and chief executives of the health authority, local trusts and social services, and the Local Medical Committee attended this meeting. Although reservations were expressed that this was not a current priority for the district, the group gave support for further exploration of the proposal. After a further meeting in September 1996 to discuss the way forward, the first meeting of the District Stroke Group (DSG) was held in December 1996. A number of people from across the district had been identified by the key organisations to become members of this group.

Clinicians from both Gateshead and South Tyneside acute trusts, social services representatives, a GP from South Tyneside, a public health doctor from the health authority and researchers attended the first meeting. There was no involvement in the early stages of the group from the voluntary or private sector, or from service users and their carers. In May 1998 a representative from the Stroke Association joined the group. This group was to meet regularly over the course of the development of the initiative (from December 1996 to March 1998) and its membership has experienced turbulence and change, including members leaving the group and district, new members being invited to join at various stages and non-attendance of some members.

The first six months of the programme (December 96 - Summer 1997) were described as a 'development' or 'preparation' phase and involved writing the 'technical document', writing bids for research and development funding and information sharing between members of the group. The technical document was to cover the local epidemiology of stroke, the local services currently provided and a description of best practice (the evidence base) and was to be used to inform priorities and derive service specifications. A grant from the Stroke Association funded this phase of the work.

Work in the next period (from Summer 1997 to early 1998) continued to focus on applications for Research and Development (R&D) funding, the technical document was completed and discussions were held about the role of a co-ordinator. In late 1997 and early 1998 two R&D applications were successfully funded, enabling the development and evaluation of the programme approach to be undertaken (this began in April 1998 to run for two years) and the appointment of a co-ordinator to take forward the implementation of the programme approach.

A co-ordinator took up post in February 1998 and for six weeks she consulted with a wide range of people in the district on the current picture of stroke services and their views on strengths, weaknesses and priorities. During this period, recommendations from the technical document were sent in a questionnaire to DSG members who were asked to select the three most important and most urgent recommendations to be tackled. They were also asked to select the three areas most important for their particular sectors. Nine of the twelve group members completed questionnaires. The data from this exercise were analysed and used as a discussion point within the DSG. Four priority areas were chosen: hypertension in primary care, multidisciplinary teams in secondary care, information and audit, and long-term care and support. A further priority area, secondary prevention, subsequently moved up the priority list and was taken forward by the group. The first co-ordinator left the post in April 1998 and a second co-ordinator took up post in June 1998. In May 1998, short, medium and long-term objectives of the programme approach were produced and circulated for discussion amongst the DSG members (see Objectives page 39).

Over the summer of 1998, the focus for the group moved to the production of a Health Improvement Programme (HImP) for stroke, taking forward implementation plans for the priority areas through working groups and reviews, and the organisation of two user and carer consultation days. Each priority area was taken forward either by setting up working groups, which involve both DSG members and others from outside the group, or through reviews of current information and services. For example, a joint sub-group of the DSG and the district Multidisciplinary Audit Group (MAG) was established to take forward the 'hypertension in primary care' priority area. The priority area 'long-term care and support' was taken forward by the co-ordinator who collected information on current practice to inform further discussion within the DSG on specific priorities in this area.

By the spring of 1998 the initiative had undergone a number of important internal changes, including the appointment of two co-ordinators, changes in the membership of the DSG and agreement on the priority areas to be taken forward. In addition, the group had to respond to changes in national NHS policy, including the publication of the *New NHS* White Paper and its associated policy innovations of Health Improvement Programmes (HImP) and Primary Care Groups (PCGs) and the move from competition and the internal market to co-operation. There had also been the awarding of Health Action Zone (HAZ) status to Tyne and Wear (which includes Gateshead and South Tyneside). Locally there were also changes in personnel at the health authority and trust level and the merger of the acute and community trusts in Gateshead to form one trust.

Much work was delegated to subgroups for the priority areas: hypertension, multidisciplinary teams, information and long-term care. This work was subsequently brought back to the DSG. In April 1999, the DSG held a 're-launch' for senior officers of the participating organisations – describing the work to date and its importance. This had the effect that the two Trusts sent more senior managers than previously although there was no change to primary care representation.

The group continued to meet during the implementation phase from April 1998 onwards until 2000. In autumn 2000 the university support withdrew (although the research element ended about the end of 1999 and a new public health physician from the health authority chaired the group. The group subsequently was made a subgroup of the District Elderly Services Steering Group in preparation for the publication for the NSF for Older People[112].

Table 3 Chronology of HCPA development in Gateshead and South Tyneside

Date	Key events for stroke programme approach	National and local events and policy changes
1996		
June	Meeting to discuss whether to pursue proposal to use programme approach to support evidence-based purchasing and provision of stroke services in Gateshead and South Tyneside	

December	First meeting of District Stroke Group	
1997		
Feb-July	Six month pilot phase funded by Stroke Association	
August	First draft of Technical Document circulated to and commented on by DSG members	
September	Second draft of Technical Document	Publication of NHS White Paper The New NHS - Modern, Dependable with new policies on Primary Care Groups, Health Improvement Programmes, etc.
November	Final version of Technical Document	
December	R&D funding application successful	
1998		
February	Further R&D funding application successful First co-ordinator begins post	Our Healthier Nation - a contract for health published - stroke included with CHD
March		Tyne and Wear (including Gateshead & South Tyneside) awarded Health Action Zone status
April	Completion of agreement of first stage of programme approach priorities First co-ordinator leaves post Evaluation study begins	Merger of two Gateshead trusts Re-organisation of Gateshead and South Tyneside trusts
May	Objectives of programme approach produced DSG invited by health authority to write a strategy on stroke for inclusion in the HImP	CSAG Report on clinical effectiveness using stroke care as an example published - Gateshead & South Tyneside one of the 13 districts studied
May - August	First round of qualitative evaluation interviews with DSG members	
June	Second co-ordinator begins post HImP appears on DSG agenda, highest attendance of members at DSG meetings, first draft of stroke HImP circulated to DSG	
July	First meeting of Hypertension priority area subgroup	A First Class Service: Quality in the new NHS - consultation document setting out national service frameworks and NICE, clinical governance, the Commission for Health Improvement, an NHS Performance Assessment Framework and a national survey of patient and user experience
August	Second draft of stroke HImP to DSG First meeting of 'Multidisciplinary Teams in Secondary Care' priority area	The new NHS modern and dependable: delivering the agenda published covering how PCGs will be formed, be governed, be accountable and operate financially Better Services for Vulnerable People - published outlining a joint investment plan framework, initially concentrating on older people
September	Stroke section of HImP sent to health authority for	Modernising Health and social services: National

	summarising	Priorities Guidance 1999/2002 - stroke not included as one of priorities, although partly covered under CHD Partnership in action (new opportunities for joint working between health and social services): a discussion document - removing barriers and introducing incentives for joint working, including pooled budgets, lead commissioning and integrated provision
October		Health Improvement Programmes: Planning for Better Health and Better Health Care - guidance for developing HImPs Commissioning in the new NHS published, setting out guidance for commissioning in 99/00 and including principles which should govern commissioning and introduction of longer service agreements
November	User/carer consultation days	
December	Proposal submitted to the health authority for funding of community stroke rehabilitation teams	The new NHS modern and dependable: developing primary care groups published, covering the role of health authorities, functions PCGs will perform, how PCGs will manage their responsibilities and the pathway to Primary Care trusts
1999		
January - March	Second phase of qualitative interviews with key local professionals and managers not directly involved in project	
February	Chair of DSG wrote to chairs of PCGs Review of group priorities and chapters of Technical Document	Results of Royal College of Physicians Sentinel Audit published (Gateshead and South Tyneside trusts had participated)
March	Analysis of Contract Minimum Data Set and Programme Budget on in-patient and day case activity tabled at DSG meeting for discussion Summary of main points and recommendations from long term care report produced by co-ordinator and tabled at DSG	A Fair Chance in Life: Tackling Health Inequalities in Tyne & Wear - action plan for HAZ - action on stroke not an explicit area
April	'Launch' meeting for senior managers and local decision makers	Three PCGs for district go live, MAG & PIG end Gateshead & South Tyneside Health Improvement Programme 1999/2000 - 2001-2002 published Stroke Care - a matter of chance: a national survey of stroke services published by Stroke Association, showing up to 50% of stroke patients

		are not getting best treatment, ie admission to a stroke unit
May - July	Third/final phase of qualitative interviews (with DSG members)	
June	Hypertension group suspended whilst discussions with PCGs and health authority take place Meeting between Chair and Project Manager of DSG and senior managers/directors from Gateshead trust to discuss linking with trust business and strategic planning	Quality and Performance in the NHS: Clinical Indicators - a clinical indicator for stroke included amongst six indicators
July	Multidisciplinary Forum discussed service specifications	Saving lives: Our Healthier Nation produced. Targets for stroke, along with CHD District HImP Implementation group met to discuss prioritising areas in the HImP
2000		
March	Research team withdraw. Group continues to be chaired by University until October.	
July		NHS Plan
2001		
March		NSF for older people

2.3 Objectives

The first stage of clarifying what the health care programme approach would be in Gateshead and South Tyneside was to set objectives. The District Stroke Group (DSG) supported by the research team did this. The results of the quantitative interviews (for example, pages 94 to 97) explain the different perspectives and agendas that lead to this list. The objectives were agreed early in the process and have not been amended but are used a criteria for success in what was and was not achieved later in the results (page 297).

Abbreviations used are 's' short-term objective, 'm' medium-term objective and the initials of the group or individual to lead that area.

(a) Objective 1

To develop a strategic approach to commissioning in order to support planned and appropriate developments

i to develop a short, medium and long-term strategy (with time-scales) based on priorities (see 2ii) (s; DSG)

ii to integrate strategy with other initiatives (e.g. Primary Care Group Commissioning, Health Improvement Programme, service specifications and service agreements) (s; DSG, DC)

(b) Objective 2

To obtain local ownership and involvement of clinical professions in order to foster a collaborative approach and better support implementation and change

i to gain support for the project from influential local groups and key individuals (Local and Health Authorities, Social Service Departments, Trusts, Primary Care Improvement Group [and its constituents; Commissioning Forum, Multidisciplinary Audit Group, Local Medical Committee], voluntary sector, the Stroke Association, service users and high risk groups (s; DSG, RR)

ii to conduct a priority-setting exercise with a wide range of professionals (s; BS, RR) iii to involve professional groups and key individuals in the commissioning process (s; DSG, Health Authority)

iv to promote intersectoral working (s; DSG, Health Authority)

v to ensure information from the DSG is actively and appropriately disseminated (s; DSG)

vi to effectively publicise the HCPA both locally and nationally (s, DSG, Health Authority)

(c) Objective 3

To commission services based on 'need' in order to better match effective services with local health needs

i to assess local need (ongoing; DSG, Health Authority)

ii to involve users and carers in the commissioning process (s; DSG, Health Authority)

(d) Objective 4

To use robust evidence of effectiveness in the commissioning process to support more effective service delivery and better patient outcomes

i to produce a core document summarising evidence of need, effective and cost-effective care (s; Technical Document)

ii to ensure wide dissemination and knowledge of above to all relevant professionals in primary, secondary and tertiary care (s; RR, DSG)

iii to incorporate evidence of effectiveness into service specifications (s; DC, DSG)

iv to periodically update research evidence (m; DC, LT, DSG)

v to share professionals' experiences of using evidence-based care (s; DSG)

vi. to identify areas where evidence is lacking or limited, where more research is needed and where local contribution might be made (m; DC, DSG, LT)

(e) Objective 5

To develop service specifications for the prevention, acute treatment, rehabilitation and long term care of stroke for residents of Gateshead and South Tyneside which reflect the core principles of the HCPA

i to develop service specifications and service agreements agreed between purchasers and providers on the basis of assessed needs, evidence, desired activity, quality and audit of services for stroke patients (s; DSG, DC)

ii to negotiate, implement and monitor quality improvement protocols (including costs, ways of assuring quality and monitoring methods such as audit) based on service specification (s;)

(f) Objective 6

To integrate the HCPA with clinical audit and measurement of health outcomes in order to enable ongoing evaluation and use of quality improvement indicators

i to agree 'targets' for best practice (to inform service specification) (s; DSG)

ii to agree clinical indicators (both global and specific to each priority area) (s; DSG)

iii to collect data and discuss these (including via audit) as part of a collaborative contract monitoring process (m; local audit departments, LT)

iv to review the quality and relevance of routinely collected data in measuring the effectiveness of care (m; DSG, LT)

v to improve routinely collected data to meet the needs of the HCPA (m; DSG, LT) [perhaps to enable linkage of cost and activity data]

vi to ensure that relevant information is more widely used for service evaluation and development (m; DSG)

(g) Objective 7

To achieve greater integration of services in order to ensure the most effective and efficient use of resources

i to co-ordinate service provision between different organisations and sectors (s; RR, DSG)

ii to use the HCPA Commissioning Matrix as a tool in mapping service provision for each priority area in order to support priority setting and identify the need for change/development (s; DSG)

(h) Objective 8

To achieve an appropriate balance of care and resources between primary, secondary and tertiary care in order to ensure that effective care is delivered in the appropriate setting

i to allocate resources appropriately between primary, secondary and tertiary care informed by the prioritisation exercise (see Priority setting process page 30) and information on local need from the Technical Document. (s; DSG)

ii to stimulate collaboration (s; DSG)

iii to consider and implement appropriate resource allocation (s; DSG)

(i) Objective 9

To achieve an appropriate balance of care and resources between health services, social services and the voluntary and private sectors in order to ensure that effective care is delivered in the appropriate setting

i to better co-ordinate services across the boundaries (s; DSG)

ii to stimulate collaboration (s; DSG)

iii to consider and implement appropriate resource allocation (s; DSG)

2.4 Summary points

- The Health Care Programme Approach (HCPA) was developed by the Academy of Medical Royal Colleges 1993-1995 to create a more health-oriented approach to contracting in the NHS internal market.
- HCPA was piloted in Oxfordshire and Gloucestershire using IHD as the condition programme
- We chose to implement and evaluate the approach in Gateshead and South Tyneside using Stroke as the condition programme.
- The key features of HCPA are:
    - the programme for the condition encompasses all levels of prevention, treatment and care;
    - a group to develop the programme is created from all the key local players including commissioners and providers;
    - a "technical document" is drawn up summarising the evidence base, and local epidemiology and services;
    - a comprehensive service specification is developed from which contracts with a range of providers can be arranged.
- HCPA is consistent with a number of theoretical developments (such as Network Management) although it does not have its own body of theory.

3 Methods

3.1 Introduction

This chapter starts with a methodological literature review and discussion to explain how the methods were chosen and developed. The details the methods for the six separate aspects of the study are then give separately:

- Quantitative indicators
- Qualitative description
- Programme budget
- Transaction costs
- Survey of practices
- Survey of other districts

3.1.1 Subjects and setting

- This study was conducted between 1996 and 2000.
- The study district, Gateshead and South Tyneside, is a deprived district in North East England. It has a population of 360,000 and is predominantly urban, with high levels of unemployment and deprivation - ONS area classification 'Ports and Industry.' There are high levels of risk factors for stroke,[113] although mortality from stroke is average (Standardised Mortality Ratio = 101).[104] At the time of the survey there were 62 practices, 187 general practitioners and three Primary Care Groups.
- The 'subjects' of the study vary with the aspect but include patients with stroke (aggregated data only), professionals dealing with people who have had stroke, those managing and planning the service, and the organisations involved.

3.2 Methodology

3.2.1 Complex interventions

The HCPA, like many organisational changes, is a **complex intervention.** This makes evaluation a complex problem. The first issue is a philosophical one.

Those with a realist viewpoint (that there is an independent knowable reality)[114] might take a reductionist position - that any intervention can be broken into component parts, which can be analysed separately. A preferred term might be **multifaceted intervention** - this is a number of simple, definable interventions combined. Their position would then be that it would be possible to know what works and what doesn't by using appropriate controls.

Those with an idealist viewpoint (that there are multiple, socially constructed realities)[114] would be concerned with describing the world as perceived by the researchers. The intervention could be perceived differently by different people and can never be shed of context. This also takes a more holistic perspective as the 'whole may be greater that the sum of the parts' and would not try to break down the process into simple interventions. The term **diffuse intervention** has been used to described changes that pervade a whole organisation.

There was a range of perspectives within the steering group and research team. It was clear from the outset that multiple methods would be required for the study and different philosophical stances would have to be accommodated.

A further term, **black box intervention,** implies that the relationship between inputs and outputs is known but that the workings of the mechanism is not.[115] I aimed to ensure that the HCPA was not a black box and to define its characteristics.

The evaluation of many simple interventions (like drugs) can result in a simple decision whether to accept or reject this new intervention as a better way of treating patients. For many complex interventions the end point is more often about improving the method of doing something you would be doing anyway. Two approaches that are becoming popular are **'realistic evaluation'** and **'theories of change'** particularly for evaluating complex community-based initiatives.[116]

> *"Instead of asking if an initiative works or not (or comparing to some other initiative), realistic evaluation tries to develop an understanding of why a programme works, for whom and in what circumstances."*[116]

Or more succinctly by Pencheon in discussing NHS Direct.

> *"...the research is aimed at clarifying not if... but how."*[117]

Action Research is an approach to research that integrates action and reflection, so that the knowledge gained in the inquiry is directly relevant to the issues being studied; and in which there is increased collaboration between all those involved in the inquiry project. Action research has a long history, going back to social scientists' attempts to help solve practical problems in wartime situations in both Europe and America. Over the past ten years there has been a resurgence of interest, and many developments in both theory and practice. The newer approaches to action research place emphasis on a full integration of action and reflection and on increased collaboration between all those involved in the inquiry project. They include, among other approaches, **co-operative inquiry**, **participatory action research**, and **action science** or **action inquiry.**[118]

I did not formally plan this study as action research but there was an overlap between staff evaluating and implementing the project so it inevitably shares some characteristics. We also fed back some results to the District Stroke Group as we went along, thus potentially influencing the way the project has developed.

It was clear from the outset that multiple methods would be required for this evaluation and that although this was a new intervention that had been developed, a randomised, controlled trial would be inappropriate. The issues initially discussed by an external reference group were:

- what methods should be used;
- how they should be combined;
- what control group (if any) should be used.

3.2.2 Evaluative Research

I initially tried to find relevant literature in the Health Services Research and Health Technology Assessment fields and found that there was limited information. I have therefore explored a number of related fields to find relevant work. These are health promotion literature,[119-121] social programme evaluation literature,[93 94] and the educational literature.[122]

More discussion has appeared over the time course of this project, notably a discussion document from the British Medical Research Council.[123]

(a) Stages of research

One point of methodological agreement is that any intervention needs to go through a series of stages in its evaluation. The best known are the phases of clinical trials for drugs:[124]

Figure 2 Phases of clinical trials

Pre-clinical	In vitro and animal studies - finding new chemicals to test
Phase 1	Safety and pharmacological profiles - usually <100 healthy volunteers
Phase 2	Pilot efficacy studies - usually a few hundred volunteers, often randomised
Phase 3	Extensive Clinical Trial - usually large RCTs
Phase 4	Post-registration looking for new effects, long-term or rare side effects

A number of authors have used the analogy of drug trials to develop a framework for evaluation complex interventions.[119 120 123 125] The MRC framework is shown in Figure 3.

Figure 3 Framework for trials of complex interventions
Adapted from MRC[123]

Phase	Definition	Description
Pre-clinical	Theory	Explore relevant theory to ensure best choice of intervention and hypothesis and to predict major confounders and strategic design issues.
Phase I	Modelling	Identify the components of the intervention and the underlying mechanisms by which they will influence outcomes to provide evidence that you can predict how they relate and interact with each other.
Phase II	Exploratory Trial	Describe the constant and variable components of a replicable intervention and a feasible protocol for comparing the intervention to an appropriate alternative.
Phase III	Definitive RCT	Compare a fully-defined intervention to an appropriate alternative using a protocol that is theoretically-defensible, reproducible and adequately controlled in a study with appropriate statistical power.
Phase IV	Long-term implementation	Determine whether others can reliably replicate your intervention and results in uncontrolled settings over the long term.

The pilot studies of HCPA in Oxfordshire and Gloucestershire could be seen as Phase I studies and this evaluation as Phase I or II. There was some initial discussion that this should then lead to a Phase III Randomised Controlled Trial. Subsequent views were more inclined to a 'Realistic Evaluation' perspective that an RCT would never be appropriate for this intervention, as most of the components had effectively become 'must dos' for the NHS through the development of Health Improvement Programmes.

The framework developed by Nutbeam[119] [120] fits better with this view since there is a less rigid approach to types of evidence and the process does not revolve around 'the definitive RCT.'

Figure 4 Framework for evaluation of new interventions
Adapted from Nutbeam[119] [120]

1. Problem definition	What is the problem?
2. Solution generation	How might it be solved?
3. Innovation testing	Did the solution work?
4. Intervention demonstration	Can the programme be repeated or refined?
5. Intervention dissemination	Can the programme be widely reproduced?
6. Programme management	Can the programme be sustained?

In this case the pilot studies of HCPA in Oxfordshire and Gloucestershire could be seen as level 2 or 3 studies and this evaluation as level 3 or 4.

(b) (Re)defining the intervention

A starting point for any evaluation must be a clear description of what is to be studied (see page 27). However, an important aspect of this evaluation is to describe more fully and redefine the intervention. With complex interventions qualitative methods are essential. Pope described the use of qualitative methods for "opening the black box."[115]

The intervention can be redefined using a number of domains including: the underlying theories, the boundaries, the objectives and the costs.[126]

An important issue for researchers is whether redefinition should be throughout the period of evaluation (an Action Research approach) or at the end of the evaluation, which maintains clarity as to what was actually evaluated. I have inclined to the latter, although I acknowledge that some aspects of the intervention will have adapted to circumstances. The aim is for the qualitative aspects of the study to capture this information.

(c) Theoretical basis of intervention

The theoretical underpinning of any intervention can be evaluated in its own right, particularly as part of an **evaluability assessment** that is done before some programme evaluations.[94] In the case of HCPA, there was no pre-existing articulated theory (see section 2.1.2 page 18), so this evaluation has a role in articulating and defining the underlying theory.

One of the most important reasons for having a theoretical base is that if the intervention fails to work in some way, the theory can be revisited and amendments made rather than discarding the whole intervention.

(d) Boundaries to the intervention

The boundaries of a complex intervention – in terms of time, person, and place – can be hard to define and may ultimately be arbitrary. This is particularly so for organisational changes. The intervention may be one-off, intermittent, continuous or a combination. Individuals may be wholly or partially involved. They may be part of the intervention or acted upon by the intervention.

For example, if a group is formed as part of the intervention, then is a subgroup still part of the intervention or a consequence of it? We defined the boundaries of the HCPA quite carefully at the outset (see section 2.2.2 page 27). For example we considered that subgroups arising from the initial priorities set by the District Stroke Group were "in" – any others were "out". The purpose of this definition was to help with the evaluation, particularly defining transaction costs. However, the evaluation is an opportunity to revisit these.

(e) Objective setting

Most interventions have objectives, in many cases explicitly stated and sometimes evaluation is against these objectives. However, it is likely that there will be a number of different perspectives each with its own set of objectives. The evaluation will therefore have elements of assessment of progress against objectives set at the outset and a search for objectives from individuals and organisations who might have differing perspectives (see page 39).

(f) Costs and other adverse effects

Not all studies have an economic element but it is a useful exercise in developing any intervention to ensure that costs and any negative elements are considered. 'Cost' is being used here in the broadest sense of any adverse or unwanted change not simply the financial value. The cost of implementing the intervention, particularly transaction costs of organisational changes are important. Describing them, even if not giving a financial value to them, is an important part of fully defining the intervention. Conversely, defining the intervention fully will allow a clearer view as to what the side effects are likely to be so that they can be measured in the evaluation.

(g) Case studies and Control groups

It was only practical to conduct this study in one district so it is by necessity a **single case study.** I consider that the stage of evaluation (see section (a) page 48) of this study does not require controls, as it is not a controlled trial. However, we felt it important to contextualise the study and therefore obtained information from a purposive sample of districts about their activities in this field (see section (d) page 58).

(h) Conclusions

It is important to define interventions, both to evaluate them properly and to have a result that is usable by policy makers subsequently. It is essential that there is enough information for others to replicate the intervention. The underlying theory or evidence needs to be articulated. The boundaries must be defined - in terms of time, person and place. Describing transaction costs is a revealing exercise with or without an economic component to the intervention. Setting objectives is always necessary, but recording whose objectives and how they were reached can add to the definition.

The next section discusses how different sets of findings can be brought together.

3.2.3 Triangulation

(a) Background

"Triangulation" is a mathematical term widely used in science and navigation. It is a technique developed from ancient Greek mathematicians, by which distances, positions or angles can be calculated using the properties of a triangle. Willebrord Snel of Leyden (1580-1626), the 'Father of Triangulation' was the first person to calculate the circumference of the Earth using triangulation, although Gemma Frisius and Tycho Brahe had proposed the method.[127] Starting only with the position of two towns in the Low Countries his estimate was only out by 3%. The current uses of triangulation are in navigation, surveying and orienteering but it has also been developed to study three-dimensional mathematical problems, for example: Delauney triangulation, Voronoi diagrams and Dirichlet Tessellation.

The term was taken as a metaphor by social scientists to describe "the combination of methodologies in the study of the same phenomenon".[128] This metaphor picks up two features of triangulation: *Confirmation*—aiming "to get a better fix on the subject matter"[129] as in navigational use and *Completeness*—giving "a more complete, holistic and contextual portrayal of the unit(s) under study"[130] as in estimating the circumference of the globe or 3D shapes.

Within the health and medical literature the term triangulation has a number of different meanings that can be distinguished as:

- *Mathematical Triangulation* – using its original meaning and found in virology (to do with viral shapes) and radiology (finding positions).
- *Psychological Triangulation* – a specific meaning found in the psychiatric and psychological literature where 'a dyad preserves its stability by directing hostility to a third person' (such as parents and a child).
- *Surgical Triangulation* – used loosely in reference to the cutting of triangular shapes such as the 'Mercedes' incision for liver operations.
- *Sociological Triangulation* – as used in this study and found mainly in nursing, sociological and some psychological literature.

(b) Multiple Triangulation

The term was adopted into social sciences in the 1950s, mostly in studies of organisations. It is conventional to cite Campbell and Fiske's work[131] as the first example. This is interesting as the paper is a quantitative one, whereas most subsequent use has been qualitative, and they did not use the term 'triangulation' to describe their methods in that paper.

Denzin's delineation of four levels of triangulation are used by most authors: **method, theory, data** and **investigator.**[128] **Multiple** triangulation refers to the combination of two or more of these.

Triangulation has also been described as an alternative to validation: if there is no 'gold standard' to validate against then we need some other way of checking how robust are the findings. Jick states that

> *"The effectiveness of triangulation rests on the premise that the weakness in each single method will be compensated by the counterbalancing strengths of another."*[130]

Thus bias can potentially be reduced and the final results can have a greater level of trustworthiness.

Some difficulties of triangulation have been summarised by Duffy:[132]

- what unit of analysis is to be used?
- how are differences between textual and numerical data to be combined and interpreted?
- what to do with overlapping concepts?
- whether and how to weight sources and methods?

'Triangulation' is a concept for which there is still much discussion, there are limited practical examples and there is no single recipe for implementation.

(c) Method Triangulation

The most widely used form is method triangulation. *Within method* is where different data are collected within one method. For example a quantitative study may use two different rating scales administered simultaneously. *Between* (or *across*) *method* is the "archetype" of triangulation and is the most used. The aim is to see if the findings from different methods are congruent and therefore give greater reliability than one method alone. There is some confusion in the literature as to what constitutes a 'method' as Denzin[128]uses very broad method groups (eg surveys, interviews, observation). Some authors use 'between method' only to describe using qualitative and quantitative methods together, whereas others apply this to using different qualitative methods (such as observation and interviews).

(d) Theory Triangulation

Theory triangulation can be controversial, since those who have a strong commitment to using articulated theory in research, may have objections to combing different paradigms.[133] However, most people working in health services research take a more pragmatic line and see value in combining different perspectives and paradigms. Denzin considered one of the strengths of theory triangulation to be that it ensures that underlying theories are fully articulated (not often done in medical research) and that

> *"Pitting alternative theories against the same body of data is a more efficient means of criticism - and it more comfortably conforms with the scientific method."*[128]

Since the HCPA was not strongly driven by theory I did not initially plan to use theoretical triangulation. However, taking Duffy's broader definition

> *"The use of several different frames of reference or perspectives in the analysis of the same data."*[132]

the differing perspectives of the research team will engender some theoretical triangulation. Furthermore, part of the work has been to look at a number of pre-existing theories to see if any fit the HCPA that has no existing articulated theory (see page 18).

(e) Data Triangulation

The use of multiple data sources is widespread in research. This can be categorised as:

- Person—Data collected from different "levels" of person: individuals, groups (dyads, families or groups), or collectives (communities, organisations, societies);
- Time—Data collected at different times;
- Place—Data collected in different settings or places.

Figure 5 Triangulation of Data page 85.

(f) Investigator Triangulation

This implies the use of different investigators with different skills and backgrounds on the same project. Some authors suggest there is a requirement to see the *raw data.*

3.2.4 Methods Chosen

This is a case study of commissioning, using a mixture of qualitative and quantitative (including economic) methods. The multiple methods used can be broadly grouped into six separate aspects of the study. The methods are summarised here and more detailed description is the given for each.

The **aim** of this study was to implement and evaluate the HCPA. The **objectives** were to:

- implement a Health Care Programme Approach to commissioning and provision of stroke services in the Gateshead and South Tyneside Health Authority area;
- identify and develop short term objectives and measurable criteria or indicators for progress in evidence-based health care for stroke;
- evaluate progress against specified objectives and criteria;
- describe the processes of this approach using qualitative interviews with key people and observation at meetings;
- describe changes to purchasing by analysing documentary sources;
- define the programme budget and describe any resource shifts;
- estimate the transaction costs of this method of commissioning;
- compare changes in commissioning with comparable districts;
- triangulate to findings from the different aspects of the study.

(a) Description of process

Qualitative methods were used to describe the process of commissioning form a range of perspectives and also to try to gain insight into how other changes occurring linked to the health care programme approach. Three main qualitative methods were used to gather information on the processes that took place during the study:

Interviews. Four sets of semi-structured interviews were undertaken by qualitative researchers.

Observation. A researcher observed most District Stroke Group and some subgroup meetings between June 1998 and August 1999.

Documentary Analysis. Documents such as letters, minutes from meetings, discussion documents, and reports were collected and reviewed by content analysis.

(b) Quantitative Indicators

Quantitative indicators were used to look for 'objective' changes in stroke care during the study period, though acknowledging that links with the HCPA would be difficult to show. Indicators specific to stroke were located from various sources. Measures were selected on their appropriateness in terms of importance and relevance, the strength of their evidence base, reliability, validity and likely sensitivity to change.

Data was collected for two time periods: in most cases the *pre-intervention* data was for April 1997 to March 1998 and the *post-intervention* data was for April 1999 to March 2000.

The CMDS provided some data that was not needed for a predefined indicator. This has been analysed separately to give a broader picture of changes to the district during the time period.

(c) Survey of Practice Managers in the District

Information from primary care was important but difficult to obtain so in addition to the indicators described above we wished to know more about structures in primary care and whether the process of commissioning influenced them. We undertook a postal survey of all practices in the district in December 1998 asking about specific structures and processes used in the prevention and management of stroke — such as disease registers and use of guidelines. The practice managers completed the questionnaires. We repeated the survey in December 1999 by asking for any changes over the preceding year.

(d) Survey of Directors of Public Health in nine Districts

This is a case study and not a controlled trail. However, we wished to set any findings in the context of changes to commissioning elsewhere in the country. We surveyed three districts from each of the nearest NHS regions: Trent, the North West and Northern and Yorkshire in December 1998 and in December 1999 to January 2000.

We requested documents from each district (such as annual reports, service specifications and other contract documents) and conducted a structured analysis of them. Documentary analysis was followed by a telephone interview with the Director of Public Health.

(e) Measurement of Programme Budget

The process of commissioning needs a financial context to understand where resources are currently used and how they might shift. We wished to know the total cost of the stroke programme across Gateshead and South Tyneside. The programme budget estimates output (or throughput) of activity. Some of this could be calculated using local data (such as consultant episodes, bed days, etc) but other parts had to be extrapolated from research data collected elsewhere (such as use of community services and nursing home beds). This meant it was not possible to detect shifts in the programme budget over the period of the study but it was possible to get a clearer picture of how resources were used across the whole stroke programme.

(f) Measurement of Transaction costs

We wished to know the costs involved in running the HCPA. This is to help those wishing to implement a similar approach to understand how the any benefits can be balanced against costs. Activities were considered in two distinct time periods: The start-up period (1996 to April 1998)and the first 'live' year (April 1998 to March 1999) as a measure of ongoing costs.

(g) Combining Methods - Triangulation

The separate aspects of evaluation are initially treated separately and then brought together by a process of **triangulation**. I have used mainly data triangulation and method triangulation.

3.2.5 Summary points

- Complex interventions, such as the Health Care Programme Approach (HCPA) are difficult to evaluate.
- A staged approach to evaluation is necessary — this is a case study testing the innovation and describing the components of a replicable intervention.
- This complex intervention required multiple methods in its evaluation:
    - identification, development and measurement of quantitative indicators;
    - a description of the processes using qualitative interviews with key people, observation at meetings and documentary analysis;
    - a survey of Directors of Public Health in comparable districts;
    - a survey of structures for stroke management in primary care;
    - a definition of the programme budget and a description of any resource shifts;
    - an estimation of the transaction costs of this method of commissioning.
- The range of methods will allow triangulation of the findings to give a clearer view of the effectiveness of the HCPA.

3.3 Qualitative Methods

3.3.1 Design

The project was designed to gather information about the health care programme approach (HCPA) to commissioning stroke services, and therefore a case study approach was adopted. Since it was necessary to understand the perceptions and actions of a range of different purchasers and providers, qualitative research methods were used. The evaluation was guided by the following principles and needs: a formative framework with a developmental focus; plurality of methods and an iterative approach; evolution in the design and specific methods used as the work progressed; and comparison over time, within the district and between comparable districts.

A process evaluation was necessary to capture and understand the dynamic processes of change and provide feedback on the successes and failures in the process of promoting and managing change. The health care programme approach has a large number of different 'stakeholders' — the organisations and individuals involved in planning, funding, managing, providing and using stroke prevention and care services. There may be differences between the various 'stakeholders' in the extent to which they interpret and implement the aims and objectives of the HCPA. These variations mean that any evaluation needs to be 'pluralistic,'[134] in the sense that these different perspectives are acknowledged and incorporated into the research design. A 'stakeholder' approach[135] was therefore an appropriate strategy to employ in this evaluative research.

A combination of methods was used including observation at key meetings, semi-structured interviews and document analysis. Along with data gathering from the dedicated researchers, the project drew on the knowledge and experience of all the evaluation team members, some of whom are also involved in the implementation of the initiative.

Within these broad outlines of the design, details of the work undertaken were expected to evolve as the study progressed. Such evolution is necessary in order to be responsive to changes in circumstances, including turbulence and change of the programme initiative itself and within national, regional and local systems.

(a) Interviews with key players (May 1998 to July 2000)

Four sets of semi-structured interviews were undertaken. The first and third sets were with members of the District Stroke Group (DSG), and the second set were with a wider set of key players and opinion leaders from the district. These three sets of interviews were carried out by JB. The fourth interviews formed a separately funded follow up set, carried out by a different researcher (GS). These were with key people, mainly from the DSG. With the interviewees' permission, interviews were tape-recorded and transcribed verbatim. Allocating a letter or number to each interviewee ensured anonymity. Lists of interviewees can be found in the appendix. Transcripts were examined independently by two of the authors (JB and RS) and analysed using a grounded approach to generate themes from the data.[136]

i First set of interviews

Nineteen semi-structured interviews were undertaken, varying in length from thirty minutes to two hours between *May and August 1998*. They are coded 1–19. These interviews were undertaken with members of the DSG, including key members who had left the group during its history. The interviews covered the following topic areas:

- Knowledge and views of the HCPA's objectives, progress and implementation plans
- Past, current and anticipated future involvement with the HCPA
- Views of general relationships and relationships with specific reference to stroke: purchaser-provider, primary-secondary care; health-social services; statutory-voluntary; lay-professional
- Understanding of the HCPA and other approaches to purchasing/commissioning
- Anticipated changes in services, balance of care and resource allocation as a result of the programme approach
- Perceived strengths and weaknesses of current services.

ii Second set of interviews

Interviewees were in senior management positions from the variety of organisations and care sectors involved in the programme approach to commissioning stroke services, including from the two NHS trusts in the district, the two social services departments, the health authority, the voluntary sector and GPs from Gateshead and South Tyneside. There were 11 semi-structured interviews, conducted between *January and March 1999*, varying in length from thirty minutes to fifty minutes and coded A–K. Several of these interviewees had specific roles related to the local implementation of national initiatives such as Primary Care Groups (PCGs), the Health Improvement Programme (HImP) and the Health Action Zone (HAZ). The topics covered in the interviews included:

- Awareness and views of the programme approach to commissioning stroke services,
- Integration with organisations' priorities and service specifications,
- Integration with national and local initiatives, and
- (Potential) impact of the programme approach.

All the key players approached to be interviewed agreed to participate.

iii Third set of interviews

The third set of 16 interviews (11 of which were re-interviews) were with District Stroke Group (DSG) members. They took place from *May to July 1999*, and are coded I–XVI. These interviews aimed to explore views of the impact and achievements of the programme approach, the facilitators and barriers to change and lessons to be learnt. The topic areas included:

- Views of any changes which have occurred compared to those changes expected (as reported during first round of interviews) and any revised expectations
- Views of the involvement in the HCPA of different professionals and agencies
- Use of evidence in decision-making
- Analysis of critical factors (e.g. barriers and facilitators) to the successful implementation of the health care programme approach

- The future of the programme approach.

One DSG member was unable to participate because of work commitments.

iv *Fourth set of interviews*

It was realised that changes were continuing to take place since the formal end of the qualitative part of the project. It was agreed that an additional round of interviews would provide valuable additional data. Seven semi-structured interviews were undertaken, six of which were repeat interviews (one was with a new DSG member). They took place between *April and July 2000* and are coded R-Z. The aims of this exercise were to:

- Identify any significant changes that had occurred during the final year of the programme
- Determine what further developments had occurred in the project
- Assess final views on the impact achieved by the programme
- Examine the factors facilitating or impeding impact
- Gather views on the future of the HCPA after the end of the research funding

(b) Observation at key meetings (April 1998 - April 1999)

In situations where there may be differences of opinion and perspectives, interviews may reveal the 'official' accounts that respondents think they ought to give. Attendance at key meetings was important to complement to the other data collection activities, enabling the expressed views of local 'stakeholders' to be placed in context. The District Stroke Group, which is the main forum for decision-making about the HCPA. The researcher (JB) attended meetings of the DSG for one year between April 1998 and April 1999. She attended in a non-participant capacity and fieldwork notes accumulated. The group were aware of her presence and the purpose of the research and most were also interviewed by her at some stage during that year. However on one occasion she took part in discussions when the findings of the first round of interviews were presented.

JB also attended the Hypertension Group – a sub-group taking forward this priority area).

(c) Collection of documentary sources (April 1998 - April 1999)

It is important to place the HCPA within the wider commissioning and health service contexts - locally, regionally and nationally. Documentary source providers were the health authority; provider trusts, primary care, social services and the voluntary sector. Specific sources included: District Stroke Group and priority area group minutes and related documents; co-ordinator's notes; policy statements and strategy documents; contract documentation, purchasing plans, annual reports, community care plans and business plans, from the range of relevant organisations within Gateshead and South Tyneside. National policy documents were also collected. These data were abstracted and analysed as part of the survey of commissioning of services for the prevention of stroke and stroke care within other districts, and the findings are given in Chapter 4.

(d) Analysis and feedback

i Analysis

Transcribed interviews were coded using a grounded approach[136] to generate themes from the data, together with themes from the programme objectives and topic guide. A second member of the evaluation team (RS) read through the interviews to check validity.

Documents were systematically reviewed and analysed by content analysis to identify the process and practice of the programme approach and to describe the context within which it was taking place.

These two sources of data were supplemented by material from observation of meetings.

ii Feedback

Feedback to the District Stroke Group was planned to follow the two main periods of interview activity with DSG members: August 1998 to October 1998 and May to June 1999.

Interim reports based on these analyses was produced and circulated to District Stroke Group members as part of the development process. JB observed the meetings where the reports were discussed.

3.4 Quantitative methods

3.4.1 Selection of indicators

Indicators specific to stroke were located from various sources including

- Department of Health publications[137] [138]
- Conference proceedings[139]
- Computerised databases e.g. 'CONQUEST' from the American Association for Health Care Policy and Research and 'SKIPPER', the Scottish Key Indicators Package for Performance[140] were also interrogated for indicators specific to stroke.

Criteria for selection included: importance and relevance, the strength of their evidence base, reliability, validity and likely sensitivity to change.[141]. We also assessed whether data would be available from routinely collected sources (e.g. the Contract Minimum Data Set; General Practice computerised records and stroke registers) and, if so, what was the likely quality and timeliness (i.e. the speed of availability) of the data. If data could be obtained from *ad hoc* sources, we assessed the ease of collection and availability of data.

We looked at whether indicators were part of an already defined or planned indicator package, such as the Department of Health Clinical Indicators and the stroke outcome indicators working group of the Central Health Outcomes Monitoring Unit. A further question was whether they related to specific objectives of the HCPA or to specific priority areas: hypertension, multidisciplinary teams, secondary prevention and long-term care. Indicators that related only to the broad aim of the HCPA (to reduce the morbidity and mortality from stroke in Gateshead and South Tyneside) were also included.

Indicators were chosen in order to give a broad range across:

- Structure, access, process and outcome;
- Primary, secondary and tertiary care;
- Health and social services;

- Prevention, acute care, rehabilitation and long-term care.

We did not expect all indicators to be sufficiently sensitive to detect change or to be influenced by the HCPA within the timescale of the study. However, several were included because they had been chosen as components of indicator sets likely to be used in the NHS Performance Assessment Framework, and hence may become 'must-dos' in the future.

As a means of selecting from a larger number of indicators, three members of the research team (DC, LT and RT) scored each indicator against the above criteria; scores for each indicator were then summed and an average obtained for each out of a possible total score of 80. For those measures with an average of more than 40 (half the possible score), we assessed whether they were likely to be influenced by the HCPA (e.g. the detection and treatment of hypertension in general practice), or whether they would describe the population of interest (e.g. incidence of hospitalised stroke; case-fatality 30 days post-admission). We then considered whether measures could be used in their present format or whether refining was necessary. The emphasis in this study is necessarily on short-term impact, but indicators include appropriate proxies for longer-term health outcomes.

3.4.2 Data Collection

Data were collected before and after the year when the priority setting within the HCPA was complete. The indicators fell broadly into two groups: those for secondary care which were available from routine data source – the Contract Minimum Data Set and those from primary care which required collection of data from practice computers and records.

(a) Contract Minimum Data Set

The Contract Minimum Data Set (CMDS) is the main source of clinical data provided to health authorities by NHS Trusts (via a central clearing house) to monitor contracts. It contains records of each admission including diagnosis (using International Classification of Disease (ICD) codes), patient information, provider information and details of admission and discharge. The data were mostly held by 'Finished Consultant Episode' (FCE), which can be difficult to interpret as one admission can generate a number of FCEs if the patient changes consultant. However, it is possible to link FCEs into 'spells' ie the full length of admission. More recently there is a grouping of diagnoses into Healthcare Resource Groups (HRGs).[99]

CMDS information was obtained from the health authority for all residents of Gateshead and South Tyneside who were admitted to any hospital between the 1 April and 31 March with a primary diagnosis of stroke (ie with stroke in first place if there was a list of diagnoses) in the years 1997/98 and 1998/99. The following ICD 10 diagnostic codes were included: I60, I61, I62.9, I63 and I64. In addition, CMDS data (and its predecessors) were obtained from the NHSE Regional Office for all residents of Gateshead and South Tyneside admitted to hospital with primary diagnosis of stroke between 1 April 1987 and 31 March 1996. This data set was used to provide trend information on certain key variables, such as length of stay (LOS) and admissions. For admissions occurring prior to 1995, ICD 9 codes were mapped onto those ICD 10 codes listed above.

(b) Primary care indicators

i Selection of practices

We sought to purposefully select practices in each Primary Care Group to give a range of single-handed, two to three partners or multiple partners and practices with and without computerised disease registers (this information was obtained from the survey of practice managers, see below). Practices were approached by letter followed by a telephone call within ten days. Practices who were willing in principle to take part at this stage were visited and the study explained. When a practice refused, another practice within the same Primary Care Group and with the same characteristics (number of partners and presence or absence of computerised disease register) was substituted. Fifteen practices agreed to participate and ten refused. Two practices were excluded because of changing computer systems in one practice and lack of computerised drug information for the pre-intervention period in the other. The final sample comprised 13 practices. Data on practice computers is mostly held using Read Codes or as prescribing information.

ii Transient ischaemic attack (TIA)

Patients were identified who had a first or subsequent TIA or a history of TIA within these time periods:

- Pre-intervention: April 1 1997 to March 31 1998.
- Post-intervention: October 1 1998 to September 30 1999

It was only possible to collect this information in three practices with a computerised register of patients with TIA. All patients, including those who had died or left the practice, were included. Practices were asked to search for Read code G65 and exclude patients with Basilar artery syndrome (G650), Subclavian steal syndrome (G652) or Transient global amnesia (G655).

Information on contraindications to antithrombotic therapy was collected for one year pre-diagnosis and during pre and post intervention periods using medical records. Contraindications included:

- Intracranial or intracerebral haemorrhage
- Gastrointestinal haemorrhage
- Active peptic ulcer
- Aspirin allergy (for aspirin)
- Asthma

iii Atrial fibrillation

We searched for all patients (including those who have died or left the practice) with a diagnosis of atrial fibrillation (AF) between these dates:

- Pre-intervention: April 1 1997 - March 31 1998
- Post-intervention: October 1 1998 – September 30 1999

The Read code G573.0 was searched, excluding Atrial flutter (G573.1).

Practices who did not have a computerised register of patients with atrial fibrillation were asked to search for patients taking Digoxin, Lanoxin or Lanoxin-PG within these time periods. These case notes were then hand-searched for a diagnosis of atrial fibrillation. This strategy was likely to identify over half of all patients in the practice with prevalent AF.[142]

Information on contraindications to anticoagulation was collected for one year pre-diagnosis and during pre and post-intervention periods. Most contraindications are relative rather than absolute, with some variation in guidance and interpretation. Following Sudlow[143] we adapted the exclusion criteria used in the Stroke Prevention in Atrial Fibrillation Study. These included:

- Gastrointestinal bleeding
- Genitourinary bleeding
- History of falls (two or more) in the previous year
- Inability to comply with anticoagulants (as judged by the hospital consultant or general practitioner)
- Uncontrolled hypertension (blood pressure greater than 180/100mmHg)
- Daily use of non-steroidal anti-inflammatory drugs (NSAIDS)

iv Stroke

It was only possible to collect this data in practices with a computerised register of stroke patients; no practice had a comprehensive written register that we could use. All patients (including those who had died or left the practice) who had a diagnosed stroke between these dates were included:

- Pre-intervention: January 1 1997 - December 31 1997
- Post-intervention: July 1 1998 – June 30 1999

The Read code G66 was searched, excluding G66.9 (congenital causes such as cerebral palsy). Information on contraindications to antithrombotic therapy was collected as for transient ischaemic attack.

3.4.3 Analysis

The indicators were calculated for the two time periods, before and after the HCPA priority setting. The main outcomes were considered as proportions or rates and 95% confidence intervals were constructed for the difference between the proportions.

3.5 Practice Survey

A self-completion postal questionnaire (see appendix) was sent to the practice manager of each of the 62 general practices in Gateshead and South Tyneside in December 1998. One practice that dealt solely with the rehabilitation of drug users was excluded from the study leaving a denominator of 61. One postal reminder was sent after four weeks. Information was sought on practice characteristics, management of stroke prevention (hypertension, atrial fibrillation and lifestyle), care of patients with stroke and transient ischaemic attacks, secondary prevention of stroke and stroke rehabilitation and long-term care. Terms such as 'register' were not defined but left open to interpretation by each practice. As the questionnaire covered practice structures, rather than clinical practice, practice managers were asked to complete the questionnaire in consultation with other health professionals as required.

One year later, practices were sent their completed questionnaire from the first round of the survey and asked to record any changes and return the questionnaire in a reply-paid envelope. Practices who had not replied to the pre-intervention survey were sent another copy of the questionnaire and covering letter. All practices that had not returned their questionnaires after three weeks were contacted by telephone.

3.6 Survey of Districts

3.6.1 Choice of districts

Three districts were chosen from each of the three northern English regions - Trent, the North West and Northern and Yorkshire – see Table 4. Districts with teaching hospitals were excluded. We looked at standardised mortality ratios for stroke and compared the standardised mortality ratio for stroke with that all causes to see if there was any reason why stroke might or might not be a particular priority. Within each region, two districts were chosen with low and high standardised mortality ratios for cerebrovascular disease; a further district was chosen which was most comparable to Gateshead and South Tyneside on a range of parameters, such as Office for National Statistics area classification. This was done to enable a comparison of the contracting process in districts where stroke may or may not be a priority area. Districts were surveyed at the beginning of the Health Care Programme Approach implementation phase (December 1998) and again a year later (December 1999 to January 2000).

A list of documents and interview schedule is given in the appendix.

Table 4 Districts surveyed

District	Region	Interviewee	ONS area classification	SMR for stroke 94-6	SMR all causes 94-6	Difference
Gateshead & South Tyneside	**Northern and Yorkshire**	**Not applicable**	**Ports and Industry**	**103**	**115**	**-12**
District 1	Northern and Yorkshire	Director of Public Health	Mixed economies	131	110	+21
District 2	North West	Director of Public Health	Coalfields	120	112	+8
District 3	Trent	Specialist Registrar in Public Health	Coalfields	111	114	-3
District 4	Northern and Yorkshire	(1) Director of Strategic Commissioning (2) Director of Primary Care	Coalfields	100	103	-3
District 5	North West	(1) Director of Public Health (2) No interview	Manufacturing	104	112	-8
District 6	Trent	Director of Public Health	Mixed urban and rural	111	106	+5
District 7	Northern and Yorkshire	Deputy Director of Public Health	Coalfields	99	111	-12
District 8	North West	Director of Public Health	Ports and industry	103	120	-17
District 9	Trent	Consultant in Health Policy and Public Health	Coalfields	93	110	-17

3.6.2 Documentary analysis

Service specifications and other contract documents were obtained for the year preceding the introduction of the HCPA (1997 to 1998) and a structured analysis was performed comparing, for example: development (e.g. use of evidence base), content (e.g. areas of priority) and the contract monitoring process (e.g. data collected and used). In view of the difficulties encountered by districts in finding relevant documents and the limited additional information gained from documentary analysis, over and above interview data, we did not collect documents for the second survey.

3.6.3 Telephone interviews

Documentary collation was followed by a telephone interview with the Director of Public Health, or the person with most knowledge of stroke commissioning, in each district as nominated by the Director of Public Health. Interview schedules were piloted with Directors of Public Health in two districts not part of the main survey and a summary of interview topics was sent to each interviewee prior to the interview.

3.7 Programme Budget

Two of the main objectives of the HCPA project were 1) to develop a strategic approach to commissioning in order to support planned and appropriate developments and 2) to commission services based on need in order to better match effective services with local needs. Clearly, it is important to know how resources are currently used before thinking about ways of changing this pattern. However, the gathering of information is not a costless activity and a balance must be struck between the accuracy of the data and the additional resources required to gather that data. Programme budgeting is a relatively straightforward technique, which may provide a useful means of assessing how resources are currently allocated between, and within, patient groups and across sectors of care provision.

Programme budgeting is a form of budgeting that focuses on the output of health services rather than the inputs required producing that output. In an ideal world, it would be possible to measure outputs in terms of health outcome, but information of this kind is rarely available so we are restricted to measuring throughput or activity; for example consultant episodes or bed days. It is important to recognise that programme budgeting is intended only to describe how resources *are currently allocated* and is not intended as a mechanism that allow conclusions to be drawn about how resources *ought to be allocated.* Such conclusions may only be reached by linking resources to health outcomes and assessing the implications of shifting resources between sectors, a technique known as marginal analysis. The main areas of activity were identified as being:

- Inpatient
- Primary care
- Outpatients
- Accident and Emergency
- Community care
- Social services

For each sector in turn, we sought data on:

- The total budget in Gateshead and South Tyneside for that sector for the financial years 1997/98 and 1998/99.

- As estimate of the proportion of the overall activity in each sector which may be attributed to stroke.

Although significant costs may be borne elsewhere, such as in the voluntary sector as well as by patients and their carers, these were not included here. Due to differences in data availability, the method used in assessing the inpatient programme budget is quite distinct and has been dealt with separately below.

3.7.1 The Inpatient programme budget

Contract minimum data set (CMDS) information was obtained for all residents of Gateshead and South Tyneside who were admitted to hospital in 1997/98 and 98/99 between the 1st April and 31st March with a primary diagnosis of stroke or transient ischaemic attack (TIA). The following ICD 10 diagnostic codes were included: I60, I61, I62.9, I63 and I64 for stroke and G45.9 and I65.2 for TIA. The CMDS includes data on provider unit, specialty, admission method, length of stay (LOS), Healthcare Resource Group (HRG), and a range of other patient details.

To estimate the PB for 1997/98, Trust financial returns (TFR) information was used to attach costs to finished consultant episodes (FCEs) and the total inpatient and day case expenditure on stroke and TIA estimated. Total expenditure was broken down by patient characteristics and provider. Implied costs per case and costs per bed days were estimated by dividing expenditure by total number of admissions and total bed days respectively.

To estimate the programme budget for 1998/99, the NHS reference cost schedule was obtained and used to attach HRG-specific costs to each episode in the data set. The different methods used in 1998/99 reflected the change in the costing system adopted in 1999 whereby all trusts were obliged to submit costs by HRGs, rather than by specialty-specific FCEs as previously.

(a) The 1997/98 inpatient programme budget

The main costing method used was the 'cost per FCE approach' outlined above. In arriving at a cost per FCE, the total cost allocated to a particular specialty (such as geriatrics or general medicine), is divided by the number of patient episodes occurring within that specialty. For example, the TFR information submitted by provider 1 shows that £8,344,221 was allocated to the specialty of general medicine accounting for 13,280 patient episodes, resulting in a cost per general medicine FCE of £628.33. This figure was then applied to all FCEs in our data set occurring within general medicine in that unit and a similar procedure carried out for all other episodes. This method assumes that stroke patients have a similar length of stay and use a similar amount of resources to other patients admitted to that specialty.

Alternatively, dividing the total specialty cost by the total number of bed days occurring in that specialty, allows a cost per bed day to be estimated. For example, the total cost of £8,344,221 allocated to general medicine in provider 1 may be divided by the total number of bed days of 62,738 and a cost per bed day of £133 estimated. This cost per bed day may then be multiplied by the length of stay (LOS) of the stroke patients in our data set. Such a cost per bed day approach was carried out for patients admitted to the two main providers in order to provide a comparison with the cost per FCE approach outlined above. This method corrects for the problem of differential LOS within a speciality, which is important as stroke patients may have different LOS than, for example, patients admitted following heart attack. However, the cost per bed day approach assumes that costs are accrued pro rata with LOS while costs are likely to be 'front loaded', with the bulk of the costs accrued towards the start of an episode of care (investigations carried out, intensive treatments etc).

(b) The 1998/99 inpatient programme budget

To estimate the programme budget for 1998/99, the NHS reference cost schedule was obtained and used to attach a HRG specific cost to each episode in the data set. The HRG system is designed to group together episodes that are clinically coherent and consume similar amounts of resource. Table 5 gives the HRG codes of the HRG groupings most relevant to stroke along with a brief description of each.

Table 5 Stroke related HRGs

A19	Haemorrhagic condition
A22	Non-transient stroke aged 70 and over
A23	Non-transient stroke aged 69 and under
A99	Complex elderly with nervous system primary

For every provider in England and Wales, the reference cost schedule estimates the average cost of an episode for a patient in a particular HRG, admitted to a particular specialty. We obtained these schedules for every provider unit in our data set, attached these HRG specific costs to all admissions in the 1998/99 CMDS and estimated total expenditure. As above, the implied costs per case and costs per bed days were estimated by dividing this figure by total number of admissions and total bed days respectively.

Ideally, we would want to compare the results derived in this manner with those we would have obtained *had we used the same costing method as in 1997/98.* However, this was not possible as the change in the method of costing at the National level meant that only HRG specific costs were readily available in 1998/99. In an attempt to partially overcome this, we did request more detailed information from the two main providers which would allow us to make a 'like with like' comparison across the two years of interest. Thus, we are able to present a more detailed comparison of the programme budget for the two main providers than the remainder of the data set.

Table 6 provides an overview of the costing methods used.

Table 6 Overview of costing methods used

	1997/98	**1998/99**
Cost per FCE	whole data set	2 main providers
Cost per bed day	2 main providers	2 main providers
Cost per HRG	**	whole data set

3.7.2 The 'non-inpatient' programme budget

Data on total budgets in each sector were sought in the health authority annual accounts and the 'common information core' outturn, and the Community Care Plans for Gateshead and South Tyneside for the years 1997/98 and 1998/99. Compiling information on stroke-related activity was more problematic. Unlike in the inpatient sector described previously, CMDS data is not yet available for outpatients, accident and emergency or the primary care sectors. Social service activity data is held by disability, not by diagnosis.

A literature review of papers that detailed the cost of stroke or reported stroke-related activity was undertaken. A number of published documents were identified, the most important of which being the 1996 Burden of Disease (BoD) document,[144] the morbidity statistics in general practice (MSGP)[145] and the OPCS disability surveys.[146]

Unfortunately, many of the better studies on the cost of stroke have been carried outside the UK,[147-154] although a number of UK based studies were identified.[155-171]

Of these, one dealt only with inpatients,[158] several involved only those patients recruited through RCTs[157 164 166 172 173] and two included only younger stroke patients[170 174] and, as such, were not considered to be representative of stroke patients in the community. In addition, studies that follow up patients following stroke only yield information on incident cases, and do not take account of the burden of stroke in the community.

Whilst a number of papers do attempt to take a prevalence approach, they rely on National estimates of activity from the documents cited above for all but inpatient activity.[161 167] The exception to this is a recent paper by Kavanagh which reports a community based survey of stroke disability based on OCPS data.[162]

Some further details of methods are given in the results section because this was to some extent an iterative process.

3.8 Transaction Costs

Transaction costs are the costs associated with the process of commissioning which therefore cannot be used for direct patient care.[75] These include the costs of contract negotiation and monitoring, development of service specifications, and provision of necessary information and IT support. These costs are likely to vary according to the organisational structure within which commissioning takes place. Posnett and colleagues who set out to estimate the cost of Total purchasing Pilot schemes give a good summary of the theory of transaction cost economics.[51] The most relevant of these to the health programme approach are those related to search and information costs (the costs incurred in identifying health needs, appropriate health care etc) and to co-ordination and organisation of activity.

The health care programme approach has a number of key structural elements, described in detail elsewhere.

- District Stroke Group
- Co-ordinator
- Technical Document
- The agreement of initial priorities

The transaction costs associated with these core activities are estimated below. As well as these key elements, there are a number of other initiatives brought about by, or in connection with, the health programme approach but are not considered as a central component of the intervention. For example, the 'hypertension in primary care' joint sub-group of the DSG and the district MAG. and the district Multidisciplinary Audit Group Health Improvement Programme for stroke. Although such activities are an important part of the programme approach, they were not considered to be part of the 'core' intervention. The costs associated with these activities have not been considered.

The transaction costs associated with the health programme approach were considered in two broad time periods:

- The start-up period (June 1996 to April 1998)

- The first 'live' year (April 1998 to March 1999)

The three main sources of costs attached to the organisational aspects of the health programme approach were considered to be those associated with:

- The role of stroke co-ordinator (including salary and 'on costs', travel expenses and additional secretarial support)
- Running the DSG (time input of the members and secretarial support)
- Writing of the technical document (time input of the authors and secretarial support)

3.8.1 Role of the co-ordinator

Data were collected on the following items relating to the stroke co-ordinator's role; *pro rata* annual salary, including national insurance and employer's contributions; mileage travelled and associated costs (car parking fees etc); as well as an estimate of secretarial support associated with the role. Information on travel costs were collected via monthly expense claims whilst estimates of secretarial support were collected via monthly activity sheets submitted by the co-ordinator. These monthly activity sheets included estimates of the co-ordinator's time spent in various activities associated with the role,

- Meetings and interviews, including those conducted by telephone.
- Presentations and research
- Report writing
- Administration and clerical.

3.8.2 Running the District Stroke Group

The minutes of all DSG meetings were used to document the attendance and the duration of meetings. Information on job title and professional affiliation of attendees was available from the documents of DSG membership, supplemented by the documentation of the co-ordinator's interviews. Travel time was estimated using two different assumptions about travel to and from meetings: estimates of 30 minutes and 45 minutes were used in the analysis. The secretary to the DSG provided an estimate of the time commitment involved in each meeting, including the preparation and circulation of the minutes.

The total cost of attending meetings was then calculated based on broad estimates of the 'cost' to the NHS, social services or others of staff involved in the DSG. Clinical NHS staff and social service staff costs were based on a list from the Personal Social Service Research Unit.[175] These are national average costs based on mid-point of salary grade and include salary 'on costs'. NHS managerial costs were based on the SMP salary scale, again, broadly based on mid-point of grade. Secretarial support was costed according to university secretary Grade 3 with 'on costs' added in. Members of the evaluation research team who play an active role in DSG were costed according to equivalent NHS grades. Members of the research team who acted as observers or were otherwise there in a strictly research capacity were not included in the costs.

3.8.3 Writing of the technical document

The technical document is a document for developing a stroke strategy for Gateshead and South Tyneside describing the local epidemiology; current provision and research findings for prevention, treatment; rehabilitation; and long-term support. Members of the research team and the District Stroke Group developed the document collaboratively with the principal investigator (DC) taking the lead in searching the literature and writing draft versions of the document. The process of developing the document began in early 1997 and the final version was completed by November 1997. Thus, estimating the cost of preparing this document had to be done retrospectively. The lead author provided an estimate of his time input into the document and the minutes of the DSG meetings were used to estimate any time input of others into this process.

The time of the lead author was costed according to mid-point on the clinical lecturer grade, including National Insurance and employer's contributions.

3.9 Triangulation

3.9.1 Triangulation in this study

The separate aspects of evaluation are initially treated separately and then brought together by a process of **triangulation**. Triangulation means "the combination of methodologies in the study of the same phenomenon"[128] and its purpose was "to get a better fix on the subject matter."[129] It can be seen as a method of validation, or an alternative to validation.[114] It is also seen as a method to generate new knowledge by giving "a more complete, holistic and contextual portrayal of the unit(s) under study."[176] See section 3.2.3 Triangulation on page 52.

Four levels of triangulation have been proposed: Method, Theory, Data and Investigator.[128] Multiple Triangulation refers to the combination of two or more of these.

(a) Method Triangulation

For the HCPA study we have used method triangulation to strengthen the qualitative process findings by interviewing, observing meetings and studying documentary sources. We have used between method triangulation to look at whether perceptions of change from the interviews match the findings from the quantitative indicators.

(b) Theory Triangulation

Since the HCPA was not strongly driven by theory we did not initially plan to use theoretical triangulation. However, taking Duffy's broader definition:

> *"The use of several different frames of reference or perspectives in the analysis of the same data."*[132]

the differing perspectives of the research team will engender some theoretical triangulation. Furthermore, part of the work has been to look at a number of pre-existing theories to see if any fit the HCPA that has no existing articulated theory (see section 1.2.2).

(c) Data Triangulation

The multiple data sources and the ways they have been collected, analysed and brought together ways summarised in Figure 5

(d) Investigator Triangulation

This implies the use of different investigators with different skills and backgrounds on the same project. Some authors suggest there is requirement to see the *raw data.*

We have undertaken some analysis of interview data by two qualitative investigators (JB and RS). Some of the quantitative data such as CMDS was analysed by both the quantitative and economic researchers (LT and AR). However, most triangulation has been discussion of analysed results by all members of the research team at regular co-ordinating meetings, during and after the period of study.

