The Scottish Parliament
Pàrlamaid na h-Alba

Official Report

HEALTH AND SPORT COMMITTEE

Tuesday 2 June 2015

Session 4

Tuesday 2 June 2015

CONTENTS

Col.
PALLIATIVE CARE 1
CARERS (SCOTLAND) BILL: STAGE 1 27
ANNUAL REPORT 34
NHS CONTINUING HEALTHCARE 35

HEALTH AND SPORT COMMITTEE
18th Meeting 2015, Session 4

CONVENER

*Duncan McNeil (Greenock and Inverclyde) (Lab)

DEPUTY CONVENER

*Bob Doris (Glasgow) (SNP)

COMMITTEE MEMBERS

*Rhoda Grant (Highlands and Islands) (Lab)
*Colin Keir (Edinburgh Western) (SNP)
*Richard Lyle (Central Scotland) (SNP)
*Mike MacKenzie (Highlands and Islands) (SNP)
Nanette Milne (North East Scotland) (Con)
*Dennis Robertson (Aberdeenshire West) (SNP)
*Dr Richard Simpson (Mid Scotland and Fife) (Lab)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Elaine MacLean (Care Inspectorate)
Niki Maclean (Scottish Public Services Ombudsman)
Jacqui Macrae (Healthcare Improvement Scotland)
Rami Okasha (Care Inspectorate)
Shona Robison (Cabinet Secretary for Health, Wellbeing and Sport)
Brian Slater (Scottish Government)

CLERK TO THE COMMITTEE

Steve Farrell

LOCATION

The James Clerk Maxwell Room (CR4)

Scottish Parliament

Health and Sport Committee

Tuesday 2 June 2015

[The Convener opened the meeting at 09:45]

Palliative Care

The Convener (Duncan McNeil): Good morning. Welcome to the Health and Sport Committee's 18th meeting in 2015. I ask everyone in the room to switch off mobile phones as they often interfere with the sound system. I ask you to note that there are committee members who are using mobile devices instead of hard copies of papers.

We have received apologies from Nanette Milne.

Agenda item 1 is an evidence session with health and care regulators. It will focus on palliative care and will inform the committee's approach to its forthcoming inquiry on that issue.

I welcome Rami Okasha, the director of strategic development, and Elaine MacLean, professional adviser on palliative care, from the Care Inspectorate. I also welcome Jacqui Macrae, head of quality of care at Healthcare Improvement Scotland, and Niki Maclean, director at the office of the Scottish Public Services Ombudsman.

We will go directly to questions and start with Dennis Robertson.

Dennis Robertson (Aberdeenshire West) (SNP): Good morning. We need to understand palliative care better. Should families and patients discuss death and dying with, say, their general practitioners much earlier than currently? Would that lead to an improvement in palliative care? Since we are talking about improvement, why do we not start with HIS?

Jacqui Macrae (Healthcare Improvement Scotland): The answer from the NHS Scotland palliative care guidelines and previous work that I have done is that it would be helpful for patients to have the discussion earlier.

We are not looking specifically at palliative care through our current inspection programmes. In the inspection programme for the care of older people in acute hospitals, for example, we touch on palliative and end-of-life care through the different themes that we look at. In our strategic inspections of adult services, which we do with the Care Inspectorate, we look at services in the wider sense. Some of the people whom we speak to are at the end of their life, but some are not. I am not sure that we have enough direct evidence from our current work to respond to the question.

Rami Okasha (Care Inspectorate): It is important to have conversations about death and dying when people are able to make informed decisions and choices and have the capacity to do so. One of the encouraging signs that we have seen in care homes for older people in recent years is an increase in the number of people who, at the point at which they died, have had an anticipatory care plan, in which some of the issues have been discussed with them and their relatives. That figure has risen from 38 per cent in 2012 to 62 per cent last year, which is a relatively significant increase.

There may be good reasons why someone who dies in a care home does not have an anticipatory care plan, but the rising number of people who have one shows that more of those discussions are taking place. We very much welcome that.

The Convener: Those figures are from the care home sector. What is the figure overall?

Rami Okasha: The figures are from care homes for older people. We also collect figures in care homes for all adults, in which the numbers who have an anticipatory care plan are slightly lower, as might be expected. I can provide those figures if that would be of interest to the committee.

The Convener: That would be useful. My experience and, I think, that of others is that the handling of the end of life in the acute sector causes some reputational damage to the health service. It would be useful to have overall figures.

Dennis Robertson: I think that we all agree that the discussions should take place earlier, but I wonder who should instigate them. If we identify that a person's long-term condition is very deteriorative, should anticipatory care plans be set up? If so, by whom? Who instigates that?

Rami Okasha: When somebody comes into a residential care service, we expect those discussions to take place. I will ask Elaine MacLean to say a few words about what those discussions might be and might look like.

One of the important things is the need to join up those discussions in the health sector and the social care sector. There have been examples of encouraging practice recently, but we would like further development there. We suspect that, as we progress down the route of integration, the structures will be there to enable that to happen.

Elaine MacLean will say something about the conversations on admission to a care home.

Elaine MacLean (Care Inspectorate): Staff in the services that we regulate should be engaged in some of the anticipatory care planning, because they know the residents and the people who use the care-at-home services. We are looking to find out what the person wants. Where do they want to be looked after? Where do they want to die? Do they have any resuscitation wishes? Have their family been involved? For services to provide good end-of-life care, we need to have those conversations, and they need to be had early, when somebody is diagnosed with a life-limiting illness.

Dennis Robertson: That is within residential settings, but how do we engage with the wider community? There are a lot more people in the community who are elderly and who have terminal conditions or long-term conditions with deteriorating aspects.

Jacqui Macrae: That is difficult. You asked who should instigate an anticipatory care plan, and I am not sure that it would be one professional or professional group. People touch services at different points during their illness or during their time with healthcare. A range of staff and healthcare professionals need to be skilled up so as to understand when the most appropriate time is to have the conversation. Different people will be ready—or not—to plan for the future and to have those conversations at different times during their illness.

As part of our work to give 200,000 days back to people who would have been in acute care, we are beginning to deal with how we build capacity for improvement and how we work with service providers to improve anticipatory care planning.

Dr Richard Simpson (Mid Scotland and Fife) (Lab): I have a question on Rami Okasha's point about ensuring that all the sectors are on board. In preparation for this meeting, I spoke to a number of colleagues. As far as I can tell, the recording of DNACPR—do not attempt cardiopulmonary resuscitation—is not being transmitted to the emergency care summary. I know that terminal care is supposed to be up there as a flag on the emergency care summary or on the key information summary—KIS—but is it recorded that there is a living will, an anticipatory care plan, an advance statement or a DNACPR decision? Those are the four existing mechanisms for people to record how they wish to be treated. Are we recording that on the emergency care plan so that, when someone contacts the system, it is up there?

I welcome the fact that the figure for anticipatory care plans in care homes is 62 per cent and rising, but is that information on the emergency care summary?

Elaine MacLean: It should be on the emergency care summary. General practitioners have an obligation to complete an anticipatory care plan.

Dr Simpson: My problem is that the DNACPR is not always recorded on that summary, because it is usually set up in the hospital and hospitals are not putting it on to the emergency care plan. There is a problem. I have had specific examples of individuals having a really rotten death because they were resuscitated in the community as a result of the previous agreement not being recorded before they went back to their care homes.

Rami Okasha: It is concerning to hear that anyone would have a death of that nature. In our joint inspections with Healthcare Improvement Scotland, when we have examined what happens across a community planning partnership area on services for adults, we have identified a need for improvements in the sharing of information between the health sector and the social care sector. We have found examples of good practice, but some of our joint inspections have made recommendations about improving practice on sharing between the two sectors.

The Convener: I have taken an interest in the inspection of older people's care in our hospitals, which does not read well over the 40 inspections. Although the guidelines are clear about screening for cognitive impairment and nutrition, we are still finding—40 inspections on—that those guidelines are not being applied and that there are failures in the system.

To go back to Dennis Robertson's question, there are wider concerns about end-of-life care. Unfortunately, people's wishes have not been followed in the acute sector, as some of the inspections have identified. What would give us confidence that guidelines will result in the end-of-life and palliative care that we expect and guarantee to people? Why would we accept the approach of having guidelines rather than a right to end-of-life and palliative care?

Rami Okasha: In the care sector, the national care standards play an important role. The review of those standards will play an even more important role. The current national care standards contain standards for end-of-life care. We expect the new ones to include a more human rights-based approach, which is based on wellbeing. That will allow us as inspectors and regulators to ensure that the care that is given is responsive, is person centred and meets the individual's needs.

That is very much the way in which care is moving. In care homes for older people, overall performance on the quality of care is good—most services are considered to be good or very good—but there remains a small number of services at any one time that are not providing sufficiently good care across the piece, and it is important to target our scrutiny and improvement work on them. We try to assist in building capacity in the workforce. I do not know whether Elaine MacLean wants to say something about the work that she does on that. Ensuring that there is good knowledge and that there are confident staff in care services is critical.

The Convener: Your figures show that around 45 per cent of the 1,000-odd patients who were reviewed did not receive screening for cognitive impairment. The guidelines are in place. The rules exist but, when you inspected, nearly half the people had not had that screening. How do we get to a stage at which we can be confident that the wider issues about end-of-life and palliative care will be addressed in the care setting? We are failing to treat almost half of those people. How can the committee be confident that it does not need to examine that?

Rami Okasha: We need to target our improvement work where it is necessary. The first stage is to identify failings and put in place the right support where it is required, whether that is support from the Care Inspectorate or support from the local authority and the health board working in partnership under the new integrated arrangements.

10:00

Dr Simpson: I will quickly highlight a fact that relates to what the convener just said. The latest study to be conducted in Scotland on patients who were admitted with a prior diagnosis of dementia—in other words, they did not require a cognitive assessment—showed that 50 per cent of them did not have that diagnosis recorded in acute hospitals. The situation is therefore even worse than the convener suggested; it is a total disgrace that people with dementia are not having that recorded on their notes in hospital. How can we expect those people to receive good care in hospital when that sort of thing is happening? That study, which as I said was a Scottish one, was published last year in *The British Journal of Psychiatry*.

Jacqui Macrae: From our inspection of older people’s care in our acute hospitals, we certainly know that there are issues around the recording and documenting of information. We are also aware of the impact that that can have on staff’s ability to deliver care consistently.

In response to the original question about how we can be assured that a guidelines approach is the right one, I have to say that such an approach—or indeed any approach—in isolation will not deliver such an assurance. In our care of older people in acute hospitals programme, the 40 inspections to date have not really shown significant improvement, but we need to remember that the inspections in the first tranche were baseline ones on which boards were expected to build. Over the past year, we have increasingly been working in a far more integrated way with our evidence colleagues on developing standards and with improvement colleagues to ensure that our inspection work is aligned with what they are doing and that we are building on inspection findings and targeting the areas where support is needed.

In fact, boards are far more frequently approaching us to ask where things are being done well and to ask our inspectors and improvement colleagues to take the post-inspection findings and run local improvement events in their areas. For example, NHS Lanarkshire, NHS Greater Glasgow and Clyde and NHS Fife have held such events, and I know that others are planning them. That is all about staff looking at their inspection findings and working with us to make improvements across the piece. It is frustrating that those improvements are not happening immediately, but the area is complex.

