HEALTH AND COMMUNITY CARE COMMITTEE

Wednesday 24 April 2002
(*Morning*)

Session 1

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CONTENTS

Wednesday 24 April 2002

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HEALTH AND COMMUNITY CARE COMMITTEE
11th Meeting 2002, Session 1

CONVENER

*Mrs Margaret Smith (Edinburgh West) (LD)

DEPUTY CONVENER

*Margaret Jamieson (Kilmarnock and Loudoun) (Lab)

COMMITTEE MEMBERS

*Bill Butler (Glasgow Anniesland) (Lab)
*Dorothy-Grace Elder (Glasgow) (SNP)
*Janis Hughes (Glasgow Rutherglen) (Lab)
*Mr John McAllion (Dundee East) (Lab)
*Shona Robison (North-East Scotland) (SNP)
*Mary Scanlon (Highlands and Islands) (Con)
Nicola Sturgeon (Glasgow) (SNP)

*attended

THE FOLLOWING ALSO ATTENDED:

Mr David Davidson (North-East Scotland) (Con)

WITNESSES

James Barbour (Lothian NHS Board)
Brian Cavanagh (Lothian NHS Board)
Dr Peter Donnelly (Lothian NHS Board)
John Matheson (Lothian NHS Board)
Hilary Mounfield (Epilepsy Action Scotland)
Dr Richard Roberts (Epilepsy Action Scotland)
Jacqui Simpson (Lothian NHS Board)
Allister Stewart (Lothian University Hospitals NHS Trust)

CLERK TO THE COMMITTEE

Jennifer Smart

SENIOR ASSISTANT CLERK

Peter McGrath

ASSISTANT CLERK

Michelle McLean

LOCATION

Committee Room 2

Scottish Parliament

Health and Community Care Committee

Wednesday 24 April 2002

(*Morning*)

[THE CONVENER *opened the meeting at 09:39*]

Item in Private

The Convener (Mrs Margaret Smith): I welcome everybody to this morning's Health and Community Care Committee meeting. Apologies have been received from Nicola Sturgeon.

It is suggested that the committee consider item 4, on the School Meals (Scotland) Bill, in private, as we will be discussing possible witnesses. Is that agreed?

Members *indicated agreement*.

Budget Process 2003-04

The Convener: Agenda item 2 is on the budget process 2003-04. We have with us this morning the squad from Lothian NHS Board. Good morning to you. Some of your faces are well kent to me and perhaps to other committee members.

In considering the budget, we have decided to take evidence from two health board areas. Lothian has been picked not just because I wanted to have a chat with you again, but because we wanted to hear views from the perspective of a more urban-based health board and trusts. We also wanted to hear about some of the ideas that arise from the fact that Lothian NHS Board is a tertiary health board and a service provider not only for the people of Lothian, but for people beyond Lothian. Those are the areas that some of our questions will address. We will visit Highland NHS Board next week to hear about the issues that face a more rural board. We are trying to find out how boards use the money that they receive to deliver health care on the ground. I will shift the issue over to you. You may make a short statement, after which we will move to questions.

Brian Cavanagh (Lothian NHS Board): Good morning, convener. This is the hit squad that you referred to. The bus is outside—I hope that it is not parked on double yellow lines. We want to demonstrate the partnership that we are trying to develop in the national health service in Lothian. We have with us a director of public health, a director of strategic planning, a director of finance from the unified board and a chief executive from the unified board. Allister Stewart, from the Lothian University Hospitals NHS Trust, is a chief executive and Aileen Brown is one of the finance people. Between us, there are enough people to answer your questions.

We thank you for the opportunity to come along to the committee. It is important that we have a discussion with MSPs. The unified board takes seriously its responsibility and accountability to the Parliament, the Executive and the wider Lothian community. As you will know, we try regularly to update and brief MSPs from the Lothian area about the effectiveness or otherwise of the NHS in Lothian and its performance in engaging in partnership.

We take the issue of fiduciary duty seriously for the simple reason that the responsibilities that we are charged with under the NHS plan, about improving health for all and tackling health inequalities, cannot be delivered effectively unless the financial basis of the organisation is sound and secure. We regard the financial basis of the organisation as an essential prerequisite to ensuring that we deliver the objectives that the

Scottish Executive, the Parliament and the people of Lothian expect of us. We take financial effectiveness as seriously as we take our fiduciary duty, because ensuring that financial effectiveness is delivered is the key to tackling the issues that we face.

I will give you three examples of issues that Lothian faces. The first is delayed discharge, which is of national importance but of particular local relevance. The second is ensuring a balance between acute and primary services and the community health agenda. The third is tackling the health inequalities agenda, which we cannot and should not do on our own, but which we should do in partnership with our partners in the rest of the NHS family in Lothian and with local authorities. It is against that background of overarching policy objectives that the finance is there to deliver.

We spend £770 million in the NHS in Lothian. Allied to the sums of money in local authorities' control, there is almost £2 billion available to tackle inequalities—in the widest sense—in the NHS in Lothian. When we look at our financial responsibilities, we try to tackle the three major objectives that we have been given by the Scottish Executive and we try to ensure that we can work in partnership with our local authorities.

We regularly share financial information within the NHS, with our colleagues and partners in local authorities and with our MSPs. We are happy to be held to account on the financial issues relating to NHS Lothian. We know why we are doing what we are doing—we want to address the inequalities that members know about. Edinburgh is not simply a wealthy area; we have to deal with a number of difficulties and inequalities. The difficulties that we face are not as great as those in greater Glasgow and Strathclyde, but the area contains pockets of deprivation that we have a responsibility, both morally and under legislation, to tackle. We cannot do that effectively until we have a solid financial base.

That view is shared by my other non-executive colleagues on the unified board and by the trust management team, which together make up the NHS family in Lothian. I want to give members a sense of the gravity of the issue and of why we want to ensure that we have a secure financial base.

09:45

The Convener: Thank you for that introduction and for the documents that you gave us in advance of the meeting, which have been useful.

Mary Scanlon (Highlands and Islands) (Con): I refer you to paragraph 2 of the document that you sent to us on the budget process—the paragraph is headed "Budget Setting Process". Paragraphs 2.1 and 2.2 are important in helping us to understand how you decide to allocate money within your budget.

Paragraph 2.2, on the timetable, refers to issues such as pay awards, supplies inflation, the new deal for junior doctors, the European working time directive and superannuation changes. We also know that the drugs budget is increasing by 10 per cent annually. You talked about having a duty and being effective—you have no choice but to do all the things that are set out in the document. Given that 70 per cent of the NHS budget relates to pay, you cannot choose whether or not to meet the targets that you list. Most of us would agree that that is how it should be.

Paragraph 2.1 refers to

> "existing criteria for determining areas of service investment".

We are trying to ascertain how much discretion you have within your budget for service development. Reference is made to primary and secondary care, management of asthma and diabetes, health improvement, reducing inequalities and effective interventions. How much discretion do you have for service development, as described in paragraph 2.1, given that you have a cancer plan and a NHS plan, that you are about to get a diabetes framework and that you are expected to meet Scottish intercollegiate guidelines network criteria and to conform to health department letters? Given that you must meet all the targets set out in paragraph 2.2, how much room do you have in your budget?

John Matheson (Lothian NHS Board): I will pick up on some of the specific issues that the member has raised and place them in the broader context. First, it is risky to focus solely on the extra money that is available. This year, NHS Lothian received an uplift of 6.8 per cent, which equates to about £42 million. Of that £42 million, £16 million has gone into maintaining the pay and supplies base of NHS Lothian. That covers projected pay awards of 4 per cent and general inflation of about 2 per cent. This year there is also movement in superannuation levels for employers—an increase from 4 per cent to 5.5 per cent. Another £5 million is required to cover that. Brian Cavanagh spoke about what is needed to maintain our base. It is important that we fully fund the core uplifts that are centrally driven.

The other challenge that NHS Lothian faces is to focus not just on the growth element, but on the totality of spending. Brian Cavanagh cited the figure of £770 million, which is the total amount spent by NHS Lothian. We also consider strategic change and the cost-effectiveness of the services that we provide; we benchmark with other health providers both in Scotland and south of the border.

I will provide members with some specific examples of that work. A good example is our learning disability strategy. Ten years ago we had Gogarburn hospital, which housed more than 300 patients. That hospital is now closed. The patients have moved either into other health provision or into the community. The cost of operating Gogarburn hospital was £10 million. The cost of providing its services in the community and other hospital settings is £15 million.

That strategic change must be planned in as part of our overview. The trick is not to examine only the following year, because the amount of flexibility in one year is not especially significant. The trick is to consider the five-year and 10-year positions. Examples of that can be found in the new royal infirmary, the planning cycle that underpins the new royal infirmary and the Anne Ferguson development at the western general. The system has flexibility, but one must consider the totality of the system.

The interface between primary and secondary care in the management of the chronic diseases of asthma and diabetes is another key matter. On top of the growth money that we have received, we have additional funding for chronic disease management. Personal medical services projects are also taking place in Lothian and elsewhere in Scotland. We are keen that, through the effective management of demand, patients will be dealt with at the appropriate interface in the system. We are focused on the effective management of asthma and diabetes and on reducing the level of admissions into hospital.

Mary Scanlon: I am unsure whether you answered my question or followed a prepared speech. I expected you to say that you are considering benchmarking, cost-effectiveness and implementing "The same as you? A review of services for people with learning disabilities", but we want to find out how much discretion you have in the budget in relation to new Executive initiatives. For example, have you costed the cancer plan?

I ask the witnesses to answer my question more directly. What is the board's priority in all the factors that were mentioned? Is the priority to balance the books or to meet the criteria that are set in the performance assessment framework? I understand that, to save money, some posts were not filled in Lothian. What priorities and criteria drive and determine your allocation of money?

James Barbour (Lothian NHS Board): I could answer Mary Scanlon's question at a number of levels. We all have accountable officer responsibilities, which mean that we have a statutory responsibility to live within our financial means. If we did not fulfil that responsibility, we would properly be held to account.

I will wrap some specifics around the question. John Matheson gave a breakdown of the growth moneys that we have this year, which are about £41 million. If one takes from that £41 million pay, price uplifts and the various programmes to which he referred, which are givens, we have a discretionary spend of about £11 million. That gives the committee a sense of the magnitude of the issue.

The national priorities that are givens—cancer, coronary heart disease and mental health are but three—are also priorities for the people of Lothian, because we face the same problems as exist throughout Scotland. It is no hardship for us to give practical effect to those priorities through investments with trust colleagues, because they are issues for the people of Lothian.

Brian Cavanagh gave the committee a sense of how we balance those responsibilities. In a budget of £740 million, there will always be movement and opportunities for moving money. We are considering whether we can zero base some of our programmes this year, so that we can consider whether the historic spend on matters such as care of the elderly is the right spend.

