HEALTH AND COMMUNITY CARE COMMITTEE

Wednesday 19 June 2002
(*Morning*)

Session 1

£5.00

Produced and published in Scotland on behalf of the Scottish Parliamentary Corporate Body by The Stationery Office Ltd.

Her Majesty's Stationery Office is independent of and separate from the company now
trading as The Stationery Office Ltd, which is responsible for printing and publishing
Scottish Parliamentary Corporate Body publications.

CONTENTS

Wednesday 19 June 2002

Col.

HEALTH AND COMMUNITY CARE COMMITTEE

17th 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) (Ind)
*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)

COMMITTEE SUBSTITUTES

Brian Adam (North-East Scotland) (SNP)
Ian Jenkins (Tweeddale, Ettrick and Lauderdale) (LD)
Ben Wallace (North-East Scotland) (Con)

*attended

WITNESSES

Lynn Adams (Macmillan Cancer Relief)
Andrew Anderson (Maggie's Centre)
Andrea Cail (Children's Hospice Association Scotland)
Pat Dawson (Royal College of Nursing)
Dr Bob Grant (British Medical Association)
Dr Duncan Jodrell (Cancer Research UK)
Nora Kearney (Royal College of Nursing)
Terry Kehoe (Amicus MSF)
Dr Martin Leiper (Scottish Partnership for Palliative Care)
Dr Linda McCallum (British Medical Association)
Gary McRandle (Tak Tent Cancer Support)
Dr David Millar (Macmillan Cancer Relief)
Susan Munroe (Marie Curie Cancer Care)
Dr Euan Paterson (Royal College of General Practitioners)
Mrs Rosemary Pennie (Tak Tent Cancer Support)
Dr Charles Saunders (British Medical Association)
Susan Smith (Royal College of Nursing)
Madeleine Stafford (Tak Tent Cancer Support)
Sandra White (Royal College of Nursing)

CLERK TO THE COMMITTEE

Jennifer Smart

SENIOR ASSISTANT CLERK

Peter McGrath

ASSISTANT CLERK

Michelle McLean

LOCATION

The Chamber

Scottish Parliament

Health and Community Care Committee

Wednesday 19 June 2002

(*Morning*)

[THE CONVENER *opened the meeting at 09:36*]

Items in Private

The Convener (Mrs Margaret Smith): Good morning everybody and welcome to this morning's meeting of the Health and Community Care Committee. I have apologies from Shona Robison.

Item 1 is to consider whether the committee should take the following items in private and partially in private. I intend to move item 7, which is consideration of possible witnesses to give evidence on the Adults with Incapacity (Specified Medical Treatments) (Scotland) Regulations 2002, to item 5 on the agenda. I suggest that we have a discussion in public session on that issue, but if we need to discuss potential witnesses we will go into private session, as is our normal practice. Is that agreed?

Members *indicated agreement*.

The Convener: I suggest that item 6, which is consideration of our draft annual report, be taken in private. Is that agreed?

Members *indicated agreement*.

The Convener: Item 7 then, will be the cancer plan. The committee will consider several options regarding possible future action, which could include a draft report. Again, I suggest that we take that item in private. Is that agreed?

Members *indicated agreement*.

The Convener: I also ask the committee to agree that at our evening meeting on 26 June we have a briefing on the proposed mental health bill, which we expect to be published in the next week or so. We will also have a report on possible advisers and witnesses for that proposed bill, which would obviously involve discussion about individuals, and a report on possible witnesses for the Public Appointments and Public Bodies etc (Scotland) Bill. We have just been informed that we will be a secondary committee for that bill. Again, we will need to discuss individuals for that. Given the timing of the bill, we expect to have that discussion in private session at the evening meeting on 26 June. Would that be agreeable to committee members?

Members *indicated agreement*.

Subordinate Legislation

National Health Service (Clinical Negligence and Other Risks Indemnity Scheme) (Scotland) Amendment Regulations 2002 (SSI 2002/239)

The Convener: No members' comments have been received on the regulations, the Subordinate Legislation Committee has no comments and no motion to annul has been lodged. The recommendation is that the committee does not wish to make any recommendation on the regulations. Is everybody agreed?

Members *indicated agreement*.

Cancer Services

The Convener: Item 3 is cancer services in Scotland. We are taking further evidence on the issue. We are trying to get a post-cancer-plan snapshot of what people from a range of different backgrounds and viewpoints feel about where cancer services in Scotland are, where they are going and what we can do to improve them.

The first set of witnesses are Gary McRandle, Rosemary Pennie and Madeleine Stafford, from Tak Tent Cancer Support, and Andrew Anderson, whom we have met previously, from Maggie's Centre. We would like to talk to you specifically about patients and patient support in relation to cancer services, but I am sure that you will be able to raise other points in your answers. I suggest that, as we are tight for time, we move on to questions. At the end of the questioning, if you feel a burning desire to add anything that we have not covered, and which you want to put on record on behalf of your organisation, just catch my eye.

We will kick off with Margaret Jamieson.

Margaret Jamieson (Kilmarnock and Loudoun) (Lab): How do you feel about the empowerment of patients and voluntary sector staff that was contained in the cancer plan? Are you more empowered and more involved in the planning and development of the services? How has that been achieved?

Andrew Anderson (Maggie's Centre): Maggie's Centre has not been involved in any of the strategic planning within the cancer plan, but we were invited to comment on it at the start. The important part of the plan for us, as an independent charitable organisation providing support, was the recognition of the role of independent support facilities. One key issue, of which I am aware from my previous experience as a health care professional in the national health service, is the need for the NHS to work with support facilities such as Maggie's Centre, Tak Tent Cancer Support and CancerBACUP to add to NHS support facilities.

Clearly, huge demands are placed on professional staff in the NHS and there are insufficient logistical resources to address all the psychological and emotional support needs of patients and their families. We must work more with the NHS in a tandem approach. In the experience of the Edinburgh Maggie's Centre, that is an effective working system, but we have done it locally through contact with health care professionals within a hospital and the wider community. I hope that that system continues to develop. However, the system has not arisen specifically as a result of the cancer plan.

Mrs Rosemary Pennie (Tak Tent Cancer Support): Our Tak Tent Cancer Support group has made contact with the specialised nurses in the local hospital. We have had those nurses as speakers to our group and we hope that because of that they will send patients to the group for help. The specialised nurse is great when people are going for surgery, but people reach the point when they do not want to bother the specialised nurse any more. We feel that the groups are good because they allow people to get help beyond that point.

Janis Hughes (Glasgow Rutherglen) (Lab): I would like to focus on the many different aspects of the care pathway for cancer patients, from first referral through diagnosis, treatments, rehabilitation, palliative care and so on. Are there any areas in that pathway that still cause frustration to patients? Have you noticed significant improvements in any areas?

Andrew Anderson: Unfortunately, there are still significant issues for people within health care systems. Speaking anecdotally about the people who use Maggie's Centre, I think that one of their continuing criticisms of the health system provision is the link between primary health care and secondary health care. Getting a diagnosis made and getting into health care systems is still a complicated procedure for some people. It is important that that has been speeded up, particularly within specialist areas such as breast cancer. In addition, the Western general has a new initiative, which is a neurological cancer unit that is starting the one-day diagnosis system. Unfortunately, several people still seem to slip through the net because symptoms are not addressed or investigated by their primary health care physician or general practitioner.

The general public's perception in those instances is that those are cost issues. The patient's perception is that they are not being sent for further investigation because of the cost that is associated with that. It is an easy avenue for the patient to target, but that may be a good clinical judgment on the part of the health care professional.

I am also aware that we see the sharp end of those problems. Many of those who use a facility such as Maggie's Centre suffer continuing distress that is associated with the process of diagnosis. It is important to note that the majority of people say that, once they get into the system of specialist care within cancer care, they are absolutely delighted with the level of care that they get from a clinical perspective. That is certainly the experience in Edinburgh.

09:45

There are still issues to do with the way in which patients are communicated with. That has been a continual problem throughout all aspects of health care. Are patients treated as individuals and made to feel that they have an important role to play in their treatment rather than processed as another bar code that is coming through the system? As a health care professional, I know that it is difficult to provide a personalised service for a large population, but we must strive to achieve that, because it allows people to feel more in control, more able to deal with their diagnosis and treatment and to be active players in that. Good evidence from randomised controlled clinical trials suggests that those who are empowered and made to feel that they are partners in their care do better because they participate more effectively in their care and therefore feel emotionally stronger.

The area that people raise and with which I still have issues is the link between primary health care and the hospital in making a quick and efficient diagnosis. Once people get into treatment, many of those issues have been levelled out.

Janis Hughes: Is that a training issue?

Andrew Anderson: It certainly is. Last week, I spoke to a group of GPs who had invited me to speak to their practice. As an initiative, that is great in its own right. People are aware of what services are available.

At a meeting last week about epithelial ovarian cancer, it was stated that a GP will see about six patients with epithelial ovarian cancer in their lifetime of care. They cannot be expected to be experts in every sub-specialty—that is an unreasonable request to make of GPs. However, awareness should be heightened, particularly on areas such as cancer, in which early diagnosis and early intervention have been shown to make a definite difference to the treatment outcome and the emotional impact. Training is an integral part of that.

Madeleine Stafford (Tak Tent Cancer Support): I attended a clinic in Glasgow for years, so I was in the system. Nothing was cancerous at that point. Three months before I was diagnosed with cancer, I was told not to go back. I am fortunate that my company sends me for a medical every two years and that I was sent that year, not the following year. Three months after having been told not to go back to the clinic, I was diagnosed with breast cancer. My point is that more facilities are needed to have a better look at patients so that early diagnosis happens. I am fortunate that I was caught early. Had I been sent for my medical in May this year, I might not be here.

The committee might think that, as I had been in the system, more attention would have been paid to me. Even when I went to the clinic with the X-rays that I had from my medical, I was examined and told that nothing could be found. Had I not had the X-rays to back me up, I would have been sent away again.

I feel that something more must be done. I know that we cannot keep examining women every day of the year and that we cannot keep giving them mammograms. I do not know whether more staff are needed or some type of procedure that ensures that patients are examined more closely.

However, once I got into the system, the speed with which I was dealt was excellent. I have no complaints about being diagnosed and the treatment that I was given. The surgery is another matter.

The Convener: That point comes through quite a lot. I spent a day shadowing Anna Gregor at the Western general, which is a few steps away from Maggie’s Centre. At the end of every consultation, because I was with her, Anna Gregor asked the patient what they thought about services. Time and again, people said that, once they got into the system, they were very happy with the specialist service that they received in the acute sector. However, patients said that they found it difficult to get into the system. They said that there were communication problems between the different parts of the system. They also said that they had problems at the point of discharge in getting a discharge plan that worked for them and their families. While patients were in the specialist side of the system, their treatment was good, but many of the problems happened on entry to and exit from the system.

Madeleine Stafford: Yes. I agree.

Mr John McAllion (Dundee East) (Lab): The Public Petitions Committee has a petition in the pipeline that is almost ready to be sent on to the Health and Community Care Committee. The petitioner proposes that all women who are called into breast cancer clinics should be given the triple examination. The fact that they are not means that some women do not receive an early diagnosis of their cancer. Do you support that proposal?

Madeleine Stafford: Yes, definitely. In the past year, I have met many women who have attended clinics only to find out at a later stage that they have cancer.

Mr McAllion: That is an important point. We received a response from the minister, which sets out that, because of resource implications—including the thousands of X-rays that will have to be taken—and because there is a slight danger of X-ray-related cancers being given to healthy women, it is not Executive policy for women to be given the triple examination.

Madeleine Stafford: It is possible to detect cancer from ultrasound examinations, which are not as dangerous as X-rays. Even though I had X-rays, the hospital had to give me an ultrasound examination to confirm the X-rays.

Mr McAllion: It will be interesting for the committee to see the petition when it arrives.

Mary Scanlon (Highlands and Islands) (Con): I want to continue on the theme of feedback from patients, who have spoken about their experience of the managed clinical networks. In doing so, I refer to Tak Tent's submission, which sets out that the

> "smooth transfer between Primary Care and the Acute Sector, and within the acute sector still is haphazard."

It goes on to say that

> "the links between the Health Service and Social Services are often poor, especially for those with palliative care needs."

I also have a question for Maggie's Centre. Within the managed clinical networks, why are only one in five newly diagnosed patients able to access Maggie's Centre to get the psychological support that is clearly so helpful to them?

Andrew Anderson: One of the most important aspects of the way in which Maggie's Centre functions is that we are a self-referral centre. It is up to the individual to choose to access us or not. There is an argument that health care professionals could identify people's needs and refer them formally to us, but that that would alter the dynamic of our centre.

We are delighted that one in four or five newly diagnosed patients at the Edinburgh centre knew about and accessed Maggie's Centre. In looking at the other side of that coin, I think that the upside could be that patients felt that they did not have a significant need to access us or felt that their needs were being met. A wide range of studies show that between 20 per cent and 30 per cent of people are affected by a diagnosis of cancer. The figure, which includes the patient and their family members or carer, relates to the degree of psychological distress, including acute anxiety or depression, which is diagnosable. It is important to note that Maggie's Centre sees a significant number of people. We see 2,500 new people each year, many of whom are distressed, but the symptoms are not diagnosable.

As we mentioned, we are keen to discuss the links between the NHS and voluntary sector organisations to ensure that all patients who come through the system are aware that facilities such as Maggie's Centre, Tak Tent Cancer Support and Macmillan Cancer Relief are available to them. That would enable patients to make decisions according to their needs.

Mary Scanlon: And Tak Tent?

The Convener: Does Tak Tent want to add anything to what has been said?