Dennis Robertson: I am struggling with this a wee bit. I believe that the majority of people who are coming to the end of their lives have appropriate support, whether that is from the GP or their family, and the appropriate palliative care. I accept that some do not, but in the majority of cases we have respect for people at the end of their lives and the appropriate services are generally available.

What I am struggling with is people saying that they are looking at things, that they would like to do this or that or that the expectation is for this or that to happen. That is all very nice, but would it not be better to have guidelines that make clear what we should be achieving and which set out the baseline and the pathway through the integration of services to ensure that everyone knows exactly what is expected of them? I am hearing that we need to upskill people, that there are patches of good and bad and that there is improvement. That is all fine, but are there any timelines? Is there a pathway? Do we have the appropriate people to give that kind of training? I have not really heard anything about that. Perhaps Rami Okasha could respond.

Rami Okasha: The Scottish Government is working on a palliative care framework, and Elaine MacLean sits on the national advisory group for what we hope will provide a framework for action. However, that kind of improvement action, particularly with regard to care services, many of which are run not by the local authority or health board but by private companies or voluntary organisations, has to be targeted and localised. Although a national framework is important and welcome, improvement, in a sense, has to happen when people walk through the doors of the building, and it is really important that we build capacity in the providers to make those improvements.

Jacqui Macrae: It is important that there is a national framework and a standard that we should all be working to. The standards of care for older people in acute hospitals are being revised. There will not be a separate standard on palliative and end-of-life care; instead, the issue will be threaded throughout the standards. For example, when we talk about dignity and respect, the draft standards now refer specifically to the conversations that we talked about earlier and the need to provide privacy for those conversations to happen.

The Convener: The local delivery plan for 2015-16, which focuses on driving improvement in the quality of healthcare, does not mention end-of-life or palliative care at all even though it is 32 pages long. Do you not see end-of-life or palliative care as something that needs to be mentioned?

Jacqui Macrae: The plan does not mention it or draw it out specifically, but in the pieces of work that we are doing in relation to older people in acute hospitals, there is an outcome for end-of-life and palliative care in the revised methodology.

We have not focused directly on end-of-life and palliative care to date as part of our revised inspection process, because we have continued to focus on themes such as food, fluid and nutrition, tissue viability, falls and cognitive impairment. That is partly about allowing boards to develop the work that was previously undertaken and is being undertaken around improvement in those areas so that we can inspect and reflect the improvement that is starting to happen.

That is not to say that we do not look at end-of-life care when we are out in clinical areas. A large percentage of people in our hospitals are older, and we cut across surgical, medical and front-door services. Within that, we will look at patients who happen to be older and at the end of their lives but we are not drawing that out as a specific theme at the moment.

Dennis Robertson: That is all very well, but what about our children, young people and adults? Some have terminal illnesses and are looking towards end of life and appropriate end-of-life care. I understand that the majority of patients are older, but surely there has to be an all-encompassing aspect to palliative care to ensure that everyone—especially children and young people—has the most appropriate care at that very traumatic time in a family's life?

Jacqui Macrae: Currently, we inspect hospices through our independent healthcare inspection programme. Overall, the standard of care in our hospice sector is very good or excellent. However, we are not looking specifically at the pathways of care for children and others across our inspection programmes. That is something that we could consider.

We inspect children's services jointly with the Care Inspectorate, which is the lead agency, so Rami Okasha may wish to follow up on that.

Rami Okasha: We both inspect the pathway of support for children in any community planning partnership area. We also regulate a small number of very specialist services that provide palliative care to children on a care-at-home basis. Those services are provided by the Children's Hospice Association Scotland, and the quality of the services that we inspect is very high.

Jacqui Macrae referred to our joint inspections. We certainly expect to see better sharing of information across agencies as more established mechanisms are developed around sharing information and working together among children's services. The quality of the joint working that we find is high. We are happy to get back to the committee with any specific scrutiny evidence that we have on palliative care from those inspections.

The Convener: I am conscious that Niki Maclean has not had an opportunity to come in. It might be interesting to know what role the ombudsman's office might play when the partnerships are discussing all those issues.

Niki Maclean (Scottish Public Services Ombudsman): As we note in our written submission, our experience relates to end-of-life care of the elderly. The complaints that we receive on the issue tend to be about that. They reflect all the issues that we have heard about here, including the issue of correctly assessing cognitive impairment and how that ties in with treatment and issues such as trips and falls. Unfortunately the cases that we see are ones in which there have not been anticipatory care plans or discussions with family members. We see cases where there is conflict between what the patient would like to happen and what the family members would like to happen because those conversations have not taken place.

We cannot offer much advice or guidance on the benefits of anticipatory care plans, because we tend to see the cases where they are not in place—we see the consequences of not having them.

The Convener: Some other members are waiting to come in, and I will certainly get to them, but I will take Bob Doris first, as he has been waiting patiently for a wee while now.

Bob Doris (Glasgow) (SNP): I sometimes wait patiently—I know that that surprises you, convener.

It is worth putting on the record that the committee was determined to do an in-depth inquiry into palliative care irrespective of the decision on Patrick Harvie's Assisted Suicide (Scotland) Bill last week. The inquiry stands in its own right and it is the right thing to do irrespective of the decision on that bill.

I put it on the record that, during the examination of evidence on that bill, we heard stories of some exceptional palliative care work in Scotland. Internationally, we are not in a bad place, but it is still not anywhere near good enough. I know that the issue has touched all the committee members' lives personally and not just through our constituency case loads.

How do we drive continuous improvement? Getting to the specifics, I see that HIS is developing palliative and end-of-life care—PELC—indicators. The four indicators focus on identification, assessment and care planning, accessing patient information and place of death.

I am sorry to go back to numbers and statistics, because I know that each individual or personal story is not a number or a statistic. However, let us start with identification. Dennis Robertson rightly spoke about a baseline. If we are looking at how effective our system of palliative and end-of-life care is in Scotland, we have to know how many people are in the system or are trying to get into it to get palliative care in the first place. How do we measure that, irrespective of whether the presentation is with a GP, in an acute ward in hospital or in a referral to a hospice? I do not really care how people get into the system, but do we count the number of people in Scotland who need palliative care and then look to identify whether they get the service that they need? How do we identify them in the first place? How do we count the numbers?

Jacqui Macrae: There is no doubt that counting the numbers is a real challenge. One issue with the indicators is trying to work out where people are, because they are looked after in a range of settings. Palliative care is a journey that does not necessarily have a distinct starting point, which creates a challenge. Some of the data is not held nationally in a central repository. There is certainly work to do on the indicators to make the capture of the data easier by developing a framework.

Our director of evidence sits on the relevant national groups that are looking to revise the indicators along with the standards for specialist palliative care, which I think are from 2001-02. Those are significantly out of date and are a priority for our organisation to review.

Bob Doris: This might be overly simplistic, but every person in Scotland has a community health index number. That information is held securely, but it is there. It cannot be outwith the realms of possibility to ensure that, as soon as someone presents as needing palliative care or a palliative care assessment, whether to the GP, hospital or whatever, that is flagged, so that we have a national record of how many people need palliative care and we can get a breakdown by age, gender and condition to allow us to design services accordingly. Does that happen now?

Jacqui Macrae: Currently, it does not happen. There is some amazing work being done through the CHI number. I have seen colleagues from NHS Health Scotland present work around being able to trace each point at which high-end users touch services and developing that to make gaps in social care data and district nursing more evident in the process. The ability is there, but it is not happening consistently at the moment.

10:15

Bob Doris: Would it be reasonable for the committee to push for that to happen consistently across the country and for us to ask for a progress update? I want us to do that. Who would lead on that? Would it be HIS?

Jacqui Macrae: It would probably be jointly between us. We would need to involve colleagues in the Information Services Division. The right thing to collect is not always the easiest thing to collect, so it is about making sure that it is possible and that the infrastructure is in place to capture the data nationally.

Bob Doris: I will not ask you any more questions on data collection, but there is an information gap that it is essential that we fill.

Jacqui Macrae: Yes.

The Convener: It is a good point that we should understand where people are and how we can help them before we can deliver any of the other objectives, but if there is no priority in respect of palliative or end-of-life care, why would we collect numbers simply on that as a standalone? Why would we do that if the issue has not been singled out as a priority? There is a contradiction there.

Jacqui Macrae: There is more than one reason to collect data. One reason is to collect local data for local improvement. Although we are not looking at palliative and end-of-life care as a separate system at the moment, that is not to say that we could not do so in future. As I have said, we touch on it across our inspection programmes and we use a range of data and information to inform those programmes. We use that not just in prioritising where we will go for inspection but to help us focus the inspection once we are on site. That sort of information would be helpful to us, not just in acute hospitals, but as we extend the scope to look at community hospitals, specialist units for people who have dementia and across our strategic inspections with the Care Inspectorate.

Elaine MacLean: The national advisory group on palliative care has had discussions on data collection and is keen that we collect data about palliative and end-of-life care.

The Convener: Does that group take a different view, which is that palliative care should be prioritised?

Elaine MacLean: The national advisory group is keen to develop a strategic framework for action, following on from the good work that was done through the living and dying well action plan and the recommendations in it, and building on the progress that has been made. The group is keen to develop palliative and end-of-life care so that there is equitable access across Scotland.

The Convener: As a priority?

Elaine MacLean: Yes.

Bob Doris: I want to develop that point further. I will move away from data collection for the moment, although that is really important as it will allow us to get on top of what we have to do as a society.

I accept that some people who should get palliative care do not receive it but, for those who receive it, how is the quality of care inspected? I am interested in the care pathway. For some time, the committee has said that inspecting a hospice, hospital or care home provides a snapshot in time. We have frequently said that, when the inspectorate goes into a hospice or care home and digs out the patient records, we want it to go back six months, one year, two years or even five years to see the story behind the individual, so that they are not a statistic.

What work has been done to pick 100 or 500 human beings—I do not know the right statistic—who are currently in receipt of palliative care and inspect their care pathway, rather than just the care that they are receiving at that moment, to find out what their human story has been throughout the system? The committee has said repeatedly that that is the sort of thing that should happen. Does it happen and is there any intention to make it happen?

Rami Okasha: That is beginning to happen in the joint inspections for services for adults that we carry out with Healthcare Improvement Scotland. We have carried out four joint inspections as part of a programme of Scotland-wide inspection. We look to see that services are working well together to deliver good care for adults and older people in particular. We have a specific quality indicator in those inspections on prevention, early identification and intervention at the right time, and that allows us to look at the way in which palliative care is planned and delivered across healthcare and social care. As you say, it is critical that the care pathway is looked at and that we do not simply limit ourselves to looking at what happens in buildings or services.

In three of the four inspections that we have carried out to date, we found some encouraging signs of partnership working, and in one case we made some recommendations about the need for social care and health to work more closely together to get the pathway joined up so that people do not fall through gaps and so that services talk to each other and share information.