Mary Scanlon mentioned staffing budgets. I have worked in the health service for 25 years—Allister Stewart, who has worked in it for even longer, would confirm what I will say. Staffing budgets in the health service are too often artefacts. They are the 1948 budgets, which have been uprated and adjusted in accordance with a variety of imperatives, some of which are professional and some of which are service driven.

There is nothing wrong with examining those budgets, as we have in Lothian. It is important to strike a balance. As Brian Cavanagh said, if we do not have financial control and if we do not fulfil our responsibilities, we will not direct the money to the priorities that the Executive and everyone in Lothian NHS Board has bought into.

Mary Scanlon: We are beginning to get to the heart of the question. We are examining the amount of discretion and how the board can change its budget around to meet new targets and new initiatives. You are saying that, of a budget of £740 million, you can adjust about £11 million—you said £42 million at first. What have you achieved in terms of health gain and changes in the distribution of health and ill health? Are those measured?

James Barbour: I will lead in and Peter Donnelly will give you specifics. The unified board has existed only since 1 October. We took an early decision to place the closing of the health inequality gap at the top of our strategic agenda, which is why at our first or second meeting we found from within our total budget about £1 million to pump-prime some important projects. We are hugely mindful of the fact that the relationship between health inputs and outputs is a difficult one to track—it is difficult for all western health care systems.

We can point to some indicators. Peter Donnelly can talk you through our indicators on coronary heart disease and cancer, for example, on which we have quite sophisticated information, but we are not content with that. We are going to launch a survey of the health status of all the people of Lothian, which will give us not only our benchmarking of their situation, but their perception of their health and well-being, against which we can track the activities of the unified board over time. Peter Donnelly will now provide specific information.

Dr Peter Donnelly (Lothian NHS Board): I am happy to do so. As James Barbour explained, and as committee members all know, the unified board has been in existence only since October, but I have been around as the director of public health since about 18 months before then. One of the first things that I did was to examine the health statistics for Lothian and publish them in two annual reports. They show that, although the scale of socioeconomic deprivation is undoubtedly greater on the west coast of Scotland, particularly in greater Glasgow, there are still large pockets of social and economic deprivation in Lothian, which many lay observers see as affluent and, therefore, healthy. In fact, if you look at the discrepancies between those who are healthy and those who are sick in Lothian, you will see that they are every bit as great as those that exist on the west coast. If anything, it could be argued that they are more noticeable in a climate that the public, and sometimes the press, perceive as one of affluence.

Against that backdrop, we tried to put in place a number of initiatives rapidly. James Barbour referred to our finding £1 million from our discretionary money to target the reduction of health inequalities. In the 20-odd years that I have worked for the health service, my experience is that that is unique. I have never in my career in public health had a board give me £1 million and say, “Peter, focus this specifically on reducing health inequalities.” We have put in place a number of initiatives to that end.

We have gone further than that in producing our local health plan, copies of which we have brought along in draft form for the committee. In it, we lay out a programme for the next five years, which outlines not only how we will try to improve the quality and comprehensiveness of the health service that we provide to people who are ill, but how we will focus on reducing health inequalities, improving people’s health status and keeping people from becoming ill in the first place.

Mary Scanlon: But can you measure those gains?

Dr Donnelly: That is exactly the point that I am coming to. It is an important point and it is a fair question. It has always seemed odd to me that the health system in this country does not attempt to measure the improvements that it is trying to achieve in health status and the reduction of health inequalities as rigorously as it measures, for example, the reductions in waiting lists and waiting times. Although, intellectually, those improvements are harder to measure, that is no excuse for not trying.

Members will see that, in our health plan, we have made specific promises and set specific targets. We have, I think, been open and honest with the people of Lothian about how we are doing. We have taken the performance assessment framework, which we all consider to be a useful initiative, and, using a traffic light system, we have laid out exactly where we are. Where we are hitting our targets, we have put a green light; where we are within acceptable limits of our targets, we have put a yellow light; and where we have further work to do, we have not shied away from being totally open and putting a red light. That rigorous and robust approach, not only in considering the investment of money but in quantifying what we want to achieve with that money, will help us collectively to make progress in tackling health inequalities.

10:00

Janis Hughes (Glasgow Rutherglen) (Lab): In paragraph 3.1 of your paper, you talk about regional services. My experience is in Glasgow, where we have a big problem with specialty services being treated as tertiary referrals but not funded as such. Do you have a similar problem in Lothian? If so, how do you deal with it?

The Convener: Before the witnesses answer that, I will ask Dorothy-Grace to ask another question in a similar vein so that the questions can be answered together.

Dorothy-Grace Elder (Glasgow) (SNP): Thank you, convener, but before I do that I want to clear up one point. You spoke about £1 million of discretionary money being used to focus on reducing health inequalities. Can we make it clear that the discretionary money amounts to £11 million in total? Is that right?

James Barbour: No. I think that it is important to—

Dorothy-Grace Elder: Earlier, £41 million was mentioned as growth money.

James Barbour: We have a total budget of £740 million. John Matheson has already explained how we try to ensure that we free money from within that total. The £41.6 million is the additional growth money that we received this year and the £11 million represents the element of it that remains unallocated once we have met our commitments on pay, prices and inflation.

Dorothy-Grace Elder: The element of the £41.6 million?

James Barbour: Yes.

Dorothy-Grace Elder: Fine. Thank you for clarifying that.

I want to ask about pressure points. Like most boards, you accept patients from other areas of Scotland—indeed, you have a good reputation for that. The penalty of your success is that you get more and more patients from other areas of Scotland. Roughly what proportion of your budget goes on patients from other areas? Do you receive full recompense for those patients? How many such patients are there?

James Barbour: I will give a general answer and then ask John Matheson to give you the numbers. The planning of specialised services and tertiary services exercises many people. The Executive has considered how we might plan so-called regional services. That immediately raises the issue of the definition of a regional service. In a country of just 5 million, do we define such a service at national level or do we do so at regional level within that country, at the level of the 15 health boards? We have to consider whether the definition makes clinical sense, organisational sense and best-outcome sense. Work on the issue is on-going and arrangements have been reviewed.

The issue is of concern to us and it is dear to the hearts of Allister Stewart and Aileen Brown. Especially with regard to the new Edinburgh royal infirmary, we are aware of the potential of the reputation of the tertiary services to suck patients in. As part of our efforts to obtain financial equilibrium, we and the surrounding boards in our consortium—boards from the south-east and Tayside—have agreed that we need to revisit each board's contribution, financially and otherwise, to the patient flow into Edinburgh. We are working with those boards to define terms of reference for a study that I will lead. John Matheson is doing detailed work on that. We hope that the study will help to rebalance the arrangements so that those boards make a fair contribution for the services that their patients use. Our income from the other boards is around £50 million, but we think that we should perhaps be receiving a number of millions of pounds in addition to that. We would like to follow that up with the boards.

John Matheson: Although £39 million of the £50 million goes to Lothian University Hospitals NHS Trust, it is important to recognise that regional psychiatric services are provided through Lothian Primary Care NHS Trust and plastic and burns services are provided in West Lothian Healthcare NHS Trust. The primary care trust gets £8 million and West Lothian gets £4 million.

Dorothy-Grace Elder: You receive a considerable number of patients who suffer from chronic pain. In asking this question, I declare an interest as convener of the cross-party group on chronic pain. Your services at the Astley Ainslie hospital and other facilities are well rated, but are under pressure because of the number of patients who go there from other areas of Scotland. Do you intend to invest any more in pain services, given that it is estimated that 80 per cent of NHS patients suffer from chronic pain in one form or another?

Brian Cavanagh: That question goes to the heart of the new NHS objectives: is it appropriate that people should move some distance to access what a lay person would assume should be a local service? The dilemma is that the NHS system in Lothian could benefit financially from a formal pricing process. However, if Lothian gains, Tayside—for example—might lose. We are dealing with the legacy of the internal market and are currently discussing with the Executive new rules of engagement. It is a policy issue with which chairs of boards throughout Scotland are trying to deal.

Dorothy-Grace Elder: If other areas of Scotland had better services, would increasing your budget be unnecessary because you would be able to cope with the number of patients from Lothian?

Brian Cavanagh: Although it is effective to have people travel some distance to access centres of excellence, pain management might be an area in which it would make sense to have accessible local treatment. That might not be the case, of course. The problem that we face relates to financial benefit and the most appropriate delivery mechanism for certain treatments. Some of the centres of excellence are quite obvious and having people travel to them can be justified. However, although I would travel from Stirling to Edinburgh to visit a centre of excellence for the treatment of chronic pain, I would probably not want to travel 120 miles to do so.

Jacqui Simpson might want to comment on the Astley Ainslie hospital.

Jacqui Simpson (Lothian NHS Board): As you know, people who turn up at a hospital's chronic pain service have reached the end of their tether and have not found other hospitals' treatments to be effective. The pain service at Astley Ainslie is well rated. The question is: what can be done in local areas by other practitioners, nurses and so on to whom specialists at the hospital can impart their knowledge? The ideal is that people who suffer from chronic pain should be able to access services as close to their homes as possible. We are trying to determine the sort of treatment that can be given only in a specialist centre by people with expertise, and what sort of treatment can be given by other professionals under guidance that can be imparted through protocols, guidelines and so on that include the outcomes that should be delivered.

Dorothy-Grace Elder: Last, do you believe that your pain services are taking some of the strain off the rest of the NHS in the area?

The Convener: I am sorry, Dorothy-Grace, but I have given you a little latitude in your questioning because I know that you are interested in chronic pain. However, we are discussing budget issues.

Shona Robison (North-East Scotland) (SNP): I want to ask about something that Dr Donnelly said. Obviously, a big debate at the moment focuses on the balance of investment in public health and front-line services in relation to the new money that has been announced. The committee will wrestle with that question.

Dr Donnelly talked about how the moneys that are given are invested in public health. I want to clarify how short-term those moneys are. Is the £1 million available each year of a five-year plan? If so, how realistic is it to expect tangible public health improvements within such a short time? In an ideal world, what would be the time scales of the targets that are set for the delivery of tangible public health benefits?

I know that that is a wide-ranging question, but your answer might help us in our debates on how budgets should be balanced.

Dr Donnelly: Your question is wide-ranging but important, because it goes to the heart of the NHS's responsibility to address health as much as it addresses the provision of health services.

I start by clarifying that the £1 million is a one-off, non-recurrent amount that was a catalyst to start the process. However, it would be wrong to give the impression that our attempts to improve people's health and reduce health inequalities come only from within that non-recurring £1 million. We have many projects on the go. We run projects as a board and in collaboration with the trusts. We also work closely with local authorities, which—as members will be aware—often have the levers that one needs to operate if one is to improve health. I am thinking of things such as education, social services, housing and environment.

On time scales, they depend on the project. To be frank, some things will take a generation to turn around. However, the fact that something will take 20 years is clearly not an excuse for not starting now. The challenge is to identify the milestones along the way that will reassure us that we are moving towards improved outcomes.