The process of triangulation is an iterative one, starting from the initial discussions about research questions and continuing to the final draft of papers. Much of this is achieved through regular interaction of investigators (see preface and appendix for list). The researchers met regularly as:

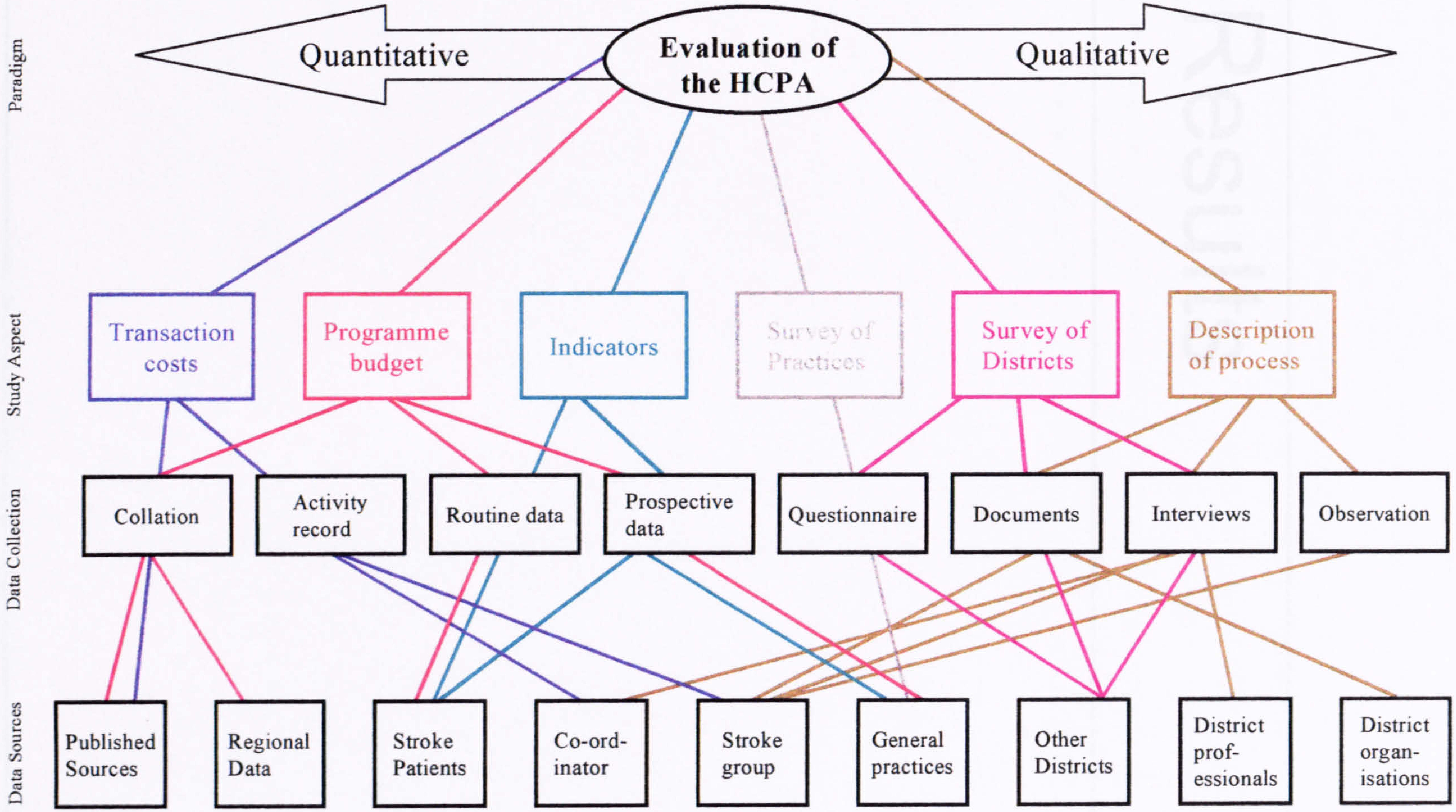
- A steering group with external advisers (quarterly)
- A co-ordinating group or the research team (monthly)
- Separate quantitative and qualitative groups (weekly)

Thus although the separate aspects of the study are run separately, there is opportunity to constantly compare and revise each aspect in the light of findings from other parts.

In bringing together the findings in was necessary to focus on common concepts such as

- Structures – e.g. District Stroke Group, coordinator, technical document
- Processes – such as priority setting
- Objectives – particularly those set by the District Stroke Group at the beginning of the project listed on page 39.

Figure 5 Triangulation of Data



4 Results

4.1 Introduction

This chapter presents the findings of the six main aspects of the study. The first section on qualitative results gives the results from the four rounds of interviews, for which the methods are given on page 60 and lists of interviewees in the appendix.

The quantitative section gives findings from the indicators to examine any measurable changes to stroke services in the district. There is also a summary of the further analysis of 10-year CMDS data obtained from the NHSE regional office to give some background to changes in the district over this time. The two economic aspects – programme budget and transaction costs are next followed by the two surveys.

These different aspects are brought together in the nest chapter – Triangulation.

4.2 Results of first round of interviews

4.2.1 Origins and development of the HCPA

Key events in the history of the programme approach to commissioning stroke services in Gateshead and South Tyneside can be found in the section on Development of the HCPA during this study on page 33

Interviewees cited several reasons for the application of the programme approach to stroke. The main reasons were the wide breadth of organisations and services needed for stroke prevention and care, including social services which had not been a major player in the previous programmes in IHD, and the need for these to be co-ordinated. Other commonly identified reasons were that stroke was an important public health issue which was rising up the NHS agenda, there was an increase in evidence about therapeutic possibilities, and there was local expertise in stroke and in research.

Gateshead and South Tyneside was selected as the geographical location for the stroke programme for a number of reasons. The pros and cons of different districts in the region were examined based upon the stroke services available in those districts, whether there were lead clinicians from the service and whether there was enthusiasm from within the health authorities for an evidence-based approach. Gateshead and South Tyneside met these criteria. Public health in the district had been trying to influence the implementation of evidence-based practice and purchasing, stroke was a major cause of morbidity and mortality in the district and both acute trusts were developing track records for improving stroke services. Despite this, several interviewees mentioned that the focus on stroke was actually

> *'against the priority wishes of the vast majority of primary and secondary care ...and against current mechanisms for prioritising and setting up groups in the district at the time' (INT18).*

However, although the original vision and impetus for the initiative came from outside the district, providing some evidence that it was imposed, most interviewees felt this was not a major problem now the project had got underway.

4.2.2 Context

It is important to understand the context in which the programme approach and any proposed changes are taking place for these have potential impact on the success or failure of the project. The relevant context can be divided into the wider NHS environment and the local context in which the programme approach is operating. The latter includes the strengths and weaknesses of current stroke services, the commissioning of those services and relationships between different sectors and professions.

(a) Wider NHS environment

At the beginning of the programme approach to commissioning stroke services, evidence-based medicine was a key NHS strategy.[177] Several interviewees mentioned this aspect as an important objective of the programme approach.

During the programme approach project major policy changes have been proposed which are now being implemented. The new NHS White and Green Papers have both been published during the life of the project.[8 12 80 178] Interviewees felt that overall these policy changes are supportive of the aims of the project. The Green Paper's greater emphasis on health promotion and public health is seen as helpful to the programme approach. Some interviewees mentioned that the programme approach was ahead of its time in terms of the new collaborative approach outlined in the White Paper and initiatives such as Health Action Zones:

> *'I mean it comes back to this theoretical stance about the adversarial versus co-operative and the programme based versus service based commissioning model and what we're seeing is the main components of the latest White Paper in terms of commissioning are much more aligned with the health care programme approach than previously. And I think part of that's the case because I think there was a developing understanding of where the problems and issues lay and therefore, thinking about the potential benefits of the health care programme approach, it's not undertaken in isolation of what was happening in the service as a whole. Therefore the latest White Paper on developments etc.*

> *reinforce, support and facilitate the health care programme approach in many respects' (INT17).*

In particular, the Health Improvement Programme was cited as an example of where turbulence in policy has had a positive effect and has actually strengthened the stroke initiative, enabling the DSG to take their work more easily into the mainstream of health authority activity.

One policy area where stakeholders expressed greater uncertainty about its possible impact on the programme approach was Primary Care Groups. Whilst some acknowledged that the programme approach could provide the PCGs with the kind of co-ordinated plan that they will need for patient care, others were concerned that the amount of activity that will occur establishing the groups themselves may have a detrimental impact on the PCGs' abilities to take on board the stroke programme.

> *'PCGs, they're all going to have to start developing co-ordinated plans for patient care and that's what, at the end of the day, the care programme approach is, so they're very compatible with each other and in many ways the opportunities which are available, the change in the political nature of the health service, are actually more in favour of the group than detrimental. But there's still this danger that because of people getting involved in all the other things that need to occur to make these things work successfully, that the Stroke Group will be pushed to the side to a certain extent. I think to avoid having that done to it, it needs to prove that it's actually going to be a valuable kind of relationship to have and so the PCGs will actually get something of value, possibly make their work easier, and give them possible resources especially in terms of skills etc that they would otherwise have difficulty accessing' (INT5)*

> *'... it's going to depend where the primary care groups are going. If they're going in at advisory level - level one, then I think it will be easier to implement something like this (if it's ready to be implemented next year). If they go in at level two I think they're going to have other things they're going to want to get to understanding. There's going to be a big learning process there just to work on what they're doing now let alone bringing in a new method of commissioning'. (INT7)*

(b) Local context

The local environment in which the programme approach is being developed and implemented for stroke services is also potentially key to the success of the project. Current stroke services, their strengths and weaknesses will be covered in the next section. In this section some of the other issues mentioned by interviewees as being key aspects of the local environment will be highlighted.

In April 1998, the two Gateshead trusts merged to form one trust, Gateshead Health NHS Trust. One interviewee felt that this merger would result in closer joint working across the community and acute sectors, which would have implications for stroke service provision. Before the merger, although at the ground level communication between the two sectors had been good, at the strategic level collaboration was felt to be inhibited because of competition between the trusts.

Within Gateshead and South Tyneside, the health authority currently commissions stroke services for its population within contracts with a number of providers, as part of either general medicine contracts or elderly contracts.

> *'At the moment stroke services are not dis-aggregated from other medical services so the acute service is still an integral part of the general medical set up, the rehab I suppose comes more under the elderly care set up and it's all piecemeal' (INT8)*

In this approach to commissioning, the different aspects of care (prevention, primary care, secondary care, long-term care) are separated. Stroke is a priority for the health authority only in relation to the Health of the Nation targets. The approach to commissioning is likely to change with the introduction of Primary Care Groups and Health Improvement Programmes and the move from competition to co-operation.

The development of Primary Care Groups (PCGs) was different on the two sides of the district. Gateshead was to have two PCGs beginning at Level 1, the advisory level. South Tyneside was to have one PCG and is likely to begin at Level 2, taking devolved responsibility for managing the budget, formally as part of the Health Authority. These differences would have implications for the implementation of the programme approach and the future commissioning of stroke services.

Locally Gateshead and South Tyneside are part of the Tyne and Wear Health Action Zone[179]. Whilst stroke is not a priority within this local HAZ, both ischaemic heart disease and the elderly are key areas and interviewees felt that stroke could be linked to both these areas.

Gateshead and South Tyneside Health Authority is approaching the development of the district Health Improvement Programme by incorporating a series of disease specific HImPs, the work of the DSG on stroke providing one of them.

> *'we are well ahead of the game as it were and the way that the programme is being developed is going to be incorporated into the Health Improvement Programme but also in our experience it can also be very useful to other developments in ways of commissioning within the health authority but also perhaps within the Health Action Zone and really we have had the benefit of the lead time to set things up properly and to get involved which we should be very grateful for because the pressure that is going to be on other people to produce on other areas is now great so I would be quite confident that what we come up with for the Health Improvement Programme is based on support and evidence really' (INT12)*

(c) Current strengths and weaknesses of stroke services

Interviewees cited a number of strengths of the stroke services in the district, including the presence of clinicians with particular interests in stroke; the acute stroke unit and rehabilitation service in Gateshead and the stroke rehabilitation service in South Tyneside; the family support workers service in Gateshead; and the relatively short waiting times for aids and adaptations.

However, interviewees also mentioned a number of weaknesses and gaps in stroke services. One of these was the poor liaison between hospital and community services, and between hospital and social services. There were also felt to be deficiencies in community provision, for example, long waiting lists for speech and language therapy and the need for longer-term rehabilitation services. A specific problem identified for social services was the focus of the Occupational Therapy service on assessments, aids and adaptations, rather than rehabilitation services. The lack of information about stroke services, in terms of numbers and health needs, was also seen as a weakness. Interviewees also mentioned the lack of prevention services, both for primary and secondary prevention.

(d) Relationships between different sectors and professions

The many different organisations and professions involved in the provision of stroke services can result in difficulties due to the need to marry together different cultures and philosophies. However, the majority of interviewees described relationships between different sectors and professions as good, especially at the operational level. For example, the ethos of the secondary care stroke units on multidisciplinary teams has meant that some of the boundaries between different professions are breaking down.

Some interviewees mentioned difficulties working at the interface between health and social care and these difficulties were described as being related to the different cultures between the two sectors. The local authority was described as being more bureaucratic, with anything strategic needing to go back to committees. A further difficulty to good working relationships between health and social care can arise because the two sectors work with different categories of client groups - so the health sector may work with stroke patients, whereas the local authority works with broader groupings such as the elderly, disability services, etc. This is felt to cause difficulties, again not so much at the ground level but more at the strategic level. Relations between social services and the health authority were felt to be good, especially between the South Tyneside side of the district, although one person commented that the frequent changes in personnel at the health authority can make it difficult to establish good working relationships.

Relationships between the health care providers were described as improving in general terms now that the health service is moving away from the idea of competition to a more collaborative approach.

Relationships between primary and secondary care were difficult to describe for many interviewees, partly because there is little direct liaison between the two sectors, most communication occurring through the referral system. Relationships between the health authority and primary care were described as being generally good and as being helped by the existence of the Primary Care Improvement Group (which is made up of the Multidisciplinary Audit Group, the Local Medical Committee and the Commissioning Forum). However, one interviewee did question where the loyalties of this group lay:

'some issues around the Primary Care Improvement Group in terms of where they see themselves and where they see their accountability and their loyalty, whether that's with the GPs or with the health authority, given that they are part of the health authority. But obviously they like to maintain some of their independence because they have much more contact with the GPs and to get the GPs to work with them they can't be necessarily seen as the big brother of the health authority type thing. But I think that helps with primary care in terms of GPs' (INT7).

South Tyneside was described as having good working relationships with the voluntary sector and the private sector, partly helped by the small size of the district. The local authority in Gateshead commissions the Stroke Association to provide family support services and the support workers liase closely with hospital colleagues through this service.

4.2.3 Aims, objectives and anticipated impact

Interviewees were asked to identify what they saw as being the key aims and objectives of the initiative and for their assessment of its potential impact on stroke services.

(a) Aims and objectives

There is some evidence in the interview data of a lack of clarity about the aims and objectives of the programme approach to commissioning stroke services amongst some stakeholders. However, the range of objectives reported by interviewees can be grouped under the following headings (see also group defined objectives page 39):

i A strategic approach

- *'a mechanism for bringing together strategic issues' (INT17)*
- *'a way of having a coherent strategy across the district for stroke ranging from prevention through to long term care' (INT12)*
- *'offers a mechanism for bringing together strategic issues - commissioning, planning and service development in a way that is more mature than what was tending to happen with the purchasing/providing*

split in the previous White Paper approach, which tended to be somewhat adversarial and centred around cost and volume' (INT15)

ii Evidence-based and/or good clinical practice

To produce best practice guidelines so that all professionals working within stroke services are following the same process.

- 'to produce a technical document which could be used as a reference source to guide clinical practice' (INT1)

- 'the opportunity to influence developments on the basis of the evidence in its broader sense and taking account of the research base within the field but also looking at local initiatives and resources'. (INT17)

iii Co-operation

Co-operation could replace the culture of competition and the programme approach would enable this to happen

- 'breaking down the barriers between health and social care and also the barriers between primary and secondary care as well' (INT1).

iv Improving stroke services

To reduce the incidence of stroke

v Co-ordination

- 'to have a co-ordinated approach to all aspects of stroke care whether it is the medical or the social or the rehabilitative or whatever aspects through from primary prevention, secondary prevention, investigation, diagnosis, rehabilitation management and longer term care of those who are disabled. (INT14)

- 'to produce more co-ordinated services because there are a lot of services out there, but it's really ensuring that they are co-ordinated ... quite often the feedback we get from people who've had a stroke or some other disability is that ... they as Joe Public find it extremely confusing as to who provides what and where they go' (INT10)

> - *'to stop the compartmentalisation and isolation of the different services, to make sure that each recognises the knock on effect ... developing an integration of service and a recognition of what the balance of services within stroke needs to be' (INT12).*

(b) Anticipated impact on stroke services

Overall, the majority of interviewees felt that it was too early in the programme to say how the approach might have an impact on services and resources. Some felt this was because there was not enough information available on the current balance of care and resources. One of the stakeholders' expectations of the approach is that the picture of current services will become clearer, including the balance and quality of the services across the different sectors and across the district. One respondent felt that there is also likely to be a huge amount of unmet need once the current picture is examined.

Several interviewees anticipated that an impact of the programme approach will be the opportunity to share good practice with each other.

In terms of resources, some stakeholders expect an increase in resources to meet health needs and identified gaps in stroke services, whilst others acknowledged that there is unlikely to be any additional resources and therefore there will need to be a shift of resources within the current allocations. These two different stances are summarised in the following quotes:

> *'I'm afraid we don't have enough funding, it's not just a question of reshuffling, you can't take from Peter to give to Paul' (INT19)*

> *'I want to see those changes occur without any extra costs to the health authority because of the reasons described earlier, the danger that we'll be essentially subverting other care in the district' (INT15).*

Several respondents expressed the view that they would expect a shift of emphasis towards prevention as a result of the programme approach. One stakeholder anticipated this would mean involving education and housing in the approach. Some respondents felt there should be more emphasis on community-based services and rehabilitation services once stroke patients have left hospital.

The potential impact on commissioning stroke services was highlighted by one respondent:

> *'at the moment we purchase a general medicine episode which includes some element of stroke, but the stroke ward could be subsidised at the moment because it's just general medicine, could be subsidised by other general medicine activity and the cost of that. So once you start separating things out, costing in a more in-depth way, there is often shifts. In total in general medicine terms it should be the same but within that, between the different sub-specialities of general medicine, there will be some shifts. .... In terms of between sectors, if you're purchasing the whole care programme approach we shouldn't be considering shifts between sectors anyway because it's an approach, it's the whole spectrum that we're buying and so we shouldn't be saying, Oh well local authority's bit has decreased and our bit has increased or vice versa, we should be saying, in total we are buying the best service we can afford across all our organisations' (INT7).*

4.2.4 The District Stroke Group (DSG)

Membership of the DSG has evolved considerably since it was established at the end of 1996 (The appendix shows the DSG membership at four time points from December 1996 to May 1998). This evolution has been a result of a variety of factors including restructuring of key organisations, members leaving the district and:

> *'there was an evolution within organisations about who was the most useful people to represent them and within the group there were further thoughts about how we structured the group so .... for example there was a feeling that the health authority needed somebody .... from the finance contracting side to come in ......' (INT15)*

Interviewees were asked for their views of the membership of the DSG, their role within the group and the roles of other members and organisations, and views of the functioning of the group.

(a) Members' views of their own role on the group

Several interviewees had very specific roles within the group, for example the chair of the group, the co-ordinator, and the overall project manager. In this section the focus is on those members who did not have a specific remit.

Some interviewees described their role on the DSG as 'representatives' of their organisations, whilst others were unclear as to their role. Those who described themselves as representatives said they reported back from the DSG meetings to their organisations and were link or liaison people:

> *'feeding back to the department on new developments and how we might develop our services in line' (INT10).*

Some interviewees described their role as providing a particular professional perspective, for example, as a GP or as a therapist, whilst others felt they provided a particular sector perspective, for example, a community, primary care or social services perspective. Some felt they acted as a resource for the group, providing specialist input and expertise, which might be for example, clinical or research, or providing region-wide information to the group. Some described their role as a one-way process, giving information to the group on their current practice, knowledge and experience; others described it as a two-way process. A couple of interviewees felt they had a watching brief only and were not active participants of the group. One person described her role as

> *'being to turn it into reality ... to help facilitate it and implement it in practice' (INT13).*

There was some misunderstanding expressed by a couple of the interviewees about their role on the group. For example, one respondent said:

> *'I was there keeping a watching brief and then all of a sudden I turned into this creature who was there representing general practice in Gateshead. That's perhaps the perception of the group but that certainly wasn't my perception and so I think there's a difficulty with group members, whether they are actually there as interested experts or whatever or actually representative. That needs to be clear. It doesn't matter until you come to deliver. If you're there as an interested individual, fine, but if you're actually there with the remit of delivering on*

> *behalf of your sector that's different, so there are two different sides and I think it can cause potential problems if people are not sure why they're there, why they're on the group' (INT18).*

(b) Views of roles of other members and organisations

Respondents supported the role of the university members on the DSG. These members were described as providing the academic input, the evidence base, and expertise in applying for and obtaining research and development grants:

> *'The University, this is potentially going to be a good area I would say in that we've got experts there and the one thing we did is, we went to the Primary Care Improvement Group and we could then offer, instead of just saying What will you do for us? we were able to say If you'll do this bit for us, we can offer these resources, and one of the resources was the expertise of stroke specialists who knew the literature, who knew the research, who could literally sift the wheat from the chaff and make the job a lot easier. Now I think that would work very, very well. I think there needs to be a lot more links between the university and the coal face because the people at the coal face are struggling to deliver the care let alone know what the most up to date research is and that's where the university could help. Literally say, these are the guidelines for good practice, these are the guidelines for this, and I think guidelines for good practice is a good way forward for things like stroke units, community stroke teams' (INT3).*

However, some interviewees felt alienated by the academic aspects of the project, one interviewee calling the DSG a 'boffins group'. One interviewee felt this may have been because during the earlier stages of the group the emphasis had been on the development of the technical document and applications for R&D funding, which some members felt unable to engage with. The more recent emphasis on the implementation of the priority areas was felt to engage more of the members.

There was general agreement that it was vital to have people from the health authority on the group, providing both a public health input (a population-based, health needs and strategic view) and a commissioning input (a finance and resource perspective). The health authority members could advise on current commissioning processes and health authority priorities and how the programme approach could link in with them. One interviewee envisaged the DSG evolving to become an advisory body to the health authority itself:

> *'They (health authority members) are very important although I felt to a certain extent the group's role would evolve to become a very much advisory body to the health authority and secondly it would evolve probably to an independent power, in that a group such as the DSG would actually influence the health authority with regards to its purchasing strategies and intentions' (INT1)*

Some interviewees felt the group was 'doctor heavy', resulting sometimes in discussions which were dominated by clinical issues. This had resulted in some DSG members feeling unable to contribute to the discussions and decision-making in the group. However, some interviewees felt that this was improving in the more recent phase of the group's working, with more nursing and voluntary sector input amongst group members.

It was recognised by the majority of members that the membership of the DSG had evolved so that it now included key players from across the different sectors and professions. It was also acknowledged that if the group became any larger it would become cumbersome. The only sectors which interviewees mentioned as missing from the group were the Local Medical Committee and the independent sector.

(c) Functioning

Some interviewees felt that the DSG had functioned at a slow pace, especially during the development phase of the approach. This was felt to be due to the nature of the work the group was undertaking (eg development of the technical document), the changes in the group's membership (including the changes in the co-ordinator post), and the infrequent attendance of some members of the group. The latter point was raised as an issue by several of the interviewees, in particular, the lack of primary care involvement from Gateshead and the infrequent attendance by Gateshead clinicians:

> *'there's been certain key players who have been recognised as being absent and unless you have them on board you feel maybe these decisions are going to be sabotaged at a later date. So it's been very hard to feel*

> *confident about decisions which have been made to a certain extent' (INT5).*

> *'I think one of the slight difficulties is that there are some regular attendees and there are some irregular attendees and the regulars have good relationships and chat away quite easily. Some of the irregular attendees cause a bit of tension because they come in and make a comment that has been discussed before and there's a feeling that they're either trying to go back to something that we've sorted out or trying to go in a direction that wasn't the consensus of the group' (INT15).*

However it was acknowledged by a couple of interviewees that this situation was now improving:

> *'What is very encouraging is that now that certainly there is responsibility for the HIP, is that senior people now seem to be turning up and are committed to it. It is moving forward, it has identified priorities and I think that's actually very encouraging for what is a very complex procedure' (INT12).*

Now that the group was in its implementation phase and the working groups were taking forward the priority areas, it was felt that the group was engaging with a wider group of professionals and managers within the district to take the approach forward. This engagement with a wider group was felt to be very important:

> *'I think it's very difficult to implement changes like this if people don't feel that they're part of it psychologically. However good the programme itself may be it's always more difficult to be persuasive if people don't feel that they've had any part in it' (INT19).*

Some members of the group were actively feeding back to their organisations the discussions and outputs of the DSG. This was felt to be vitally important to the success of the project, again as a means of engaging with a wider group of people who would be involved in implementing any changes. Where members had not cascaded information from the DSG to people within their organisations, this had caused problems when key people had little or no information about the project.

4.2.5 The role of the co-ordinator

As discussed briefly in section 2.2.3 page 33, two co-ordinators have been involved in the programme approach. The first co-ordinator was in post for only a few weeks and the second co-ordinator had only been in post for a short time when the evaluation interviews took place. Therefore, the data presented here mainly focuses on the interviewees' views of what the role of the co-ordinator should be and what skills they felt were needed to undertake the post.

The most frequently mentioned skills for the co-ordinator were communication and facilitation skills. One of the tasks described for the co-ordinator post was identifying and sharing good practice between the different sides of the district, the different sectors and organisations. The facilitation skills of the co-ordinator were seen as important to help engender ownership amongst the wider community of stakeholders in the district:

> *'It's all about ownership and so again the co-ordinator's role is to try and facilitate elements of ownership into bits of the programme such that when it comes to trying to involve people it's much easier to deliver' (INT18).*

This was seen as particularly important for driving forward the priority areas. One interviewee suggested that the co-ordinator should be on every working group arising from the DSG and accessing groups happening elsewhere, reporting information gathered to the DSG.

A further function of the co-ordinator post was seen as a selling or Public Relations function, acting as an 'ambassador', raising the profile of the DSG and its work within the larger community of stroke purchasers and providers in the district.

Few interviewees specifically mentioned knowledge of stroke disease as important for the co-ordinator to possess, although some did mention that the co-ordinator needed to have credibility and respect across the spectrum of organisations, to gain access to those organisations and to develop networks within and between them:

> *'I felt we needed someone with medical type health background who would be able to go and talk to the consultants but also that wasn't too*

> *medically based if you understand what I mean who could also go and talk very much to social services as well' (INT 10).*

There was also the view expressed that the post holder should be able to work independently across Gateshead and South Tyneside and be able to provide a link between the two sides. However, concern was expressed that, as both co-ordinators were from South Tyneside, this would result in more focus on that side of the district.

The task was viewed as a huge and difficult job for one person by several of the interviewees, partly due to the amount of work involved, but also due to the sensitivities arising from working across different professions, sectors and organisations:

> *'people need to trust you before they're going to listen to you and people are very wary of groups like this who they see as talk groups' (INT11).*

To address these issues, one interviewee felt that the post should be split between Gateshead and South Tyneside - a separate co-ordinator for each. An interviewee also suggested that a GP in the role of co-ordinator would be particularly useful in facilitating the implementation of the priority area 'hypertension in primary care'. Another interviewee felt that the co-ordinator should be accessing local structures and bringing extra local resources into the implementation of the priority areas:

> *'if it requires a lot of extra input from the co-ordinator to make things happen, it may not be that useful because it's resource heavy whereas if it requires a bit of input to get things going, then people in the area then do it then that is a more useful function' (INT15)*

4.2.6 Technical document

The technical document is a document for a stroke strategy for Gateshead and South Tyneside. It describes the local epidemiology (mortality, morbidity, prevalence of risk factors); current provision (NHS, Local Authority, Independent sector); and research findings for prevention (primary and secondary), treatment (including diagnosis, treatment, and prevention and treatment of complications); rehabilitation; and long-term support.[180] From the research findings it lists 43 potential recommendations. The DSG developed it with the project manager taking the lead in searching the literature and writing draft versions of the document. Reviews, rather than primary data sources, provided the main source of research findings on stroke. The draft versions of the document were circulated to DSG members who were invited to send in written comments and the document was also a regular agenda item for discussion at the group meetings. The process of developing the document began in early 1997 and the final version was completed by November 1997.

Interviewees were asked for their views of the technical document, its content and the process of its development.

(a) Involvement in development of technical document

The development of the document was approached differently from previous applications of the programme approach mentioned earlier in Oxfordshire and Gloucestershire. In the earlier work, a public health doctor carried out the literature search and the resulting document was peer reviewed by the British Cardiac Society. The final version was then presented to the two pilot districts, where reactions to it were different - one district accepted it as it reduced the work they themselves had to undertake, the other district 'essentially ignored' it because they had not been involved in its development. Learning from these experiences, the approach taken by the DSG in Gateshead and South Tyneside was to develop the technical document themselves, with the project manager leading the process by reviewing the literature and writing draft versions and the DSG members commenting on these - an approach described by one interviewee as 'peer review by the group'. There was debate within the DSG about the structure of the report, the language used and the level of research needed. One interviewee found being involved in the development of the document interesting, as it brought to the fore the differences in perspective between different members of the group:

> *'I thought it was interesting because people's perspectives changed depending on which way you looked at them. The public health perspective was to look at the greater good whereas when you're a clinician you tend to deal with the individual patient' (INT1).*

Through being able to discuss the document together as a group, this interviewee felt the end product was a 'consensus document' (INT1). Two respondents found the process and content too medically orientated, to the extent that they felt unable to contribute a great deal to the development process. Others commented that the process of development was too long. Some of the interviewees had circulated it amongst work colleagues to get their comments on the content of the document. Another interviewee felt that the process had not engaged the right people, those working in the field. Some remarked that, due to time constraints, commenting on the different versions of the document was difficult. It tended to arrive 'en masse as one technical document', when it may have been easier and more accessible to approach the document one section at a time. This comment was also applied to the discussions at the DSG meetings. Overall the majority of people interviewed did not feel actively engaged in the development of the technical document for a variety of reasons.

(b) Content of document

Most respondents were favourable about the content of the document, whilst acknowledging several limitations. A positive aspect of the document described was that each recommendation could be traced back to its original reference. However, some of the evidence within the document was described as 'out-of-date' by several respondents, although this was acknowledged to be inevitable:

> *'it is difficult because I guess stroke care is one of the most rapidly changing areas and it's always very difficult to plan around the corner when so much research is going on' (INT19).*

There was a concern expressed that a lack of evidence of benefit for something could be taken as a lack of benefit. An example used by two respondents was the evidence around the value of 24-hour access to CT scanning. The interviewees felt that, although evidence was not yet available supporting its cost-effectiveness, early CT scanning was now routinely used as an aid in practice. Other respondents commented on the lack of evidence for long-term care and rehabilitation. Many respondents commented that the information contained within the document on current service provision was inaccurate and limited. Some felt this was because routine data sources had been used, and the usefulness of these sources was questioned. However it was acknowledged that availability of good quality data on which to base planning decisions was difficult. The majority of respondents felt the document was easy to read and understand, although some felt the size of the document inhibited reading.

(c) Use of the document

Both co-ordinators used the technical document as a basis for discussion with a wide range of stroke care providers in the district: 'it did start people thinking'. The recommendations within the document were used in the priority setting process which are discussed on page 287. It was also used as a starting point for the development of the stroke HImP and as a backup document to the final version of the HImP. The development of the HImP provided an opportunity for review and revision of sections of the technical document, in particular the sections on current service provision, and it enabled DSG members who were not involved in the technical document's original development to have an input. On one of the stroke units the technical document was used as a 'working document', for example, nurses would refer to it for its evidence base and to reinforce their advice to Senior House Officers new to the unit. The Stroke Association included a reference to the technical document in a 'Good Practice Resource Pack', which it has sent to health authorities to help them and primary care groups develop effective stroke services.[181] One interviewee suggested that the technical document would be used as a basis for the development of service level agreements.

(d) Future of document

Some interviewees commented on the need for regular review of the statements that are within the technical document and for updating as new evidence becomes available. To meet the latter need, the DSG meetings developed a regular agenda item for members to raise new issues and developments. One interviewee suggested that the group needed to set review dates for each section in the document. One-page summaries of the key areas was suggested as a potential dissemination tool, as the whole document was felt to be too large for dissemination. However, one interviewee felt that, although there was not enough detail about specific areas within the document, it could be used as a starting point to construct a more detailed fact sheet or plan.

4.2.7 Preliminary assessment of the programme

(a) Positive outcomes

Collaboration - Despite the presence of some inhibiting factors such as the turbulence and changes described earlier, the initiative appears to have produced a number of positive impacts. One of the most significant has been the establishment of an approach which has emphasised collaboration. The number of organisations and professions involved in the purchasing and provision of stroke services is large. A DSG has been established consisting of members from many of these groups, and this group has produced a strategy for stroke services in the district. Both the formation of this group, and the production of a stroke strategy by its members, are achievements. The approach has encouraged the process of sharing good practice across the district. The level of co-operation engendered is particularly useful in a policy context where inter-agency and cross-boundary working are increasingly being encouraged.

Technical Document and Stroke HImP - Whilst acknowledging some of the limitations highlighted by interviewees, the technical document is itself an achievement. The majority of interviewees found the document useful, easy to understand and read. Some described examples of using the document for particular purposes, such as a starting point for discussions with a wider group of people. It has also been cited in a good practice resource pack by the Stroke Association. The document formed the basis for the development of a stroke HImP, another achievement for theDSG. This latter document will form a component part of the health authority's overall strategy for the district.

Different levels of involvement - The different ways that DSG members have been involved in the programme approach have been appreciated by those members. For example, all have had the opportunity to contribute to the development of the technical document and stroke HImP and to the priority setting process. Some have provided specific knowledge and expertise to the group, others have taken back to their organisations information from the group which has been useful to them. Due to the expertise available on the DSG, the group is able to 'offer these resources' to organisations outside the group, encouraging a two-way process of resource and information exchange. Members of the group are now able to become involved in the different aspects of the implementation of the programme approach, for example, joining working groups of particular interest and relevance to themselves and their organisations.

Influence over health authority commissioning - Several interviewees appreciated the opportunity to have a potential voice in the commissioning process. The emergence of the policy of Health Improvement Programmes was felt to be timely and helpful to the programme approach and was seized upon by the DSG. Interviewees felt this gave their work added credibility and increased the likelihood of having an influence on health authority commissioning.

(b) Dilemmas and tensions

There are some features of the programme approach and the environment in which it is operating which create dilemmas and tensions. These are summarised below:

- Potential impact of condition-specific programme approach to commissioning and provision of services for patient populations who had not had strokes
- Focus on the medical aspects of stroke care:

  > *'stroke is an interesting example where there is a danger we prioritise areas just because it's got an evidence base rather than seeing it from a broad perspective' (INT15)*

- Patchy involvement of primary care on the DSG
- Turbulence and frequent changes in the internal and external operating framework, for example, internally the changes in DSG membership (however this may become less of an issue now that the work is being undertaken within working groups as well as the DSG), and externally the changes in the local and national environment
- Publicity and knowledge about the initiative within the district have been patchy
- Communication issues, between and within organisations, in particular there is a need for DSG members and members of working groups to cascade information within their organisations
- Links to local authority commissioning and budgeting

- Need to link the programme approach to other agendas, for example, evolving structures such as Primary Care Groups

(c) Implications for the evolving programme

It was clear from the first interviews that a key challenge for the implementation of the programme approach would be the management of the tensions and turbulence within the initiative itself and imposed from outside. The issues raised were used to provide a focus for discussion within the DSG.

- Interviewees identified several specific points about the evolving programme.
- The need to achieve and to be seen to be achieving.
- A need to continue to review DSG membership and to respond to inevitable changes, whilst acknowledging the importance of the group maintaining coherence and stability where possible.
- The need to revisit the objectives of the programme approach to see whether these objectives were achievable. For example, one concern raised was the lack of a mechanism to influence the process of local authority commissioning and budgeting - this has particular implications for objective 9. Similarly, the focus on the medical aspects of stroke care may have implications for objectives 2 and 9 (Objectives page 39).

4.3 Results of second round of interviews

4.3.1 Awareness, knowledge and views of the HCPA

There are several aspects to awareness, knowledge and views, including the awareness and views of the programme approach as an approach to commissioning generally and specifically to its application to stroke services in Gateshead and South Tyneside. The latter includes interviewees' awareness and views of the planning and implementation of the programme approach, including the DSG, the technical document, the co-ordinator, the priority areas and the subgroups taking those areas forward. It is acknowledged that the interviews themselves may have been an awareness raising intervention.

Several interviewees had been involved in early meetings to discuss whether to pursue the proposal for a programme approach to commissioning stroke services in Gateshead and South Tyneside. The majority of these people since then had little direct involvement with the project. One interviewee was Chair of the joint District Stroke Group/ Primary Care Improvement Group subgroup taking forward the priority area 'hypertension in primary care'. One interviewee had attended two of the early meetings of the DSG before a colleague took over permanent membership on the group. One interviewee had attended one of the DSG meetings to outline health promotion policy. In late 1998 a bid to develop community rehabilitation services had been developed by the DSG and several of the interviewees had also been involved in commenting upon and inputting into the proposal's development, within a very tight timescale.

The majority of the respondents were aware of the broad objectives of a programme approach:

> *'That it was to actually look at what was provided for stroke services across the whole of South Tyneside and Gateshead, not just acute stroke but rehabilitation and community care for stroke victims and to actually look at some common themes and to try and have a consistent pathway really of the approach that we're taking for stroke victims, whether it be*

> *here in South Tyneside or in Gateshead and across the primary and secondary interface' (INT D).*

Interviewees cited a number of important positive factors of the programme approach generally:

> *'it does show you all the places where interventions can make a difference and where you ought to think about making interventions' (INT A)*
>
> *'people are meeting face to face to discuss issues so there should be an opportunity for developing joint, shared agendas' (INT B)*
>
> *'it will stop us from being quite insular, it will help us look more at what other people are doing and sharing good practice, it will hopefully help us have a more clinically effective approach to stroke and stroke disease prevention and treatment on a district basis as opposed to just what happens here' (INT D).*
>
> *'true commissioning' (INT I)*

Several respondents expressed the view that the priority of stroke had been imposed on the district, independently of current priorities and decision-making mechanisms. It was debated at the Commissioning Forum as to whether stroke should be taken forward as a priority - they decided not to support it as a priority due to workload factors and they felt that it was secondary care driven. Several interviewees felt that as a result of stroke being an imposed priority, this had hindered the project's development and could hinder its implementation. Interviewees cited the slow progress of the project and the lack of representation on the DSG of Gateshead GPs as evidence for this viewpoint.

> *'... and the Commissioning Forum had not agreed to make stroke a priority for us. ... it was set up as a separate structure. So that's caused a little bit of friction I think, over time, because people feel that it's another priority that's been foisted onto us and how many priorities can you have kind of thing, so I think from that point of view there was a little bit of political problems. But that sometimes creates problems in terms of actually moving things along a little bit ... I think there was a perception that the Stroke Group was something from afar which was being imposed upon the district' (INT C).*

Other reservations expressed by interviewees concerned the issue of control:

> *'who is going to control it across the whole spectrum?' (INT E)*

and in particular who is going to control the financial aspect of the approach.

(a) The District Stroke Group

Most interviewees were aware of the existence of the DSG, including its membership of a wide range of organisations relevant to stroke care. One interviewee felt that the social services input was peripheral to the group and another felt that members of the group did not report back effectively to the parent organisations, perhaps because of a lack of clarity as to the roles and responsibilities that membership on the group entailed. In cases where interviewees had some knowledge about the actual working of the DSG, views of it were positive:

> *'And I think the fact that the services are being proposed with a bottom up approach so we've got people on the group who actually work with stroke patients and see on a day to day basis what the needs of stroke patients and their families are, as well as having yes, managers on, who might be looking at resources and strategic planning etc. I think it's a nice mix and I think it's very good to see that, to have representatives from the coal face' (INT D).*

The DSG was seen by two interviewees as being a driver for change and a pressure group:

> *'I have no doubt, because it's got a very specialist area of interest, that at one level it can act as a pressure group irrespective of what quangos are on the horizon and satellite activities at any given point in time' (INT B).*

One interviewee mentioned the group's role in communicating with users and carers about their views and needs and was aware of the user and carer consultation days which had taken place late in 1998.

(b) The Technical Document

Nine of the interviewees had seen the Technical Document that was an early output from the DSG. Several recognised that the document had underpinned the subsequent work of the DSG. Opinions varied as to the document's content. The use of 'recommendations' was valued by one respondent and the clear sections meant that for him:

> *'you could then home in on that and then if you wanted to, if you didn't understand what they were getting at, you could then go back through the text and understand it a bit more' (INT E).*

Some respondents found it quite theoretical and difficult to understand, and felt there was a need for a more explicit action plan as part of the document. One interviewee felt that as an approach the technical document would be impractical to generalise due to the time needed to produce something so detailed. She felt that in the future people would be:

> *relying on reviews and so on and you would produce something much shorter and less comprehensive (INT J).*

(c) The co-ordinator

The majority of interviewees were aware of the co-ordinator post as part of the stroke project, and most had met with the co-ordinator on at least one occasion. Although two respondents were unclear as to the role of the co-ordinator, others viewed the role of the co-ordinator fairly consistently - to find out information about stroke services currently available, to inform the DSG in order to help them plan, and to play a part in deciding how to take that forward:

> *'I think what we really need is someone to give us a picture of exactly what services are available across the district, where and from whom ... somebody who you could go to who could say, "right, I know that that service is available from there and who does it and how much of it there is."' (INT C).*

(d) Priority areas and working groups

Although the majority of respondents were unaware of all of the priority areas chosen by the DSG, several respondents were aware of the work on hypertension in primary care (one interviewee was Chair of this sub-group in her capacity as manager of the Primary Care Improvement Group). When given the list of the main priorities that the group is focusing on, the majority of respondents felt they were appropriate. There was very little knowledge about how the individual priority areas were being taken forward. Two respondents were aware that staff from their organisations were involved in the working group taking forward the 'multidisciplinary teams in secondary care' priority area. Several interviewees expressed concern about the lack of information about the priority areas and the resulting lack of integration with their organisations' own priorities and services. This issue of integration will be discussed in the next section.

4.3.2 Policy and organisational integration

The stroke project was developed and is being implemented at a time of considerable change in the NHS in general and in the relevant organisations locally. The speed and scale of change is unlikely to lessen and this initiative can be expected to continue to experience change of a similar scale and speed as the new NHS re-organisation and other policy directives and local changes are implemented.

(a) Integration with national initiatives and their local implementation

One of the objectives of the programme approach is to integrate the stroke strategy with other initiatives. One interviewee expressed concern that stroke was slipping down the government agenda, citing as evidence that there was no mention of stroke in the recent National Priorities Guidance issued to health authorities, although it had been mentioned in 'Our Healthier Nation'. This may have important implications for the stroke project and its work, as the health authority, Primary Care Groups and Health Action Zone may base their own local priorities on these national priorities. New service developments in stroke will be in competition with other initiatives which may receive a higher profile if they are national priorities.

With regard to other recent government policy initiatives, such as PCGs, HImPs, clinical governance and HAZs, the majority of interviewees felt that a programme approach was consistent with these.

> *'Because I think it (the programme approach) embraces all of those elements that both primary care and ourselves sometimes tend to, not*

> *want to ignore, but sort of want to dismiss as being like something else and it makes you examine all of the elements of what needs to be done in some sort of rational way that can enable you to make decisions about where investments should be' (INT F).*

It is also seen as integrating well with the evidence-based practice agenda and recent initiatives such as Better Services for Vulnerable People, Modernising Health and Social Services and Partnerships in Action. In these initiatives, social services will need to target specific client groups rather than being demand or needs-led and this would thus fit more closely with the programme approach.

i Primary Care Groups:

The three Primary Care Groups in Gateshead and South Tyneside have chosen the following priorities on which to focus in the next year:

South Tyneside:	Ischaemic Heart Disease, Diabetes
Gateshead West:	Hypertension, Diabetes
Gateshead Central and East:	Ischaemic Heart Disease, Diabetes

The choice of these priority areas will have implications for the stroke project's integration with local initiatives. In the South Tyneside PCG, one interviewee reported that these priorities were chosen on the basis of the likelihood of being able to pull something together and to deliver on it, whether they were seen as important clinical areas, whether they were national priorities, and whether there was already work underway in these areas, which would continue in the future (funding was available for two facilitator posts, one in angina and one in diabetes, for the next two years).

The choice of hypertension as a priority by Gateshead West was seen as an opportunity for the stroke project by several interviewees:

> *'They (the PCG) have taken hypertension on as one of their priorities ... it would be really helpful for them to have something to get their teeth into and in some ways it may well be that what would help from the DSG would be to really get involved in the west in developing things there and I think what will happen quite a bit is that one group will, a group of people will take a lead on a thing but we will then end up you know cross*

> *referencing and getting to actually share things out across the two ... I think they're at a point where they could, they would really appreciate any kind of help and support to develop things' (INT I)*

The programme approach was seen as an opportunity for Primary Care Groups to develop a population focus, rather than the traditional individual patient focus:

> *'... I think it will be quite difficult for most primary care clinicians ... to actually be able to sit back and look at things from a population point of view rather than from the individual patient in front of them point of view so the programme approach might help' (INT A)*

However, this interviewee also foresaw problems with PCGs taking on board the programme approach:

> *'... I think the problem is, to actually appreciate what comes out of the programme approach, you already have to think in a reasonably strategic way anyway and I think the problem with a lot of Primary Care Groups is that they won't have enough strategic thinkers ..... Nominally we have had health and social services working together for the last 10 - 15 years but you know in my view there is very little evidence that that has made a difference and to assume the Primary Care Groups, which have a much more medically focused, clinically focused agenda than the health authority would have, would be able to come in and drive that through when the health authority - social services link hasn't worked I think that I'm really not optimistic' (INT A).*

ii Health Improvement Programme (HImP)

The majority of interviewees were aware that the HImP for Gateshead and South Tyneside includes a chapter on stroke, written by the DSG. This is one of twelve individual HImPs described as 'strategies for improvement'. Other individual HImPs of relevance to stroke are ischaemic heart disease, diabetes, older people and smoking prevention. However, so far, there has been no prioritisation on these different issues:

> *'I think as it (the HImP) develops it will drive the commissioning process because it will lay down the strategic areas and hopefully future ones will identify priorities. At the moment, obviously being the first one it's been*

> *difficult to, not only prioritise within the care group, if you like or the strategies that have been identified, the stroke one as an example, but across them ... there is no prioritisation taking place at all yet. Now clearly they will all be competing for the same money, if we can identify money to fund them and we need to decide. I mean the stroke group sent a proposal in which was £250,000 ish. Now I mean that's a big chunk of money just to spend on stroke. Now if it was number 1 priority out of all of them they may get that but if it was 5 or 6 you know there is a doubt whether that kind of money would be available so I think that is going to be the problem throughout. So we need several things happening I think, in the future but the HImP certainly needs to drive the priority areas' (INT E).*

One interviewee highlighted the conflict between the HImP and the priorities chosen by the PCGs:

> *'Well then you see this year round plans have been done out of synch, if you like and they don't reflect necessarily what is in the HImP. I mean diabetes for example is, is a one which they are all picking on because we have done quite a bit of work through the two diabetes groups that we have got, we have got one in Gateshead and one in South Tyneside but that's not necessarily a major priority in the HImP so again there is that conflict' (INT E).*

Diabetes is in fact one of the individual HImPs.

Although stroke is a chapter in the district HImP, two interviewees questioned whether this meant that stroke was seen as a priority by the health authority:

> *'I mean I think there's a particular issue really with the Health Authority especially, about whether this (the stroke project) is something that they're supporting as a mainstream element of developing the Health Improvement Programme, and I certainly don't get the feeling that that's the case. I mean this started out separately and it seems to run along parallel to whatever else they're doing. So that worries me, that you know, the work is being done and isn't a priority for them and how, I mean they invariably and increasingly will have an influence over any money*

> *that's associated with it, and whether they actually want to continue to develop the services. So I think making sure that it's part of some of the mainstream priorities, that is important' (INT F).*

iii *Clinical governance*

The programme approach was seen as particularly relevant to the move to clinical governance:

> *'I think in lots of ways it could inform clinical governance in that, you know, you could have your hypertension guidelines for example. If people were not managing their patients in relation to those guidelines then, you know, there's hopefully something you can do about it. But my main worry so far about clinical governance is that we've got some of the tools for it, but we're still not really 100% certain of exactly what the beast is going to be. I think, yes in theory it will do but in practice it may be a little bit more difficult than we expect it to be' (INT C).*
>
> *'... clinical governance itself is an equally systematic model of examining a practice or services so I think it complements the programme approach' (INT F).*

iv *Health Action Zone (HAZ)*

Gateshead and South Tyneside is one of the health authorities in the Tyne and Wear HAZ. Interviewees felt that the programme approach was consistent with the ideas of the HAZ, which mentions care packages and commissioning across the range of sectors for a specialty. One interviewee felt that the stroke project could act as a pilot for the programme approach, which if successful could then be taken across other districts within the HAZ.

(b) Organisational integration

There are several organisations and sectors involved in the provision of stroke services and one of the objectives of the programme approach is to improve the integration of services between them. Concern was expressed again about stroke being an imposed priority for the district and outside current commissioning and organisational planning mechanisms:

> *'....but I remember being at one or two of those meetings (the Commissioning Forum) where some of the GPs were saying, "well why are we doing this about stroke services, what's going on here, who said it was a priority, we don't think it's a priority, why are you providing that level of service?" which I think is, I mean I think it's quite good to be able to challenge that because it does make you think about, well where did this come from and I think that's a missed trick really in terms of getting some of the important people in terms of, you know, like who have the ability to influence others, to take it on board' (INT F).*

> *'I think partly there's a bit of a remoteness about the Stroke Group from the other activities that have gone on within Gateshead and South Tyneside, quite a lot of which have been centred around the (Commissioning) Forum or the MAG and although we've got some common membership, it's not actually as common as some of the other groups are and I think the fact that it's sort of been carried out outside of Gateshead as it were, with somebody looking in rather than being done internally, may create difficulties. But I think all those things can be overcome, you know, if we get the right group of people together and I think if everybody's got a willingness to improve things, you know it's the old story, nobody wants to reinvent the wheel, so if you've got something that works then we should just use it.' (INT C)*

Integration with the health authority's priority and funding mechanisms was raised by one interviewee:

> *'Well coronary heat disease is a big issue for us and you are right stroke is an element within that so again it's a question of priorities and if we have funding, do we develop the stroke programme, do we purchase more 'cabbages' (CABGs), do we put more into cardiology and angiograms and so on. I mean they are the issues, the latest thing is exercise testing, open access and all sorts of things, all very expensive stuff and they are the issues we have to grapple with, you know where do we want to put our resources, where will we get most benefit from it and that comes back to the evidence base, and it may be that there are some things we can do in stroke that are very beneficial but that we don't take the whole*

> *programme approach on board, I mean I don't know or that we do it in stages' (INT E).*

The work on hypertension in primary care was seen by one interviewee as providing the opportunity to integrate with current district mechanisms:

> *'I think that the hypertension group has sort of been brought into the fold as it were' (INT C).*

A barrier to organisational integration suggested by one interviewee was that DSG members may not have been feeding back into their organisations, as this respondent had experienced. She felt that this may have been a result of who was invited onto the group, how they were invited and what responsibilities were expected of them (INT F).

Several interviewees mentioned the use of guidelines as a method of integration with the programme approach. Guidelines are used in the trusts already, although not everyone chooses to use them. One interviewee felt that work on guidelines in the district needed to be integrated (INT A). Another interviewee mentioned the need for GPs to have a sense of ownership of any guidelines they are expected to use and the need to get influential GPs on board at an early stage in their development and implementation (INT F).

4.3.3 Impact of the programme approach

Although it may be too early for the programme approach to have an impact on the prevention of stroke and outcomes for stroke patients, some of the comments below relate to the potential impact of the programme approach.

Two interviewees felt the stroke project had made slow progress, given that the project had been running for over two years at the time of the interviews. However there was also the recognition that there had been and would continue to be a great amount of turbulence within the district, as a result of local and national changes. The national changes include those discussed in section 3.1. Local changes mentioned included changes in personnel at the health authority, the loss of a stroke consultant at one of the NHS trusts, the merger of two of the trusts and social services re-organisations. One interviewee felt these changes were a barrier to the potential impact of the DSG (INT C).

One interviewee felt the stroke project provided the opportunity for one of the trusts to broaden its view of stroke:

> *'I think it stops us being in our own little empire and actually stops us being very insular and just thinking about, "well what do we need here?". I know we need to look at local needs and address those but I think it does make us think more broadly about services which are provided and to make us think about that when we're looking at strategic services' (INT D).*

For another interviewee the stroke project had:

> *'energised and motivated me to think more laterally' (INT B).*

One interviewee felt that the greatest potential impact of the stroke programme would be if: it focused on cross-cutting themes with other work in the district such as ischaemic heart disease and diabetes:

> *'creating matrices across programmes' (INT A).*

Another interviewee described the user/carer consultation days as:

> *'an important example of the positive role of the DSG' (INT K).*

Two areas of potential impact that were seen as important will be explored in further detail - the impact on relations and joint working and expectations of shifts in resources and balance of care.

(a) Impact on relations and collaborative working

Several interviewees expressed the view that the work of the DSG and its sub-groups had a positive impact on networking between different agencies involved in stroke:

> *'What has been interesting is the networking system that does seem to be springing up from the DSG. Fellow professionals who might be there sort of counterparting another trust or whatever, who didn't know each other before and do now, and are able to discuss and compare their services and I think that would go right across all of the disciplines ... I think that has to be a good thing because it helps us all share good practice and then, you know, contacts that you can ask for advice or "what do you do about this?"' (INT D).*

> *'it's all the things that have always been said about understanding other peoples, other agencies' perspectives you know and about how we can better work together, but it does need to be equal' (INT F)*

One interviewee felt that collaborative working would result from trying to standardise services across sectors. The recent joint working around the bid to the health authority for funding for community rehabilitation teams was seen as a test of the stroke project's collaborative working (INT B). Two interviewees commented that the tight timescale for development of the bid meant that there was little opportunity for them to have an input. However it was seen by one interviewee from social services as an example of a way of involving social services, through a specific initiative rather than in the whole programme approach, when there is a tension with their needs-led working (INT G).

(b) Expectations of shifts in balance of care and resources

Interviewees had a number of expectations about the possible shift in the balance of care and resources as a result of the programme approach. These included a move of resources to community rehabilitation stroke teams with less reliance on hospital care, decreased length of stay in hospital and earlier discharge. One interviewee was looking for the DSG to provide the picture of the current balance of care, on which to base decisions about possible shifts:

> *'What I would like to see is them coming with a proposal as to how we could commission services across the board having identified what we do now. It would be no good coming up with a proposal and say, 'That's what you should do' if we don't know how we can have a transition from where we are ... so we would need to know what services we are currently buying and where, what we are spending in each of those sectors and say 'Right we have got X million to spend on stroke services, we are now going to commission these services in this way' and we could change the balance either over time or straight away in terms of we spend more on acute then primary, we could change that balance or whatever. .... I am really looking for a steer from the group as to how that programme approach could work and then we could develop it and it might be it develops slightly differently in South Tyneside as to Gateshead. ... So*

> *again we need to unpick what we spend outside the district because that would be harder to control' (INT E)*

4.3.4 The future of the programme approach

The future of the programme approach was seen by several interviewees as being partly dependent on the changes occurring on the national and local scene and therefore difficult to predict. One interviewee felt the approach could be applied to other major areas:

> *'I think there is logic in applying it in particularly major priority areas, to things like diabetes, stroke, IHD' (INT C).*

Another felt the approach would be easily transferable to other areas (INT D). The length of time that the project has taken to develop was seen as making it difficult to generalise across to other client groups (INT E). One particular aspect of the programme approach, the technical document, was also seen as too time consuming to replicate elsewhere (INT J). However this latter interviewee saw the programme approach as a useful planning tool which is currently used for other services and which could therefore be applied to other areas. One interviewee viewed the whole project as a pilot, the results of which would then raise issues about future roll-out to other areas (INT E).

4.3.5 Emerging issues and implications for the HCPA

The interviews indicated a number of issues that have arisen as a result of the programme approach to commissioning stroke services, outlined below. Given recent NHS policy changes, some of the issues identified in the development of the programme approach to commissioning stroke services will have relevance to the future of commissioning and the programme approach, regardless of changing structures and priorities for commissioning.

(a) Health authority and PCG issues:

A framework for decision-making on priority setting is needed, including a clear process, criteria and timescale. A proposed framework outlined in the HImP 1999/2000 to 2001/2002 published since the interviews consists of the following criteria by which different areas will be ranked - national/government priority, effectiveness, cost-effectiveness, disease burden, promoting self-reliance and promoting equity. Attempts to establish formal priority setting mechanisms will be constantly thwarted by further policy changes (eg winter pressures monies) and the need to spend allocations. The stroke group will be faced with similar pressures and therefore needs to develop strategies for managing these.

- The links between the DSG and the commissioning management at the health authority and PCGs need to be more explicit, including mechanisms and timescales.
- The health authority may need to make it clear whether it is supporting the programme approach as a mainstream element of developing the HImP.
- The DSG needs to be proactive in keeping stroke on the agendas of the health authority and PCGs.
- It may need to be made clearer within the district as to the accountability pathway of the DSG, especially given the emergence of PCGs - is the DSG accountable to the health authority and/or a subcommittee of the health authority?
- The tensions for a district-wide approach need to be acknowledged given the move to three PCGs covering the district and mechanisms developed for communicating with the three PCGs. Since the interviews the DSG has approached the PCGs and has representation on the DSG from two of the PCGs. In addition, a member of the West Gateshead PCG has joined the hypertension subgroup.

(b) Social services issues:

The tension between the programme approach (client group-led) and the way social services works (needs-led) needs to be explicitly acknowledged and strategies developed to tackle this. The work on the community rehabilitation teams bid was seen as one example of a way of involving social services around a specific issue.

The DSG needs to ensure the local authorities are committed to and share the same vision for the programme approach to stroke.

Two interviewees felt it may be appropriate to use pooled health and social budgets for areas of joint working. This would be in line with recent government initiatives such as the Modernisation Fund and Partnership in Action.

(c) Other issues:

Two interviewees raised the view that the DSG's work had a secondary care bias (INT G and INT I). This raises the issue of further dissemination of the group's work to primary care and other sectors (again this may have been partly addressed by the recent launch event).

Several interviewees mentioned the need for the stroke project to take into account and implement the evidence on how change is negotiated and the management of change (INT A, I)

One interviewee raised the issue of a lack of communication and knowledge-sharing about stroke data in the district, given the amount of information that is collected both in Gateshead and South Tyneside (INT B).

Following the interviews the evaluation team fed back to the DSG findings obtained for discussion.

4.4 Results of third round of interviews

4.4.1 Implementation

Key events in the implementation are listed in Table 3 page 35 and a description of the Development of the HCPA during this study on page 33.

From autumn 1998, the implementation phase of the initiative continued. In November 1998 two user/carer consultation days were organised by the DSG - one was held in Gateshead attended by 22 patients and carers, one was held in South Tyneside attended by 18 patients and carers. Facilitators from the Stroke Association and the two trusts attended both these days. Issues of concern raised by users and carers included lack of information, poor discharge arrangements and long-term care and rehabilitation.

During December 1998, and within a very tight timescale, the DSG chair led the development of a joint proposal for community stroke rehabilitation teams, one for Gateshead and one for South Tyneside, in collaboration with other DSG members and a number of other people within the trusts and social services. The lead clinician from Gateshead had submitted a draft proposal to the DSG meeting in November for discussion. South Tyneside then developed a similar proposal. These bids were discussed at the December DSG meeting and there it was decided to submit a joint bid covering both sides of the district. The final bid was submitted to the health authority for consideration for funding from district growth monies or the Modernisation Fund. It proposed to develop a minimum core service for community rehabilitation services across the district. The health authority was considering a number of proposals within the remit of the Health Improvement Programme (HImP). Monies for the HImP implementation would only be available from Health Action Zone (HAZ) monies. However it was not until July 1999 that the HImP Steering Group met to discuss priorities and the implication of this for the stroke project was still unknown at the time of these interviews.

During the first quarter of 1999 the DSG reviewed its priorities and began a review of the Technical Document, bringing this up-to-date. In April a 'launch' meeting for senior managers and local decision makers was held which aimed to raise the profile of the DSG's work and to provide a forum for discussion of the current work of the DSG and future activity. Invitations were sent to over 100 local decision makers in the district, including DSG members, chairs, directors and other senior managers of the Stroke Association, other voluntary organisations, the two health trusts, the two local authorities, the health authority, the Local Medical Committee, the Commissioning Forum, the Multidisciplinary Audit Group (MAG), the three Primary Care Groups (PCGs), HAZ co-ordinators, the Community Health Councils and Health Promotion. Approximately 40 people attended the day, which consisted of brief presentations from the project manager, co-ordinator, DSG chair and Director of Public Health, with questions from the floor. As a result of this meeting, in June, the Chair and Project Manager of the DSG met with senior managers and directors from Gateshead trust to discuss improving the links between the stroke work and the trust's business and strategic planning.

Because of the importance of the policy change towards PCGs, further details of the implementation of this policy in Gateshead and South Tyneside are provided. During the end of 1998 and the early part of 1999, PCGs were being established in Gateshead and South Tyneside. Three PCGs were established - one covering South Tyneside, one covering West Gateshead and the third covering Central and East Gateshead. These PCGs went live from April 1999, although the groups had already undertaken business such as choosing local priorities they wished to focus on in their first year. In February 1999 the Chair of the DSG wrote to the chairs of the PCGs outlining the stroke programme approach, offering to discuss this further and asking for a representative from each PCG to join the DSG. South Tyneside PCG nominated the South Tyneside GP who was already on the DSG as their representative, West Gateshead sent one of their Board members, a health visitor, who attended for one DSG meeting in March 1999 and Central and East Gateshead PCG did not feel it was appropriate to nominate a member.

Throughout this period of the initiative, the stroke co-ordinator networked with a wide range of service providers and managers across Gateshead and South Tyneside. The co-ordinator had a lead role in the multidisciplinary teams forum, led the organisation of the user/carer consultation days, was a member on the hypertension sub-group, reviewed long-term care provision in the district and produced a report from this review.

Progress on the individual priority areas together with interviewees' views of progress is discussed here.

4.4.2 Progress and achievements

Interviewees were asked for their views of the progress of the work on the priority areas chosen by the DSG and of other areas of impact and achievement of the programme approach.

(a) Progress of the priority areas

A general view expressed by several interviewees was that progress of the priority areas had been slower than anticipated:

> *'There's been a mention of various subgroups. A lot of times the subgroups say, oh we haven't met yet or we're meeting tomorrow or something's going to happen, we'll report back next time and I'm not entirely convinced it ever does. And there's one that I'm supposed to be sitting on and I am still waiting months later to be invited to the first meeting of this group ... and so I get the distinct impression from the Group that the Chair is trying his very hardest to push things forwards and has, shall we say, limited support from his clinical colleagues.' (INT XIII)*

Another general issue raised by interviewees included members involvement on the subgroups, in particular any new groups formed to take forward further priority area:

> *'to take on something that is really going to be a lot of work, I think that's a bit of a problem - trying to get somebody who's a willing person, who is enthusiastic to say, right, I'll take on this next priority area, who else is going to join this group. Because again you've got time away from whatever area that, for myself, my clinical area to go to these meetings and when we're talking about a few hours at a time that soon adds up, aside from the work that you might have to do away from the group. So I think that could be a problem with all these priorities that are coming up. But obviously it's a process that we've got to go through if we're going to try to meet the priorities that need to be addressed' (INT VII).*

i Hypertension in primary care

In July 1998, a joint sub-group of the DSG and the district MAG was established to take forward the 'hypertension in primary care' priority area (see Figure 6).

This subgroup adopted and adapted British Hypertension Society guidelines and developed a plan for their local implementation across the district, consisting of a rolling programme of local facilitation, education and audit. The idea of a district hypertension facilitator was abandoned when the local MAG felt the district already had sufficient facilitators (in angina, diabetes and cardiac rehabilitation). It was felt to be more appropriate that these facilitators should know about the hypertension guidelines and should give out messages consistent with them.

West Gateshead PCG chose hypertension as one of the local priorities on which it wished to focus in the first year (1999/2000) and engaged in discussions with the hypertension subgroup and with the DSG project manager about appropriate ways to join efforts. The other two PCGs had chosen the management of angina/cardiac rehabilitation and diabetes as their local priorities. Central and East PCG, concerned that the hypertension guidelines would deflect from the PCG's own priority work, expressed the wish that the guidelines were disseminated with no active implementation activity. If the implementation in West Gateshead was successful, then they may consider rolling this out to Central and East Gateshead. The DSG felt this raised wider issues about local and district priorities and in June the hypertension group was suspended whilst discussions took place with PCGs and the health authority. The MAG was disbanded from April 1999, the chair of the hypertension group becoming project manager of the Central and East Gateshead and West Gateshead PCGs. The DSG project manager has joined the West Gateshead group taking forward hypertension.

Five interviewees were members of the hypertension subgroup. The other interviewees mainly received news about the progress of the hypertension group from the DSG meetings and minutes from the hypertension group meetings which were circulated to DSG members. Although the majority of respondents felt progress in this area had been made, this progress had been slower than anticipated (particularly expressed by those on the hypertension group) and, with problems arising from the PCGs, they felt it likely that a longer timescale for the implementation of guidelines would be needed. However the choice by West Gateshead PCG of hypertension as one of it's priority areas was seen as an opportunity to link in to new structures in Gateshead. The marginal benefits of taking a district-wide approach to a topic such as hypertension was viewed as important by respondents, as compared to different parts of the district separately working on it.

One interviewee, who had not been involved in the project during the priority setting process, was surprised to see hypertension as a priority because he felt GPs and clinicians should be working in an evidence-based way already with regard to hypertension. He felt it was more appropriate to focus attention on more stroke-specific issues.