Bob Doris: I am conscious that I might not have articulated myself very clearly—not for the first time, I have to say. I am not talking about a linear pathway where someone is in a care home, about how GP services interact with that or about how support is provided with acute services and anticipatory care. I do not mean that. I am talking about work that looks at a timeline and digs back six months, a year or two years to look at the quality of experience so that we assess the quality of service that is provided to the individual and not the bricks and mortar in which they reside. Mr Okasha said that that work may be starting to happen more generally, but would it be helpful if we did it specifically in relation to palliative care?

Rami Okasha: If we are looking at a long-term pathway for an individual, I think that it is helpful to look more broadly than just at palliative care to ensure that all the aspects of care over a long period of time are provided to the person. One of the things that we do when we carry out a joint inspection is file readings. We look at people’s individual circumstances, just as you say. We look at the history of the interventions and the support that has been provided to the person and we assess whether it was right or whether improvements can be made and there are lessons to be drawn. That is beginning to happen.

Jacqui Macrae: We look at the files, but we also sample 20 people out of 100 who are using services and we speak to them and their families and immediate carers. We have made an early start on that work. We are also looking more broadly at the quality of care across our services. Healthcare Improvement Scotland is about to go out to consultation over the summer about what that might look like, and that will cut across all levels of healthcare. We are looking at the scope and breadth of that, and following the pathway for individuals has been discussed as part of that and other processes.

As we look to broaden our current programme of inspection of people and services in acute care to include community hospitals and other areas, one of the key things for us—and one of the reasons and drivers for doing it—is that there is a gap around inspection of community hospitals. Also, when we are in acute hospitals, we sometimes see that things have happened up or downstream that have affected a person's care in the hospital at that time. Our plan is to have a more board-wide approach. I know that that is about the system again, but one way of doing that is to trace individuals through the service. We might only get the story from the past six months, but we can use that approach and build on it to look across services at the impact on the individual.

Bob Doris: I do not have another question on that, but I will just reinforce the point. My personal view is that it would be beneficial to pick 100 families where there is palliative care—or where there was and the person is no longer with us—to do an in-depth drill down into their experiences, and then to do the same in a year's time or two years' time to see whether we really are improving the system.

I thank the witnesses for their answers.

Rhoda Grant (Highlands and Islands) (Lab): I have listened to what people have said and it seems to me that there are a number of issues. One is the lack of access. There is guidance about people being treated with dignity and respect, and we all expect that at all times, but how is it measured in relation to access to palliative care? The other issue is how we measure quality in relation to access.

In a way, the first issue is how we make sure that everyone has access. What questions do you ask to ensure that everyone can access palliative care?

Jacqui Macrae: I agree that access is not consistent. Our findings—particularly from the joint inspections of older people's services that we did with the Care Inspectorate—certainly reflect that. We are seeing some really good practice, with teams working together and endeavouring to provide access in a timely fashion. However, in the processes that we described that involve following up with individual patients and groups, we are still hearing from individuals that access to services and equipment remains a challenge.

As you know, Healthcare Improvement Scotland is working with JIT and QuEST to build a bigger team that will look at improvement across health and social care. We have had additional funding for that work programme. Some of the programme will look at the work that we need to do at the higher, national level, but a portion of it will look at targeting post-inspection support.

It is too early to say whether access will be considered as part of that work, but we know from the findings that are coming out of our inspections that it is still an issue.

Rhoda Grant: Could you explain what JIT and QuEST are?

Jacqui Macrae: JIT is the joint improvement team, which sits within the Scottish Government. On QuEST, I have a complete mental block—sorry. It is an improvement team that also sits within the Scottish Government. Those teams are coming together, so we will have a significant amount of improvement talent working across health and social care, instead of people working in silos in healthcare, social care and older people's services.

Rhoda Grant: When you carry out an inspection, how do you satisfy yourself that an institution that provides palliative care sees that as a priority? Obviously, provision varies according to the needs of each person, but the systems need to be ingrained to ensure that people are looking in that direction. As well as attending to people's immediate healthcare needs—whether that involves cure or management—that means looking ahead to palliative care. How do you measure whether that is happening? You can measure whether somebody is getting the right treatment and is on the right care path, but where does palliative care fit in?

Jacqui Macrae: To be perfectly honest, we are not doing that at the moment. There is a gap. As Rami Okasha said, we have published four strategic inspection reports, and another four reports are at different stages in the publication process.

We are about to review our methodology with the Care Inspectorate. This kind of working is all new for everybody; partnerships are at a certain stage in their development and we know that progress is not equal across the country. There is now a very good opportunity, given the breadth and vast scale of the inspections, to look at whether we are focusing on the things that matter most and where we can be most helpful to partnerships as we move forward.

It may be that, within that process, we will have an opportunity to look more closely at palliative and end-of-life care to address the issues that you raise.

Rami Okasha: On the second half of Rhoda Grant's question, which was about how we assess the quality of the care that is provided, I can certainly offer the committee some information on care services. For the purposes of palliative care, we are talking predominantly about care homes for older people among the services that we regulate, but care homes for adults and care-at-home services also play important roles.

Each of the 900-odd care homes for older people in Scotland gets at least one unannounced inspection a year—it happens more frequently where we have concerns. We ask services to complete a self-assessment of their strengths and weaknesses, and we ask for statistical information once a year. When we go in, we speak to the people who use the service, their relatives and carers, and we interview staff. Crucially, we observe the quality of interactions and how well care is actually being provided to individuals. Someone at an advanced stage of an illness may be unable to verbalise or talk with our inspectors, and it is important that we are able to assess that aspect. We have a set of trigger tools on palliative care that our inspectors use not only to understand what good practice looks like and should look like, but to assess it.

We take both the quantitative evidence and the qualitative evidence that we collect, assess it against the national care standards and arrive at our evaluation grade for the service, which is on a scale from unsatisfactory to excellent.

10:30

In all care service inspections, we look at the quality of care that is provided. In a care home for older people, palliative care is integral to the nature of the service. We also sometimes look at the particular question whether people living with life-limiting conditions are viewed as being an integral part of the home.

The quality levels for that quality statement are broadly consistent with those that we would expect to find for all aspects of care. We find that care is unsatisfactory in a very small percentage—about 1 per cent—of care homes, in some it is weak and in some it is no better than adequate. However, in the majority of care homes it is good, at about 40 per cent, or very good, which is also at 40 per cent.

The story about what is happening in care homes is good. When we identify poor practice, our improvement focus comes in and we seek to work with the service to make sure that it comes up to scratch very quickly.

Niki Maclean: In the cases that we see—and a palliative care case is in the compendium that we put out this month—the issue can be confusion as to whether the individual was receiving treatment or needed to receive palliative care.

In a lot of cases, it is not necessarily clear that the person is receiving specialist palliative care services. However, they are at the end of life and require end-of-life care, in which their families need to be involved. It is not necessarily an either/or issue, but, in the case that we published last month, it is very clear that there was confusion among the team of professionals in the clinical setting about whether the individual was receiving palliative care or treatment.

Rhoda Grant: I suppose that, with some conditions, it may be difficult to say whether it is possible to save someone’s life. There will always be cases in which people have to have an eye on palliative care while looking at prolonging life and giving treatment. It is complicated, and I understand where some of the confusion might arise.

Niki Maclean: The particular difficulty in the case that I mentioned was that conflicting messages were being given to the family. One part of the team was explaining that the individual was receiving palliative care, while the other members of the team were offering treatment. The family was obviously very conflicted in that situation.

The Convener: Can Elaine MacLean help us with the distinction between palliative care and end-of-life care?

Elaine MacLean: Palliative care is a philosophy, and end-of-life care is part of it. I think that separating the terms causes confusion.

Palliative care is good care that is given when someone is diagnosed with a life-limiting illness, and the need for good end-of-life care has to be recognised early on in the person’s journey. When I talk about palliative care, I am using it as an inclusive term that covers end-of-life care.

People have to live with their illness, as they go through all their treatments. They may eventually reach the stage where they need end-of-life care. The need for end-of-life care is not easy to determine because, with many conditions—dementia, for example—a person may need end-of-life care for two or three years. It is very difficult to diagnose when someone is at the end of their life. That difficulty is recognised in the guidance that has been produced on caring for people in the last days and hours of life.

The Convener: We are almost back to Dennis Robertson’s first question. Does Colin Keir want to ask a supplementary question?

Rhoda Grant: Can I come back in?

The Convener: Sorry, Rhoda—I will give you a fourth question.

Rhoda Grant: Should we have a staged process? It sounds to me as if what matters is when the process starts. We all know that at some point we will need end-of-life care, or at least most of us will. Perhaps we do not start palliative care early enough.

When people are hale and healthy, there could be a discussion about how they would like to be cared for if the need arose. As people’s health deteriorates, or if they are diagnosed with something that is terminal, the discussion could become more intense as the picture unfolds and the circumstances that they are up against become clearer. That would then become a plan that follows someone throughout their life and which, by the time that the need for care is imminent, has been discussed a lot, so the individual’s wishes are known and it is not such a difficult thing to talk about.

Elaine MacLean: That would be the ideal situation. It would be a cultural change that we might like to see in the future. It is easier for people to talk about death and dying when they are well. When they become unwell, however, their wishes might change. That is why it is necessary to start the anticipatory care plan when somebody has been diagnosed, so that we can learn what the patient’s wishes are for the future.

The Convener: Thank you. Does Colin Keir have a supplementary question?

Colin Keir (Edinburgh Western) (SNP): I would like to follow up an answer that was given to Rhoda Grant on identifying the gaps that appear to exist. We are talking very generally about palliative care as if it is just one thing. I know that some notice has been taken of the fact that people’s circumstances are different, but with some conditions there are serious difficulties as the person heads towards palliative care. I am trying to get my mind around the identification of the gaps that apparently exist in the services that we provide. What conditions are proving most difficult to provide for? With which do we struggle to find a pathway to end-of-life care?

Jacqui Macrae: I am not sure that we have enough information at the moment to comment on specific conditions.

Colin Keir: There are differences between how you would deal with someone who is coming to the end of their life as a result of cancer or dementia and how you would deal with people who have a condition such as Parkinson’s disease or Huntingdon’s disease. I am asking about the differences in approach, rather than there being an all-encompassing approach. At what point is what is actually required identified, and how readily available are the specialist services?

The Convener: Perhaps Elaine MacLean can help with that, given the discussions that she will have had in her group. We probably all recognise that some of the best palliative care is provided in the area of cancer, where it has been developed over a number of years. That would not be reflected with other life-shortening conditions or terminal illnesses.

Elaine MacLean: The thing with palliative and end-of-life care is that palliative care is based on need, not diagnosis. Palliative care should be provided for people with any life-limiting condition, which could include neurological conditions such as Huntingdon’s disease and multiple sclerosis, as well as end-stage diabetes and end-stage cardiac disease. Palliative care is an approach that involves looking after the affected person and centring the care around that person, no matter what condition they have.

Colin Keir: I am aware of that. What I am looking for is information about where the difficulties lie in providing that care. Someone might need palliative care, but that does not mean that we can say, “This is the right setting for them,” or, “This is the wrong setting for them.” Have you assessed how easy it is to find somewhere that someone with Huntingdon’s disease, for example, could go to? I know for a fact that it is incredibly difficult to find palliative care for some people. Has such an assessment been made, or are we still talking just about the generality of palliative care here?