I will illustrate that with a straightforward example. The single most effective measure to reduce the number of people in Lothian who die from lung cancer would be to reduce the number of people who smoke cigarettes. However, the time lag between achieving a reduction in the percentage of people who smoke regularly and the benefits in terms of the numbers who die from lung cancer is quite protracted. We are talking about 15 to 20 years. However, in the interim one can measure the effectiveness of smoking cessation programmes.

For example, we have started a programme that seeks to work with young women who are expecting a child. If we can help the young women to stop smoking, there will be a double benefit. First, the chances of their getting heart disease and lung cancer 15, 20 or 25 years down the line will be greatly reduced. Secondly, there is an immediate benefit. As members will be aware, smoking during pregnancy is one of the leading causes of low birth-weight babies. It is important to avoid having high percentages of low birth-weight babies because a high weight at birth is a good predictor of survival during the first year, and of health during the first five years. Fascinatingly, a high weight at birth is a strong predictor of health throughout life.

The question was fair. In effect, the question is how one justifies putting money into very long-term projects. The answer is that there must be a span of measures that show the short, medium and long-term benefits and which will provide reassurance that the project is making a difference even in the short term.

10:15

Shona Robison: Are you winning those arguments in the face of other competing budget priorities within Lothian NHS Board? Perhaps that is an unfair question.

Brian Cavanagh: It is a fair question. A shift is taking place in the cultural mindset within NHS boards. There is no doubt that the NHS plan has assisted a number of people who have historically been on the margins of the debate. The fact that the NHS plan stated that tackling inequalities was a key imperative of the boards shifted the culture. There is no doubt that representation on NHS boards—which has been achieved, for example, by bringing elected members from local authorities on to the boards and employing a director—has effected a move from a narrow notion about health to a broader notion of health and well-being.

Historically, the NHS has not been particularly good at public consultation. It is no coincidence that when we launched our NHS plan, we asked communities and social inclusion partnership projects where and in what way it would be most effective to hold meetings and who the communities' representatives should be.

There has been a change of view. Lothian NHS Board has acknowledged that we are involved in a long game. We must keep our nerve and realise that one cannot resolve inequalities overnight. We must create a culture that is about partnership with community-based organisations at local level, and we must encourage in the acute sector a culture of playing a preventive role. We must tie our objectives to tackling inequalities.

As Peter Donnelly said, we must have clear indicators and outcomes in relation to better relationships with local authorities. Sometimes there are negative vectors. One could ask whether the City of Edinburgh Council should take Glasgow City Council's lead and introduce free swimming at schools. Should the NHS contribute to that? Would that amount to a more effective use of resources? That returns us to the point that James Barbour made. If we start to zero-base our budget to find out what is in the budget and to tie it to health outcomes and indicators, we will start to change the emphasis. We will move away from a culture of running a national illness service towards a culture of health and well-being. We have the evidence base to back up the correctness of our desired outcomes.

The Convener: James Barbour will make a short contribution, after which Bill Butler will pick up on the patient consultation issues.

James Barbour: Brian Cavanagh has made most of the points that I was going to make. It is important not to set up a false dichotomy. If one considers the people who suffer from the diseases of poverty, homelessness, poor diet, unemployment, low self-esteem and all that flows from that, by and large those are the people who are being treated in acute hospitals for cancer, coronary heart disease and the conditions that flow from those. It is important to acknowledge that money that is spent in acute hospitals on giving those people succour and treatment, and on restoring their quality of life, is also a contribution towards closing the health inequality gap.

It must also be acknowledged that we, as employers, put about 70 per cent of our turnover into labour. That is why one of Lothian NHS Board's early commitments has been to tackle recruitment, retention and low pay. Dealing with those issues for our people has a multiplier effect in terms of the socioeconomic circumstances within which we operate.

Against that background, it should be emphasised that the total spend is having an effect in all our partnerships. For example, in Craigmillar—where the new royal infirmary is—a Craigmillar learning partnership is being established. I hope that that will provide employment opportunities for local people, so that they can progress up the NHS career ladder using the myriad employment opportunities that the hospital on their doorstep will offer. As Brian Cavanagh said, we need to take part in all the games at the same time. We cannot find many of the solutions by ourselves, but we can find them by being good partners with others. I hope that our health plan acknowledges that.

Bill Butler (Glasgow Anniesland) (Lab): I am interested in the role that consumer, patient, taxpayer and family member preferences play in the decision-making process about how you spend. How are those preferences identified and how are they acted on? Will you provide examples of how the preferences are acted on and of the existence of interplay and interrelationships?

James Barbour: This is the first year in which we have produced a local health plan in a unified board system. In a short time, Jacqui Simpson and Peter Donnelly have done a prodigious amount of work on making the process as inclusive as possible. That inclusivity has been demonstrated by stakeholder conferences, of which we have held 10 or 11. We have taken plans, proposals and priorities out to local communities and debated with them whether they will accept them. In many cases, we are encouraged by the extent to which local people accept the priorities. We have also set up free telephone lines and freepost addresses to allow people to comment. The material is available on our interactive website and people are able to leave comments there.

Beyond that, we have attended social inclusion partnership meetings, local authority discussions and local health care co-operatives. Brian Cavanagh mentioned the national plan; I must say that we are encouraged by the extent to which there is congruence between what people want us to do and what we aspire to do in national and local plans. That said, there are issues around car parking and the balance of services throughout Edinburgh. There will always be parochial issues but, as the health plan demonstrates, we are trying to deal as best we can with those.

Jacqui Simpson: Maternity services were highlighted in the papers and are an example of a strategic area on which we held a major public consultation. We held focus groups with women and clinical staff and carried out a survey of citizen's panels to identify the strategic direction that people thought was most important. We matched those against criteria that are important to us all, such as access, safety and cost. We now have a foundation on which we can build for the clinical areas in which we are involving patients and the public in the difficult prioritisation discussions that we must have.

Margaret Jamieson (Kilmarnock and Loudoun) (Lab): I want to pick up on the point that Bill Butler made. It is good that the NHS has seen the light in terms of how it consults its consumers. However, Brian Cavanagh pointed out that that has changed because of the way in which the NHS interfaces with local government. I am not saying that local government is all good, but it has good points, which will clearly assist NHS boards in setting top-line objectives. However, the initial point of contact for the majority of individuals is their GP. How do you propose to change GPs' view of the world? It is all very well having strategic objectives, but how do you get everyone in the NHS family to buy into them?

Brian Cavanagh: We need to be honest. We are starting to do some innovative work on patient consultation, but we are far behind our public sector partners. A bit of humility would do us no harm. We are doing quite well, but we are doing things that we should have done 10 years ago and we are trying to catch up.

We must be careful to avoid consultation fatigue, where we pat ourselves on the back and say that we have consulted everyone, but changes do not happen—people would think that there was a meeting but that still no one listened. Having a meeting makes no difference if people cannot see that they can influence the process. That might be worse than having no process at all. We must be realistic about a process that is sustainable and in which people's views are taken on board, and as a result of which they see a tangible difference. That will not be easy. A change of culture in the NHS at all levels is needed. The partnership with our staff and trade unions will have a vital role in delivering that change.

One of the ways in which to address such issues is to recognise that the best way to deliver many services is as locally as possible. That can be done through the LHCCs for example, which are led by GPs. That is quite an innovative development in the Lothians, because the NHS board has coterminous boundaries with the four local authorities and we can assist with the joint future and equalities agendas. The only way in which we can resolve the equalities agenda is through local initiatives. Those are not initiatives on the edge, but are initiatives that give us examples of good practice that can inform and influence our budget.

GPs, like other people, are varied specimens. Some GPs are very impressive and some are more traditional—if I can use those terms—but they are all a delivery mechanism for the changes. We must be careful that we do not overload them with information. The organisational structure of the NHS must be appropriate. There must be lowest-level delivery.

I have one final point to make, which I am surprised has not come up. On the new Edinburgh royal infirmary, our task is to ensure that it does not become a large district general hospital. It is a tertiary teaching facility. We need to have it because it is effecting the culture change, but we do not want people in the hospital who could easily be catered for at Roodlands hospital in East Lothian, at St John's hospital at Howden in West Lothian or at the Western general hospital in Edinburgh.

GPs are critical in delivering equality and to patient engagement. We need to ensure that patient services are adequately and effectively resourced. That is an area to which we will turn our minds in the next five or six months.

James Barbour: We have a GP on our board and she is an active part of the discussions. A powerful dialogue already takes place. I am sure that you know that the discussions on the GP national contract are reaching conclusion. If one believes what one reads about those discussions, powerful culture shifts are under way. The vast majority of GPs are independent contractors. That independent contractor status is a factor with which we have to deal.

Brian Cavanagh referred to LHCCs—local health care co-operatives. I apologise for using the acronym. He and I have been round to meet all of them. We have consulted them all on our local health plan. The Executive has just assessed us on our LHCC development. LHCCs—and therefore the primary care teams, which include but are not only about GPs—are communicating loud and clear a desire for more to be devolved to them. Of our £700 million or so, about £200 million is under LHCC management. The money is devolved from the primary care trust, but there is even more to do on that. For example, on areas such as health promotion and some of the social inclusion-related work that we do, we might be able to involve GPs more closely in the kind of discussions to which Brian Cavanagh referred.

With the substantial amount of money that is coming to us through the personal medical services pilots, we have the opportunity to lever behaviour changes. That will take a while, but if we do everything in line with the new contract, there will be a lot of good will with which to work.

Margaret Jamieson: I will move on to working relationships with local government colleagues, although that topic has been touched upon. Will you give us examples of such work that is in the pipeline and which would further demonstrate your partnership working with local authorities, particularly in reducing the number of blocked beds in the Lothians? Somebody had to ask that.

Brian Cavanagh: I am glad that that question has been asked now, because, at quarter past 11, we will have a special board meeting with our colleagues in the four local authorities and with the directors of social work to discuss that issue and, in partnership, to put together our submission for the Minister for Health and Community Care's £20 million. Any words that you can put in his ear would be appreciated. I am sure that that would not be a conflict of interest for anyone, except perhaps the convener.

The best way to describe the NHS is to say that, historically, we have sometimes confused the urgent with the important. We must address two things to deliver the big agenda that the board wants to tackle in relation to inequalities. I have already mentioned one of them—financial equilibrium, to use the current jargon in the NHS. The second is delayed discharge.

There are three simple reasons why we need to address delayed discharge. First, it is unacceptable to have more than 500 older people—in effect, enough for a district general hospital—in a place where they should not be living. That is just wrong, as well as economically inefficient. There is a common understanding that the problem must be resolved. Delayed discharge also militates against Lothian NHS Board's success on waiting times. We are the best in the country in that area, but we are not so good on delayed discharge. We need to improve.