Of those interviewed who were members of the hypertension group, one felt the mix of people on the group was appropriate, two felt their own role within the group was appropriate, and one felt the chair was key to the progress made on the group. However the lack of Gateshead GP involvement and the lack of consultant involvement was a concern and one interviewee felt this had resulted in a lack of ownership of the work by these two groups in the district. Another interviewee commented that because of this lack of inclusion, it was perceived in Gateshead trust that the guidelines were being imposed. An interviewee stated that Central and East Gateshead PCG were actively staying away from the guidelines because they felt the development of the guidelines had not been an inclusive process. However other respondents felt the planned review of the guidelines (in April 2000) would be an opportunity to get others in the district on board.

The issue of the resources necessary to undertake any implementation work was raised, in particular the need to be able to offer PCGs resources:

> *'I think facilitation is great but people don't tend to take it on board if there is a cost element to it and PCGs are very much aware of money just now' (INT III).*

Another interviewee felt the group had influenced the MAG to put resources from it's 98/99 budget into hypertension.

One interviewee expressed concern that the guidelines paid little attention to absolute risks and the management of hypertension in elderly people, as the British Hypertension guidelines are focused on middle-aged people.

Figure 6 Hypertension Subgroup

Membership:

- Primary Care Improvement Group Manager (chair)
- MAG audit facilitator
- 2 South Tyneside GPs (1 GP also DSG member)
- 2 Gateshead practice nurses
- District pharmacist
- DSG project manager
- DSG co-ordinator
- Senior lecturer in stroke medicine (also DSG member)
- Gateshead GP (Board member of West Gateshead PCG) attended 1 meeting

Meetings

- Eight from July 1998 - April 1999 (plus 3 smaller meetings), suspended

Action:

- Reviewed hypertension guidelines,
- adopted and adapted British Hypertension Society guidelines,
- developed patient held record,
- developed implementation strategy consisting of education, facilitation and audit.
- Guidelines disseminated to all general practices in Gateshead and South Tyneside, clinical governance leads, consultant physicians, health promotion and district facilitators.

ii Multidisciplinary Teams in Secondary Care

In August 1998 a 'multidisciplinary teams in secondary care' group was established, consisting of operational staff from the two trusts and social services (see Figure 7).

Figure 7 Multidisciplinary Forum

Membership:

- DSG co-ordinator,
- DSG project manager
- From Gateshead and South Tyneside trusts - heads of PAM services, sisters from stroke units, physiotherapists, occupational therapists, speech & language therapists, psychologists, social services

Meetings:

- Eight from August 1998 to July 1999, continuing

Action:

- Development of service level agreements and service specifications,
- Sharing good practice,
- reviewing care pathways for stroke patients across the district

This group worked on developing service specifications. It examined the results of the Royal College of Physicians' Sentinel Audit and from these set standards which could be integrated into service level agreements. An initial draft of a service specification was discussed at a DSG meeting in May 99.

Five interviewees were members of the Multidisciplinary Forum. As with the hypertension group, other DSG members received information about this priority area from minutes and DSG meetings. The majority of all interviewees were positive about the benefits of this group. These benefits were described as helping them appreciate the pros and cons of each other's practice, providing a *professional forum* for sharing good practice and providing an opportunity to meet with providers from both sides of the district, both at and outwith the meetings:

> *'it's enabled sharing of experience of practice between the two provider units ... has highlighted examples of good practice within both' (INT X)*
>
> *'understanding what their ... key priorities and problems and issues are ... learning about the actual management and care and is there differences ... you could learn so much from it' (INT VIII)*

One interviewee commented that more information was disseminated at the multidisciplinary group as compared to the DSG because representatives were present from each profession. Another viewed the group as providing the 'reality', whilst the DSG provided the theory. It was also seen as providing a source of support from others in a similar position:

> *'I thought it was useful to get that comparative view ... it's useful to have other support in recognising the plight you often feel in the paucity of services' (INT XII)*

Other positive outcomes of this group included better working relationships and improved networking. One interviewee felt it was important for social services to be involved in this group:

> *'because that's what multidisciplinary is, it's not just different professions, it's different agencies' (INT V).*

The group had also helped to inform local thinking when Occupational Therapy (OT) services had undergone a review in Gateshead, encouraging the identification of stroke medicine as a specialty requiring its own input and increased resources.

Some of the interviewees who were members of this sub-group felt more empowered as members compared to their membership on the DSG. This sense of belonging and empowerment was evident when an outside initiative on stroke was discovered, which had not involved the stroke group or multidisciplinary group:

> *'everybody got up in arms about this coming from outside and not talking to us and I suppose in that sense you feel you've created a group that feels it has an identity and then feels concern that other things going on in the district aren't part of that.' (INT XI)*

However again the slow progress of the group in undertaking specific tasks was mentioned by interviewees:

> *'partly because of the complexity about exactly how a product from that Group will be used within the trusts and the health authority. I think a part of that again reflects the changes in the health service so that there's not total clarity, partly that reflects confusion perhaps at our level about exactly what a service specification should look like' (INT XI).*

In addition, the dissimilar services across the two trusts was felt to make it difficult to set standards to apply across the whole district.

The lack of medical input into the group was raised as an issue by two interviewees, for example: there isn't any medical input into that ... I feel the balance of the Group is a bit wrong because we don't have that, it's very rehab oriented (INT IV). Another interviewee, not a member of the forum, felt the group had not used the knowledge and experience already available in this area:

> *'there's been a lot of re-invention of the wheel ... it would be much better to start with national guidelines as a basis for local discussions and that doesn't seem to be being done ... there have been, as well as the Intercollegiate stroke guidelines, there's been several other sort of initiatives to draw up standards for multidisciplinary care and several other research projects ... which really should be used as the basis for these discussions, and I'm afraid that the result of that particular Group has been to work in parallel and to come up with a different set of guidelines, service specifications and so on which are absolutely going to clash with the national work that has been going on, so I think that's been poorly organised' (INT VI).*

The potential impact of the group's work on the care of stroke patients was mentioned by two interviewees, for example:

> *'I think that will have a direct impact because we are looking at standards of care ... we agree that we need to have specific standards, have a uniform approach, not just within South Tyneside but within Gateshead' (INT VII).*

How this impact would be achieved was raised by one interviewee who felt the key decision makers had not so far been involved:

> *'they need to reform in some way and capture how they're going to get into the minds of the people who make the decisions' (INT VIII).*

However this interviewee also acknowledged that the group did contain the necessary operational staff who can influence change at their level:

> *'because it's got the team who can influence the changes at their level and it's something that you can discreetly get a hold of that you can take back to your own directorate and debate, as your idea maybe, not an imposed idea. We're saying this is what someone else is doing, what's the views' (INT VIII).*

iii Long term care and support

This priority area was taken forward by the co-ordinator who collected information on current practice to inform further discussion within the DSG on specific priorities in this area. In March 1999 a report was tabled at a DSG meeting outlining the main points and recommendations from the review. Discussions were held as to what further actions were to be taken and at future meetings these actions were reviewed. Actions included inviting a local authority representative to a DSG meeting to explain the process of aids and adaptations requisitions. One interviewee described this process as

> *'giving people a much better understanding of what's going on ... we've obviously started some thoughts and discussions in terms of how the system can be improved' (INT XI).*

An interviewee from social services felt this priority area was an appropriate area for the local authority to get more actively involved. Another interviewee pointed out that there are quality standards for long-term care and felt:

> *'it's just a matter of picking the ones which are appropriate to the local situation' (INT VI).*

iv Information and audit

Both trusts took part in the Royal College of Physicians' Sentinel Audit. A report on the analysis of the Common Minimum Data Set (CMDS) and information from the programme budget based on in-patient and day case activity were tabled by the evaluation team at DSG meetings in the spring of 1999. Discussions about data quality and interpretation took place. At one DSG meeting a representative from the Gateshead stroke research unit reported that a comparison between the CMDS results and the unit's own data showed they compared well (420 patients on the stroke register compared to 413 from the CMDS data). The representative agreed to let the evaluation team have the comparative information from the stroke unit once it was complete. Issues about coding and case mix were also discussed.

Figure 8 Information and Audit

Information and audit - elements

Evaluation - analysis of CMDS and programme budget for in-patient and day case activity tabled and discussed at DSG meetings in spring 99.

Royal College of Physicians' Sentinel Audit - Gateshead and South Tyneside trusts participated. Results published in February 99.

South Tyneside audit - prospective audit over one month. Results not yet available

Social Services audit - proforma developed for one month prospective audit. Not undertaken.

Interviewees were asked for their views on the data presented. Several interviewees felt the data was useful but that it raised many questions about data quality and interpretation. There was a mixed response to the validity of the data, with some interviewees feeling it was comparable to Gateshead's stroke register data and others feeling retrospective data was not reliable. Two interviewees raised concerns about whether the data would be robust enough on which to base commissioning decisions, in particular about shifting resources, for example:

> *'the way costs are set out in trusts ... it underpins the complete total cost of the trust ... so if you try and start moving it around there's going to be an impact on that (INT II)'*

However this interviewee felt the cost information would help the targeting of any new resources. Another interviewee felt it highlighted the inadequacies of data collection but so far had not addressed the creation of systems to allow improved recording of useful data. One interviewee felt prospective comparative data from both Gateshead and South Tyneside trusts was needed. An audit at South Tyneside had taken place but the results of the audit had so far not been fed back to the DSG.

One interviewee felt the cost data had raised interesting questions to explore further, including the appropriateness of some of the budget going to services outside the district

> *'it's raised those questions not just within the Stroke Group but it's clearly been picked up within the providers as well. So that's an example where presenting analysis of data can create a shift in thinking' (INT IX).*

Another described how data presented had started to get people thinking:

> *'I think that the audit that was done started to get people thinking a lot more and actually looking at what we were doing ... it gave some encouragement to people when they realised they weren't doing too badly, but it also identified that there are differences and we need to look at why and if it does nothing else I would hope that it pushes Gateshead and South Tyne stroke services much closer together' (INT XIII).*

One problem to be addressed by the DSG was that social services did not routinely have information about the number of stroke patients that they had contact with, because client's categorisation was based on functional categories rather than disease-specific categories. A sub-group of DSG members, including social services representatives, drew up a proforma for a month's data collection at social services to get a picture of the numbers and types of referrals. However this audit did not take place because both social services' Departments experienced a number of organisational changes including changes in documentation. One interviewee described future plans for bringing together health and social services information through the NHS number. This would mean a radical change in their information technology systems which are currently not sophisticated enough to meet this task.

v *Secondary prevention*

This priority area had not progressed due to changes in personnel at the health authority. Two interviewees expressed frustration at the lack of consultation and progress of this priority area. Both felt that when it was taken forward it would need strong medical leadership.

(b) Other impacts and achievements

Interviewees were asked to identify what they saw as the other main impacts, achievements and changes of the initiative.

Generally most interviewees felt that the DSG provided a useful forum to discuss stroke services and some felt this forum was gathering momentum and would achieve change in the future. However others were pessimistic about what they viewed as the overall lack of progress of the initiative, although they acknowledged that this was for a number of reasons, including policy changes and the setting up of the PCGs. As a result of these changes, it was felt that any change as a result of the programme approach would require a long timescale.

Two interviewees felt the approach had had little impact on social services due to changes in the organisational structure of the Local Authorities, a review that had been undertaken at one of the departments, special transitional grants had dried up putting extra strains on their resources, other issues being seen as having priority and the programme approach being seen as not as relevant to social services because of its disease-specific focus. However, one interviewee felt stroke had been kept on the social services agenda.

Some interviewees felt the profile of stroke had been raised in the district as a result of the initiative, others felt the profile of the DSG was not high, particularly in primary care:

> *'the Stroke Group still doesn't have a particularly high profile, there's a lot of people who don't know who they are and especially within the different PCGs.' (INT III).*

The Technical Document was seen as an achievement, as it was being used as a resource both locally and nationally (it was featured in a Stroke Association 'good practice' resource pack).

i Impact on collaborative working and relationships

The multidisciplinary and multi-agency DSG was itself seen as having a positive impact on collaborative working and relationships:

> *'actually getting a cross-district forum together is bound to be useful ... even to get informal discussions about the differences in organisation of stroke care, the differences in the way things are done in the two trusts are very useful ... none of the clinicians of any professions have a clue what goes on in the health authority and vice versa. Health don't know what social services are up to and so on ..., so actually getting a forum together, having a formal meeting is good' (INT VI).*

One example cited by interviewees of collaborative working was around the development of a bid to the health authority for community stroke rehabilitation teams in the district (as described in section 2 above). One interviewee felt this was the group's response to the identification of a gap in services and of unmet needs. Several were disappointed that the bid had not yet received approval:

> *'again it goes back to the different agendas that other people have, and the fact that we are very dependent on other people buying into what we put forward and I think that's just a very difficult climate. There are too many competing priorities that people see as being, maybe not more important, but being more immediate, such as PCGs having the immediate concern of succeeding in the first year or two of their existence' (INT III).*

Two interviewees commented that the tight timescale had made it impossible to consult everyone on the bid that needed to be consulted, leading to a lack of ownership - one felt this was a lost opportunity. Two interviewees felt the proposal was consistent with the social services priorities, including a community-based focus and an emphasis on partnership working, however a view was also expressed that the final bid was biased towards a medical model. A member of the DSG from South Tyneside had put the bid forward to the director of social services for consideration of modernisation funds but it had not succeeded, due to other priorities being judged higher. One interviewee involved in the development of a bid from Gateshead, which was then taken forward along with the South Tyneside proposal to produce a joint bid, felt their original bid would have had a greater chance of getting funded as it was less expensive - the lack of success with the health authority so far was felt to be partly due to the size of the sum requested for funding. The disparity of funding between the two bids, which was equalised during the merging of the two bids was felt to be a stumbling block. Two interviewees felt there was still opportunity to work on the bid as a district-wide proposal, trying to identify other sources of funding. This would also provide the opportunity to consult and get on board people not involved in the original bid due to the tight timescale. Two interviewees felt the lack of success with the bid potentially reflected the status of the DSG in the district:

> *'You sort of hope that if this Group's got any power or any influence at all then that sort of proposal you would have hoped would have got support. So once that was turned down I started to think well what is this Group. It's just a group of people sitting chattering, because if it can't influence that decision to fund a community stroke rehab team, then what can it do?' (INT XIII)*

Several interviewees mentioned that the programme approach enabled members to appreciate the roles and responsibilities of the different agencies and professionals involved, where areas of overlap and gaps occurred and provided an opportunity to develop networks between these:

> *'it gives the mandate to work collaboratively particularly given we've emerged from this nonsense of having to compete with each other' (INT XII).*

The focus on one disease enabled DSG members to see how many professionals and agencies were actually involved in stroke and to realise how confusing this complexity may be for patients.

Another example of collaborative working as a result of the DSG work was when colleagues from the two social services departments in the district met to discuss ways to take forward a social services audit of stroke referrals.

One of the clinicians interviewed expressed the opinion that his pessimistic view about the lack of practical progress and outcomes may be different from other group members, particularly from the social services and community nursing side, who, he felt, may feel that getting people together is achieving something, *placing more value on that.* For him this was *not enough* and it was more important to have practical outcomes. However he did acknowledge that in the longer term

> *'the sort of relationships that have been encouraged to develop in the DSG will show themselves to be of value' (INT III).*

The impact on relationships was viewed as being greater at an individual level than at an organisational level. Several interviewees mentioned the impact on them personally, enabling them to get to know other stroke care providers and to develop good working relationships with them:

> *'being a member of the Group is helpful because then I've got access to the various people that I just wouldn't have had ... it's helpful for me and it translates to me in my clinical role because I have got this awareness of what's going on at district level. I'm more informed so I'm sure the fact that I am more informed is helpful for me in my role and informing others' (INT VII).*

Being involved in the approach had cemented relationships for some, for example between the acute trusts and the Stroke Association:

> *'the links that have been made in Gateshead will continue and ... will grow' (INT IV).*

ii Impact on services for prevention of stroke and care of stroke patients

The work of the DSG had highlighted and heightened the awareness of gaps in stroke services and the differences in services between Gateshead and South Tyneside for several interviewees:

> *'now it is much clearer that they are very dissimilar' (INT IV).*

There was a general view expressed that, as yet, there had been little or no impact on actual services to patients and carers, or on the working practices at grass roots level. However, one interviewee felt it may have an impact on service provision in the future:

> *'with the Stroke Association ... it has allowed them an opportunity to perhaps understand the whole picture from a group point of view and to see how things work and what the broader picture is so that they can actually look themselves at how they would like to provide their services and fit in with health and social services (INT X)'.*

Another mentioned the impact on plans for changes in OT services in Gateshead:

> *'the work of both the District Group and the Multidisciplinary Group has helped to inform local thinking, because we have had to review that, and we've identified stroke medicine as being a speciality that requires its own input as it were, and we've actually looked to increase the amount of resource' (INT XII)*

iii *Impact on strategy and commissioning*

Many felt it was too early to say if there had been or would be any impact on commissioning because of changes in policy such as PCGs and HImPs and changes in personnel at the health authority. However, most acknowledged there had been an impact on strategy because of the presence of a stroke chapter in the district HImP:

> *'it not only has an immediate impact but it's going to be there for a period of time so it's become a strategic issue for the health authority (INT IX). However: the question is whether any of the stroke priorities are sufficiently high up the agenda to get anywhere' (INT XI).*

The importance placed on the HImP by DSG members is evident from their increased attendance at DSG meetings at the time the HImP appeared on the DSG agenda during the summer and autumn of 1998 (see appendices).

There was no evidence of any impact on trust strategy as yet and there was nothing in the trust business plans about the stroke programme or any aspects of its work. Interviewees felt this was partly because the relevant decision-makers at the trusts had not been engaged in the process. However, since the 'launch' event, there was evidence that these people were becoming more actively engaged.

One interviewee described how there had not been an impact on commissioning yet because of the way the DSG was set up:

> *'it was set up to do some work and then put a recommendation to the health authority and then the health authority would consider that and decide whether it was the right thing to do ... so the health authority's awaiting that if you like. I mean it's had a bit of an impact in terms of work that the health authority's doing like the elderly strategy work and things like that' (INT II).*

However, because of the HImP, the 'launch' day and the bid for community stroke rehabilitation teams, the directors at the health authority were more aware of stroke services and what was needed and therefore these had raised the profile of stroke within the health authority. Prior to this, stroke had not been one of the district priorities and one interviewee mentioned that stroke was not a priority within the national priorities issued by the Department of Health.

iv Impact on balance of care and resources

Interviewees again felt it was too early for any impact to have occurred on the balance of care and resources. Some issues had been highlighted which may have an impact in this area, such as the amount of imaging/scanning work undertaken for the district at Newcastle General and the length of stay at South Tyneside trust. The bid for community stroke rehabilitation teams, if supported, would potentially lead to a shift from in-patient settings to the community. Some of the MAG budget from last year was being used for the hypertension work. The Royal College of Physicians' Sentinel Audit had involved audit monies from the two trusts going into stroke audit. Further OT resources for stroke patients had been identified (as mentioned in 07 2.1.2).

4.4.3 Facilitators and barriers to change

Interviewees were asked to identify the facilitators and barriers to change which had impacted on the implementation of the programme approach in Gateshead and South Tyneside.

(a) Factors facilitating change

Interviewees identified a number of factors which they described as facilitators or drivers to change:

Structure of the programme approach, with its elements of the multidisciplinary DSG, the Technical Document, priority setting and working subgroups - providing mechanisms for taking forward implementation of work.

Evidence-based approach, as encompassed in the Technical Document. Exchange of evidence at DSG meetings and multidisciplinary Forum meetings.

NHS policy changes, including the Health Improvement Programme and the 'Modernisation' move with its emphasis on partnerships:

> *'the whole sort of thrust is about ... moving towards these programmes of care and longer term service agreements. So I think it can only strengthen what the Group's trying to do really' (INT II)*

National drivers, such as the Royal College of Physicians Sentinel Audit, the Intercollegiate Stroke group, national research.

Research-driven and funded:

> *'because it is a research project with commitment from them, it was an experiment that had to be followed through and the thing which has kept the Group together' (INT III).*

Key individuals:

> *'and their ability to communicate and share and really wanting to understand where other people with slightly different perceptions were coming from. So I think the Chair has done a very good job of chairing what at times have been very difficult meetings and facilitating and enabling things to happen. Similarly in terms of the Multidisciplinary Forum, the co-ordinator has obviously been key to that. And I think to be fair with the now defunct Hypertension Group, I think the Chair was key to making that happen. But the successes I think relate to individuals rather than to organisations' (INT X)*

Involvement of clinicians in a strategic approach:

> *'I think that the involvement of clinicians with the strategic process has influenced both what the strategy is but also has resulted in greater ownership of the strategy' (INT XI)*

(b) Barriers to change

Respondents described a wide range of obstacles faced during the course of the initiative:

i *District Stroke Group*

Changes in membership of DSG and non-attendance of some members at DSG meetings:

> *'it's been made difficult because new people have constantly seemed to have been coming into the Group and that disrupts the Group's formation and working together' (INT II)*

Process of involvement in DSG:

> *'it has been difficult to get representatives ... from some key components of stroke services, involved on a regular basis ... some of the individuals haven't seen themselves as representatives of their organisation and the networks of feeding back into their organisation haven't always been as strong as we would have liked' (INT X)*

Lack of Gateshead primary care involvement on DSG:

> *'so I think for credibility and also for support and to add to the dimensions that the Stroke Group has to offer it should have greater primary care involvement and that's been lacking' (INT III)*

Lack of a high profile for the DSG:

> *'the Stroke Group still doesn't have a particularly high profile, there's a lot of people who don't know who they are and especially within the different PCGs' (INT III)*

ii *Local changes*

Changes in personnel within key organisations, particularly the health authority and the acute trusts (eg loss of a stroke consultant from South Tyneside):

> *'I think the instability within the district health authority itself has not helped, particularly in the public health department and the loss of consultants. And so in a way it's not been possible to engage that department at quite the level we'd have wanted to ... because they don't have a consultant in post, and it's not just the public health, there's been lots of problems within the health authority itself' (INT IX)*

Structural changes in organisations and policy, eg social services review and re-organisation

iii National policy changes and their local implementation

Primary Care Groups:

> *'I don't think we were quite anticipating that PCGs would actually be a barrier. I think we were expecting them all to be keen to co-operate and work with us ... I think we were a bit taken aback that it's not been as straightforward as that. And I think there was a feeling that because we had the backing of organisations that were on their way out, that that sort of commitment would continue with new organisations' (INT III)*

> *'and I think it's difficult to know whether the problems have been more or less in Gateshead and South Tyneside than elsewhere but possibly because there's been very little fundholding and total purchasing pilots, so commissioning is quite new to GPs ... so in a sense they're having to work through a lot of the issues about what has to be done on a wider basis by the health authority and what can be done locally ... what does that mean to us and what PCGs can and can't do' (INT XI)*

Different and competing priorities of others, in particular PCGs:

> *'there are too many competing priorities that people see as being, maybe not more important, but being more immediate, such as PCGs having the immediate concern of succeeding in the first year or two of their existence' (INT III)*

Amount of policy changes:

> *'it was very unfortunate that there have been an awful lot of changes within a very short period of time ... that creates all sorts of difficulties for an organisation which is trying to achieve a particular aim, especially when that aim is very much dependent upon external factors' (INT III)*

Stroke falling down national agenda:

> *'The other area ... has been the falling of stroke off the national agenda. ... but certainly some people I've talked to perceive that actually that's*

> *very important that basically organisations, health authority and social services, will respond very much to what's perceived as the thing to do and if it's an important target in Our Healthier Nation then it's jumped at, if it's not in there then you don't have to worry about it ... with discussions with PCGs it's harder to raise Health of the Nation targets, so that might have some negative influence' (INT XI)*

iv Paradigm issues

Programme approach versus locality approach:

> *'the reform that's sort of proved the most problematic for the programme approach has been the development of Primary Care Groups ... there's a number of ways of looking at it but to some extent the reason is that that's emphasising a locality, horizontal approach to commissioning which it's then difficult to see how a programme (vertical) approach does fit in with that' (INT XI)*

Disease focus and working with social services (which is disability-focused):

> *'one of the problems I have and the department has is that we wouldn't identify stroke as one area, ... we look holistically at all of the various people and somebody referred to social services, the assessment procedure's the same whether they have a stroke or not ... I think all we would be looking at is the effects that the stroke has, the social effects and the effect on care' (INT V)*

v Other barriers

Stroke as an imposed priority within the district

Externally driven project, link to evaluation/research:

> *'probably that's just the nature of a project like this, that to an extent because it's an evaluation and because it's trying out a new model and a new approach, it's not part of the mainstream activity, and even though getting plugged into the HImP has helped with that, there's always this slight tension between an externally driven project, at least partly*

> *externally funded, and what is core business for the local services' (INT IX)*

Availability and quality of information, eg activity data, costs and information

4.4.4 Key elements of the health care programme approach

Interviewees were asked for their views of the importance of the key elements of the programme approach, namely, the formation of a DSG, the development of a Technical Document, the appointment of a co-ordinator and the agreement of priorities.

The majority of interviewees felt all four elements were important and necessary to the programme approach.

(a) District Stroke Group

The DSG was viewed as essential by the majority of interviewees:

> *'the Group itself was very important because obviously bringing people together who have an interest and want to push this forward is the driving force behind everything we've done, and I think the whole thing would have been a lot slower if we hadn't had the Group, and I think it would have been harder to get people on board, and you wouldn't have got the sort of add-on benefits of more working together and all those things' (INT II)*

The importance of having the key decision-makers and change agents from all the relevant organisations and sectors with an interest in stroke as members of the Group was stressed, with the emphasis being on the 'right' stakeholders, including policy makers, care professionals who regularly see stroke patients and user/carer representation. Members of the DSG should be clear about their own roles and responsibilities as members of the Group, in particular, their responsibilities in relation to feeding information between their parent organisation and the DSG:

> *'the District Stroke Group ... is also essential because it is the only forum where people can meet but I think you would need to look at how that*

> *actually fits in with other organisations, particularly those who are responsible for deciding and influencing policy' (INT X)*

To enable the 'right' members to be identified for the group, one interviewee emphasised the need for initial networking.

Interviewees were asked for their views of their role within the DSG and the effectiveness of the DSG in involving the relevant professionals and agencies. None of the interviewees mentioned that they should not be involved on the DSG. However some felt they did not have a very active involvement - describing their role as a 'messenger' or a conduit between the DSG and their organisations:

> *'to take back the information to my organisation and feed the various bits back through the appropriate channels' (INT VII).*

One felt this was in part because within her organisation she cannot make decisions. Others felt they had a very specific role within the DSG, bringing their knowledge and expertise to the group, whether it be stroke-specific knowledge, knowledge of the way their organisations function or knowledge about a particular discipline or care perspective such as a GP, an OT, etc. Some expressed frustration at the lack of attendance of some members of the DSG at the meetings. A few interviewees who felt that this had had various 'knock-on' effects, including the sole GP on the group feeling pressured to attend meetings and join sub-groups, mentioned the lack of effectiveness involving Gateshead primary care. One interviewee attended on behalf of two DSG members who could not make the meetings due to busy work schedules and saw her role as feeding back and keeping up-to-date in both directions. There was a view that key decision-makers were missing from the group or were not engaged via the current members of the group:

> *'and I know that everyone's got a representative on the Group, it's maybe, are they the right representatives within the Group?' (INT VIII)*
>
> *'how people who sit on it are actually lodged within their host organisation' (INT XII).*

The need to have representatives from more senior management within the trusts and social services was felt to be necessary. Social services representatives felt they had a 'watching brief' on the group because of the more medical focus of the group. They felt they fit in with multidisciplinary forum better:

> *'because it is very much hospital and health based, it is very difficult for social services, and we tend to get dragged along in the wake in a way' (INT V).*

One interviewee particularly valued the strategy of the DSG to invite people to the meetings to discuss particular issues, without becoming formal members of the group.

(b) Technical Document

The Technical Document was seen as a necessary working tool providing a baseline on which to start and providing evidence of the effectiveness of interventions. It provides the basis for discussion within and outside of the DSG and gives a legitimacy to decisions:

> *'if we didn't have the Technical Document to support the decision making, then again everything would be a bit waffly and everyone would be trying to put across their perspective of what the evidence is for whatever intervention you are looking at the time' (INT III)*

People outside the group have found it useful: *outside the group people were perhaps unaware of what were the issues and so it has perhaps drawn attention to those.* Involving DSG members in putting the document together was valued by DSG members, rather than having an external document imposed on the group. However the time taken to develop the document and the need for regular updating needs consideration. A social services representative reported that she and her social services colleagues had found the document difficult to digest because of 'medical jargon'.

(c) Co-ordinator

The role of co-ordinator in a programme approach was valued as it was seen as a dedicated point for networking amongst all the relevant parties and on a day-to-day basis keeping the various elements of the approach moving forward:

> *'you need to have somebody to keep the thing rolling on a day to day basis and to actually be a contact point for interested parties and to actually initiate contact' (INT III).*

One interviewee was less sure about the importance of the co-ordinator post. He felt this was because the post had been more of an networking and information-gathering post rather than an active change facilitator which he had originally envisaged for the post. The skills necessary for a co-ordinator post were described:

> *'I think the co-ordinator needs to be somebody who is very senior and very able and has demonstrated good management skills and who has been responsible for implementing change, not necessarily somebody who in the first instance is knowledgeable about stroke but who is ...., who knows how to persuade people about it and take people with them' (INT X).*

One interviewee valued the co-ordinator post because she viewed it as bridging the gap between a medical model and a more social model of care, through the networking undertaken across different sectors and agencies.

4.4.5 Outstanding issues

(a) Future for the programme approach

The future of the programme approach to commissioning stroke services in Gateshead and South Tyneside was seen by several of the interviewees as closely linked to the changing NHS structures and policies. Some felt the Group should continue because of its strategic emphasis through being part of the district HImP. However it was also felt that the group would need to be adaptable and flexible to the changing structures and that it should widen its influencing base to include PCGs. Because of the wealth of knowledge within the Group, the Group could be seen as a resource for PCGs and other agencies to utilise. A wider role for the DSG was envisaged by one interviewee who felt the group could provide valuable lessons to others undertaking similar programme approaches:

> *'there will be another role for the Group in terms of, well if this is the thrust from the Government and Department, then the Group could be used to guide other groups if we're going to have to do this more widely ... the Group can be used to offer advice and help on approaches, something that we've learnt from' (INT II)*

The recent Partnership in Action government publication and associated legislation could help the DSG focus its efforts of shifting resources and targeting new resources. Interviewees felt it was important to have continued involvement of social services in the group, particularly because of the government's commitment to this partnership working.

There was little awareness of any succession or longer-term planning for the initiative. Some were unclear how it could continue once the research funding ended which provided support for, for example, the co-ordinator and secretary. The link to the evaluation component was seen as a driver to the whole project and without this one interviewee was concerned that:

> *'the Group will fade away' (INT III).*

Two interviewees who had expressed dissatisfaction with the progress of the DSG's work felt that the project had a limited life-span as it was not achieving what it set out to achieve. One interviewee could only see it continuing if:

> *'there's a purpose to it continuing, in other words, if people can see a reason why these two dissimilar trusts and services should be working together. So I guess that's down to the health authority or something, how they're going to fund it' (INT IV).*

Two interviewees felt in the future the DSG should be more closely aligned with the health authority and more formally recognised as a working group of the health authority, perhaps with the Group chaired by one of the new consultants in Public Health. However another interviewee felt the group may decide to hand over the chair to one of the local clinicians.

There are likely to be other issues in the future which would need to be addressed by a stroke strategy group, including changes in treatments and assessments available, some of which may be very costly:

> *'it would be much easier to deal with that if there was a group, a functioning group in place, rather than having to meet quickly, get an ad hoc group to make decisions' (INT XI).*

The importance of keeping a specific disease focus was also addressed by one interviewee:

> *'because unless there is a specialist focus, how the hell else can we bear down, on an even marginally consensus basis, across voluntary and statutory sector to impact on what's happening?' (INT XIV).*

One possible change to the stroke strategy group in the future may be to split the group into two to cover both sides of the district:

> *'it may be that we don't have a DSG. It may be that we have a South Tyneside Stroke Group and a Gateshead Stroke Group and that might fit with the PCGs better, because then you would just have one authority, one local authority and one main provider for acute and community, and that might make it easier than trying to wrestle with two main providers, two local authorities, and it might make it easier in terms of how the groups are going to prioritise different things' (INT II).*

This was felt to be particularly appropriate given the likelihood that the two Gateshead PCGs would merge in the future when applying for trust status. Another interviewee felt that PCGs:

> *'should be co-ordinating across district for some projects, and doing their own thing for other projects, especially as the PCGs want to form their own identity' (INT XVI).*

However another view expressed was that a split across the district could result in fragmentation and inequalities, and would be more costly than a district-wide focus.

Two interviewees mentioned the potential future impact of the group's work on training issues, perhaps informing future stroke-specific training modules particularly for nursing, social work and professions allied to medicine.

(b) Lessons

This section summarises the lessons identified by interviewees from their involvement in the stroke programme approach.

Contextual analysis — the identification of key people and networks through both initial and ongoing contextual analysis was thought to be an important lesson from this initiative. This contextual analysis should consist of an understanding of who are the local change agents and local champions, an understanding of the local politics of the district, and identification of potential facilitators and barriers to change. This should also involve obtaining agreement from all relevant organisations for their involvement at the beginning of the initiative and going through what one interviewee described as *due process*, including taking the proposed plans to relevant boards and meetings for approval. That this contextual analysis needs to be ongoing was stressed by one interviewee:

> *'that's the lesson of the DSG, that the environment is constantly changing so you're adapting to one environment and suddenly you were having to adapt to a different kind of environment and the needs of those different environments are very different. You have to target and kind of deal with the problems in a different way depending on the structures around you' (INT III).*

This analysis would also help with the identification of local and national knowledge and expertise which could be utilised by the approach.

Anticipatory activities including focusing on proposed and developing policy changes, scanning government publications to anticipate what might happen around proposed changes, both informing the early preparation of bids for possible calls for funding.

Involvement of decision-makers in relevant organisations. As the programme approach is about developing a strategic approach to commissioning, more involvement of senior people was felt to be important, in particular those people within each of the relevant organisations and sectors who are responsible for making decisions and for managing change within their organisations.

DSG members roles and responsibilities. When establishing a DSG or similar disease-specific group, clarity about members' roles and responsibilities was felt to be vital, in particular any expectations about feedback and communication responsibilities necessary within parent organisations. Induction for incoming members of the group was felt to be important and should include a briefing of the background and rationale of the initiative, from the different perspectives involved, as well as discussion of roles and responsibilities.

Profile — A key lesson mentioned by several interviewees was the need to undertake more 'selling' of what the group is doing, keeping senior people and operational people better informed. This should be through different methods depending on the group to be targeted. Events such as the 'launch' were felt to be useful, however, interviewees felt this event should have been conducted earlier in the development and implementation of the intervention. Other methods mentioned included publicising in relevant organisations' own newsletters and formal letters to boards.

User and carer involvement. Two interviewees felt earlier and greater involvement of users and carers and their representatives was important:

> *'you need more involvement there with users and carers. We should have had someone on that group from the Carers' Association or from Crossroads Care' (INT I).*

Paradigm issues. An issue highlighted by interviewees was the scale of a programme approach, which aims to provide a comprehensive strategy ranging from prevention through to long-term care. This scale creates tensions, as described by one interviewee:

> *'I think the DSG set off with very ambitious aims and because they were very ambitious I think they got diluted, and maybe that was one of the dangers of the health care programme approach, that they set out to look at the big picture but inevitably by looking at the big picture you, to a certain extent, dilute your activities, become a bit unfocused and what you need is to focus on the particular areas of need. So my kind of instinctive reply is to say start small and start geographically small as well, and I think that's easier to say now, but I think at the time it was hard because obviously the health authority commissioned right across Gateshead and South Tyneside. I think if you were starting in the current climate I would say, why don't you just target a PCG and look at how a PCG can adopt the care programme approach to tackle a particular subject that they want to deal with' (INT III).*

Future programmes may need to find a balance between comprehensiveness and achievability.

A further paradigm issue that needs to be addressed by future programmes is the implication of a disease-specific focus when involving social services, which takes a person/needs-centred approach.

Core business — several interviewees mentioned the importance of the programme approach being part of core business of the organisations involved, which was difficult in the case of this project because of its link to the evaluation/research component:

> *'it would be more likely to be effective were it to be picked up and engaged with routine business of the health authority and become part of their annual programme and planning' (INT IX).*

Role of co-ordinator. The co-ordinator needs to be someone with change management, networking and facilitation skills. They should preferably be involved from the beginning of an approach in order to help establish the necessary networks and participate in the contextual analysis.

Technical Document — Less time should be spent on the development of the Technical Document, providing more time for initial networking:

> *'spending the time working on the networks because in a sense the bigger problem is changing behaviour than deciding what's best' (INT XI).*

Different levers: The approach should involve finding appropriate levers for change (via the contextual analysis) rather than using a single lever. This was felt to be a strength of this approach, for example, using reviews and sub-groups to take areas forward, using guidelines in the case of hypertension, involving others outside the group who are expert in their own field.

4.4.6 Frameworks for change management

Developing and implementing a programme approach involves changes in processes, structures and relationships. Theoretical frameworks have been developed to explain why some new interventions may be taken up more readily than others and it may be useful to provide here a brief review of these frameworks in order to illuminate the evaluation findings.

Both local and wider environments must be conducive to the proposed change. For change to occur, the general institutional and ideological environment must be favourable. Elements that can contribute to a favourable climate for change include the availability of research evidence supporting change, national consensus statements and other expert views, consistent policy initiatives and demand from patients and patient groups. Changes that are harmonious with existing beliefs and customs (their *compatibility*) and which do not require radical re-organisation of working practices (*complexity*) are easier to assimilate [82 182]. Innovations which can be seen in operation (their *observability*), tested on a pilot basis (*trialability*) and modified to suit local needs (*adaptability*) are also more likely to be adopted. Once introduced, the process of change in individuals is thought to follow an 'S' shaped curve, being initially adopted by the venturesome *innovators*, followed by the *early adopters* who are often the opinion leaders of any profession, through the *majority* to *laggards* who may never change their ways.[183] Different change implementation strategies are likely to be more effective with these different subgroups of people, for example, for early adopters, written scientific information may be sufficient, whereas for late adopters, there may need to be additional resources, incentives, official statements and rules.[184]

In both the diffusion of innovation theory[183] and the social influences model of behaviour change[185 186] the importance of local opinion leaders to the successful implementation of new interventions is acknowledged. The pattern of change among people is shaped not only by personal characteristics but also by the social relations of power and influence that exist in the working community. Local opinion leaders can be critical 'product champions', keeping an issue on the professional agenda and developing local coalitions in favour of change. However, this can be double-edged, as if a change is heavily dependent on a particular individual who then moves on, this raises concerns about the sustainability of the change. A successful change strategy should be sensitive to the local context and seek to involve local professionals in shaping the change agenda.

Environment: In recent years, there has been a range of national policy guidance on improving clinical effectiveness, on evidence-based medicine and evidence-based purchasing. With the establishment of a new National Centre for Clinical Excellence (NICE), the issues of EBM and clinical effectiveness have again been put to the fore. These issues were central to the programme approach to commissioning stroke services. In addition, by focusing on stroke, the approach was consistent with past and current trends in national policy prioritising stroke care and prevention as an area in need of improvement (Health of the Nation, Saving Lives). In the context of Our Healthier Nation, stroke slipped down the agenda, but with Saving Lives, targets for stroke care are again highlighted. Stroke was not a priority for the district at the start of this project and this has resulted in some barriers to the implementation of the approach. Through the work of the approach and the inclusion of stroke in the district strategy document (the HImP), stroke is now more firmly placed on the district agenda. However, it competes with many other priorities and it is not clear how high up the list of the priorities it is placed by key decision makers in the health authority and Primary Care Groups. In fact there is some evidence that PCGs do not see it as a priority. Pressures in the environment arose from many changes that took place, including changes in personnel and organisational structures. The instability and uncertainty arising out of the reorganisation of primary care (PCGs) was perceived as a barrier, rather than an opportunity.

Existing priorities cannot be viewed in isolation from other, often conflicting, environmental factors and a keen desire for change can be easily overridden when those take precedence.

Relative advantage: The perceived relative advantage of a programme approach to commissioning stroke services was an important factor for most DSG members participating in the initiative. For the members, the programme approach offered the framework to bring together strategic issues of commissioning, planning and service development, to improve the standard of care given to stroke patients and to increase the co-ordination of services across the different sectors and agencies involved. However, the opportunity costs, both time and money, of new initiatives are a major barrier to their implementation and are often underestimated by those directly involved.

Compatibility: Elements of the programme approach were seen as compatible with current working practices, philosophies and practices, for example, the move to more collaborative working. The hypertension in primary care work was seen as being highly compatible with what primary care should already be doing. The work of the multidisciplinary forum was viewed as philosophically compatible with people's ways of conceptualising care provision. However, in practice the difficulties of setting standards and specifications across two trusts with dissimilar services created difficulties.

Complexity: The changes and decision-making involved in developing and implementing the programme approach were highly complex. They required the involvement of many different professionals from a wide range of organisations and sectors. Hence they were difficult to assimilate. However, where more complex changes are implemented successfully, they are more likely to be sustainable because of the effort and re-organisation involved in their implementation.

Observability and trialability: The DSG had been able to draw lessons from the previous use of the programme approach in other areas. The focus on a few priority areas provided the opportunity to take forward the approach in a staged and incremental way, allowing for effort to be more focused in these areas, leading to more likelihood of success than if effort was spread over a wider number of areas. However, it may have been that too many areas were taken forward, and this may have resulted in the perceived lack of progress in some of the areas. The staged approach is consistent one of the imperatives for change - the need for iteration between decision and action [187]. Planning and implementation are not discrete sequential processes but, if linked through an incremental approach, they allow early success stories to contribute to and maintain the momentum of the change programme. The perceived lack of early successes in this programme approach may be a further inhibitor to progress.

Adaptability: An attractive feature of the programme approach is its adaptability and flexibility - its focus on the involvement of *local* stakeholders and taking forward *local* priorities. Different change levers were employed for different priority areas. This adaptability potentially enables a stronger sense of ownership of the approach to develop.

There was evidence that some of the local opinion leaders were not engaged with and supportive of the development, and aspects of the implementation, of the programme approach (for example, key people within the Primary Care Groups). Other key decision-makers were felt to be missing from the process, for example, from trust management, and there was also concern about lack of attendance of key individuals. An association can be made between the degree of involvement and the ease with which planned activities were implemented. These local champions are needed in order to gain support from colleagues. Research evidence still shows that *practice change has to be led by professional groupings themselves and cannot be imposed* *from outside.*[188] The imposition of stroke as a priority and the lack of involvement of key individuals may continue to inhibit the progress.

In summary, in this programme approach it may be that the barriers to successful implementation have been stronger than the driving forces. Strategies are needed for reducing these restraining forces and the literature on the management of change may provide pointers to these strategies. The factors that influence how and why people change their behaviour must be taken into account when any evidence-based change programme. The choice of implementation strategy for the various elements of the programme approach should be based upon consideration of the designated activity, the targeted professional groups, the perceived barriers to change, the available resources and management of change processes. There needs to be a combination of strategies so that the programme will have an impact on most people, whatever their knowledge, attitudes and skills.

4.5 Results of fourth round of interviews

4.5.1 Changes in the programme's environment

Respondents were asked to identify changes in the programme's environment that had occurred during the previous year. There was much consistency in the changes seen as important, though not all (as respondents themselves acknowledged) can necessarily be dated to within the previous year.

(a) National level

i RCP Guidelines

The precise impact of these recent guidelines was seen as still being in the future:

> *'... but that's just now, and so really that hasn't had an impact at all so far' (INT Y).*

Some doubt was expressed as to whether they were freely enough available:

> *'The fact that I had to pay £22 to get the guidelines meant that in fact I didn't' (INT R)*

ii HImPs

The advent of the HImP was seen as an important external influence:

> *'It's certainly given greater emphasis to the Stroke Group, and within the Stroke Group, on strategic planning. So I think that's probably the biggest external influence that I'm aware of' (INT W)*

This was however balanced by some scepticism as to how much might be achieved on behalf of patients by the operation of the HImP:

> *' ... at a working level I'm not aware of any real impact that the HImPs have had ... Many people see the HImPs as a paper exercise to keep central government happy' (INT S)*

iii PCGs and PCTs

> *'There was also the PCGs nationally and how we interact with them from a Health Authority perspective, given that they're only at the first level, but the PCGs certainly are going to have in the future quite a lot of power, and particularly commissioning many of the services that they buy in for their particular population"* (INT Z)

> *'Well, I think the PCTs, because they're going to be in the position of actually providing as well as commissioning services ... I think as part of the commissioning process at secondary care level I think there will be a lot more expectation of quite clear standards and markers of quality service'* (INT S)

iv Changes within the Stroke Association

A national internal reorganisation within the Stroke Association had diverted the energies of their representative on the DSG:

> *'We have a representative from the Stroke Association in the Group and he's been unclear of his future role and how the Stroke Association will continue to feed in, subject to this larger reorganisation that the Stroke Association seems to be going through'* (INT W)

v Other related government policy

Respondents identified Clinical Governance, National Service Frameworks and the government priority accorded to CHD, expectations on Joint Working and Better Services for Vulnerable People as important factors:

> *'The other big one is obviously the section of NICE ... you can see that it will take an interest in the national guidelines on stroke care, for example.'* (INT S)

> *'One thing that will impact on the Stroke Group in the future will be the National Service Framework for Older People.'* (INT W)

> *'With the National Service Framework for Heart Disease coming out, we will be updating our register of stroke patients. People with atrial*

> *fibrillation, we'll be looking to make sure they're anti-coagulated. There hadn't been a particularly strong wish to do that before.' (INT R)*

> *'There is a lot of push just now on CHD care ... and I think there's kind of advantages and potential disadvantages, in that a lot of focus just now is very much on coronary heart disease as opposed to stroke. However, there is quite a lot of overlap and that's where the advantage comes in.' (INT S)*

> *'In general terms, I'm aware that stuff's emerged over the last year/eighteen months which wasn't as apparent initially ...., the kind of expectations that government have on the partnership front, and how they're supposed to be demonstrating Joint Working.' (INT U)*

vi British Hypertension Society Guidelines

These guidelines appeared soon after the DSG had prepared and issued their own guidelines:

> *'We had a bit of resistance trying to use the guidelines produced ... by the Stroke Group. The fact that then the Hypertension Society produced their national guidelines with the great and the good was a great opportunity for us.' (INT R)*

(b) Local level

i Health Improvement Programmes

The Gateshead and South Tyneside HImPs contain a chapter on stroke. That this became possible was due in a large part to the work on the priorities and strategies undertaken by the DSG:

> *'When we set up the HImP process that we've got locally we identified stroke as being one of the priorities and we saw the DSG as being the key strategy group to influence the HImP in terms of stroke.' (INT W)*

As part of the process of moving forward from the end of the research project funding, it has been agreed that the DSG will transform to become formally part of the Health Authority's HImP planning structure and will be designated a Health

Improvement Group chaired by a public health clinician. This is seen as a positive development:

> *'That will raise the profile of this work if it's getting to that sort of level, so I think that's a positive thing.' (INT T)*

ii Health Action Zone

The creation of the Tyne and Wear Health Action Zone has brought into play additional resources and a prioritisation of CHD and a focus on the causes of ill health, which are potentially useful:

> *'I think there's quite a lot of crossover and there's HAZ money trickling into projects in the area, so for example, there's cardiac rehabilitation which will have a knock-on effect. .... However, I think there are wider issues within the HAZ which potentially may be more beneficial, such as focusing on helping relationships between local authorities and the health authorities etc and actually setting up more partnerships in terms of healthy living, access to health information... access to available exercise, food of good quality etc.' (INT S)*

Because of the work of the DSG, priorities had been agreed and it was possible at relatively short notice to apply for resources to improve community rehabilitation services:

> *'One of the encouraging things was there was no need to debate about what sort of things should go into the proposals for funding because the priorities had already been agreed and that's quite unusual in my experience.' (INT Y)*

Funding was obtained for South Tyneside but not for Gateshead. This is seen as an artefact of the decision making structures within HAZ being created to coincide with local authority boundaries, thus raising the possibility of different decisions being taken in the two parts of the District.

iii Primary Care Groups

The creation of PCGs significantly altered the environment within which the DSG was operating. The principal effect was that the initial negotiations about working on hypertension were rendered ineffective by the creation of the new bodies, with the determination of their priorities in the hands of different individuals and processes:

> *'It was thought that everyone would be involved with this, and it became apparent that although people had signed up to it they weren't really involved. In particular, PCGs were very cagey about it and thought this work was going to detract from their chosen priorities for that year.' (INT S)*

The priorities determined by the PCGs themselves were heavily influenced by the government's emphasis on CHD, but in the event, one PCG did adopt hypertension as its priority and it has made full use of the resources available via the programme and has instituted a number of changes:

> *'Certainly the practice nurses have been trained in how to manage very early stages of people presenting with high blood pressure .... We introduced and made sure the practices all had copies of the British Hypertension Society guidelines.' (INT R)*

iv Gateshead Health Trust Stroke Project Team

This had led to improved focus and cohesion and provided a mechanism whereby the Trust can more readily identify ways to link within the Stroke Group:

> *'We've recognised that it tends to get a bit lost between medicine and older people etc. ... We've developed a stroke project team to bring together the people who are involved with stroke within the Trust. It's focused their discussions about that area in the Trust, and we see that as linking into the things that happen at the DSG.' (INT T)*

4.5.2 Developments in the programme's priority areas

It became evident that many respondents lacked an overview of the work of the DSG, being knowledgeable only about their own particular involvement in taking forward the DSG's agreed priorities, and sometimes lacking clear information even about developments close to their own interests.

In some cases this was because individuals had only just become involved, and in others because of time pressures causing irregular attendance.

An example of this is the additional funding gained for South Tyneside. This has three components:

- Community based rehabilitation developments
- Information for patients and carers
- Developing secondary prevention

Only two respondents stated this in its entirety. Most mentioned only the community-based rehabilitation. Others were not aware of the outcome of the funding application at all.

This section therefore needs to be read in conjunction with the section of the report listing significant events, and respondents' comments interpreted in that context.

(a) Secondary prevention

Respondents felt that progress had been slow in this priority. There had been delays in getting the consultants together who were to form the sub-group, and disagreements about timing:

> *'That group was to be at consultant level and it hasn't really been resolved as to who will head that and actually what their remit is in relation to secondary prevention.' (INT Z)*

Nevertheless, some additional funding has been obtained:

> *'They've now identified and are appointing a nurse practitioner who will spend the next year working on both supporting primary and secondary care and better secondary prevention processes.' (INT Y)*

(b) Hypertension in primary care

A great deal of work had been achieved by West Gateshead PCG. This had been possible for two reasons:

- The PCG adopted hypertension as its priority
- David Chappel had been able to offer considerable support to assist in setting up programmes and introducing the guidelines. Respondents felt that the work had not had impact with other PCGs.

(c) Information and audit

> *'The work the Stroke Group did initially, trying to get baseline data was very useful. It highlighted a lot of problems in terms of data collection. The difficulty now is to take that forward in a constructive way and set systems up.' (INT S)*

The initial groundwork of the DSG had proved valuable but had highlighted a complex situation that would be difficult to resolve, not least because it would have repercussions for other specialties and different sectors:

> *'... people can be coded several times in different ways for the same condition. For any one admission they can be coded two or three times depending on which consultants they see ... In terms of getting good accurate data which allows you to follow a patient through their natural history of care with stroke from the secondary through to the primary arena, it's not well set up.' (INT S)*

Other respondents dealt with the provision of information for patients and carers. This had had to compete for agenda time:

> *'It was difficult to get that agenda'd within the Group as an important issue.' (INT U*

However, there had been progress made:

> *'We're hoping to recommend ... a shared location, centralised database and that will contain ... two key areas of detailed information which service users, professionals and carers can access.' (INT U)*

There was some uncertainty about whether the issue was being progressed:

> *'It seems to me that we did that piece of work, we had the presentation and I am not aware – and it could be just because I've missed a couple of meetings – of what's going to be done with that information, you know.' (INT W)*

(d) Long term care and support

An application for additional funding for community rehabilitation had been successful. Many respondents were not aware of this aspect of the work at all. One respondent, for whom this was a most important area of work thought that the bid had been unsuccessful. Despite the work that had been put in around the bid, this individual felt that this particular priority had not been given much emphasis:

> *'What we influence and put on the ground around patients and carers still looks sparse in comparison to some other issues that the Group's dealt with.' (INT U)*

(e) Multidisciplinary teams in secondary care

Respondents were aware of increased communication and networking through participation in the DSG itself:

> *'People have found it very useful to get together on a multidisciplinary level and also cross-district as well.' (INT S)*

This had achieved spin-offs outside the Group:

> *'I feel that there is more collaborative working. I am asked to attend meetings with social services and the voluntary sector as ... the representative for the DSG.' (INT Z)*

A multidisciplinary forum was initiated which has proved a valuable means of networking and information exchange and has delivered useful input to other sub-groups:

> *'That Group has been key in terms of delivering some input into the Information sub-group of which I'm a member.' (INT U)*

The Forum was not completely successful however:

> *'The Group proved less valuable as a way of developing service specifications as a result of which we've created a higher level group.' (INT Y)*

It was acknowledged that the Multidisciplinary Forum suffered from the non-involvement of senior clinicians:

> *'It's actually getting the clinicians and the clinicians' time, the medical staff, to attend.' (INT Z)*

The new higher-level group has succeeded in this respect:

> *'There's a particular project I've been asked to get involved in around developing cross-district services specifications, so the Group is actually chaired by Professor Barer.' (INT T)*

4.5.3 Impact of the Health Care Programme Approach

At an earlier stage in the research, interviewees had identified four major areas where it was hoped that the HCPA would achieve some impact. A year further on, respondents were asked again for their views on changes in these areas.

(a) Collaborative working and relationships

One conclusion from the earlier interviews was that change had occurred for individuals involved in the DSG or Multidisciplinary Forum, but had not necessarily extended to organisational change. Such views were repeated during this set of interviews:

> *'It probably has had an impact in terms of the people on the Stroke Group, but I think there's a big dilemma in terms of people on the Stroke Group taking that back to their relative organisation and disseminating back ... and also about feeding that into the corporate agendas of all the other organisations represented – I don't think that's been successful.' (INT W)*
>
> *'Around budgets and policy-making I think there's still a long way to go.' (INT U)*

Others saw practical changes in service organisation as being of greater importance:

> *'Having a stroke team at the QE had made a big difference ... That probably has had more impact to us locally than the wider work of the Stroke Group.' (INT R)*

More positive views were, however, expressed. Improved cross-district cross-sector communications were identified:

> *'It certainly seemed to promote communication and talk across the District, across South Tyneside and Gateshead. I think that's worked particularly well at secondary care level. I think the two stroke units are actually talking to each other ... It has improved communications with*

> *social services because there has been social services' input into the Group and it's been useful for social services to have feedback from the Group ... It's been good for the Stroke Association ... It's allowed them to get a feel for what's going on at the local level, and I think it's been quite good for people on the Group to know ... what sort of activities the voluntary organisations are up to.' (INT S)*

> *'Communication between different professionals has also been stimulated and has been a factor in engaging attention of the consultants. The Multidisciplinary Group has definitely brought professions together to talk about stroke ... Senior clinical staff are aware that it exists and that this Multidisciplinary Forum is up and running.' (INT T)*

An important indicator that the HCPA is beginning to have a greater impact is the recent changes in membership of the DSG. Two factors have aided this process. First, the DSG has been given the lead for the HImP, and second, the DSG has achieved a practical success in securing additional funding for services in South Tyneside:

> *'The membership of the DSG has changed ... As it's become more influential and been given the lead for the HImP it's become apparent to senior managers, for example, in Gateshead Queen Elizabeth Trust, that actually they needed to be better plugged into that. ... Because South Tyneside have got some money ... they're actually beginning to realise that there is some opportunity for them to create influence and potential to change things through that Group.' (INT Y)*

(b) Impact on services

The yardstick by which many interviewees measure the worth of the HCPA is whether its strategic interventions result in tangible improvements in services for patients:

> *'I come from a point of view of how quickly can we improve what's happening around individual patients, what needs changed on the ... ground, and how quickly can we achieve that.' (INT U)*

Some have found it hard to identify tangible benefits:

> *'There is significant progress at a strategic level but I don't know about at an implementation and operational level.' (INT Z)*

> *'I've not seen anything really which I can directly link to the Stroke Group ... That's been a bit disheartening because when the Stroke Group was set up and I was first invited to go on the Group I was very enthusiastic that this was going to be a major driving force in terms of improving services in the District.' (INT S)*

Nevertheless, there has been a significant impact on services in the Gateshead West PCG in terms of helping to carry forward that body's priority on hypertension:

> *'PCG West – great round of applause – major, major impact there.' (INT U)*

Though a note of caution was also sounded about the relative impact of the HCPA and its reception overall:

> *'To be honest, people had felt excluded from the generation of those guidelines, and certainly the Central and East PCG stayed well away from them.' (INT R)*

> *'Within that one PCG - some really quite current new developments in a particular area, and with clear change happening. The challenge for us now is to try and roll that out to the other PCGs.' (INT Y)*

The other large impact on services was the securing of additional funding for South Tyneside:

> *'It was possible to put bids in against HAZ/HImP development monies ... on both sides of the District ... which led to some success in the South Tyneside side of the district in terms of winning some additional funding for three components really – one, community based rehabilitation developments, the second, on information for patients and carers, and the third, on developing secondary prevention.' (INT Y)*

As stated in "Developments in the HCPA's priority areas", these impacts were not visible to all interviewees.

Another respondent pointed out that although the additional funding was valuable, the real measure of impact should be how the much larger amount of mainstream funding is applied:

> *'I can't remember what the total spend on stroke services across the district is, but that [the additional funding] is going to be quite a small proportion of that ... so I think we need to start thinking about what we already spend mainstream.'* *(INT W)*

(c) Strategy and commissioning

The DSG had already assisted in the process of getting a chapter on stroke included in the HImP, and that was seen as a major influence:

> *'It has impacted strategically, it's clear. The fact that we're in the HImP is evidence of that undoubtedly.'* *(INT U)*

As the University research project and its funding was coming to a close, the DSG was designated as a lead group (a Health Improvement Group) for the HImP. This has clearly placed the HCPA within the mainstream decision making structures of the Health Authority. This should enable earlier problems caused by the DSG being perceived as an outsiders' group to be left behind:

> *'I think because of an early perception that this was a partly external initiative I think it's now quite important that it does become seen increasingly as a Health Authority led initiative.'* *(INT Y)*

There were feelings that the DSG earlier in the project had not got sufficiently to grips with the strategic decision making structures:

> *'I think it's got lost in the bigger world of what's going on, and it's not influencing sufficiently.'* *(INT T)*

Becoming a Health Improvement Group (HIG) is seen to mean that the character of the DSG will change under a new, Health Authority chair, and with the loss of the academic input:

> *'There is a role for a stroke group in the future, but it may have to metamorphosise from the group that we've got at the moment.'* *(INT T)*

(d) Balance of care and resources

Respondents felt that it had not been possible to make an impact on this issue so far. The piece of work intended to do this, a programme budget exercise, had run into difficulties with the data available:

> *'We don't collect data that says, 'this was a stroke patient'. We collect data that says, 'a community nurse went in and saw this person'.' (INT T)*

Moreover, it represented a new way of thinking about budgets and services which the DSG as a whole found difficult:

> *'We had hoped that creating a programme budget would offer a lever for change ... I don't think that has happened. ... The Group as a whole found it hard to engage with the concept of the programme budget and the Health Authority is not working in that way.' (Y)*

In a situation of scarce resources it is not easy for managers to contemplate giving up a proportion of what they currently have available:

> *'I can't see that you could look at how we're using that money and decide to shift some of it out to primary care ... If we looked at things in a different way, maybe we could shift some of that resource to community based care, but I just don't think we've got enough to move around really.' (INT T)*

4.5.4 Facilitators and inhibitors of change

(a) Factors facilitating change

The programme approach itself was identified as well suited to working with stroke services:

> *'I do feel that because stroke encompasses a wide range of medical and social factors that a health care programme approach is a good way of tackling services for that specific disease.' (INT Z)*

Benefits of this approach compared with that adopted in other subject areas were identified:

> *'It's common sense to me that if you are going to develop a service or a way you manage a condition, you need to take that approach. I think if we had done the care programme approach for CHD the Group would be rockin' and rollin' by now.'* *(INT S)*

As well as the intrinsic merits of the HCPA, the fact that it was being operated in a policy environment based on similar principles has been crucial:

> *'The health care programme approach ended up fitting ... hand in glove into the Health Improvement Programme model ... It meant that the work that had been initiated then had a firm base to build on – that there was a rationale for it that was also built into national health policy.'* *(INT Y)*

(b) Factors inhibiting change

Interviewees identified barriers to change, which can be grouped into three categories:

- a changing environment;
- difficulties with the DSG itself;
- problems with structures.

i Changing environment

The fast pace of change itself is seen to create problems:

> *'The pace of change that's occurring within the NHS and social services is a barrier because this is just one part of a much more massive agenda.'* *(INT W)*

The rapidity of change has involved key individuals in changes of role and responsibility. This was particularly the case when PCGs were formed, undermining the basis of consultations that had taken place before their formation and engendering a rapid turnover:

> *'In South Tyneside, I think we've had three different consultant physicians as members of the Group over a three year period.'* *(INT Y)*

PCGs having been formed, are having to concentrate on developing their functions as organisations, and this has inhibited their ability and willingness to take up the HCPA:

> *'I think they [PCGs] are still quite immature as organisations ... They've tried to establish their priorities and I don't see stroke figuring among them at the moment.' (INT T)*

> *'All these changes mean that they're not actually looking at the work they should be doing. They're more concerned with forming themselves. They've looked inward rather than outward.' (INT R)*

ii Difficulties with the District Stroke Group

Respondents identified the erratic and changing membership and attendance as a factor inhibiting the effectiveness of the DSG:

> *'Attendance of the Stroke Group has been very erratic, there's been lots of people coming and going, there's been very little continuity other than a core group of people. There's been people come and then not appear for a long time, and then they appear again. ... It's very hard to feel that everybody's pulling together in a nice way in that sort of situation.' (INT S)*

This can be identified as one of the consequences of the rapidly changing environment.

More crucially, in regard to the operation of the approach, there were problems with the role expected of DSG members. Some were clear in their own minds that they were there to contribute their own particular perspective:

> *'I went there, not to be a representative of the PCG. I went there as a resource, and my resource was as a general practitioner. ... So I never viewed myself as being a representative who had a duty to feed back.' (INT S)*

Nevertheless, this same respondent was aware that these expectations had changed:

> *'At one point the Chair did get an OK from the PCG that they were happy for me to be there, but it wasn't really as a representative ... There was never any kind of formal linkage developed between using myself as the link between the PCG and the Group, and I do think that formal linkage does need to be developed.' (INT S)*

Others were not clear what their role was expected to be:

> *'I've never been clear what other people's expectations of me have been within the Group. It was never explicit.' (INT U)*

Clearly this left the individuals concerned in an awkward position and under pressure from the general tacit expectations of the DSG to act, in effect, as a representative once issues started to be tackled:

> *'My comment was based on an assumption on my part that I had a wider representative responsibility. No-one had actually spelled that out at any stage.' (INT U)*

This is no doubt an important factor contributing to variable performance within the DSG:

> *'There've been some individuals who've done good work on specific things on the Group and others who've perhaps been less engaged and less involved until recently and could have done more perhaps. But what group hasn't?' (INT Y)*

Respondents described problems in involving the "right" people, both in the DSG and in consultation. Some felt that the hypertension work was not sufficiently involving all of the stakeholders, though the unfairness of this view was simultaneously acknowledged:

> *'I think it fell down because it wasn't inclusive, too top-down rather than involving the grass roots.' (INT R)*

On the other hand, some who were needed in the DSG could not be engaged:

> *'The Chair has done a lot of work with the Group and he just hadn't engaged our clinicians and it's not his fault.' (INT T)*

Sometimes, inappropriate representatives were sent:

> *'I just didn't know anything about it at all, and I found out at a later date that there was a community physiotherapist on the Group who just didn't communicate with us and they didn't have any involvement in stroke at all. But you know if you approach the Trust you expect them to send the right people.' (INT T)*

As already mentioned it had not proved possible to gain the crucial involvement of the PCGs.

iii *Problems with structures*

There were also problems connected with the nature of the HCPA itself. In some quarters the HCPA was seen as being imposed from outside because it was funded as a University research project:

> *'One of the suspicions that people external to the Group have is that this has been a research exercise by the University and I think that just creates an amount of distrust ... GPs in particular are very suspicious of anything which is research linked because they always think there's another agenda going on somewhere.' (INT S)*
>
> *'Sometimes I've heard that people think the DSG is going off addressing things on its own and not involving, say the trusts or primary care or whatever.' (INT W)*

One reason for the DSG being perceived in this way was the fact that it lay outside the organisational structure of the District and it found its ability to achieve change limited by this:

> *'I think this Group has actually stimulated – it's prodded people into some sort of activity but it hasn't got overall, over-riding authority.' (INT U)*

The existing structure of services and the concerns of those operating them was seen as being at odds with the Health Care Programme Approach and the possibility of radical change which it represents:

> *'Changing people's attitudes is a big part of going forward. It's not only a matter of the resources the community require, but it's changing attitudes in relation to how you balance the way resources are used.' (INT Z)*

Part of this scenario has been the way planning and management of services within the District is split:

> *'We're not a unitary organisation like say Sunderland where you've got one trust and health authority and one local authority. We've got two*

> *acute community trusts, we've got two local authorities, and they all do things differently.'* (INT W)

This was graphically illustrated by the partially successful application for additional funding discussed earlier. Monies were granted for South Tyneside but not for Gateshead although application was made with equal priority for both parts of the District. This resulted from the structure of the HAZ which is organised into two separate Health Partnerships covering South Tyneside and Gateshead local authority areas. One partnership agreed the expenditure, the other did not. Ironically this reverse in the short term turned out to have medium term benefits:

> *'Whilst it's created a perceived sort of inequity – one side of the District's got some resources, the other hasn't – it's also brought the other side of the District back into the process saying 'we're going to get ourselves into this as well!"* (INT Y)

4.5.5 The Future

Interviewees were asked how they saw the HCPA in the future in relation to four key elements of the programme: the DSG; the co-ordinator post; the Technical Document; priority setting.