Mrs Pennie: Communication between some doctors and their patients is patchy. My daughter had thyroid cancer five years after I had breast cancer; she was diagnosed four years ago. She finds it extremely difficult to speak to her oncologist, which makes me quite upset. I was lucky in that the surgeon who looked after me was excellent at communicating. The quality of communication seems to be patchy. That could be addressed in the training of doctors. To be a patient is to sit on a different side of the fence and it is hard.

Mary Scanlon: You drew attention not just to the communication between health professionals and patients but to the communication among health professionals, which is haphazard. That causes me concern.

Madeleine Stafford: When I was in the system, I had to deal with three consultants. I was sold—if that is the right word—a team that would help me through the surgery and the treatment. In time, I found that the consultants did not speak to each other. When I saw one consultant, he asked me what another consultant had said. I did not feel that I was a messenger and did not want to give information to a consultant that might have been wrong, as a result of which something might have happened to me that should not have happened, such as an operation. I had to write to the three consultants to ask them whether what I had said to the surgeon was correct, so that I could have it in writing on my file.

Mary Scanlon: Is that a unique experience or, in your opinion as a member of an organisation that represents patients, is it something that happens commonly to people who come to you for support?

Andrew Anderson: Unfortunately, such an experience is not unique. One of the problems is that people who receive cancer treatment come to large institutions and organisations and many professionals are involved in providing their care. I have worked in the NHS and I know how difficult it is for information to transfer from specialist to specialist.

Each cancer specialty must be managed within a multidisciplinary team—that is written into the cancer plan. In my experience, the functioning of those multidisciplinary teams has made communication easier. Not all the communication issues have been resolved, because personalities are involved and the fact that some medics work in different ways produces different opinions. There is no doubt that the multidisciplinary aspect of professional working makes a difference to communication within teams.

Mary Scanlon: Would patient-held records help?

Andrew Anderson: Absolutely. That was the second point that I was going to make. Patient-held records are an essential part of that. The content of those records is still up for debate, but the National Cancer Alliance did a piece of work at the end of the 1990s and there is no doubt that patient-held records make a difference to the way in which people feel enabled to challenge and ask questions to ensure that their quality of care is maintained. I hope that all hospitals will use patient-held records to some extent. Those records do not have to be extensive, but they should include things to be noted from previous clinics along with plans about future treatment.

The other important aspect of patient-held records is the link with the community that they establish. You have suggested that the link between primary health care and hospital health care is one of the problem areas. It is easy to target the blame for that on GPs, but that should not be done. There should be more integrated working between primary and secondary health care and I hope that patient-held records will be a key to making communications much more effective.

Mrs Pennie: Although I feel that I was lucky that there was communication between the different doctors who looked after me, the situation is often hard. I am the secretary of the south-side group and I know that there are patients who experience difficulty in going between different hospitals and different doctors. I have noticed that the more mature doctors are better at communicating with one other. I do not know whether the young doctors have been trained in a different way, but they do not tend to communicate as well with other doctors in other hospitals.

Dorothy-Grace Elder (Glasgow) (Ind): I was about to ask how good is the information that is provided to patients and their families, but my question has been answered in part. However, I want to pin down some of the reasons behind the lack of communication: is it caused by a lack of clerical and medical secretaries to pass the notes on? It was mentioned that some young doctors might be over-ambitious, so is the lack of communication due to personality differences between doctors? Why do patients receive poor or even muddled information?

10:00

Mrs Pennie: The lack of communication is probably caused by a mixture of things. Just before Christmas, I was awaiting the results of a mammogram. Although the letter was dictated the week after I had had my mammogram, it took four weeks to reach me. By the turn of the year I was going off my head waiting for the results so, unable to contain myself, I phoned the breast-care nurse. I was fortunate in that she was able to access the information and to put my mind at rest because everything was okay. However, even though it was a holiday, that was quite a long time to wait. The letter stated when it was dictated, when it went to the typing pool and when it was typed; there was quite a time between those.

Dorothy-Grace Elder: Was the letter typed approximately four weeks after the consultant or surgeon had dictated it?

Mrs Pennie: Yes.

Dorothy-Grace Elder: We have heard anecdotes that doctors sometimes give up trying to get a letter out through the NHS because they say that it can take 12 weeks. That is a clear clerical problem that is caused by the lack of medical secretaries. Does anyone have any other suggestions about the reasons for poor communication?

Madeleine Stafford: The staff might be overworked—patients are pushed through very quickly. Apparently, on the day on which I was diagnosed, my surgeon had seen 60 patients, four of whom were diagnosed. It might help if, instead of surgeons telling patients what is wrong and then sending them home, information could be made available to patients, which they could read and ask questions about when they have recovered from the trauma of being told devastating news. At the moment, patients are just told what treatment they are likely to receive and then sent home.

Dorothy-Grace Elder: Perhaps that can be attributed to shortage of time and people being overloaded with work.

Madeleine Stafford: It is also possible that there are not enough resources to give patients that information. Not every patient that is seen needs such information, but some information should surely be given to those who need it. I had never in my life dealt with cancer—it is not the kind of thing on which you have books at home; rather, you need people who know about it.

Dorothy-Grace Elder: Finally, does anyone want to comment on lack of pain relief? CancerBACUP claims that about one third of cancer patients do not receive adequate relief in the community. Does anyone have any comments on denial of certain cancer medications?

Andrew Anderson: In my experience, people are never denied treatment. The issue has much to do with educating the general public.

Dorothy-Grace Elder: I am talking about the denial of funding and postcode prescribing of medicines such as those for colorectal cancer.

Andrew Anderson: I have absolutely no experience of that.

On the previous point about how people communicate with those who are affected by cancer, we must recognise an important thing. It is fair to say that the logistics of such a huge work load can mean that people are under pressure, but often even the best communicators do not get things absolutely right. In part, that is because—as has been described—going to a clinic when you expect to be given bad news is an extremely stressful experience, no matter how that news is delivered.

Good evidence has shown that people retain only 15 per cent to 20 per cent of the information that is given at a consultation, which makes it difficult to pass all the information directly to the patient and their family. The way in which clinics operate must take that into account and we must consider whether extra clinics should be provided for follow-up information and to give patients and families the opportunity to make sense of matters and ask questions.

Dorothy-Grace Elder: Did you have difficulties with sending letters, with communications and with weeks of delay when you worked in the service?

Andrew Anderson: Yes I did, unfortunately.

Dorothy-Grace Elder: How long were delays?

Andrew Anderson: I will not give examples, but there are delays and missed communications, even interdepartmentally. Such delays are not always caused by a unit's being overworked. They can be caused by the way in which a system has been established or the nature of some of the staff who work in that system. Not everybody is 100 per cent motivated to ensure that things are done effectively on the day. I would not necessarily blame only the system or a lack of resources.

The Convener: The Scottish cancer plan acknowledges that facilities for teenage and adolescent cancer patients are limited. Have your organisations had experience of dealing with younger people who suffer from cancer?

Andrew Anderson: We and Tak Tent have such experience. In Maggie's Centre Edinburgh and the other Maggie's Centres that we are developing, a key part of the programme is a young person's support group, which is for people from the age of about 16 to the mid to late 20s. There is a deficit of service provision for that population.

I will speak from an Edinburgh perspective. Kids are extremely well catered for in the sick kids hospital in Edinburgh and young adults are well catered for in the Western general hospital, but a gap exists in which many needs are not being met because of developmental and psychological issues that are associated with that period of life, in addition to any impact of cancer.

An adolescent nurse specialist was recently appointed and a Sargent Cancer Fund for Children social worker is working with that age range in the Western general. Maggie's Centre also provides a resource as a support facility. The matter must be addressed and examined. The Teenage Cancer Trust is keen to increase awareness UK-wide by providing facilities or increasing awareness of the need for provision.

Gary McRandle (Tak Tent Cancer Support): When I first took ill in 1991, I was 11, and there was nothing for young children of my age. There was nothing until about four years ago, when I was introduced to Tak Tent. It had started a young adults group for people aged between 16 and 25. The name of that group has recently changed to conTak. Kids who are aged between 16 and 25 can go along and chat about general issues. If they want, they can chat about their illness, but they do not have to. From when I was 11 until I was 18, there was nothing.

The Convener: Was nothing in the health service geared to young people?

Gary McRandle: There was nothing for that age range.

Nicola Sturgeon (Glasgow) (SNP): To what extent have the problems of long-term underfunding and staffing shortages at the Beatson oncology centre in Glasgow compromised patient care?

Madeleine Stafford: I am just a year from diagnosis. I last saw my consultant—who has now left the Beatson—in October last year, when he told me to return after six months. I phoned the centre after I heard about his leaving and was told that my appointment would be rearranged with one of the remaining consultants. Before my appointment, I received a letter that told me not to return at all. Patients who have finished their treatment are referred to their surgeon. If another problem occurs, the Beatson will see me again.

Given that I was not even a year from diagnosis, I would have preferred to see a consultant, so that the consultant could tell me that I was okay. I would have preferred to have a chat about what had happened in the examination. However, I was simply told not to come back.

Mrs Pennie: In the same week that Madeleine Stafford had that experience, another lady from our group phoned me to say that at her six-week check-up she was told after radiotherapy not to come back. That lady was absolutely devastated, because she had a very aggressive type of cancer and felt that the oncologists were abandoning her. She found that to be very upsetting.

Patients also find much of the publicity in the newspapers to be upsetting. Another young lady with two young children is currently undergoing chemotherapy. A couple of weeks before she was due to see the breast surgeon, she read in the paper that the breast clinic at the Victoria infirmary had been closed. She phoned me in a panic and the next day she spoke to the breast care nurse, who told her that the hospital did not know the basis for the story. Staff assumed that it must be about the fact that oncologists were no longer holding clinics in the hospital. The information that was given in the story in no way reflected the real situation. Oncologists had not been holding clinics at the hospital for six months. I do not know whether there is a way in which to deal with publicity that is not accurate and disturbs patients.

Nicola Sturgeon: Over the past few months a great deal has been done to improve the situation at the Beatson. As patients and patients' representatives, have you been able to discern any improvements, or is it too early to say?

Mrs Pennie: It might be too early to say.

Madeleine Stafford: I am not at the Beatson any more. However, as has been said, the centre suffered from a lack of administrative staff; administration was not always as good as it could have been. The day after I received a card for the October appointment to which I referred, I received a card to attend a clinic in Ayr. I phoned the Beatson to ask why I had to go to Ayr and was told that there had been a mistake. The appointment in Ayr was cancelled, but when I went for my correct appointment I found that that had also been cancelled. I then had to wait until I was given another appointment. Administration at the Beatson could be improved. It is traumatic for someone who is waiting to see an oncologist to be told, when he or she arrives at the clinic, to go home. Fortunately, I live in Glasgow. What would be the situation of someone who lived elsewhere and had to arrange travel?

The Convener: Would you like to raise any other issues about which we have not asked you?

Madeleine Stafford: At hospitals, patients are assigned breast cancer nurses, whose performance is particularly poor. On diagnosis, patients are given a number that they are supposed to be able to phone at any time. However, when they phone up they often reach an answering machine. Perhaps three days later, they are called back. That is not good enough.

I spent a week in hospital, where breast cancer nurses were supposed to look after me and help me through the trauma. However, while I was there I did not see one breast cancer nurse. That aspect of care could be improved considerably. To whom are people supposed to turn? They do not know anyone who has information that can help them, and because the experience is so new to them they do not know about groups such as Tak Tent.

Andrew Anderson: We need formally to pursue a structured approach to psychological support within the NHS. I know that such an approach is mentioned in the national cancer plan, but the root problem is the training spaces that exist for clinical psychologists and the positions that are available after training. We are aware that we will have difficulty recruiting clinical psychologists for our new centres, partly because there is currently a dearth of such professionals. We are having difficulties, even though we are an independent organisation that might be seen as a more attractive employer than the NHS.

Structured psychological and emotional support should be integral to the way in which people who have been diagnosed as having cancer are cared for. Such support does not always have to be provided by clinical psychologists. However, it must provided by people who are allocated to the task and who are able to provide that support effectively on an on-going basis. As a voluntary sector organisation, we are happy to provide such support and to work in tandem with the NHS, but structured psychological support should be an integral part of the way in which the NHS works. At the moment, it is either under-resourced or under-utilised.

10:15

The Convener: Thank you for your oral and written evidence. I put on record our thanks to both Maggie's Centre and Tak Tent Cancer Support for all the great hard work that they, their volunteers and staff put in. I know a little more about Maggie's Centre, because it is located in my constituency. I know from talking to patients that they get an incredible amount of support from organisations such as Maggie's Centre and Tak Tent Cancer Support. Both organisations are expanding, which is good news. The need for the services that they provide is increasing all the time.

We will break for a couple of minutes before taking evidence on primary care.

10:16

Meeting suspended.

10:22

On resuming—

The Convener: Our next section of witnesses—I am not sure what to call a collection of witnesses; victims, probably—will address primary care. We are trying to get a snapshot of where cancer services in Scotland are post the cancer plan, and to tease out the key issues that surround primary care. We have heard this morning that there are problems with communication between the primary and secondary sectors. Our anecdotal experience is that once people are in the system, they are relatively happy much of the time with the care that they get. However, accessing the system, being diagnosed and then coming out of the acute sector into community care is at times difficult. Multidisciplinary primary care professionals are ideally placed to give us an insight into that.

We will go straight to questions. If, after that, there is anything else that the witnesses wish to address, we will give them time to do so. Thank you for coming this morning.

Margaret Jamieson: Do our GP witnesses believe that the recently published referral guidelines for GPs will result in marked improvements for patients who are referred to secondary care?