Because our area contains three landward authorities and a big, powerful city, all of which experience the pressures of a prosperous Edinburgh, property sales are an issue. A number of care homes are going out of business because of the attractive property market, a number are going up for sale for positive reasons, such as improvements in standards, and a number of organisations are unable to sustain themselves.

We want to ensure that there is a better and more creative mixed economy in the market. Dependence on a sole provider is dangerous. All the partners share a philosophical aspiration—that services should be brought to the person, rather than that the person should be brought to the service. We want to shift the emphasis towards community and home-based support. We would like to see more emphasis on prevention and step-down and step-up beds. That aspiration is shared and endorsed by the authorities.

The partnership is very powerful. We have recognised that we will take a pan-Lothian approach to spending the £2.7 million, if we get it. We are not talking about each of the four authorities getting a cut. We recognise that it may be in Edinburgh's interest for additional residential care facilities to be located in Midlothian, West Lothian or East Lothian, where land is cheaper and easier to sell. Our colleagues in the local authorities are relaxed about that approach. I use the word "relaxed" not as a euphemism, but in its normal sense.

10:30

We recognise that a range of alternatives is required. West Lothian has introduced a number of groundbreaking initiatives in community care and smart technology. It will take the lead in that area on behalf of the partnership. Midlothian employed a consultant to do some work, who will also work for East Lothian on a partnership basis. When we reach a resolution—I hope today—we will use the money to provide short-term beds and, more important, to increase capacity to the level that we want to have in two or three years' time. We are strong on medium to long-term plans and aspirations. At the moment we are short on bed capacity. We do not want to create bed capacity that is not relevant to choice in the medium to long term, but there is a problem that needs to be dealt with quickly.

The item was on the agenda of one of the first meetings of the unified board since it was set up six months ago. James Barbour has now been round all the local authorities, met their leaders and addressed the councils. He meets authorities regularly. We have a handle on the issue and there is action that we want to take. We must translate the good promises that have been made into action, but the partnership is working well.

The partnership is aided in no small measure by the fact that there are elected members on the unified board. Those members are either council leaders or the conveners of social work committees. In the past, there tended to be hostility between partners, with each side blaming the other. Local authorities saw the NHS as a cash cow to be milked, while the NHS dismissed local authorities because they took too long to make decisions. That problem is not solved by the existence of the unified board, but the partnership is strong and there is an understanding of the situation. Ultimately, we have a responsibility to improve conditions for people in the community who are inappropriately placed.

The Convener: The improvements to which you refer may have something to do with the fact that conveners of social work committees are members of the unified board.

Brian Cavanagh: Indeed.

The Convener: You spoke about the need for increased bed capacity in the short term, and that is obviously important. However, in Lothian we also need to ensure that we have the required work force. That is important not just in relation to bed blocking, but generally. How are you tackling some of the work force planning issues that you have to take into account, given the buoyancy of the economy in Lothian, where there is virtually full employment?

Brian Cavanagh: One of the first things that we did was to address recruitment and retention. People can earn more working in McDonald's or in a Wimpy bar—I am showing my age—than they can earn in the NHS. We devised a package totalling £3.6 million to raise some people's pay from £4.19 an hour to £5 an hour. That is not a big deal, but it is a significant increase. We recognised that specific measures were needed in the NHS in Lothian.

We are working very hard on work force planning. We have held a number of recruitment fairs, which have been relatively successful, and we will continue to hold such fairs in future. We need to show that there is a good relationship.

We also have to deal with issues arising from the report of the joint future group. There is a need for partnership at strategic level with the employee director on the unified board. If we are to get work force planning right for the service, local links with trade unions and staff associations are important. We need to ensure that there is equality of opportunity.

Even within the Lothians, there is an Edinburgh issue and a West Lothian issue—there is an issue about the relative buoyancies of economies. We are starting to work in partnership with the councils to address the matter. We are not quite scratching our heads, but we are having difficulties sustaining people in the NHS. That is why the recruitment and retention move is a start.

We regard the staff governance committee of Lothian NHS Board as a vital way of getting into detailed discussion. After dealing with the recruitment and retention issues, we want to start personal development plans for the 18,000 staff of Lothian NHS Board. We need to start that type of development. Again, the staff governance committee gives us an unprecedented vehicle for those discussions. The committee is not yet resolving issues, but it is enabling those types of discussions to get a much higher profile than they had.

The changes that we have talked about this morning are predicated on two things. First, there must be a culture change, which means that our human resource strategies must be central to the board's objectives, rather than human resources being regarded as personnel with a fancy name, as has often been the case. Human resources must be a central driving force for change in the NHS. That is about having a work force plan and about the personal development of staff—reaching out to staff, not to co-opt them into decision making, but to ensure that they are involved in the choices that we make on budget delivery and service options. We must engage staff at the earliest opportunity. The staff governance committee is helping us to do that.

The Convener: Does John McAllion want to ask a supplementary question before moving on to his other question?

Mr John McAllion (Dundee East) (Lab): I will move on to other questions. You mentioned several times that the new unified board was established only on 1 October 2001. On almost exactly the same date, the decision was taken to set up the pan-Lothian review group. Was that done to find money to commission the new royal infirmary and the new Anne Ferguson building at the Western general hospital? Did the new unified board decide to set up the review group? More important, can you explain to the committee why it was felt necessary to set up the review group?

Brian Cavanagh: I can answer some of that. I guess that two issues are involved. First, I will tell you why we set up the pan-Lothian review group.

Mr McAllion: Was that a unified board decision?

Brian Cavanagh: No. The decision predated the unified board. At the end of August 2001, we discussed our accountability review. The board was a shadow board at that stage. Lothian NHS Board officially started on 1 October, but before that a shadow board worked with the then Lothian Health Board. James Barbour and I had been in the job only weeks, but we wanted to make obvious, symbolic changes. There was a financial difficulty within the NHS system in Lothian, which we regarded as an issue for that system. We set up the review board to demonstrate our view that we had shared problems that would require shared solutions.

We wanted it to be recognised that we all owned the problems, because under the board and trust arrangements, the tendency was for the board to give money to the trust and say, "Get on with it." The trust would say, "We don't have enough money." To which the board would say, "We gave you plenty, but you can't deliver." That batting backward and forward did not help patient care, did not address accountability issues, and allowed some people to get off the hook.

The new NHS board decided that we have shared ownership of financial responsibility issues and other issues, although the accountability lines remain clear. We wanted to demonstrate that we all owned the financial problem and that we would all help each other out of the problem. The historical way to respond would have been to set up a task force, but we did not want a task force; we wanted a review group.

We dealt with issues around the Lothian University Hospitals NHS Trust—John Matheson and Allister Stewart will expand on this point, if you wish—by saying that those issues were about the NHS system in Lothian. We needed to have financial equilibrium in the system to address the agendas that we wanted to pursue, which were the equalities agenda and the well-being agenda. That is why the review group was set up. The review group wanted to be as broad as possible, and included trade unions and independent experts in the task of finding the extent of the financial problem in the Lothian NHS.

That describes the review group's genesis. John Matheson and Allister Stewart can give you chapter and verse on what the group did and what its recommendations were.

The Convener: Does Allister Stewart want to come in?

James Barbour: I have a small point of clarification on what Brian Cavanagh said. The chief executive of the NHS in Scotland held us to account at a series of meetings, from June 2001 to August 2001, which were intended to ensure that we had a clear understanding of the financial pressures that we faced—the lessons of Tayside were fresh in everyone's minds. We needed that understanding of financial pressures to produce a five-year local health plan, which is underpinned by a five-year financial strategy. As Brian Cavanagh said, we decided that we could progress better by being part of a partnership, rather than taking an adversarial, task force approach.

Mr McAllion: It is not clear to me whether you are saying that the pan-Lothian review group was set up to consider problems with the NHS system or problems associated with the two new buildings.

John Matheson: I would like to deal with that. The specific focus of the pan-Lothian review group was to identify the additional investment required for the new Edinburgh royal infirmary and the Anne Ferguson building at the Western general hospital, to enable those two developments to function effectively.

Mr McAllion: Following pressure from the committee, the Minister for Health and Community Care eventually put the full business case for the new Edinburgh royal infirmary in the Parliament's library. Is the full business case exactly the same as the agreement that you signed with your private partners?

John Matheson: The full business case reflects what was signed with the private sector partners.

Mr McAllion: Is it exactly the same? Were there any changes between the final agreement and the full business case that is available to MSPs?

John Matheson: The changes concern human resources requirements, which have been clarified since the full business case was signed. For example, staff who transfer from the NHS system to the private sector are entitled to the same terms and conditions as they would have received in the NHS. That applies to staff who transfer and to new starts.

Mr McAllion: For the *Official Report*, will you tell the committee what payments Lothian University Hospitals NHS Trust makes for the new Edinburgh royal infirmary? Are payments to be made monthly or annually?

John Matheson: The payment to Consort Healthcare, which is the private sector partner, is £31.9 million per annum.

Mr McAllion: Is that paid yearly?

John Matheson: It is paid in quarters.

Mr McAllion: Is that a problem that the pan-Lothian review group sought to address? Did you not have £31.9 million?

John Matheson: The pan-Lothian review group was set up to address the issue of additional investment. An interesting comparison between the new Edinburgh royal infirmary and the Anne Ferguson development is that one is a PFI project and the other is a traditional public sector project. Additional investment is required for both to enable them to function effectively. That reflects the move from a Victorian institution to a 21st century building. Costs will be greater, irrespective of whether it is a PFI—

Mr McAllion: So more than £31.9 million is needed for Edinburgh royal infirmary.

John Matheson: No. The £31.9 million is the operating cost.

Mr McAllion: What is the additional financial investment?

John Matheson: The pan-Lothian review group identified an additional investment of £14.8 million for the two projects.

Mr McAllion: Can you break that down between the two projects?

John Matheson: The split is £10 million for the new royal infirmary and £4.8 million for the Anne Ferguson buidling.

Mr McAllion: Who gets the £10 million for the new royal infirmary?

John Matheson: It is part of the payment to Consort.

Mr McAllion: So Consort gets £39.1 million and £10 million on top of that.

John Matheson: No. The £10 million relates to the difference from what it currently costs to operate the royal infirmary of Edinburgh. The current expenditure within the royal infirmary and associated hospitals is around £20 million. The cost for the new royal infirmary will be £31.9 million, which I mentioned.

Mr McAllion: You must have known that when you signed the agreement with Consort.

Allister Stewart (Lothian University Hospitals NHS Trust): The business case that John McAllion has seen is full and proper. The Consort payments reflect what was in the full business case. In Lothian, we have grappled with business cases that were put together in the mid-1990s and the reality of today. A range of assumptions were made about pay and staffing. For example, a big assumption, which was legitimate at the time, was made in the business case about local pay bargaining. There was a view that we could crack down on unit labour costs. In a short time, local pay bargaining was no longer available, so there was an immediate gap in funding. John Matheson is trying to indicate that the full business case then became a contractual agreement between Lothian Health Board and Consort and we have a contractual agreement to pay those payments, as stipulated in the business case.