Elaine MacLean: On care home providers, we must remember that some are private providers. The care home assesses whether it can meet the needs of that person, and—

Colin Keir: That takes me back to the question of how easily available palliative care is if we are leaving it to individual care homes to decide what type of care they provide. How can somebody in Aberdeen spend the end-of-life stage in their own community if they have to be sent to Glasgow for the facilities that they require for their particular end-of-life need?

Rami Okasha: The local authority has some responsibility, but you make a very important point about how and where services are provided. One thing that we are likely to see in the future is a change in the nature of provision. For some people, a residential setting, such as a care home for older people, is not necessarily the right place for them, or the place where they wish to spend their final years. Some people might prefer intensive care at home. It is important to make sure that there is a choice and that people have the ability genuinely to exercise that choice.

Colin Keir: I do not think that that answers my question, but there we are.

The Convener: I suppose that the issue is what choice there is, and the greatest challenge is how we can create that choice at the end of life.

Dr Simpson: If I remember correctly, QuEST is the quality, efficiency and support team—I just wanted to put that on the record.

I am considerably interested in a number of the points that have been made. We have talked about audit, and obviously the inspection system is mainly audit based. However, my first question is about research, which we have not mentioned yet. Should we think about developing research so that we know whether Marie Curie is right that 11,500 people are dying every year without effective palliative care? I do not know where that figure came from, but there should be research into it.

My next question is about the £3 million for community palliative and end-of-life care that the Government announced some years ago. Do we know what happened to it? Has there been any assessment of that?

On primary care, general practitioners are best placed in the community to provide the final anticipatory care plan. I have just been through that with my mother-in-law. We had an excellent GP who said, “These drugs should be administered if this happens.” We did not have to call in a doctor to find out what was going to happen because the drugs were there—there was a package that could be opened, so we did not have to go to the chemist to get it; the drugs were available 24/7 for that last phase. Okay—the medicines might have been wasted, because they were not actually used. Nevertheless, there was an excellent plan. We all felt good about it, and the person concerned had a good death.

Will end-of-life care be part of the new inspection system for primary care that the Government has announced? If so, will your organisations be involved in it? Are you involved in discussions on the nature and format of the inspection process?

My questions are: do you agree that we need research to give us information; what happened to the £3 million that was announced; and what is going to happen under the inspection system for primary care, in which GPs will be critical to delivery?

Niki Maclean: The SPSO is on the edges of the discussion, but there are two things that it may be helpful for you to know.

First, I know that Marie Curie is looking closely at our investigation report summaries to see whether there is anything that can inform its work. I think that that is useful. The Scottish palliative care partnership is doing the same thing. I hope that that will support some of the research that needs to happen.

Secondly, we receive very few complaints about GP provision of end-of-life care, which suggests to me that it is being done well.

Jacqui Macrae: Healthcare Improvement Scotland is involved in the work regarding GPs. I am not close to it but I am happy to ask for some written information to be submitted, if that would be helpful.

Rami Okasha: We are not involved in the inspection of healthcare services. However, in relation to social care services, we are reviewing our methodology, both for scrutiny and improvement, with a view to the new national health and care standards being in place. That will be critical to developing a way of assessing the quality of care to make sure that it really meets the needs of individual people. That goes back to Mr Doris’s point about ensuring that we look at people’s real experiences and not just statistics.

10:45

Dr Simpson: I have one further question. When I chaired a hospice management committee, I was involved in developing close liaison between the hospice and hospitals or hospital units. Does the inspection system ensure that there is good liaison? Hospices have people with really good, expert knowledge. Are those people being brought into the acute units so that they can advise people quickly on effective end-of-life care? Does that happen in all 32 acute hospitals?

Jacqui Macrae: I am not 100 per cent sure whether it happens in the 32 acute hospitals. In my experience, there is good communication between hospices and acute hospitals. It is not something that our inspection programme of older people in acute hospitals looks at.

Dr Simpson: That might be something for you to have a think about.

The Convener: Has there been any assessment of that? You say that there is good—

Jacqui Macrae: I am not aware of any assessment happening recently.

The Convener: We have heard that those who have experienced specialist palliative care, and their families, have found it to be very good. It is generally thought to be good, but it goes beyond specialist in-patient care. What assessment, evaluation or inspection—

Jacqui Macrae: Do you mean of palliative care teams within hospitals?

The Convener: I am asking about the interface between the hospital and the community. Has there been any assessment of that area so that we can say confidently that all these services are of a certain standard and quality?

Jacqui Macrae: No.

The Convener: Do we just presume that they are of that standard and quality?

Jacqui Macrae: We touch on that very lightly within our joint inspection programme when we speak to patients who have moved from hospital to a hospice in the community and when we speak to their relatives. However, it is not something that we look at formally.

The Convener: Is the issue one that the SPSO has identified?

Niki Maclean: We have seen a very small number of cases that relate not to the interface between hospices and hospitals but to instances of people returning home and being put under the care of their GP. We have seen some cases that relate to issues around pain management, for example, in the transition from hospital to home.

Bob Doris: Dr Simpson returned to the issue of identifying those who are in need of palliative care and assessing the quality of service that they receive. I think that we will need to be brave and fearless in accepting that the more that we do that, the more we will identify service shortfall. That is where we are and it is our responsibility to plan forward in that respect.

We have talked about palliative care teams in hospitals and various health and social care professionals. Who is the champion of the person who needs palliative care? Is there a single point of contact for that person and their family? Is it the GP, a nurse specialist or a social worker? I get that there is a multi-agency approach, which by its very nature can lead to potential communication issues, but is there a single, identifiable point of contact for providing support for the individual?

Given that we are scrutinising the Carers (Scotland) Bill, which looks at the bigger picture—not just the person potentially in receipt of palliative care, but the at-home carer who is providing some of that palliative care and the support that they need—can we point to an individual who would not see a patient needing care just as a number or statistic, within a rigid or flexible structure or whatever, but as a person with a family? They would be the go-to person for championing the patient and their family. Who would that be?

Jacqui Macrae: The joint inspection findings show evidence of good practice in some areas where there is a named healthcare professional for a particular family; it might be a different professional, depending on the person’s primary needs. I am not sure whether that is consistent across the country, but we are certainly seeing good evidence of that. Carer’s assessments are being undertaken, but there is a still a gap there, as there is with the subsequent assessment. Some carers are saying that they are not being provided with the personal support that they might want, and that is also coming through in our inspection findings.

Bob Doris: Does anyone else want to come in on that? I should point out that we are trying to set the scene for a future inquiry. Who would be responsible for drawing this together on a national basis? I accept that a social worker might have an interest in one area, but in other areas a nurse specialist might be the champion, depending on the condition; indeed, that was a point well made by Colin Keir. Ms Macrae, you mentioned good work at a local level on having a lead professional or champion for an individual and their family. Is anyone drawing that work together at a national level and rolling it out as best practice?

Jacqui Macrae: Within the boards, there will be an executive lead for palliative care. That will eventually link indirectly to families to ensure that there is a strategic lead as well as individual local work.

Bob Doris: That might be something for us to consider.

The Convener: If there is a lead person, do they look at inequalities in a region and at areas where there is good practice or where there is an absence of that or poorer practice? How do they evaluate and identify the gaps?

Jacqui Macrae: I am not sure how they are doing that, but they are certainly linked to the national groups and to national work at Government and strategic levels.

The Convener: Do you know whether any of that is being worked on? Are we learning from best practice and sharing intelligence? Is the ombudsman’s office, with its experience and intelligence, being involved?

Jacqui Macrae: I do not know that information to that sort of level.

The Convener: Do you know whether that is happening, Niki?

Niki Maclean: No, but perhaps I could make a slightly tangential but related and, I think, important point. Certain areas have a lead person, but in the cases that we see, one of the primary issues is that those who have most information about patients—the carers and families—are not being involved in discussions and decisions around end-of-life care. It would be helpful if a lead person had that responsibility, but the more basic issue is that we are not asking the people who have information on the patients about how to treat them. That seems a shame, because they are the people who know those patients best.

Rami Okasha: That is an extremely important point. One indicator of quality that we assess is the views of the relatives and carers of individuals who are resident in a care setting. We find that their views are essential in understanding how good the quality of care is that is being provided.

The Convener: This is not always about clinical intervention; I am thinking about care in the community and people’s choice to be at home at that point. Given that carers might go to someone’s home every day—perhaps three, four or five times a day—how would we develop that workforce? Continuity in such a situation is very important.

Rami Okasha: Absolutely. We regulate and inspect care-at-home services, and they are subject to an annual unannounced inspection. The nature of that inspection is very different, because inspecting what happens in someone’s home is different from inspecting what happens in a residential setting where we have right of access 24 hours a day. We do inspect care-at-home services, and we have found the quality of care to be good. Last year, we published an extensive report on our findings over a number of years, which I am happy to share with the committee if that will be helpful.

The Convener: My question was whether we are moving to a point at which we are not just caring for people so that they can be at home and stay at home over a longer period of time but whether we are moving into a phase where the objective is to give people the choice, for example, to die at home.

Rami Okasha: Absolutely.

The Convener: It is going to be quite a different challenge for care workers to go through the whole process of someone whom they have known over a considerable period reaching the point of death. We know that nurses and others are trained to deal with those situations, but is any investment being made in the care workforce to enable those people to play a full role in such situations?

Rami Okasha: That is a really important question, and it will become increasingly important as the nature of provision changes. As a result of our joint inspections with Healthcare Improvement Scotland, we have found a number of examples in some areas; when we looked at the provision in Angus, for example, we found that the proportion of older people living at home for the last six months of their lives was significantly higher than in other parts of Scotland and that they had improved access to palliative care, including day treatment. There are some parts of the country where such provision is clearly more embedded and is working better than it is in other parts of the country.

The Convener: As an inspection agency, are you able to evaluate the quality of palliative care at community level?

Rami Okasha: To a limited extent. We would have to be quite careful about the conclusions that we would draw from that.

The Convener: Is that something that you as an inspection body have identified as a priority?

Rami Okasha: Absolutely. One of the things that we are doing at the moment is reviewing the way in which we scrutinise and inspect all types of care service. How we look at care-at-home services will form a really important part of that, because they will become an increasingly important aspect of how people are cared for in future, not just in palliative care but across the piece.

The Convener: I am aware that that was a conversation between Rami Okasha and me, but does anyone else wish to comment on that point? If not, we will move on. I call Mike MacKenzie.

Mike MacKenzie (Highlands and Islands) (SNP): In a sense, I wish to return to the territory that you have just covered, convener. I have to say that the discussion seems to have been largely subjective, and almost anecdotal. Dr Simpson mentioned the Marie Curie study suggesting that 11,500 people are not receiving adequate palliative care. If the committee were to return to this subject in three, five or 10 years’ time, how would it know whether the quantity and quality of palliative care had improved?

Rami Okasha: The evidence that we seek to present on quality of care is based on our scrutiny evidence. We are able to say that, in a given year, a certain number of care services are providing certain types of care and are performing at a certain level and at a certain percentage. That work is very much focused on outcomes—in other words, what we observe to be the quality of life for people using the services.