Dr David Millar (Macmillan Cancer Relief): I sat on the sub-group that produced those referral guidelines. They were adapted from the English ones, which were evidence based, and which have been in force in England for some time. The evidence that is coming through from England is mixed. My view is that the referral guidelines were needed, but I am not convinced that they will make a big difference. Historically, a lot of the evidence that has been built up around how patients present with cancer has come from the secondary care sector. A specialist will see a series of lung-cancer patients and identify how they presented to him. In general practice, every day we see people with coughs, breathlessness, chest pain and occasionally blood in their spit. It is very difficult to identify those who should go on for further investigation and we will never get it right 100 per cent of the time. There will always be people who appear to have been missed.

The referral guidelines might help us to focus on one or two patients about whom we have not made a decision on whether to refer them. That will work both ways. Some of the guidelines will prevent us from referring people whom we might otherwise refer, because the likelihood of that individual's having a malignancy is very low.

Every medical student leaves university knowing the symptoms of cancer. Ovarian cancer, which we heard about earlier in the meeting, is incredibly difficult to pick up in general practice, so we miss it. However, I referred the most recent case of such cancer that I saw to the specialist three times and he missed it three times. The issue is not simply about training. Training will help but we, as GPs and primary care professionals, have to be able to sit at the table with specialists and work through the referral guidance locally to produce fast tracking for patients who have problems.

Dr Bob Grant (British Medical Association): The referral guidelines will be very useful, but GPs must be able to access them easily. In their current paper form, they might lie in inaccessible parts of the doctor's surgery. I know that work is going on to make them available through GPs' information technology systems. If they come up on the screen at the time of the consultation, that will help.

The other point is that GPs and the secondary care sector must have ownership of the guidelines. I believe that the cancer networks will have the opportunity to discuss the guidelines and accept them in modified form for individual services as they are provided. Once there is ownership and accessibility, the guidelines might work better.

Dr Linda McCallum (British Medical Association): Dr Millar talked about primary and secondary care working together. I have experience of working with the Edinburgh breast unit on the referral guidelines and a pathway for fast access that is IT-linked. Both secondary and primary care owned that and worked together closely. The project is going ahead and it is being audited. The early audit shows that referrals are very fast if they are done electronically using the guidelines on the computer in the GP's surgery. The pro forma is worked out and sent electronically to the breast unit and the appointment is speeded up.

The other aspect, which came out of the earlier discussion, is that there has been a revamp of the administration in the breast unit to allow it to cope. The administration staff can get the appointments and letters out earlier, which makes a big difference. The work that has been done in partnership has been very successful.

Dr Euan Paterson (Royal College of General Practitioners): We must try to ensure that people get across the primary-secondary care divide appropriately. Leaving aside screening to start with, the first concern is that patients' concerns are perhaps not elicited in the consultation with the primary care practitioner, whether that practitioner is a GP or a nurse. Fundamentally, that is a time issue. Some patients are slow to present at consultation and we are constrained by our consulting time of 10 minutes. The average consultation time in this country is eight and a half minutes, which is inadequate.

Our second worry is about patients' concerns being elicited and not being dealt with appropriately. I suspect that we need to improve our knowledge and skills base in that area; referral guidelines might well be introduced. Another issue is that sometimes, when concerns are elicited and dealt with appropriately, patients do not get secondary services. As David Millar says, people will always be screened out because we deal fundamentally with uncertainty. We could refer virtually everybody whom we see to secondary services, but the system would simply grind to a halt.

Finally, I have some concerns about the referral guidelines, because they do not refer to contextual issues. Contextual issues are the bread and butter of general practice. We tend to ask why a patient is suddenly attending again and again although we have never seen them before, or why a family has requested a house call when they never usually do that. That sort of information is useful, but it is probably impossible to produce a guideline on it. Referral guidelines might even make matters worse for certain groups of people—the rare presentation and the presentation in the wrong kind of person. For example, young people should not get rectal cancers, so a 20-year-old might be missed because we will not refer them. No one under the age of 45 will be referred for upper gastrointestinal cancer, although someone in our practice is currently dying because of an oesophageal tumour. There are big concerns that people will be missed. Referral is an art, not a science.

10:30

The Convener: You are saying that a GP should occasionally be able to use his or her judgment and knowledge of the patient. I came across a situation in which someone had returned to his GP four times. It turned out that the chap had a brain tumour, but no one seemed to twig. The GP must have thought that there was something seriously wrong, because the patient had not presented in 25 years but suddenly started coming back. In the end, the patient was rushed to hospital. That kind of information would not fall within the guidelines, but a GP would need some flexibility to be able to cover that sort of thing.

Mary Scanlon: One of the written submissions mentions the fact that less than 4 per cent of the new cancer money is going to primary care. What needs to be done to involve primary care fully in the delivery of services? The BMA submission states:

> "The use of the secondary care sector as a screening facility for the 'worried well' is an inappropriate use of specialists time and skill."

You say that poor investment in community staff has hampered primary care in taking forward the agenda.

We have a nurse here from the Highlands. I am concerned about the fact that

> "Research has found that rural patients with cancer present with advanced disease at diagnosis, receive poorer treatment and have poorer survival rates".

Can you address those issues in your answer, along with the issue of low investment in primary care?

Dr Millar: The investment is low because primary care was not prepared for the cancer plan. There is little about primary care in the cancer plan and no primary care professional was involved in its production. We do not have a mature network of individuals in primary care with an interest in cancer services. Therefore, not many groups prepared proposals, although some of those that did are represented today. Macmillan Cancer Relief, whose hat I am wearing today, has recognised the importance of primary care in cancer care for some time and has invested heavily in nursing and in GPs over the past 10 years.

Mary Scanlon: How can there be a managed clinical network if 90 per cent of patients' contact with the NHS is with GPs and if GPs and primary care are not involved in that network?

Dr Millar: We are getting there. We have an idea of what should be done. The local health care co-operative structure feeds into primary care trusts and unified health boards. I cannot speak for the nursing side, but we believe in the small network that exists within general practice. We hope to develop a network of LHCC cancer leads who would have a number of tasks, including feeding into cancer networks, so that primary care would be fully engaged, if you like, with the emerging regional cancer networks. Therefore, primary care issues would be addressed more formally and, along with our hospital colleagues, we would be able to bid for cancer moneys, which we have been unable to do from a standing start.

Dr Paterson: I was the representative of the Royal College of General Practitioners on the managed clinical network working party for palliative care. By definition, it is almost impossible for general practitioners to be really involved in managed clinical networks, which are disease specific—that is the networks' specialty. GPs' specialty is the individual patient. I could be a member of anywhere between 150 to 200 managed clinical networks, but that would not leave me with a lot of time to see patients.

The Convener: Susan Smith wants to pick up on the rural dimension.

Susan Smith (Royal College of Nursing): I work in a specialist palliative care unit, so I meet patients who are reaching the end of their journey. They often encounter problems with accessing services if they live in rural areas. They are happy once they get into the unit, but a problem for them is knowing how services integrate.

I also meet nursing staff who work in the primary care sector and who are keen to learn more about palliative care in cancer in order to meet their patients' needs. However, they have difficulties accessing the education that they require to enable them to meet patients' needs in the community. Patients recount their feeling that more is available to them once they have accessed the service. However, services such as psychological and social support, which nurses want to be able to provide, can prove difficult to access.

Mary Scanlon: The BMA's submission says that the

> "screening facility for the 'worried well' is an inappropriate use of specialists time and skill."

Does Dr Saunders think that more resources should be put into primary care, rather than being put into the "inappropriate" screening of the "worried well"?

Dr Charles Saunders (British Medical Association): It may be helpful for me to explain the role of screening. The idea behind screening is to take a group of people who may or may not have something wrong with them, apply a screening test or procedure and refer on people who are much more likely to have something wrong with them for more specialist tests and investigations. However, if we were to refer that entire group of people to the specialist centres, the centres would become totally overwhelmed and we would end up giving inappropriate, unnecessary and quite possibly damaging or dangerous tests to people who do not need them.

General practice and primary care have the key roles of helping to sift out people who do not need to be referred on for specialist investigations and of trying to reassure them at that level. It is inevitable that some people who do not need specialist investigation will receive it, but that is part of the nature of the game—it is impossible to be entirely precise. As a broad statement, in the vast majority of cases, it is not sensible to refer people on to secondary care purely in order to reassure them.

Mary Scanlon: Given that Susan Smith sees patients who are at the end of their journey, I ask the witnesses to address the point in the BMA's submission that

> "rural patients with cancer present with advanced disease at diagnosis, receive poorer treatment and have poorer survival rates".

As a list member for the Highlands and Islands, that concerns me. What should we be doing in the Highlands and Islands to get equity of access and treatment?

Dr Millar: That claim is based on the work of Dr Neil Campbell in Aberdeen. He examined a number of patients with breast and colorectal cancer who lived at different distances from the cancer centre in Aberdeen and found that, on average, the cancer at presentation was at a slightly more advanced stage. However, there was no implication that that had anything to do with any difficulty in accessing cancer services.

Mary Scanlon: We are talking about the BMA's submission.

Dr Millar: Well, I know that the BMA has said that. However, I challenge the claim.

Mary Scanlon: The BMA submission says that there are

> "poorer treatment and … survival rates".

Dr Millar: Although there were slight differences in survival rates, those related not to services but to the patients' late presentation. In other words, it was not that the GP delayed putting the patient into the system, but that there was more of a delay on the part of patients, which affected eventual survival.

Dr McCallum: I want to link the issue to people in deprived areas, because my practice includes quite a large area of deprivation. Those people access primary medical care less readily and present themselves later. Because we deal with them later in the journey, they do not do as well. It is also more difficult to get them to have screenings or to take up health promotions. We must find more novel ideas to attract people, either by taking services into the community or by making access easier. Certainly, later presentation in deprived and rural areas makes the outcomes worse, but that is more of a problem about educating patients on what to look for and when to present themselves.

Mary Scanlon: I appreciate that patients might present later because of their distance from services. However, the BMA submission clearly states that patients

> "receive poorer treatment and have poorer survival rates".

I am concerned by the comment about poorer treatment. Will the managed clinical networks help to overcome the inequity of access, diagnosis and treatment for people in rural areas?

Dr Grant: Managed clinical networks have the potential to do that. However, the three regional networks are all at different stages of maturity. I wanted to mention earlier the primary care input into the managed clinical network. In south-east Scotland, the primary care community is well represented in the regional cancer advisory group, which oversees the south-east Scotland cancer network. We feel that we have a strong voice in the network and that we are getting ourselves organised; indeed, we made a successful bid for £185,000 of the new money for cancer in Scotland.

However, one of the problems with the new money is that we have to bid for it rather quickly. Because GPs are so spread out, they cannot gang together all that quickly to work up and submit a bid. At least we have learned to organise ourselves to ensure that, in future, we can submit good bids for improving services. We believe that money invested in primary care is money well spent. As the cancer networks pick up speed, we can address problems of rurality. The desire is that the networks should contribute to evenness of care provision across the country.

Janis Hughes: I want to move on to the question of resources. My colleague Mary Scanlon has already mentioned that less than 4 per cent of the new cancer money is being allocated to primary care. In its submission, the RCGP says that

"investing adequately in primary care is an essential part of improving cancer services."

Do you think that those new resources are adequate? If not, will you outline the areas in primary care provision where more adequate resources could be targeted?

Dr Grant: We are seeing the beginning of that process. We have successfully bid for each practice in south-east Scotland to have support for a register of all its cancer patients. We hope that practices will be able to have regular multidisciplinary meetings, involving the whole primary care team, to discuss their cancer patients and improve their care. We hope to lift the quality of care for all our patients. Investment will lead to a general improvement in care. General practitioners have to get organised to bid for money.

10:45

Mr McAllion: Has the inadequacy of having less than 10 minutes' consulting time been a factor working against early diagnosis and referral? I recently came across a practice in Dundee that now has a list of 11,500 patients. It has had to set a practice boundary; if people move beyond that boundary, they are taken off the list. Is that an increasing problem in practices across Scotland? If people have less time to see patients, they may miss what is wrong with them.

Dr Paterson: The problem is increasing. A huge recruitment crisis and a huge logistic problem are brewing. People who want to do general practice are not coming through the system. Morale is not high in general practice and people are not choosing to do it.

We need more time with patients. The job has become infinitely more complicated in the 17 years in which I have been practising. What I am trying to do has become infinitely more complicated as well. In the midst of that, I am still trying to practise patient-centred care—listening to people and trying to empathise and sympathise with them. Many people whom we see with cancer will, unfortunately, die. How we deal with that fact is every bit as important as what we do to them. The problem that Mr McAllion highlights will grow and it will be difficult to fill jobs.

Mr McAllion: My wife runs one of the few NHS homoeopathic clinics and she gets half an hour with each patient. Is that the kind of time that GPs would require?

Dr Paterson: That would be fantastic. I suspect that, whatever time I was given, I would want more, but the idea of having even 15 minutes is very appealing. I rely on patients' not attending; I rely on gaps.

Mr McAllion: So a key to any effective cancer plan would be to have more GPs with more time to see patients.

Dr Paterson: I am a passionate generalist. We need more generic workers, more general practitioners, more community nurses and more practice nurses seeing fewer patients so that there is better continuity and availability. If we had that, we would empower patients and even head towards a citizen-led NHS rather than a primary care-led NHS. That would be great.

Janis Hughes: The issue of training came up with our previous witnesses. Do GPs have the training and the support that they need to implement the cancer plan? I would be interested in the nurses' views on that.

The Convener: Dr McCallum, did you want to come in on another point as well as on that one?

Dr McCallum: I will comment on training. In Lothian, we have had funding from the new opportunities fund to carry out nurse and doctor training on cancer. There is also support for GPs from the Macmillan Cancer Relief network.