We played a part in the pan-Lothian review, and Aileen Brown was on the group for that. Our challenge was to bridge the gap and to achieve, from the good assumptions that were made in 1990, what is—let us not fool ourselves—one of the best and newest teaching hospitals in Europe, of which we should be justly proud. The price that we have had to pay for that is to ensure that we have sufficient funds in the totality of the Lothian system to pay for it. The payment to Consort Healthcare is but one of our financial challenges.

Mr McAllion: Let us be absolutely clear about this: the business case involved the sum of £31.9 million.

Allister Stewart: Yes.

Mr McAllion: That was in the contractual agreement.

Allister Stewart: Yes.

Mr McAllion: And that figure has never changed.

Allister Stewart: Yes, that is right.

10:45

Mr McAllion: What has changed is that, when you examined the budget for the whole of Lothian NHS Board, you found that you did not have the £31.9 million, and you have had to find savings. Is that where the figure of £10 million came from?

Allister Stewart: The business cases were always predicated on making manpower savings. Assumptions were made that, in moving from an old hospital and a set-up that involved trailing patients around the system, to a new hospital with improved technology and a different design, we could perhaps do the same work with fewer people, and we could perhaps do what we do now with lower overhead costs and estate costs. All that fed into what was called the manpower plan, which underpinned the business case.

Mr McAllion: Then the assumptions were wrong.

Allister Stewart: I arrived in 1999, but my view is that the assumptions were very good when they were made.

Mr McAllion: You have just told us that they were £10 million out.

Allister Stewart: You and I are both from Dundee, and know that there was something similar in the history of Ninewells hospital, which goes back to the 1960s. It is perhaps unfair to say that the assumptions were £10 million out. I am trying to demonstrate that the people who made the assumptions at the time did so quite reasonably, given their desire to achieve a new teaching hospital.

We now have to implement the business case and the contractual arrangement. The pan-Lothian review was an important vehicle for considering that across Lothian. We now have six projects to examine how we can improve the quality of care that we provide while ensuring that we live within our financial means.

For example, we are considering whether we can share services, information technology and human resources across Lothian more sensibly than was the case when we were working in our own trusts. We may be able to consider the split in emergency care between the Western general hospital and the new royal infirmary of Edinburgh. Now that we have an amalgamated board, we can do that more easily than the three former trusts could have done. Those are some of the challenges that have emerged from the pan-Lothian review. Last but not least is a whole host of other projects associated with the challenges around care of the elderly and delayed discharges, which the committee has—quite rightly—asked us about.

Mr McAllion: Is the figure of £14 million—the

£10 million that applies to the royal infirmary of Edinburgh and the £4 million that applies to the Anne Ferguson building at the Western general hospital—recurring?

Allister Stewart: Yes.

The Convener: I would like to ask a more general question. I am not a great expert when it comes to PFI, but I have been interested to hear what you have been saying about emergency services at the Western general hospital. I will come back to you about that.

You have recently had to deal with the new royal infirmary and with the Anne Ferguson building at the Western general. What have you learned from that experience that you might be able to use in the future, and what best practice—or worst practice—can you share across the health service in Scotland? I ask John Matheson and Allister Stewart to reply to that.

Allister Stewart: I will have the first go at answering that. We had a very good session with the Finance Committee, which asked us similar questions about PFI. We are almost unique as a trust in that we have had a £60 million Treasury-funded project, the Anne Ferguson building, and a PFI project at the new royal infirmary. Those are substantial projects in their own right.

There are lessons to be learned. We need to ensure that the PPP projects, which started in the early 1990s, are well understood not just in the health sector but in the public sector generally. That is about commercial acumen and understanding financial modelling. There is a host of lessons on PPP and the Finance Committee is on to them big time.

The other lesson for us concerns whether one trust should undertake two big projects at the same time. From a personal point of view and from my team's point of view, the answer is no, because doing so places enormous pressure on our management, which must continue to operate the services that we are required to run while transforming services that are to move into new facilities and work differently.

Maternity services provide a relevant example. While we worked in our loved Simpson memorial maternity pavilion, we had to transform the service from being predominantly hospital based to being community based, and transform it again for the facility at the new royal infirmary. We have had a big lesson on management capacity to deliver on such projects. I am pleased to say that we delivered the new royal infirmary and the Anne Ferguson building on time and on budget. That was an enormous challenge for all my professional staff.

We have had a range of managerial lessons. The Finance Committee is producing an important piece of work on PPP that will benefit from that learning and from which people like me might benefit. It is clear that PPP projects present a host of technical challenges for those of us at this end of the table.

John Matheson: I will link common themes from today's discussion. One of the pan-Lothian review group projects that Allister Stewart did not mention involves discussions with neighbouring boards on the appropriate level of payment for tertiary services, to ensure that Lothian is recovering appropriately for them. On work force planning and development, we are considering using the new physical environment and its benefits for clinical support workers, to provide career opportunities for nursing auxiliaries and to maximise their potential and career options.

Brian Cavanagh: If there is a lesson to be learned, it is that the only way in which we are similar to the royal family is that we are responsible for the sins of our fathers. We have an issue with the new royal infirmary. Most of the people before the committee were not around when the deal for the new building was signed—that is not an excuse.

The Convener: We have a similar problem down the road.

Brian Cavanagh: The NHS would be happy to do some consultancy for the Parliament.

We are serious about making the new royal infirmary work. We have no difficulty with people asking us questions that are uncomfortable for us to receive.

The Convener: I will use the new royal infirmary as an example. Like others, I have visited the new royal, which is a tremendous and wonderful hospital that I am sure will serve well the people of Lothian and beyond. Issues that crop up, along with its cost and the PFI aspect, are the number of beds, and behind that, the need for the service on several fronts to move from the acute into the primary and the community. Witnesses have mentioned maternity services and other services.

When we have examined the budgets in the past two years, we have found that we have an enormous amount of money—£6 billion or something—but that at local health board level, it is difficult to see whether great shifts are happening in acute, primary and community care services. If we are tracking what is happening in the shift from acute to primary, how does that relate to what is happening in Lothian?

We try to follow the money through the system. We and other people are told by the Executive about the key priorities of cancer, mental health and children's services. There are others, but those are the key ones. However, on every occasion on which we ask the Executive how we can follow what is happening to the money, we are told that not only is that difficult, if not impossible, for us to do, but we should not want to do it, as it would not show us much anyway because the service is so diffuse.

We are left to say only that some of the big umbrella issues, such as the shift from acute to primary care, are happening. We are asked by the Finance Committee if that is happening on the ground and we are asked if the way in which the money is being spent is delivering on the priorities, but half the time we cannot answer the questions. When we come down to the issue and ask, "What is happening? Is the money being spent and is it going to the right places?" it is difficult at our level to get answers. I would like an answer in terms of the shift from acute to primary care.

From the point of view of somebody who wants to track through what a health board is doing to deliver at the local level on the key priorities, how do you ensure that what you want to happen is happening on the ground?

Brian Cavanagh: Let us resolve the issue of the number of beds once and for all: the beds are fine. That issue has been constantly trawled over. There has been a detailed discussion. There was a difference of 12 beds between our figures and those of the information and statistics division, but the issue has been resolved. There was a shortfall in maternity and orthopaedics, but we sorted that out. The design of the new building was developed in such a way that had we been wrong, the central services capacity was big enough to enable additional wards to be made. I take the opportunity to state that that issue is resolved.

The more important issue is how we ensure that there is capacity in the community, so that the pressure is not on tertiary services. John Matheson and James Barbour have the figures and they will take you through them.

James Barbour: Convener, your questions address the area where politics, health care and expectation collide. In the time that I have worked in the health service, the rhetoric has always been about disinvesting in the acute sector and investing in primary care and prevention. The actual direction of the funds, in my experience, has been the opposite of that, and that is because of the imperatives around waiting list reductions in particular, but also because of the big, high-profile national diseases. I guess that that has been as true in Scotland as in England.

To hone in on the new royal infirmary, we recognise that the bed numbers are fine, but we need to sort out delayed discharges. That is a fundamental requirement for us, because although the suggestion that there would never be delayed discharge at the new royal infirmary was not realistic, there should be a lot less of it than there is.

As far as the balance between primary care and secondary care is concerned, we have a five-year strategic plan and a financial plan that underpins it. The situation will be monitored through our finance and performance review committee, which the unified board specifically set up. At the end of the five-year period, if everybody does what they are supposed to do, we will show a substantial resource transfer between acute services and primary and community-based services. We can track that by beginning to zero-base our budgets and by running the budgets on programmes rather than on institutions.

One difficulty for the committee, and for primary care colleagues who have the same frustration, is in understanding how the costs of an institution are met, as opposed to the costs of the health care programmes—whether it is renal dialysis, diabetes or what have you—that are provided within the institution. Managed clinical networks, which have begun to emerge in Scotland, may be one way forward. The work in Scotland is quite sophisticated compared with work I have seen in England. If we get away from the imperatives of running institutions—which have overhead costs to apportion, estate costs to deal with, and other black arts that trust colleagues and trust directors of finance engage in—the programme approach, with managed clinical networks comprising the people who provide the service, may offer a greater degree of transparency.

In summary, we can demonstrate a resource shift. We are actively pursuing the concept of demand management, which I hope will mean that the primary care sector will treat as many people as possible within the sector. We are also actively examining with local health care co-operatives devolution to LHCCs, bearing in mind the fact that we can already show that £200 million is under their management.

John Matheson: I will put some flesh on that. When we talk about acute and primary care, we tend to focus on the royal infirmary and the Western general. However, acute services are also provided in the royal Edinburgh hospital. Mental health is a national priority and, over the past three to four years, community psychiatric teams have been developed in the primary care setting of the royal Edinburgh hospital.

The teams were funded initially from a non-recurring income source—in effect, the funding came from capital receipts. Over three years, £5 million was put in to develop that work. The benefit of doing that was that the community infrastructure was put in place before the closure of acute hospital beds took place. That allowed a more seamless transfer than has happened elsewhere. Acute and primary care is not only about the cutting edge approach of the royal infirmary—it takes place in a broader context.

11:00

Mr David Davidson (North-East Scotland) (Con): I want to follow on from the convener's question and to respond to some of the comments that were made about the budget. Under the Arbuthnott distribution formula, Lothian NHS Board is given the second-lowest per capita allowance. The board also suffers from not pulling in fully its tertiary care costs. Will you supply the committee—and the Finance Committee, which would also be interested in the information—with a breakdown?

It would be helpful if you would do so using the per capita sum of £700 million—or whatever the sum that is used nowadays—and if you set out how much of it goes into acute services, how much into primary care services, how much goes into cross-cutting services and how much subsidises tertiary care. That would give us a financial handle on the tensions and the expectations about which you talked earlier and on the resources that are available.