We are also able to collect and track more raw data, which is about inputs. Data such as the number of care services in which NHS Scotland’s do not resuscitate policy is in place or that have an effective bereavement policy are measurable and can be tracked, which is what we do.

However, it is important to recognise that, as far as people’s outcomes are concerned, such inputs on policies go only so far. It is insufficient to consider just the inputs in measuring quality; we need to consider the outcomes, too. What is the impact of all the policies, and do they help people in difficult circumstances live better lives?

Jacqui Macrae: In response to your question how, in five years’ time, we would know that things had improved, I think that we are moving into quite a different landscape with regard to the delivery of health and social care, and we have a way to go to make our methodology and how we measure things really robust. Things that we are measuring around the fundamentals of care, including dignity, respect, person centredness, food, fluid and nutrition and the assessment of capacity, should be there for absolutely everybody, regardless of where they are.

We are starting to see an improvement, and hopefully that trajectory will continue. Measures are already in place, as we can see, but we have to consider how we can get better at capturing, using and sharing data across agencies and how we approach measurement in general.

11:00

Niki Maclean: Because our work is by its very nature about telling the stories of families, our evidence will always be anecdotal.

As for knowing whether there had been improvement, I think that it would be seen in the stories that families tell and in better communication. We recently produced a video with NHS Education for Scotland featuring a family in which the mum and her three daughters were all nurses. When the daughters talked about their attempts to bring a complaint about the end-of-life care of their mum, they said things like, “We felt that we were an annoyance,” “We were dismissed,” and “We were too intimidated to raise concerns.” Improvement would mean not having those kinds of stories.

With regard to the handling of complaints, we see a lot of good practice—indeed, we note that in our submission—but we also see a lot of defensiveness when people bring complaints. Improvement would mean not being defensive when families raised issues.

Mike MacKenzie: Data collection and analysis and presenting the overall picture always seem to be a work in progress, and there is no baseline against which we can measure and demonstrate progress. Perhaps I can turn my initial question round and ask for your views on how things have improved in a measurable way over the past five years.

Rami Okasha: As far as baseline statistics are concerned, we have an annual return in which we seek from care services the same or similar information over a consistent number of years, and we use that to track whether the indicators are going in the right direction. As I have said, the number of people who died with an anticipatory care plan in place has risen from 38 to 62 over the past three years. If we look at other areas, we see similar rises in the number of services—

Mike MacKenzie: I am sorry to interrupt, but is it right that the figure has increased from 38 to 62 across the whole country?

Rami Okasha: Yes, from 2012, there has been a rise from 38 per cent of people in care homes for older people—

Mike MacKenzie: I see. You mean 38 per cent.

Rami Okasha: The percentage of people in care homes for older people who, when they died, had an anticipatory care plan in place rose from 38 per cent to 62 per cent. There is improvement that can be tracked there. There are other indicators that can be considered, including the number of care homes for older people that have a bereavement policy in place to ensure that staff are very clear about what to do at the point of death. Over the past three years, that figure has risen to 84 per cent.

However, although there are indicators that can be tracked, the important point to stress is that those indicators relate to inputs and the policy that is in place, and we need to ask whether those increases are having an impact on the quality experienced by service users. That is where our inspectors’ evaluative judgments about the quality of care become really important.

We have seen the quality of care improving across the piece over the past three years, but there are still cases where the quality is not sufficient. However, that does not mean that it is always the same care service that is doing badly. When a care service is not performing well, we try to bring it up to the level at which it should be performing.

Sometimes it is difficult to sustain improvements. When a service performs poorly, interventions are put in place and the quality goes up, but then it slips back again. The area that we need to address is how we embed and sustain improvements.

The Convener: If there are no more questions from committee members, I thank the witnesses very much for attending and taking part in this discussion. We decided to use this morning’s evidence session as a scoping exercise for the inquiry into end-of-life and palliative care that we intend to carry out not in 10 years’ time but, I hope, sooner than that.

Thank you very much for your time, your evidence and your patience this morning. I suspend the meeting for a changeover of witnesses.

11:04

Meeting suspended.

11:16

On resuming—

Carers (Scotland) Bill: Stage 1

The Convener: We move on to agenda item 2, which is an opportunity for the members who attended the fact-finding visit to Glasgow and the meeting with members of the Marie Curie expert voices group for Scotland to report back. Bob, do you have any comments from the group that you sat with in Glasgow?

Bob Doris: Yes. I sat with a group of younger carers—that term does not necessarily mean carers of the age that is specified in the bill—and a couple of things came through quite strongly to me. First, the carer support that they feel that they need is not necessarily support in their caring duties, because it is not just their duty to care. It is also the duty of social services and the wider support agencies. Some of the support that they need is support to get on with their lives so that they are not seen only as being in a caring role. That could be support to facilitate access to college, university, training or work, or to enable them to socialise with their peer group. They feel that they also need that support as part of any carer plan that might emerge.

There was also recognition that schools are not always as attentive as they could be to the carer issues of young people who attend them. That is of some concern. The support that other agencies could provide, whether within the school or elsewhere, is important. Also, as we would expect, the issue of transitions came up quite strongly.

Those were the initial points that I picked up. The thing that I was most struck by, to repeat myself, was that young carers sometimes want support to get on with their lives. One person talked about respite care and told me that what they were looking for was to ensure that they could get a couple of hours to go out in the evening once a week and socialise with friends. That would be respite for them, knowing that they could do that and not have to worry about the loved one that they routinely have to care for. Often, the asks are not huge. They are specific, focused and unique to their lives and family circumstances.

It was pretty humbling to speak to the young carers. Their asks are really important, and they are not always huge. We just have to focus on and drill down into what is most important to the person. After all, they just want to be able to get on with their lives as well as performing their caring duties.

The Convener: Thanks, Bob. Does anyone else wish to comment on their groups?

Rhoda Grant: I had quite a varied group, but what they had in common was that a lot of them were from more rural areas. There were parents who look after their adult children, someone who had cared for a partner but they had passed away, and others who care for elderly parents.

The people in the group raised a number of good points. They were glad about the bill and thought that it would provide a focus on caring, which was good. They also welcomed the change in terminology from references to “carer’s assessment” to references to “adult carer support plan”.

However, they felt that a number of things were missing from the bill, such as emergency planning, carer involvement in admissions to hospital and discharge planning, and what the carer needs as their personal outcome in how they go about living their lives. They also referred to a carer’s ability to say, “I can’t do this any more” and to opt out of caring altogether; they thought that that was missing from the plan in the bill.

They also had concerns about the eligibility criteria and were keen for there to be a national minimum level, which would mean that everybody had equality of support; that was really important to them. They also said that when people were being assessed, it should be about not only how long they had been caring for, but the skill that was involved.

A lot of people in the group were concerned about what they were being asked to do and the level of skill involved. Indeed, they were concerned about being asked to do things that paid carers would not be asked to do. For example, they said that carers on their own were being asked to use ways of lifting and handling that were appropriate for two people to do together, but they were being asked to do that without any expert training or help, or, indeed, equipment. That is an example of the level of help and assessment that they said was required.

People were concerned that the support they receive at present is crisis support rather than on-going preventative support that would allow them to care properly. There was also concern about advice and information services. Many people had been involved in local groups that were set up through the voluntary sector to provide advice and information services, and they were concerned that because provision for such services was part of the bill, local authorities might take the services in-house instead of supporting good practice within communities. That concern is why I raised the issue with the local authorities at last week’s meeting, because it is important that there is expertise within the community.

As I said, the carers were concerned about hospital admissions and discharges, and in that regard felt that they were not being treated as equal partners. They believed that people should be discharged with a care plan, but that the carer's needs should also be assessed when the cared-for person was being discharged. They felt that an awful lot was put on them; someone said that they felt they were being bullied by being asked whether they loved their partner, when they were being asked to take on a large amount of care. It is really important that carers are valued for the contribution that they make, but they should not be forced into doing it.

The group talked about identifying carers, which is really important. They also talked about short breaks; perhaps we need to think about that issue, given that others have also talked about it and the context seems to be short breaks versus respite care. The group said that they were being asked to work long hours without a break, so perhaps respite care needs to be part of their day to allow them to go about their lives or, indeed, to go to work or whatever. That ability for carers needs to be put into the care plan.

The issue of short breaks is different, because it is about people being able to take a holiday. However, people from the islands pointed out that that sometimes does not work, because by the time they get off the island, they have lost half their week, and they never get their full entitlement. That issue needs to be looked at.

Another issue that was raised was that if the cared-for person was also the carer's partner, the carer would not necessarily want to have a short break without them. The question then was how to facilitate their care on holiday and find the right accommodation and support to allow both the carer and the cared-for person—or even the whole family—to go away together and enjoy a break. It is a difficult issue, but it has to be considered in the proposals for short breaks and, in a different vein, respite care. The two issues were being confused, and we need to ensure that that does not happen.

The important issue of the right to advocacy was also highlighted, as was the inverse relationship between deprivation and the amount of care that was received. Articulate people who can stand up for themselves get more help and support, whereas people with lower expectations who might not know the systems or who are not quite as articulate are not getting the care that they need. It was felt that it was important to tackle that in looking at support for carers.

The Convener: Thank you, Rhoda. Does anyone else wish to comment? I note that Dennis Robertson is not here. Colin, did you attend any of the sessions?

Colin Keir: Yes, I attended the expert voices group session. Given that it covered a lot of the issues that have already been highlighted, I will be fairly minimalist in my comments.

What came out at the end of the session was that, as one of the attendees commented, we are trying to get a bill that addresses certain obvious difficulties. When a person is diagnosed with a terminal illness and a carer duty is foisted upon someone else, someone somewhere has to take the lead in helping the carer through the bureaucracy of the benefits system, removing the stress of filling in endless forms and making the links between the partners in social care, local authorities and so on and helping them get a handle on how to deal with the fact that they are living with someone who is coming to the end of their life. To cut it down to the basic points that people were making, I think that they wanted help with getting through the bureaucracy and help with the various issues that my colleagues have highlighted.

The Convener: Thanks very much.

I attended the Glasgow session, which comprised a group representing minority interests and backgrounds. As one would expect, one of the issues that arose was the need to understand and respect the cultures and the community who were being cared for. That context was important and was being looked into.

Other issues that were raised have already been covered, but I note that with regard to work and employment there was an assumption that, if there was a strong family in place, people could do everything. As has been mentioned, there were issues not just with dealing with employers but with self-employment; after all, this is about not just social services, but the work situation, and having a good employer or the ability to work in a flexible way can change a person's situation and care dramatically.

Following on from that are the cultural aspects with regard to those who provide support and the issue of training for carers to allow them to understand the condition in question and to recognise the line between what they can and cannot do. I think that Rhoda Grant referred to that.

I do not know whether it was mentioned in other groups, but as a committee we have recognised that we are all living longer lives and, as a result, carers are becoming people who need care for themselves: they are carers, but they are also living with conditions that limit their quality of life. That needs to be recognised. In terms of financial support, there were issues around flexibility, respite care and other such things.