I wanted to add something to the earlier point. Many patients with cancer also have other diseases. We look after the whole patient, not only their cancers. Dealing with patients can be very complex and, yes, we would like more time with each patient, especially when their needs are complex and they have more than one disease.

Sandra White (Royal College of Nursing): Although I work in the acute sector, I work closely with colleagues in primary care. Education is a much-debated topic. I am a specialist nurse, but we cannot all be specialists. I echo what Dr Paterson said: we need more generic training and not necessarily so many specialised qualifications. The problem is that there are too many patients for one practitioner—whether a medic or a nurse—to cope with.

More modular-type training for nurses would help. Nurses have a great problem in getting away from wards to facilitate their education. The problem lies not only in getting time off, but in financing education. Often, the education must be in people's own time. In a work force, there can be people who can afford to pay for education and people who cannot. More general training would be advantageous to me and my colleagues—district nurses, practice nurses, health visitors and nurses in wards. I do not think that the cancer plan adequately addresses that issue.

Finance is not necessarily the answer to the problem. Skills and reskilling multiskilled people should be considered. I cannot speak for the primary sector, but shortages obviously have an impact. Sometimes, people are overqualified to do the tasks that they must do and that is a problem. Restructuring services would help.

Dr Grant: Between 1998 and 2000, I visited every practice in Fife to find out how they delivered cancer services to their patients, their problems and what they thought they did well. I was keen to hear about postgraduate cancer education and was distressed to find that only half the GPs to whom I spoke recalled receiving any postgraduate cancer education in the previous five years. Therefore, we set up an educational programme, which has done well in attracting input from primary care professionals in the past two years. A need exists and it must be constantly measured and responded to.

In the primary care teams, we found that district nurses were keen to be involved in cancer care. They thought that cancer care was one of the most satisfying areas of their work. Many had specialist qualifications and much had been achieved with their own funding in their own time. Since then, a primary care cancer educator in Fife has ensured that all our district nurses and community care nurses have generic training in palliative care and cancer care. In some areas of the country, education and training issues are certainly being addressed, but we can never relax. Such matters must be constantly addressed.

Nicola Sturgeon: The written submissions refer to the many cancer treatments that are prescribed and administered in primary care and the role of primary care in hospital-based treatments and follow-up care. Should the role of primary care be expanded in such areas? If so, in what way? What would be the general resource implications of doing so?

Sandra White: I work in acute care, but many patients with whom I work—such as breast cancer patients—come into hospital for treatment. There is a theory that care in their own homes would be more advantageous to them.

In the past few months, I have been involved with three or four patients who have had their chemotherapy or symptomatic control in, for example, hypercalcaemia and bone metastatic disease treatment, in their own homes, as they can afford such treatment with their private insurance. At first, I was sceptical of that approach, but patients have felt much better cared for. They have felt that care has been in their own environment. They have not had to sit and wait in a clinic or wait until chemotherapy comes down from the lab.

Such an approach is patient focused and satisfies many of the patient's needs. A professional will spend time alone with the patient and their family. If the patient is a young woman, the children can come in from school and see what is happening. There is not such a threat to the whole family. It would be good if such an approach were implemented in the NHS—I believe that it has been in areas of England. However, much more training would be needed.

Dr Grant: The pharmaceutical industry predicts that the next generation of anti-cancer drugs will be effective, less toxic, probably oral and very expensive. Many of those drugs will be given at home, so there are implications for primary care prescribing budgets. We are looking at an eight to 10-year period for that, so we have to think well ahead. If we do not do that, we will be in big trouble. Currently, the treatments that we give in general practice often arrive on our doorsteps without advance warning. Generic information about treatments must be provided to the primary care sector in advance. The contact between the consultant who prescribes the medication and the GP who gives it has to be good, so that the patient is treated safely to the highest standard.

The Convener: Does anyone wish to add to that?

Dr Paterson: Our concern is that we are more or less running flat out to keep up just now. Any shift of work into primary care will have to be met with more workers to do the work—not money, but workers.

Dr Grant: Euan Paterson gave an example of recruitment difficulties. I will give a personal example. In 1983, when our practice last advertised for a partner, we had 70 applicants. I am taking early retirement this year on medical grounds and my replacement has been appointed, but the number of applicants was less than 10 per cent of what we had before. We are fortunate to have been able to appoint a good applicant to the post, but there are many practices in Scotland with vacancies and with lists that are too large for the remaining number of GPs. That is a serious problem.

Dorothy-Grace Elder: Dr Millar stated in his written submission to the committee that many people die in institutions, despite wishing to die in their own homes. Marie Curie Cancer Care's submission states that about 68 per cent of patients want to die in their own homes but do not get the chance. What is the reason for that barrier, which prevents people's wishes from being respected?

Susan Smith: Patients who wish to stay at home often go into institutions. They recount that one of the reasons for that is general support for themselves and their families. Other reasons are the fear that their needs will not be met in the community as quickly as they would like, the belief that medications or special equipment, such as special mattresses, will not be available, or the worry that they may have to wait for practitioners to meet their needs. Patients may go into institutions when there is a crisis. Short admissions may be needed at such times to sort things out, because in the community it is difficult to react suddenly to a crisis.

Dorothy-Grace Elder: Could the issues to do with mattresses, for example, be solved?

Susan Smith: Yes. Many of the issues could be resolved. I am not sure about the resources for equipment. There is equipment in the community, but I have no experience of how it is managed.

Problems in the community could be pre-empted through giving nurses and doctors more education on the problems that will arise—not just the physical problems, but the ones that relate to whole-family needs. Nurses and doctors should have time to talk to families about their needs and concerns for the future. If nurses and doctors were proactive about meeting families before there is a crisis, that would go some way towards meeting the problem.

Dr Paterson: I am speaking as a GP from one of the most deprived areas of Glasgow. The situation will be different in more affluent parts of the country, such as Edinburgh, but we have a huge problem. The south side of Glasgow has 360,000 patients. We have 14 palliative care beds and we have no facilities for what I term intermediate care. Some nursing homes can be used, but there are huge problems with staff.

Moreover, we have completely inadequate support services, especially at night. It is not possible to guarantee the provision of a night nurse to a patient and their family or carers. It is no good saying to someone, "You might have a nurse tonight," because they need to know whether they will. We are not talking rocket science. We are not talking about highly skilled workers. Janis Hughes talked about what would help primary care. I make a huge plea for fairly low-level auxiliary grade nursing—a pool of people who have worked in old folks homes or geriatric units and who are experienced, nice people who are used to death and dying. The ability to put such people into a house at night would revolutionise care in the city. It is not clever stuff.

On aids and appliances, people can get a doctor within about 15 minutes—with the sort of on-call system that we run in the practice—a nurse in half a day, a urinal in two days, a commode in three or four days and a mattress in couple of weeks. That is ludicrous.

Dorothy-Grace Elder: You are saying that we have the worst of both worlds. There are only 14 palliative care beds in your area, yet there is no joined-up access to social work services and so on that could help in the home.

Dr Paterson: That is correct.

Dorothy-Grace Elder: Sometimes, the social work departments arrange good teams, but only after pressure has been applied.

Dr Paterson: The problem is huge in Glasgow, as social work services in the city are desperately strapped for cash and are really struggling.

Dorothy-Grace Elder: You are telling us that the dying are not getting the help that they need and want either way.

Dr Paterson: That is correct.

11:00

Dr McCallum: In Lothian, we got a small proportion of the cancer money compared with what went into the secondary sector. It allowed us to purchase more equipment for the community, but we had no way of getting the equipment to the patient. We were lucky in that we were able to find the small amount of money that we needed to get a man with a van to transport the equipment. That arrangement has benefited 50 or so patients who have been able to die at home. Small amounts of money can, when they are used well, make a huge change for people.

We are doing proactive work in relation to our cancer registries. Some people are unaware that it is possible to stay at home and we can tell them about their options if we are more proactive. When we have built up care plans in the community, people will be more confident about what is available.

The Convener: We are pressed for time, so I will ask a final question. How do you feel about nurses in primary care being involved in the changes to cancer service delivery? I expect the nurses to answer that question, but I expect that the doctors will have an opinion as well.

Sandra White: My knowledge of primary care nurses is limited, but we work in partnership in Ayr and I hear a lot of what goes on through the Royal College of Nursing. In Ayr, a sub-group is examining ways of developing joint protocols with primary care so that nurses can more effectively link with services.

The Convener: Are there any areas at the primary care level in which the role of nurses could be developed further? You have talked about going into people's houses and so on and, obviously, community nurses have a role to play in that regard.

Sandra White: The acute trusts are developing specialist nurses that will link with the community, not so much as a hands-on service as a resource for education to help outwith the primary care sector. In Ayrshire and Arran NHS Board, there is a chance to develop chemotherapy nurses in the community so that patients can be nursed throughout their treatment pathway.

Susan Smith: In the Highland NHS Board area, all community nurses who work with palliative care patients work closely with the palliative care team and see themselves as a vital part of that team.

Many nurses in nursing homes are struggling to meet palliative needs and more could be done to help them. Perhaps nurses in primary care who have more knowledge of palliative care could be linked in to offer support and give greater input into strategies that are being developed in their areas.

Dr Paterson: The huge strength of primary care is often the pre-morbid knowledge of the patient and the carers, which both general practitioners and district nurses have. More district nurses could give a more general and holistic service, perhaps with bits added on at the edges, using the same number of people, so that we could keep the number of team players down. I appreciate that there needs to be a team, but we have already heard a patient representative talking about the problem of having a relationship with a team, which is difficult.

Dr McCallum: One of the points that has come out of patient-centred research is that patients feel that the part of the journey at which they have the least support is the beginning, when they first present to the GP—before they even get into specialist services—for testing and diagnosis. We have been considering the role of the district nurse, practice nurse or link nurse as an early support worker in asking patients what their concerns and anxieties are at that stage. Patients will not necessary come with questions, because they think that they are being difficult. Support at the early stages is being developed, but it is not being resourced well.

Dr Millar: Macmillan Cancer Relief has piloted a model that involves a tracker nurse. That model is based on primary care in a big practice or group of practices. The individual nurse tracks through the system the progress of patients who are diagnosed as having cancer. Those nurses do not provide hands-on care, but are based firmly in primary care. The evidence from that is building up.

The Convener: Some Macmillan nurses will be here later, so we can ask them to pick up on that point.

I am afraid that we have overrun on this part of the meeting and we have a few other people to hear from this morning. Thank you for your written and oral evidence and for your continuing work in your communities.

11:07

Meeting suspended.

11:09

On resuming—

The Convener: I welcome the next panel of witnesses to the Health and Community Care Committee. We will ask a series of questions, after which witnesses should indicate to me whether they wish to come in on the back of a question.

Mr McAllion: I want to ask about the quality and consistency of pain control that is given to cancer patients in Scotland. Marie Curie Cancer Care suggested in its submission that 58 per cent of cancer patients suffer uncontrolled pain. The submission also contains a couple of examples of situations in which the standards of the Clinical Standards Board for Scotland are not being applied because of lack of provision. Can you tell me whether the Scottish intercollegiate guidelines network's guidelines and the core principles in the Clinical Standards Board for Scotland's standards are at fault? If those guidelines and standards are fine, is the problem that resources are not being made available locally to apply them?

Susan Munroe (Marie Curie Cancer Care): I do not think that the SIGN guidelines are at fault—they are very good and are well integrated into the Clinical Standards Board for Scotland's standards. Some of the GPs alluded to the problem that guidelines and standards are often difficult to access and that they are not always used as well as they should be.

Mr McAllion: Is the problem one of educating GPs to apply the standards? Is it a problem of resources?

Susan Munroe: I am sorry—could you repeat the question?

Mr McAllion: Is the problem that the resources are not available on the ground, or is the problem ignorance among GPs and district nurses?

Susan Munroe: We must acknowledge that the problem is about GP resources. GPs are very busy people; many pressures come at them from different angles and they have interests in different areas. Some GPs who have an interest in palliative care are good. They read all the information that comes in and they follow the guidelines, but others are not able to do so.

Mr McAllion: We heard evidence from a number of GPs that empowering GPs and district nurses, who know the patients best, would be the most effective way in which to deliver palliative care throughout Scotland. Is it simply a question of providing those non-specialist health professionals with adequate training?

Susan Munroe: One of the important elements of palliative care is the team approach, the benefit of which is that different members of the team bring different things to it. Empowerment of district nurses and GPs is an important part of that approach, but they should not—they cannot—work in isolation. They should continue to work as part of, or with support from, the specialist palliative care teams.

Mr McAllion: Are those specialist teams common in Scotland?

Susan Munroe: They are not common. They tend to exist in areas where there are hospices or hospital support teams.

Mr McAllion: Should specialist teams be part of a managed clinical network?

Susan Munroe: Absolutely. One of the issues around equity of access to services is that there is no written standard that says that there should be X services of any kind per head of population, or per thousand population. Specialist centres arose in areas that had pressure groups or where funding was available. That is how voluntary hospices that deliver specialist palliative care were established. There are some NHS specialist palliative care units, but they tend to be based in the central belt. That is the way in which provision has grown.

Mr McAllion: Is there no national strategy?

Susan Munroe: No.

Dr Martin Leiper (Scottish Partnership for Palliative Care): I do not believe that all our patients expect good pain control. We have a job to do to tell them that good pain control is available. The Scottish partnership hopes that we can work towards that with our partners.

Medical culture is such that diagnosis is sometimes seen as being more important than symptoms. Palliative medicine needs to redress that balance. Symptoms and suffering are as important as accurate diagnosis.

The Convener: Are the facilities in Scotland for children with cancer adequate?