(a) The District Stroke Group

The interviewees felt that the DSG was very valuable and should continue beyond the end of the University research funding. Very recently more senior managers and clinicians have engaged with the Group, and most importantly it has been designated a lead group (Health Improvement Group) for the HImP. Some interviewees were not aware of the latter development but had all felt that the Group needed to become more grounded in District structures. This has now been achieved.

(b) The co-ordinator post

Interviewees acknowledged that this post had been crucial in networking and information sharing, and that many aspects of the DSG's work would not have been completed without it:

> *'The role of the co-ordinator has been absolutely essential and has ended up inevitably with giving a lead to key areas of work more than anyone else on the Group.'* (INT U)

There were concerns that the role had not been able to develop as hoped:

> *'The sort of co-ordinator that one would have ideally would move on from the initial networking and information function into one that was much more about stimulating the sorts of changes the DSG wanted to see.'* (INT Y)

With the DSG becoming a HIG, a HImP lead group, difficulties in arranging for this role to continue were foreseen. These concerned funding and precedent:

> *'There's a funding issue there. The Stroke Group has been very unusual in having a dedicated person with no other responsibilities but facilitating the stroke project.'* (INT W)
>
> *'I think I understand their thinking there. This is a core part of their function. If they had a co-ordinator for one HImP group they would need one for every HImP group.'* (INT Y)

(c) The Technical Document

Interviewees felt that this had been a valuable piece of work in the early days of the project, but is seen as less useful now:

> *'It did serve a useful role in terms of internal prioritisation of where the Group went first ... I think it was useful initially but I think it became less useful as time went by.'* (INT S)

Because the evidence base is not changing a great deal Group members feel little need to review it regularly, but it is still useful in reviewing progress:

> *'It remains a reference point when we review our Health Improvement Programme annually alongside the original priority setting of which it was a part.'* (INT Y)

Some respondents felt that the document was so technical that they could not readily relate to it, and suggested it might be superseded by a strategy document giving a clearer statement of what the Group is trying to achieve in given timescales.

(d) Discussion

Despite considerable efforts on the part of DSG members, the Co-ordinator and the Chair, the Group experienced a number of difficulties in establishing legitimacy and carrying its work forward.

The HCPA was seen as an outsider's intervention on the part of the University with its own primarily research orientated agenda. Key stakeholders could not be engaged. The Group lacked authority to push for progress on its priorities.

The underlying reasons for these problems can be seen to be structural:

- the DSG was set up outwith the normal structures of the District;
- the Group was seeking priority in a crowded world for an area of work which did not align exactly with government, and therefore others' priorities;
- the HCPA asks stakeholders to make a radical re-think of areas crucial to their working lives and professional interests (for example, structure and management of services, control of resources, handling of information). As such, it is both professionally and personally challenging as well as requiring a significant time input.

As the HCPA has become more integrated into District structures, particularly in terms of the HImP, some of the earlier difficulties have been overcome, and key stakeholders have engaged.

For the future ...

- given that the HCPA is a strategic approach, and given its close fit with the government's policy framework, it would appear productive to establish such an initiative within existing policy and planning structures from the very beginning;
- leadership of the HCPA in such a scenario would rest not with academics but with local players;
- the role of the University personnel would shift to become more of a resource to local players as a source of academic skills and objectivity:

> *'That's been a source of knowledge that not every strategy group has got in terms of being based on sound academic backing. We can all trawl literature. It would be someone like me doing it ... and I'm sure*

> *academics must bring something more than I do ... They can take a more objective approach and aren't caught up in some of the politics.' (INT W)*

(e) Summary Points

- Positive outcomes of the HCPA project are perceived to have included the establishment of the DSG, with involvement of members from different areas of expertise. Members of the group valued joining specialist working groups to progress work of particular relevance to themselves and their organisations.
- The qualitative research has revealed some important tensions. These have included structural issues, including the relationship of the DSG to the University, paradigm differences between social services (needs-led) and medical/programme approach (client group led) ways of working, and the changing NHS context.
- Initiatives like the HCPA need to fit as closely as possible with government policy frameworks and need to include integral planning for their future.
- A series of lessons, identified by interviewees from their involvement in the stroke programme approach, has been identified, and an overview of frameworks for change management has been identified.

4.5.6 Preliminary assessment of the programme

(a) Collaboration

Despite the presence of some inhibiting factors such as the turbulence and changes described earlier, the initiative appears to have produced a number of positive impacts. One of the most significant has been the establishment of an approach which has emphasised collaboration. The number of organisations and professions involved in the purchasing and provision of stroke services is large. A District Stroke Group was established consisting of members from many of these groups, and this group has produced a strategy for stroke services in the district. Both the formation of this group, and the production of a stroke strategy by its members, are achievements. The approach has encouraged the process of sharing good practice across the district. The level of co-operation engendered is particularly useful in a policy context where interagency and cross-boundary working are increasingly being encouraged.

(b) Technical Document and Stroke HImP

Whilst acknowledging some of the limitations highlighted by interviewees, the technical document is itself an achievement. The majority of interviewees found the document useful, easy to understand and read. Some described examples of using the document for particular purposes, such as a starting point for discussions with a wider group of people. It has also been cited in a good practice resource pack by the Stroke Association. The document formed the basis for the development of a stroke HImP, another achievement for the DSG. This latter document forms a component part of the health authority's overall strategy for the district.

(c) Different levels of involvement

DSG members have been involved in the programme approach in different ways, and this has been appreciated. For example, all have had the opportunity to contribute to the development of the technical document and stroke HImP and to the priority setting process. Some have provided specific knowledge and expertise to the group, others have taken back to their organisations information from the group, which has been useful to them. Due to the expertise available on the DSG, the group is able to 'offer these resources' to organisations outside the group, encouraging a two-way process of resource and information exchange. Members of the group are now able to become involved in the different aspects of the implementation of the programme approach, for example, joining working groups of particular interest and relevance to themselves and their organisations.

(d) Influence over health authority commissioning

Several interviewees appreciated the opportunity to have a potential voice in the commissioning process. The emergence of the policy of Health Improvement Programmes was felt to be timely and helpful to the programme approach and was seized upon by the DSG. Interviewees felt this gave their work added credibility and increased the likelihood of having an influence on health authority commissioning.

(e) Maintenance of priorities

The effort in setting priorities has had an important payback in that they have not subsequently been challenged and so the effort of the group has been channelled into issues of implementation.

(f) Dilemmas and tensions

There are some features of the programme approach and the environment in which it is operating that create dilemmas and tensions. These are summarised below.

- Potential impact of condition-specific programme approach to commissioning and provision of services for patient populations who have not had a stroke.

- Focus on the medical aspects of stroke care:

  'stroke is an interesting example where there is a danger we prioritise areas just because it's got an evidence base rather than seeing it from a broad perspective' (INT 15).

- Patchy involvement of primary care on the DSG.

- Turbulence and frequent changes in the internal and external operating framework. For example, internally the changes in DSG membership and externally the changes in the local and national policy. The former became less of once the work started to be undertaken by working groups as well as the DSG.

- Publicity and knowledge about the initiative within the district have been patchy.

- Communication issues, between and within organisations. In particular there is a need for DSG members and members of working groups to cascade information within their organisations.

- Links to local authority commissioning and budgeting have been minimal.

- The need to link the programme approach to other agendas, for example, evolving structures such as Primary Care Groups.

4.5.7 Evolving programme

(a) Challenges

It was clear from the first interviews that key challenge for the implementation of the programme approach would be the management of the tensions and turbulence within the initiative itself and imposed from outside. The issues raised were used to provide a focus for discussion within the DSG.

Interviewees identified several specific points about the evolving programme.

- The need to achieve and to be seen to be achieving
- A need to continue to review DSG membership and respond to inevitable changes, whilst acknowledging the importance of the group maintaining coherence and stability where possible.
- The need to revisit the objectives of the programme approach to see whether these objectives were achievable. For example, one concern raised was the lack of a mechanism to influence the process of local authority commissioning and budgeting - this has particular implications for objective 9. Similarly, the focus on the medical aspects of stroke care may have implications for objectives 2 and 9 (see pages 39 and 42).

(b) Health authority and PCG issues

A further set of challenges was identified relating to NHS structures:

- A framework for decision-making on priority setting across all services was needed, including a clear process, criteria and timescale. A proposed framework outlined in the HImP 1999/2000 to 2001/2002 consisted of the following criteria: national priority, effectiveness, cost-effectiveness, disease burden, promoting self-reliance and promoting equity. Attempts to establish formal priority setting mechanisms were constantly thwarted by further policy changes (eg winter pressures) and the need to spend allocations. The stroke group was faced with similar pressures and therefore developed strategies for managing these.

- The links between the DSG and the commissioning management at the health authority and PCGs needed to be more explicit, including mechanisms and timescales.

- The health authority should make it clear whether it is supporting the programme approach as a mainstream element of developing the HImP. However, the DSG needs to be proactive in keeping stroke on the agendas of the health authority and PCGs.

- The accountability of the DSG needed to be clearer, especially given the emergence of PCGs. For example, was the DSG directly accountable to the health authority?

- The tensions for a district-wide approach were acknowledged given the move to three PCGs covering the district and mechanisms developed for communicating with the three PCGs. The DSG subsequently approached the PCGs and has representation on the DSG from two of the three PCGs. In addition, a member of the West Gateshead PCG has joined the hypertension subgroup.

(c) Social services issues

The issues for local authority structures were different:

- The tension between the programme approach (client group led) and the way social services works (needs-led) needs to be explicitly acknowledged and strategies developed to tackle this. The work on the community rehabilitation teams bid was seen as one example of a way of involving social services around a specific issue.

- The DSG needs to ensure the local authorities are committed to and share, the same vision for the programme approach to stroke.

- Two interviewees felt it may be appropriate to use pooled health and social budgets for areas of joint working. This would be in line with recent government initiatives such as the Modernisation Fund and Partnership in Action.

(d) Other issues

- Two interviewees raised the view that the DSG's work had a secondary care bias (INT G and INT I). This raises the issue of further dissemination of the group's work to primary care and other sectors. This may have been partly addressed by the launch event in April 2000.
- Several interviewees mentioned the need for the stroke project to take into account and implement the evidence on how change is negotiated and the management of change (INT A, I).
- One interviewee raised the issue of a lack of communication and knowledge-sharing about stroke data in the district, given the amount of information that is collected both in Gateshead and South Tyneside (INT B).

4.5.8 Future for the programme approach

The future of the programme approach to commissioning stroke services in Gateshead and South Tyneside was seen by several of the interviewees as closely linked to the changing NHS structures and policies. Some felt the Group should continue because of its strategic emphasis through being part of the district HImP. However it was also felt that the group would need to be adaptable and flexible to the changing structures and that it should widen its influencing base to include PCGs. Because of the wealth of knowledge within the Group, the Group could be seen as a resource for PCGs and other agencies to utilise. A wider role for the DSG was envisaged by one interviewee who felt the group could provide valuable lessons to others undertaking similar programme approaches:

> *there will be another role for the Group in terms of, well if this is the thrust from the Government and Department, then the Group could be used to guide other groups if we're going to have to do this more widely ... the Group can be used to offer advice and help on approaches, something that we've learnt from (INT II).*

The recent Partnership in Action government publication and associated legislation could help the DSG focus its efforts of shifting resources and targeting new resources.

Interviewees felt it was important to have continued involvement of social services in the group, particularly because of the government's commitment to this partnership working.

There was little awareness of any succession or longer-term planning for the initiative. Some were unclear how it could continue once the research funding ended which provided support for, for example, the co-ordinator and secretary. The link to the evaluation component was seen as a driver to the whole project and without this one interviewee was concerned that:

> *the Group will fade away (INT III).*

Two interviewees who had expressed dissatisfaction with the progress of the DSG's work felt that the project had a limited life-span as it was not achieving what it set out to achieve. One interviewee could only see it continuing if:

> *there's a purpose to it continuing, in other words, if people can see a reason why these two dissimilar trusts and services should be working together. So I guess that's down to the health authority or something, how they're going to fund it (INT IV).*

Two interviewees felt in the future the DSG should be more closely aligned with the health authority and more formally recognised as a working group of the health authority, perhaps with the Group chaired by one of the new consultants in Public Health. However another interviewee felt the group may decide to hand over the chair to one of the local clinicians.

There are likely to be other issues in the future which would need to be addressed by a stroke strategy group, including changes in treatments and assessments available, some of which may be very costly:

> *it would be much easier to deal with that if there was a group, a functioning group in place, rather than having to meet quickly, get an ad hoc group to make decisions (INT XI).*

One interviewee also addressed the importance of keeping a specific disease focus:

> *...because unless there is a specialist focus, how the hell else can we bear down, on an even marginally consensus basis, across voluntary and statutory sector to impact on what's happening? (INT XIV).*

One possible change to the stroke strategy group in the future may be to split the group into two to cover both sides of the district:

> *it may be that we don't have a DSG. It may be that we have a South Tyneside Stroke Group and a Gateshead Stroke Group and that might fit with the PCGs better, because then you would just have one authority, one local authority and one main provider for acute and community, and that might make it easier than trying to wrestle with two main providers, two local authorities, and it might make it easier in terms of how the groups are going to prioritise different things (INT II).*

This was felt to be particularly appropriate given the likelihood that the two Gateshead PCGs would merge in the future when applying for trust status. Another interviewee felt that PCGs:

> *should be co-ordinating across district for some projects, and doing their own thing for other projects, especially as the PCGs want to form their own identity (INT XVI).*

However another view expressed was that a split across the district could result in fragmentation and inequalities, and would be more costly than a district-wide focus.

Two interviewees mentioned the potential future impact of the group's work on training issues, perhaps informing future stroke-specific training modules particularly for nursing, social work and professions allied to medicine.

(a) Lessons

This section summarises the lessons identified by interviewees from their involvement in the stroke programme approach.

(b) Contextual analysis

The identification of key people and networks through both initial and ongoing contextual analysis was thought to be an important lesson from this initiative. This contextual analysis should consist of an understanding of who are the local change agents and local champions, an understanding of the local politics of the district, and identification of potential facilitators and barriers to change. This should also involve obtaining agreement from all relevant organisations for their involvement at the beginning of the initiative and going through what one interviewee described as *due process*, including taking the proposed plans to relevant boards and meetings for approval. For example, the proposal was not taken to the Local Medical Council (the representative body for GPs) but was taken to the Health Authority Board. That this contextual analysis needs to be ongoing was stressed by one interviewee:

> *that's the lesson of the DSG, that the environment is constantly changing so you're adapting to one environment and suddenly you were having to adapt to a different kind of environment and the needs of those different environments are very different. You have to target and kind of deal with the problems in a different way depending on the structures around you (INT III).*

This analysis would also help with the identification of local and national knowledge and expertise which could be utilised by the approach.

(c) Anticipatory activities

Including focusing on proposed and developing policy changes, scanning government publications to anticipate what might happen around proposed changes, both informing the early preparation of bids for possible calls for funding.

(d) Involvement of decision-makers in relevant organisations

As the programme approach is about developing a strategic approach to commissioning, more involvement of senior people was felt to be important, in particular those people within each of the relevant organisations and sectors who are responsible for making decisions and for managing change within their organisations.

(e) DSG members roles and responsibilities

When establishing a DSG or similar disease-specific group, clarity about members' roles and responsibilities was felt to be vital, in particular any expectations about feedback and communication responsibilities necessary within parent organisations. Induction for incoming members of the group was felt to be important and should include a briefing of the background and rationale of the initiative, from the different perspectives involved, as well as discussion of roles and responsibilities.

(f) Profile

A key lesson mentioned by several interviewees was the need to undertake more 'selling' of what the group is doing, keeping senior people and operational people better informed. This should be through different methods depending on the group to be targeted. Events such as the 'launch' were felt to be useful, however, interviewees felt this event should have been conducted earlier in the development and implementation of the intervention. Other methods mentioned included publicising in relevant organisations' own newsletters and formal letters to boards.

(g) User and carer involvement

Two interviewees felt earlier and greater involvement of users and carers and their representatives was important:

> *you need more involvement there with users and carers. We should have had someone on that group from the Carers' Association or from Crossroads Care (INT I).*

(h) Paradigm issues

An issue highlighted by interviewees was the scale of a programme approach, which aims to provide a comprehensive strategy ranging from prevention through to long-term care. This scale creates tensions, as described by one interviewee:

> *I think the DSG set off with very ambitious aims and because they were very ambitious I think they got diluted, and maybe that was one of the dangers of the health care programme approach, that they set out to look*

> *at the big picture but inevitably by looking at the big picture you, to a certain extent, dilute your activities, become a bit unfocused and what you need is to focus on the particular areas of need. So my kind of instinctive reply is to say start small and start geographically small as well, and I think that's easier to say now, but I think at the time it was hard because obviously the health authority commissioned right across Gateshead and South Tyneside. I think if you were starting in the current climate I would say, why don't you just target a PCG and look at how a PCG can adopt the care programme approach to tackle a particular subject that they want to deal with (INT III).*

Future programmes may need to find a balance between comprehensiveness and achievability.

A further paradigm issue that needs to be addressed by future programmes is the implication of a diagnosis-centred approach when involving social services, which takes a disability-centred approach.

(i) Core business

Several interviewees mentioned the importance of the programme approach being part of core business of the organisations involved, which was difficult in the case of this project because of its link to the evaluation/research component:

> *it would be more likely to be effective were it to be picked up and engaged with routine business of the health authority and become part of their annual programme and planning (INT IX).*

(j) Role of co-ordinator

The co-ordinator needs to be someone with change management, networking and facilitation skills. They should preferably be involved from the beginning of an approach in order to help establish the necessary networks and participate in the contextual analysis.

(k) Technical Document

Less time should be spent on the development of the Technical Document, providing more time for initial networking:

> *spending the time working on the networks because in a sense the bigger problem is changing behaviour than deciding what's best (INT XI).*

(l) Different levers

The approach should involve finding appropriate levers for change (via the contextual analysis) rather than using a single lever. This was felt to be a strength of this approach, for example, using reviews and sub-groups to take areas forward, using guidelines in the case of hypertension, involving others outwith the group who are expert in their own field.

4.5.9 Impact of the Health Care Programme Approach

At an earlier stage in the research, interviewees had identified four major areas where it was hoped that the HCPA would achieve some impact. A year further on, respondents were asked again for their views on changes in these areas.

(a) Collaborative working and relationships

One conclusion from the earlier interviews was that change had occurred for individuals involved in the DSG or Multidisciplinary Forum, but had not necessarily extended to organisational change. Such views were repeated during this set of interviews:

> *'It probably has had an impact in terms of the people on the Stroke Group, but I think there's a big dilemma in terms of people on the Stroke Group taking that back to their relative organisation and disseminating back ... and also about feeding that into the corporate agendas of all the other organisations represented – I don't think that's been successful.' (INT W)*
>
> *'Around budgets and policy-making I think there's still a long way to go.' (INT U)*

Others saw practical changes in service organisation as being of greater importance:

> *'Having a stroke team at the QE had made a big difference ... That probably has had more impact to us locally than the wider work of the Stroke Group.' (INT R)*

More positive views were, however, expressed. Improved cross-district cross-sector communications were identified:

> *'It certainly seemed to promote communication and talk across the District, across South Tyneside and Gateshead. I think that's worked particularly well at secondary care level. I think the two stroke units are actually talking to each other ... It has improved communications with social services because there has been social services' input into the Group and it's been useful for social services to have feedback from the Group ... It's been good for the Stroke Association ... It's allowed them to get a feel for what's going on at the local level, and I think it's been quite good for people on the Group to know ... what sort of activities the voluntary organisations are up to.' (INT S)*
>
> *'Communication between different professionals has also been stimulated and has been a factor in engaging attention of the consultants. The Multidisciplinary Group has definitely brought professions together to talk about stroke ... Senior clinical staff are aware that it exists and that this Multidisciplinary Forum is up and running.' (INT T)*

An important indicator that the HCPA is beginning to have a greater impact is the recent changes in membership of the DSG. Two factors have aided this process. First, the DSG has been given the lead for the HImP, and second, the DSG has achieved a practical success in securing additional funding for services in South Tyneside:

> *'The membership of the DSG has changed ... As it's become more influential and been given the lead for the HImP it's become apparent to senior managers, for example, in Gateshead Queen Elizabeth Trust, that actually they needed to be better plugged into that. ... Because South Tyneside have got some money ... they're actually beginning to realise*

> *that there is some opportunity for them to create influence and potential to change things through that Group.' (INT Y)*

(b) Impact on services

The yardstick by which many interviewees measure the worth of the HCPA is whether its strategic interventions result in tangible improvements in services for patients:

> *'I come from a point of view of how quickly can we improve what's happening around individual patients, what needs changed on the ... ground, and how quickly can we achieve that.' (INT U)*

Some have found it hard to identify tangible benefits:

> *'There is significant progress at a strategic level but I don't know about at an implementation and operational level.' (INT Z)*
>
> *'I've not seen anything really which I can directly link to the Stroke Group ... That's been a bit disheartening because when the Stroke Group was set up and I was first invited to go on the Group I was very enthusiastic that this was going to be a major driving force in terms of improving services in the District.' (INT S)*

Nevertheless, there has been a significant impact on services in the Gateshead West PCG in terms of helping to carry forward that body's priority on hypertension:

> *'PCG West – great round of applause – major, major impact there.' (INT U)*

Though a note of caution was also sounded about the relative impact of the HCPA and its reception overall:

> *'To be honest, people had felt excluded from the generation of those guidelines, and certainly the Central and East PCG stayed well away from them.' (INT R)*
>
> *'Within that one PCG - some really quite current new developments in a particular area, and with clear change happening. The challenge for us now is to try and roll that out to the other PCGs.' (INT Y)*

The other large impact on services was the securing of additional funding for South Tyneside:

> *'It was possible to put bids in against HAZ/HImP development monies ... on both sides of the District ... which led to some success in the South Tyneside side of the district in terms of winning some additional funding for three components really – one, community based rehabilitation developments, the second, on information for patients and carers, and the third, on developing secondary prevention.' (INT Y)*

As stated in "Developments in the HCPA's priority areas", these impacts were not visible to all interviewees.

Another respondent pointed out that although the additional funding was valuable, the real measure of impact should be how the much larger amount of mainstream funding is applied:

> *'I can't remember what the total spend on stroke services across the district is, but that [the additional funding] is going to be quite a small proportion of that ... so I think we need to start thinking about what we already spend mainstream.' (INT W)*

(c) Strategy and commissioning

The DSG had already assisted in the process of getting a chapter on stroke included in the HImP, and that was seen as a major influence:

> *'It has impacted strategically, it's clear. The fact that we're in the HImP is evidence of that undoubtedly.' (INT U)*

As the University research project and its funding was coming to a close, the DSG was designated as a lead group (a Health Improvement Group) for the HImP. This has clearly placed the HCPA within the mainstream decision making structures of the Health Authority. This should enable earlier problems caused by the DSG being perceived as an outsiders' group to be left behind:

> *'I think because of an early perception that this was a partly external initiative I think it's now quite important that it does become seen increasingly as a Health Authority led initiative.'* *(INT Y)*

There were feelings that the DSG earlier in the project had not got sufficiently to grips with the strategic decision making structures:

> *'I think it's got lost in the bigger world of what's going on, and it's not influencing sufficiently.'* *(INT T)*

Becoming a Health Improvement Group (HIG) is seen to mean that the character of the DSG will change under a new, Health Authority chair, and with the loss of the academic input:

> *'There is a role for a stroke group in the future, but it may have to metamorphosise from the group that we've got at the moment.'* *(INT T)*

(d) Balance of care and resources

Respondents felt that it had not been possible to make an impact on this issue so far. The piece of work intended to do this, a programme budget exercise, had run into difficulties with the data available:

> *'We don't collect data that says, 'this was a stroke patient'. We collect data that says, 'a community nurse went in and saw this person'.'* *(INT T)*

Moreover, it represented a new way of thinking about budgets and services which the DSG as a whole found difficult:

> *'We had hoped that creating a programme budget would offer a lever for change ... I don't think that has happened. ... The Group as a whole found it hard to engage with the concept of the programme budget and the Health Authority is not working in that way.'* *(Y)*

In a situation of scarce resources it is not easy for managers to contemplate giving up a proportion of what they currently have available:

> *'I can't see that you could look at how we're using that money and decide to shift some of it out to primary care ... If we looked at things in a*

> *different way, maybe we could shift some of that resource to community based care, but I just don't think we've got enough to move around really.' (INT T)*

(e) Factors facilitating change

The programme approach itself was identified as well suited to working with stroke services:

> *'I do feel that because stroke encompasses a wide range of medical and social factors that a health care programme approach is a good way of tackling services for that specific disease.' (INT Z)*

Benefits of this approach compared with that adopted in other subject areas were identified:

> *'It's common sense to me that if you are going to develop a service or a way you manage a condition, you need to take that approach. I think if we had done the care programme approach for CHD the Group would be rockin' and rollin' by now.' (INT S)*

As well as the intrinsic merits of the HCPA, the fact that it was being operated in a policy environment based on similar principles has been crucial:

> *'The health care programme approach ended up fitting ... hand in glove into the Health Improvement Programme model ... It meant that the work that had been initiated then had a firm base to build on – that there was a rationale for it that was also built into national health policy.' (INT Y)*

(f) Factors inhibiting change

Interviewees identified barriers to change which can be grouped into three categories.

(g) Changing environment

The fast pace of change itself is seen to create problems:

> *'The pace of change that's occurring within the NHS and social services is a barrier because this is just one part of a much more massive agenda.' (INT W)*

The rapidity of change has involved key individuals in changes of role and responsibility. This was particularly the case when PCGs were formed, undermining the basis of consultations that had taken place before their formation and engendering a rapid turnover:

> *'In South Tyneside, I think we've had three different consultant physicians as members of the Group over a three year period.' (INT Y)*

Having been formed, PCGs are having to concentrate on developing their functions as organisations, and this has inhibited their ability and willingness to take up the HCPA:

> *'I think they [PCGs] are still quite immature as organisations ... They've tried to establish their priorities and I don't see stroke figuring among them at the moment.' (INT T)*
>
> *'All these changes mean that they're not actually looking at the work they should be doing. They're more concerned with forming themselves. They've looked inward rather than outward.' (INT R)*

(h) Difficulties with the District Stroke Group

Respondents identified the erratic and changing membership and attendance as a factor inhibiting the effectiveness of the DSG:

> *'Attendance of the Stroke Group has been very erratic, there's been lots of people coming and going, there's been very little continuity other than a core group of people. There's been people come and then not appear for a long time, and then they appear again. ... It's very hard to feel that everybody's pulling together in a nice way in that sort of situation.' (INT S)*

This can be identified as one of the consequences of the rapidly changing environment.

More crucially, in regard to the operation of the approach, there were problems with the role expected of DSG members. Some were clear in their own minds that they were there to contribute their own particular perspective:

> *'I went there, not to be a representative of the PCG. I went there as a resource, and my resource was as a general practitioner. ... So I never viewed myself as being a representative who had a duty to feed back.' (INT S)*

Nevertheless, this same respondent was aware that these expectations had changed:

> *'At one point the Chair did get an OK from the PCG that they were happy for me to be there, but it wasn't really as a representative ... There was never any kind of formal linkage developed between using myself as the link between the PCG and the Group, and I do think that formal linkage does need to be developed.' (INT S)*

Others were not clear what their role was expected to be:

> *'I've never been clear what other people's expectations of me have been within the Group. It was never explicit.' (INT U)*

Clearly this left the individuals concerned in an awkward position and under pressure from the general tacit expectations of the DSG to act, in effect, as a representative once issues started to be tackled:

> *'My comment was based on an assumption on my part that I had a wider representative responsibility. No-one had actually spelled that out at any stage.' (INT U)*

This is no doubt an important factor contributing to variable performance within the DSG:

> *'There've been some individuals who've done good work on specific things on the Group and others who've perhaps been less engaged and less involved until recently and could have done more perhaps. But what group hasn't?' (INT Y)*

Respondents described problems in involving the "right" people, both in the DSG and in consultation. Some felt that the hypertension work was not sufficiently involving all of the stakeholders, though the unfairness of this view was simultaneously acknowledged:

> *'I think it fell down because it wasn't inclusive, too top-down rather than involving the grass roots.'* (INT R)

On the other hand, some who were needed in the DSG could not be engaged:

> *'The Chair has done a lot of work with the Group and he just hadn't engaged our clinicians and it's not his fault.'* (INT T)

Sometimes, inappropriate representatives were sent:

> *'I just didn't know anything about it at all, and I found out at a later date that there was a community physiotherapist on the Group who just didn't communicate with us and they didn't have any involvement in stroke at all. But you know if you approach the Trust you expect them to send the right people.'* (INT T)

As already mentioned it had not proved possible to gain the crucial involvement of the PCGs.

(i) Problems with structures

There were also problems connected with the nature of the HCPA itself. In some quarters the HCPA was seen as being imposed from outside because it was funded as a University research project:

> *'One of the suspicions that people external to the Group have is that this has been a research exercise by the University and I think that just creates an amount of distrust ... GPs in particular are very suspicious of anything which is research linked because they always think there's another agenda going on somewhere.'* (INT S)
>
> *'Sometimes I've heard that people think the DSG is going off addressing things on its own and not involving, say the trusts or primary care or whatever.'* (INT W)

One reason for the DSG being perceived in this way was the fact that it lay outside the organisational structure of the District and it found its ability to achieve change limited by this:

> *'I think this Group has actually stimulated – it's prodded people into some sort of activity but it hasn't got overall, over-riding authority.' (INT U)*

The existing structure of services and the concerns of those operating them was seen as being at odds with the Health Care Programme Approach and the possibility of radical change which it represents:

> *'Changing people's attitudes is a big part of going forward. It's not only a matter of the resources the community require, but it's changing attitudes in relation to how you balance the way resources are used.' (INT Z)*

Part of this scenario has been the way planning and management of services within the District is split:

> *'We're not a unitary organisation like say Sunderland where you've got one trust and health authority and one local authority. We've got two acute community trusts, we've got two local authorities, and they all do things differently.' (INT W)*

This was graphically illustrated by the partially successful application for additional funding discussed earlier. Monies were granted for South Tyneside but not for Gateshead although application was made with equal priority for both parts of the District. This resulted from the structure of the HAZ which is organised into two separate Health Partnerships covering South Tyneside and Gateshead local authority areas. One partnership agreed the expenditure the other did not. Ironically this reverse in the short term turned out to have medium term benefits:

> *'Whilst it's created a perceived sort of inequity – one side of the District's got some resources, the other hasn't – it's also brought the other side of the District back into the process saying 'we're going to get ourselves into this as well!'' (INT Y)*

(j) Summary Points

- Positive outcomes of the HCPA project are perceived to have included the establishment of the DSG, with involvement of members from different areas of expertise. Members of the group valued joining specialist working groups to progress work of particular relevance to themselves and their organisations.

- The qualitative research has revealed some important tensions. These have included structural issues, including the relationship of the DSG to the University, paradigm differences between social services (disability-focused) and medical approach (disease-focused) ways of working, and the changing NHS context.

- Initiatives like the HCPA need to fit as closely as possible with government policy frameworks and need to include integral planning for their future.

- A series of lessons, identified by interviewees from their involvement in the stroke programme approach, has been identified, and an overview of frameworks for change management has been identified.

4.6 Indicators

Detailed results on the selection and application of indicators are given first and then the main findings summarised.

4.6.1 Indicators from Contract Minimum Data Set

(a) Indicator 1

Discharge within 56 days of emergency admission from home with a stroke by NHS hospital

Table 7 shows the proportion of hospital spells where the patient was discharged home with a primary diagnosis of cerebrovascular disease within 56 days of emergency admission from home, by NHS hospital. This analysis only includes people also admitted from home.

Table 7 Length of stay less than or equal to 56 days

Length of stay	**QE and STGH 1997/8 Number of hospital spells (%)**			
	QE		**STGH**	
	1997/8	**1998/9**	**1997/8**	**1998/9**
<=56 days	135 (86)	208 (74)	120 (78.9)	138 (72)
57 days or more	22 (14)	72 (26)	32 (21.1)	55 (28)
Total	**157**	**280**	**152**	**193**

There were some concerns about the accuracy and completeness of data on source of admission and discharge destination: we would expect more patients to be admitted from nursing or residential homes. In the National Sentinel Audit data the figure is 8% for the QE and 28% for STGH. It may be that these patients are coded as coming from their 'usual place of residence', rather than this being coded as a nursing or residential home. Also, 24.2% of QE spells pre-intervention do not have a specified discharge destination, but a 'not applicable' code. It may be that these spells go on to be treated at Bensham Hospital, but we cannot be certain of this. We also analysed data for this indicator including patients discharged to any destination and excluding patients who died in hospital.

Table 8 shows the proportion of hospital spells where the patient was discharged to any destination with a primary diagnosis of cerebrovascular disease within 56 days of emergency admission from home, by NHS hospital. This analysis excludes patients who died in hospital.

Table 8 Length of stay excluding spells ending in death

Length of stay	**QE and STGH 1997/8: discharged to any destination Number of hospital spells (%)**			
	QE		**STGH**	
	1997/8	**1998/9**	**1997/8**	**1998/9**
<=56 days	242 (73)	293 (77)	158 (67)	159 (73)
57 days or more	91 (27)	90 (23)	77 (33)	59 (27)
Total	**333 (100)**	**380 (100)** **(3 missing)**	**235 (100)**	**218 (100)**

In both locations the majority of patients were discharged within 56 days of admission. However, the percentage of patients staying 57 days or more is greater at South Tyneside DGH.

(b) Indicator 2

Discharge within 56 days of emergency admission from home for stroke by District Health Authority

This indicator is similar to Indicator 1, but for district health authority residents treated anywhere in England (i.e. derived from the health authority Common Minimum Data Set). Again, we have analysed the data in line with Department of Health definitions, but due to our concerns about the accuracy and completeness of source of admission and discharge destination data, we have re-run the analysis excluding patients who died in hospital and including patients discharged to any destination.

Table 9 Length of stay less than or equal to 56 days

Length of stay all DHA residents (only people discharged home)	**1997/8**	**Number of hospital spells (%) 1998/9**
<=56 days	288 (84.0)	342 (79)
57 days or more	55 (16.0)	90 (21)
Total	**343**	**432**

Table 10 Length of stay less than or equal to 56 days

Length of stay all DHA residents [people discharged anywhere, excluding dead patients]	**1997/98**	**Number of hospital spells (%) 1998/99**
<=56 days	420 (72.2)	458 (76.6)
57 days or more	157 (27.0)	140 (23.4)
Missing data	5 (0.9)	0
Total	**582**	**598**

This analysis excludes patients who died in hospital and includes patients discharged to any destination. The percentage of patients remaining in hospital for 57 days or more is greater than in the two main hospital providers and drops slightly from 1997/8 to 1998/9 (27% to 23.4%).

(c) Indicator 3

Provider-based incidence per 1000 resident population of hospitalised stroke by age and gender

Table 11 Incidence per 1000 resident population of hospitalised stroke (M 97)

Males					Age	(%)			
1997/8	<=24	25-34	35-44	45-54	55-64	65-74	75-84	>=85	Total
QE	1	-	4	16	34	71	50	13	189
	(0.5)	(-)	(2.1)	(18.5)	(18.0)	(37.6)	(26.5)	(6.9)	(100)
Incidence per 1000	0.03	0	0.30	1.37	3.02	8.14	13.39	22.61	1.96
STGH	-	1	2	7	14	69	37	14	144
	(-)	(0.7)	(1.4)	(4.9)	(9.7)	(47.9)	(25.7)	(9.7)	(100)
Incidence per 1000	0	0.09	0.19	0.82	1.61	9.41	13.17	31.18	1.94
Total	1	1	6	23	48	140	87	27	333

Table 12 Incidence per 1000 resident population of hospitalised stroke (M 98)

Males					Age	(%)			
1998/99	<=24	25-34	35-44	45-54	55-64	65-74	75-84	>=85	Total
QE	0	0	6	14	41	101	72	16	250
	-	-	(2.4)	(5.6)	(16.4)	(40.4)	(28.8)	(6.4)	(100)
Incidence per 1000	0	0	0.44	1.20	3.65	11.57	19.29	27.83	2.60
STGH	0	2	2	12	22	45	53	11	147
		1.4	1.4	8.2	15	30.6	36.1	7.5	(100)
Incidence per 1000		0.18	0.19	1.41	2.53	6.14	18.86	24.50	1.98
Total	0	2	8	26	63	146	125	27	397

Table 13 Incidence per 1000 resident population of hospitalised stroke (F 97)

Females					Age	(%)			
1997/98	<=24	25-34	35-44	45-54	55-64	65-74	75-84	>=85	Total
QE	-	-	2	11	24	51	81	55	224
			(0.9)	(4.9)	(10.7)	(22.8)	(36.2)	(24.6)	(100)
Incidence per 1000			0.15	0.94	2.03	4.65	11.42	27.75	2.17
STGH	-	-	2	10	13	48	63	40	176
			(1.1)	(5.7)	(7.4)	(27.3)	(35.8)	(22.7)	(100)
Incidence per 1000			0.20	1.18	1.38	5.24	12.40	23.90	2.19
Total	-	-	4	21	37	99	144	95	400

Table 14 Incidence per 1000 resident population of hospitalised stroke (F 98)

Females					Age	(%)			
1998/9	<=24	25-34	35-44	45-54	55-64	65-74	75-84	>=85	Total
QE	0	1	0	10	23	54	81	62	231
		(0.4)		(4.3)	(10)	(23.4)	(35.1)	(26.8)	(100)
Incidence per 1000		0.07		0.85	1.94	4.92	11.42	31.28	2.24
STGH	0	0	1	4	13	42	71	27	158
			(0.6)	(2.5)	(8.2)	(26.6)	(44.9)	(17.1)	(100)
Incidence per 1000			0.10	0.47	1.38	4.58	13.97	16.13	1.97
Total	0	1	1	14	36	96	152	89	389

(d) Indicator 4

Case-fatality rate within 30 days of a hospital admission for stroke

Table 15 Case-fatality rate within 30 days of a hospital admission for stroke

Deaths (% of total hospital spells)	**QE**		**STGH**	
	1997/98	**1998/99**	**1997/98**	**1998/99**
	(n=413)	**(n= 481)**	**(n=320)**	**(n= 305)**
Died within 7 days in hospital	40 (9.7)	60 (12.5)	47 (14.7)	39 (12.8)
Died in hospital between 8 and 30 days	29 (7.0)	27 (5.6)	19 (5.9)	26 (8.5)
Died post-discharge between 8 and 30 day*		3 (0.6)		3 (1.0)
Total	69 (16.7)	90 (18.7)	66 (20.6)	68 (22.3)

*This information is only available for 1998/99.

A higher proportion of patients died within seven days than between eight and 30 days of admission to hospital. In the pre-intervention year a greater percentage of patients died within this period at South Tyneside DGH (14.7% compared with 9.7%); there are no differences between South Tyneside and Gateshead post-intervention (12.8% and 12.5 respectively). These figures are lower than those from the Tees Stroke Register where the crude case fatality rate for first ever strokes at seven days was 17.5%. Findings are similar to the Oxford Community Stroke Project. Our figures may, however, include subsequent strokes so may not be directly comparable.

The number of deaths in hospital between 8 and 30 days fell slightly post-intervention in Gateshead (7.0% to 5.6%) and rose slightly in South Tyneside (5.9% to 8.5%).

A greater percentage of patients died within one month at South Tyneside DGH both pre (20.6% compared with 16.7%) and post (22.3% compared with 20.6%) intervention. These figures are lower than those in the Tees Stroke Register (28% fatality rate at one month) and more in line with the Oxford Community Stroke Project (19%).

(e) Indicator 5

Rate of emergency re-admissions within 30 days of discharge

Table 16 Rate of emergency re-admissions within 30 days of discharge

Provider unit	**1997/98 (%)**	**1998/99 (%)**
QE	22/413 (5.3)	7/481 (1.5)
South Tyneside	21/320 (6.6)	14/305 (4.6)

The rate of emergency admissions was low in both provider units and dropped in both from 1997/8 to 1998/9, particularly in Gateshead (5.3% to 1.5%).

(f) Indicator 6

Percentage of patients aged over 50 years with a primary diagnosis of stroke who return to their pre-admission category of accommodation on discharge from hospital.

Table 17 Return to their pre-admission category of accommodation

Provider unit	**1997/98 (%)**	**1998/99 (%)**
QE	66 (20.3)	142 (37.4)
South Tyneside	106 (43.1)	96 (50.3)

This indicator is one of the NHS Performance Indicators covering the 'Effective Delivery of Appropriate Health Care'. Figures published in July 2000 give the figure for Gateshead and South Tyneside Health Authority as 47%; this equals the percentage for England as a whole. There are wide variations between the two provider units, however; as previously reported this may be due to inaccurate discharge information for Gateshead.

4.6.2 Primary Care Indicators

(a) Indicator 7

The proportion of patients in general practice who are prescribed aspirin three months after their stroke

Table 18 patients who are prescribed aspirin three months after their stroke

	Yes	No	Missing	Total
Pre-intervention	41 (70.7)	15 (25.9)	2 (3.4)	58
Post-intervention	27 (62.8)	16 (37.2)	--	43
Total	68 (67.3)	31 (31.7)	2 (2.0)	101

It was only possible to collect this data in three practices due to lack of a register of stroke patients in the remaining practices. The majority of patients were prescribed aspirin three months post-stroke but this figure fell slightly from pre to post intervention (70.7% to 62.8%). The table below shows the majority of patients not prescribed aspirin had definite contraindications.

Possible reasons why patients were not prescribed aspirin three months after their stroke.

Table 19 reasons why patients were not prescribed aspirin

	Definite contra-indication	Possible contra-indication	No contra-indication	Subsequently prescribed aspirin	Missing	Total
Pre-intervention	8 (53.3)	--	2 (13.3)	--	5 (33.3)	15
Post-intervention	11 (68.8)	1 (6.3)	2 (12.5)	1 (6.3)	1 (6.3)	16
Total	19 (61.3)	1 (3.2)	4 (12.9)	1 (3.2)	6 (19.4)	31

(b) Indicator 8

The proportion of patients in general practice with a diagnosis of transient ischaemic attack who are prescribed aspirin

Table 20 patients in with a diagnosis of TIA who are prescribed aspirin

	Prescribed aspirin	Aspirin contra-indicated	No contra-indications	Missing data	Total
Pre-intervention	54 (78.3)	9 (13.0)	2 (2.9)	4 (5.8)	69
Post-intervention	46 (83.6)	4 (7.3)	5 (9.1)	---	55
Total	100 (80.6)	13 (10.5)	7 (5.6)	4 (3.2)	124

For reasons mentioned above, it was only possible to collect this data in three practices. A high proportion of patients with transient ischaemic attack were prescribed aspirin; this increased slightly pre to post intervention (78.3% to 83.6%). Very few patients had no contraindications and therefore should have been prescribed aspirin. The percentage of these patients increased pre to post intervention, but numbers are too small to draw conclusions.

(c) Indicator 9

Percentage of general practice patients with a diagnosis of atrial fibrillation who have a prescription for anticoagulant therapy

Table 21 Patients prescribed warfarin

	Prescribed warfarin	Warfarin contra-indicated	Warfarin not contra-indicated	Missing	Total
Pre-intervention	234 (38.6)	216 (35.6)	142 (23.4)	15 (2.5)	607
Post-intervention	284 (44.2)	226 (35.1)	122 (19)	11 (1.7)	643
Total	518 (41.4)	442 (35.4)	264 (21.1)	26 (2.1)	1250

More than two thirds of patients with atrial fibrillation were prescribed warfarin or warfarin was contraindicated. The percentage prescribed warfarin role pre to post intervention (38.6% to 44.2%); this is higher than the figure reported by Sudlow et al in another area in the North East in 1996-98 (23% Lancet paper). The percentage of those with no identifiable contraindications who could possibly have been prescribed warfarin fell slightly over the course of the study (23.4% to 19%).

Table 22 Patients NOT prescribed warfarin

	Prescribed aspirin	Aspirin contra-indicated	Aspirin not contra-indicated	Missing	Total
Pre-intervention	211 (56.6)	59 (15.8)	89 (23.9)	14 (3.8)	373
Post-intervention	221 (61.6)	58 (16.2)	73 (20.3)	7 (1.9)	359
Total	432 (59)	117 (16)	162 (22.1)	21 (2.9)	732

Of those patients not prescribed warfarin around two thirds were prescribed aspirin. A similar pattern emerges with the number prescribed aspirin rising slightly pre to post intervention (56.6% to 61.6%) and the number with no contraindications falling slightly (23.9% to 20.3%).

(d) Indicator 10

Avoidable deaths: mortality from hypertensive and cerebrovascular disease (ages 35 - 64). Age-standardised rates of death from hypertensive and cerebrovascular disease per 100,000 population (ages 35-64).

Table 23 deaths from hypertensive and cerebrovascular disease

	Observed	Rate	95% CI Rate lower limit	95% CI Rate upper limit
Male	73	36.29	27.91	44.67
Female	53	26.42	19.24	33.61
All	126	31.20	25.70	36.70

This indicator forms part of the Population Health Outcome Indicators[104 189]. Figures for Gateshead and South Tyneside Health Authority are well above those for England as a whole (rates 28.95, 21.39 and 25.13 for males, females and all persons respectively).

4.6.3 Summary of main findings

Table 24 shows the indicators selected. All refer to patients with a primary diagnosis of Stroke or cerebrovascular disease depending on data source.

Where the CMDS was used it was possible to obtain findings by provider (ie the two hospitals) or by purchaser (ie the District Health Authority). Where the former was used only district residents were included (there were a small number of admissions from outside the district) and the denominator was taken as the local authority area of Gateshead or South Tyneside as these coincided very closely with the catchment area of the hospitals. The CMDS had some weaknesses, notably the 'place of discharge' field which was recorded as 'not applicable' in over 25% of stroke admissions to hospital 1.

Primary care data were reliant on a searchable computerised register ie the patients with stroke TIA or AF had appropriate Read Codes or prescribing information in their record. Written records, where available, were then used to ensure completeness of information.

Indicator 10 (and the denominator for Indicator 3) is taken from The Public Health Common Data Set[104] subsequently called the Compendium of Clinical and Health Indicators.[189]

Table 25 shows the indicators data for both time periods. Where appropriate results for both hospitals, or males and females are shown separately. Where 95% Confidence Intervals of the difference did not overlap zero, results are shown in bold.

Indicators 1 and 2 were redefined using all admissions because of the low level of recording of place of discharge.

Table 24 Indicators used for this study

Indicator Name	Definition	Source	Purpose	Expected Change	Comment
1. Discharge <56 days (hospital)	Percentage of emergency admissions from home discharged home within 56 days (by hospital)	CMDS	Quality of care Mainly secondary but also across agencies	May increase if multidisciplinary care and multiagency co-operation improves	There was poor coding of discharge destination, especially at hospital 1 so the indicator was also recalculated for all admissions
2. Discharge <56 days (district)	Percentage of emergency admissions from home for stroke discharged home within 56 days (by district)	CMDS	Quality of care Mainly secondary but across agencies	May increase if multidisciplinary care and multi agency cooperation improves	There was poor coding of discharge destination, especially at hospital 1 so the indicator was also recalculated for all admissions
3. Incidence of hospitalised stroke	Incidence of hospitalised stroke per 1000 resident population	CMDS and PHCDS	Contextual Background	May fall in line with falling death rates for stroke or may rise if a higher percentage of people with stroke are admitted.	Calculate for males and females separately
4. Case fatality	Case-fatality rate within 30 days of hospital admission for stroke	CMDS	Quality of care mainly secondary	Should be falling unless case-mix changes	Data on deaths after discharge but still under 30 days only available for second time period.
5. Readmission	Percentage of emergency readmissions within 30 days of discharge for stroke	CMDS	Quality of care All agencies	May fall if multidisciplinary care and multiagency co-operation improves. May increase if indicator 1 is reduced inappropriately or initial quality of care is not ideal	
6. Return to own home	Percentage of patients over 50 who return to their pre-admission category of accommodation after discharge	CMDS	Quality of care especially rehabilitation	May rise if multidisciplinary care and multi agency cooperation improves	There was poor coding of discharge destination data, especially at hospital 1
7. Aspirin after stroke	Percentage of patients in general practice who are prescribed aspirin three months after their stroke	Primary care records	Quality of care especially secondary prevention in primary care	Should increase with improving care	Data only available in three practices
8. Aspirin after TIA	Percentage of patients in general practice who are prescribed aspirin after a transient ischaemic attack	Primary care records	Quality of care especially secondary prevention in primary care	Should increase with improving care	Data only available in three practices
9. AF on anticoagulants	Percentage of patients in general practice with Atrial Fibrillation who are prescribed anticoagulation	Primary care records	Quality of care especially primary prevention in primary care	Should increase with improving care	
10. Avoidable hypertensive deaths	Age standardised rates of death from hypertensive and cerebrovascular disease (age 35-64) per 100,000 resident population	PHCDS (CoCaHI)	Background risk factors and primary prevention in primary care	Should decrease with better prevention or improving care	Three year pooled data used 1995-1997 (pre) 1997-1999 (post)

Table 25 Results of Indicators

Indicator Name	Hospital	First Measurement % (n)	Second Measurement % (n)	Difference (95% CI)	Comment
1. Discharge <56 days (hospital)	1	86% (157)	74% (280)	**−12% (-3.8,-18.8)**	May be distorted by poor recoding of place of discharge
	2	79% (152)	72% (193)	−7% (-16.3,1.8)	
1. As above but all admissions	1	73% (333)	77% (380)	+4% (-1.9,10.8)	A better measure, though is not the original indicator
	2	67% (235)	73% (218)	+6% (-2.8,14.0)	
2. Discharge <56 days (district)		84% (343)	79% (432)	−5% (-10.2,0.8)	May be distorted by poor recoding of place of discharge
2. As above but all admissions		72% (582)	76% (598)	+4% (-0.6,9.4)	A better measure, though is not the original indicator. Probably most robust of the 4 measures as denominator >500
3. Incidence of hospitalised stroke (males)	1	1.96	2.60	+0.64	Hospital 1 has had a policy of encouraging admission of everyone who has had a stroke since 1996 Data not available to calculate confidence intervals for difference.
	2	1.94	1.98	+0.04	
3. Incidence of hospitalised stroke (females)	1	2.17	2.24	+0.07	
	2	2.19	1.97	−0.22	
4. Case fatality	1	16.7% (413)	18.7% (481)	+2.0% (-3.1,7.0)	Second measurement includes deaths post discharge before 30 days (0.6% Hosp 1 and 1.0% hosp 2). Increase is only in first week for Hosp 1 and 8-30 days Hosp 2.
	2	20.6% (320)	22.3% (305)	+1.7% (-4.8,8.0)	
5. Readmission	1	5.3% (413)	1.5% (481)	**−3.8% (-6.6,-1.5)**	
	2	6.6% (320)	4.6% (305)	−2.0% (-5.7,1.7)	
6. Return to own home	1	20.3% (325)	37.4% (380)	+17.1% (10.4,23.4)	According to NHS Performance Indicators is now 47% for district as a whole, which is average for England and Wales. May be distorted by poor recoding of place of discharge at Hosp 1.
	2	43.1% (246)	50.3% (191)	+7.2% (-2.2,16.4)	
7. Aspirin after stroke		70.7%	62.8%	-7.9% (-25.9,10.2)	About half (first measurement) to two thirds (second measurement) not on aspirin had a definite contraindication
8. Aspirin after TIA		78.3%	83.6%	+5.3% (-9.0,18.8)	Of those not on aspirin there was a small increase in the proportion with a recorded contraindication
9. AF on anticoagulants		38.6%	44.2%	**+5.6% (1.5,11.0)**	Of those not on warfarin, most had a contraindication (% with no identifiable contraindications fell from 23.4% to 19.0%) and most were prescribed aspirin (56.6% rising to 61.6%)
10. Avoidable hypertensive deaths	Males	30.6 (22.9, 38.4)	31.9 (24.0, 39.9)	+1.3	96% confidence intervals given in brackets. Data not available to calculate confidence intervals for difference.
	Females	30.9 (23.1, 38.7)	28.7 (21.3, 36.2)	-2.2	
	Persons	30.7 (25.2, 36.2)	30.2 (24.8, 35.7)	-0.5	

Of the ten indicators, 5 and 9 show 'significant improvement; 1,2,4,6 and 8 move in the 'right' direction; 3 and 10 are equivocal and 7 moves in the 'wrong' direction.

Interpretation of these changes is difficult because they are influenced by many different factors. Furthermore, there are limitations to the data sources. This will be picked up in the discussion.

Overall, changes between pre and post intervention were small. This may suggest indicators were too blunt as instruments measuring change. Furthermore, inconsistencies discovered in routinely collected data (for example discharge destination) affected the credibility of findings and in some cases necessitated additional analyses to give a more accurate picture.

Findings could, however, mean that the HCPA did not change the quality of stroke care. Generally, indicators were not specific to priority areas but priorities of the HCPA which may have brought about change did not progress fast enough for this to be apparent in the post-intervention phase. For example, the 'multidisciplinary teams in secondary care' group developed standards based on the Royal College of Physicians' Sentinel Audit; implementation of these may have affected indicators such as length of stay, but the draft specification was not discussed until May 1999 and implementation is still taking place. One set of indicators (hypertension) was specific to a priority area, but only two practices were able to provide the data required from their computerised records and not enough data was available for analysis. It may be, then, that the HCPA does result in improvements in stroke care, but change took longer than anticipated and the timescale of the evaluation did not allow enough time for change to both occur and be measured.

4.7 Further analyses of CMDS

4.7.1 Key findings

Key findings from the CMDS (Figure 9, Figure 10, Figure 11) and Compendium of Clinical and Health Indicators 2000 (Figure 12) are summarised in the following graphs. Data from CMDS for 1996/7 was not available.

Figure 9 Ten-year trend in stroke admissions

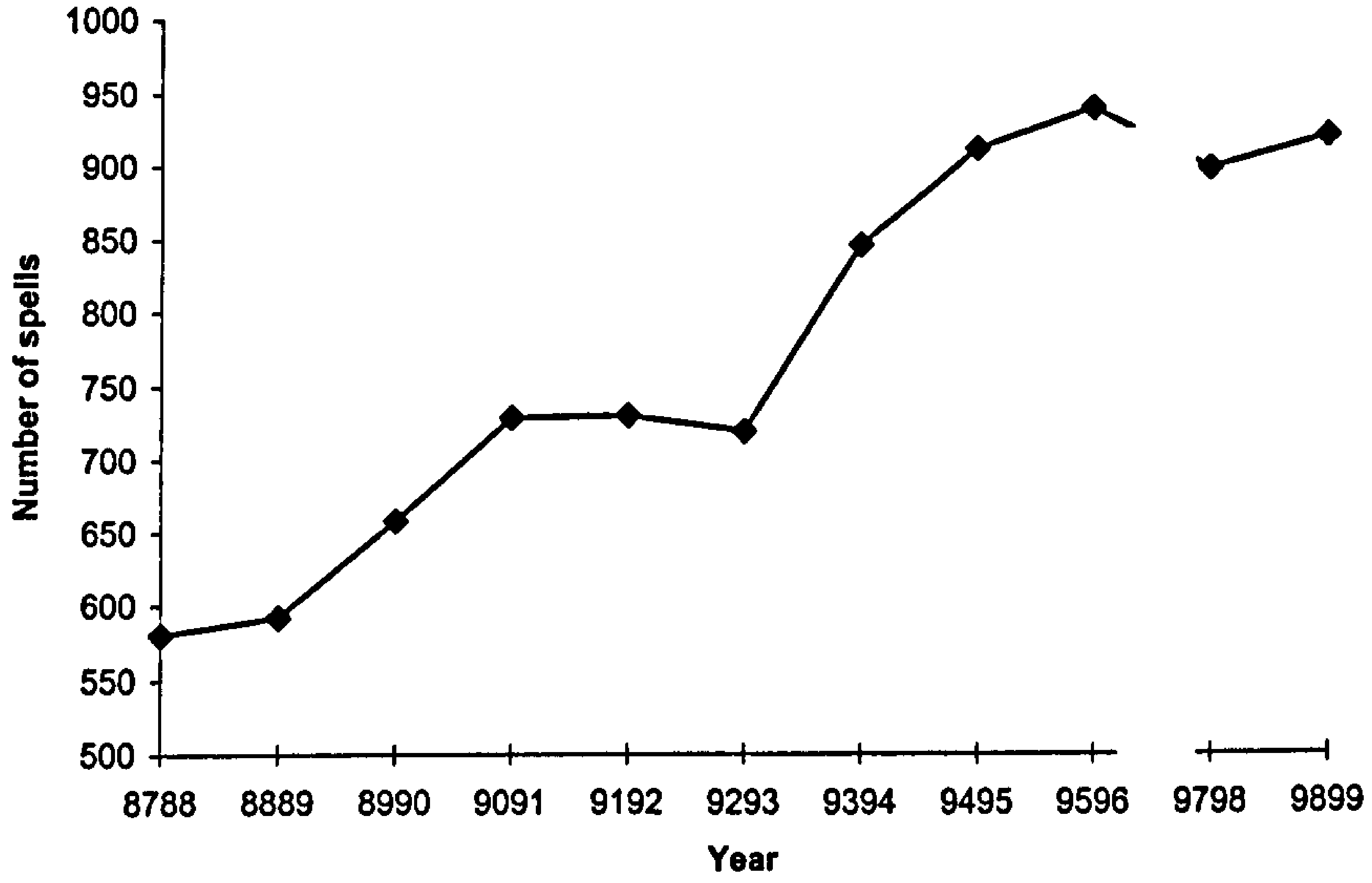


Figure 10 Median Length of Stay (excluding deaths)

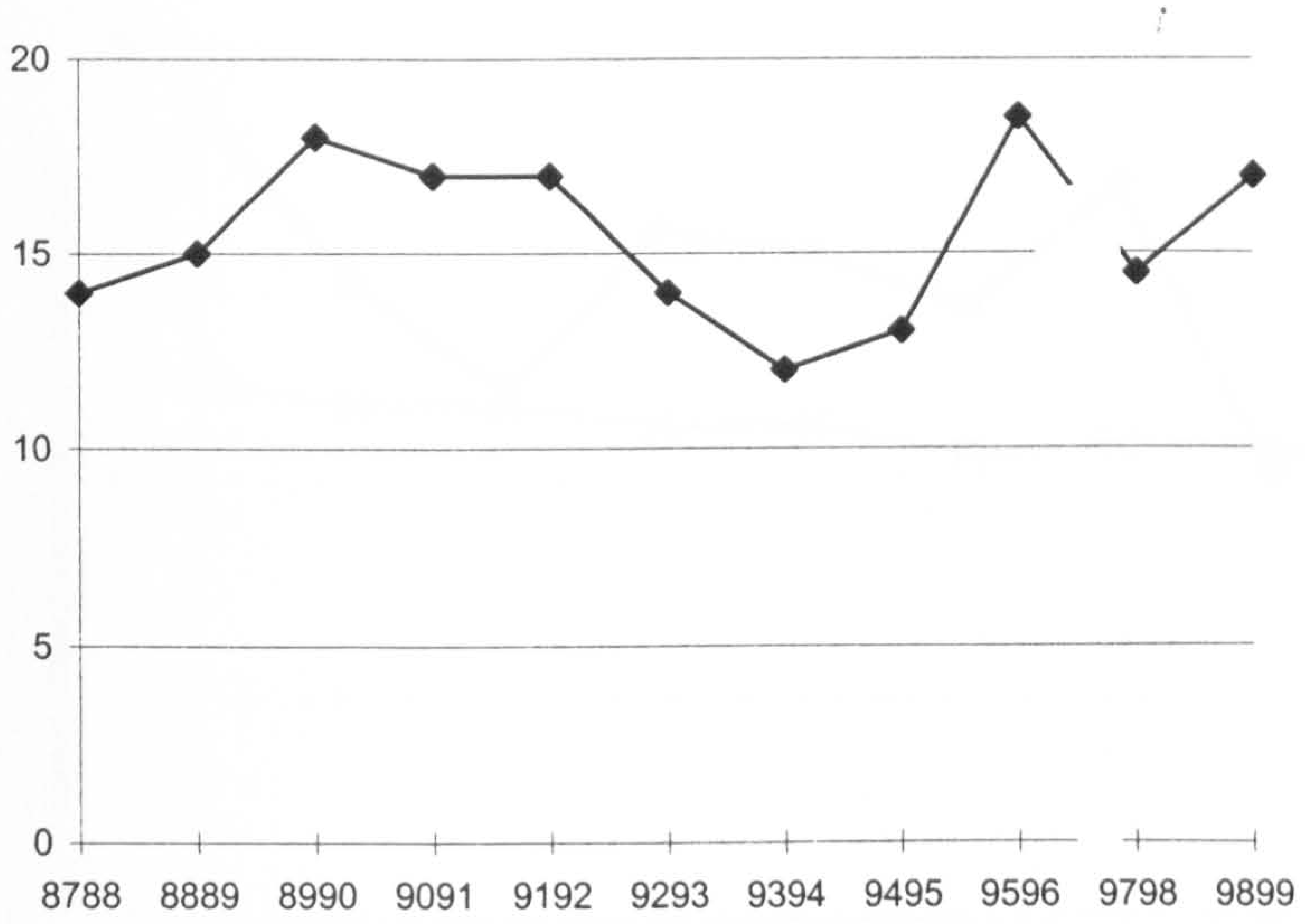


Figure 11 Case-fatality Rates

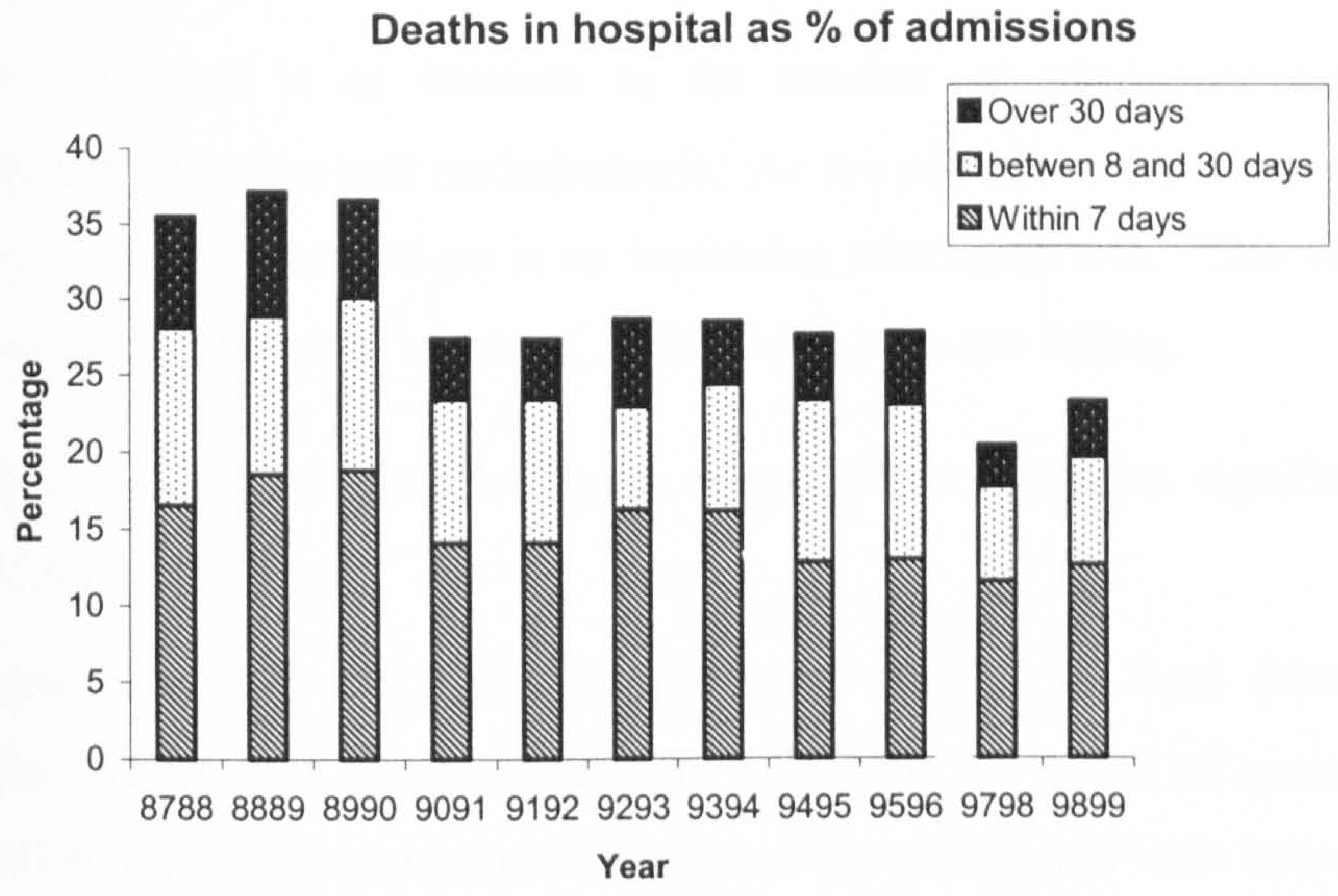
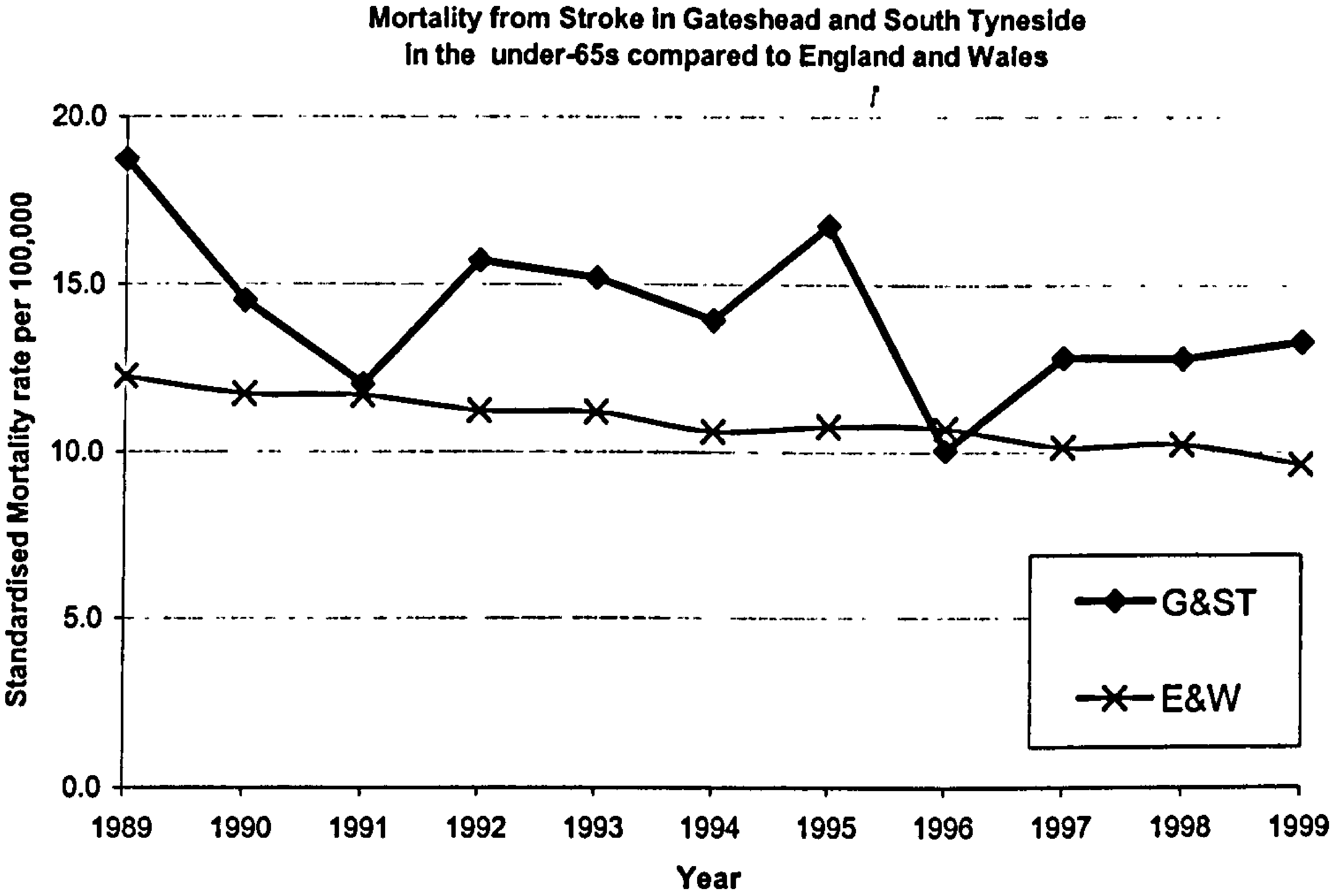


Figure 12 Mortality



Overall there is an increase in the number of admissions (including first and subsequent stroke and readmissions). As the population has been fairly constant over this time this means there is an increasing admission rate. This may reflect a higher proportion of strokes admitted, as the death rates are falling.