11:30

Rhoda Grant mentioned that a change in environment can be as good as a break, and that taking someone out of the home environment and creating a holiday environment for the family and those who are close can feel like respite and a break from that situation. However, that does not seem to be recognised. As we discussed this morning, if a carer is looking after someone in a terminal situation, they do not want a break away for a week; rather, they want to be there as often as possible, but they might need a break within that developing situation. Again, that led us into discussions about the importance of assessment and the rapidly changing needs of someone who is caring for someone in a declining situation. People just struggle on and two people could end up in hospital as a result. That is not good for them as human beings and it is certainly not good for the national health service, as we know.

The people in the group had access to support and information, but they value the independent information services. They have some concerns about access to that and the importance of face-to-face information and dealing with people rather than with phones and answering machines. If there is a bit of a crisis developing, or the carer just feels low that day and wants to call on support, they do not want an answering machine and no one getting back to them for two days. As we know, that breakdown in confidence can lead to unplanned hospital admissions. The committee has heard evidence that that can happen.

The carers told me strongly how important it was that they could have confidence in the continuity of services, and in people who they could rely on—people who were valued, trained and could do the job. The assessment process is seen as sometimes being a bit random and ad hoc; if families do not know or understand the rules of engagement, the process can become adversarial and very stressful. Families do not necessarily understand the timetable—if any has been set—and they are anxious that there is no set review process, which is particularly important if someone has a progressive terminal illness.

The other areas that we discussed included identification. There was an anxiety in the group about identifying more carers and why we would do that. I suggested that we were doing that because, if we anticipated someone’s caring role at an earlier stage, we could help them cope, even thought they might not need help at that given point. There was anxiety that, if we started to identify more carers, that would put pressure on the limited resource that exists at present, which would affect members of the group as carers.

There is a point to be made about transition, and how we support the carers who are already identified and who in some cases do not feel that they are supported adequately at all times. How do we reach the unmet need while striking a balance so that we do not put a question mark around the care packages that are already in place? There was a wee debate about that, and we could well understand that people were getting a bit anxious, but there is a point about unmet need. There are carers out there who need to be identified and supported—perhaps at a lower level—-or even just recognised as carers. That is important if we are to manage the situation.

There was quite a long discussion with the groups, but it was very well organised.

I see that Bob Doris wants to come in with a quick point before we finish the session.

Bob Doris: My apologies, convener—I also apologise to the young carers I spoke to. I have just consulted my notes, and I see that there are some points that I think the young carers would be surprised that I did not mention earlier, so I will do that briefly.

First, picking up on Rhoda Grant’s point about the lack of communication when the cared-for person is in hospital, a lot of young carers felt that there was no mention in hospital records of who the carer was. Young carers felt that they were being squeezed out of the process. They even suggested having a young carers card that could aid recognition when they were engaging with various public services, so that people knew that they were the carer. They noted that there is already an emergency carers card; the committee has not looked at that but it exists, although it is not universal.

The bill refers to young carers rather than specifically to young adult carers, and there was a feeling among the young carers that, because there is no statutory obligation to provide services specifically for young adult carers, the young carer services and the more generic adult carer services might evolve while young adult carers do not get what they need. There is a need for specific services for that group, and the carers wanted me to put that point on the record.

They also wanted me to put on the record a question about the review process in relation to assessments. If a carer disagrees with the local authority assessment about what a young person’s support plan includes, what recourse do they have, and how independent is that recourse?

I have covered most of the points that the young carers raised. They spoke about their feeling that social services were not particularly good at signposting young people to support services. They thought that the young carer statement could be an opportunity to improve that, but they felt that, quite often, identification as a carer came far too late in the process. They felt that, deliberately or otherwise—I am sure that it is otherwise—social work seemed to focus primarily on the cared-for person and not enough on the carer and their role in the process. However, they were hopeful that the young carer statement could address that. Again, they said that it is about driving change at a local level, not just having words in a piece of legislation.

I offer my apologies to the young carers for not putting those points on the record when I had my first cut at reporting back.

Rhoda Grant: A lot of what the expert voices group said is reflected in what we have discussed, but there is one point that we have not highlighted. One member of the group suggested a named person for carers to be able to contact. The member of the group who raised that point is used to dealing with children's services and the like: she works in that field, and thought that it would be good to have one person who co-ordinated all the services to whom she could speak. She made a really good point in that regard.

Colin Keir: That takes us back to our earlier discussion. The patient, so to speak, may be on a benefit of some kind, but we are moving towards a situation in which a change in that benefit may be due to come into effect. Not everybody knows about the system, and the point about having someone to help carers through the bureaucracy came through strongly from the people we spoke to.

The Convener: That point was reflected in both the events.

I have spoken to people who attended the Marie Curie expert voices group meeting, which I was unable to attend, and the Glasgow event. Those events were a great opportunity for the committee to meet people who are on the front line of caring across Scotland. The carers were young and old and from diverse groups. I express our sincere appreciation to those who made it possible for us to engage in that way in Glasgow and in Edinburgh. It was very useful indeed, and I hope that we have reflected those discussions in some way in today's discussions, which are now on the record and will be considered further during our scrutiny of the bill. I thank the organisers very much on behalf of the committee.

As I said earlier, we do not expect the Cabinet Secretary for Health, Wellbeing and Sport to arrive until 12 o'clock. We have time to consider agenda item 4 now, return to agenda item 3 when the cabinet secretary arrives, and have our break in between. Do members agree to do that?

Members *indicated agreement.*

Annual Report

11:41

The Convener: Agenda item 4 is consideration of the committee's annual report for the parliamentary year from 11 May 2014 to 10 May 2015. The convention is that we consider the draft report in public. We need to hear comments from members before we consider making any changes to the report, but I presume that, since the report is a factual account and record of our work, there will not be any changes. I am happy to take any comments.

Bob Doris: I am not suggesting any changes to the report. I just wanted to highlight the significant amount of work that we have done on health inequalities, and in particular our debate in the chamber on 26 March 2015, in which we sought the advice of all the other committee conveners in the Parliament who were looking to play their part in tackling health inequalities. I am sure that we will wish to return to that issue and work with the other committees on it. I know that the convener will want to push forward with that work on an ongoing basis. For the *Official Report*, I want to draw attention to the fact that our health inequalities work will endure, and will do so on a cross-committee basis.

The Convener: Thank you.

As there are no other comments, does the committee agree to the draft annual report?

Members *indicated agreement.*

11:43

Meeting suspended.

11:57

On resuming—

NHS Continuing Healthcare

The Convener: We move to agenda item 3, which we agreed to defer until the Cabinet Secretary for Health, Wellbeing and Sport was available. I welcome the cabinet secretary, Shona Robison, and her Scottish Government officials. Brian Slater is the policy manager for health and social care integration and Clare McKinlay is a solicitor in the directorate for legal services.

I invite the cabinet secretary to make some introductory remarks, after which we will move directly to questions.

The Cabinet Secretary for Health, Wellbeing and Sport (Shona Robison): Thank you, convener. I will be brief. I am pleased to introduce our guidance on hospital-based complex clinical care, which we published last Thursday and which came into effect yesterday. The guidance replaces the previous arrangements for national health service continuing healthcare. It simplifies and clarifies the process, brings transparency about decision making and brings fairness and equity in funding arrangements. It is firmly based on the recommendations of an independent review that reported last year. I thank Ian Anderson, a past president of the Royal College of Physicians and Surgeons of Glasgow, who led the review.

No one who has been in receipt of NHS continuing healthcare under the previous arrangements will be disadvantaged by the new guidance. Such people will continue to have all costs met by the NHS for as long as they remain eligible under the old criteria. In future, however, the primary eligibility question will simply be:

> “Can this individual’s care needs be properly met in any setting other than a hospital?”

We want people to be cared for in their own homes within our new integrated services, with joined-up health and social care provision and vital roles for our third sector partners. As Irene Oldfather from the Health and Social Care Alliance Scotland said in welcoming the guidance,

> “Hospital is not a place to live. It is a place to be treated, when clinically appropriate.”

I am happy to take any questions, convener.

12:00

The Convener: Thank you, cabinet secretary. The first question is from Richard Simpson.

Dr Simpson: I said when the report came out that I had considerable concerns. They have been partly addressed by the cabinet secretary’s decision to ensure that the 385 people—I think that that is the number—who are getting NHS continuing care in the community will continue to get it for as long as they are eligible. That is welcome.

However, we need to recognise that there is now a substantial divergence between the situation in England and the situation in Scotland. In England, 60,000 people are in receipt of the equivalent continuing healthcare and are having their full costs met, and there is a national decision-making tool and an independent appeals system. Neither of those is going to exist in Scotland. There will be no decision-making tool and, as far as I can judge from reading the guidelines, there are no clear guidelines. There is simply that one question that needs to be answered.

The appeals system will be within the health board, with appeals to the medical director, who will be driven partly by clinical need but also by costs because, if the health service does not have to pay for wherever the person is living, there will be a saving to the health board. The system does not have any independence or any clarity, and that concerns me.

I am also concerned because I have no clear idea, from reading the guidance, whether there will be support for somebody who is receiving considerable and intense care on a continuing basis and can live in the community in a care home but requires, for example, support for things such as percutaneous endoscopic gastrostomy—PEG—feeding or assisted ventilation or who requires specific and intense care for problems including advanced dementia and learning disability with additional needs. Such individuals may previously have been supported under chief executive letter 6 from 2008 but, as far as I can judge, they will not be supported under the new rules.

If I was running a care home in Scotland, I would be concerned that I would have to meet those needs without receiving additional funding and that the additional funding that was necessary would have to be supplied by the individual if they could afford it or by the local authority if they could not.

The last issue that I want to address is terminal care, which we discussed earlier this morning. I do not know where that fits into the situation. In England, under the clinical commissioning groups, care homes receive additional funding from health boards for all the things that I have mentioned—complex care needs and terminal care. What is the mechanism in Scotland for ensuring that such people will be properly supported in the community at home or in care homes and that that support will be properly funded?

Shona Robison: The review was set up because there were many complaints about the previous system. That is why we reviewed it. The previous cabinet secretary kicked that independent review off and, when it reported, it concluded that the previous system was unclear. There could have been two people in rooms next door to each other in a care home, one of whom was being funded under the previous arrangements through the NHS and one of whom was not, even though they had similar needs. The system was found not to be consistent, which is why the overhaul happened and the recommendations were made.

The simple question of whether someone's needs can be met in any setting other than a hospital brings a clarity to the situation that was not there before. It is a clinical decision, but the simple question that must be answered is about where the person can be cared for.

The appeals process involves a second opinion and then determination by the medical director within the board. Ultimately, the ombudsman will be the port of call beyond that if there is still a dispute.

Richard Simpson mentioned the position in England. We have two different systems and two different policy positions. It would be a mistake to think that the situation in England is perfect and that there are no complaints. I will illustrate that with some quotes. The Alzheimer's Society has said that there are huge failings and "people facing endless delays". We are told that

> "Experts are demanding an overhaul",

and that

> "the system is not fit for purpose and fails vulnerable people"

and is "a postcode lottery". We are also told that the

> "Health Ombudsman says there are 40,000 outstanding cases, with some having waited years for a decision".