Andrea Cail (Children's Hospice Association Scotland): I will try to answer that, but I can do so only with my palliative care hat on. I realise that there is no one here from the acute sector. In my experience, children in Scotland who have cancer are cared for very well. The expertise is in the tertiary centres in Edinburgh, Glasgow, Aberdeen and Dundee. However, there is a good support network in the community, involving nurses, community children's nurses and nurses in the tertiary centres. Generally speaking, support in the community and in the acute sector for children with cancer seems to be fairly good.

The Convener: Are both their physical and psychological needs covered?

Andrea Cail: Yes. A multidisciplinary team approach is taken, as Susan Munroe said. The hospitals all have Sargeant social workers who are dedicated to the families of children with cancer, who support the Macmillan and Cancer and Leukaemia in Childhood—CLIC—nurses who work in the community and on the wards.

11:15

Lynn Adams (Macmillan Cancer Relief): Some district nurses struggle to care for children with cancer in the community because it is a rare condition; they do not regularly encounter children with cancer. They find it difficult. It is an emotional journey for nurses. There is an issue about support for nurses and the way in which they are educated to look after such patients. There must be better integration of the hospital service and the primary care service. The primary care staff need the back-up of the specialist services in caring for patients in their homes.

Nicola Sturgeon: Given the fact that more people are now expected to live longer with cancer, what developments are taking place to plan the future capacity of palliative care services?

Dr Leiper: It has been important to have representatives of palliative care on the Scottish cancer group. You are right to say that, as cancer care improves there is—rather than a need for less palliative care—a need for more palliative care, because the illnesses will become more complex and last longer. Most Scottish hospices and NHS palliative care units have waiting lists, which is not good. There are no specific plans to increase the number of beds or to expand services at the moment. However, through the Scottish Partnership for Palliative Care, we are right up there with the Scottish cancer plan and the Scottish cancer group.

Nicola Sturgeon: Are you saying that more needs to be done?

Dr Leiper: More will need to be done as people increasingly live alone, as symptoms become more complex and as people's expectation of good symptom control increases.

Susan Munroe: There are a few initiatives in Scotland to improve the quality of care that is delivered at home. Some areas are trying to deliver 24-hour access to community palliative care; however, I believe that none of those initiatives is being properly funded yet. It is a fairly new concept in redesigning services and improving care, which aims to ensure that people can stay at home longer instead of being admitted to hospices.

Mary Scanlon: Given the fact that people are going to live longer with cancer, how do you respond to the point that the Royal College of Nursing made about work-force planning when the most reliable data on appropriately educated cancer nurses are six years old? Given the fact that hospices and the NHS have different information technology systems, which you say hinders the transfer of information and communication between them, how can we plan effectively for patients?

Dr Leiper: On IT, all the voluntary hospices in Scotland should be linked to the NHSnet. I do not know why that has not happened, but as a matter of urgency they should be made able to communicate quickly with hospitals and primary care services.

Mary Scanlon: Have you submitted a bid for money from the cancer plan to do that?

Dr Leiper: Actually, I happen to work in one of the minority of NHS hospices, which means that I am linked to the system. My colleagues have not submitted a bid for that; however, they requested a link to NHSnet several years ago and expected to join, but that has not happened, which is probably down to resources from the local trust.

Mary Scanlon: The RCN's submission says that its information on appropriately trained cancer nurses is six years old. What is the current situation?

Lynn Adams: Throughout Scotland, most nurses in most settings are involved in the delivery of some kind of cancer care. For example, a local study that we carried out in the north-east of Scotland showed that about 90 per cent of nurses are involved in some form of cancer care. There are different levels of education. Lead cancer nurses and senior nurses in primary and secondary care need cancer care qualifications to become nurse specialists.

At another level, we need to support and educate other nurses who are involved in cancer care—indeed, primary care is an example. Moreover, as that needs to be provided regularly instead of on a one-off basis, we need to consider a system of continuing education.

Mary Scanlon: My final question is on palliative care. Recently, Macmillan House in Orkney, where Lynn Adams is based, was threatened with closure because the nurses were needed for the acute hospital. Will that become a wider problem throughout Scotland, given the future shortage of staff?

Dr Leiper: What is happening is wrong. As I said, there is as much need for palliative care as there is for cancer care; indeed, both should grow together. What you have mentioned has not happened in my area, because palliative care will probably be linked with primary care in the primary care trust. That is a good mechanism for protecting palliative care.

As Mary Scanlon said, nurses in the acute sector can be transferred from work that is seen as being less urgent. It is a shame to see waiting lists or other targets drive nurses from support and symptom control to other forms of acute care.

Mary Scanlon: Although the threat to Macmillan House was averted, it still hangs over the centre. Is it wrong to take nurses from palliative care and put them in the acute sector?

Dr Leiper: Yes, for the reasons that I stated.

Mr McAllion: Lynn Adams mentioned the need for nurse education, nurse specialists and so on in cancer care. Is palliative care training for non-specialist health professionals adequate, or can it be improved in some respects?

Lynn Adams: Training in general is not adequate. Individuals and groups of staff have been well educated and have gained experience in cancer care over a number of years. However, as I said, we need to consider different ways of providing education.

Mr McAllion: Should palliative care form part of the basic training for nurses, GPs and so on?

Lynn Adams: Yes. Nursing and medical students should be introduced to palliative and cancer care in pre-registration courses, which should continue throughout their careers.

Mr McAllion: Is such training introduced at that stage at the moment?

Lynn Adams: Yes.

Mr McAllion: Are you satisfied with the current level of training?

Lynn Adams: A lot more could be done.

Mr McAllion: So training could be improved.

Lynn Adams: Yes.

Mr McAllion: In what ways?

Lynn Adams: We should allow more nurses to take courses and degrees in cancer care. Furthermore, we must think about continuing education in the form of updates, short courses and training in the workplace.

Mr McAllion: Is more postgraduate training than undergraduate training required? The problem is that education after qualification should be better.

Lynn Adams: Yes. Education needs to continue.

Janis Hughes: The cancer plan said that the provision of 24-hour support at home varied throughout the country. Will you outline any measures that are being taken to address that?

Susan Munroe: Quite a few projects around the country are intended to address that. The Marie Curie nursing service is working with a variety of health boards and trusts to consider developing hospice-at-home services around the country. I am involved with a project in the north and east sector in Glasgow that is conducting a pilot study on redesigning a range of services to provide 24-hour access to palliative care services and make better use of the available resources, before we start considering the additional resources that we need. That is fairly high up the agenda and is being addressed.

Dorothy-Grace Elder: Your written submission highlights the variation in the provision of specialist palliative care. Is the Scottish cancer group addressing that problem? What would you like to be done?

Susan Munroe: I am not part of the Scottish cancer group, so I do not know about it in detail, but the information that is available on it suggests that it is not doing anything to deal with provision. We need to consider setting minimum standards of service availability throughout the country. We have many standards for services that are delivered, but nothing says what level of service should be available anywhere.

Dorothy-Grace Elder: Are you confident that every patient is receiving adequate pain relief? Could that be improved?

Susan Munroe: There is enough evidence to suggest that that needs to be improved.

Dr Leiper: We know from a study that the Scottish Partnership for Palliative Care conducted for the Scottish cancer group that palliative care support in our Scottish hospitals is patchy. Some hospitals are quite large, but have little specialist input to dealing with the suffering that palliative care can address. That is new information that has been taken back to the Scottish cancer group.

Dorothy-Grace Elder: We have heard about a lack of communication with patients. One patient group said that patients must wait up to four weeks to receive a letter after it has been dictated. I have spoken to doctors privately who told me that they have waited up to six months to receive a letter. Have you experienced such delays?

Dr Leiper: The first part of your question related to letters between doctors and patients.

Dorothy-Grace Elder: Most often, communication is between hospitals and patients and between hospitals and GPs.

Dr Leiper: I work in palliative care in the NHS and I receive instant e-mails from managers and central Government. I am not permitted to put any patient details in e-mails. Equally, I am not permitted to use faxes, for reasons of confidentiality. That is completely wrong. We need major investment in systems to allow me to e-mail a GP, a district nurse or a hospital consultant with patient details.

Dorothy-Grace Elder: Is that because you experience delays with paperwork?

Dr Leiper: The other delay is in secretarial support. That appears particularly in the cancer wards from which I receive referrals.

Dorothy-Grace Elder: How long do you have to wait to have a letter typed?

Dr Leiper: We might wait two or three weeks.

Dorothy-Grace Elder: Have you applied for any funding or help with that?

Dr Leiper: I am talking about incoming letters to me. I do not know whether people who are experiencing problems have asked for support.

The Convener: I thought that Dorothy-Grace Elder was going to ask about the voluntary sector generally.

Dorothy-Grace Elder: I am sorry; I thought that, as I had asked another question, I would take up too much time by asking about the voluntary sector.

Evidence suggests that some of you believe that cancer services have become overdependent on the voluntary sector. Is the state leaning too heavily on you and expecting too much of you?

Dr Leiper: I work in the NHS, but I have gained a great deal from the voluntary sector. It made me go into my specialty and helped us to design the rooms in our NHS unit.

Dorothy-Grace Elder: Yes, I do not doubt that, but—

Dr Leiper: We need the voluntary sector.

Dorothy-Grace Elder: Oh yes—I do not doubt that at all—but are we becoming over-dependent on, and expecting too much of the voluntary sector, time and again?

Dr Leiper: Yes. One current issue is that we expect the voluntary sector to train consultants and to bear the whole burden of cost. That is not fair.

Susan Munroe: I work in the voluntary sector but I do not feel over-burdened. We feel that we are equal partners with the NHS and most of us would like that to continue. We are equal partners in the provision of the care but we are not equal partners in receiving funding.

The Convener: I think that we have covered most points so, if there are no further points, I thank the witnesses for their evidence this morning.

We will take a short break before we hear from the trade union side.

11:30

Meeting suspended.

11:33

On resuming—

The Convener: We welcome witnesses from the Royal College of Nursing and Amicus MSF. We do not have anyone from Unison, which is a change from the information that members have. We will go through questions first, but if there is anything that the witnesses wish to pick up on later, please let me know.

Margaret Jamieson: One of the aims of the cancer plan was to empower staff, the voluntary sector and patients in order to give them a voice in the planning and development of services. To what extent has that been achieved, nearly one year on?

Nora Kearney (Royal College of Nursing): I am a senior lecturer in cancer nursing at the University of Glasgow and I am here with the RCN. I have been greatly involved in cancer service development across the United Kingdom and I worked with the Commission for Health Improvement in managing the review of cancer services in England.

The cancer plan in Scotland has resulted in some moves to support staff development, but a lot more could be done to empower staff. The managed clinical networks would facilitate empowerment of staff if there were more support for professional development within the teams. There is still concern that the networks function around a medical model of care, which means that they often fail to empower other professionals or patients, because they do not focus on a patient agenda. Such an approach is sometimes at odds with the provision of supportive care and it therefore negates the empowerment of professionals other than doctors.

Margaret Jamieson: You mentioned the medical model of care. Traditionally, that was the only care package that was available. How does the cancer plan provide an opportunity for you to make that into a team model of care?

Nora Kearney: The managed clinical network structure has the potential to do that. There needs to be a much more patient-focused approach to care throughout Scotland and the UK. Although such an approach is much talked about as being best practice, it is not happening in clinical care. The biggest reason for that is probably the way in which cancer services are developed and structured, which means that the patient is not put at the heart of those services. Chemotherapy and radiotherapy are normally managed between the hours of nine and five o'clock. It is difficult for patients to continue working throughout their cancer treatment. Supportive care is usually provided on the same basis. Previous witnesses spoke about out-of-hours support for patients. Although there is much rhetoric about putting the patient at the heart of care, that does not appear to be happening in practice.

Margaret Jamieson: Is there a need to look at the whole patient journey and to ensure that we redesign the services rather than just building in certain areas and saying, "This is it"? Should we dissect the journey in an effort to involve the patient and to encourage the whole team approach?

Nora Kearney: Absolutely. There are examples that show that that is happening. The managed clinical network structure is being used to facilitate that, especially in relation to the lung cancer patient problems in Glasgow, for example. Lung cancer is a huge issue, in the west of Scotland in particular. We are working as a group with the health board, with all the clinicians, with patient advocacy groups and with the Roy Castle Lung Cancer Foundation to tease out where the patient pathway lies and where the bottlenecks are. We are working with the industry to assess how we can work in partnership to improve the care processes for patients. That takes a lot of energy and effort. There should be more central support in recognition of the time and energy that is required to ensure that the best possible care is obtained. Such care should be patient centred. The process is not simple, but it is certainly possible.

Janis Hughes: One of the biggest issues to affect all disciplines in the NHS is staff shortages. What needs to be done to address work force shortages in the specific professional groups that your organisation represents?

Pat Dawson (Royal College of Nursing): Yes, we have a problem. The Parliament has debated shortages of nurses and other health care professionals. The facing the future group is looking across our work force issues. If we hone in on cancer, the fact that our community and district nurses have an older age profile means that we will lose a high proportion of those nurses to retirement.

We face issues associated with specialist qualifications; for example, we do not know how many nurses in Scotland have specialist cancer qualifications. In our submission, we argue that that lack of knowledge means that we do not know whether we have adequate coverage to meet patient needs and to deliver on a patient agenda. If we are not doing work on team modelling and team working, how do we know that we are attracting the right people with the right skills to deliver on the team-working agenda? If we do not know what kind of future we want for the shape and delivery of cancer services, how do we know that our education preparation for the future will stand up to the test?

Although we are at the cusp of new regional centres to consider work force planning and although the student nursing intake, which the facing the future agenda will examine, will increase, the education and training of nurses needs to be researched in a wee bit more detail. We heard earlier that about 60 nurses have done specialist cancer courses over the past five years and we do not think that that is enough. One in three of the population gets cancer. We heard earlier from our RCN colleagues that we are not talking only about specialists; we have to train appropriately everybody who encounters a patient with cancer.