Figure 10 suggests that the length of stay has not changed significantly over the last 10 years.

Figure 11 shows a falling in-hospital case fatality rate from about one third to one fifth. Taken with Figure 9 this may reflect the admission of more, milder strokes as well as improved care (stroke units were introduced into both hospitals around 1996). Given the stable length of stay it is not likely to be an artefact of the length of stay.

4.7.2 Summary Points

- We adopted and adapted previously developed quantitative indicators of change in stroke care for this study.

- Most secondary care indicators were measured from the Contract Minimum Data Set. Most primary care indicators were from ad hoc data collection.

- They were measured at two time points – before and after the priority setting of the HCPA.

- Most changes were small and were difficult to interpret, as there were limitations of completeness of data, small numbers and other changes locally.

- 10 year trend shows:
  - Increasing number of patients admitted
  - Constant length of stay
  - Decreasing in-hospital case fatality
  - Decreasing death rates

4.8 Programme Budget

4.8.1 Inpatient programme budget

Using the cost per FCE approach, total inpatient and day case cost of stroke and TIA in Gateshead and South Tyneside in 1997/98 is estimated at £2,480,225, representing 2.80% of total expenditure in the general and acute secondary sector. Stroke admissions accounted for £2,139,577 (86%) of this total expenditure. Using the cost per HRG approach, total inpatient and day case cost of stroke and TIA in Gateshead and South Tyneside in 1998/99 is estimated at £3,339,674. Stroke admissions accounted for £3,076,090 (92%) of this total expenditure.

Table 26 shows how the programme budget for stroke (TIAs have been excluded) breaks down by age whilst other tables show this breakdown by provider (Table 27), specialty (Table 28) and HRG (Table 29) respectively.

Table 26 breakdown of inpatient stroke costs according to age

	1997/98		1998/99	
Age group	Estimated costs (in £'s)	%of total	Estimated costs (in £'s)	%of total
50 or under	151,910	7.1	116,364	3.8
51 to 60	209,679	9.8	295,353	6.0
61 to 70	442,892	20.7	657,929	21.4
71 to 80	828,016	38.7	118,156	36.3
Over 80	507,080	23.7	888,288	33.0
Total	2,139,577		3,076,090	

Table 27 Breakdown of inpatient stroke costs by provider

	1997/98		1998/99	
Provider	Estimated costs (in £'s)	%of total	Estimated costs (in £'s)	%of total
1	519,917	24.3	1,413,594	45.9
2	1,048,383	49.0	1,344,463	43.7
3	295,262	13.8	123,022	4.0
Other	276,015	12.9	195,011	6.3
Total	2,139,577		3,076,090	

Table 28 Breakdown of inpatient stroke costs by specialty

	1997/98		1998/99	
Specialty	Estimated costs (in £'s)	% of total	Estimated costs (in £'s)	% of total
General medicine	539,173	25.2	1,371,888	44.6
Geriatrics	1,038,551	48.5	972,381	31.6
Neurosurgery	295,262	13.8	186,071	6.0
Other	266,591	12.5	545,750	17.7
Total	2,139,577		3,076,090	

Table 29 Breakdown of inpatient stroke costs by HRG

	1997/98		1998/99	
HRG	Estimated costs (in £'s)	% of total	Estimated costs (in £'s)	% of total
A19	281,559	13.2	295,378	9.6
A22	668,959	31.3	1,465,214	47.6
A23	193,774	9.1	490,500	15.9
A99	468,227	21.9	59,392	19.3
Other	527,058	24.6	231,076	7.5
Total	2,139,577		3,076,090	

(a) Differences in costing methods used

As outlined above, the estimate of the total inpatient programme budget for stroke and TIA in 1998/99 was some 26% higher than in the previous year. Whilst there was an increase in stroke admissions from 891 to 921 in this period, much of this increase seems to be due to differences in the costing method used. In particular, it appears as if costing by HRGs is giving a more realistic picture of the amount of resources stroke patients consume.

In 1997/98, the implied cost per case of a stroke admission was £2,382, whilst the cost per bed day implied by this method works out at £72.55. These estimates (based on the cost per FCE approach outlined above) are considerably lower than those estimated using input-based costing techniques and vary markedly between the providers. In 1998/99, using HRG specific costs, the implied cost per case of a stroke admission had risen to £3324 and the implied cost per bed day to £110.

As indicated above, separate analyses were carried out on the data from the two main provider units. Table 30 shows that, in 1997/98, the mean cost of stroke admission implied by the cost per FCE approach varied markedly between the two providers with mean costs of £1,428 and £3,410 for providers 1 and 2 respectively. However, adopting a cost per bed day approach resulted in higher mean costs in both cases and removing some of the apparent disparity between the two providers. In 1998/99, the bed day approach again results in estimates that are markedly higher than that based on FCEs and reduces the apparent disparity between the two provider units. Costing according to HRGs results in estimates somewhere between the two, though closer to those using the bed day approach.

Table 30 Mean cost of inpatient stroke admission

	Provider 1		Provider 2	
	1997/98	1998/99	1997/98	1998/99
FCE	1,428	909	3,410	2,282
Bed Days	2,442	4,275	2,442	4,819
HRG	**	3,028	**	4,437

4.8.2 Non-inpatient programme budget

(a) Primary Care

i Cost data

Information on the cost of primary care in Gateshead and South Tyneside was derived from the health authorities' annual account information for years ending 1997/98 and 1998/99. This showed that total expenditure in primary care in Gateshead and South Tyneside in 1997/98 and in 1998/99 was £21,676,000 and £22,061,000 respectively. This total excludes purchase of secondary health care and drugs by GP fund holders. Of this total, expenditure on general medical services cash limited and non-cash limited amounted to £17,699,000 in 1997/98 and £18,712,000 in 1998/99. These figures exclude spending on pharmaceuticals by non-fundholding GPs and the purchase of general dental and general ophthalmic services.

ii Estimated activity

In the Burden of disease study[144] expenditure was allocated pro rata according to data from MSGP[145] with home consultations given three times the weight of surgery visits. This results in an estimate that expenditure on stroke accounts for 1.47% of cash limited and non-cash limited general medical services expenditure in primary care (as defined above). This would make the local primary care budget for stroke to be £260,175 in 1997/98 and £275,066 in 1998/99.

Source of estimate: Burden of Disease document[144]

Underlying data source: Morbidity statistics in General Practice 1991-92 study[145]

Method: The overall expenditure was first distributed into four broad categories; general medical services (both cash limited and non-cash limited), pharmaceutical services, general dental and general ophthalmic. Net expenditure on general dental services was allocated to mouth disease and expenditure on general ophthalmic services to eye disease. Expenditure on general medical services includes both cash-limited and non-cash limited expenditure but not funds allocated to GP fund holders for the purchase of drugs, hospital and other services. Expenditure included is distributed between diseases using MSGP by ICD 9 sub-chapter. It is distributed pro rata to consultations with home consultations given three times the weight of surgery consultations. Expenditure was then estimated as a proportion of cash limited and non-cash-limited general medical services in primary care (defined above).

Definition of stroke: ICD 9 codes 430-438

Assumption made: This method assumes that G&ST has the same pattern of consultations as the national average. That home visits cost 3 times as much as surgery visits. Subject to this, all consultations have a uniform cost.

Disadvantages: The pattern of stroke consultations in G&ST may be different from national average. The definition of stroke does not directly correspond with the codes used in the inpatient and day case sector and our analysis of the CMDS.

In order to overcome these problems, we carried out our own analysis of the MSGP data using a definition of stroke that matches the one used previously and applying age and sex specific consultation rates to Gateshead and South Tyneside population information. Consultations were adjusted to allow for the standard mortality ration for cerebrovascular disease in the District.

Source of estimate: Own analysis of MSGP

Underlying data source: Morbidity statistics in General Practice 1991/92 study [145] and Gateshead and South Tyneside population figures.

Method: Age and sex specific consultation rates were applied to Gateshead and South Tyneside population information. The ICD 10 codes used in the inpatient programme budget and the analysis of CMDS were first mapped onto the ICD 9 codes used in the MSGP survey. Consultations for stroke and TIA were estimated as a proportion of all consultations after adjusting for home visits, nurse visits and the standardised mortality ratio for cerebra vascular disease in the district. Expenditure was then estimated as a proportion of total primary care expenditure (as described above) pro rata with rates of consultations.

Definition of stroke: As defined in the inpatient and day case section and in the analysis of the CMDS. Stroke is defined as ICD 10 codes I60, I61, I62.9, I63, I64, and TIA as G450 and I65.2

Assumption made: This method assumes that the pattern of home to surgery visits and of doctor to nurse visits is constant across ICD 9 subchapter headings 430-438.

That home visits cost 3 times as much as surgery visits. Subject to this, all consultations have a uniform cost.

The results of this analysis are given in Table 31, which yields estimates that are considerably lower than those yielded by applying the BoD estimate. For example, our analysis estimates that consultations for all stroke - including TIA (the patient group that corresponds to how 'stroke' is defined in BoD), make up just 0.94% of Gateshead and South Tyneside primary care consultations after weightings for home visits have been taken into consideration (compared to 1.47% in BoD). This suggests that Gateshead and South Tyneside does have a different pattern of consultations than England and Wales as a whole.

Table 31 Estimates of stroke-related activity in primary care

Estimates of stroke-related activity in primary care (based on our own analysis of MSGP)		
	1997/98	**1998/99**
All stroke +TIA (ICD 9 430-438)	£166,371	£175,893
Stroke *	£90,265	£95,431
TIA *	£60,177	£63,621

* As defined in the inpatient section and analysis of CMDS. NB the sum of these two will *not* correspond to the total in row 1 as certain ICD 9 codes 430-438 are excluded from our definitions of stroke and TIA.

(b) Outpatients

i Cost data

Information on the cost of outpatient services in Gateshead and South Tyneside was derived from the 'common information core' outturn reports for 1997/98 and 1998/99. This showed the total health authority budget for outpatient services in 1997/98 (1998/99) to be £26,015,000 (£28,097,000) of which £22,755,000 (£24,574,000) was spent in the general and acute sector.

ii Estimated activity

Whilst there are a number of different ways of estimating outpatient activity, the method used here allocates outpatient according to referral rates from general practice. The estimate provided in Burden of disease [144] is that stroke activity accounts for 0.32% of *total* outpatient activity. Applying this estimate to the total outpatient budgets for Gateshead and South Tyneside outpatient activity for 1997/98 results in estimates of £83,248 (0.32%*£26,015,000) in 1997/98 and £89,910 (0.32%*£28,097,000) in 1998/99 for stroke related outpatient attendances.

Source of estimate: Burden of Disease document [144]

Underlying data source: Morbidity statistics in General Practice 1991-92 study [145]

Method: The overall expenditure was first distributed into four broad categories; acute and geriatric, obstetrics, mental illness and learning disability. Data on each category is distributed between diseases according to data from MSGP [145]. Expenditure is distributed pro rata to the rate of referral from general practitioners to outpatient departments.

Definition of stroke: ICD 9 codes 430-438

Assumption made: That the distribution of outpatient attendances is similar to the distribution of referrals from general practice. The method assumes a constant cost per attendance within each of the four broad categories.

Disadvantages: This estimate does not allow us to differentiate between stroke and TIA, as all ICD 9 sub chapter codes 430-438 are included.

Unfortunately, MSGP does not give information on referrals to outpatients by individual ICD codes, so we were unable to carry out the kind of detailed analysis described above for the primary care sector. In an attempt to break down the BoD estimate figures in a way that corresponds to the definition of stroke and TIA used in the inpatient sector and the analysis of CMDS, we have allocated outpatient expenditure according to consultation rates in general practice. The results are shown in Table 32.

Table 32 Estimates of stroke-related outpatient activity (in £'s)

	1997/98	1998/99

All Stroke + TIA (ICD 9 430-438)	83,248	89,910
Stroke*	45,166	48,781
TIA*	30,111	32,520

* Again as defined in the inpatient section and analysis of CMDS. This breakdown is *not* available in BoD; these estimates are based on consultation rates in general practice (and again do not sum to the figure in the first row certain ICD 9 codes 430-438 are excluded).

(c) Accident and Emergency

i Cost data

Information on the cost of accident and emergency care in Gateshead and South Tyneside was derived from the health authorities' annual account information for years ending 1997/98 and 1998/99. This showed that total expenditure in A&E was £7,754,000 in 1997/98 and £8,658,000 in 1998/99.

ii Estimated activity

Accident and emergency care is not estimated in the BoD report or in any of the other sources we came across. However, data from the CMDS inpatient data set shows that 445 of the 899 patients admitted with stroke in 1997/98 and 488 of the 921 patients in 1998/99 had attended an A&E department. In addition, 102 of the TIA patients in 1997/98 and 111 in 1998/99 had also attended an A&E department. When calculated as a proportion of total A&E attendances, this results in the estimates in Table 33.

Source of estimate: Own research

Underlying data source: Inpatient CMDS

Method: The CMDS data was analysed and numbers of patients admitted via an accident and emergency department recorded. This was done for both stroke and TIA.

Definition of stroke: As defined in the inpatient and day case section. Stroke is defined as ICD 10 codes I60, I61, I62.9, I63, I64, and TIA as G450 and I65.2.

Assumption made: All patients who are seen in A&E with stroke are subsequently admitted. All attendance has a uniform cost.

Disadvantages: This method undoubtedly under-estimates the number of stroke-related A&E attendances as patients will attend who are not subsequently admitted.

Table 33 Estimates of stroke-related Accident and Emergency activity

Estimates of stroke-related Accident and Emergency activity (using admission data from CMDS)		
	1997/98	**1998/99**
*All stroke +TIA	43,752	53,496
*Stroke	35,593	43,582
*TIA	8,159	9,914

* All as defined in the inpatient section and analysis of CMDS.

(d) Community Services

i *Cost data*

Information on the cost of community health services in Gateshead and South Tyneside was taken from the health authorities annual account information for years ending 1997/98 and 1998/99. The community health services budgets were £15,836,000 in 1997/98 and £16,658,000 in 1998/99.

ii *Estimated activity*

The Burden of disease estimates that 7.4% of NHS community health services are used by stroke patients. This would result in an estimate of £1,171,864 for 1997/98 and £1,232,692 for 1998/99.

Source of estimate: Burden of Disease document [144]

Underlying data source: OPCS disability surveys [146]

Method: Expenditure on chiropody and health promotion is allocated to the most appropriate disease group. Expenditure on professional advice and support, general patient care and other community health services is allocated between disease groups according to the OPCS disability study. The OPCS disability surveys included information on receipt of a range of health and social services and on diseases. The disease categories used in OPCS were mapped onto ICD-9 sub-groups; stroke was mapped directly to ICD-9 430-438. Expenditure is allocated pro rata with receipt of community nursing services.

Definition of stroke: ICD 9 codes 430-438 (there is a direct mapping between ICD-9 coding and the OPCS disability list for stroke).

Disadvantages: This estimate does not allow us to differentiate between stroke and TIA, as all ICD 9 sub chapter codes 430-438 are included. However, it is reasonable to assume that patients classified within OPCS as having a disability due to stroke, are more likely to have suffered completed strokes than TIA only.

(e) Social Services

i Cost data

Expenditure on personal social services was initially allocated between services and client groups using data on net expenditure provided by local authorities on their revenue outturn (RO3) returns. Gross social services expenditure on adults in 1997/98 and 1998/99 was £85,682,320 and £91,302,810 respectively, including grants from the health authority.

ii Estimated activity

The Burden of disease estimates that 6.2% of social services for adults expenditure is used by stroke patients. This would result in an estimate of £5,312,304 for 1997/98 and £5,660,774 for 1998/99.

Source of estimate: Burden of Disease document [144]

Underlying data source: OPCS disability surveys [146]

Method: Expenditure on personal social services is initially allocated between services and client groups using data on net expenditure provided by local authorities on their Revenue Outturn (RO3) returns. Expenditure on children is excluded. Expenditure on day care, residential care, home care, meals and social work is allocated using data from OPCS disability survey. The method is as described above for community nursing. Expenditure on income support for residents of independent residential care and nursing homes was also included.

Definition of stroke: ICD 9 codes 430-438

Disadvantages: Again, this estimate does not allow us to differentiate between stroke and TIA, as all ICD 9 sub chapter codes 430-438 are included. As in the case of community health services, we may assume that the 'stroke' patients in the OPCS disability survey will correspond reasonably closely to our definition of stroke.

4.8.3 Overall programme budget

Combining these results with those in the inpatient sector discussed previously, allows the breakdown of expenditure across sectors to be estimated. Table 34 shows how the expenditure on stroke (not TIA) breaks down across the sectors whilst Table 35 shows the corresponding results when TIA is included.

Table 34 Budget for stroke patients

	1997/98		**1998/99**	
	Estimated expenditure	**% of total***	**Estimated expenditure**	**% of total***
Inpatient	2,139,577	61.4	3,076,090	68.4
Outpatients	45,166	1.3	48,781	1.1
Primary care	90,265	2.6	95,431	2.1
A&E	35,593	1.0	43,582	1.0
Community	1,171,864	33.7	1,232,692	27.4
Total NHS	**3,482,465**		**4,496,576**	
Soc services	5,312,304		5,660,774	
Total	**8,794,769**		**10,157,350**	

* *Excluding social service provision*

Table 35 Budget for all stroke activity

	1997/98		**1998/99**	
	Estimated	**% of total***	**Estimated**	**% of total***

	expenditure		**expenditure**	
Inpatient	2,480,225	62.8	3,339,674	68.2
Outpatients	83,248	2.1	89,910	1.8
Primary care	166,371	4.2	175,893	3.6
A&E	43,752	1.1	53,496	1.1
Community	1,171,864	29.7	1,232,692	25.2
Total NHS	**3,945,460**		**4,891,665**	
Soc services	5,312,304		5,660,774	
Total	**9,257,764**		**10,552,439**	

* *Excluding social service provision*

4.8.4 Summary points

- Programme budgeting is a technique that sets out to describe how resources are currently allocated, not how they *ought* to be allocated.
- The accuracy of the estimates largely depends on the quality of the underlying data sources.
- It is estimated that approximately £2.14 million and £3.08 million were spent on inpatient care for stroke in 1997/98 and 1998/99 respectively accounting for 61% and 68% of all NHS spending on stroke.
- Interpretation of these results has to be done alongside the analysis of the CMDS as the costing level used in the NHS changed between the two years.
- The estimate for social services was highest with approximately £5.31 and £5.66 million in 1997/98 and 1998/99 respectively.
- The figures for community care and social services rely on broad apportionment rules that do not allow real changes in the pattern of service use over time to be detected.

4.9 Transaction costs

4.9.1 Role of the co-ordinator

There were two stroke co-ordinators employed during the first 'live year'; the first taking up the post in February 1998, and leaving in April 1998, and the second co-ordinator taking up post in June 1998. Annual costs of the co-ordinator were based on the second co-ordinator, Ruth Richardson a senior nurse (Grade I) who was employed for 22.5 hours per week.

For the first live year between April 1998 and March 1999, the stroke co-ordinator was contracted for 22.5 hours per week, although this subsequently reduced to 15 hours from May 1999. The direct annual cost of employing the stroke co-ordinator was estimated to be £16,584, including pension and employer's national insurance contributions. For purposes of estimating the costs of the first live year, it is assumed the co-ordinator was in post for the whole 12-month period. Although the level of secretarial support varied, it was estimated on average as 4 hours per month giving an estimate of secretarial support of £408.

The co-ordinator travelled an average of 121 miles per month in carrying out her duties and attending the many meetings throughout Gateshead and South Tyneside. Travel costs were reimbursed at the usual university travel rate of 36p per mile (applicable to journeys of less than 80 miles). This puts the estimate of the annual cost of travel at approximately £523. The monthly average for additional expenses, such as car parking and public transport was £5.16 per month, working out at a further cost of £62 for additional costs.

This results in an estimate of the cost associated with the stroke co-ordinator's role of £17,577.

As outlined in the qualitative description of the process, the majority of interviewees had met with the co-ordinator on at least one occasion and sometimes several times. The importance of this aspect of the role is reflected in the analysis of the activities of the co-ordinator. On average, 65 hours per month were directly attributed to one of the four main activities listed above; interviews and meetings, presentations and research, report writing, and administration and clerical. The remainder may be attributed to holiday leave, sickness leave, and liaising with members of the research team (such as providing details on the information for the transaction cost). Of the 65 attributable hours per month, an average of 27.5 hours (42%) were allocated to meetings and interviews, including those conducted by telephone, 7.50 hours (11.5%) to presentations and research, 14 hours (22%) to report writing and 15.5 hours (24%) to administration and clerical duties in connection with the post.

4.9.2 Running the District Stroke Group

There were a total of 10 meetings held in the start up period, from June 1996 to April 1998 including the two initial launch meetings, with the first meeting of the DSG in the format it exists now held in December 1996. The first two 'launch' meetings lasted 150 and 75 minutes respectively, whilst the remainder each lasted 90 minutes. During the first live year there was a total of 11 meetings, the first lasting 90 minutes with the remainder lasting 120 minutes. The average length of time of all meetings, including the launch is 106 minutes. The secretarial support for the group was estimated at 4 hours per meeting.

As is clear from the qualitative description of the process, the membership of the DSG was rather fluid and changed markedly over the course of both the start up period and the first live year. At least 40 different people have attended the meetings throughout the course of the programme approach, including many individuals who attended only once or twice. With the exception of the fist two launch meetings, only those attending twice or more have been included in the estimated activity. Columns 2 and 3 of Table 36 show the estimate of the total time spent in connection with DSG meetings including secretarial input assuming travel times of 30 minutes and 45 minutes respectively. Columns 3 and 4 show the associated estimate of the total cost based on hourly rates as outlined above.

Table 36 Estimate of activity and cost of DSG

	Total time input (minutes)		Cost of time input (pounds)[f]	
	Travel time		*Travel time*	
	30 mins	45 mins	30 mins	45 mins
Start up period	15,345	16,785	£7,844	£8,706
First live year	11,790	19,305	£7,541	£8,257

4.9.3 Writing of the technical document

As indicated above, the writing of the technical document was a collaborative effort between the research team and members of the DSG. The time input proved to be difficult to estimate retrospectively. The lead author estimated that in total, the document took up approximately 40% of his time over a period of 6 months. Based on this and the annual salary of grade 4 clinical lecturer this resulted in an estimate of around £7,500, including employer's contributions. As pointed out by the lead author, this estimate fails to reflect the 'mental trauma' of the process!

Whilst other members of the DSG clearly played a major role in discussing drafts of the document, much of this was undertaken within the regular meetings and, hence, already accounted for in the estimates given above. Therefore, this was considered to reflect the main additional cost of preparing the technical document.

The estimates of the transaction costs of the programme approach are given in Table 37. These figures are based on the assumption that travel time to and from the DSG meetings was 45 minutes.

Table 37 Transaction costs of programme approach to end of the first live year

	Co-ordinator	*DSG*	*Technical document*	*Total*
Start up period	*	£8,706	£7,500	£16,206
First live year	£17,577	£8,257	*	£25,834
Total (to end of first live year)	£17,577	£16,963	£7,500	£42,040

The estimates of the transaction costs of the health programme approach indicate that costs in the start up periods and first live year were around £16k and £26k respectively. The transaction costs estimated here are considerably less than those reported by Posnett et al in relation to the total purchasing scheme, but it is difficult to draw meaningful comparisons as the role and function of the TPP schemes was very different from those of the health programme approach.[51] The TPP project estimated the total costs across all projects of the 'preparatory year' to be £679,055, whilst that of the first 'live year' to be £698,952, resulting in per capita cost estimates of £3.10 and £3.32 respectively (tables C1 and C2, page 67). However, unlike our study, these costs take account of the whole range of activities involved in the actual purchasing and commissioning services, whereas the HCPA approach makes use of an existing contracting structure.

There are a number of caveats to be made before these may be considered as the total costs associated with the health programme approach. First, there are additional costs that have not been accounted for here. For example, in the qualitative description of the process, some interviewees described their role on the DSG as being 'representatives' of their respective organisations. Those who described themselves as representatives said they reported back from the DSG meetings to their organisations and acted as a liaison officer between the group and colleagues. It was not possible to estimate the extent of such activity within the limitations of this research.

Second, there are on going costs that have not been accounted for within the time frames studied. For example, it was intended that the technical document would be subject to revision and up-date as and when new evidence becomes available and was formally reviewed in 1999. There was also a 're-launch' meeting for senior managers and local decision makers held in 1999 involving over 40 people, including the Director of Public Health.

Third, the estimate of the cost of the co-ordinator's role is based on the salary scale of the particular person appointed to the post, in this case, a senior nurse with a great deal of expertise in stroke care. However, at least one interviewee is reported as suggesting a more managerial role for the post, involving an individual with a track record of implementing change, not necessarily in relation to stroke care. Clearly, different views about the nature of the co-ordinator's post will have important cost implications were the approach to be adopted elsewhere.

4.9.4 Summary Points

- We estimated the main transaction costs —stroke group, co-ordinator, technical document.
- The cost of running the HCPA was about £26,000 per year, with set up costs of about £16,000.
- This is about 0.25% of the programme budget for stroke or about £3.91 per person with a stroke.
- It is difficult to make meaningful comparisons with estimates yielded elsewhere, such as the TPP study as HCPA approach used an existing contracting structure.

4.10 Survey of Districts

4.10.1 Quantitative findings

This section summarises the main aspects of commissioning stroke services in Gateshead and South Tyneside and at each point picks up the findings from the surveys. The findings from the surveys are summarised in Table 38 and Table 39.

(a) Commissioning

Gateshead and South Tyneside have a predominantly health authority approach to commissioning. There were very few fundholders and there were no Total Purchasing Pilots within the district. Consequently, there was a slow start to the Primary Care Group commissioning with stroke services continuing to be commissioned by the health authority. This is similar to the pattern in most districts with limited GP commissioning.

There was a strong pressure on using evidence within the district and this was one of the reasons why the Director of Public Health supported the project. There was a clinical evidence resource centre within the health authority containing both materials and a member of staff dedicated to this. Analyses of routine data such as the Contract Minimum Data Set were done but the use of routine data for Commissioning was limited. Stroke was a priority in the district in as much as it was in the Health of the Nation and Our Healthier Nation but as is clear from some interviews stroke was not a high priority for any group or organisation and not a priority at all for many groups. Most districts claimed stroke was a priority and about half had used 'evidence' or 'health needs assessment'.

Service Specifications had not been developed for stroke at the start of the project and work was still under development at the end. There was no written district stroke strategy prior to this project. There was no clearly defined evidence-base for stroke services before the project (except for the stroke unit - see below). Both trusts had a lead clinician for stroke during 1996 but one left during the time-scale of the project. There was no district wide co-ordinating group and no clearly defined lead for stroke within the health authority until this project started. One of the trusts was developing a stroke register for all admissions. Both trusts had done ad hoc audits in the past looking at all stroke patients. Most districts had a 'strategy' but only a minority had service specifications. A stroke co-ordinator or lead person for stroke was found in about half the districts as was some sort of advisory group.

(b) Services commissioned

There were no specific health promotion activities for stroke prevention. There were smoking cessation strategies, particularly in South Tyneside, and other initiatives such as a healthy lifestyle survey in each part of the district. There had been work on lipids in primary care and on the use of aspirin in angina (PACE project). There had been no specific work on hypertension. There had been work on anticoagulant clinics but no specific work on atrial fibrillation. There was a very mixed picture in the other districts – see Table 39.

Both hospitals had stroke units but these had been commissioned differently. In South Tyneside the stroke unit arose following a successful proposal to the health authority. The proposal was widely supported particularly because of the evidence-base to support this. In Gateshead, the arrival of a professor of stroke medicine together with a senior lecturer allowed the development of a stroke unit. Tertiary services, predominantly carotid endarterectomy, were provided outside the district through a general contract with one neurosurgical unit. Stroke Units were found in about half the districts, although some had them only in one unit. However, the second survey showed that a number of districts were commissioning stroke units.

Long-term support was predominantly provided by social services through their elderly and disability directorates. There was no explicit commissioning for stroke. At the time of starting the project there were no explicit mechanisms for reporting on stroke services either to the commissioners or to the public. There were no explicit plans for development either. The South Tyneside stroke unit should have had some clear reporting mechanism but this did not seem to have been set up when it was funded. The Gateshead stroke unit had a research element and so was reporting to funding bodies rather than the health authority commissioners. Stroke-specific commissioning of rehabilitation or long-term support was unusual.

There were strong links to Newcastle University through the professor of stroke medicine in Gateshead, which again started in 1996. The voluntary sector, predominantly the Stroke Association, had an input into services but no clear mechanism to link to the planning of services. The Stroke Association provided a family support service in Gateshead funded by the local authority. Most districts had involvements with local universities and the Stroke Association was active in all but one.

Gateshead and South Tyneside is part of the Tyne and Wear first wave Health Action Zone. There was no specific work on stroke within this Health Action Zone stroke. There was work on coronary heart disease and on the elderly but these did not impinge on stroke in Gateshead and South Tyneside. Stroke was included in the Health Improvement Programme but this may have been as a result of this project being undertaken. Details of areas for further development and constraints can be found in her rest of this document. Interestingly, all districts had been involved in applications to become Health Action Zones – the majority were first wave zones and all succeeded by the end of the study. This probably reflects higher deprivation in the north of England.

Table 38 Commissioning across the nine districts

District	General approach to commissioning		Sources used to inform commissioning		Stroke a district priority	Written strategy for stroke care	Service specification or contract for stroke services	Service specification evidence-based	Stroke co-ordinator	Lead person for stroke	Advisory group	Stroke register
	largely health authority	primary care commissioning	needs assessments from routine data	evidence								
(1)	✓				✓	✓	✓	✓	✓	✓	✓	
(2)	✓				✓*	✓	✓	✓	✓			
(3)	✓		✓	✓	✓	✓				✓	✓	
(4)	✓			✓	✓					✓		
(5)	✓		✓	✓	✓	✓			✓			
(6)		✓	✓		✓	✓	✓	✓	✓	✓	✓	
(7)		✓	✓								✓	
(8)	✓	✓	✓	✓	✓	✓			✓	✓	✓	
(9)	✓				✓	✓	✓					

* listed as priority in documentary sources but not in interview

Table 39 Commissioned Stroke Services across the nine districts

District	**Health Promotion and Prevention**									**Acute Services**		**Rehabilitation**	**Long Term support**		**Research and Development**		**Voluntary Sector**	**Changes**	
	Diet	Salt reduction	Obesity	Exercise	Smoking	Drink	Healthy Schools	Hypertension	Atrial Fibrillation	Stroke Unit	Part of General Medicine	Stroke specific rehab services	Family Support	Specific Long term care	Local research	Links to academia	Active links to Stroke Association	Health Action Zone (Wave 1 or 2)	PCGs (number – all stage 1 or 2)
(1)	✓			✓	✓	✓						✓				✓	✓	1	4
(2)	✓	✓			✓			✓	✓	✓			✓		✓		✓		6
(3)					✓		✓			*	✓				✓	✓	✓	1	2
(4)	✓			✓	✓					*	✓				✓	✓	✓	1	4
(5)	✓	✓		✓		✓		✓		✓	✓		✓	✓	✓	✓	✓	2	3
(6)	✓	✓	✓	✓	✓			✓				✓				✓	✓		3
(7)											✓				✓		✓	1	5
(8)	✓			✓	✓					✓			✓	✓	✓	✓	✓	1	5
(9)	✓			✓						✓	✓		✓					1	3

* planned

4.10.2 Qualitative findings from the first survey

(a) General commissioning

i Health authority or primary care led general commissioning

In the majority of districts (1,2,3,4,5,8 and 9), services were commissioned largely by the Health Authority. In District 9, services for some conditions were specifically commissioned (eg breast cancer services), while District 8 commissioned services based on core priorities (heart disease and stroke, mental health, respiratory health and cancer). Two Districts (2 and 3) mentioned service specifications; for District 2 these were used to commission services where there was good evidence of effectiveness (eg leg ulcers) and where changes in services are sought; District 3 described these as

> *'not terribly well developed...quite broad and non-specific' (District 3)*

District 5 described how they had once had detailed specifications, drawn up by project groups and involving health professionals, but:

> *'it proved very unwieldy to try and implement change through the contracting process, partly because we would have needed an army to go out and monitor it' (District 5)*

Now, they had moved away from specific contracts to a "minimalist" summary of activity expected and summary of financial allocations. This District was operating a "locality commissioning" model, but without devolution of budgets and commissioning.

Three districts (1,3 and 8) described a priority-setting process; for District 1 this was linked to the medium term strategy:

> *'We have a medium term strategy, in high priority areas we have individual plans which are usually led by multidisciplinary steering groups and those plans are transferred either into specific contracts with our providers or into chapters in the community care plan or into quality initiatives which might be guidelines, they might be audit programmes or whatever in primary care.' (District 1)*

In District 3, this process was used to commission new services.

In three Districts (6,7 and 8) commissioning had moved, to a greater or lesser extent, into primary care. In District 6, there were three 'primary care commissioning teams'; General Practitioners (GPs) either commissioned services directly from individual trusts, or worked with the Health Authority on developing a "common commissioning agreement" with involvement in contract negotiations. District 7 was a Total Purchasing Pilot Site,[29]] involving all GPs divided up into five locality commissioning groups, each managing the commissioning budget. Links with the Health Authority were maintained via the Health Authority Strategy Board; a lead GP from each group was represented on this board, whose remit was co-ordination and providing a forum for discussing commissioning practice. Changes made by the groups in terms of services commissioned were, however, small and described as "tinkering at the edges of the commissioning process". In District 8 there was a mixture of Health Authority and GP Fundholder commissioning, with increasing involvement of primary care groups in the process. In District 4, discussions had begun with primary care groups about the range of services which would be their responsibility.

ii Sources used to inform commissioning

The most commonly named source was needs assessments derived from routinely collected data (Districts 3,5,6,7 and 8):

> *'health needs assessment is the core and we have very detailed health information here...it is used pretty well in the localities...the GPs can quote you SMRs coming out of their ears' (District 8)*

Routinely collected data was used for examining variations in health and use of hospital services across localities (District 5) and also for moving towards an equitable distribution of resources in primary care (District 6).

The importance of commissioning being based on evidence also arose frequently (Districts 3,4,5 and 8), for example District 4 stated that they were working towards basing their strategy on evidence. District 3, however, acknowledged that not all commissioning is based on evidence, but because "there's a wide feeling in the health community that this is the right thing to do"; an example was GPs wanting more attached, rather than district-based staff (such as district nurses).

Various written sources were cited either specifically, for example audit commission reports (District 5), Effective Health Care bulletins and local and national guidelines (District 7), or generally, for example "literature" (District 3). Two Districts also cited discussions with professionals, users and carers (Districts 2 and 4), while District 7 viewed visits by the pharmaceutical industry as a potential influence. District 8 had a "New Drugs and Technologies Committee" which aimed to provide a systematic approach to new interventions. District 6 stated that activity levels and finance were based on "historical" information.

iii *Role of the DPH in the commissioning process*

Interviewees' roles ranged from taking the lead in the commissioning process to providing a supportive, advisory role. Districts 1,2,3,4,5 and 8 took a lead role in setting the strategic direction, including deciding on priorities:

> *I'm also involved in assessment of other people's bids, scoring if you like, and I could if I wished be involved in the meeting which is sort of a big jamboree where everyone gets together and decides what they think are the top priorities and which ones are the most important to fund. (District 3)*

Districts 6, 7 and 9 had a more supportive role, including the provision of needs assessments (District 6), providing clinical advice (District 7) and preparing papers to inform strategy groups (District 7). In District 6, standing back from the nitty-gritty of the commissioning process seemed to be a deliberate approach:

> *I've tended to avoid getting involved in the details of contracting and similarly the public health department don't. We see our role as supporting the contracting and commissioning process, particularly by looking at needs assessment and looking at the effectiveness of services and looking at gaps and developments and doing some of the problem solving but not getting involved in the routine arguments about activity. (District 6)*

In District 9, however, Department of Public Health involvement in commissioning was described as "probably not enough" and input as "rather ad hoc and informal".

(b) Commissioning of stroke services

i Contracting mechanisms

Table 38 shows the position of districts with regard to commissioning stroke services. In the majority of districts most, if not all, stroke services were not commissioned specifically, but were part of general medical contracts (Districts 3,4,5,6,8 and 9). Three interviewees mentioned a stroke plan (Districts 1 and 6) and/or service specification for stroke (Districts 2 and 6). Two (Districts 1 and 9) also provided a service specification or contract for stroke services. In three districts recommendations in service specifications were based on a review of the evidence. A further five districts (2, 3, 5, 8 and 9) provided documentary evidence of a written strategy for stroke care.

District 1 described a comprehensive model for commissioning stroke services comprising a medium term strategy and a stroke plan (led by a multidisciplinary steering group); these formed the basis of specific contracts with providers (including secondary care and community care plans involving social services). This district also had a strategy for assuring the quality of services in primary care and had commissioned an audit to look at the implementation of the plan in the commissioning of stroke services.

While one district believed stroke services were not as good as they could be (District 4), another did not believe specific contracts were superior:

> *'we tend not to have specific contracts like that but we do through the year have a lot of discussions with the trusts about their services and about how they can move them forward which we feel is a better way than just putting something down on paper and coming back a year later.' (District 8)*

ii Role of the local authority in commissioning

The majority of districts stated that the local authority played no role in commissioning (Districts 2,4,5,6,7,8 and 9). In other districts social services had a role, for example in discussing aspects of the stroke plan in community care plans (District 1). Two districts mentioned involvement of social services in a 'stroke project group' (District 5), a 'disability strategy group' and a 'continuing care group'

(District 9); District 7 also stated there would be social service representatives on primary care groups.

Three districts outlined the role of social services in commissioning nursing home care and longer term placement (Districts 5,6 and 7). Several districts also pointed out that social services commissioning was not stroke-specific (Districts 5 and 8) but was divided into sections according to disabilities and age groups.

iii Sources used to inform the commissioning of stroke services

Interviewees cited many sources that informed commissioning:

a Literature reviews

Including meta-analyses and evidence of effectiveness (Districts 1,2 and 9)

b Specific documents

Such as: Health of the Nation handbook on heart disease and stroke (Districts 1 and 3); Royal College of Physicians' national guidance on stroke management (District 5); Clinical Standards Advisory Group (CSAG) report on Stroke (District 3).

c Clinical guidelines

Such as: hypertension (Districts 1 and 5); cholesterol screening and management (District 5); aspirin (Districts 5 and 8); local (Districts 8 and 9) guidelines on stroke management.

d Original research

Cited in Districts 2 and 3 eg research on hearing impairment as a possible cause of communication problems in stroke patients

e Audit information

Cited in Districts 8 and 9:

> *'I'm not particularly happy about the way those services are commissioned at the moment and we did do an audit last year and that revealed certain areas that were unsatisfactory, so information from that*

> *audit has been used to try and sort of focus on areas where the care is less than satisfactory'. (District 9)*

Two districts could either not remember sources used (District 6) or stated that commissioning was largely rolled over from previous years (District 7).

iv Reporting systems for monitoring progress to the health authority

Routine information, for example on levels of activity, costs and lengths of stay, was used to monitor contracts with providers (Districts 1,5, 6 and 7). Audits were also used (Districts 1, 5 and 6). Other systems for monitoring progress included qualitative feedback by consultants, GPs, nurses and other interested parties to a steering group on stroke services (District 1); reports by management to regular contracting meetings (District 2); reports on service specifications (District 4); quality assurance nurses (District 5) and a 'balanced score card' for stroke (District 8) which monitored progress in key indicators against dimensions of patient expectations, clinical effectiveness and organisational development. District 1 also mentioned an ongoing project assessing the 'quality of structured care' in primary care; issues covered included the management of hypertension, atrial fibrillation and secondary prevention of stroke.

District 3 stated that there was no systematic collection of outcome data; while District 9 believed there to be methods of reporting in existence but was not aware of the details.

v Reporting systems for monitoring progress to the public

Two districts (Districts 1 and 9) produced a newspaper distributed to households. In Districts 3 and 4 the health authority met regularly with voluntary carers and service users; District 4 attempted to incorporate users' and carers' views in plans for the forthcoming year by seeking the views of organised groups of stroke patients on an annual basis. District 3 was carrying out focus groups with users and carers to seek their views as well as consulting them on the stroke plan:

> *'I'm going to lay on a special consultation process for the stroke club, you know, try and produce a version of the report which is accessible to lay people and hold special meetings just for them to come and comment. So I'm doing my best if you like with my users and carers. I've met with and*

> *I'm pretty pally now with the stroke club but I'm aware that there's some weaknesses in the users and carers involvement if you like but we're doing what we can to improve it within the resources we have available to us.'* *(District 3)*

Similarly District 8 had 'health forums' around the district where members of the public could come to discuss health issues; there were also links with other groups, such as tenants' associations, and there were plans to set up 'Citizens' Panels'. District 8 also had a full time worker responsible for co-ordinating the two-way flow of information between the health authority and the public. These initiatives were not exclusively concerned with stroke.

Districts 6 and 8 used the media: in District 6 this was media coverage of the launch of the 'Stroke Action Plan'; District 8 used press releases and put out pieces of information in local newspapers; radio was also used where necessary. Districts 6 and 9 also mentioned the Director of Public Health's annual report as a means of communicating information to the public (although this obviously had a much broader coverage than stroke alone).

Districts 2 and 7 stated there were no methods in place for reporting back to the public on stroke services.

vi Stroke services as a district priority

Stroke was a priority in eight districts. In District 1 it formed part of the medium term strategy; in Districts 5, 6, 8 and 9 stroke was a priority in the Health Improvement Programme, while in District 3 it was mentioned in the performance agreement as part of the elderly services review. Reasons given for priority status were:

- stroke being a priority in national initiatives (Coronary Health Disease service framework, District 6; Our Healthier Nation, District 9)
- stroke being national priority (District 3)
- stroke being local priority (District 1)
- mortality rate from stroke high (District 3
- 'people' unhappy with current service provision (District 3) and district not making very good progress with stroke services; underdevelopment of specialist services

- interest stimulated by district being used as one of the Clinical Standards Advisory Group in-depth sites

In District 7 stroke was not a priority.

vii Priority areas within the provision of stroke services

Primary prevention of stroke was the most frequently mentioned priority area. District 9 just stated 'prevention' was a priority; management of hypertension was given by four districts (1,2,6 and 8), atrial fibrillation by two (2 and 8) and aspirin by one (8). Three districts cited rehabilitation as a priority (2,3 and 4), along with better co-ordination (1 and 3); two cited the provision of a stroke unit (4 and 8). District 5 singled out community rehabilitation (using a 'community rehabilitation team'). Rapid access investigations and CT scanning were considered important in Districts 2 and 6 respectively, while District 3 mentioned 'appropriate medical interventions'. District 9 gave the development of pathways of care as a priority, to "assure people at all stages of what type of care they can reasonably expect".

Reasons given for selection of priorities included evidence of effectiveness (Districts 1,3,6 and 8), ie those interventions with most impact in terms of preventing stroke or reducing morbidity and mortality post-stroke. Two districts (4 and 5) chose their priorities because of gaps in the present service:

> *'There was a recognition that hospital rehabilitation wasn't providing a very good service. We had these, quite a number of slow rehabilitation beds and we weren't convinced that there was all that much active management. We thought we might get both a better model and also more dedicated resources if we were to try and establish community rehabilitation teams.' (District 5)*

District 7 stated there were no priority areas within the provision of stroke services.

(c) Structures to help commissioning

i Stroke co-ordinator

Five districts had a stroke co-ordinator (1,2,5,6 and 8). In District 1, as mentioned previously, each general practice had a 'key worker' responsible for the co-ordination of care for stroke patients; these were supported by a 'stroke development co-ordinator', whose role was to identify a key worker in each practice and ensure they have the necessary skills and support for the task. District 5 had a co-ordinator funded by the Stroke Association and a 'stroke rehabilitation sister'. In District 6, the acute trust had a stroke co-ordinator, while the community trust had a 'rehabilitation co-ordinator' (a physiotherapist) for stroke patients. Districts 1 and 8 mentioned the strategic role of the Director of Public Health in overall co-ordination of stroke services.

Districts 3,4,7 and 9 did not have a stroke co-ordinator, although one was planned in District 3.

ii Lead person for stroke

District 1 again outlined how there was a lead in each general practice, a nurse led at trust level and the Director of Public Health led at a strategic level. In District 3 the Senior Registrar in Public Health Medicine was the lead in the health authority. Districts 3, 4 and 8 mentioned lead consultants in the trusts who took responsibility for co-ordinating stroke services, but in District 6 the role seemed implicit:

> *'We don't have a lead, we've also got some clinicians who are de facto leading, providing real kind of leadership.' (District 6)*

Districts 2,5,7 and 9 had no lead person in stroke.

iii Advisory group for the co-ordination of stroke services

Five districts had some form of advisory group for stroke services (Districts 1,3,6,7 and 8). For example, in District 1 the 'Integrated Commissioning Group for Prevention and Treatment of Stroke' was convened intermittently to produce and update the commissioning plan for stroke services; similarly, in District 6 the 'Health of the Nation Stroke Group' was responsible for developing a strategy for stroke services, including recommendations on primary and secondary prevention, stroke treatment and rehabilitation. District 7 did not have a formal advisory group, but a group looking at guidelines for stroke services which also acted in this capacity.

Districts 2,4,5 and 9 had no advisory group; in District 5 one was constituted on an ad hoc basis; in District 9 a group had not yet met but was to be convened to "set the strategic direction of stroke services...and to ensure a co-ordinated approach, providing the delivery of stroke services."

iv Stroke register

No district had an ongoing stroke register. District 5 had commissioned one as part of a two year project undertaken by a University, but this had ended with the project. Some districts did not see any benefit in having a register: District 6 considered it not to be cost-effective at an estimated price of £40,000 per annum. District 3 similarly stated:

> *'No. I'm not recommending one either - too much. That might come later. You've got to think very carefully about registers I think. I've yet to be convinced unless you've got someone who's absolutely in love with the topic and plenty of resources and you're going to use it for something so no, that would be one step too far at the moment.' (District 3)*

v Research

Seven districts (2,3,4,5,7,8 and 9) had no district-led research in stroke services. District 3 was, however, conducting some focus groups with users and carers but this was within existing resources following a rejected bid for funding. District 8 benefited from 'excellent research' going on in a neighbouring trust, which also covered some of its general practices, and had made a decision to use this to inform stroke management planning rather than duplicating it within the district.

In District 1, a study of atrial fibrillation had just finished, but the data was being analysed further to look at risk of stroke in the county. Another ongoing study was examining the management of hypertension in four general practices; a further funded study concerned good prescribing for hypertension. The District was also involved with Community Health Councils in qualitative research. In District 6 a community stroke rehabilitation project was being externally evaluated.

Seven districts (1,3,4,5,6,8 and 9) had links with one or more academic departments; in District 3 there was also a plan to make two vacant consultant geriatrician posts linked to university senior lecturer posts. Two districts (2 and 7) had no links, but Districts 8 and 9 also felt links were not yet fully developed:

> *'you know there is support available but I think it's not exploited to its full potential' (District 9)*

vi Involvement with non-statutory sector organisations

All districts had greater or lesser involvement with non-statutory sector organisations, most commonly the Stroke Association (Districts 1,2,5,7 and 8) and Community Health Councils (Districts 3,5,6 and 8).

a *Stroke Association*

In District 1, the Stroke Association was involved in 'awareness training and education about stroke' for GPs, nurses and others as part of the implementation of the stroke plan. They also provided day care, home support and other services. Districts 2,7 and 8 similarly had 'family support' funded by the Stroke Association, while District 5 had a 'stroke liaison worker'. In District 4 the Stroke Association regularly met with representatives from the Health Authority; meetings were followed up with reports submitted to Health Authority staff and relevant trusts. District 6 was planning to invite a representative from the Stroke Association to their Health of the Nation Stroke Group meeting.

The Stroke Association did not appear to be active in District 9.

b *Community Health Councils*

District 1 was involved with the Community Health Councils (CHC) in various kinds of qualitative research with lay people, consultation exercises and other projects associated with stroke planning. In Districts 3, 6 and 8 CHC representatives were involved in reviewing and/or planning stroke services. For example, in District 6 the CHC were involved in discussions on the stroke plan and the Health of the Nation Stroke Group. District 5 also met them regularly.

In other districts there was no stroke-specific input from CHCs (2 and 9) while District 7 stated CHCs were 'not particularly interested in stroke services'.

c *Other voluntary bodies*

In District 3 the voluntary sector was represented by Help the Aged on their elderly care review. District 5 also linked with the Council for Voluntary Services in "joint planning networks" in relation to the use of joint finance or housing initiatives. Links with Age Concern were cited by District 8.

d *Patient and carer groups*

Districts 1 and 5 felt involvement with patient and/or carer groups was more appropriate at trust, rather than district, level:

> *'we've tended to avoid getting drawn into voluntary sector steering groups or ad hoc liaison groups, we felt it's more appropriate, particularly if they're carer and user led, that they link into staff within the local trusts.' (District 5)*

Other districts had varying degrees of contact with patient and/or carer groups; often the purpose of this was to inform future plans for stroke services (Districts 4,7 and 8):

> *'We do have regular meetings, the health authority, with as I mentioned voluntary carers, users of the service which will include a representative organisation like the OK Stroke Club for example. It was actually a practice of seeing representatives on an annual basis and obviously it's a challenge for us trying to take into account some of the views and things they have about services. They will be taken up both with the trusts and as far as possible in our developing plans for the forthcoming year.' (District 4)*

vii Health Action Zone status

Six districts (1,3,4,7,8 and 9) had been successful and three (2,5 and 6) unsuccessful in their bids to become Health Action Zones. Of the six, only one bid specifically covered stroke (District 1) and was given as one of the reasons why Health Action Zone status was sought. Other districts stated that while stroke was not mentioned specifically, bids did encompass components which would have some effect on stroke:

> *'one of the elements of the bid was for better integration of services generally. Now stroke clearly fits very well into that and that better integration is about better integration across primary, secondary and tertiary care as well as between health care and social services care. We*

> *would expect stroke services to be included within that but it wasn't explicitly mentioned in the bid'. (District 7)*

viii Health Improvement Programme

Eight districts included stroke within their Health Improvement Programmes; in four it was included as a priority area (Districts 5,6,8 and 9). District 7 had not yet decided what was going into the Programme.

(d) Services commissioned

i Services commissioned for stroke prevention and health promotion

One District (7) stated that no services were commissioned "explicitly" for stroke prevention. All other Districts outlined health promotion initiatives designed to prevent strokes (see Table 39)

With the exception of Districts 4 and 7, all Districts had initiatives in place for the management of hypertension. The level of sophistication varied, however, from one District which described itself as being at "stage one", which comprised developing a programme of work with one Primary Care Group involving training general practice staff and developing protocols (District 8), to a District with a comprehensive hypertension strategy (District 1):

> *'the other strand is a kind of hypertension strategy...and that's focused around the development and support of guidelines for better treatment of blood pressure, the development of and the commissioning of people who help better prescribing, there's that aspect of it and finally the commissioning and support of information systems to support structured care of hypertensives.' (District 1)*

Other secondary prevention measures cited were provision of aspirin for high-risk individuals (District 8) and routine anticoagulation for people with atrial fibrillation (Districts 2,4 and 8). One District (6) provided a fast access service for patients with Transient Ischaemic Attacks in the form of a TIA clinic; however in District 1 there was "very little" in terms of services for TIA patients, as this was regarded in the strategy as being of low priority.

Two Districts (5 and 6) had commissioned the following secondary prevention audits: aspirin in TIA patients (District 5), stroke prevention (District 5) and the management of hypertension (Districts 5 and 6).

In District 4, the maintenance of effective relations, both with local community regions and groups and with the media (in order to publicise health promotion messages), was included in specifications for trusts.

ii Services commissioned for acute stroke care and rehabilitation

The range of services commissioned for stroke patients was on a continuum from all services through to no services. In District 1, services were commissioned according to the principle of "organised" stroke services from providers across the District. Given its rural nature, commissioning a stroke unit at a single site was not considered feasible. Four districts had stroke units (Districts 2,5,8 and 9), however in two of these (Districts 5 and 8) only one hospital in the district had one. Districts 1,3,6 and 7 did not have stroke units, but in District 6, 12 beds at the end of one ward served as a focus for stroke care.

Direct access CT scanning was detailed in District 1's plan; District 6 had also undertaken a health technology assessment review on CT scanning and stroke, as well as developing guidance on referral for Doppler and carotid angiography: this was also the subject of an audit by local clinicians.

In Districts 3,4,5,7 and 9, stroke services were largely commissioned as part of general medical services:

> *'All stroke care would be, or almost all, would be included within general medical services contract and we just have big block contracts with general medical services which haven't been split up in any way at all between sub-specialisms within that. They're very crude contracts.' (District 7)*

With regard to rehabilitation, districts provided rehabilitation services, for example in community hospitals (District 1), but these were not commissioned specifically for stroke patients (Districts 1,3,4 and 7). Several districts also commissioned individuals or teams to care for stroke patients: in District 1, every primary health care team had a key worker for stroke who maintained a register of stroke patients and was supported by community occupational and physiotherapy; key workers also co-ordinated care for patients who did not need admission to hospital. District 6 had a stroke co-ordinator in the acute trust and a rehabilitation co-ordinator (a physiotherapist) in the community as part of a team. District 2 commissioned "family support workers" to provide advice and information to stroke patients' families as well as community rehabilitation teams. District 9 had a stroke outreach team; one was also planned in District 5. District 8 commissioned the Stroke Association to provide family and dysphasic support for stroke patients.

iii Services commissioned for long-term care

In the majority of districts (1,2,3,4,6 and 9), long-term care was not commissioned specifically for stroke patients. Several districts mentioned the provision of places in residential or nursing homes (1,2,5,7 and 9), but again this was not specific to stroke. In District 5, younger patients with substantial disability were placed in specialist units in the private sector. One district (8) mentioned carer support along with long-term care: a carers' strategy was in place and the issue was considered important, particularly, but not specifically, for stroke patients.

iv Co-ordination of service provision between different organisations

There were two main ways in which services were co-ordinated for stroke patients: via stroke co-ordinators and via policy or strategy groups. With regard to the former, District 1 had a 'key worker' in every general practice whose role was to 'monitor the implementation of integrated services'; key workers were supported by a stroke development co-ordinator. District 5 employed a specialist nurse responsible for community co-ordination in each of two trusts: her role was to do needs assessments for each patient with substantial health needs at discharge and liase with appropriate bodies, for example social services, hospital consultants and nursing staff.

Secondly, co-ordination was managed by an 'integrated stroke services steering group' (District 1), a 'Health of the Nation stroke group' (District 6), a 'discharge policy group' (District 6; not specific to stroke patients), a 'group of people' looking at what would be local best practice in stroke care (District 7); a 'strategy implementation group' (District 8) and a 'disability strategy group' (District 9; again not specific to stroke patients). District 4 was not clear how services were co-ordinated, but believed it to be via contract specifications which covered 'maintaining effective relations and working with local community professionals'.

Several districts believed services were not co-ordinated in a formal way or were poorly co-ordinated (Districts 3,5,7 and 9):

> *'Probably not well. I shouldn't say that, not in a very formalised way.' (District 5)*
>
> *'It's very poorly co-ordinated and it's something that we're trying to improve. At the moment we don't have a lead clinician with responsibility for stroke services, we don't have any lead person within either of the acute or the community trusts or indeed within social services who takes responsibility for stroke care and as a result everybody is doing their own thing.' (District 7).*

(e) Recent and planned changes

i Recent changes in the management of stroke services

Three districts stated there had been no recent change in the management of stroke services (Districts 3,4 and 9); in District 3 this was because they had not yet finished work in progress. Changes in other districts were diverse.

- A change in trust structure bringing in input from a consultant with a specialist interest in stroke (District 1)
- Setting up a stroke unit and work on atrial fibrillation and smoking cessation (District 2)
- Providing CT scans for all acute stroke patients (District 5)
- Development of a 'Stroke Action Plan' (District 6)
- Development of a 'Stroke Guidelines Group' (District 7)
- Appointment of a new Director of Public Health with an interest in stroke (District 8).

ii Future changes envisaged in the commissioning of stroke services

Two districts outlined changes arising from the advent of primary care groups (PCGs):

> *'Not in the way it's done from the point of view of the overall strategy but clearly aspects of quality, aspects of whether or not the service is actually being delivered, how the contracts are agreed, all of that will change because of the PCGs. But the content and the strategic direction probably won't change at all.' (District 1)*

District 4 also believed PCGs would want to take stroke on board. Two districts (3 and 9) also envisaged care pathways: in District 9 a multidisciplinary group had been convened to work on this, while District 3 was working on a care pathway spanning acute care, rehabilitation, discharge planning and care after discharge; there were also plans to extend this into primary care. Other future changes included:

- A stroke unit:

  '...with capacity to treat more patients' (District 2)

  '... open to patients of all ages' (District 3)

- A service specification for stroke (District 3)
- A rapid access clinic for stroke and TIA patients (District 3)
- Development of rehabilitation services (District 5), community rehabilitation (including a co-ordinator role) and hospital-at-home schemes (District 3)
- A new model of service delivery, comprising a new acute centre with 'intermediate care units' (District 7)

Two districts said that changes would depend on external guidance from the White Paper on public health (District 6) and whether a National Service Framework for Stroke was produced (District 6). In District 8, change was a 'dynamic process' they were working on; it was not clear at the moment what changes might occur.

iii Major resource shifts planned for stroke services

In three districts (3,4 and 8) a stroke unit was planned, although in District 3 this was not thought to involve major resource shifts:

> *'I think the trust will want a significant amount of money to provide a stroke unit and staff it appropriately. And then I think we should argue appropriately with them that there isn't any dramatic increase in use of resources and I think we'll have to come up with an agreement because I do recognise that they will need more therapy time and so on and it has been very thin on the ground so the reason for an acute stroke unit I don't believe will require any more resources.' (District 3)*

Otherwise, districts mentioned a variety of resource shifts planned: management of hypertension (District 8); pharmacists to help facilitate good prescribing for hypertension (District 1); employing another consultant in the trust with an interest in stroke (District 1); increase in number of CT scans (Districts 1 and 6) and purchase of a colour Doppler (District 6); provision of rapid access clinic (with consequent increase in investigations such as carotid Doppler and CT scanning) (District 3); community rehabilitation; employing community rehabilitation staff to support general practice based stroke co-ordinators (District 1); andtransferring resources into community rehabilitation (District 5)

Several districts (2,4,7 and 9) said they were unsure about what resource shifts were planned or were in the process of deciding (District 8).

No district had an identified specific budget for stroke services, and no district was able to state the proportion of the total budget spent on stroke services.

iv Areas where more could be done in stroke provision in the district

a Stroke prevention (Districts 2, 5, 6 and 9)

- Prevention and management of hypertension (Districts 2, 5 and 6)
- Improving nutrition and reducing salt intake, particularly in ethnic minority groups (District 5)
- Promoting physical activity (District 5)
- Managing atrial fibrillation (District 2).
- Secondary prevention and drug treatment (District 6).

b Acute care

- An acute area for stroke patients, as well as a stroke unit (District 2)

  'proper acute care based on evidence' (District 3)

- A 'rapid access clinic' for patients choosing not to be cared for in hospital (District 3).
- New drugs may mean emergency admission for all stroke patients (District 8).

c *Rehabilitation*

- Faster admission to the stroke unit in one part of the district (District 2)
- 'Co-ordinated rehabilitation' delivered in a stroke unit (Districts 3 and 4)
- A stroke co-ordinator spanning primary and secondary care to ensure patients received the right blend of input from different professionals without delay (District 3)
- The development of an appropriate team to care for stroke patients (District 4)
- More active rehabilitation on wards at the weekends (District 6).
- More input into community care for stroke patients (Districts 3, 5, 6, 7 and 8) carer support and respite (District 6)
- 'Active management' of stroke patients in their own community (District 5)
- Improvement in GP care, including GP education in the management of stroke (Districts 7 and 8).

  'I suspect that the care given by GPs to those patients is probably very patchy and variable and I don't know how many of them get onto a decent secondary prevention regime and so on and so forth. So I think that's an area that does need looking at, it possibly needs to be improved and some GPs have said to me, 'well of course one of the problems we have is that when we choose to look after somebody at home we don't have access to CT scanning and the other kinds of investigations in hospital that we would like to have access to and sometimes we just send patients in as inpatients in order to get the scans and get cardiac echo or whatever seems appropriate'. So I think that that's again another area where there's possible room for improvement.' (District 7)

- A stroke register to help identify numbers of people with stroke (District 9)
- General lists of areas which could be improved:

> *'Well we could spend more money, have more staff, do more education, carry out more research, I mean there's just no end to it really. It would be more of the same though really. I don't think there's anything that we really want to do that we're not doing if only in the most modest way. But there's always more that can be done'. (District 1)*
>
> *'better prevention, better co-ordination and a clearer direction really'. (District 9)*

v Constraints on the improvement of stroke provision

a Lack of resources

Financial resources were mentioned by districts 1,3,4,5,6,7 and 8. Human resource constraints were mentioned by 1,3, 4,7 and 8 - specifically:

- Individuals not having enough time to devote to stroke (District 1)
- A shortage of specialist skills (eg speech therapy, occupational therapy; (Districts 1,4 and 8)
- A shortage of consultant geriatricians (District 3), neurologists (District 4) and consultants with a special interest in and primary responsibility for stroke (Districts 1 and 7).

b Stroke only one of a competing set of priorities

Districts 6 and 8 mentioned this.