It must be understood that there are significant concerns about the English system, which is certainly not perfect.

On the different policy positions, we should bear in mind the fact that 78,000 people in Scotland are benefiting from free personal and nursing care, whereas that is not the situation in England, where there is no policy of free personal care. We have made a policy decision to assist 78,000 people by providing them with free personal and nursing care, whereas in England a different policy route has been followed. That is absolutely in line with the fact that health is a devolved area in which we can make different policy decisions.

If Richard Simpson feels that this would provide him with some comfort in relation to his concerns, I would be happy to review how the new guidance was working over a period of, say, six to 12 months, once it had been operating for a period of time, and then come back to the committee with any information that arose from that. I hope that that would address any concerns that Richard Simpson or anyone else might have in that regard.

Dr Simpson: Thank you for that.

I agree that we have the absolute right to make separate decisions that are quite different from those that are made in England. I also concur with the view that England is wrestling with similar difficulties to the ones that we are wrestling with. However, the fact remains that in England 60,000 people are receiving full funding, whereas in Scotland, in a care home context, the free personal care policy provides roughly £9,000 out of a £34,000 funding requirement, on average. The families who, in time, will replace the 385 families who are being supported will have to find £24,000, if they can afford it. If they cannot afford it, that cost will fall on the local authority.

That leads me to my supplementary question. What additional funding will be provided to care homes to fund those people who will now be looked after in care homes but who will not be funded by the NHS? What transfer of funds will be made for those patients—the current figure is 385, but it used to be considerably higher—who will now be looked after in the community, if they are fit to be looked after there, but who will no longer be funded by the NHS?

Shona Robison: I want to probe the issue of the number of people who are affected. No one who was assessed under the previous guidance will be affected; they will continue to receive their full entitlement. Going forward, it is estimated that around three quarters of people will continue to meet the criteria in the new guidance and a quarter will not. That amounts to just over 100 people—112 is the figure that I have.

Because of their income levels, two thirds of those people will be entitled to have their full costs met by the local authority—I think that I am correct in saying that those include accommodation costs as well as the costs of free personal and nursing care. That means that around 35 people will be regarded as self-funding for the accommodation costs, although those people will still get free personal and nursing care if they are over 65. The situation will be different for those who are under 65, but the vast majority of the people concerned are over 65. I am not seeking to take anything away from the fact that those people will have to pay their accommodation costs but, in the grand scheme of things, a relatively small number of people will be affected.

As far as resource transfer is concerned, we are in a different world now because of integration and we have an integrated budget—in the light of the new integrated joint boards, health and social care budgets are now one. The old idea of resource transfer from one system to another does not apply because there is one system and those resources come out of the integrated joint board. There will be no significant saving anyway. We worked out that the new system will save about £3 million a year, which, in the overall scheme of things, is not a huge amount. It is not about savings; it is about bringing clarity to decision making because, as you know, the old system led to many complaints about a lack of consistency. That is why the review came up with the new system.

Is there ever a perfect system? Every system will have challenges, but I feel that the new system has a simplicity about it that will bring a clarity that the old system lacked. I hope that knowing the numbers who will be affected has brought a bit of perspective as well.

The Convener: Rhoda Grant is next. I will let you back in later, Richard, if you have more questions.

Dr Simpson: I just wanted to say that I am surprised by the numbers. I will look at them more closely, but they do not seem to add up.

The Convener: You can come back in later, when Rhoda Grant and Bob Doris have asked their questions. You will get all the time you need later.

Rhoda Grant: The cabinet secretary said that no one who is included under the old system will be disadvantaged as they will remain covered, but that presupposes that people will be disadvantaged in the future, because people who would have received that support will no longer receive it. It seems to me that, despite what the cabinet secretary said, it is a cost-saving exercise. The new system does not seem to come from the perspective of putting patient care first and putting patient needs and how best to look after patients up front rather than how money is paid out and indeed what they will pay. What benefit will patients get from the new system?

Shona Robison: First, it is not a cost-saving exercise, because hardly any costs are saved. If it was a cost-saving exercise, we would be saving a lot more than the £3 million that I mentioned to Richard Simpson. That is not a large cost saving. At the end of the day, all the resource will be in one integrated budget, so it is not about saving resources for the NHS. All the resource will be part of one system.

It would not have been fair to retrospectively apply the new guidance to people who were assessed under the old system. When I said that people will not be disadvantaged, that is what I meant. The new guidance is effective from 1 June. As I explained to Richard Simpson, around a quarter of those who are going to be assessed under the new guidance will not get their costs met through the NHS. We have looked at the modelling, and about three quarters will. The quarter who will not amounts to just over 100 people. Two thirds of them will get their costs met in a care home because of their income level, so we are talking about a third of the quarter—which amounts to about 30 to 40 people in any one year—being required to pay their accommodation costs. If they are over 65, they will still be entitled to free personal and nursing care.

The benefit that patients will get is fairness. If we look at previous complaints, they were based on a lack of consistency. Two people could live next door to each other in a care home—one whose costs were covered under the old NHS continuing care system and one, who might have similar needs, whose costs were not being covered. That lack of consistency was the basis of a number of complaints about the old system, and that is why the independent review came up with the new system.

In policy terms, we want as few people as possible to be living in hospital. The policy aim for a number of years has been to try to avoid people living in hospital. For a relatively small number of people, the clinical assessment will be that, because of their particular health needs, the only place where they can be looked after is in a hospital environment. However, I am sure that we all agree that we want to minimise the number of people who are in that situation.

Rhoda Grant: You have still not said what the benefit of the new policy is to patients.

12:15

Shona Robison: The benefits are fairness, consistency and clarity. It did not benefit people to be in a care home in a situation of inequity. If people do not need to be in a hospital, it is better for them not to be there but to be in a different environment, either at home or in a homely setting. Hospital is not where people want to be. Some people have to be in hospital because of clinical decision-making, but it will be a relatively small number.

Rhoda Grant: Is it not the case that, under the old policy, people received funding outwith hospital depending on their care needs, while the new policy means that people will only receive funding in hospital? In fact, you are putting a disincentive in place—if families and carers cannot afford to make that provision themselves, they will try to get people to remain in hospital rather than move to a more homely setting. The policy could have the unintended consequence of more people spending time in hospital, rather than fewer.

Shona Robison: The complaints about the old system were about the inconsistency of some people in care homes being funded under that system when they had the same needs as other people who were being funded by the local authority or were self-funders. That is why we had the review. We would not have had it if the old system was working perfectly well, everybody was happy and it was all hunky-dory. That was clearly not the case, and that is why there were so many complaints. We had to bring clarity and consistency to the process.

I have already explained to you about the relatively small number of people—the self-funders—who will be required to pay their accommodation costs. In the scale of things, it is a relatively small number of people, albeit that I accept that they will be required to pay their accommodation costs.

I do not think that the new system will generate an increase in people remaining in hospital, because that will be a clinical decision. It is not about people deciding that they will stay in hospital. There will be a clinical decision about whether their health needs determine that they should stay in hospital. Otherwise, they will not stay in hospital but will be in a different setting.

Rhoda Grant: Surely the care should be gauged according to the person’s needs rather than where they are being looked after. If somebody has complex needs, they would have been looked after and their whole care costs would have been borne by the NHS. If they are under 65, under the new system, they or their families will bear the whole care costs.

Shona Robison: If they have complex care needs, they will still be cared for under the new guidance. That will be a clinical decision. However, if they can be cared for in a different environment, that means that their health needs are not such that they require hospital care. Surely we do not want to keep people in hospital who do not need to be there. They will then be in a different setting. I have already explained to you that the vast majority of those people will get their accommodation and free personal nursing care costs met by the local authority. A small number, who are self-funders, will have to pay their accommodation costs.

Those who are under 65 are in a different situation, but only a very small number of those people are under 65. The vast majority of them already get all their costs paid because of their income level. Of course, those who are under 65 are also eligible for disability living allowance—or personal independence payments, as the new system is brought in. We are looking at free personal care for those who are under 65, and that will be part of our discussions.

Brian Slater (Scottish Government): We need to differentiate between the finance and the clinical care. People will still get the care that they need. A very small number might have to pay for elements of that but, under the new system, people will still get the care wherever they are. If they are in a hospital, they will receive appropriate care; if they are in a care home, they will receive appropriate care; and if they are in their own home, they will receive appropriate care.

In England, the system dictates that, if someone meets the eligibility criteria, the NHS covers for their personal care needs, their social care needs and their health needs. However, the system is very muddled down in England and, as the cabinet secretary explained, there were a huge number of complaints about the old system. We have integration in Scotland that is bringing health and social care together. Why would we then want to differentiate between them, almost splitting them back up and saying, “This is for you and that is for you”?

Rhoda Grant: But that is what the policy is doing. We are talking about moving care out of hospitals into the community and providing complex care within the community, at home or in a homely setting. Surely to base it on where people are cared for rather than on their care needs is the wrong starting point.

Shona Robison: There has to be a system to decide whether someone requires very specialised, hospital-based care. There are some people who require that and cannot be looked after anywhere else. Unless you are suggesting that we start charging people for that within the NHS, which I do not think we could do because the NHS has never charged for accommodation, that would not be the right thing to do.

There has to be a clinical decision-making process about whether a person can be cared for in any setting other than a hospital. If they do not need hospital-based care, where they should be cared for is a matter for discussion. It could be a care home setting, a specialist care home setting or at home. However, there has to be a clinical decision about whether the person requires hospital care.

The Convener: Dr Simpson wants to come back in. I will let you do that, Dr Simpson, but we are not going to—

Dr Simpson: My question was just on the numbers. I think that I have got it clear now.

The Convener: There is no time pressure. You will get an opportunity to come back in, but first we will hear from other members who have asked to come in, starting with Bob Doris.

Bob Doris: Maybe I am just getting a bit grumpy, convener, but I would say to Dr Simpson that he asked five questions rolled into one over a five minute period and had a supplementary on all of them, and now he wants to come back in and ask even more questions. There is a balance to an evidence session, Dr Simpson.

I will ask my question. Dr Simpson mentioned that the process could be an incentive to get people with complex needs out of hospital in order to save the NHS money, but Ms Grant said that it could be an incentive to keep people in hospital. It cannot possibly be both, but both positions have been put in questions to the cabinet secretary.

I would like some clarity and an assurance that every single time one of my constituents is assessed, they will be assessed purely on clinical need and not on any other issues, including financial issues, and that they will be cared for in the most appropriate setting. I would like an assurance that clinicians do that on a daily basis and will continue to do that irrespective of the guidelines. That was my supplementary question from earlier. Can we get that reassurance on the record today?

Shona Robison: Absolutely. Financial considerations are not part of the assessment. The figures that I have shared with the committee show that there is no cost saving, and in any case, because of the world of integration, there is no benefit to one part of the system. It is absolutely not about that. I can give you that reassurance.

Bob Doris: Thank you. I return to the structure. In the figures that you gave, which are helpful, you estimate that about 100 or 105 cases are—

Shona Robison: We estimate that about 385 people each year will be looked at through the process and that about 112 of them will be assessed as not needing to remain in hospital under the new guidance. Those are obviously ball-park figures, but in general about a quarter will not stay in hospital under the new guidance. Of those, two thirds will be eligible for all their costs to be met by the local authority because of their income level.