Our view goes rather against what the RCGP said about having some kind of granny clone come in when people are dying—nice people who come in and give support. Although there is sense in having family support and people to talk to, we are talking about specialist care and equipment and people who need adequate training and support to deliver care at times of great need and crisis for individuals and their families.

We have serious problems now and we will have serious problems in the future in the nursing work force, but there are points in the plan that will address those problems. We have clinical leadership models to try to ensure that nursing and nurses influence the structure of the plan and the structures that have been set up to resource it, but we are not far enough down the road. We acknowledge that nurses are close to the patient agenda, but we will make clear gains only when we can facilitate a nursing voice in partnership with a patient voice.

The Convener: We heard earlier about problems of communication. Some of the specialist cancer nurses whom I have come across in the acute sector have been the named person to whom the patient can come back and speak on the phone. We heard from patients groups earlier that that communication sometimes breaks down. Do you see communication as critical for specialist nurses?

Pat Dawson: That is an important point. I talked to our colleagues about that when we were backstage. The situation for specialist nurses is patchy. Many of them have no sickness cover or holiday cover and sometimes nobody else is there with them. Neither the Scottish Executive nor we are able to give the committee evidence on how many specialist nurses there are, what they are doing and whether they are resourced adequately. Nurses often cannot play the support role that they would like to play and they cannot co-ordinate and share information, because there are not enough of them and they are not prepared, trained or resourced adequately to do so. One of the witnesses gave powerful evidence this morning when she said that she phoned and all she got was the answering machine. That is backed up by what we know—nobody else is there to take on the role that specialist nurses play.

Nicola Sturgeon: My question is for Terry Kehoe. Your written submission talks about the eight-year period for training a clinical scientist and says that, in your view, training places are not sufficient currently and that a solution would be to increase the number of places. There is a more immediate problem. Last week we heard from Society of Radiographers about staffing shortages. The college raised a concern about the inability of perhaps the Beatson oncology centre to use the new linear accelerators to maximum effect because of staffing shortages. Would you like any action to be taken immediately or in the short term to try to recruit and retain clinical scientists in Scotland rather than waiting eight years to get more on stream?

Terry Kehoe (Amicus MSF): Our submission states that a two-stage process is involved. One stage is the grade A training scheme, which is very general and which people who come straight from university go into. We can accelerate that process a little by increasing the number of people in grade B, the higher training scheme for physicists. We propose to double that number to six in Scotland. Two years after their appointment, those physicists would become practising radiotherapy physicists. The training period would therefore be shorter than eight years. Such an approach would help. The Scottish Executive could take the strategic step of allowing training posts to be created and funded centrally. In that way, we hope that we will get enough people to fill the gaps that exist.

We must bear it in mind that a huge expansion of services is taking place in England. More than 100 posts for physicists are yet to be filled. That may well happen, so retention of staff is an issue.

11:45

Nicola Sturgeon: Do you recommend specific measures to assist retention? We face competition from south of the border and elsewhere.

Terry Kehoe: At the moment, the career grade for physicists is grade B. Every three years, those physicists have to be reassessed. If they want to move up the scale, they are required to undergo an assessment, which is sometimes an external assessment. We should give local line managers, who know their staff, more flexibility and allow them to retain staff by providing them with local incentives to stay. I am talking about local promotions and new projects.

The guidelines to which we must work recommend that a formal assessment should take place every three years. After eight years of training and four years at university, radiotherapy physicists may be told after three years that they will remain at the same grade. That is a disincentive.

Nora Kearney: The work that has been done with the Clinical Standards Board for Scotland and the Commission for Health Improvement in England highlighted the role of clinical nurse specialists in communication. There is concern about the variation in clinical nurse specialist activity. We know that the case loads of clinical nurse specialists range from 70 to nearly 1,000 patients. With such wide variations in case loads, there can be no equity in the communication and supportive care that clinical nurse specialists provide.

In Scotland we do not have a handle on the issue—we know the figures for England, but not for Scotland. We have specific information for small areas, but we need to know what case loads clinical nurse specialists have. We need to know how to manage the case loads of clinical nurse specialists much more effectively, to ensure that their role in communication and supportive care is more standardised across the country.

Mr McAllion: Last week, when we visited the Beatson, we spoke to a physicist who was using scanners and big computers to draw up treatment plans for patients—identifying exactly where tumours were located and how they should be attacked. That work is a vital cog in the treatment plan. However, we were told that the starting salary for a physicist in the NHS is around £15,000 a year, which is a joke compared with what physicists can earn in the private sector. There is a real recruitment problem. Surely you are not suggesting that the way in which to address that is to replace national pay bargaining in the NHS with local pay bargaining? In his answer to Nicola Sturgeon's previous question, Terry Kehoe seemed to suggest that, when he spoke about offering local incentives.

Terry Kehoe: The incentives that I was suggesting do not relate to pay. At the moment, if staff want to have career progression at the centre where they are working, they and the job that they are doing must be assessed after three years. There should be ways of developing jobs and individuals together. That does not mean making local pay agreements. However, in England certain posts have been advertised at more than the established rate, in order to attract people away.

Mr McAllion: The hospitals in England to which you refer are undermining national pay bargaining in the health service and setting a precedent that is not welcome in Scotland. It is argued that we should increase the starting pay of physicists to make the job attractive. However, we should do that for all physicists in the NHS.

Terry Kehoe: I agree entirely. I am not saying that one measure should be traded off against another. Rather, we should seek to raise salaries and improve career prospects for the whole staff group.

Mr McAllion: Towards the end of your written submission, you make a number of recommendations to the Scottish cancer group and the Scottish Executive about grade A and grade B physicists. Have any of the recommendations been implemented or listened to?

Terry Kehoe: No. That information was submitted to the Executive in April and the

Executive confirmed receipt of it. However, there is no plan to implement anything. My point is that we need to take a strategic look at the recommendations. We need the Executive to consider the recommendations and try to implement them for our staff group.

Mr McAllion: Is there any indication of an Executive response? Is a timetable expected?

Terry Kehoe: I am not aware of that. I have not heard anything.

Mr McAllion: So the recommendations have just disappeared into the vast bureaucracy that is the Executive.

Terry Kehoe: I would not necessarily say that. I say only that we have not had any response yet. I think that there are plenty of opportunities for regrading at the Beatson. My understanding is that that issue has been raised again. The grading recommendations come not only from a trade union perspective but from a professional group's perspective—Scottish radiotherapy physicists. Everybody is as one on the issue. We are all awaiting feedback from the Executive. Similar grading recommendations have been implemented by the National Assembly of Wales.

Mr McAllion: It has been done there.

Terry Kehoe: The recommendations have been partly implemented there. The grade A posts have been increased.

Mr McAllion: Ah, well—that is excellent.

Terry Kehoe: So there is a precedent and I hope that the Executive will follow that example.

Mr McAllion: I certainly hope so. Thank you.

The Convener: Perhaps we will look into that.

Mary Scanlon: I attended a men's health forum on Friday and I heard of brachytherapy for the first time. You must be quite unique, because you are a brachytherapy physicist.

In your submission, you say that there is a 30 per cent shortfall in radiotherapy physicists, which amounts to 16 posts throughout Scotland. Given what John McAllion said about the importance of teamwork for patient care and how treatment plans are designed, can you tell us how that shortfall is affecting cancer care?

You also say in your submission:

> "Scotland now has equipment with IMRT capability **but** there are not enough physicists to … implement this advance.

Am I right in saying that we now have the equipment but we do not have the personnel? Am I also right in saying that brachytherapy is available only at one centre in Scotland—the Western general?

Terry Kehoe: It is not true to say that brachytherapy is available only at the Western general. It is available at the Beatson and at Dundee and Aberdeen. Inverness is too small to provide that service. You must realise that brachytherapy requires a certain expertise and a certain volume of patients to develop that expertise in order to provide an appropriate service. It is not automatic that every centre should provide a brachytherapy service.

Brachytherapy has been around for a long time, treating many different types of cancer. The latest development, for example, is prostrate brachytherapy. I am responsible for that in Edinburgh, but Glasgow is also on board with that. Therefore, two centres in Scotland are performing brachytherapy. The therapy is specialised, but widespread.

Mary Scanlon: Are you saying that everyone who would benefit from such treatment has access to it? How does the shortfall of 30 per cent in radiotherapy physicists affect treatment of patients in Scotland?

Terry Kehoe: There are two aspects to that. In terms of the numbers, it depends on which model is applied. The 30 per cent figure comes from my professional body, the Institute of Physics and Engineers in Medicine. That figure is the institute's latest recommendation of the number of physicists for the work load in Scotland. However, different models give different numbers. The figure varies from 10 to 30 per cent in different models, so there could be a shortfall of approximately 10 jobs.

The first thing to say is that we are not providing an unsafe service. We provide a safe service for patients. The shortfall concerns the latest developments. You alluded to that when you referred to intensively modulated radiotherapy. We have the equipment in Scotland to do that, but it takes time for the new techniques and the utilisation of the equipment to come on line to be useful for patients. We are struggling in that area. We do not have the physicists in post to do that development work.

The tendency is for physicists to be employed when new equipment is installed in the departments, but the physicists are needed sooner. The ideas and techniques for using the equipment need to be worked up to hit the ground running. That does not always happen.

Mary Scanlon: So we need a work force plan as well as a cancer plan.

Terry Kehoe: Absolutely. That is what we are calling for. We should forget about absolute numbers such as 20 per cent or 30 per cent. To be honest, I think that the Executive does not have a role in telling each department that it will have X number of staff. That is a local management decision. However, the Executive has a role in ensuring that people are coming in at the bottom and that we stop losing people down to England or wherever.

Mary Scanlon: I have a question for the RCN. In your written submission, you make a number of recommendations that relate to the education and work load of clinical nurse specialists—for example, monitoring case loads and including nursing standards in reports by the Clinical Standards Board for Scotland. Have any of those recommendations been put to the Scottish Executive? If so, have they been acted on?

Nora Kearney: Pat Dawson would need to answer whether the recommendations have been put to the Scottish Executive. They have certainly been discussed at a number of fora in which representatives of the Scottish cancer group have been involved and nurses on the Scottish cancer group are aware of how we need to move forward. The difficulty is that the development of strategic management for cancer nursing has largely been lacking in the past. For example, there is a group of lead cancer nurses in Scotland, which comprises four nurses. In England, there is a lead nurse for every network and every region. Lead nurses have no link whatever into the Scottish cancer group and no link into the Scottish Executive. Therefore, there is little strategic management of cancer nursing development across Scotland. Things happen locally that are not overseen nationally.

Mary Scanlon: How can there be a managed clinical network if the lead cancer nurses do not link in?

Nora Kearney: The situation is confusing. I cannot answer that question, because I am not part of the managed clinical network system nor am I a lead cancer nurse in a clinical situation. There is on-going work. A lead cancer nurse has been appointed at the nursing and midwifery practice development unit and it is hoped that that will drive forward strategic nursing issues and that there will be closer links with the Scottish cancer group, but that has not happened yet.

Janis Hughes: Does the Scottish cancer group adequately represent all disciplines that are involved in the delivery of cancer care? If not, who else should be on the group?

Terry Kehoe: The Scottish cancer group does not have radiotherapy physicist involvement, for example. It might be argued that everybody in the universe cannot be represented, which is true, but we perhaps do not have formalised paths for information. My submission says that we feel that we are a vital part of the team, but we are not always approached for information. Perhaps there is sometimes a lack of awareness of who we are. Developmental work is needed in that respect.

Nora Kearney: I echo that. There is significant medical dominance on the Scottish cancer group, which is at odds with how patient cancer services are delivered. There seems to be an imbalance in respect of the representation of those who are involved in delivering cancer care.

Dorothy-Grace Elder: What should be done to improve cancer services in Scotland? What would your priority areas be?

The Convener: That is just a small question.

Nora Kearney: I will answer from a nursing point of view. We would like a cohesive nursing strategy that is developed around patients. There should be a clinical focus that is driven by patient need and supportive care. There is definitely a need to improve recruitment into clinical trials and access to treatment, for example. Much of that could be achieved by using nurses much more creatively at the point of contact in primary care, acute cancer services and palliative care.

The nursing work force that is available to the Scottish people is potentially huge, but so far, it has not been used to its full potential. There is a real opportunity to develop nurse-led initiatives in the UK and Europe. Powerful international nursing research in Scotland is not being implemented in Scotland, but is supported elsewhere—in England and by European moneys. There is a real mismatch between the potential that is available and how that is being utilised. That is partly due to the lack of a strategic approach.

Dorothy-Grace Elder: Does anybody else want to comment on where the gaps are?

Pat Dawson: Our written evidence contains suggestions. I want to follow on from what Nora Kearney said and the RCN's value nurses campaign by saying that we should demonstrate that we value nurses. Instead of having a lead doctor, let us have an identified lead nurse who works at strategic level to make the voice of nurses and the patients' agenda live issues in the planning process. They could work to ensure that issues such as work force education, multidisciplinary working, research and patient information, which has not yet been mentioned although it is crucial for nurses' communication role, are put on the agenda.

Let us demonstrate that we are committed to lead nurses working at regional and local level in our LHCCs and in our cancer centres and ensure that we resource them adequately to do that. Let us demonstrate that we are committed to finding out where our cancer specialists are and what they are doing. We must ensure that their work load is manageable, that they have holiday and sickness cover and that they are resourced adequately to help the co-ordination between primary and acute care.