We are not disputing the fact that the difference is in how those resources are managed. The anoraks on the Finance Committee will get down eventually to the number crunching on the budget. After that, the Health and Community Care Committee and other subject committees will discuss how NHS boards lay out, manage and develop services. That is an item of great interest this morning. However, I suspect that the basic numbers have been avoided in the discussion that has taken place so far.

James Barbour: Someone said to me once that words are easy, but numbers are hard. We do not want to avoid the numbers—John Matheson will do the numbers for the committee. I would like to respond to the member's general point about Arbuthnott. Although, in Arbuthnott terms, our allowance is the second lowest, that does not alter the fact that we receive substantial amounts of growth. Although we have not yet seen the outcome of the recent budget, we hope that that will allow us even more substantial amounts of growth. We have a responsibility to ensure that the funding is used wisely.

We are concerned in particular to ensure that the arcane nature of the Arbuthnott formula does not work in a perverse way for the Lothian NHS Board. Our population is increasing. At the moment, we are in a dialogue to ensure that the population element of the Arbuthnott formula acknowledges that fact. We need to ensure that whatever parameters are allowed to manipulate the formula within its overall internal workings; we do not find ourselves in a situation where Arbuthnott penalises us for the increase in our population. Having made that general point, John Matheson will give the precise numbers.

John Matheson: I can give the committee reams of numbers or I can give the high-level numbers and provide further detail.

The Convener: Give us the high-level numbers and we can come back to you.

John Matheson: The total allocation that comes to Lothian NHS Board is £750 million. That is made up of a cash-limited element, which is £655 million. That figure covers all the hospital services, all the primary care services and an element of the resource transfer that we make to local authorities in respect of patients who were previously in hospital, but who are now being cared for in nursing homes and by local authorities directly. That local authority resource transfer equates to just under £30 million.

On top of the cash-limited element, there is a non-cash-limited element, which includes payments to opticians, pharmacists and general practitioners. That is in excess of £90 million. If we focus on the cash-limited element of £655 million, of that £570 million goes to the three trusts within the Lothian NHS Board area. Over and above that, we get an allowance for the additional costs that are involved in teaching. The allowance recognises that Lothian NHS Board is a teaching centre that has close links with the various academic institutions in the Lothian area, including the University of Edinburgh and the other universities. That allowance for the additional cost of teaching is £24 million.

It is difficult at this time to put an exact figure on the level of subsidy for tertiary services. We are conducting a precise costing exercise within Lothian University Hospitals NHS Trust and the other trusts to identify those costs. We are engaging with neighbouring health board areas and involving them in that process and in the agreement on the costing methodology. When they have been fully engaged in that process, I hope that the outcome will be that they are signed up to the implications of that process.

Mr Davidson: I accept that that is the focus of the exercise. The Common Services Agency has an automatic transfer system for primary care services such as GP services. Is tertiary support through the acute trust the issue that you are reviewing at the moment?

John Matheson: It is indeed. I quoted the figure for the current level of payment, which is £50 million, for tertiary services provided outwith

Lothian. The exercise that we are undertaking as one of the specific projects under the pan-Lothian review group recommendations is to assess whether that £50 million is the correct figure.

Allister Stewart: As a teaching trust, we have three big responsibilities. We provide local services for the Lothian population, we provide a range of tertiary services to the Forth Valley area, the Borders, Fife and sometimes even Tayside or the Highlands, and we also provide a national service. Lothian University Hospitals NHS Trust gets £260 million from Lothian NHS Board to provide district general hospital services for the population of Lothian. Within that, there is an element of tertiary services that the people of Lothian get, but we also get £31 million from the Scottish Executive through the national services division to provide national services for everyone in Scotland. We also get £38 million from other health boards in Fife, the Borders and the Forth Valley area as well as from Tayside to some extent.

The responsibility to provide services for other health boards is an issue that has been causing us concern for some time. We would suggest that we do not get full recompense for those patients who come to us from other areas. The interesting challenge is that the Executive has just produced a draft circular on regional services, which is the first indication that we need to consider the funding of regional services. I am encouraged that that circular is now alive and well, as the Arbuthnott formula dealt with funding at a macro-level and did not necessarily help teaching hospitals to cover their costs.

As John Matheson said, we also get money for the additional cost of teaching, which amounts to £18 million, and money for research and development amounting to £7 million. We get income from a range of sources to make up our total budget. What is important to us is that we get full recompense for those services from other boards. We have suggested that, as a teaching centre and as a tertiary centre, it is right and proper that patients from other areas should come to us if we have the expertise and infrastructure to treat them.

We need to be smarter and sharper about the funding of those services and how money flows through the system. That is why we have asked James Barbour to lead a piece of work on behalf of the neighbouring boards. When I put the begging bowl out, the view is, “Well, he would ask for that, wouldn’t he?” However, there is a debate to be had about how services and money are distributed around neighbouring boards and within our own board. Neurosurgery and cancer services are good examples of the services that we provide for people from other board areas. In those areas, we need to ensure that the money follows the patient.

Mr Davidson: Are you satisfied that the Scottish Executive payment of £31 million is properly costed?

Allister Stewart: As you might imagine, I do not think that we will ever get enough from the Scottish Executive.

Mr Davidson: I did not ask whether it was enough. I asked whether it was properly costed.

Allister Stewart: We are more secure about the money that we get from the Scottish Executive for the national services division, which is more robust than the funding from other boards for the services that we provide for their patients. That is why we welcome the circular on regional services.

The Convener: I am aware that we do not have enough time to ask further questions. If there is anything else that you want to add, please feel free to write to us about it. Thank you for your evidence this morning and for the written submission that you sent. We have covered a fair range of issues and it will certainly be interesting to hear the evidence from Highland NHS Board and to learn what similarities and differences there are between that health board and Lothian NHS Board.

Brian Cavanagh: Thank you, convener. This morning’s meeting has been helpful. If MSPs—including those who represent areas outwith Lothian—want to contact us about detailed matters, we are more than happy to make that information available.

The Convener: I made a fairly prophetic comment at one of my first meetings with Lothian Health representatives after I was elected as an MSP. I said that, once members had worried about the health system in the area where they live, the next area that they would worry about would be Lothian, because if anything happened to them when they were in Edinburgh it would be Lothian’s health resources that they would call upon.

Thank you for your contributions. We shall take a very short break before the next witnesses take their places.

11:11

Meeting suspended.

11:15

On resuming—

Petition

Epilepsy Service Provision (PE247)

The Convener: Agenda item 3 is on a petition about epilepsy services in Scotland. We welcome Hilary Mounfield and Dr Richard Roberts. You may start by making a short statement to us, although we have a series of questions to ask you, which may elicit more information.

Hilary Mounfield (Epilepsy Action Scotland): Thank you very much. I shall try to make this short—what do you consider "short" to mean?

The Convener: Two minutes.

Hilary Mounfield: I was told that I might perhaps have five minutes. This will be the condensed version. I am delighted to have the opportunity to speak for even two minutes and I hope to be able to answer your questions.

I am here representing not only the 30,000 people in Scotland who have epilepsy, but their families, friends and carers. The condition is not just a medical condition like any other; it has a fantastic impact on the lives of people who have it, because of the poor health care that they receive and the stigma that is still attached to it. The impact that that has on the education facilities that are available for children with epilepsy and on employment opportunities should not be underestimated. The condition has an impact in a much wider sense than the purely medical.

In respect of medical services for people with epilepsy, Scotland can truly be said to be a third-world country. Our standards of care, particularly in relation to the number of specialists, roughly equate to those in the emerging eastern European countries. There is a misdiagnosis rate of at least 25 per cent. That means that people are carrying the label of having epilepsy when they do not have it, simply because the diagnosis has been made by someone with insufficient experience and expertise. That is shocking and totally unacceptable; something needs to be done about it.

We are pushing to change services and to get epilepsy on to the agenda. There has been report after report on the scale of the problem and what the solution might be. There is no lack of evidence about what a good epilepsy service would be; indeed, there is huge consensus. I am here today sharing the platform with a clinical colleague. We work together to try to put epilepsy on the agenda. However, the sad truth is that the service that someone receives if they have epilepsy depends on the interests of one or two people, whether general practitioners or clinicians. There are only three epilepsy clinics in the whole of Scotland—one in Dundee and two in Glasgow—yet every report that has been produced has said that the key to providing decent epilepsy services is having specialist epilepsy clinics where people can be seen by someone who has enough experience to make the diagnosis. There is a lot to do.

Janis Hughes: You make a powerful case about misdiagnosis, saying that one in four people is misdiagnosed. You state that your claim that that happens because the doctors have insufficient experience and knowledge is underpinned by research. Could you give us details of the research?

Hilary Mounfield: I can, but I cannot quote chapter and verse at the moment. Much of the research comes from Professor Brodie's clinic in Glasgow, which is the biggest epilepsy clinic in the country. A quarter of the people who are sent to his clinic for review of their medication are found not to have epilepsy. People who have been on medication for 10 or 15 years might not have had their epilepsy reviewed until they are seen by a specialist. Those are the sorts of figures that give us our figure of 25 per cent to 30 per cent.

Janis Hughes: I take it that that is Scottish research. Are the figures borne out nationwide?

Hilary Mounfield: We are not much worse than England is, except that England has decided to do something about the situation. As a result of a meeting that I was involved in with the chief medical officer in England just over a year ago, moves were made to establish a national service framework for epilepsy. The plans will be drawn up by 2004 for implementation beyond that date. There is recognition in England that, without some setting of standards, there is no reason for health boards to find out how many people have epilepsy in their area. Our research has shown that they know neither whom they are treating nor whether the treatment is effective.

Margaret Jamieson: The level of misdiagnosis obviously works both ways and, as you have said, some people are often incorrectly diagnosed as having epilepsy and some people with epilepsy are incorrectly diagnosed as having had a panic attack, for example. Are you indicating that the training of GPs and paediatricians has been insufficient in that area? Does their initial training have to be better? Could that be done in relation to managed clinical networks or clinical governance? Are we going in the right direction?

Dr Richard Roberts (Epilepsy Action Scotland): General practitioners face a difficult task, as they are supposed to be able to cover all medical conditions. One cannot expect every general practitioner to become an expert in the diagnosis of attack disorders. One might expect that, in the future, there would be a lead GP in large group practices who would take a special interest in epilepsy, but the diagnosis would still be based in secondary care because of the expertise that is required and because of the need to access specialist investigations. A large study in Liverpool suggested that there was a 25 per cent misdiagnosis rate in relation to chronic epilepsy.