> *'Well the general constraints that affect resource allocation within health authorities. We are, we have never been able successfully to disinvest in areas where we know there's been inefficient activity. Even if we've managed to change clinical practice through our clinical networks it never frees up money that we get back to invest in other priorities. So it's sort of consumed by the local providers as their efficiency gain as it were or they spend it on their own priorities.' (District 5)*

c Other organisational change

District 3 said Review of elderly services awaited before reconfiguration of stroke services and District 7 was awaiting a decision on a bid to replace two small hospitals with a new acute hospital before decisions could be taken regarding future provision of hospital care.

d Links with other organisations were listed as constraints

Lack of 'intersectoral planning' and the *ad hoc* way in which problems were resolved between social, housing and health services was described by District 5.

> *'The third major problem I think is probably the history of difficult relationships with social services locally which is slowly getting better but on the whole there hasn't been a history of co-operation and joint working.' (District 7)*

e Lack of evidence

Far example, wanting to know the 'right' way to provide rehabilitation (District 9)

f Involving users and carers

> *'I mean you've mentioned involving both lay people and services users, carers, that sort of thing. I mean everybody is very willing and trying hard to do that but evidence based techniques and technologies to do that sort of qualitative work better is wanting, I think. It's not saying we don't try and do things but I'm sure we could be more sophisticated about that.' (District 1)*

g The 'image' of stroke services

District 6 described the area as having no 'glamour' and others thought many lay people and health professionals hold a 'nihilistic' view:

> *'They just regard it as one of the things that happens to old people and it's not really very important and you know, why are we getting excited about it? So there's that sort of nihilistic view if you like of stroke...which is held by quite a lot of people from individual consultants through to GPs down to community staff sometimes. Not to mention mainly the public themselves.' (District 1)*

h *Obtaining the co-operation of trusts*

Mentioned by District 2.

i *Inability to provide adequate community support*

Mentioned by District 8.

j *Lack of co-ordination*

District 9 was concerned with stroke services provided in different locations.

4.10.3 Qualitative findings from the second survey

Post-intervention, one Director of Public Health (District 5) declined to be interviewed as there had been, in his opinion, no changes in the commissioning of stroke services.

(a) Changes in general commissioning

The change mentioned most frequently was the involvement of Primary Care Groups (PCGs) in the commissioning process; the number of PCGs in each district are shown in Table 39. In four districts (Districts 1, 4, 6 and 9) commissioning had moved to a greater or lesser extent to PCGs. In District 1, the commissioning of all acute services had been delegated to PCGs; in District 4 this was an average of 55%, with the health authority providing advice and support. District 6 also stated that from this commissioning round general district-based and community services would be commissioned primarily by PCGs, with the health authority retaining the lead on specialist and supra-district services.

In Districts 7 and 8, while PCGs were constituted, the health authority appeared still to be in negotiation with the PCGs about the best way to hand over commissioning responsibility:

> *'we are trying to get the Primary Care Groups, who obviously have been constituted since last April ... to take a more active role in the commissioning of individual servicing and we've reached agreement with them that individual Primary Care Groups will take on a lead function for particular service areas, and work with the local trusts to develop long term service agreements in those areas. Er, now we haven't actually gone*

> *beyond the agreement that that's what we should be doing. There hasn't .., haven't yet been any agreed ....., such agreements signed although they're being worked on, but that's the intended direction of travel.' (District 7)*

> *'to some extent in that we're now working more closely with the Primary Care Groups and em, we're ..., we've got em, our Health Improvement Programme priorities and each of those, or a large number of those anyway, have Health Improvement Programme groups which are sort of expert groups in the district which think about what the needs are and what the priorities are within each of those areas... and there's Primary Care Group involvement in those groups and, we need to go back to the Primary Care Groups to agree with them that those are the priority areas for funding and then, you know, as things move forward of course and we move from Primary Care Groups to Primary Care Trusts, increasingly the decision making about what spend is agreed to, we'll move to them rather than stay with the Health Authority. We're doing a lot of discussion at the moment as to exactly how that process is going to work, because it's quite a change in the way of doing things so it does require a lot of discussion, and there are papers flying around describing how it will work and they change it every week at the moment!' (District 8)*

In the former, a restructuring of the health authority was underway to support the development of PCGs and there had been significant movement of personnel (including health authority staff) to staff these groups.

In District 3 the PCGs were "just getting themselves together", whereas District 2 stated there were no changes in commissioning as a result of the advent of PCGs.

Other general changes in commissioning included the demise of General Practitioner fundholding (Districts 1, 6 and 7) and the introduction of a strategic background to commissioning in the form of a series of strategies arising from the Health Improvement Programme planning process (District 4).

Interviewees were asked whether their role in the commissioning process had changed in the last year. The majority of respondents felt their role had changed from hands-on commissioning to a more strategic and advisory role. The latter now involved advising PCGs and public health rather than colleagues in the commissioning directorate. In some districts (eg District 7) the strategy for stroke services was still being developed; other districts (eg 1 and 6) were now in the implementation phase, requiring less direct involvement of the Director of Public Health:

> *'I'm much less involved now. There's two different reasons for that. One is with ..., in terms of overall services we have delegated a lot more autonomy to the PCGs, both in terms of needs assessment and service planning, they are getting on with things where I'm now more acting as an advisor than a hands on doer and I mean if you give the example of stroke services, the second reason would be, inevitably I tend to take a strategic view of things and that's interspersed with operational needs and stroke is a good example. Two years ago we were talking an awful lot about what's the evidence, you know, what theoretically should we be doing whereas this last twelve months has been dominated by much more right well, lets set up a stroke unit, lets do this, lets do that, and that doesn't involve me at all, and that's just for the Trust and the GPs to get on with basically.' (District 1)*

i Factors facilitating change in general commissioning

Interviewees identified a number of factors which facilitated change in commissioning: Setting up of PCGs (Districts 1 and 8); Larger number of stakeholders (District 8) -

> *'last year it was quite an ad hoc top-down process where a few people actually made the decision as to what we were going to spend our money on. Now it's much more of an open process where a large number of stakeholders are involved...'(District 8)*

The demise of fundholding (District 1); Health Action Zone status (District 1); Health Improvement Programme (District 4) –

> *'the creation of the formal HImP ... has demanded, and we have enthusiastically welcomed it, that we do develop strategies for health improvement in clinical areas and, but the fact that we have been given both the opportunity and the expectation to do that has allowed us, both*

> *from a primary care perspective and a public health perspective, to influence the strategic commissioning exercise and take it away from just a number counting exercise.' (District 4)*

Other factors cited included: the time consuming nature of annual commissioning and need for longer term service agreements (District 7); Change of personalities (Director of Public Health and Director of Primary Care)(District 4); Creation of a new trust (District 1); Primary Care Act Pilots in three General Practices (District 1) -

> *'the PMS pilots are a completely different way of running general practice where it's a local contract now with the Health Authority and it's set on the basis of historical budgets, so in other words they no longer need to do all these things separately to get all the money, it comes as a lump sum, but in the return we set them contractual obligations to do with the quality of service that they provide and we have chosen some clinical markers to do with the secondary prevention of heart disease, so, and it is governance in a sense but it's not just clinical governance, it's actually the corporate governance of these practices because what we have said is, we don't want you to count all the silly things that you normally used to count in the old days, what we want to do now is prove you are managing people who've got ischaemic heart disease properly and so on and so forth.' (District 1)*

Also mentioned were: Financial constraints (District 1) -

> *'the financial constraints generally in the system is a main driver always'. (District 1)*

Districts 2 and 3 could identify no drivers for change.

ii *Barriers to change in general commissioning*

Respondents described a wide range of obstacles to change:

Difficulty in introducing change (District 4)

> *'everything is difficult to change and it's been more difficult to change it quickly. All providers at the sharp end are interested in developing their own services within their own interest rather than about improving health*

> *care as a whole, and the process of agreeing strategies and agreeing distributing of resources is wading through treacle'. (District 4)*

Resource issues:

> *'there are issues in resourcing, which has implications for the pace of change and capacities of organisations for change' (District 6)*
>
> *'not enough time, not enough staff' (District 7)*

Also, lack of service agreements or pathways of care not yet in place (District 6); Inability to agree with providers whether it is a stroke unit which brings favourable outcomes or bringing together a multidisciplinary team (District 6); Relationships between trusts and primary care (District 7); and lack of any system for disinvesting in services which are clinically limited and not cost-effective (District 4):

> *'creating a system for disinvesting, and reinvesting in higher priority areas is like wading through seven foot of treacle.' (District 4)*

Districts 1, 2, 3 and 8 did not give any barriers, but District 1 stated that the amount of change in commissioning could also be a hindrance as:

> *'it slows some things down'. (District 1)*

(b) Changes in stroke commissioning

Interviewees were asked whether there had been any changes in the commissioning of stroke services. In several districts there had been change at a strategic level: in District 4 a new group had been created to review the strategy for stroke services and develop a model of service which could be commissioned. The model comprised a new diagnostic assessment unit for patients with acute stroke, satellite therapy-led in-patient rehabilitation units, a community rehabilitation programme and a primary care-led secondary prevention programme. One of the trusts in District 1 had also set up a clinical review group, run jointly between the trust and a Primary Care Group, with responsibility for planning stroke services. District 3 also now had a policy for stroke services within which commissioning would take place:

> *'we are looking to commission stroke, you know, actually say something about the services we want for stroke where we didn't say what we wanted*

> *for stroke before. So actually saying what we would like for stroke, that'll be a change.' (District 3)*

The Health Improvement Programme was seen as bringing about change in stroke commissioning in Districts 6 and 8. In the former, stroke was given a high priority by PCGs because it was a priority in the Health Improvement Programme; in the latter the Health Improvement Programme raised the status of an existing group looking at stroke services:

> *'We did have a stroke group last year, which didn't have a lot of status to be honest. It was rather isolated on its own. Now we've got this system of having Health Improvement Programme groups for all the priority areas and that stroke group has become one of those Health Improvement Programme groups. It's gained more of a status than a purpose and...it's become a very useful one, because, you know, as we're thinking of what the priorities should be, what we should spend our money on, this group is the one that ... is the best placed to advise the Health Authority on that.' (District 8)*

Interviewees gave several more examples of changes in stroke services over the last year: New (Districts 1 and 3) or agreed (District 4) stroke units; Development of a business case to commission increased community services (District 1); Setting up a transient ischaemic attack clinic (District 1); Provision of an additional family support worker from the Stroke Association (District 2); Closer working relationships with social services (District 3); Development of a care pathway for stroke (District 3); A full complement of geriatricians (District 3); New Computerised Tomography scanner (District 4).

As discussed previously, in Districts 1 and 6 PCGs were actively involved in commissioning stroke services. Stroke was not a priority for any Primary Care Group in Districts 7 and 9, but was planned in the former:

> *'we will ask one of the Primary Care Groups to take the lead on commissioning stroke services and they will then be asked to work out long term service agreements for the trust and the community trust and social services ... they've got an awful lot on at the moment and stroke*

> *isn't one of the first wave of services that they're working out long terms service agreements for.' (District 7)*

Districts 2 and 4 were still at the stage of involving PCGs in discussions about commissioning stroke services.

i *Factors facilitating change in the commissioning of stroke services*

Interviewees identified a number of factors which facilitated change in the commissioning of stroke services. National priority guidance included stroke and the National Service Framework for coronary heart disease was expected to include stroke prevention (District 4)

Change of consultant personnel in District 1:

> *'the fact that the Trust has merged meant that they already had a consultant with an interest in stroke now so although he was based at ... he's been taking a lead on developing stroke services for the whole Trust which has meant that ... has benefited a lot. Now you could argue that he's nothing to do with commissioning services but he's delivering them, but in many respects there's always bound to be a partnership between the people who've got the money and the people who provide the service. He's the key to the change in the last 12 months I would say.' (District 1)*

District 3 described a review of stroke services and dissatisfaction with elderly services generally and stroke provision specifically. District 6 mentioned the drive from one locality which had the highest SMR for stroke in the district and in District 8 Stroke was a high priority in the Health Improvement Programme.

Effective lobbying from user organisations took place in District 4:

> *'I think we'd have been doing this work at a gentler pace, we'd have been doing it but we'd have been probably starting it in April rather than finishing it, if it hadn't been for a very effective lobby from user organisations which have got to the powers that be and as a result of that, you know, the chairman of the Health Authority and the Chief Executive of the Authority and our members of Parliament have decided that it will leapfrog the priority areas.' (District 4)*

District 9 mentioned the need for quality:

> *'there's still what I feel should be the drivers for change, you know, the need for quality. Em, and hopefully this work being done, it will be done, as part of the HAZ, should help to identify the gaps in the service that's currently being provided and produce a more cohesive sort of service.' (District 9)*

ii Barriers to change in the commissioning of stroke services

Respondents described a wide range of obstacles to change in commissioning stroke services. Districts 1, 3 and 6 said that stroke only one of a number of priorities:

> *'the trust did have a very big, big agenda so finding the right people to talk to and to get agreement on staff changes [to set up new stroke unit] and so on has probably been the thing.' (District 1)*

Districts 1, 4 and 7 said that Consultants were resistant to change:

> *'that has been hindered by lack of agreement amongst the clinicians about what form more organised stroke services would take so that, for example, the neurologists and the elderly care physicians have different views about what would be in the stroke unit. The elderly care physicians are much more interested in developing rehabilitation and ensuring that patients with stroke have got proper rehabilitation. The neurologists are more interested in the hi-tech acute end of it, thrombolysis and all this sort of stuff. So there hasn't been that agreement, and I've been trying to get the acute trust to come to some agreement about the clinical model and say, well, you know, once you've agreed on a clinical ..., once we can agree on a clinical model then we can talk about how that might be delivered. (District 7)'*

> *the medical consultants in ... aren't ..., how should I put this, teamwork isn't their strongest point if I put it like that, so bringing about any change could always be quite difficult. So if you like, the things that's hindering it there is the autonomy of the individual consultants. (District 1)*

Other issues mentioned were: resources (Districts 3, 4 and 6); the difficulty of maintaining the 'separateness' of beds for stroke patients and making sure patients in need of rehabilitation have access to these (District 2); Organisational change (Districts 1 and 4);

> *'when you've got new organisations, you've got new people and new ways of working and it just tends to slow things down.' (District 1)*
>
> *'the process of that change and the management structure changes that are still evolving have meant that the negotiation for change has been more cumbersome and just as with every other area. It's not been a major issue but it's certainly been a problem' (District 4)*

and Health Action Zone bureaucracy (District 9)

> *'I think our sort of Health Action Zone bureaucracy seems to... has taken quite a long time to approve projects and things have gone back and forwards between different committees.' (District 9)*

In District 8 there were no perceived barriers to change in the commissioning of stroke services.

iii Impact of the Health Action Zone on commissioning stroke services

Interviewees were asked what impact Health Action Zone (HAZ) status had had on the commissioning of stroke services. With the exception of Districts 2 and 6 all districts had Health Action Zone status. The remaining districts were split between those where there had been no impact so far (Districts 3, 7 and 9) and those where the HAZ had had various beneficial effects, principally in stroke prevention. Examples were smoking cessation (Districts 1 and 8) and the promotion of physical activity (District 8).

Other effects of the HAZ given by interviewees were: introduction of enhanced computer systems for *managing structured care* in primary care (District 1); developing more effective models of rehabilitation by working across organisations (District 8); provision of aids and adaptations to prevent delay in discharge from hospital (District 8).

4.10.4 Results in Gateshead and South Tyneside

Below is a brief summary of the same issues in Gateshead and South Tyneside at the same time as the interviews for comparison.

(a) Commissioning

Gateshead and South Tyneside have a predominantly health authority approach to commissioning. There were very few Fundholders and there were no Total Purchasing Pilots within the district. Consequently, there was a slow start to the Primary Care Group commissioning with stroke services continuing to be commissioned by the health authority.

There was a strong pressure to use evidence within the district and this was one of the reasons why the Director of Public Health supported the project. There was a clinical evidence resource centre within the health authority containing both materials and a member of staff dedicated to this. Analyses of routine data such as the Contract Minimum Data Set were done but the use of routine data for Commissioning was limited. Stroke was a priority in the district in as much as it was in the Health of the Nation and Our Healthier Nation but as is clear in Chapter 2 stroke was not a high priority for any group or organisation and not a priority at all for many groups.

Service Specifications had not been developed for stroke at the start of the project and work was still under development at the end. There was no written district stroke strategy prior to this project. There was no clearly defined evidence-base for stroke services before the project (except for the stroke unit - see below). Both trusts had a lead clinician for stroke during 1996 but one left during the time-scale of the project. There was no district wide co-ordinating group and no clearly defined lead for stroke within the health authority until this project started. One of the trusts was developing a stroke register for all admissions. Both trusts had done ad hoc audits in the past looking at all stroke patients.

(b) Services commissioned

There were no specific health promotion activities for stroke prevention. There were smoking cessation strategies, particularly in South Tyneside, and other initiatives such as a healthy lifestyle survey in each part of the district. There had been work on lipids in primary care and on the use of aspirin in angina (PACE project). There had been no specific work on hypertension. There had been work on anticoagulant clinics but no specific work on atrial fibrillation.

Both hospitals had stroke units but these had been commissioned differently. In South Tyneside the stroke unit arose following a successful proposal to the health authority. The proposal was widely supported particularly because of the evidence-base to support this. In Gateshead, the arrival of a professor of stroke medicine together with a senior lecturer allowed the development of a stroke unit. Tertiary services, predominantly carotid endarterectomy, were provided outside the district through a general contract with one neurosurgical unit.

Long-term support was predominantly provided by social services through their elderly and disability directorates. There was no explicit commissioning for stroke. At the time of starting the project there were no explicit mechanisms for reporting on stroke services either to the commissioners or to the public. There were no explicit plans for development either. The South Tyneside stroke unit should have had some clear reporting mechanism but this did not seem to have been set up when it was funded. The Gateshead stroke unit had a research element and so was reporting to funding bodies rather than the health authority commissioners.

There were strong links to Newcastle University through the professor of stroke medicine in Gateshead which again started in 1996. The voluntary sector, predominantly the Stroke Association, had an input into services but no clear mechanism to link to the planning of services. The Stroke Association provided a family support service in Gateshead funded by the local authority.

Gateshead and South Tyneside is part of the Tyne and Wear first wave Health Action Zone. There was no specific work on stroke within this Health Action Zone. There was work on coronary heart disease and on the elderly but these did not impinge on stroke in Gateshead and South Tyneside. Stroke was included in the Health Improvement Programme but this may have been as a result of this project being undertaken. Details of areas for further development and constraints can be found in the rest of this document.

(c) Comparison

While all but one district agreed that stroke was a priority area, there was great variation between districts in terms of taking this forward. In the first survey, less than half had a specific service specification or contract for stroke services but the majority of these were based on evidence of effectiveness. In terms of structures in place to facilitate change in stroke commissioning, one third of districts had a stroke co-ordinator, someone taking the lead and an advisory group for taking forward the stroke agenda. All but one district had one or more structures in place.

Again in the first survey, the majority of districts had a written strategy for the provision of stroke services. One year later, for some districts (typically those who also had a service specification for stroke services), the plan was now being implemented and major changes were underway. For others, however, the strategy was still at the development stage and negotiations were still underway about the best model of stroke commissioning.

Not surprisingly, the change with most impact on commissioning in the second survey was the rise of primary care groups; half the districts had delegated commissioning to them to a greater or lesser extent. Primary care groups were, however, at varying levels of development and in the remaining districts negotiation was still in progress to decide on the best way to hand over commissioning responsibility. Only one district where there was some form of primary care commissioning in place pre-intervention had devolved commissioning post-intervention.

Other government initiatives, namely the Health Improvement Programme and Health Action Zones, were also seen as facilitating change in stroke commissioning. The former influenced primary care groups to give priority status to stroke and also, in one district, raised the status of an existing group looking at stroke services. The latter mainly had beneficial effects in health promotion. Other drivers for change ranged from the involvement of a consultant with an interest in stroke to an effective lobby from local user organisations. Obstacles to change mentioned most frequently were the need to also focus on other priority areas, consultants' resistance to change and lack of resources to implement change.

(d) Summary points

- We surveyed nine districts in December 1998 and December 1999 to find out about commissioning of stroke services.
- There was a wide range of structures and processes for commissioning and services provided.
- The major change over the year related to Primary Care Groups.
- Gateshead and South Tyneside Health Authority was less developed in terms of stroke commissioning at the beginning of the Health Care Programme Approach intervention.
- It developed further than other districts over the implementation year.
- No one feature of the Health Care Programme Approach or Gateshead and South Tyneside was unique. However, the breadth of progress was a notable feature of Gateshead and South Tyneside in comparison to other districts.

4.11 Survey of Practice Managers

(a) Response Rates

Forty-six completed questionnaires were returned, a response rate of 75% (46/61). Twelve practices (26%) were single-handed, 12 (26%) had two or three partners and 22 (48%) had four or more partners. Differences in response rate by practice size were not statistically significant.

Forty of the 46 practices that had previously responded returned questionnaires. A further five previous non-responders returned questionnaires giving an overall response rate of 74% (45/61). The response rate completing both surveys was 66% (40/61).

(b) Findings

The main findings are summarised in the following tables. The denominator for the first ('pre-intervention) survey is 46 (all responses) and for the second ('post intervention') is 40 (responders who also responded to the first). The results for the whole second survey response (45) are not given.

Table 40 Practice Structures - numbers (percentages)

	Lead professional			**Register**			**Clinics**	**Audit**
	Doctor	Nurse	Either	'Computer'	'paper'	Either	Present	Present
Hypertension	12 (26.1) *12 (30.0)*	21 (45.7) *21 (52.5)*	23 (50) *23 (57.5)*	29 (63.0) *26 (65.0)*	7 (15.2) *7 (17.5)*	34 (73.9) *32 (80.0)*	27 (58.7) *25 (62.5)*	11 (23.9) *11 (27.5)*
Atrial fibrillation	10 (21.7) *9 (22.5)*	3 (6.5) *3 (7.5)*	10 (21.7) 9 (22.5)	16 (34.8) *16 (40.0)*	1 (2.2) *1 (2.5)*	17 (37) *17 (42.5)*	23 (50.0)* *20 (50.0)**	2 (4.3) *2 (5.0)*
Lifestyle	n/a	n/a	n/a	n/a	n/a	n/a	41 (89.1) 36 (90.0)	n/a
Stroke	8 (17.4) *8 (20.0)*	4 (8.7) *5 (12.5)*	9 (19.6) *9 (22.5)*	21 (45.7) *19 (47.5)*	00	21 (45.7) *19 (47.5)*	3 (6.5) *3 (7.5)*	3 (6.5) *4 (10.0)*
Secondary prevention	8 (17.4) *8 (20.0)*	8 (17.4) *7 (17.5)*	10 (21.7) *10 (25.0)*	n/a	n/a	n/a	7 (15.2) *7 (17.5)*	3 (6.5) *3 (7.5)*
Rehabilitation	5 (10.9) *5 (12.5)*	3 (6.5) *3 (7.5)*	5 (10.9) *5 (12.5)*	n/a	n/a	n/a	n/a	n/a

Numbers (percentages) in ITALICS are post-intervention figures for those practices who returned questionnaires both pre and post intervention.

n/a = question not asked   *anticoagulation clinics

Percentages do not always add up to 100 as some practices had both a doctor and a nurse with a lead role and a computerised as well as a non-computerised register.

Table 41 Prevention Guidelines or Protocols

Guidelines	Pre-intervention (number)	Pre-intervention (percent)	Post-intervention (number)	Post-intervention (percent)
Hypertension	**38**	**82.6**	**34**	**85.0**
-screening	26	56.5	25	62.5
-diagnosis	32	69.6	30	75.0
-management	31	67.4	32	80.0
-referral	20	43.5	19	47.5
-comprehensive guideline covering all above	18	39.1	19	47.5
Atrial fibrillation	**7**	**15.2**	**5**	**12.5**
-screening	1	2.2	1	2.5
-diagnosis	2	4.3	2	5.0
-management	4	8.7	3	7.5
-referral	5	10.9	3	7.5
Anticoagulation	**18**	**39.1**	**18**	**45.0**
-initiation of warfarin anticoagulation	3	6.5	3	7.5
-monitoring of warfarin anticoagulation	17	37.0	17	42.5
-referral for warfarin anticoagulation	5	10.9	6	15.0
-comprehensive guideline covering atrial fibrillation and anticoagulation	4	8.7	4	10.0
Lifestyle interventions	**18**	**39. 1**	**19**	**47.5**
-smoking cessation	14	30.4	17	42.5
-exercise	8	17.4	6	15.0
-diet	14	30.4	12	30.0
-alcohol	11	23.9	9	22.5

Numbers (percentages) in BOLD are practices with *any* guidelines for hypertension, atrial fibrillation etc.

Table 42 Management Guidelines or Protocols

Guidelines	Pre-intervention (number)	Pre-intervention (percent)	Post-intervention (number)	Post-intervention (percent)
STROKE	**5**	**10.9**	**5**	**12.5**
- diagnosis	3	6.5	2	5.0
- management	3	6.5	2	5.0
- referral	4	8.7	4	10.0
Transient ischaemic attack (TIA)	**3**	**6.5**	**4**	**10.0**
- diagnosis	2	4.3	2	5.0
- management	2	4.3	3	7.5
- referral	3	6.5	3	7.5
- comprehensive guideline covering stroke and TIA	-		1	2.5
Secondary prevention	**20**	**43.5**	**18**	**45.0**
- antiplatelet therapy for ischaemic heart disease	15	32.6	13	32.5
- antiplatelet therapy for stroke	11	23.9	12	30.0
- assessment of vascular risk	9	19.6	7	17.5
- follow-up of stroke patients at high risk	3	6.5	3	7.5
- secondary prevention in general	6	13.0	8	17.8
Rehabilitation	**2**	**4.3**	**3**	**7.5**
- rehabilitation	2	4.3	2	5.0
- information for patients and carers	1	2.2	2	5.0

Structures were most commonly found to support the detection and management of hypertension. The majority of practices ran some form of 'lifestyle' clinics, but well under half had guidelines or protocols to support this aspect of their work. While half the practices ran anticoagulation clinics, less than half had an identified lead professional in atrial fibrillation, a register of patients or guidelines or protocols in place for the management of atrial fibrillation or anticoagulation. There were few specific structures in place to support the care of patients with stroke, transient ischaemic attack or patients with stroke requiring rehabilitation. Nearly half of practices did, however, keep a register of stroke patients and have guidelines for secondary prevention; most commonly these were for antiplatelet therapy for stroke.

Audit of current practice in preventing and managing stroke was rare: two thirds of practices had conducted no audits of stroke prevention or management in the last two years.

Findings suggest that while structures were in place to facilitate recall and monitoring of patients with hypertension, for other groups of patients this was left to individual general practitioners with the consequence that opportunities for prevention or treatment may have been missed.

Changes as a result of the implementation of the Health Care Programme Approach were small. This could be due to the lack of specific initiatives by the DSG targeting general practice. An exception was the drive to increase the detection and management of hypertension, which included the distribution of guidelines to every practice, but this had little effect on practice structures.

4.11.2 Summary Points

- We surveyed practice managers in December 1998 and 1999 about structures in place to facilitate stroke prevention and management in general practices.
- Structures to facilitate the management of hypertension and lifestyle risk factors were most common.
- Structures for the identification and management of patients with atrial fibrillation or transient ischaemic attack were rare.
- Few practices had a lead clinician or guidelines for the care of stroke patients, although almost half had a stroke register.
- An initiative to increase the detection and management of hypertension and other activities of the Health Care Programme Approach had little effect on primary care.

5 Triangulation

This section brings together the findings from the different aspects of the study. It does this firstly around the key *structures* of the HCPA (District Stroke Group, Co-ordinator, and Technical Document), secondly around critical *processes* (Priority setting, interagency co-operation and levers of change) and thirdly around the nine *objectives* described on page 39. I will leave the interpretation and conclusions to the Discussion although there is considerable overlap between the two.

5.1 Structures

5.1.1 Stroke Group

Interviews: Most information on the stroke group comes from the qualitative part of the study and is given in detail on pages 97-102, 112, 145, 148-150, 175-178, 190, 198-200. The majority of interviewees considered the group was a necessary part of health care programme commissioning and interagency working (eg quotes on page 148).

Indicators: A number of indicators may reflect interagency co-operation. Length of stay may be affected by a reduction in the number of 'bed blockers' measured as length of stay over 56 days (indicators 1 and 2 pages 203-205). This indicator has moved in the right direction, although it may be part of a longer-term trend. Return to pre-admission type of accommodation (indicator 6 page 209) might also be affected by better interagency co-operation and again this indicator has moved in the right direction. However there are problems of interpretation because of the low proportion of cases where this was accurately recorded within the routine data systems. The rate of emergency readmissions (indicator 5 page 209) might increase as a corollary to these decreases if collaboration was not maintained but these have also decreased, although again this could be part of a longer-term trend.

Survey: The survey of directors of public health suggests that 'stroke groups' exist in about half the districts we surveyed (section iii page 252). Although we did not ask in detail about their membership and role it is likely that they had similar functions. We can conclude that there is frequently a perceived need for such a group, though little about their effectiveness. It also suggests that a stroke group may have been formed in the district without the HCPA.

Programme budget: The programme budget gives an estimate of the current balance of resources across the stroke programme (Overall programme budget section 4.8.3 page 231 Should the DSG reflect this balance? If so, then social services should have had a much greater role and the limited role of primary care can be justified. However, that would have reflected historical patterns and may not have been appropriate. Since the budget balance was not known at the outset it was not possible to use it as a tool to help determine membership.

Costs: The results in section 4.9.2 on page 234 suggest the total cost of this group is about £8,000 per year although, with the exception of GPs these are normally 'hidden costs' because they are the cost of people's time for which their employer pays.

Conclusions: a district stroke group was a necessary part of the health care programme approach. The is some evidence of improved interagency co-operation which is likely to be partly due to the group. This was achieved at relatively small cost. They is no easy answer to who should be a member but they is no evidence that membership was particularly inappropriate or skewed. There is some evidence that individual members were not always clear of their role or relationship between this group and other organisations.

5.1.2 Co-ordinator

There were two co-ordinators during the study, which makes it less likely that findings relate to one individual (although one person covered the bulk of the study period). The qualitative interviews suggest considerable success in networking but less success in change management. The indicators are probably too indirect to reflect how well the post worked.

The first round of interviews show expectations of the co-ordinator (4.2.5 The role of the co-ordinator page 102) which suggested a leadership role. There was less consensus about what was expected or happening in the second round (4.3.1(c) The co-ordinator page 113) and third round (4.4.4(c) Co-ordinator page150). By the fourth round (4.5.5(b) The co-ordinator post page 178) a number of members of the stroke group expressed concern at the end of the project that the group needed a co-ordinator when it became clear that the district did not wish to continue that post.

The surveys of directors of public health suggest that stroke co-ordinators exist in about half the districts we surveyed (page 251). However, we did not find out any details of their roles and it is likely that many would have a clinical role, co-ordinating care around individual patients, rather than an interagency role. This is how the

Stroke Association (which has funded a number of posts) perceives the concept of stroke co-ordinators.

Costs: The results on page 233 suggest the total cost a co-ordinator is about £17,500 per year although that is dependent of the profession and seniority of the person in post.

Conclusion: a co-ordinator was a useful part of the health care programme approach. There were a range of views on what their role should be, and what happened is in part a result of who was be appointed and what their skills and competencies were.

5.1.3 Technical Document

One aim of the technical document was to ensure that priority setting was evidence based. All the priority areas in prevention and acute care can be traced back to 'evidence' within the document.

The interviews (pages 103, 112, 150 and 179) suggest it also had some success in spreading awareness of issues in stroke care and in clarifying different perspectives. This inclusiveness helped in the priority setting process and gained ownership of the findings across the DSG. It may have helped in forming the district stroke group by giving it an early circumscribed task. This was notably different to the experience of the pilot of HCPA for IHD in Oxford where an externally produced document was mistrusted and had limited use.

Costs: the transaction costs show this to be a costly process accounting for nearly half of the start up costs of the project (page 233). Some interviewees thought these resources would be better put towards change management.

Conclusion: The National Service Framework for older people[112] has superseded the need for other districts to go through a similar process for stroke but it may still be a useful process in other clinical areas.

5.2 Processes

5.2.1 Priority Setting

The results of the priority setting process are shown in Table 43. Table 44 gives the four primary priority areas identified at the end of the process and the ten others that were included in the HImP for implementation over the next three years. Table 44 Priority areas also outlines the ways in which these priorities have been developed, and have drawn in resources from the district. The qualitative findings are described below.

Table 43 Results of priority setting

Action	Result	Findings
1. Formation of DSG	All organisations in the district agreed to the setting up of the stroke group and to send representatives. Subsequently, there was variable attendance, particularly from primary care. The group initially had twelve members.	Membership discussed on a number of occasions but it was felt appropriate to maintain as a professional group (health, social services, voluntary sector)
2. Review of Evidence	All members saw drafts but only about half commented on them and three contributed the bulk of the work. Work took six months.	Forty-three potential recommendations made
3. Postal Survey of DSG members	Nine out of twelve responded, though some questions were not completed in areas where the respondent thought they had little knowledge.	Some recommendations combined and four areas with >90% score for importance were developed as initial priorities (see Table 44).
4. Survey of other key professionals & managers	Twenty-nine people were seen including patient representatives (two Community Health Councils and two voluntary groups), managers and professionals.	General validation of four priorities and more comprehensive list of secondary priorities
5. Consensus within DSG	Although an ongoing process, the key meeting in March 1998 was attended by nine members. Subsequent meetings developed action plans for each area.	Priorities set out in Table 44 and HImP. These happened to be spread across the sectors so there was little debate.
6. Consultation with local users and carers	Sixty-five people responded to the invitations and forty attended the two days.	The majority of issues raised by the users were in the area of long-term support and continuing rehabilitation (rather than prevention, acute care or early rehabilitation), which we were able to feed into a review taking place.

Table 44 Priority areas

Hypertension in Primary Care (93%)

A joint subgroup of the primary care Multidisciplinary Audit Group (MAG) and the DSG was set up to review currently available guidelines for the management of hypertension, and adapted one for local use. The MAG met the costs. The guidelines have been disseminated and will be implemented through the Primary Care Groups. One of the PCGs has set aside part of its clinical governance budget to develop this priority further.

Multidisciplinary Teams in Secondary Care (100%) [plus two other areas]

A multidisciplinary forum for stroke professionals in secondary care has been formed to facilitate exchange of information and good practice, encourage audit and develop service specifications. Service Specifications have been developed and are under negotiation between purchasers (health authority) and providers (NHS Trusts). In one part of the district, £65K of Health Action Zone money (out of £300K allocated for HImP priorities) has been found to develop community multidisciplinary rehabilitation services.

Long Term Care and Support (93%)

A review of current practice and issues has been completed. This informed discussion of specific priorities in this area and has been linked to other reviews of elderly care going on in the district. Members of the DSG have been invited onto steering groups taking forward a number of priorities in the care of the elderly.

Audit and Information (93%) [plus four other areas]

Both trusts have taken part in the Royal College of Physicians sentinel audit with encouragement from the stroke group. There has been other work to improve quality and availability of routine information about stroke. In one part of the district, £10K of Health Action Zone money (out of £300K allocated for HImP priorities) has been found to develop a strategy for patient information.

Secondary Priorities for future activity

Prevention

*†Secondary prevention (80%)
*Atrial fibrillation (78%)
*Assessment of transient ischaemic attacks (86%)
Smoking (83%)
Diet (62%)
Physical activity (65%)
Alcohol (62%)
Cholesterol (60 %)
Diabetes (62%)
Aspirin (86%)

Treatment, Care and Rehabilitation

*CT scanning (73%)
*Feeding management (85%) [+1]
*Prophylaxis of deep vein thromboses (71%)
*Pressure sore treatment and prevention (73%) [+1]
*Complication rate audits (80%)
Referral & admission policies (85%)
Layout of services
Assessment and documentation (86%) [+1]
Speed of intervention

Long Term Support

*Information (Understanding of stroke and stroke services by patients, carers and professionals) (93%)

(Percentages in round brackets refer to results of stage 3 (see Table 1 Priority setting process page 31). Those without percentages came from stage 4 in tables 1 and 3.)

[In some areas two or more priorities were combined (eg multidisciplinary teams for acute care and for rehabilitation) and this is stated in square brackets.]

*Now in the Health Improvement Programme.

† In one part of the district, £25K of Health Action Zone money (out of £300K allocated for HImP priorities) has been found to develop a strategy for secondary prevention.

(a) Stroke as a priority

Despite the health authority's assumption that stroke was already a priority, several DSG interviewees expressed concerns:

> *'... against the priority wishes of the vast majority of primary and secondary care ... and against current mechanisms for prioritising and setting up groups in the district at the time'(INT 18).*

Several respondents from the second phase of interviews, particularly from primary care, also expressed the view that the priority of stroke had been imposed on the district, outside of current priorities and decision-making mechanisms. However, other DSG members felt that, as stroke was in the district HImP, this implied that it had become a major priority for the district.

One interviewee expressed concern that stroke was slipping down the government agenda, citing as evidence that stroke was not one of the national priorities in guidance issued from the government to health authorities[190] although it had been mentioned in *Our Healthier Nation* green paper,[178] strengthened in the white paper,[80] and features in one of the clinical indicators in the performance assessment framework.[191]

In April 1999, Primary Care Groups (PCGs) came into being. These were a new sub-district structure, led by primary care physicians, which will ultimately take a lead on commissioning services. Another interviewee highlighted the conflict between the HImP and the priorities chosen by the PCGs:

> *'... this year round, plans have been done out of synch and they don't reflect necessarily what is in the HImP. I mean diabetes for example, is one which they* [PCGs] *are all picking on because we have done quite a bit of work through the two diabetes groups that we have got, ... but that's not necessarily a major priority in the HImP so again there is that conflict' (INT E).*

Of note, diabetes was in the district HImP.

Conclusion: Stroke was (and is) a national priority but was not accepted as a local priority by all group members.

(b) The process of priority setting

The majority of DSG members felt the priority setting process was a necessary and important element of the programme approach, allowing boundaries and foci to be set on the work:

> *'It's helped to put some boundaries around what we're doing otherwise there's a tendency just to ... try and do everything ... so I think without it, it would have been very difficult to have said, these are the priorities, let's focus on them.' (INT IX)*

However members acknowledged a number of problems, including the risk of competing priorities in other areas. They stressed the need for flexibility in the approach, the need for integration with relevant organisations' own priority setting processes, and the need for the 'right' stakeholders to be involved in the decision-making process.

There seemed to be agreement that a balance between 'the evidence' and stakeholder priorities had been reached. One interviewee described the approach as ongoing and stressed the importance of flexibility to be able to respond to changing local needs, local developments or changes in the evidence base:

> *'... it's ongoing because again it would be inappropriate to set in stone the priorities and ... then something like secondary prevention actually begins to creep up the agenda because of local developments or research or knowledge-based, evidence-based developments and we need to be flexible to take those on as well' (INT 17).*

This was echoed by another interviewee who was concerned about a purely evidence–based approach:

> *'... published evidence lags a long way behind actual knowledge ... it's important that we don't develop a wonderful evidence-based system which*

> *is fifteen years out of date ... we've got to be very responsive in our plans to current developments.' (INT 8)*

However, most DSG interviewees were unclear about the process of priority setting, in particular how the survey of other professionals and managers related to the structured priority questionnaire sent to DSG members:

> *'I wasn't quite sure about the science behind developing those priorities and therefore how valid they were for the group [DSG] to actually then prioritise those priorities.'(INT 5)*

In relation to the questionnaire itself, one person commented that she had found it difficult to prioritise some of the clinical areas because she was not medically trained:

> *'I found doing the matrix quite difficult in some aspects because I'm not a clinical person and some of them were quite clinical. But I tried to comment on the ones that I felt I could comment on.' (INT 7)*

No one involved (professional or manager) expressed any views that they should not have been involved or that anyone else should not have been. However, there was confusion at times as to whether people were acting as individuals or representatives of the organisations they came from – this was particularly difficult for primary care, but also occurred with people from NHS trusts, the health authority and social services.

Only two mentioned the lack of public, patient and carer input to the process (see also discussion of stroke group membership pages 97, 112, 145, 175, 190, 198 and 284).

Conclusion: the process 'worked' in that priorities were set and there was general satisfaction with the outcome. However, the process was not transparent.

(c) Outcomes of priority setting

Despite the lack of clarity about the priority setting process, all DSG interviewees agreed with the priority areas chosen as a result.

One interviewee was pleased to see that the priorities selected covered the breadth of issues related to stroke, as he had been concerned that the focus may have been solely on acute care, where most of the evidence base was available. Another interviewee also shared this view and felt the process was about 'balancing':

> *'everyone has their own priorities and their own area and if we prioritise in a way that says all of our priorities are social services and none of them are acute care ... then equally that would be inappropriate as well, so it's about balancing' (INT 17).*

One interviewee was concerned about taking too many issues forward at once where this would involve people changing their working practices. However he was happy with the staged approach taken by the DSG to implementation of the priority areas.

One interviewee also voiced the importance of choosing areas that were 'achievable'. Another interviewee expressed concern about the scale of the whole project and the length of time it takes to create change. Two interviewees were concerned that the priority areas chosen by the DSG could be used by those outside the group, particularly the health authority, to undermine clinicians' assessment of what is appropriate care for their patients. One cited an example where the health authority would not support a bid for a 24-hour Computerised Tomography (CT) scanner because:

> *'CT scanning has not been noted as a priority by the DSG.' (letter from health authority)*

Although the majority of respondents in the second phase of interviews were unaware of all of the priority areas chosen by the DSG, several respondents were aware of the work on hypertension in primary care. When given the list of the main priorities that the group was focusing on, the majority of respondents felt they were appropriate. There was very little knowledge about how the individual priority areas were being taken forward. Two respondents were aware that staff from their organisations were involved in the working group taking forward the 'multidisciplinary teams in secondary care' priority area. Several interviewees expressed concern about the lack of information about the priority areas and the perceived resulting lack of integration with their organisations' own priorities and services.

Conclusions: the priorities were agreed and 'owned' by the group. They were robust in that they were maintained throughout the study and were not replaced by competing priorities in stroke. The National Service Framework for older people[112] has produced a similar set of priorities.

(d) Wider integration and competing priorities

The DSG developed a chapter for the district HImP on stroke. However, many other issues were also included in other chapters and at the time of final interviews, there had been no prioritisation of these:

> *'I think as it* [the HImP] *develops it will drive the commissioning process because it will lay down the strategic areas ... the stroke group sent a proposal in which was £250,000 ish [for community rehabilitation]. Now I mean that's a big chunk of money just to spend on stroke. Now if it was number one priority out of all of them they may get that but if it was five or six you know there is a doubt whether that kind of money would be available ... we need several things happening I think, in the future but the HImP certainly needs to drive the priority areas.' (INT E).*

Although stroke is a chapter in the district HImP, two interviewees from the second phase of interviews questioned whether this meant that stroke was seen as a priority by the health authority:

> *'I mean I think there's a particular issue really with the Health Authority especially, about whether this* [the stroke project] *is something that they're supporting as a mainstream element of developing the Health Improvement Programme, and I certainly don't get the feeling that that's the case... I think making sure that it's part of some of the mainstream priorities, that is important.' (INT F)*

One interviewee raised integration with the health authority's priority and funding mechanisms:

> *'Well coronary heart disease is a big issue for us ... do we purchase more CABGs* [Coronary Artery Bypass Grafts], *do we put more into cardiology and angiograms and so on ... all very expensive stuff and they are the issues we have to grapple with, you know where do we want to put our*

> *resources, where will we get most benefit from it and that comes back to the evidence base ...' (INT E)*

The issue of stroke not being a priority for primary care and being an imposed priority for the district and outside current commissioning and organisational planning mechanisms has meant there has been less integration with PCG priorities:

> '... *GPs were saying, "well why are we doing this about stroke services, what's going on here, who said it was a priority, we don't think it's a priority, why are you providing that level of service?" which I think is, I mean I think it's quite good to be able to challenge that because it does make you think about, well where did this come from...?' (INT F)*

One of the three PCGs in the district has chosen hypertension on which to focus in its first year. The other two PCGs have chosen ischaemic heart disease and diabetes. The choice of these priority areas by the PCGs was felt by interviewees to have implications for the stroke project's integration with local initiatives. In one PCG, one interviewee reported their priorities were chosen on the basis of the likelihood of being able to pull something together and to deliver on it, whether they were seen as important clinical areas, whether they were national priorities, and whether there was already work underway in these areas which would continue in the future. This is in line with government advice to PCGs that there will need to be a rigorous prioritisation of tasks in order to concentrate resources on the most critical areas.[12] The choice of hypertension as a priority by one PCG was seen as an opportunity for the stroke project by several interviewees:

> '... [The PCG] *have taken hypertension on as one of their priorities ... it would be really helpful for them to have something to get their teeth into and in some ways it may well be that what would help from the district stroke group would be to really get involved...' (INT I)*

In the final phase of interviews with DSG members, concern was raised about the ownership of the priorities by key players within the trusts, in particular those managers responsible for business planning and strategic direction. Some interviewees felt that these players had so far had little involvement and therefore limited ownership of the work of the DSG and that this would have an impact on implementation of the stroke priorities. However, in October 1999, £100,000 was allocated in one part of the district to develop stroke HImP priorities and allocation of further resources to stroke HImP priorities is currently being discussed.

There is no evidence from the indicators that prioritised areas improved more quickly than other areas. However, the more detailed description of the process shows progress in the priority areas with changes occurring (see Table 44 on page 289), which should ultimately lead to improvements in patient care. Furthermore, the priorities remained stable, allowing the DSG to concentrate on implementation.

(e) Final thoughts on priorities

The final round of interviews allowed reflection on the processes and outcomes. There were some differences of opinion between interviewees. Some felt that the programme the DSG set itself was far too large:

> *'When I looked at the programme, it's massive – it's absolutely enormous – and I wonder whether targeting smaller areas in a more high profile way would have helped rather than trying to do everything.' (INT R)*

Another respondent who felt that although the priorities were still valid in themselves, cognisance ought to be taken of their practicality in a changed environment echoed this:

> *'The priorities are still valid and at some stage our priorities will line up with external priorities, in which case great - get cracking on it! But I would be very cautious about steaming ahead with priorities which are not going to be consistent with what's out there.' (INT S)*

This is however part of the HImP process and will be addressed by the DSG in its new guise as a HIG:

> *'Part of the whole process of the Health Improvement Programme is the original priorities and saying, 'what have we achieved?' and 'what do we need to achieve?' And it's another three year rolling programme, so I think the priority setting process will inevitably occur on an annual basis.' (INT Y)*

5.2.2 Interagency co-operation

Most of the interview results focused on the interagency District Stroke Group (5.1.1 page 284), which probably tells us more about strategic (planning) than operational ('on the ground') co-operation. Furthermore, this group was complicated by the fact that there are two of each agency representing Gateshead and South Tyneside (eg Problems with structures page 177 quotes 5 and 6).

However, links were made between individuals which were not previously there and the group created a route for dialogue between agencies (page 121). There was a continuing theme of the difficulty of 'Primary Care' as a *sector* of care made up of individuals rather than an *agency* (like the health authority, trusts, social services, etc.). This is, at least in part, because General Practitioners are independent contractors rather than NHS employees. While there is a gradual change with the formation of PCGs and subsequently PCTs, and other initiatives such as out-of-hours co-operatives and salaried GPs, it will take many years to change that culture.

It is difficult to know how important the 'neutral' external chair and university support was to reducing rivalry between Gateshead and South Tyneside and tensions between: statutory and non-statutory organisations; between health and social care; between purchasers and providers; and between primary and secondary health care. See pages 89, 192 and 197. These tensions certainly exist elsewhere (eg page 252).

5.2.3 Levers of change

The original HCPA study used contracting as the primary lever of change as this was during the early stages of the 'purchaser-provider split.' Even at the outset we were clear that a number of different mechanisms would be used.

There was an attempt to develop *Service Specifications* to sit within Service Level Agreements (the form of contracts at the time). This was the main work of the multidisciplinary forum (eg pages 131 and 168). This developed specifications, did not fully succeed in getting them agreed at a senior level so a more senior group had to be set up. However, the work of the group in developing them was seen by some as important in sharing experience and good practice and perhaps in changing practice.

Guidelines were developed by the hypertension group (eg pages 129 and 166). These were disseminated but not fully implemented because of the changes in the district: winding up the Primary Care Improvement Group (Commissioning forum and Multidisciplinary Audit Group) and forming three Primary Care Groups (PCGs). However, it seems this did influence one of the PCGs to take up hypertension as a priority later.

Audit was encouraged. The DSG put some pressure o the two trusts to take part in the Royal College of physicians audit (eg pages 135, 161 and 167) which they not have done otherwise. This provided an important focus for the Multidisciplinary Forum.

These three levers are clearly similar and related. The emphasis is on facilitating change in clinical practice by providing evidence, and feedback rather than demanding change with a contract (which proved to be ineffective).

5.3 Objectives

The stroke group developed the set of nine objectives given in full on page 39. Progress towards the majority of these could only be measured using qualitative methods, although in some cases there are 'objective' events or products to record or evidence from the other aspects of the study. Each will be discussed.

5.3.1 Objective 1

To develop a strategic approach to commissioning in order to support planned and appropriate developments

Documentary evidence: There is clear evidence of a strategic approach in the documents produced such as the Strategy Document itself, the Technical Document and the HImP, but integration with other processes was more variable. Integration with contracting took longer than expected, although we completed a draft service specification by the end of the study. There was less engagement with primary care throughout the study as can be seen in the interviews and by attendance at the meeting. Consequently no primary care documents such as investment plans incorporated stroke strategy.

The Health Authority requested that the DSG continues as a Health Improvement Group and it is expected to become a subgroup of the NSF for Older People Local Implementation Team.

Other Evidence: the final programme budget shows the breadth of services in the programme and that the approach encompassed these. The interviews showed most people felt that they were working strategically and that commissioning would lead to more appropriate developments.

5.3.2 Objective 2

To obtain local ownership and involvement of clinical professions in order to foster a collaborative approach and better support implementation and change

There appeared to be local ownership by the main statutory organisations: Health Authority, Social Service Departments, Trusts, and Primary Care Improvement Group at the outset. However, it is clear that support from primary care was very limited. Additionally the Trusts, Health Authority and social services had variable support 'from the top' as staff changed. This support was revitalised by the 're-launch' in April 1999, particularly by the Trusts, which increased the seniority of officers attending the DSG. There was notable lack of involvement of the voluntary and private sectors at the outset although the Stroke Association joined later. The involvement of users and carers was done through a separate mechanism(see page 284).

The formation of the Multidisciplinary Forum, as a subgroup of the DSG, engaged most professionals - with the notable exception of the medical profession whose primary input was through the DSG (see page 131).

The priority-setting exercise obtained local ownership for the strategic direction although it actively involved few individuals (see page 287).

Local knowledge of a DSG seems to have been widespread from the interviews outside the group but knowledge of HCPA was limited even within the group. National publicity included an article in *Stroke Matters*, a book chapter and abstracts at conferences. The Stroke Association put contact details in their good practice guide and there were about six calls from around the country as a result of this.

For evidence of any effects of interagency working see the section page 297.

5.3.3 Objective 3

To commission services based on 'need' in order better to match effective services with local health needs

The priority setting process attempted to bring together different types of need. For example the technical document looked at epidemiology and effectiveness, whereas the consultation days looked at a more patient-centred approach to need. Furthermore, the DSG strongly encouraged the trusts to take part in the National Sentinel Audit, as well as their own audits giving important information on service gaps and perhaps a further approach to need. The strategy was in line with these, but there is no corroborating evidence of how much services were better matched to need. However, the development of community rehabilitation in South Tyneside was certainly matched to a perceived need (see Table 44 page 289).

5.3.4 Objective 4

To use robust evidence of effectiveness in the commissioning process to support more effective service delivery and better patient outcomes

We produced a core document summarising evidence of need, effective and cost-effective care (the Technical Document). This was widely disseminated and received positive comments, though many felt they did not understand parts of it. By using this as the starting point for prioritisation most developments were evidence based.[110] Draft service specifications incorporated evidence of effectiveness.

There was an attempt to update research evidence periodically but this did not produce any changes to the broad recommendations of the technical document. Despite criticisms by some DSG members that the technical document was out of date, no one was able to present new evidence to change the document. Little attempt was made to share professionals' experiences of using evidence-based care other than using evidence of guideline development and implementation when developing the hypertension guidelines.

We identified areas where evidence is lacking or limited, where more research is needed but did not take this further or identify where local contribution might be made.

5.3.5 Objective 5

To develop service specifications for the prevention, acute treatment, rehabilitation and long term care of stroke for residents of Gateshead and South Tyneside which reflect the core principles of the HCPA

By the end of the project we had not implemented service specifications or service agreements agreed between purchasers and providers. However, the Multidisciplinary

Forum had developed some specifications for acute care and so may have started the process of change since these reflected the sentinel audit. A subsequent senior cross-district group took on the role of:

- defining service structures and processes across the district;
- developing service specifications from these; and
- identifying inequities for further HImP prioritisation.

This group continued to develop the work but was superseded by the need to have a Local Implementation Team responding to the National Service Framework.[112]

5.3.6 Objective 6

To integrate the HCPA with clinical audit and measurement of health outcomes in order to enable ongoing evaluation and use of quality improvement indicators

The DSG and co-ordinators facilitated the entry of both providers into the Royal College of Physicians Sentinel audit for stroke and subsequently findings were shared and reflected on, leading to the start of the process for improvement.

One provider had a detailed data collection process, the other had done an ad hoc audit of admissions. There was some sharing of these data and some validation of the routine data collection (specifically the Contract Minimum Data Set) was undertaken. This was discussed at the DSG. However, this was not formally linked back to the Trust's information systems so is unlikely to have had much impact on future data flows.

5.3.7 Objective 7

To achieve greater integration of services in order to ensure the most effective and efficient use of resources

The evidence for better integration can be found on pages 297 and 284. However, the evidence for improved effectiveness is limited (See for example 297) and for increased efficiency can only be surmised. There were increased resources in some areas such as South Tyneside Community rehabilitation (see Table 44 Priority areas page 289).

5.3.8 Objective 8

To achieve an appropriate balance of care and resources between primary, secondary and tertiary care in order to ensure that effective care is delivered in the appropriate setting

A programme budget was produced and discussed by the DSG. See page 231 Table 35 for details of this. The major point where it was considered that the balance might be inappropriate was in tertiary care i.e. referrals to neurosurgery for investigation and management.

While this provided useful background information for discussion of the balance of care, there is no map of what the balance 'ought to be' so that priorities are balanced across all the sectors (see page 289 Table 44 Priority areas). There was no clear agreement by the end of the project as to how resources could be shifted back from tertiary care.

5.3.9 Objective 9

To achieve an appropriate balance of care and resources between health services, social services and the voluntary/ private sectors in order to ensure that effective care is delivered in the appropriate setting

Similar comments apply to Objective 9 as to Objective 8. However, the possibility of shifting resources is more limited because of the different funding methods. As a result of discussions at the District Stroke Group there was a clearer understanding of how each agency was funding and on the pressures within that sector.

5.4 Summary

- Triangulation is "the combination of methodologies in the study of the same phenomenon" for *confirmation* and *completeness.*
- This study used data and method triangulation to pull together the results from the six aspects of the study: qualitative evaluation, indicators, survey of DsPH, survey of practice managers, programme budget and transaction costs.
- There has been considerable use within the qualitative part of the study and limited use between the different aspects of the study.
- Where triangulation was possible, there was agreement between the different aspects of the study.

6 Discussion

6.1 Key findings

At baseline, stroke commissioning in Gateshead and South Tyneside seemed under-developed compared to most districts. During the period of the study the breadth of activities to improve stroke services in Gateshead and South Tyneside was greater than other districts, though no individual activity was unique.

The length of time necessary to develop an effective structure - in particular a functioning District Stroke Group - was more than two years. The group eventually became effective as evidenced by its ability to get proposals developed, funded and changes to happen. Barriers which slowed the process included lack of clarity as to who individuals in the group 'represented', changes of personnel, and failure to get full commitment of primary care as a sector. Facilitators included the 're-launch' of the group to senior officers in the constituent organisations, regularly reviewing membership and adjusting to external changes. For example 're-badging' the District Stroke Group as a Health Improvement Programme group after *The New National Health Service*[8] was published, and potentially as a part of the Local Implementation Team for the National Service Framework for older people.[112]

The co-ordinator role was important in actively maintaining the network of organisations and members, but it was difficult to find evidence that it was necessary to achieve all the changes that occurred.

The technical document had an important role in the priority setting process in allowing a shared knowledge base but it was time-consuming and expensive to produce. The agreed priorities were not changed throughout the project allowing the District Stroke Group to concentrate on implementation rather than revisiting earlier discussions. This meant the group was effective at responding to potential sources of funding (such as from the Health Action Zone) within tight deadlines.

The majority of indicators moved in the 'right' direction. However, ascribing causation is difficult as some of the changes could be explained by other changes at the time and underlying trends.

There were few detectable quantitative changes in the programme budget. These could not really be expected but the study was able to show the broad balance of stroke programmes and revealed the need for further research into National Health Service costs and how they are applied and interpreted.

The main benefits of this process were a series of evidence-based initiatives in prevention, treatment, and rehabilitation together with improved communication about long-term support of stroke patients. There were no detectable changes in outcome during the period of study, though a number of measures of process showed positive changes.

The cost of running the Health Care Programme Approach was about £26,000 per year, with set up costs of about £16,000. This is about 0.25% of the programme budget for stroke or about £3.91 per person with a stroke. No problems to other patient groups were noted.

6.2 Comparison with other studies

6.2.1 Commissioning

The most comparable studies on the commissioning of stroke services are those by Susan Law in Oxford (Susan Law, DPhil project, personal communication) and the *Getting Research into Practice and Purchasing* project in Northampton.[192] Each of these had different focus, the former looking at the issues of contracting in the new purchaser-provider environment, the latter at the evidence base for clinical activities. However, a number of aspects are similar and some findings concur with this study:

- the difficulty of getting a group together and starting to function,
- the difficulty of maintaining the interest of individuals if good ideas are not funded quickly,
- the danger of being separated from the decision making processes of the main organisations such as the health authority
- the danger of being dominated by one sector or agency.

The most comprehensive study of purchasing is the *Total Purchasing Pilot* (TPP) study[41]. This looks at a locality rather than a programme approach to commissioning. Since the Total Purchasing Pilot looked at a broader range of commissioning it had different outcomes to this study. Of particular interest are the transaction costs as locality and programme approaches might be competing for the same management resource. This will be picked up in the section below as there are difficulties making a fair comparison.

There were a number of stoke projects run by the King's Fund in the *Promoting Action on Clinical Effectiveness* programme.[109] However, these tended to be very focused projects, such as developing an integrated care pathway in one hospital rather than a broad approach like the HCPA. They are therefore of more relevance to the subgroups and subsequent activities as a result of the HCPA.

6.2.2 Programme budgeting and other economic studies

Kavanagh et al [162] compare the results of 'top down' methods, such as those used in BoD[144] and elsewhere [161] which imply that stroke patients consume a large amount of resources, with those from 'bottom up' studies that show low rates of utilisation of services one year and longer following stroke.[170] [174] It is difficult to draw too many conclusions from such comparisons, which take a different perspective (prevalence versus incidence) and include a different range of services in the overall estimates. Nevertheless, some examples of the estimates yielded elsewhere are provided for comparative purposes with the data we report above.

For example, in one study data were collected on resources used by stroke patients in the year following discharge from an inner London teaching hospital.[157] [172] Data were collected as part of an RCT comparing conventional care with a package of care for early discharge. Data on contacts with hospital physicians, GPs, social services were obtained with the use of questionnaires given to patients and care givers at 2, 4, 6 and 12 months. Detailed information on the amount of contact with occupational therapy, speech therapy was collected. Using the data relating to the 164 patients who received conventional care, it is possible to compare the programme budget with estimates yielded by other approaches.

If we assume that 80% of stroke cases in Gateshead and South Tyneside were hospitalised, this results in an estimate of 1124 strokes in the district in 1997/98 and 1152 in 1998/99. We may then apply estimates of average resource used to these figures in order to arrive at a 'bottom up' estimate of services used in Gateshead and South Tyneside. For example, Beech et al found that stroke patients had an average of 2.20 home visits and 2.20 surgery visits in the first year following stroke. The estimate that home consultations account for 50% of all stroke consultations fits with the estimates from MSGP reported above. Using National unit cost information, Beech et al estimated that the cost of a home visit is £27 and that of a GP visit £9 at 1997 prices. Applying these figures to our stroke population in 1997 results in a figure of £22,255 (1124 * 2.20 *£9) for surgery visits and £66, 766 (1124 * 2.20 * £27) for home visits, resulting in an overall primary care total of £89,021. This compares with our estimate of £90,265 based on our analysis of MSGP data.

The study also found that there were an average of 1.5 appointments to see a physician in hospital out patient clinic at a unit cost of £10.66 per visit. This results in an estimate of £17,973 (1124*1.5*10.66) for stroke outpatient attendance in 1997/98, which is considerably less than the estimate of £45,166 given above, although it excludes outpatient visits for physiotherapy etc. Table 45 gives the estimates from Beech et al of average resource utilisation in the 12 months following stroke along with the implied total for 1997/98 assuming there were 1,124 stroke patients in Gateshead and South Tyneside in that year.

Table 45 Estimates of resource use from Beech

Estimates of resource use from Beech et al study

	Average visits/units	Unit cost	Total (in £'s) for 1997/98
GP home visit	2.2	27	66,751
GP surgery visit	2.2	9	22,250
Outpatient	1.5	10.66	17,968
Physiotherapy	3	14.57	49,119
Occupational therapy	3.9	15.23	66,747
Speech therapy	1.3	14.73	21,518
Day hospital	3.2	36	128,456
District nurse	9.5	13	138,783
Meals on wheels	23.8	3.3	88,259
Home help	52.4	52.8.175	481,086
Lunch club	9.7	3.3	35,971

In contrast, Kavanagh et al use the OPCS data to arrive at a prevalence-based estimate of the resources used by people for whom stroke was reported as a condition underlying their disability. The surveys included 518 stroke survivors in households (105 living alone) and 563 in communal establishments. The main findings were that 87% of stroke survivors living alone had seen their GP in the previous year (with a mean of 7.3 consultations, 59% of which were at home) whilst 92% of those living with others saw their GP (with a mean of 9.4 consultations; 56% of which were at home). Twenty six per cent of people of living alone had been an in-patient in the previous year (mean 46 days, median 35, for those with an admission). Thirty per cent of those living with others had been an in-patient (mean 41 days, median 28, for those with an admission). Other services used by more than 10% of people in households were: outpatients, district nursing, nursing auxiliary, home help, meals on wheels, social worker and day centre.

Among people living alone, the major contributions to costs were: inpatient care (mean of £27 per week for full sample in 1994-95 prices) and home help (£30 per week). Among people living with others, inpatient hospital care was also a major component (£28 per week). Other services costing more than £5 per week were GP consultations, hospital out patient care and day centre attendances. For stroke survivors living in households, mean service and adaptation costs were £89.15 per week for those living alone and £68.37 for those living with others. Social service costs differed significantly; £45.31 for those living alone compared to £18.95 for those living with others. This does not include patients living in communal establishments.

These results are reported for illustrative purposes only. It is not possible to estimate a programme budget for Gateshead and South Tyneside based on these estimates without first knowing the prevalence of disability due to stroke along with the proportion of those living alone or in communal establishments.

6.3 Methodological limitations

6.3.1 Qualitative

The aims of the qualitative aspects of the study are to describe the process in detail from a variety of perspectives. This is a case study so cannot provide definitive answers to the effect of implementing Health Care Programme Approach elsewhere.

The interviews provided a depth of understanding of what was happening from a range of perspectives. They are effectively four cross-sectional surveys rather than a longitudinal study as different people were interviewed at different stages so that any apparent changes in time need to be interpreted with caution. The interviewer was independent of the implementation but would have been known to be closely linked to the implementation team which might have inhibited the interviewees.

Observation at meetings was important but could only take place over one year and was mostly restricted to District Stroke Group meetings (and a few hypertension and multidisciplinary forum meetings). It would have been useful to have this observation over a longer period and ideally from the outset of the work in order to get a more longitudinal picture of changes and see the dynamics of the groups evolve.

Documentary analysis provided limited additional data. Part of the reason for this may be that official documents simply summarise the work done up to that point so, with the richness of information from interviews and observation we already had, they are unlikely to add much. However, a similar problem was found with official documents from other districts, and a more interesting source may have been correspondence (including emails) but we were unable to obtain much of this (see page 293 for a notable exception).

Attribution of cause is not possible with these methods. However the detail and range of methods allows a judgement to be made on what has occurred and how this does or does not relate to the Health Care Programme Approach. This in turn allows reasonable decisions to be made on how this would or would not apply in other settings. Some of the findings of the process were fed back to the District Stroke Group in November 1998 and there was agreement that the issues raised were correct.

Many of the findings are based on structure and process changes rather than on improvement to outcomes. However, in most of these cases the evidence base allows a reasonable assumption that improved outcomes will result

How much of the findings were dependent on particular individuals is hard to resolve. However the change of staff throughout the study, including two co-ordinators, suggests that most of the findings are independent of any individual.

Other issues of context are harder to resolve. The survey of other districts shows how much might happen anyway, particularly in the way the 1997 reforms moved away from 'markets' to a more collaborative approach.