Some of our lead cancer nurses consider only one aspect of cancer care. Only two cancer nurses straddle the divide and are able to examine the patient journey and take the cohesive approach to managing cancer care that an NHS board might take in its area. Others' role is sub-divided, even though they are lead cancer nurses.

Earlier today, we heard that medics and others cannot mention cancer services without describing the key role that is played by nurses in their various guises, as district nurses or in other facets of the profession. We have to capitalise on that fact and see the nursing work force as a key deliverer of strategic, co-ordinated change and improvement. Nurses are leading on the patients' agenda; they are delivering the changes that are required in the cancer plan.

12:00

Dorothy-Grace Elder: A point was made earlier about the fact that 68 per cent of people who are dying wish to die at home. Are nurses a key factor in ensuring that greater provision is made for aid to be given in the home to those who wish to remain there?

Pat Dawson: That is not an area I know terribly well. This morning, we have heard about patchy palliative care services, lack of integration and the key role that nurses can play in that regard. We have also heard about the generic skills that are needed in the palliative care sector, not only in cancer care. Education is needed to support symptom control, whether that is through pain management or other systems, including chemotherapy administration or generalist support for palliation. We need all those things.

A nurse told me that to complete her training in cancer nursing, she had to undertake six modules, each of which cost her £500. That is ridiculous. Where are the infrastructure, resources and local incentives for nurses who want do those courses?

Dorothy-Grace Elder: Did the nurse pay £3,000 to train in various areas including pain management?

Pat Dawson: Yes.

Dorothy-Grace Elder: In one year?

Pat Dawson: Yes.

Nora Kearney: It is important to note that money was ring-fenced in the English cancer plan to consider the provision of generic palliative care education for district nurses. There was a recognition that district nurses did not have the skills to manage patients with cancer in the community. As we speak, that education process is about to start—it will come on stream in the next two months.

We have to recognise that there is a definite need to provide resources to support nurses in the community to manage patients in their own homes. If we can do that, there is a real possibility that we can retain patients in their own homes, which is exactly where they want to be.

Dorothy-Grace Elder: Lastly, are all those patients getting adequate pain relief?

Nora Kearney: No. There is overwhelming evidence that they are not and that their other symptoms are not well supported.

The Convener: Does Terry Kehoe want to come in on the original question? Do you want to say what you would do if you could have your wish list fulfilled?

Terry Kehoe: I want to emphasise that I am a practising radiotherapy physicist, which means that I am heavily involved in treatment. However, colleagues of mine and medical physicists who are in the diagnostic field say that, if we are to bring about earlier diagnosis of cancer, we will need access to other equipment. Physicists are involved in computed tomography, magnetic resonance imaging and with positron emission tomography scanners, which are not yet available in Scotland. They take a primary role in developing that tool to address clinical need. We should not lose sight of that, as we need to talk about not only treatment but diagnosis.

Nora Kearney: In order to improve cancer services, we need to implement the research knowledge that we have to date. The problem is that that knowledge is not implemented clinically. We could shift things very quickly if we were to implement the existing research knowledge in clinical practice within a short time.

The Convener: That is a good link, because we will talk to someone from Cancer Research UK next. I thank the witnesses for their oral and written evidence and for their on-going work.

The final witness on cancer services is Dr Duncan Jodrell, from Cancer Research UK. He is based at the Western general. I thank him for coming to give evidence.

Janis Hughes: How have things changed in cancer research since the introduction of the cancer plan, if they have changed at all?

Dr Duncan Jodrell (Cancer Research UK): One of the issues that we raised the last time that we presented evidence to the committee was that a lot of the standard service care was being provided by clinicians who were funded by the Cancer Research Campaign and the Imperial Cancer Research Fund, as they were then. I can speak mainly for the south and east of Scotland, as that is where I work. In that area, there has been an expansion in the number of NHS consultants, so service provision will be by those people. I hope that that will free up time for academics to perform clinical and basic laboratory research. It is early days, so we will have to wait and see whether that occurs.

Janis Hughes: What are the priorities for the cancer research agenda? How do you rank those priorities?

Dr Jodrell: I am one member of the group of Cancer Research UK specialists in Scotland. I suspect that there is a danger that I would vote for my own area. Most of us feel that there needs to be an expansion in cancer research and that we should be looking at prevention and screening. We should also be considering translational research, where we take the developments from the laboratory and from clinical trials and apply them in clinical practice. My area of expertise is in new drug development and that is one area in which translating the results of clinical research into clinical practice is being seen as a potential block.

Margaret Jamieson: In the research work that is taking place throughout Scotland, is there a strategy to ensure that a consistent and complementary approach is being taken in each area so that you do not reinvent the wheel?

Dr Jodrell: That is a good point. There may now be more strategic developments following the merger of the two major British charities. Previously, although the Cancer Research Campaign and Imperial Cancer Research Fund units interacted, they had separate funding and, to a certain extent, there was an element of competition between the organisations. Now that the two charities have merged, we are going through a busy period of sorting out the administrative details. I hope that once that period is over, there will be an opportunity for Cancer Research UK in Scotland to come together and have a more strategic approach.

Margaret Jamieson: Do you believe that, at some time in the future, that approach would benefit the patients whom you strive to serve?

Dr Jodrell: Without a doubt. I would not be in the game if I did not feel that that was likely to happen. As I have said, although the research must be co-ordinated, there must also be a co-ordinated plan for translating the fruits of that research into clinical practice. That might cost money.

The Convener: Most things do.

Nicola Sturgeon: Your written submission suggests that the Scottish Executive should match pound for pound the funding that charities make available for research, on which you give some figures. Have you any information about how research spending in this country compares with spending in other countries?

The Convener: As I said, I am one of Cancer Research UK's funded researchers in Scotland, so I do not have that information to hand. As has been said, we lag a long way behind the rest of Europe in spending on new cancer drugs. I suspect that our spending on cancer research is not as high as spending is in the United States, but I do not have the figures for you. I am sure that someone could provide them, if that would be useful.

Dorothy-Grace Elder: How are cancer trials being integrated into the work of cancer services across Scotland?

Dr Jodrell: In the south and east of Scotland—and I suspect in other regions, too—we are trying to base the organisation of clinical trials within the region, using the clinical networks as a basis. We are implementing a process in which we will develop research networks with adequate nurse and data management support in the peripheral units and cancer centres. That is an exciting development. We have heard numbers and figures, but we have not yet seen any tangible results and it is not quite clear what the structures will be. The different clinical networks might want slightly different structures for their research networks. Clearly that is something that we should consider. In Scotland, we should also have another group to consider how to translate research findings into the clinic.

Dorothy-Grace Elder: When we visited the Beatson clinic earlier this month, we heard that it is estimated that it conducts the largest number of clinical trials on cancer in Britain. How important is the Beatson clinic to your work?

Dr Jodrell: I did part of my training at the Beatson, so I am aware of the set-up, which is excellent. The Beatson is the second-highest recruiter to new drug therapy trials in the world. That is based on its large patient work load. Linking and collaborating with the Beatson is fundamental to what my organisation does. We are all members of the new drugs committees for Cancer Research UK and we collaborate on clinical trials. There should be an air of collaboration with others. As I said, the clinical research networks should perhaps be based on top of the existing clinical networks in the west, north and south-east. I see that as the way forward.

Dorothy-Grace Elder: Do you have a view on the denial to most patients of certain cancer drugs, such as those for colorectal cancer, because of decisions made by the National Institute for

Clinical Excellence and the Health Technology Board for Scotland? Obviously your work is at the start of research and eventually newer drugs will be produced. However, drugs are being denied to patients as a first-line treatment. Does your organisation have views on that?

Dr Jodrell: The organisation takes the view that any developments that have been shown to be cost-effective and have been approved should be available in clinical practice. The situation in the south-east of Scotland is different, as sometimes even drugs that have been approved by the HTBS are not available to the clinicians who are treating colorectal cancer. I feel very strongly about that situation, which I believe we should sort out before we consider whether NICE has made the wrong decision about combination therapy. Future clinical trials must be designed in a way that will inform clinical practice, rather than simply as a means of getting the drug a licence, which can allow commercial pressures to take over. That is how I see the partnership between the clinical trials organisations and the Executive working in future developments. There must be some exit strategy if the trials that we perform are positive.

Dorothy-Grace Elder: Are you indicating that non-prescribing in your area, the south of Scotland, is entirely due to the local health board or trust refusing to give the funding, or is there another reason?

12:15

Dr Jodrell: The area drug and therapeutics committee assessed the data on Irinotecan and felt that there was insufficient evidence to recommend its routine clinical use. However, that is in the face of HTBS guidance and clinicians are therefore in a slightly difficult position. The difficulty is that there is no join-up between funding and the approval of drugs. When a drug is a completely new development and the health board is told that it has to find the money, the question that arises is where the money will come from. The local committee prioritises and assesses local clinical need and it may make a decision that is different from the national one. Unless funding follows the approval of new drugs, there will be postcode access differences. I use the word “access” rather than “prescribing”, because it is the holders of the purse-strings who will not allow clinicians to use those drugs.

Mary Scanlon: Do you think that the cancer plan provides a balance across prevention, detection, treatment and care? If not, can you describe where you think there should be more emphasis?

Dr Jodrell: That is not a question that I can answer. Professor Rankin, who unfortunately cannot be here today, might have been able to answer it more appropriately. We should clearly be looking at the early stages of cancer development and diagnosis in terms of prevention, screening and particularly radiological support. That is where we should be nipping cancer in the bud—before it develops into the metastatic disease where we have to use drugs and consider palliative care. We certainly need to focus on the early stages of cancer development—I am sure that my organisation does not need to bang the stop-smoking drum again. If we can have an impact on smoking, we will probably have a huge impact on cancer and perhaps a bigger impact than a lot of the research programmes that we are talking about.

Mary Scanlon: On early diagnosis, do you think that GPs are adequately included in the managed clinical network in the system, given that they represent 90 per cent of patient contact with the NHS?

Your submission mentions something that causes concern to me as a member for the Highlands and Islands. It says:

> “Dr Neil Campbell … revealed that patients in rural areas are less likely to have cancer diagnosed before death and are less likely to survive cancer once diagnosed”.

We have also heard from the BMA that patients in rural areas get poorer treatment. How can we overcome that?

Dr Jodrell: Again, I can only apologise. That document has come from the organisation as a whole and you will see that a number of people are listed in it as having specific interests. That is not an area of research in which I have been particularly involved, so it would be wrong for me to comment. I apologise for that.

GP representation in the managed clinical networks is fundamentally important. In the south-east of Scotland, we are having increasing interaction with our GP colleagues. Guidelines for referral have now been published on the cancernet and will be fundamentally important in helping to prioritise those patients—particularly those with colorectal cancer—who should be referred as urgent cases. That will allow us to audit how quickly we are seeing urgent cases, as opposed to people with non-specific bowel symptoms. Those developments are being made and I hope that we are moving in the right direction.

Mary Scanlon: Could the committee ask Cancer Research UK for a summary of Dr Campbell’s research on patients in rural areas before we draw our own conclusions?

The Convener: Yes. That would be okay.

I thank Dr Jodrell for attending and for his evidence, which brings the item to a close. Later in our agenda, we will consider the next phase of the work that we have been doing on cancer services in Scotland.

Petition

Genetically Modified Crops (PE470)

The Convener: Item 4 concerns petition PE470 on genetically modified crops. The petition was submitted on behalf of the Munlochy vigil to end the farm-scale trials of GM oil-seed rape, which is modified to resist herbicides. The Transport and the Environment Committee has forwarded the petition to us, having previously considered a similar petition from Friends of the Earth Scotland, which I think the Rural Affairs Committee also considered.

The Transport and the Environment Committee has asked us to consider the public health aspects of the issue. I am interested to hear the committee's views on what to do with the petition. We can do a range of different things, such as write to the Minister for Health and Community Care or the European Commission on the health issues. Much of what the Scottish Parliament information centre and others have given us on the issue has focused more on the environmental issues rather than on what research—if any—has been done on the health matters. There might be some scope to go in that direction.

We could take evidence on the petition, although I am aware of our work load. We are coming up to the summer recess, after which we will immediately be into consideration of the mental health bill. We could also appoint a reporter, or we could take no action. Those are some of the options. I am sure that the committee will think of others.

Nicola Sturgeon: There is a job of work for us to do. The previous inquiries have concentrated largely, but not exclusively, on the environmental impact of GM crops. We need to consider more closely the alleged or potential public health implications.

We have a timing problem, because we are about to go into recess. It would not do any harm to write to the minister and get a response from him. However, we also need to take evidence. The problem is that the matter is urgent, as the crops are flowering. To wait until after the recess would be to wait too long. Perhaps someone might be prepared to act as a reporter over the recess so that we have something concrete to return to at the end of the summer.

Mary Scanlon: I spoke to Charles Saunders from the BMA after he gave evidence this morning. He said that there are no data on the impact of GM crops on public health. In fact, at the end of the trials at Munlochy, we will know more about the effects of GM crops on moths, beetles and butterflies than on public health. He also said that the BMA wrote to the health department two months ago and has still not received a reply.

John McAllion and I were at the Medical Research Council at the Royal College of Surgeons last week. The MRC sent some evidence to us because we said that we, as members of the Health and Community Care Committee, were concerned about the issue because of the Munlochy trials. The evidence says:

> "GM foods raise several human health issues, some of which are specific to GM technology … Given the range of potential health effects and the complexity in studying some of them,"

more research is needed.

Highland Council supports the recommendations of the Agriculture and Environment Biotechnology Commission that further data be gathered and considered. I think that Highland Council has said that to the convener as well.

I see from paragraph 2.3 of the submission from Highland Council that the Labour and Liberal Democrat parties in the National Assembly for Wales have entered into a partnership arrangement pressing for a moratorium on all GM crop trials in Wales. They also seek to exploit the marketing opportunities of identifying Welsh agricultural produce as GM free.