A current problem is the lack of specialists. The number of neurologists in Scotland and the rest of the UK is at third-world levels, as Hilary Mounfield dramatically put it. The number of neurologists per head of population in Scotland is tiny compared with that in any other European country. In Italy, there are 21 times as many neurologists per head and in France, which provides a good neurological service and is next to us on the list, there are four and a half to five times as many. It is therefore not surprising that people have difficulty accessing specialists.

Margaret Jamieson: Are you saying that, even if we got agreement today that every health board area would have a seizure clinic, for example, we would be unable to staff those clinics?

Dr Roberts: We could not staff a service overnight, but we must start to implement such a policy for the longer term, otherwise it will not happen. As Hilary Mounfield said, endless reports in the past 20 years have highlighted the deficiencies in services for epilepsy, but no action has been taken. New money is coming to the health service over the next few years and I hope that there will be an increase in the number of neurologists and specialists in epilepsy. That is absolutely necessary.

Other things can be done in the short term. We need more epilepsy specialist nurses to advise people. Those nurses can be produced more quickly. We certainly need to improve the education and training of those who are forced to take diagnostic decisions about epilepsy, but that has been difficult. As a result of the lack of neurologists, general physicians see much acute neurology in the UK. General physicians have wide interests, but they are a dying breed. Everyone is now a specialist. General physicians who are in training as specialist registrars do not receive any specific neurology training. It is no longer appropriate for people with attack disorders such as epilepsy to be referred to any old general physician.

In district general hospitals in more remote parts of Scotland in particular, some general physicians may take an interest in and will have had some training in neurology. They will be good, but the expectation now is that, if one has a neurological problem, one should see a neurologist, just as if one has a cardiac problem, one should see a cardiologist.

The idea that one goes to see a generalist has to change, but that will take time. Training a neurologist takes around 15 years, but there has been an increase in the number of specialist registrars. As long as the number of specialist registrars continues to increase, we can produce more neurologists. Training a specialist registrar takes only five years.

The Convener: The issue is not just about epilepsy. Neurologists are involved in a range of issues, from multiple sclerosis to Parkinson's disease—some of us discussed that yesterday. I want to clarify what you are saying. Are you saying that, for the most part, people are being diagnosed by general practitioners who have had no neurological training at all?

Dr Roberts: That depends on what area of the country a person is in. Glasgow, Dundee and most of Tayside decided to prioritise epilepsy, no doubt at the expense of other neurological conditions. We considered that diagnosing epilepsy correctly should be a priority. We try to see new patients who are referred to us within a couple of weeks if a condition looks as though it might be epilepsy.

That is not always possible—it may take three weeks or four weeks—but we try to see them soon enough. That is how things should be, as patients often have their second fit—if they are going to have one—fairly soon after their first fit. They need to be seen and investigated urgently and a decision about treatment must be made promptly. Where neurological services are thinly provided, the waiting time for a routine neurological appointment can be up to a year. That is completely unacceptable for someone who has had a first epileptic seizure.

Epilepsy is usually prioritised, but even where it is, waiting times may be months. In parts of Scotland where there are no neurologists, such as the whole of the Highland area—no neurologists are based in Inverness or Elgin, although there are intermittent clinics—patients will be referred to general physicians for assessment and investigation. The same applies to paediatrics. Paediatric neurologists are even fewer and farther between—there are only a few in Scotland and there are none north of Dundee.

The Convener: I am sure that Mary Scanlon wants to pick up on that point.

Mary Scanlon: I was interested in Hilary Mounfield's comment that Scotland is a third-world country as far as epilepsy services are concerned. In your paper, you say that there are no epilepsy specialist nurses, paediatric neurologists or neurophysiologists north of Dundee. I confirm that there is nothing in the Highlands—there is not even one epilepsy specialist nurse. I set up a group because, when people are diagnosed, they are told to go home and get on with it.

My other point, which stems from my colleagues' discussion, concerns disinvestment in older, unsuitable drugs. I have found that, in the Highlands, many people who got a prescription 20 years ago are still on the same prescription. They have never seen a neurologist—they have not been asked to see one. How can we disinvest in old drugs? In addition, there has been a Scottish intercollegiate guidelines network—or SIGN—guideline on epilepsy for five years. Is that an example of such guidelines not being worth the paper on which they are written?

11:30

Hilary Mounfield: SIGN guidelines are remarkably good documents—indeed, Scotland has led the world in the area. I have attended conferences in other countries at which people say to me, "You are from Scotland—you have SIGN guidelines. They are wonderful things." Other people use them because they provide independent evidence.

The guidelines are not necessarily implemented, however. As Mary Scanlon said, we have had a SIGN guideline on epilepsy for five years. We just spent two years revising that guideline—a revised guideline will come out later this year under the chairmanship of Dr Richard Roberts. The guideline should be even more evidence based and stringent on what the service should be. However, will it just lie around on the shelf gathering dust, like the first SIGN guideline? The first guideline did not change practice in service.

If the Clinical Standards Board for Scotland, or a similar organisation, does not set standards, or if there is no service framework similar to the one that has been developed for diabetes—as I said, such a framework is to be developed in England—there is nothing that requires the health boards to address the problem or to recognise that a problem exists. Without that beginning, how can we move forward? We are trying to move forward. It is simply appalling if someone is on the same drug, which is probably old and ineffective, for 20 years. At the very least, everyone should have an annual assessment of their drug regime.

Mary Scanlon: That certainly does not happen. We have just discussed regional centres of excellence in the context of the budget. Margaret Jamieson mentioned managed clinical networks. How does a patient in the Highlands who gets no advice or support fit into the system? How can they know what they should or should not be getting? At a recent meeting, a woman told me, "My daughter is 14, has started her periods and is still seeing a paediatrician. She has never seen a neurologist. Should I be asking for that?" How can we get through to the patients that they are not getting good value from the care that they are receiving? How can we end the postcode lottery? Are you on course for a managed clinical network? Will that address the issues?

Hilary Mounfield: I would be on course for a managed clinical network, but, unfortunately, it is beyond my organisation's competence to develop one. We have supported the idea of a managed clinical network since it was first mooted more than three years ago.

Mary Scanlon: Everything is in the SIGN guideline. There is a shortage of specialists in the shorter term. How do we overcome that? How can we ensure some equity of care?

Hilary Mounfield: In the absence of standards that health boards are required to review and to monitor their services against, the situation is not encouraging. We have tried all the carrots, saying, "This is a good thing." We have provided evidence to show the scale of the problem, but there is still no requirement on health boards. Obviously, we are competing with every other priority.

Mary Scanlon: Should the requirement be in the performance assessment framework?

Hilary Mounfield: Something like that should happen. I do not care what label is put on it. Within the managed clinical network, there is a requirement on the Clinical Standards Board to set a quality framework. That would be super, but I cannot see how to bring about that shift. We are discussing it with people in different health boards. However, even where we have discussed and examined the available services with health boards, that has not translated into new services. The response is, "This is very nice. We have done the report and listened to the patient's view, but—sorry."

Mary Scanlon: Margaret Jamieson mentioned MS. I understand that all MS sufferers in Scotland are eligible for an assessment to find out whether beta interferon would help their condition. Most of us would agree with that increased emphasis on MS, but does it mean that epilepsy slips further down the list and that the skills of people such as Richard Roberts are required for MS because it has become a greater priority?

Dr Roberts: I will be able to answer that question in a couple of months. We have argued with our local health board that, if we do not have extra resources, we cannot implement the plan for MS—which we are eager to do—without detriment to current services. We have therefore applied for funding for additional neurological sessions, MS specialist nurses, additional secretarial time and a database co-ordinator. Even in our small patch of Tayside and north-east Fife, we have 1,200 patients with MS and three and a half neurologists, one of whom has a particular interest in MS. About half the patients will need to be assessed. We have a database and know about all the patients, which is pretty unique.

Mary Scanlon: Are you saying that, without additional resources, you could not decide who is eligible for beta interferon?

Dr Roberts: We cannot do that without additional resources or detriment to other services.

The Convener: You mentioned specialist nurses for MS. Earlier you mentioned specialist nurses for epilepsy. How many epilepsy specialist nurses do we have in Scotland and what role do they play? Is there scope not only for more such nurses, but for increasing their role?

Hilary Mounfield: I think that there are 12 epilepsy specialist nurses in Scotland, including those who work in paediatrics and those who work in adult services. Most of them are in Glasgow. There are a couple in Edinburgh and a couple in Dundee.

Dr Roberts: There are two in Tayside.

Hilary Mounfield: One post has recently been developed in Forth Valley, although I am not sure whether anyone has been appointed.

The Convener: On the geographical spread throughout Scotland, we are not talking about the 12 epilepsy nurses being spread evenly across the 15 health boards; we are talking about small pockets of specialist nurses.

Hilary Mounfield: That is correct.

The Convener: Do the majority of health boards in Scotland have no specialist nurses?

Hilary Mounfield: The majority of health boards do not have a neurologist, never mind an epilepsy specialist nurse.

The Convener: We have covered neurologists. I think that we know where they are. Are the specialist nurses, who could play a specific, helpful role, also missing from most of Scotland?

Hilary Mounfield: Only four health boards have specialist nurses.

The Convener: What role are those nurses who are in place playing and what scope exists for expanding that role?

Dr Roberts: The nurses can take on a number of roles. One of their most important roles is counselling patients on the diagnosis of epilepsy. An epilepsy specialist nurse is always in our clinic when we broach a diagnosis of epilepsy, because such a diagnosis has many implications. Initially, at least an hour is required to discuss those implications. After that, the nurse will visit the patients at home, see them in the home setting and see the rest of the family within the next week or two. That is a major difference in the quality of care from the neurologist saying, “You’ve got epilepsy. Take these pills. Off you go. You can’t drive and you will lose your job.” The nurses’ role is obviously crucial.

The specialist nurses also provide support for many patients with drug-resistant epilepsy. About a third of patients will have epilepsy that does not respond completely to the medication and will have persistent seizures. A lot of support can be provided. The specialist nurses can reduce the number of times that such patients need to visit the epilepsy clinic. The nurses become experts in the management of epilepsy and can advise about changes in drug dosage—in other words, they can take on some of what the doctor would normally do. They will have more expertise in the drugs that are used to treat epilepsy than the GP will have. There are a lot of new drugs with which most GPs are not comfortable and not familiar.

As with other areas, specialist nurses have an important role to play. In a sense, they pay for themselves by reducing the amount of consultant time spent reviewing patients. They are an additional cost, but they allow the consultant to see more patients. Effectively, having a specialist epilepsy nurse is a cheap way for the consultant to buy time.

Mr McAllion: You have painted a frightening picture of what cannot as yet be called a national service in Scotland and you have said that many reports back up your statements. What is missing is action by the Executive. Do you know of any plans by the Clinical Standards Board to review epilepsy services in Scotland?

Hilary Mounfield: Funnily enough, yesterday afternoon I had a meeting with Dr David Steel of the Clinical Standards Board, at which I was told that the board has no plans to add epilepsy to its list of subjects for review. We talked about elements relating to managed clinical networks and we will certainly deal with that, but the fact is that he is waiting for a steer from the health department.