6.3.2 Quantitative

The indicators were intended to provide 'objective' measures of changes to services for stroke in Gateshead and South Tyneside. They are potentially important for local audit and planning as well as a wider measure of quality of services. They were a number of different purposes to the indicators including: directly measuring the effects of the intervention; giving indirect indication of changes that might be affected by the intervention; and giving a description of general changes to give some context to the intervention. However, they had a number of limitations.

- There was limited availability of routine data and ad hoc data was expensive and time consuming to collect
- The quality of data could be poor for example aspects of the CMDS were incomplete, the Public Health Common Data Set (Compendium of Clinical and Health Indicators) is two years out of date and it has not been possible to validate the primary care data
- Numbers were often small so differences did not reach 'statistical significance'
- The indicators are not very sensitive to change, particularly over only two years
- Ascribing cause and effect is difficult because of the many changes occurring.

There is still a lot of research needed to create indicators that could used to measure quality of care in a robust way so that users have confidence in the findings. This will be an important issue for the Commission for Health Improvement and local Clinical Governance Structures.

6.3.3 Economic

(a) Programme Budgeting

The programme budget was more difficult to compile than had been originally expected. At the planning stage of the study, we had considered the possibility the programme budget could be used as a tool to track shifts in resources within the district and so measure outcomes. It became clear very quickly that there were a number of problems.

- Information about activity and costs was recorded differently for different areas,
- NHS accounting methods were changing and would give differently results for the same activity
- Some areas would have to be extrapolated from other research so could not be measured locally

There had been a secondary aim of using the programme budget as a tool for the stroke group to see how services were currently configured. This happened to a limited extent because of the difficulty of producing comparability of each area. There was particular interest in the unexpectedly large volume of activity in the Tertiary (neurosurgical unit) in Newcastle, which lead to discussion about referral patterns. There was no expectation of conducting a Marginal Analysis[60] – although there may be some 'implicit marginal analysis' in the decisions by the group about priorities.

Programme budgeting is a relatively straightforward technique that offers useful insights into how health budgets are currently allocated both between, and within, patient groups. Conducting a programme budget of the type described above is less resource intensive than carrying out detailed costing study and has the advantage that it reflects how actual budgets are apportioned. However, there are limitations on the estimates generated, governed largely by the quality of the underlying data used to generate these estimates. In those sectors where data are not routinely collected by diagnosis (i.e. all sectors apart from inpatient care), we must rely on broad apportionment rules that do *not* allow any year-on-year change in the *proportion* of resources directed to stroke patients to be detected. It is important to note that the increase in the programme budget between 1997/98 and 1998/99 in those sectors reflects *only* the increase in the total budget in that sector and must be interpreted with caution.

The lack of routinely collected information by diagnosis was a major stumbling block to compiling an accurate programme budget and attempts to uncover local information on stroke-related activity were largely unsuccessful. Whilst information was made available in certain of the key areas (such as outpatient information provided by one trust), this was generally considered too incomplete to form a reliable estimate of activity across the whole sector. This highlights the need for better routinely collected data on local stroke-related activity.

In contrast, the move towards costing inpatient care according to HRG, rather than specialty specific FCE has improved the quality of the data available in that sector, (although the change in costing methods between the two years of interest here made year-on-year comparison difficult). Relying on specialty-specific FCE costs will underestimate the cost of a stroke admission if stroke patients use a different amount of resource than other patients admitted to that specialty and there was some evidence to suggest this was the case. For example, the average LOS in general medicine in one of the two main providers studied was 4.7 days whilst our data set shows that stroke patients admitted to that specialty spent an average of 7.8 days in hospital. Though not discussed in detail here, further analysis of the 1997/98 data from the two main providers showed that the apparent difference in the mean cost of a stroke case (£1,428 and £3,410 in providers 1 and 2 respectively) was partly due to differential patterns of LOS of stroke patients *relative* to other patients admitted to that specialty.

Despite the limitations of the approach, the programme budget provides a useful broad outline of the pattern of stroke-related resource use and has highlighted a number of specific issues of interest to the commissioners of stroke services. When presented to the District Stroke Group, the inpatient budget in particular raised a number of issues that formed the basis for further analysis of the data set. These included the apparent disparity in the mean cost per stroke case between the two main providers outlined above, but also the estimate of the inpatient resource allocated to neurosurgery. The proportion of the 1997/98 inpatient budget allocated to neurosurgery (approximately 14%) was unexpectedly high and prompted a more thorough examination of the CMDS data for those patients admitted to this sector. Data on provider unit, diagnosis and procedures were compiled on all stroke patients admitted to neurosurgery and recently circulated to members of the group for their information.

In itself, programme budgeting is only intended to describe how resources *are currently allocated* and does not allow conclusions to be drawn about how resources *ought to be allocated.* In order to make recommendations of this type, the further step of marginal analysis would have to be undertaken in which the implications of moving resources from one sector to another are examined. This requires data on the effectiveness of various services at delivering good outcomes.

(b) Transaction costs

The Transaction Costs are probably quite robust and the areas that might not have been accounted for (such as work of DSG members within their own organisations, updating of the technical document and the potential for co-ordinators to be on a higher salary) are unlikely to change the amount significantly. The absolute cost should be of interest to any district considering undertaking something similar. However, comparison with other studies such as on Total Purchasing Pilots or GP Fundholding is more difficult.

The estimates of the transaction costs of the HCPA for the start up periods and first live year were around £16,206 and £25,834 respectively. The Total Purchasing Pilot (TPP) project estimated the total costs across all projects of the 'preparatory year' to be £679,055, whilst that of the first 'live year' to be £698,952, resulting in per capita cost estimates of £3.10 and £3.32 respectively.[51] The transaction costs estimated here are considerably less than those in total, but it is difficult to draw meaningful comparisons as the role and function of the TPP schemes was very different from those of the health programme approach.[51] Unlike our study, these costs take account of the whole range of activities involved in the actual purchasing and commissioning services, whereas the HCPA approach makes use of an existing contracting structure.

The 'per capita' transaction cost of about £3.91 per person with a stroke is more comparable, although it could be argued that since the programme is also about prevention the denominator should be everyone in the district, which brings it down to about £0.07 per head.

6.3.4 Surveys

(a) Practice survey

This survey was concerned with identifying structures for stroke prevention and care in primary care: we have no information on whether or how these were used in the practice. For example, availability of guidelines does not mean that they are used routinely to guide practice; indeed the low levels of audit would suggest this might well not be the case. Also, we have no information on the quality of guidelines used: these may have ranged from protocols developed by the practice to national or international evidence-based guidelines. Similarly, presence of a disease register does not mean this was used to recall patients or monitor their treatment. The practice survey had a good response rate, which can be hard to achieve in primary care.

To set the findings in context, an average GP with a list size of 1866 would have around 214 patients with hypertension, 88 with atrial fibrillation, 500 smokers, 1200 taking insufficient exercise, 112 extremely obese and 53 with dangerous levels of alcohol intake. He or she would see about four patients with new strokes and one new case of transient ischaemic attack per year.[193 194] Structures probably mirror prevalence rates: for hypertension, this ranges from 5% to 15%,[195] whereas transient ischaemic attacks affects less than one percent of the population.[196] Furthermore, hypertension is almost entirely managed in general practice, in contrast to the management of atrial fibrillation, transient ischaemic attack and stroke, where secondary care frequently has a major input. However, while atrial fibrillation affects 4.7% of people over 65 years, the number needed to treat to prevent one stroke is only 35, in contrast to several hundred people with hypertension. The discussion about who is best positioned to manage such conditions is ongoing,[142] but the responsibility of primary care in identifying and referring appropriately remains key.

Some differences between practices may be expected, for example it may not be efficient for single-handed practices to run clinics. Other structures, for example an identified lead professional and practice guidelines, are not likely to be affected by practice size.

Care needs to be taken in generalising from this survey. While practice size is average for England, there may be important regional differences. The survey took place in 1998. The health promotion banding system, which rewarded clinics and protocols, was introduced in 1993 and was changed in 1996. In 1998, 98% of GPs received funding for "providing full programmes of primary prevention of coronary heart disease and stroke."[194] Some health authorities are currently introducing incentive payments for chronic disease management similar to the 1993 health promotion banding,[197] but this is not the case in the study district.

Atrial fibrillation and hypertension are two examples of areas where there are treatments of proven efficacy, but several studies have shown treatment to be sub-optimal.[143 198 199] The development of Clinical Governance in primary care will provide GPs with corporate responsibility for the quality of patient care,[200] and primary care groups will be judged on their 'performance' on the basis of indicators in the national framework for assessing performance relevant to primary care.[137] These developments may provide an opportunity for addressing the issue of what structures need to be in place to provide optimum detection and management of chronic disease.

It is difficulty to make judgement about quality of care based on a survey about structures. However, there are probably an important prerequisite for developing a quality service. Furthermore, there is an emphasis on this type of structure in the National Service Frameworks.[112 201]

The aim was that the survey would give us a clearer understanding of stroke care in primary care as information and how it was changing. We had more information about secondary care from the CMDS and from the DSG members. However, the survey now seems to 'stand alone' from the rest of the study and is barely referred to in the triangulation. But it was important for the primary care indicators because the practices used for data collection were chosen from the results of the first survey.

(b) District Survey

This survey provided important contextual information. Although all the districts selected responded they constitute only nine out of 100 districts at the time. However, the aim was to have comparable rather that representative districts so this selection meets that purpose.

Most of the information came from one individual in each district. Although that person probably had the best overview of what was happening at the time, the results of this study in Gateshead and South Tyneside show the complexity of activities in any one district and the impossibility of knowing everything that was happening at the time. However, the aim to give a general context (for example whether stroke groups were being formed or co-ordinators appointed in most districts) was met.

6.3.5 Triangulation

Triangulation remains a useful idea rather than a 'method'. It has been possible to pull together many of the aspects of the study to look at the same issues. This has given a broader picture of what was happening in process of commissioning stroke services during the period of study. It has been less effective at being able to validate one aspect of the study with another. I have learnt a number of lessons about its application.

Having 'triangulation' as part of the research protocol ensured that we were much more explicit about how different parts of the study were brought together. Without using the term there would only have been an implicit linkage in the discussion.

Triangulation is an iterative process. It should part of the process of research from the initial discussions about research methods to the writing of the final paper. Interaction between researchers, particularly if they are from different disciplines, needs to be built into the study methods.

There is still further methodological research needed in the field of triangulation to develop practical advice on how to use triangulation. It is not a panacea for resolving differences between qualitative and quantitative researchers.

6.3.6 Overlap between implementation and research

The dual role that I held as researcher and implementer was discussed in the preface on page vii. This clearly has a number of implications for the interpretation of research findings.

The first is how much the implementation changed as a result of early findings. This was not planned as action research (page 47) but there were occasions of explicit feedback to the project (eg reporting of the first round of interviews to the DSG, page 64) and opportunities for implicit feedback (such as my role, page vii). However, leaders and managers in any setting gather 'intelligence' on how the project is going (for example, whether lack of attendance at a group signified lack of involvement or simply unavoidable clashes in timetable). It is therefore unlikely that the findings added significantly to decisions taken within the project.

The second problem is of bias. The implementation team were clearly keen to see the HCPA 'work' and yet were closely involved with the research. However, there was separation of key roles where bias might most affect the outcome, such as the three Senior Research Associates (who only did research) and the stroke co-ordinator (who only did implementation). There was also an independent steering group to ensure that overlapping roles such as mine did not confuse the research. It is therefore unlikely that significant bias was introduced.

I believe that the advantages of being able to ensure that the insight from the research could ultimately feed back in to practice, and that the research was looking at practical questions, outweighed the potential problems described above.

6.4 Interpretation

6.4.1 Priority setting

I developed a process for local priority setting, which integrates evidence-based and stakeholder-based processes. This has been used to develop a set of agreed priorities. Everyone felt that the right priorities were identified, although there remained some lack of clarity about how they were derived. There was also a concern that they are insufficiently owned by other organisations to be actively taken forward. Proof of the value of this process comes from the way in which district resources have already been harnessed to implement the priority areas identified. For example, the Multidisciplinary Audit Group and one Primary Care Group took hypertension forward, professionals from the trusts developed service specifications, and £100,000 of Health Improvement Programme development money has already been allocated to stroke.

The timetable for the process became overtaken by the timetable for Health Improvement Programme development so that user consultation could not inform priority setting directly, although it has now informed how the areas are taken forward. I think that the patient consultation days would have been better held around the time of completion of the technical document so that patient input could come at that stage.

Many of the outcomes will be long term, so not yet detectable, but the changes outlined in the results show that there are reasons to believe that the priorities are already having an effect.

This process of reaching consensus centred on the evidence base is similar to Delphi techniques used in other priority setting processes.[202] However, the need to involve different groups in different ways led to the stages described. This may be a useful lesson. A single means of input to the process can create a dichotomy between those 'involved' and those not, but having multiple means of input allows a spectrum of different levels of involvement.

Previous work on 'what people who have had a stroke want' has found very similar issues to our user consultation.[203-205] The Total Purchasing Pilot projects have concentrated on the use of evidence in priority setting and not looked at who was involved and how.[206] Decisions about which services to concentrate on seem to have been made on the basis of interests and views of general practitioners, which may not always coincide with population need. There has been very little research into prioritisation within programmes of care.[207]

I believe there are a number of lessons for commissioners, whether health authority or Primary Care Group. All key people need to be involved: clinical professionals, managers, users and carers. However, the mechanism for involvement need not be the same for everyone.

The process of priority setting needs to be explicit and clear to participants in the process and the wider community. People must be clear as to whether they are acting for an organisation or as an individual. If the former, they need to have mechanisms for communicating back to that organisation.

Engaging the public in decision-making is important but difficult. I involved users of the service and their carers rather than the "general public." This side-stepped the problem that prevention is an issue for everyone, and that better services for one group might mean worse services for another, but did produce good results in terms of information to aid decision making. Mechanisms for user or public consultation will be essential for Primary Care Groups and Primary Care Trusts which become involved in reducing services or making high profile prioritisation decisions.

6.4.2 Time

The finding that groups take time to work is not new, but one that needs reiteration in the context of political timescales within the National Health Service. Many new initiatives have required formation of a group to deliver changes within a year – for example Drug Action Teams, National Service Framework Local Implementation Teams and Health Improvement Programme groups. One solution to this is political: to try to change the process of new developments so that funds are limited in the first year to developing structures, with the promise of larger funds in year two to create changes in the service. The way in which the District Stroke Group was able to deliver the Health Improvement Programme suggests another solution to this problem: to maintain programme groups in the disease and client areas such as cancer, stroke, Coronary Heart Disease, children, elderly and mental health. They may need to 'tick over' between major initiatives but will be in a much stronger position to deal with the next one.

6.4.3 Engagement and representation

The District Stroke Group managed to engage most agencies at some point in the study. We obtained high-level agreement at the start of the process but needed to regain it with the 're-launch' event in April 1999.

Of all the agencies and groups on the District Stroke Group, primary care had the least engagement considering its importance. This partly stems from structural problems: General Practitioners are independent contractors and therefore it is very difficult for an individual to represent General Practitioners and there is a tendency for other members of primary health care teams to be forgotten or to defer to General Practitioners. There was also a political problem that stemmed from the start of the study when we were asked not to approach the Local Medical Committee by the then Director of Public Health. This meant the work had not been 'endorsed' and led later to some of the issues described in the section about priorities. One lesson is clear: that it is important to go through 'due process' with all statutory organisations in setting up a multiagency group. While it may not win 'hearts and minds' it ensures a mandate to work and is an important basis for negotiation with new members of groups.

It is likely that the development of Primary Care Groups and Primary Care Trusts will make the mechanisms for engaging primary care much clearer, although involvement of primary care remains a problem for the District Stroke Group. Primary Care Groups and Trusts are still engaging with their new roles and seeking to meet large agendas and multiple demands. Other 'levers' to engagement of primary care are the National Service Frameworks and the inclusion of stroke in the Older People's framework[112] may help this process.

Engagement of social services was better than might have been expected. There was a persistent difference of approach in that a diagnosis-specific group was not easily encompassed by social services structures but it was possible to work on many areas so that contact was maintained through changes of staff. However, District Stroke

Group membership remained at a relatively low level within the local authorities (and even within social service hierarchies) so limited progress was made in many areas.

Exclusion of patients and carers from the group was a decision by the District Stroke Group that many would consider inappropriate. However, the problems of representiveness and legitimacy are particularly acute here, and many efforts were made directed at eliciting and acting on service users' views. The involvement of the voluntary sector was also delayed because of disagreements around whether one group (The Stroke Association) could, or should, represent the voluntary sector as a whole.

There was a lack of clarity for many District Stroke Group members as to whether they were formal representatives of organisations, or individuals with skills able to offer a viewpoint. This is something that should have been addressed earlier but which started to resolve itself. For example in primary care the development of Primary Care Groups provided an organisation that could send a representative. Both Trusts increased their level of commitment after the re-launch and one developed an internal stroke group to link to the district wide group.

6.4.4 Leadership and co-ordination

Leadership for the District Stroke Group came from the local University, which is unlikely to happen in many places. The advantages were: neutrality (between sectors and between the two 'sides' of the district), expert knowledge, and energy because of the ongoing study. The disadvantages were being seen as remote ('Boffins Group'), potential disengagement from district structures and staff, and failure to engage local staff in the process. Overall the effect seems to have been positive, but since the end of the study health authority support for the group has waned. The group itself has expressed a desire to continue as a 'Health Improvement Group' but with a constituency and chairmanship derived from the district.

My role as a 'champion' in the health authority was able to strengthen this but it became clear that other staff from the health authority (such as Commissioning) were needed and subsequently the emphasis has shifted to Primary Care Groups.

The co-ordinator role was considered by most District Stroke Group members to be important. There were different views as to how much this was about networking and how much about change management. The role played in this project was predominantly networking; a different set of skills would have been needed for a more active change management role. It is difficult to find solid evidence that a co-ordinator post was necessary but the consensus seems to be that no one would have sufficient time to do this otherwise.

6.4.5 Context and Hawthorn effects

It is hard to resolve how much of the findings were dependent on particular individuals. However the change of staff throughout the study, including two co-ordinators, and the fact that no individual completely derailed the process suggests that the structure is reasonably 'individual proof.'

The rapid changes of the National Health Service during this period may suggest that the structure is reasonably 'reform proof.' However the reforms in this case encouraged the sort of structures that formed the Health Care Programme Approach. Had the reforms been along the lines of the internal market and competition, then this is likely to have been more destabilising.

It is difficult to determine how much effect the study had on the participants. Although not 'action research' there was feedback of findings to the District Stroke Group, which allowed reflection and redirection as necessary. For example, the results of the interviews may have strengthened the view that a re-launch was needed to engage higher-level staff across the district.

6.4.6 Primary care

Structures were most commonly found to support the detection and management of hypertension. The majority of practices ran some form of 'lifestyle' clinics, but well under half had guidelines or protocols to support this aspect of their work. While half the practices ran anticoagulation clinics, less than half had an identified lead professional in atrial fibrillation, a register of patients or guidelines or protocols in place for the management of atrial fibrillation or anticoagulation. There were few specific structures in place to support the care of patients with stroke, transient ischaemic attack or patients with stroke requiring rehabilitation. Nearly half of practices did, however, keep a register of stroke patients and have guidelines for secondary prevention; most commonly these were for antiplatelet therapy for stroke.

Audit of current practice in preventing and managing stroke was rare: two thirds of practices had conducted no audits of stroke prevention or management in the last two years.

Findings suggest that while structures were in place to facilitate recall and monitoring of patients with hypertension, for other groups of patients this was left to individual general practitioners with the consequence that opportunities for prevention or treatment may have been missed.

Changes as a result of the implementation of the Health Care Programme Approach were small. This could be due to the lack of specific initiatives by the District Stroke Group targeting general practice. An exception was the drive to increase the detection and management of hypertension, which included the distribution of guidelines to every practice, but this had little effect on practice structures.

6.4.7 Areas with greater success

The development of the priority setting process proceeded broadly as planned. The consistency with which the agreed priorities were adhered to for the next two and a half years was important in concentrating efforts on implementation. The development of some of the priority areas had mixed successes: the District Multidisciplinary Forum was successful but it was difficult to develop service specifications that could go into contracts. The hypertension guideline work had more limited success because it became 'orphaned' by the abolition of the Multidisciplinary Audit Group. However, it spawned a successful project in one Primary Care Group. Work on information to patients and long-term support was slow and difficult to assess in the time scales of the project.

The role of the technical document is more equivocal. It had an important role in the priority setting process in allowing a shared knowledge base but was time-consuming and expensive to produce. Furthermore, it was difficult to get many of the group to contribute to its production. It was however, promoted nationally by the Stroke Association and copies were requested by a number of districts in other regions. In one of those districts, the document was used to develop the HImP (R. Curless, personal communication). In major areas of policy, the development of National Service Frameworks is likely to make this process unnecessary but in smaller disease and client groups there is still a case for initial review of the evidence base and development of priorities.

6.4.8 Areas with limited success

Work on routine information proved less successful although apparently straightforward. It was difficult to engage one provider because the stroke unit had its own separate register. The other provider lacked a consultant in stroke medicine and so had limited resources to devote to this. The suspicion of routine data and its uses may have contributed to the lack of further work and discussion around the programme budget.

6.4.9 Underpinning theories

The Health Care Programme Approach was not developed within a theoretical framework and so a number of relevant theories were discussed in the introduction. This study showed the Health Care Programme Approach fits the ideas of network management very closely (page 18). There was development of social relationships and informal ties within and across organisational barriers. The ability to develop proposals across the two halves of the district shows the development of trust and reciprocity.

However, the need to work within formal structures and policies was also apparent, as the organisational hierarchies of the NHS will remain for sometime even if the market is disappearing.

6.5 Recommendations for policy and practice

The context of commissioning has moved considerably during this study. But just as work of Total Purchasing Plots has informed the development of Primary Care Groups,[29] so work on Health Care Programme Approach can inform the development of Health Improvement Programmes[8] and implementation of National Service Frameworks.[208] These 'vertical' planning structures will be briefly explained.

6.5.1 National Service Frameworks

> *'National Service Frameworks set national standards and define service models for a specific service or care group, put in place programmes to support implementation and establish performance measures against which progress within an agreed timescale will be measured. Building on the frameworks for cancer and paediatric intensive care the first two National Service Frameworks are for mental health (published in September 1999) and coronary heart disease (published in March 2000). The four National Service Frameworks are coronary heart disease, mental health, older people [finally published 27March 2001] and diabetes [due for publication later in 2001]. There will usually be only one new topic a year'.*[209]

Each district has to form Local Implementation Teams for the National Service Frameworks. The organisations forming membership of these have tended to be similar to the District Stroke Group and other Health Improvement Programme groups. For example I am currently a member of the Newcastle and North Tyneside District Adult Mental Health Programme Board, which also functions as the Health Improvement Programme group and the National Service Framework Local Implementation Team.

The NSF for Older People[112] sets out in Standard Five a similar set of components for the development of integrated stroke services that we used for the technical document and the HCPA generally:

- prevention: including the identification, treatment and follow-up of those at risk of stroke

- immediate care: including care from a specialist stroke team
- early and continuing rehabilitation
- long-term support, for the stroke patient and their carers.

The milestones include 'stroke units' (2002), audit to Royal College of Physicians guidelines (2003), protocols in General Practices (2003).

6.5.2 Health Improvement Programmes

> *'The Health Improvement Programme will be the local strategy for improving health and healthcare... The Health Authority will have lead responsibility for drawing up the Health Improvement Programme in consultation with National Health Service Trusts, Primary Care Groups, other primary care professionals such as dentists, opticians and pharmacists, the public, and other partner organisations...The Health Improvement Programme will cover:*
>
> *- the most important **health needs** of the local population, and how these are to be met by the National Health Service and its partner organisations through broader action on public health;*
>
> *- the main **healthcare requirements** of local people, and how local services should be developed to meet them either directly by the National Health Service, or where appropriate jointly with social services;*
>
> *- the **range, location and investment required** in local health services to meet the needs of local people.'*[8]

Most districts have formed Health Improvement Programme groups with responsibility for a section or chapter of the Health Improvement Programme. These tend to be in a number of key areas: major disease areas such as Coronary Heart Disease, cancers, mental health, and stroke and major client groups such as children, elderly, and disabled. Usually the same group (for Coronary Heart Disease and Mental Health) is used for the Health Improvement Programme and the National Service Framework.

6.5.3 Health Care Programme Approach

The Health Improvement Programmes and National Service Frameworks envisaged in *The New National Health Service*[8] have been focused on health care more than health. The Health Care Programme Approach has aimed more broadly to balance prevention and long-term support with treatment and rehabilitation. In practice many Health Improvement Programmes have had a broad focus and similar process to Health Care Programme Approach.

When the next reforms change the Health Improvement Programme process I consider it worthwhile maintaining these groups to ensure that future needs for programmes can be met quickly. In the case of the Health Care Programme Approach the existence of the group allowed a very quick response to the introduction of Health Improvement Programmes and will allow a response to requirements in the National Service Frameworks for Coronary Heart Disease and Elderly where stroke issues will be raised.

However a district stroke group needs active maintenance to continually link to local structures. Not only will personnel change, requiring the re-establishment of old links, but also organisations themselves will change from time to time (eg Primary Care Groups and Trusts).

A co-ordinator appears important to the active maintenance of a network and maintenance of the stroke group's agenda with other groups and organisations. A co-ordinator with greater change management skills or seniority may have led to further changes.

A technical document may not be necessary where there are National Service Frameworks. In other disease areas it should be considered, but requires careful management to make it a tool and not an end in itself. It had a key role in the process of prioritisation.

A range of methods for developing change have been used including:

- Service specifications
- Use of a local audit group
- Formation of ad hoc working groups

- Information exchange
- Influencing the agenda of other groups

The effectiveness of the contracting process and service specifications is unproven in this study but the use of a range of levers seems to be effective

6.5.4 Recommendations

Groups to develop Health Improvement Programmes or implement National Service Frameworks should contain representatives of all stakeholders. The stakeholder organisations need to agree at a senior level the process through which the group will proceed and its powers.

Members of the groups should clarify whether they formally represent their organisation or are there to offer individual expertise. If the former, a mechanism for communication should be established.

The group is unlikely to be fully functional for about two years from inception, but may be able to do some tasks at an earlier stage. Once established, it should be able to take on new roles quite quickly.

The group will need to keep its remit under review and regularly renew its links with senior officers in the organisations represented as well as other constituents.

6.6 Recommendations for future research

The initial discussion in chapter one of the process of evaluating a complex intervention might suggest a progress to a Randomised Controlled Trial. I do not believe this is appropriate for the following reasons.

The Health Improvement Programmes and National Service Frameworks are now 'must do' for health authorities. Furthermore, there is a rapidly changing policy framework.

The intervention cannot be standardised (nor could the control group), as it has to be adapted to the local environment.

There are no obvious quantitative outcomes: the indicators we used had limited sensitivity. The qualitative results show the range of different and sometimes conflicting outcomes that need to be considered.

There are many confounding factors making interpretation of quantitative results very difficult.

The maximum sample size is limited (about 100 health authorities or 400 primary care groups and trusts) making the power of any study limited especially considering points 3 and 4 above.

Others have recommended major changes in the use of randomised controlled trials, for socially complex service interventions.[210] I believe that it is often inappropriate as well as impractical to do Randomised Controlled Trials for some complex interventions. Furthermore, the belief that randomised controlled trial is the 'gold standard' may inhibit development of the research strategy most likely to produce information usable in practice.

George Davey Smith and colleagues have argued that 'evidence-based thinking can lead to debased policy making'[211] because public policy cannot use the sorts of evidence used in clinical decision-making. The health care programme approach is in a grey area between 'an intervention' and a framework for (political) decision-making. This is further reason why it is inappropriate to think about a randomised controlled trail as a next step.

There may, however, be a role for randomised controlled trials in looking at specific aspects of the intervention such as having a co-ordinator or producing a technical document.

The role of co-ordinators in improving services needs further exploration. A closer study of the work of co-ordinators for a number of disease and client groups would be instructive.

The links between 'vertical' (currently Health Improvement Programmes and National Service Frameworks) and 'horizontal' (currently Primary Care Groups and Primary Care Trusts) needs exploring. It seems likely that these will coexist for the foreseeable future.

Development of process and outcome indicators, especially those that could be used in primary care is already happening at many levels, but the National Service Frameworks and future role of the Commission for Health Improvement will be important in taking these forward.

Development of costing methods to produce more robust programme budgets has also been the subject of much work, but is still an area that requires further work in the links between National Health Service accounting methods and economic costing methods.

6.6.1 Summary Points

- The Health Care Programme Approach was successfully implemented and evaluated in Gateshead and South Tyneside despite rapid changes to the health services.
- The use of programmes and vertical planning is now much more widespread than it was in 1996 – notably with Health Improvement Programmes and National Service Frameworks – and the Health Care Programme Approach can be seen as a predecessor to these.
- The Health Care Programme Approach process was successful in agreeing a set of priorities and developing streams of work to implement them. There was variable success with the different priority areas but in some cases significant resources were gained to ensure developments.

- Quantitative indicators suggest that stroke care was improving during the period of the study, but a direct link to the Health Care Programme Approach is not possible.
- There was evidence of overall improvements in stroke care over the time of the study. The cost of implementing the Health Care Programme Approach was small (~£25K) compared to the total amount spent on stroke (~£10m).
- The qualitative study of process allowed a number of recommendations to be made regarding the development of similar processes:
- Groups to develop Health Improvement Programmes or implement National Service Frameworks should contain representatives of all stakeholders. The stakeholder organisations need to agree at a senior level the process through which the group will proceed and its powers;
- Members of the groups should clarify whether they formally represent their organisation or are there to offer individual expertise. If the former, a mechanism for communication should be established;
- The group is unlikely to be fully functional for about two years from inception, but may be able to do some tasks at an earlier stage. Once established, it should be able to take on new roles quite quickly;
- The group will need to keep its remit under review and regularly renew its links with senior officers in the organisations represented.
- Further research is needed into the role of co-ordinators, development of indicators and more robust costing methods.
- Further methodological research is needed into the evaluation of complex interventions and triangulation of multiple methods.

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8 Appendices

8.1 District Stroke Group membership

December 1996	October 1997	February 1998	May 1998
Health Authority Senior Registrar in Public Health Medicine	*Health Authority* Senior Registrar in Public Health Medicine	*Health Authority* Senior Registrar in Public Health Medicine Senior Finance Manager	*Health Authority* Senior Registrar in Public Health Medicine Senior Finance Manager
Trusts (acute sector) Professor of Stroke Medicine and Elderly Care, Gateshead Consultant Physician, South Tyneside Director of Medical Services, Gateshead Hospitals Trust	*Trusts (acute sector)* Professor of Stroke Medicine and Elderly Care, Gateshead Senior Lecturer in Stroke Medicine, Gateshead Consultant Physician, South Tyneside	*Trusts (acute sector)* Professor of Stroke Medicine and Elderly Care, Gateshead Senior Lecturer in Stroke Medicine, Gateshead DSG Co-ordinator (& Sister, Stroke Unit, South Tyneside)	*Trusts (acute sector)* Professor of Stroke Medicine and Elderly Care, Gateshead Senior Lecturer in Stroke Medicine, Gateshead Ward Sister, Stroke Unit, South Tyneside Consultant Physician, South Tyneside Director of Nursing, Gateshead (invited)
Trusts (community sector) Director of Business Development, Gateshead Healthcare Trust	*Trusts (community sector)* Physiotherapy Services Manager, Gateshead Community Liaison Nurse, South Tyneside	*Trusts (community sector)* Physiotherapy Services Manager, Gateshead Continuing Care Nurse Assessor, South Tyneside	*Trusts (community sector)* Physiotherapy Services Manager, Gateshead DSG Co-ordinator, Continuing Care Resource Centre
Primary Care GP, South Shields GP, Gateshead	*Primary Care* GP, South Shields GP, Gateshead	*Primary Care* GP, South Shields GP, Gateshead	*Primary Care* GP, South Shields GP, Gateshead (replacement being sought)
Social Services Gateshead Social Services Principal Officer, Disability Services, South Tyneside Social Services	*Social Services* Group Leader, Gateshead Social Services Principal Officer, Disability Services, South Tyneside Social Services	*Social Services* Group Leader, Gateshead Social Services, Principal Officer, Disability Services, South Tyneside Social Services	*Social Services* Group Leader, Gateshead Social Services, Principal Officer, Disability Services, South Tyneside Social Services
Newcastle University Senior Lecturer in Public Health Medicine Senior Lecturer in Stroke Medicine	*Newcastle University* Senior Lecturer in Public Health Medicine (Chair) Senior Lecturer in Stroke Medicine	*Newcastle University* Senior Lecturer in Public Health Medicine (Chair) Senior Lecturer in Stroke Medicine	*Newcastle University* Senior Lecturer in Public Health Medicine (Chair) Senior Lecturer in Stroke Medicine
			Voluntary Sector and Users Regional Manager, Stroke Association

8.2 District Stroke Group attendance

		1997				1998				1999		
	Dec 96	Jan-Mar	Apr-June	July-Sept	Oct-Dec	Jan-Mar	Apr-June	July-Sept	Oct-Dec	Jan-Mar	Apr-June	July
Health Authority												
Senior Registrar in Public Health	✓	✓	✓✓	✓✓	✓	✓✓	✓✓✓	✓✓	✓✓	✓✓✓	✓✓✓	✓
Senior Finance Manager					✓	✓✓	✓	✓✓	✓✓	✓✓	✓	
Trusts (acute sector)												
Professor of Stroke Medicine, G		✓				✓		✓✓	✓			
Senior Lecturer in Stroke Medicine, G	✓			✓								
Deputy Director of Nursing, G							✓		✓	✓✓	✓✓	
Services Manager, Nursing, G												✓
Consultant Physician, ST	✓	✓	✓✓	✓✓								
Sister, Stroke Unit, ST							✓	✓	✓✓	✓✓	✓	
Sister, Stroke Unit and Co-ordinator, ST					✓	✓✓						
Consultant Physician, ST							✓					
Consultant Physician, ST										✓✓	✓✓	✓
Trusts (community sector)												
Physiotherapy Services Manager, G		✓	✓	✓	✓		✓					
Occupational Therapy Service Manager, G								✓	✓	✓		
Stroke Co-ordinator			✓✓	✓✓	✓	✓	✓✓	✓✓	✓✓	✓✓	✓✓✓	✓
Primary Care												
GP, ST	✓	✓	✓	✓	✓	✓✓	✓✓✓	✓	✓✓	✓✓	✓	
Gateshead representative still being sought												
Social Services												
Principal Officer, Disability Services, ST	✓	✓	✓	✓			✓					
Group Leader, G			✓	✓		✓	✓✓	✓✓	✓✓			
Group Leader, G									✓	✓✓✓	✓	
Voluntary Sector												
Regional Manager, Stroke Association							✓✓	✓	✓✓	✓		
Regional Manager, Stroke Association										✓✓	✓	
Newcastle University												
Senior Lecturer in Public Health Medicine	✓	✓	✓✓	✓✓	✓	✓✓	✓✓✓	✓✓	✓✓	✓✓✓	✓✓	
Senior Lecturer in Stroke Medicine		✓			✓	✓✓	✓	✓✓	✓✓	✓	✓✓	

8.3 List of Interviews

Note: The order of interviewees above does not correlate with the interviewee numbers in the main text of this report.

R = Repeat interview

8.3.1 Round 1

Job title and organisation	**Membership of District Stroke Group (DSG)**
Physiotherapy Services Manager for Gateshead Healthcare Trust	Attended DSG from March 97
Previously Senior Sister on Stroke Unit, South Tyneside District Hospital and Co-ordinator of implementation of HCPA (Feb-April 1998)	Attended DSG from Dec 97, as a replacement for Consultant Physician from Stroke Unit who had left Group. Left DSG and district in April 98.
Consultant Physician, previously of South Tyneside District Hospital	Original member of DSG. Last attended Sept 97. Left DSG and district late 97.
Senior Finance Manager, Gateshead & South Tyneside Health Authority.	Joined DSG in Dec 97.
Ward Sister on Stroke Unit, South Tyneside District Hospital	Joined DSG in May 98.
Professor of Stroke Medicine & Elderly Care, based at Queen Elizabeth Hospital, Gateshead. Head of Stroke Unit and research unit	Original member of DSG.
Senior Lecturer in Stroke Medicine and clinician, Queen Elizabeth Hospital, Gateshead	Original member of DSG.
Continuing Care Nurse Assessor until took up post as Co-ordinator for HCPA (from June 98).	Member of DSG from May 97 as community representative then as co-ordinator.
Principal Officer, Disability Services, South Tyneside Social Services	Original member of DSG.
Group Leader, Gateshead Social Services	Joined DSG in June 97.
GP in South Shields, South Tyneside.	Original member of DSG.
GP, Gateshead	Original member of the DSG. Has never attended any meetings.
Regional Manager of Stroke Association.	Joined DSG in May 98.
Business Manager, Gateshead Health NHS Trust	Invited to join DSG May 98. Attended first meeting in June 98.
Consultant Physician (Geriatrician), South	Invited to join DSG in May 98.

Job title and organisation	Membership of District Stroke Group (DSG)
Tyneside District Hospital, South Shields	Attended first meeting in June 98.
Chair of Northumberland Health Authority	One of the lead instigators of the project. Member of the Evaluation Steering Group.
Lecturer in Public Health Medicine & Senior Registrar in Public Health Medicine (Gateshead & South Tyneside Health Authority). Member of evaluation team.	Original member of DSG. Project manager for HCPA.
Senior Lecturer in Stroke Medicine, Newcastle. Member of evaluation team	Original member of DSG.
Senior Lecturer in Public Health Medicine. Member of evaluation team.	Original member and Chair of DSG.

8.3.2 Round 2

Job title and organisation	Other relevant role(s)
Assistant Director Older People & Physical Disability Gateshead Social Services	
Deputy Director of Social Services South Tyneside	
Director of Finance & Commissioning Gateshead & South Tyneside Health Authority	
Director of Nursing & Midwifery Gateshead Health NHS Trust	Clinical lead for stroke
Director of Public Health, Gateshead & South Tyneside Health Authority	
Gateshead GP	Chair of Commissioning Forum, Chair of Gateshead Central and East Primary Care Group
Head of Services, Gateshead & South Tyneside Health Promotion	On various HAZ groups

Job title and organisation	Other relevant role(s)
Manager Primary Care Improvement Group	Chair of subgroup on Hypertension
Regional Manager Stroke Association	
Service Manager (Medicine/Elderly) South Tyneside Health Care NHS Trust	
South Tyneside GP	Chair of Multidisciplinary Audit Group, Member of Health Improvement Steering Group, Member of South Tyneside Primary Care Group

8.3.3 Round 3

	Job title and organisation	Membership of District Stroke Group (DSG) and subgroups
R	Senior Finance Manager, Gateshead & South Tyneside Health Authority	Joined DSG in Dec 97
R	Ward Sister on Stroke Unit, South Tyneside District Hospital	Joined DSG in May 98 Member of Multidisciplinary Forum
R	Professor of Stroke Medicine & Elderly Care, based at Queen Elizabeth Hospital, Gateshead. Head of Stroke Research Unit	Original member of DSG
R	Deputy Director of Nursing & Midwifery, Gateshead Health NHS Trust	Joined DSG in June 98
R	Previously Principal Officer, Disability Services, South Tyneside Social Services	Original member of DSG, left in May 99
R	South Tyneside GP	Original member of DSG Member of Hypertension subgroup
R	Regional Manager of Stroke Association	Joined DSG in Jan 99, replacing previous representative
R	Co-ordinator for stroke programme approach	Member of DSG from May 97 as community representative then from June 98 as co-ordinator Member of Hypertension subgroup and Multidisciplinary Forum
R	Lecturer in Public Health Medicine &	Original member of DSG

	Job title and organisation	Membership of District Stroke Group (DSG) and subgroups
	Senior Registrar in Public Health Medicine (Gateshead & South Tyneside Health Authority). Member of evaluation team	Project manager for programme approach Member of Hypertension subgroup and Multidisciplinary Forum
R	Senior Lecturer in Stroke Medicine, Newcastle. Member of evaluation team	Original member of DSG Member of Hypertension subgroup
R	Senior Lecturer in Public Health Medicine. Member of evaluation team	Original member and Chair of DSG
	Occupational Therapy Manager, Gateshead Health NHS Trust	Joined DSG in Sept 98, replacing previous representative Member of Multidisciplinary Forum
	Group Leader, Gateshead Social Services	Joined DSG in Dec 98, replacing previous representative Member of Multidisciplinary Forum
	Gateshead GP, board member of West Gateshead PCG	Member of Hypertension subgroup Lead on hypertension for West Gateshead PCG
	Research Manager, Stroke Research Unit, Gateshead	Attended DSG from May 98 Member of Multidisciplinary Forum
	Consultant Physician/Geriatrician, South Tyneside District Hospital	Joined DSG Feb 99, replacing previous representative

8.3.4 Round 4

	Job title and organisation	Membership of District Stroke Group (DSG) and subgroups
R	Senior Finance Manager, Gateshead & South Tyneside Health Authority	Joined DSG in Dec 97
R	South Tyneside GP	Original member of DSG Member of Hypertension subgroup
R	Regional Manager of Stroke Association	Joined DSG in Jan 99, replacing previous representative
R	Co-ordinator for stroke programme approach	Member of DSG from May 97 as community representative then from June 98 as co-ordinator Member of Hypertension subgroup and Multidisciplinary Forum
R	Professor of Public Health Medicine. Member of evaluation team	Original member and Chair of DSG
R	Gateshead GP, board member of West Gateshead PCG	Member of Hypertension subgroup Lead on hypertension for West Gateshead PCG
	Clinical Director Therapy & Central Clinical Services	Joined DSG in July 99

8.4 Survey of Districts

8.4.1 Documents collected prior to interviews

	Document	**Year/month produced**	**Source**
	Stroke strategy – any (if stroke group exists, minutes of group meetings)		DPH
	Dir Public Health Annual Report		DPH
	Health Authority's Corporate Contract/Corporate Objectives (annual aims/objectives of HA)		DPH?
	Purchasing plan	Sept	Director of Finance (HA)
	Corporate contract monitoring document (annual reports on progress/for review - to regional office?)		Director of Finance (HA)
	Trust business plan	Sept	Chief Executive (trust)
	Community care plan (other key reports/docs produced by LA)		Director of Social Services
	Contracts	Mar	
	- general	Mar	CE/director of contracting/ commissioning/ purchasing/ finance (HA)
	- stroke-specific	Mar	above or DPH
	Service specifications - general - stroke-specific	Mar	ditto
	Contracts for health promotion	Mar	ditto
	Contract monitoring documents	Jun, Sep, Dec, Mar	CE/director of contracting/ commissioning/ purchasing/ finance (HA)
	Health of the Nation/ 'Our Healthier Nation' plans		DPH
	Primary care - standard information required of practices in annual reports		MAG or equivalent
	Primary care development plans		Director of primary care, primary care medical advisor
	Annual reports on medical/clinical audit		Audit department

Statutory documents that each organisation must produce

Stroke-specific strategies and other documents that we are aware of

Are there any other documents you think are critical which we may not be aware of?

8.4.2 Information to be extracted from documents

- Population
- National rates - stroke (SMR) (others? E.g. CHD)

- % population served by fundholding practices (standard, community, TPP)
- Number & type of main providers
- Plans for Primary Care Groups (number, level)
- Part of HAZ?
- Is stroke mentioned as a priority?
- Local audit data
- Activity data
- Local epidemiology

Is there a written strategy for stroke care?	YES/NO
IF YES	General statement What is the method of review/audit? What are the aims and objectives of the strategy? What is the timescale? What targets/indicators are being used? What is the method of review/audit? How are stroke services defined? Does this cover: prevention, acute treatment, rehabilitation, long-term care and support? Any evidence of an integrated approach?
Are priority areas listed?	YES/NO
If YES, list these	What are the aims, objectives and timescale for each priority area? What targets/indicators are being used? What is the method of review/audit?
Is there a service specification or contract for stroke services?	YES/NO
IF YES Does this cover: -prevention -acute treatment -rehabilitation -long-term care and support	For each, list areas cited and for each: What are the aims, objectives and timescale? What targets/indicators are being used? What is the method of review/audit?
Is there any written documentation about contract monitoring?	YES/NO
IF YES	Give details Standards specified? Quality or performance indicators? Incentives/penalties?
Is there any evidence of a needs assessment for stroke patients?	YES/NO

IF YES	Evidence of link between needs and specified services/resources?
Does this cover: -prevention -acute treatment -rehabilitation -long-term care and support	IF YES, list areas covered
Is service specification/agreement 'evidence-based'?	
	Has there been a review? If yes, any evidence/recommendations arising from this? Are they graded or prioritised? Match content to evidence base Any reference to other documents? (national, local) Use of guidelines (referral, treatment)? If yes, are they specific or general? Source of the guidelines (locally developed, national)?

8.4.3 Interview Schedules

a Background information

Explain evaluation project and survey.

b Aim of study

The study aims to evaluate the Health Care Programme Approach to commissioning to see if services organised in this way can improve the delivery, quality and outcome of care for patients with stroke.

The health care programme approach is defined as a complex process of collaborative development of a "technical document" and subsequent identification of priorities with a view to creating change in the development and balance of services for stroke in order to improve the health and healthcare of the population of Gateshead and South Tyneside Health Authority.

c Aim of survey

To compare current and previous practice in commissioning of services for the prevention of stroke and stroke care in Gateshead and South Tyneside with other purposively selected non-teaching districts before and after the implementation of the

Health Care Programme Approach in Gateshead and South Tyneside, in order to support assessment of the impact of the HCPA.

The following are minimum undertakings; interviewee can of course request additional safeguards of confidentiality.

- The views of individuals or statements representing the views of named organisations will not be attributed to them without their agreement.
- Details of participants, interview tapes and other material shared with the research team by participants will be kept securely during the project.
- At the end of all interviews, participants will be asked whether they wish any of the material discussed during the interview to remain confidential or not to be attributed.
- Audiotapes will be wiped clear at the end of the project.
- Participants have a right under the 1988 Data Protection Act to see any information relating to them that is stored on computer.

d Questions

Main question	**Prompts**
Commissioning - general	
How are services commissioned in your district?	
What mechanisms are used for commissioning services?	DHA, locality, other?
What sources are used to inform commissioning?	Use of evidence? Heath Needs Assessment? Historical? Local and/or national sources?
What is your personal role in commissioning?	
Commissioning of stroke services	
What services are commissioned for: a. stroke prevention b. Stroke care?	Range of providers? Acute stroke unit? Rehabilitation? Long-term care?
How is service provision for stroke patients coordinated between different organisations and sectors?	
How are current stroke services commissioned?	Specific stroke contract/specification or included within others, e.g. part of general medicine, elderly, etc.?

Main question	Prompts
What mechanisms are used for commissioning stroke services?	Does this differ from methods used for commissioning services for other patient groups? If yes, why?
What role, is any, does the local authority play in commissioning stroke services (joint commissioning)?	
What sources are used to inform commissioning of stroke services?	Use of evidence? Heath Needs Assessment? Historical? Local and/or national sources? Use of clinical guidelines? (e.g. HT, referral, acute treatment, AF, etc.)?
Reporting systems used for monitoring contracts/progress?	To: DHA Regional Office public local NHS
Are stroke services a district priority?	IF YES why? (national/ local issue)
Does your district have any priority areas in the provision of stroke services?	IF YES: why these areas? (Evidence-linked? HNA?) What are the aims, objectives and timescale for each priority area? what targets/indicators are being used? What is the method of review/audit? who was consulted about these priorities and how?
Have there been any recent changes in your district's approach to stroke commissioning?	IF YES: what? why?
Are any future changes envisaged in the way stroke services are commissioned?	IF YES: what? why?
Resource issues	
Are any major resource shifts or developments planned for stroke services?	IF YES details timescale
Is there a nominal budget for purchasing stroke services?	
How much of the district's budget is spent on stroke services?	
Structures	
Does your district have a stroke co-ordinator? Does your district have a lead person for stroke?	IF YES: within health authority, trust, local authority, other? As above
Does your district have an advisory group for co-ordination of stroke services?	IF YES: purpose membership functioning
Does your district have a stroke register?	IF YES: provider or population-based?
General	
Is there any district-led research in stroke services?	

Main question	**Prompts**
Does your district have any input from local academic departments?	e.g. public health, primary health care, medicine, geriatrics, etc.?
What is your district's involvement with non-statutory sector organisations?	e.g. Stroke Association, charities, CHC, patient/carer groups IF YES how involved?
Have you applied to become a Health Action Zone?	IF YES: did bid succeed? Did bid cover stroke?
Is stroke to be included in HIP?	Details (how, etc.)
Is there any more which could be done in terms of stroke provision in your district?	
Are there any constraints that hinder the improvement of stroke provision in your district?	
General information (if not available from documentary sources)	See Doc analysis e.g. number of hospitals, number of GP practices (breakdown by fundholding, other), etc.

8.5 Survey of Practices

8.5.1 Questionnaire

Note: not in original format

STUDY NUMBER

PRIVATE AND CONFIDENTIAL

STROKE PREVENTION AND CARE IN GENERAL PRACTICE

University
of Newcastle
(crest)

GATESHEAD &
SOUTH TYNESIDE
DISTRICT STROKE
GROUP

Thank you for assisting us by completing this questionnaire.

Your answers will be treated in confidence and will not be used in any way which could identify you personally.

INSTRUCTIONS FOR ANSWERING THE QUESTIONS

There are several types of question in this questionnaire. Most of them can be answered by circling a number.

For example:

1 Does your practice run clinics for the following?

(please circle one number)

	Yes	No
Diabetes	1	2

SECTION 1 YOU AND YOUR PRACTICE

Firstly, we would like to ask a few questions about you and your practice

1 What is your *practice* list size? __ __ __ __ __

2 How many patients on your practice list are over 65 years old? ___ ___

___

3 How many partners are there in the practice?

a) number of partners ___

___

b) whole time equivalent partners ___

___

4 How many other doctors are working in your practice (e.g. GP trainees; assistants, retainers, salaried GPs, etc.)?

a) number of other doctors ___

___

b) whole time equivalent of other doctors ___

___

5 Which of the following health care professionals work in your practice?

(*please tick all that apply*)

	is employed by practice	**is attached to practice**	**is an independent practitioner (from a private agency)**	**whole time equivalent** (*please write on the dashes below)*
Practice nurse				— —
District nurse				— —
Health visitor				— —
Physiotherapist				— —
Occupational therapist				— —
Speech & language therapist				— —
Dietician				— —
Psychologist				— —
Counsellor				— —
Social worker				— —
Other (*please list*) __________ __________				— — — —

6a What type of computer system does your practice have? (e.g. Emis, Meditel)

----

b Do GPs use the computer in consultations with patients?

(please circle one number)

Yes	1
No	2
Not applicable	3

c Could the following information be obtained from your computer?

(please circle one number on each line)

	Yes	**No**
Number of patients aged 18 or over whose blood pressure was recorded in the last 5 years	1	2
Number of hypertensive patients	1	2
Number of hypertensive patients whose blood pressure was recorded in the last 12 months	1	2
Number of hypertensive patients whose most recent systolic blood pressure was less than 160mmHg	1	2

SECTION 2 STROKE PREVENTION

In this section, we would like to ask some questions about your practice's management of stroke prevention.

1 HYPERTENSION

Does your practice have any of the following?

(please circle one number on each line)

	Yes	No
A doctor with an identified lead role in hypertension	1	2
A nurse with an identified lead role in hypertension	1	2
A nurse-run hypertension clinic	1	2
A doctor-run hypertension clinic	1	2
A computerised register of patients with hypertension	1	2
A non-computerised register of patients with hypertension	1	2
An audit of patients with hypertension conducted within the last two years	1	2

Does your practice have written or computerised guidelines/protocols for any of the following?

(*please circle one number on each line*)

	Yes	No
Screening for hypertension	1	2
Diagnosis of hypertension	1	2
Management of hypertension	1	2
Referral for hypertension	1	2
A comprehensive guideline/protocol covering all the above	1	2

2 ATRIAL FIBRILLATION

Does your practice have any of the following?

(*please circle one number on each line)*

	Yes	No
A doctor with an identified lead role in atrial fibrillation	1	2
A nurse with an identified lead role in atrial fibrillation	1	2
A nurse-run anticoagulation clinic	1	2
A doctor-run anticoagulation clinic	1	2
An anticoagulation clinic run by another professional	1	2
A computerised register of patients with atrial fibrillation	1	2

A non-computerised register of patients with atrial fibrillation	1	2
An audit of patients with atrial fibrillation conducted within the last two years	1	2

Does your practice have written or computerised guidelines/protocols for any of the following?

(*please circle one number on each line*)

	Yes	**No**
Screening for atrial fibrillation	1	2
Diagnosis of atrial fibrillation	1	2
Management of atrial fibrillation	1	2
Referral for atrial fibrillation	1	2
Initiation of warfarin anticoagulation	1	2
Monitoring of warfarin anticoagulation	1	2
Referral for warfarin anticoagulation	1	2
A comprehensive guideline/protocol covering all the above	1	2

3 LIFESTYLE

Does your practice run clinics for any of the following?

(please circle one number on each line)

	Yes	No
General lifestyle (e.g. well man; well woman)	1	2
Elderly - general	1	2
Smoking cessation	1	2
Exercise	1	2
Diet	1	2
Alcohol	1	2
Other clinics relevant to stroke *(if yes, please specify)* --- ----------	1	2

Does your practice have written or computerised guidelines/protocols for any of the following?

(*please circle one number on each line*)

	Yes	No
Smoking cessation	1	2
Exercise	1	2
Diet	1	2
Alcohol	1	2

SECTION 3 MANAGEMENT OF STROKE AND TRANSIENT ISCHAEMIC ATTACKS

In this section, we would like to ask some questions about your practice's management of stroke and transient ischaemic attacks

1 STROKE AND TRANSIENT ISCHAEMIC ATTACKS

Does your practice have any of the following?

(please circle one number on each line)

	Yes	**No**
A doctor with an identified lead role in stroke	1	2
A nurse with an identified lead role in stroke	1	2
A nurse-run stroke clinic	1	2
A doctor-run stroke clinic	1	2
A computerised register of patients with stroke	1	2
A non-computerised register of all patients with stroke	1	2
An audit of patients with stroke conducted within the last two years	1	2
An audit of patients with transient ischaemic attacks conducted within the last two years	1	2

Does your practice have written or computerised guidelines/protocols for any of the following?

(please circle one number on each line)

	Yes	No
Diagnosis of acute stroke	1	2
Management of acute stroke	1	2
Referral for acute stroke	1	2
Diagnosis of transient ischaemic attacks	1	2
Management of transient ischaemic attacks	1	2
Referral for transient ischaemic attacks	1	2
A comprehensive guideline/protocol covering all the above	1	2

2 SECONDARY PREVENTION OF STROKE

Does your practice have any of the following?

(please circle one number on each line)

	Yes	No
A doctor with an identified lead role in secondary prevention of stroke	1	2
A nurse with an identified lead role in secondary prevention of stroke	1	2
A nurse-run secondary prevention clinic	1	2

A doctor-run secondary prevention clinic	1	2
An audit of secondary prevention conducted within the last two years	1	2

Does your practice have written or computerised guidelines/protocols for any of the following?

(*please circle one number on each line*)

	Yes	**No**
Antiplatelet therapy (e.g. aspirin, dipyridamole) for ischaemic heart disease	1	2
Antiplatelet therapy (e.g. aspirin, dipyridamole) for stroke disease	1	2
Assessment of vascular risk	1	2
Follow-up of stroke patients at high risk of a further stroke	1	2
Secondary prevention of stroke in general	1	2

SECTION 4 MANAGEMENT OF STROKE REHABILITATION AND LONG TERM CARE

In this section, we would like to ask some questions about your practice's management of stroke rehabilitation and long-term care.

Does your practice have any of the following?

(please circle one number on each line)

	Yes	No
A doctor with an identified lead role in stroke rehabilitation and/or long-term care for stroke patients	1	2
A nurse with an identified lead role in stroke rehabilitation and/or long-term care for stroke patients	1	2
Another professional with an identified lead role in stroke rehabilitation and/or long-term care for stroke patients *(if yes, please specify type of professional)* --	1	2
Guidelines or protocols for stroke patient rehabilitation	1	2
Guidelines or protocols on information to be given to patients and/or carers	1	2

Finally, is there anything else you would like to add about the prevention and management of stroke in your practice (for example, any plans for development)?

....

....

....

....

....

Thank you for your help.

Please return the questionnaire in the envelope provided.

8.6 Acknowledgements

8.6.1 Funding

The National Health Service Executive, Northern and Yorkshire Regional Office, Research and Development Directorate funded this study with two grants.

a EHCIG 10 C

The Health Care Programme Approach: implementation and evaluation

National Research Register Project: N0461044525, University of Newcastle project RES/2302/6240

Start date: 01/02/1998, *End date*: 01/06/2000. *Amount* £92,468

Commissioned by the Effective Health Care Implementation Group working group in 1997 to implement and evaluate methods to increase the uptake of evidence based health care.

Applicants: JH (lead), HR, RT, DF, DB, TC, DC, JMO'B

Principal Investigators: DC (named), RT, HR.

b HC6C

Programme Commissioning of Stroke Services: a descriptive study

National Research Register Project: N0461021762, University of Newcastle project RES/2302/6386

Start date: 30/09/1998, *End date*: 01/06/2000, *Amount* £70,325

Commissioned by the Health Services Research Working Group in 1997 to focus on effective purchasing or commissioning.

Applicants: DC (lead), JH, JMO'B, DP, HR, RS, RT.

Principal Investigators: DC (named), RT, HR, RS, DP.

This thesis includes work done between April 1996 and July 2000. Some of this work was funded by a grant from the Stroke Association for £9,197 between 01/02/97 and

31/07/97. This earlier grant was used to conduct a literature review and develop the initial ideas and the proposals to NHS R&D.

8.6.2 People

The project team came from the Departments of Epidemiology and Public Health and Primary Health Care in the School of Health Sciences at the University of Newcastle upon Tyne. They worked closely with colleagues in the NHS. Authorship refers to the final report to funders.

a The research team

Jackie Bailey (JB), Senior Research Associate (qualitative)

Conducted most of the interviews, observation and documentary analysis. Lead author for chapter 3.

David Chappel (DC), Lecturer in Public Health Medicine

Principal investigator and editor of final report. Lead author for chapters 1, 2, 9, 10, 11 and 12.

Emma Hutchinson (EH), Secretary

Administered both implementation research sides of the study and did the referencing for the final report.

David Parkin (DP), Senior Lecturer in Health Economics

Supervised the health economic part of the study.

Angela Robinson (AR), Research Associate (economics)

Conducted the economic aspects of the study. Lead author for chapters 7 and 8.

Helen Rodgers (HR), Senior Lecturer in Stroke Medicine and Services

Supervised the clinical and quantitative aspects of the study.

Rosie Stacy (RS), Senior Lecturer in Medical Sociology

Supervised the qualitative aspects of the study. Co-author for chapter 3.

Lois Thomas (LT), Senior Research Associate (quantitative)

Conducted the quantitative aspects of the study and the two surveys. Lead author for chapters 4,5,6 and 9.

Richard Thomson (RT), Professor of Epidemiology and Public Health

Supervised the quantitative aspects of the study.

Additionally, Graham Stacy (GS), Health and Social Care Researcher, carried out the final round of interviews.

b The implementation team

David Chappel (DC), Honorary Senior Registrar in Public Health Medicine

Emma Hutchinson (EH), Secretary

Ruth Richardson (RR), District Stroke Co-ordinator (From May 1998)

Helen Rodgers (HR), Senior Lecturer in Stroke Medicine and Services

Barbara Scott (BS), District Stroke Co-ordinator (Until April 1998)

Richard Thomson (RT), Professor of Epidemiology and Public Health

c The steering group

This group was drawn from outside the School of Health Sciences and consisted of all project research team members plus:

Charlotte Clark (CC), Principal Lecturer (Nursing research), University of Northumbria at Newcastle

Nick Freemantle (NF), Senior Research Fellow, University of York

Jane Halpin (JH), Consultant in Public Health Medicine Gateshead and South Tyneside (now at East Hertfordshire HA)

J Michael O'Brien (JMO'B), Chair of Northumberland Health Authority and honorary Senior Research Associate, Department of Medicine, University of Newcastle upon Tyne

Sue Straughair (SS), Research Programme manager, NHS R&D N&Y (now at Department of Health)

We would also like to thank those who gave time to discuss the project in its initial stages including John Bond (University of Newcastle upon Tyne), Senga Bond (University of Newcastle upon Tyne), Sue Dopson (Templeton College, Oxford), Nick Hicks (Oxfordshire Health Authority), Paul Miller (University of Nottingham).

d The District Stroke Group (DSG)

This group was key to the implementation. Its membership varied throughout the project (See Appendix 1). The District Stroke Group in October 1997 included:

David Barer (DB), Professor of Stroke Medicine and Elderly Care, Queen Elizabeth Hospital, Gateshead.

Marion Brumwell (MB), Physiotherapy Services Manager Dunston Hill Hospital, Gateshead.

Tim Cassidy (TC), Consultant Physician South Tyneside Health Care Trust (Now at Newcastle City Health Trust.

Michelle Davis (MD), Senior Lecturer in Stroke Medicine, Queen Elizabeth Hospital, Gateshead.

Dr David Finnigan (DF), General Practitioner, Marsden Road Health Centre, South Tyneside.

Ms Janice Haydon (JH), Principal Officer Disability Services, Social Services Department, South Tyneside District Council.

Dr Alan Reekie (AR), General Practitioner, Longrigg Medical Centre, Gateshead.

Mrs Ruth Richardson (RR), Community Liaison Nurse, South Tyneside Health Care Trust.

Mrs Judith Wilkins (JW), Group Leader Older people and Physical Disabilities Division, Social Services Department, Gateshead MBC.

Plus the members of the implementation team.

e Other Acknowledgements

For help with collecting the CMDS data:

Val Oliver, information officer, Heath Authority

John Reid, information officer at NHSE N&Y - for the 10 year stroke data

For help with costing and other information and for the programme budget

John Pickering, finance officer, Heath Authority

Mike Coughlin, finance officer, Gateshead Health NHS Trust, Whinney House

Clive Irving, finance officer, South Tyneside Healthcare NHS Trust

For statistical advice on the indicators: Michael Hutchinson, Centre for Health Services Research

8.7 Glossary

a Commissioning

Planning is a "... deliberate, systematic, and objective process of mobilizing information and organizing resources."[1]

The aim of (Public Health) *commissioning* is to maximise the health of the population and minimise illness, by purchasing health services and by influencing other organisations to create conditions which enhance people's health.[2]

(Health) *purchasing* is buying the best value for money services to achieve maximum health gain for those most in need.[2]

(Health) *contracting* is a narrower concept of negotiating between a purchaser and provider and includes specifying a service, tendering, specifying a contract, monitoring and reviewing.[2]

b Health care programme approach (HCPA)

See Introduction.

c Primary Care Group (PCG)

Primary Care Groups are groups of local health care and social care professionals who together with patient and Health Authority representatives take devolved responsibility for the healthcare needs of their local community.

Primary Care Groups may operate at one of four levels, although prior to 1 April 2000 they have operated at levels 1 or 2 only. *Level 1*: at a minimum, act in support of the Health Authority in commissioning care for its population, acting in an advisory capacity; *Level 2*: take devolved responsibility for managing the budget for healthcare in their area, acting as part of the Health Authority; *Level 3*: become established as free-standing bodies accountable to the Health Authority for commissioning care; *Level 4*: become established as free-standing bodies accountable to the Health Authority for commissioning care, and with added responsibility for the provision of community services for their population. PCGs which operate at level 3 or 4 are known as *Primary Care Trusts* (PCTs). A further stage of *Care Trusts* incorporating social services was announced in the NHS Plan.[3]

d Health Improvement Programme (HImP)

Each Health Authority (HA) in England produces a HImP that sets out the strategic framework for improving health, reducing inequalities and delivering faster more responsive services of a consistently high standard.[3] These were renamed Health Improvement and Modernisation Plans (HIMPs) during 2001.

e Other abbreviations used

DSG - District Stroke Group
NHS - National Health Service
GST – Gateshead and South Tyneside
TPP - Total Purchasing Pilot

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8.8 Co-ordinator Job Description

a Background

Well-organised services are important in providing care for stroke patients and their families. Gateshead and South Tyneside Health Authority wishes to ensure that stroke services are commissioned in the best possible way. They will be using a health care programme approach to do this. As this is a method that has only been piloted in the past there will be an evaluation of this alongside the work done.

b Overall purpose

To act as co-ordinator for the implementation of the health care programme approach to stroke across Gateshead and South Tyneside. The aim is to improve the overall quality of services across the district.

c Objectives

- To facilitate the implementation and monitoring of the health care programme approach
- To co-ordinate activities across different organisations and between different professional and managerial groups
- To ensure that key individuals are well focused on progress and requirements
- To report progress to the District Stroke Group
- To co-ordinate the production of a strategy document
- To maintain a close record of meetings, activities and progress

d Required skills and knowledge

- Experience and knowledge of health and social care
- Good verbal and written skills
- Good listening qualities
- Good organisational skills

- Ability to communicate with, enlist support from and gain co-operation from different individuals in health and social services. These will include clinicians and managers, patients and carers and voluntary agencies
- Good knowledge and understanding of the organisation and function of the NHS and local authority Social Services

e Desirable skills and knowledge

- Good knowledge of local health and social services structure, function and relationships. Understanding of service development and audit
- A network of local contacts in health and social services, or the ability to create one quickly
- Good knowledge (preferably clinical) of stroke disease
- Ability to drive and access to a car

f Accountability and supervision

- The post holder will be accountable to the District Stroke Group
- They will be supervised by Dr David Chappel

g Support

There will be secretarial support (equivalent to half-time over two years). There will be an office (site to be decided), access to a computer and funds for organising meetings, correspondence, photocopying, etc.

h Working Relationships

The post-holder will be in contact with a wide range of individuals and organisations. These will include professionals and managers, from health and social services, people from the voluntary sector including organisers, carers and people who have had strokes.