The BMA, the MRC and Highland Council are seeking information and there are genuine concerns relating to GM crops and public health not only in relation to Munlochy, but throughout the Highlands. We have to address the issue and assure people that GM crops are safe or otherwise. There is a concern that there is more information on moths and beetles than there is baseline data on public health. I do not want to be a reporter on the issue, but I think that we have to seek reassurances.

The Convener: Let me establish what your suggestion is. We have to acknowledge that we are approaching the summer recess. There is a work load issue for when we come back, because we will have a contentious bill to consider, which will be time consuming. Nicola Sturgeon has put forward her suggestion; what do you propose we do at this stage, Mary?

Mary Scanlon: I suggest that we take evidence from the Minister for Health and Community Care and representatives of the Scottish Executive health department. I would like to hear evidence from the BMA and from Professor Hooper of the University of Sunderland, who has done a considerable amount of research into the effect of GM crops on public health.

The Convener: So you are suggesting a full inquiry. Bear in mind that, once we open that up, we have to hear from everybody, to be fair.

Mary Scanlon: We have to hear from both sides, but we have to hear from the people whom I mentioned. Professor Hooper's comments make quite frightening reading. I know that time is not on our side, but we have to reassure people about public health. We cannot just leave it.

Dorothy-Grace Elder: Could we hold a special meeting early in the recess to handle this? It is a serious issue. The problem is that the crops are flowering right now.

The Convener: I would find that suggestion a bit difficult.

Mr McAllion: We have to keep in mind the fact that the Transport and the Environment Committee was sufficiently worried by the petition to recommend to the Minister for Environment and Rural Development that the field trial be ended and the crop ploughed into the ground. That committee took the issue very seriously. It did not feel qualified to comment on the field trials' health implications, but felt that those should be pursued. That is why the petition was referred to this committee. We cannot just ignore the matter; we have to do something about it. The question is; what do we do?

Serious allegations have been made, and it is clear from the Transport and the Environment Committee's correspondence that nobody has considered the health implications for the population in the Munlochy area. The Minister for Environment and Rural Development accepted that. No tests have been carried out. We have to take seriously the comments made by Dr Charles Saunders and the other experts who have been mentioned in e-mails that have been sent to committee members.

There are two ways of doing this. We could hold a full meeting of the committee and invite those experts to give evidence, along with the Minister for Health and Community Care, or we could appoint a reporter to contact all those people and report back. But when would the reporter report back?

The Convener: Let me pick up on the point that Nicola Sturgeon made about timing. If we knew that we were to hear from the minister next week, I do not feel that I have enough background information to do justice to that opportunity. I would be surprised if most other members did not feel the same. If we had a reporter working over the summer and then considered whether to take further evidence on that basis as soon as we return after the recess, that would probably be the best solution, given the time scale available.

Nicola Sturgeon: I think that that is the way to go. I would be happy to do some work on the matter over the summer, contacting the relevant people so as to form a view on whether it would be desirable for us to inquire fully into the matter and, if so, on whom to invite to speak to us. If we let the matter lie over the summer, we would not be giving due consideration to the seriousness and urgency of the issue.

Mary Scanlon: The chief medical officer for Scotland was at a meeting with the Medical Research Council that John McAllion and I attended. We all know that there is a lot of conflicting evidence. As a responsible committee, we want to make the best judgment that we can. Would it be possible for us to ask the CMO to ask someone on the Medical Research Council to review the evidence and give us a steer, rather than tying up a member of the committee?

The Convener: I think that the only way to go forward is by accessing as many different points of view as possible. I have only one concern. I take on board the comments and the offer that Nicola Sturgeon has made and that is very good. However, we were in a comparable situation in relation to the measles, mumps and rubella vaccine report, for which we agreed to have one reporter, Mary Scanlon. On reflection, I think that we made a mistake because it was too much work for one person and it was very technical. We did not appreciate at the outset what a difficult task we had set. We might go down the reporter route, but I think that the situation is similar to that of the MMR report and that we might need a second reporter or perhaps require SPICe involvement at a much earlier stage. I put that suggestion into the melting pot. On reflection, I felt guilty that the Health and Community Care Committee had, because of the nature of the inquiry, put too much on the shoulders of one individual.

12:30

Nicola Sturgeon: We are not necessarily looking for someone to go away and come back with definitive conclusions. We need someone to make preliminary inquiries and suggest a way forward for the committee. That way forward might be a full inquiry or involve taking evidence from a few people. We do not need someone to come back to us by the end of the summer and say that GM crops are safe or not. I would share your concerns if that were what was expected. My concern is that we make progress over the summer. If we do not, we will miss the opportunity to do anything on the subject.

The Convener: Certain key people, such as the MRC, the BMA, the petitioners and local residents, have to be contacted over the summer or we will not make the best use of the time. I take on board that point.

Dorothy-Grace Elder: Perhaps the committee could write to some of the people who might wish to make submissions in relation to health or tell us where we can find the health information. It should be easy to get a few names to give us a kick start. We all suspect that there is very little information in relation to human health.

The Convener: If we decided to appoint a reporter, the committee would make such an inquiry. The information would be put on the website that the reporter, on behalf of the committee, was seeking information on the health aspects of GM. It would be up to the reporter to take forward all the work that they were able to over the recess. After the recess the committee as a whole could make a judgment about the next steps on the basis of that work.

Margaret Jamieson: In our advertising we need to be specific about the fact that the individual reporter would be acting as a sieve for the committee, finding out what evidence is available, what is relevant and what the committee could undertake. The reporter would look at all the material available and suggest the direction that the committee should take. We need to be specific about the remit of the reporter.

Mary Scanlon: The problem is that there are no data on public health. That is what Charles Saunders was saying. Even if we recommend a study, there are no data, which is why the BMA, the MRC and the people in Munlochy are so concerned.

The Convener: That is for the reporter to investigate and substantiate. For example, I understand that the schemes that are in place—obviously we are not at the forefront in this and other countries are much farther down the road—require to have on-going monitoring.

There must be data somewhere, even data that rule out a potential impact on human health. You cannot tell me that research has been done on the matter for 20 years—or whatever length of time it is—and there is not somebody somewhere who has got some kind of data, even if those are data that actively rule out an impact on human health. These things have been monitored all the time.

We need to put the matter into the hands of a reporter. I welcome the fact that Nicola Sturgeon is happy to take on the role. She will consider the issue over the summer and, when the committee returns after the recess, we can decide on the way forward on the basis of the work that she will have done. I know that the timing is not perfect, but that is the best that we can do in the circumstances. Is that agreed?

Members *indicated agreement.*

The Convener: I thank Nicola Sturgeon for that.

Subordinate Legislation

Adults with Incapacity (Specified Medical Treatments) (Scotland) Regulations 2002 (SSI 2002/275)

The Convener: We now move to item 5 on the rejigged agenda. A number of people have raised concerns about the fact that the Adults with Incapacity (Specified Medical Treatments) (Scotland) Regulations 2002 have been laid under the negative procedure. In particular, people were concerned about the provisions on neurosurgery for mental disorder.

All members should have received a copy of the minister's letter, which states:

> "On reflection, however, I have decided to amend the Regulations to exclude NMD to allow fuller opportunity for Parliamentary consideration of this very sensitive matter."

That picks up on what was said previously at the Justice and Home Affairs Committee. There was grave concern about the regulations in certain sectors, particularly from the Scottish Association for Mental Health, which has made its views known. However, the Mental Welfare Commission for Scotland took a different view.

We were heading in the direction of taking evidence on the regulations, but we now have a bit more time on our hands. We should be able to hear more detailed evidence during the passage of the forthcoming mental health bill. The minister has decided that the bill will provide an appropriate forum for such discussion and has therefore proposed to introduce amending regulations to remove NMD from the regulations that were laid before Parliament on 7 June.

With that in mind, is everybody happy that the issue should be dealt with in the mental health bill and that we should take no further action on the regulations at this time?

Mr McAllion: I was not a member of the Health and Community Care Committee when the original legislation went through, but I know that the regulations allow not only neurosurgery but sterilisation and abortion. Are we quite happy about that? Those issues will not come back to us in the bill.

Margaret Jamieson: Those issues were dealt with during the passage of the Adults with Incapacity (Scotland) Act 2000.

Mr McAllion: At last week's meeting of the cross-party group on mental health and the cross-party group on human rights, the representative of the Mental Welfare Commission pointed out that, if people are upset about neurosurgery, they should be upset about sterilisation and abortion as the same principle applies.

The Convener: All that I know is that those who have written to the committee have been concerned about the provisions on neurosurgery, which is what we have focused on. John McAllion is right that there may be concern about other things that are included in the regulations. However, my understanding is that Adam Ingram has lodged a motion to annul. If that motion is still there, we will need to return to the issue when we deal with the regulations after the recess.

The issue on which the committee had to decide was whether we wished to take evidence prior to the recess. At this point, representation had been made to the committee only on the issue of psychosurgery. My understanding is that the Adults with Incapacity (Scotland) Act 2000 covered issues such as sterilisation as well as neurosurgery and psychosurgery. However, I think that the Mental Welfare Commission will say that there are safeguards in so far as, before such sterilisation or whatever could be performed, the matter would need to go to the Court of Session.

Mr McAllion: Will the regulations come back to the committee anyway?

The Convener: Yes. Theoretically, they could come back to the committee in one of two ways. If nobody lodged a motion to annul and the committee had not done anything about it, our hands would be tied because of the timing. However, I understand that Adam Ingram has lodged a motion to annul, which means that we will be given the opportunity to consider the regulations when we return at the beginning of September. We will then be able to decide whether to accept the regulations or to throw them out, but we cannot amend them. We will be given that option at that point.

I put the item on the agenda at this stage because it looked as if that would be the only way in which we would have an opportunity to take evidence in good time. When I put the item on the agenda, I was not aware that Adam Ingram had lodged a motion to annul. I thought that a committee member might end up lodging such a motion and I wanted to ensure that we did not get caught out because of the recess.

Psychosurgery is the issue on which most people have written to us. As far as I am aware, no one else has picked up on the other points. We will return to the issue in September anyway.

Mary Scanlon: I attended the same meeting as John McAllion. One point that was made was that, if we address the issue when we come back in September, we will be outwith the 40-day period for the annulment of the statutory instrument.

The Convener: No. The 40-day period is suspended over the recess, so we would still be within the 40 days. The reason that the item is on today's agenda is so that we could take evidence on the regulations next week in order to be able to make a judgment within the required time when we return in the first week of September. I did not want us to be in the situation that has happened before, where we have said that we would like to have heard evidence but have run out of time.

Are people happy with the minister's welcome change of heart?

Members *indicated agreement*.

The Convener: That concludes the public part of this morning's meeting.

12:41

Meeting continued in private until 12:55.

Members who would like a printed copy of the *Official Report* to be forwarded to them should give notice at the Document Supply Centre.

No proofs of the *Official Report* can be supplied. Members who want to suggest corrections for the archive edition should mark them clearly in the daily edition, and send it to the Official Report, 375 High Street, Edinburgh EH99 1SP. Suggested corrections in any other form cannot be accepted.

The deadline for corrections to this edition is:

Monday 1 July 2002

Members who want reprints of their speeches (within one month of the date of publication) may obtain request forms and further details from the Central Distribution Office, the Document Supply Centre or the Official Report.

PRICES AND SUBSCRIPTION RATES

DAILY EDITIONS

Single copies: £5
Meetings of the Parliament annual subscriptions: £350.00

The archive edition of the *Official Report* of meetings of the Parliament, written answers and public meetings of committees will be published on CD-ROM.

WHAT'S HAPPENING IN THE SCOTTISH PARLIAMENT, compiled by the Scottish Parliament Information Centre, contains details of past and forthcoming business and of the work of committees and gives general information on legislation and other parliamentary activity.

Single copies: £3.75
Special issue price: £5
Annual subscriptions: £150.00

WRITTEN ANSWERS TO PARLIAMENTARY QUESTIONS weekly compilation

Single copies: £3.75
Annual subscriptions: £150.00

Standing orders will be accepted at the Document Supply Centre.

Published in Edinburgh by The Stationery Office Limited and available from:

The Stationery Office Bookshop
71 Lothian Road
Edinburgh EH3 9AZ
0131 228 4181 Fax 0131 622 7017

The Stationery Office Bookshops at:
123 Kingsway, London WC2B 6PQ
Tel 020 7242 6393 Fax 020 7242 6394
68-69 Bull Street, Birmingham B4 6AD
Tel 0121 236 9696 Fax 0121 236 9699
33 Wine Street, Bristol BS1 2BQ
Tel 01179 264306 Fax 01179 294515
9-21 Princess Street, Manchester M60 8AS
Tel 0161 834 7201 Fax 0161 833 0634
16 Arthur Street, Belfast BT1 4GD
Tel 028 9023 8451 Fax 028 9023 5401
The Stationery Office Oriel Bookshop,
18-19 High Street, Cardiff CF12BZ
Tel 029 2039 5548 Fax 029 2038 4347

The Stationery Office Scottish Parliament Documentation Helpline may be able to assist with additional information on publications of or about the Scottish Parliament, their availability and cost:

Telephone orders and inquiries
0870 606 5566

Fax orders
0870 606 5588

The Scottish Parliament Shop
George IV Bridge
EH99 1SP
Telephone orders 0131 348 5412

sp.info@scottish.parliament.uk

www.scottish.parliament.uk

Accredited Agents
(see Yellow Pages)

and through good booksellers

Printed in Scotland by The Stationery Office Limited

ISBN 0 338 000003 ISSN 1467-0178