Mr McAllion: Last May, in an answer to a parliamentary question, the then Minister for Health and Community Care said that Epilepsy Action Scotland was willing to co-operate in the development of managed clinical networks, which would play a part in ensuring greater equity. On 14 February 2002, the current Minister for Health and Community Care said that he was examining the possibility of establishing a pilot managed clinical network for epilepsy, but that the only thing that had happened was a symposium.

Hilary Mounfield: We held the symposium.

Mr McAllion: Well, the Executive is claiming the credit.

The Convener: Did the Executive fund it?

Hilary Mounfield: The Executive funded it, but it was our initiative.

Mr McAllion: What disturbed me was that, in the parliamentary answer, Malcolm Chisholm said that there were no plans for the establishment of an epilepsy framework. What is the reason for the Executive's resistance? You have obviously given good reasons why there should be such a framework, but the Executive just seems to be saying no. Why is that?

Hilary Mounfield: I wish that I could answer that question. We have presented a case that there is a poor service that needs energy and effort put into it by the people who have the power to make policy. The only thing that I can suggest is that epilepsy is one of many competing causes and that, as ever, the Government cannot risk adding epilepsy to the list of its priorities.

Mr McAllion: Last May, Susan Deacon said that the chief medical officer had been given a remit to work with patients groups to develop managed clinical networks. However, that has not happened.

Hilary Mounfield: We have been trying to work with individual health boards to move the matter forward. The answer from the health department is that the money is with the health boards and that, although it makes the overall policy, the decision lies with the boards.

There has been some movement. Some areas are starting to consider having epilepsy services, but that is not being translated into something that will make a difference to people's lives. Greater Glasgow NHS Board is the only health board that has allocated money specifically for epilepsy services.

Mr McAllion: That is why you argue that we need a national service framework like the one that has been agreed in England.

Dr Roberts: I would strongly support that, as it is the only thing that would create change. The health department gave us funds to conduct a large study into the implementation of SIGN guidelines in Tayside. I will not go into the details of the study, but it involved all the GPs throughout Tayside. The study showed that, on average, the GP notes of people who suffer from epilepsy mention epilepsy less than once every three years. Even in the high-intervention group, where we attempted to get an annual review going, the rate remained the same. We are preparing a paper on the study, which will be submitted soon. There is a lot of inertia. The study had to be done within three years; in the subsequent two years, quite a lot of general practices have inquired about setting up reviews and have sought advice, so perhaps change is slowly happening. However, GPs have an enormous number of competing demands and, if they are not instructed or given a financial carrot to do something, I do not think that they will.

Dorothy-Grace Elder: I was going to ask the question on specialist nurses, which has been asked. On the paucity of NHS provision, it was said that there are 12 specialist epilepsy nurses who are confined to certain areas of Scotland. I recall that we were told that there were eight specialist multiple sclerosis nurses in Scotland and it turned out that several of them were financed by charities. Does Epilepsy Action Scotland or any other charity contribute to the funding of the 12 epilepsy specialist nurses or units? The Church of Scotland, for instance, has done a lot of good work on epilepsy.

11:45

Hilary Mounfield: Certainly—the church has a care home. Many epilepsy nurse posts in Scotland were established with charitable funding in the first instance, on the undertaking that the health board would continue the funding. Continuation of funding has sometimes been in doubt, but that is how posts have normally started up. Posts are being created in Glasgow. Another couple of epilepsy specialist nurse posts have been created that are funded purely by the health board and have not been subject to such sideways funding. The worth of such posts has been established.

Dorothy-Grace Elder: Are any such posts in Scotland still wholly or partly funded by charity money? We do not want to claim that the NHS provides 12 specialist nurses if you are doing much more.

Hilary Mounfield: I cannot be specific about that. I think that most of the epilepsy specialist nurses are now funded by health boards, except perhaps those who work in one of the clinics in Glasgow. For years, most staff in that clinic were funded by research moneys from various sources and were not funded by the NHS.

Dorothy-Grace Elder: It was said that it could take 15 years to train a neurologist and for him or her to gain proper experience. To return to Margaret Smith's question, could some managed clinical networks be more nurse led? Has there been any resistance to that within the medical profession?

Dr Roberts: I do not think that there has been any resistance to the idea of specialist nurses contributing to care; on the contrary, there has been enthusiasm.

Dorothy-Grace Elder: Has there been any resistance to nurses leading?

Dr Roberts: Epilepsy nurses are concentrated where there are epileptic services and where there are specialists who have an interest in epilepsy.

Dorothy-Grace Elder: So that is one way that can be gone down.

Dr Roberts: Those of us with an interest in epilepsy have campaigned for the appointment of specialist nurses. The trouble is that in regions such as Highland, there is simply nothing.

Dorothy-Grace Elder: We are going to Inverness next week and I hope that that is on our agenda.

Shona Robison: It would be useful and helpful if the committee were provided with written evidence to put more meat on the bones in respect of what is provided in each health board area. That would give us a better picture.

I want to pick up on the possible impact of MS trials on current epilepsy services, which is beginning to worry me. Have other services in other health board areas also put in bids for additional resources?

Dr Roberts: Scottish neurologists will meet on Friday and that is one of the items on the agenda. I have not yet heard what the bids have been in Glasgow and Edinburgh, but I have no doubt that there will be bids for appropriate funding. In Aberdeen, the situation is more complicated because many patients are already on beta interferon. The implications of implementing the new scheme there are much fewer, because most of the patients are already on the drug and will not require the detailed review.

Shona Robison: Are you optimistic about the outcome of the bids for additional funding? I know that it is difficult for you to answer that question.

Dr Roberts: It is too early to say. I am reasonably optimistic. We will certainly get the MS specialist nurses, because industry will fund them for the first couple of years. All that we require is a commitment from the board that it will take up the funding thereafter. We do not want to get into the position in which we found ourselves with an epilepsy specialist nurse, who was trained up, was in post for a couple of years and was really getting stuck in when the funding suddenly ceased. In the short term, there will be quite a lot of funding from industry to support the MS specialist nurse posts. However, longer-term commitments from the boards are required.

Shona Robison: Perhaps the committee should keep an eye on the outcomes of those funding applications and any possible impact on epilepsy services when the MS trials begin.

The Convener: The evidence that we have heard shows that a number of the neurological issues are interrelated. Because of the shortage of consultants, change has a knock-on impact beyond any particular disease.

Mary Scanlon: I will add to the point that Shona Robison made. Inverness, which covers a huge area, buys in the services of a neurologist from Aberdeen for three days a month. I understand that the demand in Aberdeen for neurologists' time is such that it is difficult to fulfil the obligations at Raigmore hospital. I am concerned about the testing of all MS sufferers for suitability for beta interferon because the knock-on effect could be that Grampian NHS Board says that the demands are too great in Grampian and that it cannot afford to let the neurologists go to Inverness for three days a month. The effects ripple through the system.

The Convener: A certain amount of that is happening throughout Scotland. The Lothian neurologists, who go to Fife, are in a similar situation. That is an issue.

I thank the witnesses for their evidence. Is there anything else that you feel that we have not covered and that you want to put on the record, or do you feel that you have made the main points?

Mary Scanlon: May I ask a general question so that we can get a clear answer from Dr Roberts and Hilary Mounfield? What are the biggest obstacles to improving services for people with epilepsy and how do we overcome them?

Hilary Mounfield: The biggest obstacle is the inertia about which we have spoken. It is partly a function of the ignorance about epilepsy, which is historical and widespread. In many ways, that applies to the medical profession as well as the general public. That may sound shocking, but it is a fair comment.

As you know, to remove the inertia, we need the biggest energy at the beginning to get things going. We feel that a head of steam has been built up: we have the evidence, we know what to do and we have consensus. The biggest obstacle is the lack of a requirement for anybody to do anything. Without some sort of standard monitoring of services or requirement for health boards to know what their services are, nothing will happen. We did a survey of services in Scotland two years ago—we can let the committee have a copy of it. Most health boards could not answer the questions because they did not know what services they had or did not have any services.

Dr Roberts: I concur with that. There are no really good services. Where there are better services, they have developed because there happens to be a clinician—a neurologist or clinical pharmacologist—who is interested in epilepsy and has developed the services. There has been no planning of services anywhere. Much more central direction is required if we are to have equity of service throughout Scotland.

Dorothy-Grace Elder: Shona Robison asked for more details. Would it be possible, convener, to set a deadline for that in view of our visit to Inverness on Monday? Is it possible for the witnesses to get something in to us by Thursday or Friday?

Hilary Mounfield: We can give you copies of our survey because it has been published. It does not deal with the situation today, but provides a snapshot of the situation 18 months ago. In regard to your visit to Inverness, a response that I have seen from Highland NHS Board on the subject of epilepsy services and the SIGN recommendations contained phrases such as “no comment”, “don’t know”, “we think the GPs do this” and “not a hope”. The letter closed by saying that the board hoped that its comments were helpful. We can let you have a copy of that letter.

The Convener: We might ask the board members whether they find our quoting that letter back at them helpful.

We will wait until we hear from you again. On Monday, we have to deal with the budget, but we can use certain points to talk about specific issues.

Some of our members are not present today, but the committee must discuss what can be done to take forward the issue in relation to the Executive, the Clinical Standards Board for Scotland and others who might be involved. We will return to that at a later date.

We have touched on the fact that there is an interrelationship between epilepsy and other neurological conditions and we have talked about the lack of neurologists and specialist nurses. Have you ever joined forces with other organisations in the same sort of field to lobby about general issues rather than just epilepsy?

Hilary Mounfield: Yes. A couple of years ago, an organisation called Voluntary Health Scotland, of which I am currently chair, was established. It works at the widest possible level, dealing with the voluntary sector’s input to health services. I am passionately committed to ensuring that organisations work together.

A couple of weeks ago, there was the first meeting of organisations such as ours that have an interest in a neurological condition. There is a recognition that the Neurological Alliance, which is a UK body, has been largely ineffective in Scotland and that there needs to be a Scottish lobbying group. We agree that we have some degree of common cause and that it serves nobody to view our causes as being specifically to do only with the neurological condition that each group is primarily interested in. We must use our combined strength to make our voices heard, while fighting for our specific interests when we need to. We hope to work through the Neurological Alliance to strengthen its position in Scotland and ensure that it is focused not only on Westminster and is aware that, in relation to health in Scotland, Holyrood is the centre of the world.

The Convener: That is useful.

I thank our witnesses for their attendance and for the evidence and background information that they have given to us and the Public Petitions Committee. We will return to this matter at a later date to discuss what we want to do with it next.

We now move into private session to deal with agenda item 4, which deals with witnesses for our consideration of the School Meals (Scotland) Bill

11:59

Meeting continued in private until 12:28.

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