The post-holder will work most closely with members of the District Stroke Group and specifically with Dr David Chappel.

The post-holder will co-operate with the research steering group and the two senior research associates who will be undertaking the evaluative side of this work.

i Duration and time of post

The post-holder should start as soon as possible, but must be before the end of February 1998. This post is funded for two sessions per week for two years. There will be flexibility in the way this time is best used: for example more time may be needed during the development of service specifications and less time at other times of year.

j Salary

Secondments are welcome and salary will be dependent on level of experience and qualifications (but approximately: Nursing - grade H, Medical - GP sessional rate, social work - Social Worker - level 3 or Professions Allied to Medicine - Superintendent 3/ head 3). If the post-holder is seconded from another organisation they will continue on their current salary.

k Applications

Application should be made by sending your CV to: Dr David Chappel, Lecturer in Public Health Medicine, Department of Epidemiology and Public Health, University of Newcastle upon Tyne NE2 4HH. Telephone; 0191 222 8899, Fax: 0191 222 6746, E-mail D.B.Chappel@Newcastle.ac.uk. Further information can be obtained from the same address. Closing date for applications Monday December 22nd 1997, Interviews will be on Thursday 15th January 1998.

8.9 Publications arising from study

***** Those marked with a triple asterisk are appended to the thesis *****

8.9.1 Papers

a Peer reviewed papers - published

*** Chappel D, Miller P, Parkin D, Thomson R. Models of commissioning health services in the British National Health Service: a literature review. *Journal of Public Health Medicine* 1999;**21(2)**:221-227.

*** Chappel D, Bailey J, Stacy R, Rodgers H, Thomson R. Implementation and evaluation of local-level priority setting for stroke. *Public Health* 2001;**115**:21-29.

b Peer reviewed papers - in press

none

c Peer reviewed papers - submitted

Thomas L, Chappel D, Bailey J, Thomson R, Rodgers H. Stroke prevention and care in general practice: a local survey. Submitted to *Family Practice.*

d Peer reviewed papers - in preparation

Chappel D, Thomas L, Bailey J, Robinson A, Rodgers R, Thomson R, Stacy R, Rodgers H, Thomson R. Evaluation of a health care programme approach to commissioning stroke services in Gateshead and South Tyneside.

Robinson A, Thomson R, Parkin D. Costs, prices, and programme budgeting for PCGs.

e Articles

*** Chappel D, Rogers R, Thomson R, Thomas L. Programme Commissioning of Stroke Services in Gateshead and South Tyneside. *Stroke Matters* 1999;3(2):3.

8.9.2 Abstracts

a Conference Abstracts

Thomas L, Bailey J, Chappel D, Thomson R, Rodgers H, Stacy R, Robinson A, Parkin D,. Stroke prevention and care in general practice: a local survey. *NoReN (Northern General Practice Research Network) Annual Scientific Meeting, 16th November 1999.* [platform: RT presented]

Thomas L, Bailey J, Chappel D, Thomson R, Rodgers H, Stacy R, Robinson A, Parkin D,. Stroke prevention and care in general practice: a local survey. *British Association of Stroke Physicians, Nottingham, 8th-10th September 1999.* [platform: LT presented]

Robinson A, Parkin D, Bailey J, Chappel D, Stacy R, Rodgers H, Thomas L, Thomson R. The use of programme budgeting (PB) in assessing the burden of stroke. *Society for Social Medicine, Sheffield, 8th-10th September 1999.* [platform: AR presented]

Chappel D, Bailey J, Thomson R, Stacy R, Rodgers H, Thomas L, Robinson A, Parkin D. Evaluation of complex interventions: how do we define the intervention? *Faculty of Public Health Medicine conference, Glasgow, 6th-9th July 1999.* [platform: DC presented]

Chappel D, Bailey J, Thomson R, Stacy R, Rodgers H, Thomas L, Robinson A, Parkin D. The use of triangulation in the evaluation of complex interventions. *Faculty of Public Health Medicine conference, Glasgow, 6th-9th July 1999.* [poster: DC attended]

Chappel D, Bailey J, Thomson R, Stacy R, Rodgers H, Thomas L, Robinson A, Parkin D. The use of triangulation in the evaluation of complex interventions. *15th International Society for Technology Assessment in Health Care conference, Edinburgh, 20th - 23rd June 1999.* [poster: DC attended]

Chappel D, Bailey J, Thomson R, Stacy R, Rodgers H, Thomas L, Robinson A, Parkin D. Evaluation of complex interventions: how do we define the intervention? *15th International Society for Technology Assessment in Health Care conference, Edinburgh, 20th - 23rd June 1999.* [poster: DC attended]

b Invited Presentations

Chappel D, Bailey J, Stacy R, Rodgers H, Thomson R. Implementation and evaluation of local-level priority setting for stroke. Regional Consultant Publication Prize (first prize). York, April 2002. [presentation]

Chappel D, Miller P, Parkin D, Thomson R. Models of commissioning health services in the British National Health Service. Regional Trainee Publication prize giving (joint first). Harrogate, Dec. 1999. [presentation]

Chappel D, Bailey J, Thomson R, Stacy R, Rodgers H, Thomas L, Robinson A, Parkin D. Evaluating a health care programme approach to purchasing stroke services. NHSE N&Y R&D conference, Harrogate, 1997. [poster]

8.9.3 Other

a Book Chapter

*** Chappel D. *Commissioning Stroke Services* (Chapter 12) in Gabbay M, Ed. *The evidence-based primary care handbook.* London; Royal Society of Medicine Press, 1999. 135-141.

b Reports

Chappel D, Bailey J, Robinson A, Rodgers H, Stacy R, Thomas L, Thomson R. *Evaluation of a health care programme approach to commissioning stroke services: report to NHSE N&Y R&D.* Newcastle: University of Newcastle upon Tyne, 2000.

Chappel D. *Stroke Strategy in A Health Improvement Programme for Gateshead and South Tyneside, 2000 - 2003.* Gateshead and South Tyneside Health Authority, 1999.

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Chappel D. *Technical Document for the health care programme approach to Stroke in Gateshead and South Tyneside.* Newcastle: University of Newcastle upon Tyne and Gateshead and South Tyneside Health Authority, 1997.

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Models of commissioning health services in the British National Health Service: a literature review

David Chappel, Paul Miller, David Parkin and Richard Thomson

Summary

The commissioning of health services is an under-researched area and yet it is critical to the way services meet health needs and to the quality of care. Recent emphasis in the United Kingdom and elsewhere has been on a 'primary care led National Health Service', particularly on locality commissioning through primary care groups. However, there are other models of commissioning using 'programmes of care' (focused on diseases or patient groups rather than geography) which may offer greater benefits. There is little research comparing the benefits and costs of these models, and most are not even clearly enough described to be replicated. There will always be a political dimension to models of commissioning, dependent, for example, on the balance of power in the decision-making process. None the less, a broader knowledge of possible models and a willingness to evaluate rigorously are needed if commissioning of health services is to result in better patient care.

Keywords: health planning, health policy, health care reform, health services administration

Planning, purchasing and commissioning health services

Planning is a 'deliberate, systematic, and objective process of mobilizing information and organizing resources'.[1] The formation of the National Health Service (NHS) in the 1940s made it possible to plan for the whole service, although it was only in the 1960s that comprehensive health service planning systems were widely used internationally.[2] The focus of planning was predominantly on buildings and staff, with a primary aim being a more equitable geographical spread of resources.[3]

In the 1970s there was a move from historical budgets, to those based on 'need',[4] although the ability to assess need was limited.[5] This included both a geographical reallocation[4] (the Resource Allocation Working Party – RAWP – formula) and a shift between patient groups from 'acute services' such as medicine and surgery to 'priority services' such as the mentally ill, mentally handicapped, elderly and the chronically sick.[4]

In the late 1980s two important developments took place in the NHS: the separation of strategic planning from service provision, and 'market' reforms to introduce competition. The former has allowed the strategic planners (now 'purchasers' or 'commissioners') to focus on health improvement. Their aims now also include improving the quality and effectiveness of services, reducing inequalities and restraining costs. This separation of roles, but not the market, seems to have become accepted across the political spectrum.[6,7]

The political context has often determined the terminology, as much as the aims, of planning. Although good definitions exist,[8] and commissioning tends to encompass a broader range of activities than planning, their use in the literature is very variable. Therefore, we have not distinguished the terms planning, purchasing or commissioning in this paper. We have used the term commissioning except in referring to other work where the terms purchasing and planning have been kept.

Another focus for recent reform has been the desire to move from a demand or supply led service, to one that is more focused on need. This is usually defined in terms of capacity to benefit,[9] although different definitions exist.[10] Alongside this, an important development and influence has been the emergence of the concept of 'consumerism' centred around ideas of patient choice and health service accountability.[11] Commissioners and providers have been encouraged to seek and respond to the views of patients and public, and to incorporate those views into their strategies, service development and quality improvement.[12]

Commissioning includes assessing need,[13] setting priorities, allocating resources, influencing providers, involving patients and the public, minimizing transaction costs and managing financial risk. The task of commissioning is so

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large that it is often divided into manageable components. Two ways of doing this have been division into 'localities' – e.g. by geography, general practice or hospital – or 'programmes' – by condition (e.g. stroke), care group (e.g. children) or specialty (e.g. orthopaedics). A programme approach based on a condition or care group is likely to incorporate such approaches as 'integrated care pathways'[14] and 'disease management'[15] (although 'managed care' has a number of different meanings[16]).

'Evidence-based commissioning' is a recent term that can have two meanings. The first focuses on the providers and is about *what* is commissioned.[17,18] This is dependent upon the evidence base (e.g. in stroke, summaries of evidence are available from the Cochrane Library,[19] the Department of Health,[20] the Stroke Association,[21] and others) and the ability of commissioners to create,[22] access[23] and interpret[24,25] that information. The second focuses on the commissioners and is about *how* commissioning is done. This is dependent upon structures and processes of commissioning and is the subject of this review.

Research

The methodology of research into commissioning is still being developed.[26,27] Like most health services research it requires a multidisciplinary approach. De Wildt *et al.*[28] have described some of the difficulties of this type of research, which include a lack of clarity about the meaning and goals of commissioning, the speed of change of reforms, and problems of access to information. There is also a danger that valuable research is discarded with each reform, when findings may still be instructive.

Below, we compare the locality and programme approaches and appraise the published research in these areas.

Locality focus

Theory

Locality commissioning is a geographical or general practice based division of the health authority's work. The potential advantages include: responsiveness to local needs and demands, a clear primary care lead and a focus to involve patients and the public. Potential disadvantages include: higher transaction costs than commissioning for a larger population, lack of a broad population perspective and fragmentation of (secondary and tertiary care) services.

Although primary care groups have now been defined[7] with populations around 100 000 questions remain. Is this an optimum size of population for commissioning all services, or should this vary with different conditions?[29] How are resources allocated fairly to each locality?[3,30] What is the role of health and local authorities?[31] How should patients be involved?[11,32]

Practice

The Dawson report in 1920 suggested that British health facilities should have a tiered administration system based on health centres.[33] Although this was not implemented at the time, the NHS has (perhaps inevitably) always had a hierarchy of tiers of administration of varying shapes and sizes, for example, regions, areas, districts and localities. The lowest tier at any one time is, arguably, where locality commissioning takes place. The decision on the size, responsibilities and boundaries of these tiers seems to have been always based on political pragmatism rather than epidemiology.

However, there is little research on which to base these decisions. White described the 'ecology' of medical care[34] in similar terms to Dawson. Later he and others compared the patterns of health systems in 12 areas in seven countries[35] and came to conclusions about appropriate population sizes for provision of care (2000–30 000 for primary care, 200 000–500 000 for secondary care and 0.5–1.0 million for tertiary care). McLachlan's study of planning in eight European health systems found broadly similar patterns but suggested that primary health care was organized on populations of 10 000–50 000 people.[36] However, these studies relate to catchment populations for the provision and delivery of care rather than its planning or commissioning.

There are many reviews of locality commissioning.[6,37,38] However, the focus of most seems to be general practitioner (GP) fundholding, and only Balogh's review[38] gives a broader, historical perspective. GP fundholding has been the most prominent example, but subsequent developments have seen a range of locality commissioning organizations (Table 1). A wide range of sizes and structures is possible for locality commissioning groups,[39] seen for example in the total purchasing pilots.[40] However, the recent White Paper, *The new NHS*,[7] looks to larger, more uniform organizations in

Table 1 Typology of locality focused commissioning in the NHS (adapted from Refs 6 and 40)

Health authority models
Geographically based
Conventional (centralized)
GP consultation schemes
Formal GP involvement with the health authority
Locality commissioning

GP practice-based
GP commissioning

Fundholding models
Fundholding multifunds
Fundholding consortia
Standard fundholding
Community fundholding

'Hybrids'
GP total purchasing pilots
Extended fundholding pilots

the form of primary care groups covering a population of approximately 100000 people.

Research

Most research has also addressed GP fundholding and its successors. There have been detailed descriptions of processes.[6,40] However, the more rigorous research, comparing fundholders and non-fundholders, has concentrated on the behaviour of GP fundholders as providers,[41] such as changes to patterns of prescribing[42,43] and referring,[44] rather than as commissioners (although referral patterns may represent a mixture of both[45]). This probably reflects the availability of data, rather than the pursuit of the key research questions. Fundholders appeared to restrain prescribing costs better than non-fundholders, although this was not always sustained, whereas patterns of referral were similar. There are some descriptions of improvements[46] to the responsiveness of secondary care providers, for example, to waiting times and outreach services, at the expense of inequity. Evaluation of total purchasing pilots has also found greater change in primary than secondary care.[47]

The additional management costs for GP fundholders were about 4–5 per cent of their budget with further administrative costs to the trusts.[48] Results of research on the transaction costs of other forms of locality commissioning are still awaited.[40,49]

Programme focus

Theory

In programme-focused commissioning the cake is sliced differently: by condition, care group or, less commonly, by specialty. A potential advantage is the involvement of commissioners, providers and clinical professionals (from primary and secondary care) leading to better co-ordination of services and a more explicit and shared acknowledgement of cost restraints.[50] Condition-specific programmes are a logical approach to the use of evidence of clinical effectiveness and facilitate the development of clinical outcomes with the integration of clinical audit into commissioning. Potential disadvantages include: high transaction costs; unintentionally emphasizing one condition over another, with patients outside the programme being disadvantaged; and domination by secondary care. Whether programmes are best defined by condition, care group or (less likely) specialty is unresolved.

Practice

The use of programmes has a long history. The district (health care) planning teams in the NHS in the 1970s represent an early programme focus based upon consensus management. '[They] were set up to plan either for a specific client group, e.g. the elderly or children, or for specific services, e.g. maternity services.'[51] They contained clinical professionals, administrators, community physicians, local authority representatives (mostly social services) and others such as the community health council, with variable success in developing and improving health services.

More recently the Calman–Hine report[52] on cancer services provides another programme approach. The UK Government's latest proposals *The new NHS*[7] suggest that 'service agreements will generally be organised around a particular care group (such as children) or disease area (such as heart disease)'. They also prepare for the development of 'evidence-based National Service Frameworks to set out what patients can expect from the health service in major care areas or disease groups'.[53]

The Academy of Medical Royal Colleges has recently described the health care programme approach (HCPA).[50,54] This is a clinically led programme approach to commissioning for, in this instance, ischaemic heart disease.[55] Table 2 summarizes the key features of the HCPA and potential (though yet, unproven) benefits.

The financial aspect of any plan or strategy is its budget. Interestingly, the use of programme budgeting and marginal analysis (PBMA), led by health economists,[56] seems to have been more common than clinical health care programmes. The aim is to achieve maximum health gain from the fixed overall budget, by explicitly assessing the benefits and costs of changes from the current position (marginal analysis). PBMA aims to focus resources where there is the largest potential health gain, whereas the HCPA may have a 'burden of illness approach' focusing resources where there is most need.[57,58]

There are two approaches to programme budgeting: the 'macro' approach initially divides the whole budget into programmes.[59] The 'micro' approach assumes that the programme has the right budget and changes within programmes are tackled first. There have been a number of descriptions of the application of these methods.[60,61]

Research

Most research on programme approaches has been in the form of pilot and demonstration projects. It remains to be shown that the programme approach leads to improved decision-making, better services and better patient outcomes. There is also a need to quantify transaction costs and the knock-on effects on other programmes. Furthermore, there has been no comparison of condition-specific or care group-specific approaches. Condition-specific programmes seem better demarcated and more relevant to searching for evidence of effectiveness and cost-effectiveness. Care group-specific programmes may be better for facilitating working between different agencies.

Table 2 The health care programme approach (adapted from Refs 54 and 55)

Key features
The programme for the condition encompasses all levels of prevention, treatment and care
A group to develop the programme is created from all the key local players including commissioners and providers
A 'technical document' is drawn up summarizing the evidence base, and local epidemiology and services
A comprehensive service specification is developed from which contracts with a range of providers can be arranged

Potential benefits
Health care programmes:
- have the potential to improve health
- provide a balanced programme of care spanning primary prevention to rehabilitation and provide co-ordination between different organizations
- focus on health rather than simply on health care services
- actively involve the clinical professions
- more clearly relate to identified need than previously
- aid the development and use of clinical outcomes
- use evidence of effectiveness
- integrate clinical audit into the commissioning process

Discussion

Compatibility of localities and programmes

The different methods of commissioning described are not, in theory, incompatible.[7,62] A programme approach could be 'primary care led'. A locality group could have programmes of work, or engage with a wider programme strategy.[63] However, both cannot hold budgets and the transaction costs may be higher if both approaches exist. Some choice will have to be made. Although *The new NHS*[7] re-emphasizes locality commissioning through primary care groups, it also gives impetus to national frameworks which are programme based (mostly condition specific). Programmes are likely to be the better framework for collaborative planning and development of evidence-based practice. However, they will require locality intelligence to be most effective.

Power and influence

The different approaches could also be seen as representing a struggle for influence on health strategy. Both locality and programme commissioning may focus on clinical issues,[64] giving more influence to professionals than managers, compared with the current broad contracts between commissioners and providers. In contrast, choosing between localities or programmes may shift power between different professional groups. In the NHS, expert power[65] is important. Locality-focused commissioning is likely to favour GPs, who have a greater knowledge about the practice populations. Programme-focused commissioning may shift more power to the specialists, who have a greater knowledge about specific conditions and treatments. This could be balanced by those with a public health perspective 'holding the ring' between competing interests.

The difference between localities and programmes at a commissioner level mirrors a tension at provider level between generalists and specialists. There are good examples of improved patient outcomes with increased professional specialization, such as stroke units[66,67] or vascular surgical units.[68] However, it is more difficult to address whether the associated shift of resources will disadvantage patients elsewhere in the service.

There is also an echo of the debates between 'vertically integrated' services (managing conditions through a centrally organized programme, such as a malaria control programme) and 'horizontally integrated' services (having services to meet all needs organized together, such as a village health worker) seen particularly in developing countries.[69–71] This may represent an extreme, ideological form of the debate. However, it is important to be aware that a programme approach could appear to succeed on its own terms without improving the health of the population. For example, a stroke programme could reduce mortality and morbidity from stroke, but if the resources used came from reducing care to other groups, there may not be an overall benefit.

There is increasing emphasis on the influence of patient and consumer views on commissioning.[11] The locality focus has shown itself able to bring in consumer perspectives,[32] although in theory the programme approach might engage specific patient groups, such as the Stroke Association, which have important perspectives to contribute to particular programmes.

Research

Governments are usually reluctant to encourage research on structural change. But research is needed to describe the processes of different models, their effectiveness and cost-effectiveness, to measure change and to evaluate the role of the intervention in this. Initial studies on the commissioning process are by necessity descriptive, usually case-studies or uncontrolled before-and-after studies (comparable with phase 1 and 2 clinical (drug) trials[72]). It is important that new models of commissioning are clearly described and do not become 'black box' interventions, partly to allow others to apply them, but also so that hypotheses about the effective components of the complex interventions can be developed and tested. This can be illustrated by the studies that demonstrated the effectiveness of stroke units,[66] where key aspects of the intervention are only now becoming clear. Combining both qualitative and quantitative methods are particularly valuable for this.[73]

Nevertheless, describing the process is of limited value without measurement of resulting change. One major difficulty is that the ultimate aim – improved patient outcomes, including prevention of disease – is at the end of a cascade of change. These effects may be both long term and confounded by many other coincident changes, particularly in the rapidly shifting field of service development.

Very few direct comparisons of different methods of commissioning have been attempted. These are unlikely to provided a clear-cut 'best practice', as can be achieved with clinical research. But they will be valuable in informing the subsequent implementation of commissioning models, including the choice of models best suited to local circumstances.

A critical element of any comparison of different models will be the quantification of transaction costs – costs associated with the process of commissioning, which therefore cannot be used for direct patient care.[74] These include the costs of contract negotiation and monitoring, development of service specifications, and provision of necessary information and IT support. This needs to be a focus of future research, as these costs may outweigh any benefit obtained, although evaluation will itself be an additional cost.

Conclusions

The new NHS[7] emphasizes both locality commissioning and the strategic framework of health improvement programmes (HImPs). Furthermore, at a national level, it proposes the development and specification of national frameworks, the first of which will address coronary heart disease and mental health.[53] We believe that these strategic frameworks must drive locality commissioning if this model is to be effective.[75] Programmes of care should form the basis of HImPs. Programmes probably provide a better framework for partnership between sectors (leading to more integrated care) than one sector commissioning from another. Programmes may also lead to better uptake of effective and cost-effective interventions, and thus to better quality services. Additionally, a programme approach should support the broader public health perspective including disease prevention and health promotion.

In summary, a locality-based approach, in the absence of an over-arching strategic programme approach, may be ill equipped to influence partnership and the stimulation of evidence-based practice, whereas a programme-based approach could meet these needs with or without GP-led locality commissioning.

There will always be a political dimension to planning health services to balance with evidence of effectiveness and cost-effectiveness. However, there is enormous potential for good research in this area to improve commissioning and therefore improve the health of the population. We hope that this Government will be more amenable to evaluating its reforms than the last.

Acknowledgements

The Stroke Association supported the authors in a literature review of commissioning. The authors would also like to thank Dr J. Michael O'Brien and Dr Jane Halpin, whose ideas have helped with this review.

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Commissioning Stroke Services

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The commissioning of health services involves assessing need, setting priorities, allocating resources, influencing providers, involving the public, and managing financial risk. The large task of commissioning is often divided into localities - that is by geography or general practice; or programmes - that is by condition (e.g. stroke), or care group (e.g. elderly).

The organisation of care can have a major impact on patient outcomes, as demonstrated by the work on stroke units. "Evidence-based commissioning" can have two meanings. The first focuses on the providers and is about what is commissioned. This is dependent upon the evidence base - for example, summaries of evidence are available from the Cochrane Library, and the Stroke Association. It is also dependent on the ability of commissioners to obtain and interpret that information. The second focuses on the commissioners and is about how commissioning is done. This is dependent upon structures and processes of commissioning which is an under researched area.

In conventional health authority commissioning there have been broad contracts with a small number of providers. The development of Primary Care Groups may improve the responsiveness of providers to local issues, but this may not improve the integration of services.

Implementing a health care programme approach

The Academy of Medical Royal Colleges recently completed a two-year pilot study of a programme approach for patients with ischaemic heart disease. We are developing this model for stroke and evaluating its costs and benefits. The key features are:

- **The stroke** programme encompasses all levels of prevention, treatment and care;
- **A District** Stroke Group is created from all the key local players;
- **A "technical document"** summaries the evidence base, and local epidemiology and services;
- **A co-ordinator** is appointed to bring together the different agencies and disciplines:
- **A comprehensive** stroke strategy is developed from which service specifications can be arranged.

Potential strengths of this model include: a focus on public health, the provision of effective and equitable services, and the promotion of partnership within the NHS and between health, social services and other agencies. Our work has lead to a strategy which forms part of the district's Health Improvement Programme (HImP) and will lead to more detailed service specifications.

Progress to date

A District Stroke Group was formed in December 1996 and meets every month. This has members from the health authority, social services, primary care, trusts, and the voluntary sector.

The District Stroke Group has produced a "technical document" which describes current epidemiology and local stroke services and a review of evidence of best practice. This document is being used to develop the local strategy for the commissioning of local stroke services. It has also informed the development of objectives, and the identification of appropriate measures of outcome and of change.

Using the "technical document" and consultation within the group, a set of priorities for the coming year has been agreed. These are:

- **Hypertension** in primary care - to be a joint project with the local Multidisciplinary Audit Group:
- **Multidisciplinary** teams in secondary care - to be part of a service specifications;
- **Long term** care and support - to be part of a review
- **Information** and audit - to take part in the Royal College of Physicians audit, and to improve quality and availability of information about stroke.

Areas for future development include community rehabilitation, secondary prevention of strokes, atrial fibrillation, criteria for admission to hospital, and support and information to carers. The chapter in the district HImP, written by the District Stroke Group defines a three year plan for implementation of these priorities.

Evaluating the outcome

The programme is being implemented and evaluated with set up funding from the Stroke Association and subsequently from Northern and Yorkshire NHS Reaseach and Development. This evaluation includes quantitative, qualitative and economic approaches to give a description of changes to structure and processes and well as an assessment of costs and benefits. We hope this approach will lead to improves commissioning of stroke services and ultimately to better prevention, treatment, rehabilitation and long term support for stroke.

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Commissioning Stroke Services

David Chappel

This practical chapter differs from others in this book because it is about decision making for a population rather than for an individual patient. This leads to a number of differences in approach. Although health authority commissioners worked up the example described here, fundholders faced similar issues and primary care groups (PCGs) will shortly do so.

The question

What is the best way to organise stroke services for our population?

The question arose because the condition is common and serious (it was a target in *Health of the Nation* and *Our Healthier Nation*) rather than because there was a perceived problem with services, i.e. a proactive rather than reactive approach. Such an approach is not easily amenable to the formulation of a clear-cut question. Indeed, it would be a mistake to focus too quickly on answerable questions before thinking through the breadth of the problem. I have used a similar question as a 'trick' question in training staff on search strategies. I asked them when they arrived to 'see how many references you can find (on MEDLINE) on the topic 'effective treatments for stroke'. The point about the need to refine questions and use a strategy was quickly apparent.

A district stroke group, comprising staff from the health authority, primary care, trusts and social services, discussed the breadth of the problem. They defined four broad areas:

- *Prevention*: This includes primary prevention (i.e. interventions to prevent stroke) and secondary prevention (interventions to prevent further strokes following a first stroke or transient ischaemic attack) since many of the activities are similar in both areas.
- *Treatment*: This includes the diagnosis and initial treatment for patients with stroke in the acute stage, including acute nursing care and the prevention of complications.
- *Rehabilitation*: This includes early and long-term rehabilitation (and its organisation), particularly therapies such as physiotherapy, occupational therapy and speech therapy.
- *Long-term support*: This includes the work of carers, the voluntary sector (e.g. support groups) and the private sector (e.g. accommodation), as well as the work of the statutory sector (local authority and NHS).

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This process ensures that prioritisation is not simply based on the presence or absence of evidence (which is predominantly available for treatment and primary prevention), but takes a broad view of the important issues. The formation of a group to work on this topic is also important for other reasons. Implementation of any findings will need to involve many professionals so their co-operation is needed throughout, and the group will form a useful network to help with the search for evidence (later additions to the group included the voluntary sector). However, each member of the group will bring his own specific interests and prejudices and this bias must always be borne in mind.

The search

One thing you can be sure of is that someone else has worked on a question like this before. Virtually all health authorities (and increasingly PCGs from 1999 onwards) are likely to have thought about it, even if not at the level that you want. This means that someone can save you time, if you can identify them. The problem is that the review you want may not have been formally published but may just be a locally used report – so-called 'grey literature'. Chapter 3 outlines how this type of literature may be searched in more detail.

Contact with 'experts'

No-one is an expert in all aspects of stroke care but there are many people who may be able to point to others who have done the work. It was through this 'networking', both within and outside the stroke group that the most useful references were found.

Through public health contacts I was already aware of the Oxford Region's GRiPP (Getting Research into Practice and Purchasing) project (Blais 1994), and was able to obtain a copy of its stroke literature review. I was also aware that the Department of Health had a review of evidence (Wade 1994) that was in the local medical school library. A local consultant in stroke medicine put me on the track of a Stroke Association document (Wolfe *et al* 1996) and a recently published book (Warlow *et al* 1996). A senior lecturer in public health medicine had a copy of a document from another region (MacLeod *et al* 1993), and reminded me to start from *The Cochrane Library* (The Cochrane Collaboration 1999) before going much further and that there was an *Effective Health Care Bulletin* on stroke rehabilitation (though it was already a bit out of date) (NHS Centre for Reviews and Dissemination 1994).

The Cochrane Library looks promising as there is an active Stroke Collaborative Review Group. Disappointingly, a search through the titles showed that many topics have not progressed beyond protocols, and those that have cover only a small part of overall stroke care. However, where a topic has been covered, the authoritative nature of Cochrane reviews are helpful in controversial areas; e.g.

> *'there is insufficient evidence to recommend the use of thrombolytic drugs to treat acute ischaemic stroke at the moment . . .'* (Wardlaw *et al* 1998)

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Without these contacts most of the documents could still have been found through local consultants, contacting the Royal Colleges and the appropriate research charities (such as the Stroke Association). A new GP group, interested in stroke and evidence-based practice, has recently been established (Action for Stroke Group, PO Box 9939, London W6 9WZ). A potential network to contact may include:

- physiotherapy departments;
- community nursing;
- local academic departments of primary care, public health, nursing, physiotherapy, neurology and care of the elderly;
- relevant charities;
- Royal Colleges of nursing, physicians, GPs etc.

Using the Internet

Chapter 3 covers searching the Internet. In this case searching the Internet for information on 'effective treatments for stroke' is likely to be as futile as it would be for a MEDLINE search.

There are, however, a number of other ways in which the Internet is useful. First, it gives the chance to ask the advice of many more people – 'electronic networking'. This is where mailbases are particularly useful. (The Mailbase Consortium provides electronic discussion lists for the UK higher education community. Available from: URL: http://www.mailbase.ac.uk.) In this case I used three:

- Public Health (public-health@mailbase.ac.uk);.
- Evidence-Based Health (evidence-based-health@mailbase.ac.uk);
- Northern Public Health Medicine (northern-phm@ncl.ac.uk).

Others may be contacted via the list owner or joined. These should not be used as a first-line search method, as others on the lists would expect you to have done some groundwork first. However, new or obscure reviews can be picked up this way and contact made with people addressing similar issues.

No new reviews were uncovered although the ones described were mentioned again. One system used by public health doctors is EPINET. This was originally designed for exchanging communicable disease information but as it is based in every health authority, it is sometimes used by consultants in public health medicine to ask for advice on other topics. I did not use EPINET and it may become obsolete as new links develop through the NHSnet.

For those that wish to browse, it is best to start with a suitable Internet gateway and the public health (available from URL: http://fester.his.path.cam.ac.uk/phealth/phweb.html), evidence-based health (available from: URL:http://www.shef.ac.uk/~scharr/ir/netting.html) or medical ones (available from: URL: http://omni.ac.uk/) are good starting points. These can link, for example, to Health Technology Assessment and Development and Evaluation Committee sites in some regions and provided me with some (now rather dated) information on CT scanning (South and West Regional Development and Evaluation Committee 1994, Ferguson and McCabe 1997). They also provided links to the Agency for Health Care Policy and Research (US Department of Health 1995) in the USA (available from: URL: http://www.ahcpr.gov/). A stroke-specific site has been created with drug company funding (available from: URL: http://www.strokeforum.com/).

Using specialist libraries

There are many librarians with great expertise and ingenuity who can help. The local university or medical school is a good starting point. I was lucky to have a Clinical Effectiveness Resource Centre at the Health Authority who found the AHCPR document. Regional Health Authority (now NHSE outpost) libraries or those of large organisations such as the King's Fund, Royal Society of Medicine or British Medical Association are often useful sources of information (not used here).

Searching for grey literature

There are now some useful databases of grey literature. The King's Fund has an excellent library and database for 'grey literature' (not used here). The local librarian should be able to help access some of the grey literature databases held by the British Library (available from: URL: http://www.bl.uk/), such as *British Reports Translations and Theses* and *System for Information for Grey Literature in Europe*, but I did not use these and do not think they are likely to have yielded anything to change recommendations. Chapter 3 covers this form of searching in more detail.

Appraising what you have found

Much of the grey literature will come with unsolicited appraisal ('you ought to look at X's excellent report, and I suppose you might glance at Y's'). This can be useful in getting some 'peer review' of grey literature, although it needs to be used with care. The amount of time available will determine how much effort can be put into appraising literature. There are good guidelines for reviewing reviews (see Chapter 2), but it is inevitable with 'secondary' literature that much will have to be taken on trust.

One advantage of this search was the relatively large number of documents that could be compared, focusing effort into areas of disagreement. Each review had its strengths and weaknesses: none was ideal for my purpose. The GRiPP review was as near to a systematic review as was possible, though the Stroke Association document covered a greater breadth of areas and was more up to date. The Department of Health document had good coverage of epidemiology, and the textbook gave immense detail (although it was very difficult to evaluate how evidence based some of it was). *The Cochrane Library* provided the strongest evidence, but only for very small areas when the breadth of stroke services is considered.

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Keeping abreast of new developments

The information derived from previous reviews of the topics will gradually (occasionally rapidly) go out of date. Three papers were identified during the search that contained important new information (Stroke Units Trialists Collaboration 1997, International Stroke Trial Collaborative Group 1997, CAST 1997). The local consultant easily spotted them as they were in mainstream journals. It would be impossible to keep a broad review such as this fully updated and so some sort of regular search and appraisal are necessary.

'Consensus statements' and 'guidance' from respected authorities are rarely evidence based but they often point to areas where the evidence base is changing (e.g. on thrombolysis), giving the impetus to further searches. All Department of Health circulars are now on the Internet (available from: URL: http://tap.ccta.gov.uk/doh/coin4.nsf). The planned National Institute for Clinical Effectiveness may provide some help in the future with keeping abreast of 'best evidence' (Department of Health 1998).

The answer

The question has been kept broad so the answer is not simple. The findings of this search were summarised in a 70-page 'technical document' (available from the author (Gateshead and South Tyneside Health Authority and Newcastle University 1997)). The aim was to derive an agreed evidence base for developing (what has now turned out to be) the Health Improvement Plan. Some areas (e.g. hospital stroke units) had strong evidence from which to work and others (e.g. long-term support) had little.

However, a list of 43 potential recommendations was drawn up and circulated to the group to prioritise. Four areas came out 'top':

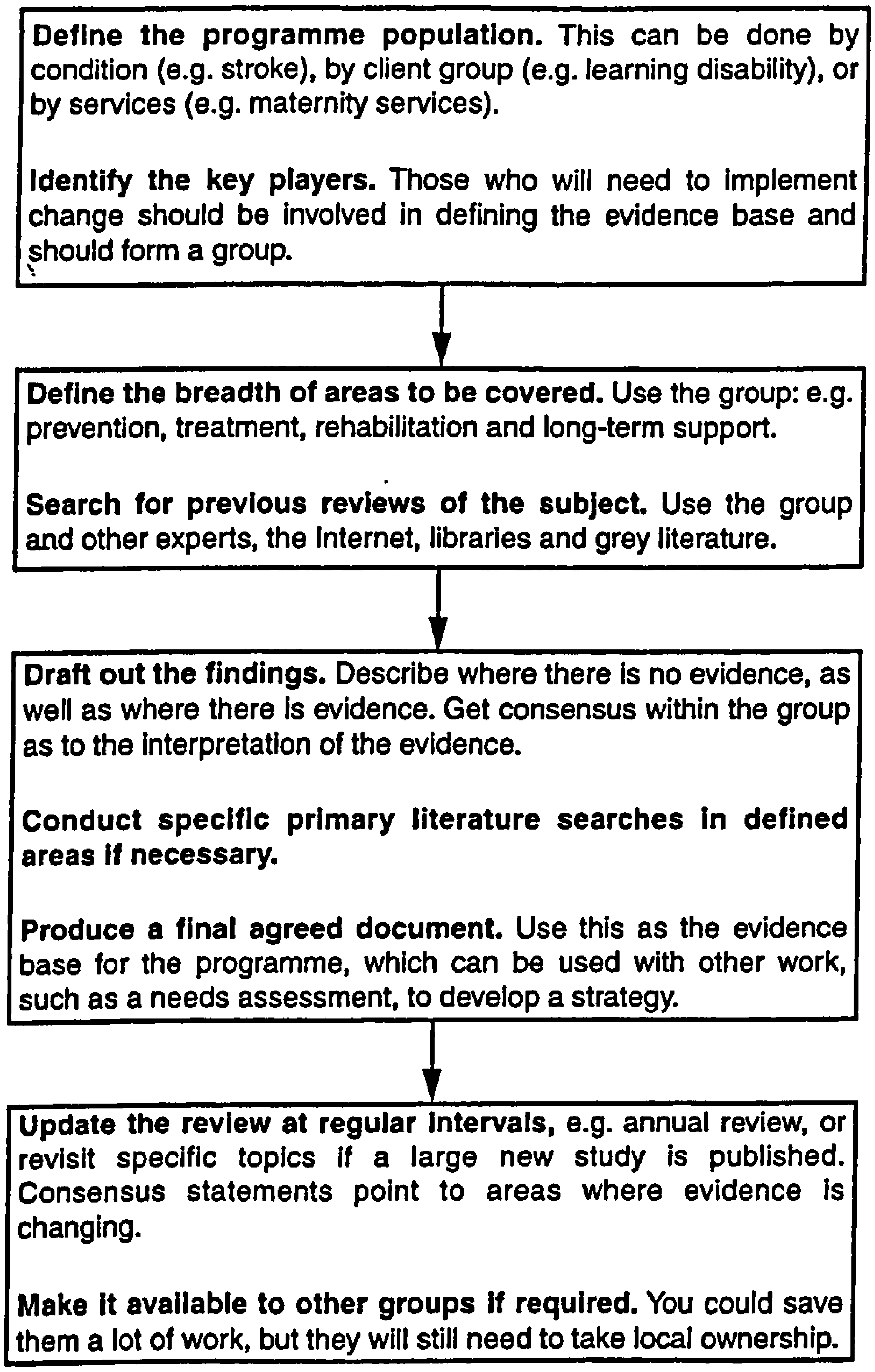
- hypertension in primary care;
- multidisciplinary teams in secondary care;
- availability of routine information on stroke;
- long-term support.

These are areas that need further refinement. Although 'evidence' was the starting point, there are many other factors to balance in deciding what to do, such as practicality and perceived importance. Although a balancing of emphasis and priorities is required with individual patient decisions, decisions on service delivery resulting in changes in other people's practice makes this even more likely.

The first priority area was hypertension in primary care. The District Stroke Group, together with the District Multidisciplinary Audit Group, set up a subgroup to implement local guidelines. Hypertension is a sufficiently focused area to define a tight question with which to search, using approaches outlined elsewhere in this book (see Section 3). Indeed, there are already systematic reviews in this field, e.g. Ebrahim (1998). The Hypertension Group took the advice of a previous district group who had looked at vascular risk:

> *'scoring systems were not yet feasible in primary care in this district as practices did not yet have the information systems in place.'*

They therefore favoured the British Hypertension Society Guidelines (Sever *et al* 1993) over the more evidence-based New Zealand guidelines (Jackson and Sackett 1996). Once again the formation of a group allows exchange of information on other



Define the programme population. This can be done by condition (e.g. stroke), by client group (e.g. learning disability), or by services (e.g. maternity services).

Identify the key players. Those who will need to implement change should be involved in defining the evidence base and should form a group.

Define the breadth of areas to be covered. Use the group: e.g. prevention, treatment, rehabilitation and long-term support.

Search for previous reviews of the subject. Use the group and other experts, the Internet, libraries and grey literature.

Draft out the findings. Describe where there is no evidence, as well as where there is evidence. Get consensus within the group as to the interpretation of the evidence.

Conduct specific primary literature searches in defined areas if necessary.

Produce a final agreed document. Use this as the evidence base for the programme, which can be used with other work, such as a needs assessment, to develop a strategy.

Update the review at regular intervals, e.g. annual review, or revisit specific topics if a large new study is published. Consensus statements point to areas where evidence is changing.

Make it available to other groups if required. You could save them a lot of work, but they will still need to take local ownership.

Fig. 12.1. Searching for evidence for a programme of care.

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work that could be used to save time. Other priority areas are being developed in a similar way.

This work is part of a research programme into commissioning of services. In time I hope to have more information on the usefulness of this approach (summarised in Fig. 12.1) and whether the 'technical document' leads to more 'evidence-based' commissioning of services.

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Implementation and evaluation of local-level priority setting for stroke

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We aimed to develop and evaluate a prioritisation process to combine the evidence base with stakeholder involvement within a stroke programme for a Health Improvement Programme (HImP). Implementation involved: formation of a district stroke group (DSG); review of the evidence; survey of DSG members; survey of other key professionals; consensus within the DSG; consultation with local users of the service. Evaluation was through semi-structured interviews and documentary analysis. The process was accepted as appropriate and valuable by the majority of participants, and a district HImP implementation group allocated £100 000 for stroke development as a result of this process. However, some felt that stroke itself had been an imposed, rather than an agreed, local priority. The priority setting process was not clear to all participants and change of personnel, particularly in the NHS trusts, led to some perceived lack of ownership. Professionals from secondary care participated, but later criticised the process when they felt that the priorities in the HImP could limit their ability to access money for other service developments. The user consultation days occurred too late to influence the 1999/2002 HImP. We have shown that it is possible to develop an approach that is broadly accepted by stakeholders and balance the evidence base with local ownership. The participation of stakeholders, clarity of procedures, local ownership and awareness of local politics are important in effective priority setting. The model developed will be of value in other settings. *Public Health* (2001) **115**, 21–29.

Keywords: priority setting; stroke; stakeholder; health improvement programme

Introduction

Prioritisation and rationing have been much discussed at a national level over the last decade.[1] There has been a move away from the view that there is a technical solution to rationing by marshalling all the available evidence and calculating the best solution.[2] There is recognition that this is 'inescapably a political process'[3] and a developing interest in defining that process. There has been much less discussion about how prioritisation is done at a local level, but a view that there should be more central guidance and reduced scope for local differences.[1]

However, there will always be a need for local prioritisation, as national priorities can only be broad.[4] National decisions can only be made on a relatively small number of specific treatments,[5] usually expensive ones, and so may have relatively little impact on the totality of care locally. They need to be operationalised locally. Studies of local priority setting have been limited and have, as in the national situation, focused more on evidence-based solutions[6] or on the mechanism for gaining public input[7] rather than the whole process leading to decisions. They have also focused on ways to deal with new problems, rather than on prioritising within the current service.[8]

There are a number of tensions to acknowledge at both national and local levels. Firstly, those between the evidence base and the views of stakeholders: health and other professionals, the public and patients, managers and administrators.

Secondly, the appropriate involvement of professionals: many view the input of professionals as important,[2] but others believe that there is an ethical incompatibility between fidelity (caring for patients) and stewardship (optimising the use of resources).[9]

Thirdly, the appropriate involvement of users (patients and carers) and the public: whilst most agree that this is important,[10] there are concerns that the framing of questions, and the amount of information and time given, can substantially alter the views expressed.[11]

We chose stroke because it is an important cause of morbidity and mortality locally, and a national priority in England.[4,12,13] We describe prioritisation in a single district health authority (DHA) in the North East of England. It was used to inform a chapter of the district's Health Improvement Programme—a local strategy required in all DHAs in England. We developed a process designed to balance the need for an evidence base with the need for wide stakeholder involvement. The evaluation of the process is part of a larger study evaluating a health care programme approach

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to commissioning stroke services[14,15] based on a model developed by the Academy of Medical Royal Colleges of the United Kingdom.[16,17]

Methods

Implementation

There were six stages of priority setting which are summarised in Table 1. A district stroke group (DSG) was formed which aimed to have representatives from all groups involved in the care of people who have had strokes. The DSG produced a 'Technical Document',[18] summarising evidence, epidemiology and local services. This was to ensure not only that evidence was used, but also that the stakeholders agreed on it.

Members of the DSG were asked to prioritise the large number of recommendations from the evidence review using a questionnaire which listed potential recommendations (Table 2). The local stroke coordinator conducted structured interviews with stakeholders outside the DSG to validate the provisional priorities, help order the secondary priorities, and seek important areas not previously identified. The data from the postal survey and interviews was discussed at DSG meetings held in early 1998. The priority areas were agreed and the group started to develop them into clear action plans. Two user and carer consultation days were undertaken to get public input into the priorities.

Table 1 Priority setting process in Gateshead and South Tyneside

Action	Date	Method
1. Formation of District Stroke Group (DSG)	Dec 96	A stroke group was formed, initially consisting of professionals from primary and secondary care together with health authority and social services staff. It has subsequently grown to encompass the voluntary sector, although membership does not include users or carers or the private sector (eg nursing homes).
2. Review of evidence	Feb–July 1997	One member of the DSG reviewed and summarised the evidence base around stroke, the local epidemiology, and current services. Each draft was discussed and debated in the DSG and finally summarised in a 'Technical Document'. This listed 43 potential recommendations, linked to the evidence in the technical document, in four areas: prevention, acute treatment, rehabilitation and long term support.
3. Postal survey of DSG members	Dec 1997	Members of the DSG were sent a questionnaire which listed the 43 recommendations in the technical document. They were asked to score (1–5) the importance of each recommendation. An extract of the questionnaire is shown in Table 2. They were also asked to select the three areas most important for their particular sectors. As not all responders gave a score for every recommendation, the average score for each recommendation was used, expressed as a percentage. Some related recommendations were combined. Four areas scored over 90% and became provisional priorities: hypertension in primary care, multidisciplinary teams in secondary care, long term care and support, and information and audit. A number of secondary priorities were listed scoring 70–80% (Table 3).
4. Survey of other key professionals and managers	Feb–Mar 1998	A co-ordinator took up post in February 1998. She conducted structured interviews with 29 people including patient representatives (two Community Health Councils and two voluntary groups), managers and professionals, but again not directly with patients or carers.
5. Consensus within DSG	March 1998	The data from the postal survey and interviews was discussed at DSG meetings. The priority areas were validated and the group started to develop them into clear action plans.
6. Consultation with local users and carers	Nov 1998	Two user and carer consultation days were undertaken in November 1998. This was after the initial priorities had been set, because the time scale for the HImP was too short to organise them before. Invitations to patients and carers were sent to all people with a known stroke in contact with services and to all local stroke groups, and posters were put up in local libraries, and hospital wards. At each event the users were put into groups of about eight and facilitators and note-takers were used to find out about the issues that concerned people.

Table 2 Extract from questionnaire with examples of Technical Document recommendations

Recommendation (number and page reference*)	Importance 1–5	Urgency 1–5	Year 1,2,3†	Lead sector (see notes‡)	Group (see notes‡)	Comments
1. The quality of routine information (contract minimum data set) needs to be better if it is to be used to monitor the stroke programme. Although some improvement is already occurring, the stroke group should work with providers to improve the quality. p 13						
2. More use should be made of existing data to highlight deficiencies and encourage improvements. The stroke group should work with purchasers to improve the dissemination of information. p 13						
3. The information obtained from ad hoc audits should be made available to add detail to, and to help validate, routine information provided by the minimum data set. It may also be appropriate to try to make such audits compatible between providers. p 15						
...						
6. Local guidelines for the diagnosis and treatment of hypertension in primary care are needed. There are many available eg British Hypertension Society, New Zealand guidelines so local consensus as to which to use or adapt is required. Case finding and treatment of hypertension is traditionally undertaken in general practice. Case finding has also been undertaken elsewhere eg in the work place. p 24						
...						
25. Hospitals should have a designated multidisciplinary stroke team and, if possible, a designated stroke ward. p 37						
...						
42. There is a need for a broad review of long term support facilities and access for stroke patients, including addressing co-ordination of services. p 48						
43. A local strategy is required to ensure that professionals, patients and carers have an appropriate level of understanding about stroke and its effects, and are aware of services available for patients and their carers. p 49						
...						

*Pages refer to Technical Document.
†Year refers to the Health Improvement Programme.
‡Notes gave suggestions for these columns.

Evaluation

Evaluation consisted of semi-structured interviews and documentary analysis. Three sets of interviews were undertaken by a qualitative researcher (JB). These were DSG members (19 interviews, May–August 1998, coded 1–19), a wider group of people in senior positions within the district not directly involved in the project (11 interviews, January–March 1999, coded A–K), DSG members (16 interviews, 11 of which were re-interviews, May–July

1999, coded I–XVI). Interviews were tape recorded and transcribed verbatim. Transcripts were examined independently by two of the authors (JB and RS) and analysed using a grounded approach to generate themes from the data.[19] Documents such as letters, minutes from meetings, discussion documents, and reports were collected and reviewed by content analysis.[20] Findings were summarised and fed back to the DSG for comment on accuracy.

Results

The results of the priority setting process are shown in Table 3. Table 4 gives the four primary priority areas identified at the end of the process and the ten others that were included in the HImP for implementation over the next three years. Table 4 also outlines the ways in which these priorities have been developed, and have drawn in resources from the district. The qualitative findings are described below.

Stroke as a priority

Despite the health authority's assumption that stroke was already a priority, several DSG interviewees expressed concerns:

> *'against the priority wishes of the vast majority of primary and secondary care...and against current mechanisms for prioritising and setting up groups in the district at the time' (INT 18)*

Several respondents from the second phase of interviews, particularly from primary care, also expressed the view that the priority of stroke had been imposed on the district, without current priorities and decision-making mechanisms. However, other DSG members felt that, as stroke was in the district HImP, this implied that it had become a major priority for the district.

One interviewee expressed concern that stroke was slipping down the government agenda, citing as evidence that stroke was not one of the national priorities in guidance issued from the government to health authorities[21] although it had been mentioned in *Our Healthier Nation* Green Paper,[13] strengthened in the White Paper,[4] and features in one of the clinical indicators in the performance assessment framework.[22]

In April 1999, Primary Care Groups (PCGs) came into being. These are a new sub-district structure, led by primary care physicians, which will ultimately take a lead on commissioning services. Another interviewee highlighted the conflict between the HImP and the priorities chosen by the PCGs:

> *'this year round, plans have been done out of synch and they don't reflect necessarily what is in the HImP. I*

Table 3 Results of priority setting process

Action	Result	Findings
1. Formation of DSG	All organisations in the district agreed to the setting up of the stroke group and to send representatives. Subsequently, there was variable attendance, particularly from primary care. The group initially had twelve members.	Membership discussed on a number of occasions but it was felt appropriate to maintain as a professional group (health, social services, voluntary sector)
2. Review of evidence	All members saw drafts but only about half commented on them and three contributed the bulk of the work. Work took six months.	Forty-three potential recommendations made
3. Postal survey of DSG members	Nine out of twelve responded, though some questions were not completed in areas where the respondent thought they had little knowledge.	Some recommendations combined and four areas with > 90% score for importance were developed as initial priorities (see Table 4).
4. Survey of other key professionals and managers	Twenty-nine people were seen including patient representatives (two Community Health Councils and two voluntary groups), managers and professionals.	General validation of four priorities and more comprehensive list of secondary priorities
5. Consensus within DSG	Although an ongoing process, the key meeting in March 1998 was attended by nine members. Subsequent meetings developed action plans for each area.	Priorities set out in Table 4 and HImP. These happened to be spread across the sectors so there was little debate.
6. Consultation with local users and carers	Sixty-five people responded to the invitations and forty attended the two days.	The majority of issues raised by the users were in the area of long term support and continuing rehabilitation (rather than prevention, acute care or early rehabilitation) which we were able to feed into a review taking place.

Table 4 Priority areas

Hypertension in primary care (93%)
A joint subgroup of the primary care Multidisciplinary Audit Group (MAG) and the DSG was set up to review currently available guidelines for the management of hypertension, and adapted one for local use. The costs were met by the MAG. The guidelines have been disseminated and will be implemented through the Primary Care Groups. One of the PCGs has set aside part of its clinical governance budget to develop this priority further.

Multidisciplinary teams in secondary care (100%) (plus two other areas)
A multidisciplinary forum for stroke professionals in secondary care has been formed to facilitate exchange of information and good practice, encourage audit and develop service specifications. Service Specifications have been developed and are under negotiation between purchasers (health authority) and providers (NHS Trusts). In one part of the district, £65K of Health Action Zone money (out of £300K allocated for HImP priorities) has been found to develop community multidisciplinary rehabilitation services.

Long term care and support (93%)
A review of current practice and issues has been completed. This informed discussion of specific priorities in this area and has been linked to other reviews of elderly care going on in the district. Members of the district stroke group have been invited onto steering groups taking forward a number of priorities in the care of the elderly.

Audit and information (93%) (plus four other areas)
Both trusts have taken part in the Royal College of Physicians sentinel audit with encouragement from the stroke group. There has been other work to improve quality and availability of routine information about stroke. In one part of the district, £10K of Health Action Zone money (out of £300K allocated for HImP priorities) has been found to develop a strategy for patient information.

Secondary priorities for future activity

Prevention	*Treatment, care and rehabilitation*	*Long term support*
Secondary prevention (80%)*†	CT scanning (73%)*	Information (understanding of stroke and stroke services by patients, carers and professionals) (93%)*
Atrial fibrillation (78%)*	Feeding management (85%)* [+1]	
Assessment of transient ischaemic attacks (86%)*	Prophylaxis of deep vein thromboses (71%)*	
Smoking (83%)	Pressure sore treatment and prevention (73%)* [+1]	
Diet (62%)		
Physical activity (65%)	Complication rate audits (80%)*	
Alcohol (62%)	Referral and admission policies (85%)	
Cholesterol (60%)	Layout of services	
Diabetes (62%)	Assessment and documentation (86%) [+1]	
Aspirin (86%)	Speed of intervention	

Percentages in round brackets refers to result of stage 3. Those without percentages came from stage 4 in Tables 1 and 3.
In some areas two or more priorities were combined (eg multidisciplinary teams for acute care and for rehabilitation) and this is stated in square brackets.
*Now in the Health Improvement Programme.
†In one part of the district, £25K of Health Action Zone money (out of £300K allocated for HImP priorities) has been found to develop a strategy for secondary prevention.

> *mean diabetes for example is, is a one which they* [PCGs] *are all picking on because we have done quite a bit of work through the two diabetes groups that we have got,... but that's not necessarily a major priority in the HImP so again there is that conflict' (INT E).*

Diabetes is in the district HImP.

The process of priority setting

The majority of DSG members felt the priority setting process was a necessary and important element of the programme approach, allowing boundaries and foci to be set on the work:

> *'It's helped to put some boundaries around what we're doing otherwise there's a tendency just to... try and do everything... so I think without it, it would have been very difficult to have said, these are the priorities, let's focus on them.' (INT IX)*

However members acknowledged a number of problems, including the risk of competing priorities outside the stroke group. They stressed the need for flexibility in the approach, the need for integration with relevant organisations' own priority setting processes, and the need for the 'right' stakeholders to be involved in the decision-making process.

There seemed to be agreement that a balance between 'the evidence' and stakeholder priorities had been reached. One interviewee described the approach as ongoing and stressed the importance of flexibility to be able to respond to changing local needs, local developments or changes in the evidence base:

> *'... it's ongoing because again it would be inappropriate to set in stone the priorities and... then something like secondary prevention actually begins to creep up the agenda because of local developments or research or knowledge-based, evidence-based developments and*

> *we need to be flexible to take those on as well' (INT 17)*

This was echoed by another interviewee who was concerned about a purely evidence-based approach:

> *'...published evidence lags a long way behind actual knowledge...it's important that we don't develop a wonderful evidence-based system which is fifteen years out of date...we've got to be very responsive in our plans to current developments.' (INT 8)*

However, most DSG interviewees were unclear about the process of priority setting, in particular how the survey of other professionals and managers related to the structured priority questionnaire sent to DSG members:

> *'I wasn't quite sure about the science behind developing those priorities and therefore how valid they were for the group [DSG] to actually then prioritise those priorities.' (INT 5)*

In relation to the questionnaire itself, one person commented that she had found it difficult to prioritise some of the clinical areas because she was not medically trained:

> *'I found doing the matrix quite difficult in some aspects because I'm not a clinical person and some of them were quite clinical. But I tried to comment on the ones that I felt I could comment on.' (INT 7)*

No one involved (professional or manager) expressed any views that they should not have been involved or that anyone else should not have been. However, there was confusion at times as to whether people were acting as individuals or representatives of the organisations they came from—this was particularly difficult for primary care, but also occurred with people from NHS trusts, the health authority and social services.

Only two mentioned the lack of public, patient and carer input to the process.

Outcomes of priority setting

Despite the lack of clarity about the priority setting process, all DSG interviewees agreed with the priority areas chosen as a result.

One interviewee was pleased to see that the priorities selected covered the breadth of issues related to stroke, as he had been concerned that the focus may have been solely on acute care, where most of the evidence base was available. Another interviewee also shared this view and felt the process was about 'balancing':

> *'everyone has their own priorities and their own area and if we prioritise in a way that says all of our priorities are social services and none of them are acute care...then equally that would be inappropriate as well, so it's about balancing.' (INT 17)*

One interviewee was concerned about taking too many issues forward at once where this would involve people changing their working practices. However he was happy with the staged approach taken by the DSG to implementation of the priority areas.

The importance of choosing areas which were 'achievable' was also voiced by one interviewee. Another interviewee expressed concern about the scale of the whole project and the length of time it takes to create change. Two interviewees were concerned that the priority areas chosen by the DSG could be used by those outside the group, particularly the health authority, to undermine clinicians' assessment of what is appropriate care for their patients. One cited an example where the health authority would not support a bid for a 24 h Computerised Tomography (CT) scanner because:

> *'CT scanning has not been noted as a priority by the DSG.' (letter from health authority)*

Although the majority of respondents in the second phase of interviews were unaware of all of the priority areas chosen by the DSG, several respondents were aware of the work on hypertension in primary care. When given the list of the main priorities that the group was focusing on, the majority of respondents felt they were appropriate. There was very little knowledge about how the individual priority areas were being taken forward. Two respondents were aware that staff from their organisations were involved in the working group taking forward the 'multidisciplinary teams in secondary care' priority area. Several interviewees expressed concern about the lack of information about the priority areas and the perceived resulting lack of integration with their organisations' own priorities and services.

Wider integration and competing priorities

The DSG developed a chapter for the district HImP on stroke. However, many other issues were also included in other chapters and at the time of final interviews, there had been no prioritisation of these:

> *'I think as it* [the HImP] *develops it will drive the commissioning process because it will lay down the strategic areas...the stroke group sent a proposal in which was £250,000 ish [for community rehabilitation]. Now I mean that's a big chunk of money just to spend on stroke. Now if it was number one priority out of all of them they may get that but if it was five or six you know there is a doubt whether that kind of money would be available...we need several things happening I think, in the future but the HImP certainly needs to drive the priority areas.' (INT E)*

Although stroke is a chapter in the district HImP, two interviewees from the second phase of interviews questioned whether this meant that stroke was seen as a priority by the health authority:

> *'I mean I think there's a particular issue really with the Health Authority especially, about whether this* [the

> stroke project] *is something that they're supporting as a mainstream element of developing the Health Improvement Programme, and I certainly don't get the feeling that that's the case... I think making sure that it's part of some of the mainstream priorities, that is important.' (INT F)*

Integration with the health authority's priority and funding mechanisms was raised by one interviewee:

> '*Well coronary heart disease is a big issue for us... do we purchase more CABGs, do we put more into cardiology and angiograms and so on... all very expensive stuff and they are the issues we have to grapple with, you know where do we want to put our resources, where will we get most benefit from it and that comes back to the evidence base....' (INT E)*

The issue of stroke not being a priority for primary care and being an imposed priority for the district and outside current commissioning and organisational planning mechanisms has meant there has been less integration with PCG priorities:

> '*... GPs were saying, 'well why are we doing this about stroke services, what's going on here, who said it was a priority, we don't think it's a priority, why are you providing that level of service?' which I think is, I mean I think it's quite good to be able to challenge that because it does make you think about, well where did this come from...?' (INT F)*

One of the three PCGs in the district has chosen hypertension on which to focus in its first year. The other two PCGs have chosen ischaemic heart disease and diabetes. The choice of these priority areas by the PCGs was felt by interviewees to have implications for the stroke project's integration with local initiatives. In one PCG, one interviewee reported their priorities were chosen on the basis of the likelihood of being able to pull something together and to deliver on it, whether they were seen as important clinical areas, whether they were national priorities, and whether there was already work underway in these areas which would continue in the future. This is in line with government advice to PCGs that there will need to be a rigorous prioritisation of tasks in order to concentrate resources on the most critical areas.[23] The choice of hypertension as a priority by one PCG was seen as an opportunity for the stroke project by several interviewees:

> '... [The PCG] *have taken hypertension on as one of their priorities... it would be really helpful for them to have something to get their teeth into and in some ways it may well be that what would help from the district stroke group would be to really get involved....' (INT I)*

In the final phase of interviews with DSG members, concern was raised about the ownership of the priorities by key players within the trusts, in particular those managers responsible for business planning and strategic direction. Some interviewees felt that these players had so far had little involvement and therefore limited ownership of the work of the DSG and that this would have an impact on implementation of the stroke priorities. However, in October 1999, £100 000 was allocated in one part of the district to develop stroke HImP priorities and allocation of further resources to stroke HImP priorities are currently being discussed.

Discussion

We have developed a process for local priority setting which integrates evidence-based and stakeholder-based processes. This has been used to develop a set of agreed priorities. Everyone felt that the right priorities were identified, although there remained some lack of clarity about how they were derived. There was also a concern that they are insufficiently owned to be actively taken forward. Proof of the value of this process comes from the way in which district resources have already been harnessed to implement the priority areas identified. For example, hypertension was taken forward by the Multidisciplinary Audit Group and one PCG, service specifications were developed by professionals from the trusts, and £100 000 of HImP development money has already been allocated to stroke.

The range of sources of information used gives strength to the findings of this study. Some of the findings of the process were fed back to the DSG in November 1998 and there was agreement that the issues raised were correct.

The timetable for the process became overtaken by the timetable for HImP development so that user consultation could not inform priority setting directly, although it has now informed how the areas are taken forward. We think that the patient consultation days would have been better held around the time of completion of the technical document so that patient input could come at that stage.

Many of the outcomes will be long term, so not yet detectable, but the changes outlined in Table 4 show that there are reasons to believe that the priorities are already having an effect.

This process of reaching consensus centred on the evidence base is similar to Delphi techniques used in other priority setting processes.[24] However, the need to involve different groups in different ways led to the stages described.

Previous work on 'what people who have had a stroke want' has found very similar issues to our user consultation.[25–27] The Total Purchasing Pilot projects have concentrated on the use of evidence in priority setting and not looked at who was involved and how.[28] Decisions about which services to concentrate on seem to have been made on the basis of interests and views of general practitioners, which may not always coincide with population need. There has been very little research into prioritisation within programmes of care.[29]

We believe there are a number of lessons for commissioners, whether health authority or Primary Care Group. All key people need to be involved: clinical professionals, managers, users and carers. However, the mechanism for involvement need not be the same for everyone.

The process of priority setting needs to be explicit and clear to participants in the process and the wider community. People must be clear whether they are acting for an organisation or as an individual. If the former, they need to have mechanisms for communicating back to that organisation.

Engaging the public in decision making is important but difficult. We involved users of the service and their carers rather than the 'general public'. This sidestepped the problem that prevention is an issue for everyone, and that better services for one group might mean worse services for another, but did produce good results in terms of information to aid decision making. Mechanisms for user or public consultation will be essential for PCGs which become involved in reducing services or making high profile prioritisation decisions.

A framework for decision-making on priority setting between disease groups is also needed, including a clear process, criteria and timescale. A proposed framework outlined in the HImP for 1999/2002, published between the second and third phase of interviews, consisted of the following criteria by which different areas will be ranked: national priority, effectiveness, cost-effectiveness, disease burden, promoting self-reliance and promoting equity.[30]

But what is a national priority? Clearly not all groups feel that stroke is a priority, even though it is a national target in *Our Healthier Nation*.[4] This may have important implications as 'local priorities', apparently based on national priorities, may be in conflict at different levels such as Health Action Zone, Health Authority, or Primary Care Group.

Attempts to establish formal priority setting mechanisms can be complicated by local politics and policy changes. There must be a clearly defined process but with flexibility to respond to the issues described, such as professional views and circumstances where evidence lags behind good practice.

There is no simple answer to priority setting but the process we described has acknowledged the complexity of decision making and produced agreed priorities. The process has been widely accepted across the district and created a positive impact, to the extent that new resources have been put into the areas defined as priorities.

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Competing interest

DC was an honorary Senior Registrar in Public Health Medicine with Gateshead and South Tyneside Health Authority during this work and DC, RT and HR were members of the District Stroke Group.

Contributions

DC, HR, RT and RS developed the original research proposal. RT, HR and DC developed the priority setting process. JB and RS developed the evaluation. JB conducted the interviews and reviewed documentation. DC and JB led the writing and all authors contributed and are guarantors of the paper.

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