Bob Doris: What I am driving at is whether the number of constituents who are in hospital beds because they have complex clinical needs will change. Is there a bed management issue regarding ensuring that we have the right beds in the right places and at the right time within hospital settings? Is there a zero-sum game in relation to that?

Shona Robison: There is always a need for every health board to plan the beds that they will require in the short and long term, and there is a tool that enables them to do that. They need to make sure that they plan for their share of those 385 minus 112—which is 200-odd—people a year who will require to remain in hospital. The number for each health board will be relatively small, but they will need to plan to ensure that there is appropriate care for those people. People who are already under those arrangements will not be affected at all.

Bob Doris: Okay—I understand that. I support the equity argument and not charging for accommodation. The suggestion that we charge for accommodation in hospitals is ludicrous, and we should not go there. The NHS is too important for that.

We have a different situation in the social care sector. As we integrate health and social care and as the system develops, we might have increased expertise and capacity to deliver clinical care in a more homely setting outwith hospitals. As the system evolves, will the Scottish Government take cognisance of that and review and update the guidance, whether after one, two or three years? We have precedents for things such as delayed discharge, and we now have step-down beds.

Shona Robison: As I indicated earlier, I would be happy to do that. We can pick a fixed point, for example a year, to allow us to have more experience of the new system.

You hit on the important point that there is a changing environment in which intermediate care and step-up or step-down beds—whatever one wants to call them—are a growing area. Of course, there should be no charging for the intermediate care model either, which covers short stays of around four to eight weeks, because those are to provide assessments for people who are going home. Those beds provide an additional mechanism to help to keep people out of acute beds or get people home when they are clinically ready for discharge from hospital but need more rehabilitation or aids and adaptations before they can get home. They are an important part of the system, and we want to see that capacity grow across Scotland.

Bob Doris: I appreciate your answer. I will be interested to see how any review is taken forward. I am thinking of the medium term, where in theory clinical care units could be co-located with social care settings. There might be issues in relation to the resources that will be needed on site to do that, but it is important to make sure that the Scottish Government takes cognisance of evolving patterns of clinical and social care delivery.

Shona Robison: Totally.

The Convener: I have a couple of follow-up questions. The committee has taken a lot of evidence and we have probably all been involved in casework. Where there is any assessment—social work or clinical—there will be disputes and complaints, and the committee has focused on that issue. It is very controversial when someone is making a judgment about a person's condition alongside the family and is considering what is appropriate. Into that mix is then added the financial cost.

I do not know whether a system that operated completely within the health board would address some of those issues, given the evidence that we have taken about local authorities making such decisions. In the health system, there are allocations for new drugs and for innovation, but how do people get access to those things? The board has a financial envelope, and that can bear down on the independence of the decisions that are made. I do not know whether you have considered that, or how you look to ensure that there is the greatest independence within the system.

I accept that, in the health service budget, a £3 million saving is not something that would drive you to make particular decisions, but I would be interested to know where it comes from. Is it from a reduced number of beds?

12:30

My final question is on paragraph 5.8.2 of the review, which states:

> "The Panel recognises that the current situation in Scotland, in which only those individuals aged over 65 years are eligible for free personal and nursing care, is unfair and inequitable. That view was also expressed by some Voluntary Organisations, who voiced concerns that the provision of free personal and nursing care is based on age rather than clinical need."

At its heart, the policy is not correct. Paragraph 5.8.3 states that your review panel, which made the recommendations,

> "believes that there is inequity in the funding of personal and nursing care needs for individuals under the age of 65."

The new guidance does not mention the extension of free personal care to under-65s, although you mention that there is to be a review. Given that strong statement, why are we delaying action on that recommendation but pushing forward with the others?

Shona Robison: I will come back to that in a second.

On the dispute mechanism, I accept that there will undoubtedly be disagreements, as there were under the previous system. However, the process that the independent review recommended is that resolution should remain within the boards, there should be a second opinion and there should then be a case for the medical director to look at—all from a clinical perspective. Ultimately, the ombudsman is there as a backstop and can take an independent look to decide whether the decisions are right or whether they have concerns about them. As part of a look back over maybe 12 months, we would want to monitor that area.

The Convener: Can I respond to that, cabinet secretary? You are talking to the committee that took evidence on access to new drugs and medicines, and you are saying that medical directors or whoever will decide. We have taken extensive evidence on the subject, so it will be hard to convince us about that. I also understand that the ombudsman has no powers to direct health boards to take action. Everybody has the right, when they come up against a decision that they do not like, to go to the ombudsman, but we know from our casework—you probably do, too—that, in the case of a clinical decision, the ombudsman has no powers to direct a health board or do other than determine whether the procedures that are in place have been adhered to.

I do not know whether we need to reflect on that. We can never say that people will always agree—there will always be disputes—but if there is no final arbiter at the scene who is somewhat independent and can give direction or make recommendations that can change something, that is a big weakness. I am not saying whether it is wrong or right, but I suggest that there is a significant weakness in that appeals procedure.

Shona Robison: I am not sure whether I will be able to convince you otherwise, but the ombudsman's recommendations, decisions and comments on cases are listened to—boards do not ignore them, because it is a very public thing to have the ombudsman find against a board. The Scottish Government also has a role in monitoring that element of the procedure, and I give an undertaking to do so and see what we have captured after our 12-month review.

As you say, we are looking at the issue of free personal and nursing care for under-65s. We have been discussing the matter with the Convention of Scottish Local Authorities for some time, and we are doing some modelling. The biggest area of that is care at home, as the number of under-65s who are in a care home setting is very small. I think I saw the figure that 3 per cent of folk in care homes who are under 65 would be self-funders, which amounts to about 90 people. That is a relatively small number of people; nevertheless, we are looking at the issue and we are doing some modelling, because it is a complex area.

Various campaigns have called for various groups to be exempt and for elements of free personal and nursing care for under-65s to be looked at. We are looking at that as part of a proper review process with COSLA and we will come to conclusions about that. I am very happy to keep the committee informed, because I know that there is a lot of interest in the issue.

The Convener: What stage are we at with those discussions? The review recommendation about the current system being inequitable is a wee spur from the people who looked into the issue. I can understand that, as a result, the discussions are broader. What stage are you at in the discussions with COSLA? When are you likely to conclude?

Shona Robison: Some financial modelling research is under way and we will wait to see what that tells us.

The Convener: I was looking for a timescale.

Shona Robison: Obviously, we want to do that in as short a time as possible. I am not going to put a firm date on it; I will get back to you.

The Convener: Cabinet secretary, you know that you can trust us—whisper it to us. I am not looking for a drop-dead date. Can I take it from your response that the financial modelling is in the very early stages, or are you further into the process? What is the direction of travel? Do you accept the review recommendation that the current system is inequitable and needs to be dealt with?

Shona Robison: It is not just the review that has said that; a number of bodies—organisations and campaign groups—and individuals have all said something very similar.

The issue is more complex, though, because it is not just about the current number of people who are under 65 who, if they were eligible, would not have to pay. It is also about what the demand would be in the future. That is why financial modelling is important to look at the current level of need and demand, and to project that into the future. I want to make sure that we have all that in proper order as we take forward discussions about what is affordable and what can be delivered. I certainly take on board what the review has said.

Brian Slater: As regards the £3 million savings that the cabinet secretary mentioned, that estimate is based on the 100 new people who would come in. If the old eligibility system continued, we estimate that 112 people would be coming into the system and would be cared for in care homes. The NHS would pay the entire cost of that care, which would be around £600 a week. To do a very rough estimate, 112 times £600 times 52 comes to just over £3 million.

That is not a saving as such because, under the new system, most of those costs will be picked up by the new integration joint boards. We are not talking about resource transfers to local authorities; we are talking about the single pooled budget of the IJBs. Much of the cost will transfer to the IJBs. The balance of any saving will be reinvested by the IJBs in caring for more people at home.

The Convener: So making provision for the under-65s would result in a cost transfer to local government of what amount?

Shona Robison: If you did the same for the under-65s, do you mean?

Brian Slater: Of those people, very few of the under-65s are in care homes.

The Convener: Yes, but what if you extended that?

Shona Robison: I worked out that there were about 90 people, but many of them will be entitled to DLA or PIP, so we would need to look at that in a bit more detail and get back to you.

The Convener: So no costings have been worked out in relation to free personal care for the under-65s.

Shona Robison: That work has been caught up in the other review. The work that has been done here has been around the modelling of those who were eligible under the previous guidance. Under the new guidance, we have not looked at the under-65s, because that has been captured by the work and financial modelling that is being done elsewhere, which has not concluded as yet.

The Convener: Okay. Does anyone else have any other questions?

Dr Simpson: I am sorry if I irritate Mr Doris with my questions, but I want to get things clear in my mind. I may be confusing incidence and prevalence. A figure of 100 cases a year has been talked about, but they will not be replaced every year, of course. If there are 100 new cases a year, that is the incidence, but the prevalence is the number that will be involved permanently or over a period of time. I understand that that number is currently 385. We need to understand that, when you talk about a very small number of 100, the prevalence demonstrates that there are considerably more than that.

Brian Slater: I will explain the numbers. We asked ISD to come up with estimates for us based on the census information that it collects. You are quite right: there are 385 people in care currently. The turnover rate is between 30 and 34 per cent. It is clear that the continuing care numbers have been coming down for the past seven years. In each census, roughly 30 per cent of people are new and 34 per cent of people come off the census at each point.

Dr Simpson: That is the incidence.

Brian Slater: The calculation to work out in the next year how many new people would be eligible and would go into care under the new system is based on that.

Dr Simpson: So I am right: we are talking about incidence. There are 112 new cases, but they are not the permanent census cases. I know that the census data is also questionable, as the census is done on one day a year—that was questioned in the review report.

I have a final question about another thing that I am trying to understand. In the past, we have talked about category A and category B patients in relation to CEL 6 (2008). As I understand it, all our discussion is about category A patients. Can I get some clarity on category B patients and code 9 patients, as they are also a group of considerable importance? They account for 10,000 occupied bed days in any given month, or 120,000 occupied bed days a year.

Brian Slater: I will start with the code 9s.

The Convener: Mr Slater, for the record, will you explain what categories A and B and code 9 patients are?

Brian Slater: Right. We are talking about the past seven years in which we have done the census. Category A people are those who are in hospital and are eligible under the previous NHS continuing healthcare criteria. We also asked ISD to capture information on people who have been in hospital for more than 12 months, do not meet the eligibility criteria and are not delayed discharges. Although they are not clinically ready for discharge, they are not under NHS continuing care. That number of people generally runs at around 500. They could be in hospital for any number of good and valid reasons. Those are category A and category B people.

Code 9 patients are delayed discharges who are outwith the immediate control of either the NHS board or the local authority to discharge within the agreed discharge timescale. That timescale has been two weeks; before that, it was four weeks and six weeks.

The code 9 cases are predominantly adults with incapacity who have gone into hospital for an emergency reason, and it has been deemed that they lack capacity to make decisions. If the family agrees, the discharge can take place as it routinely should; if there is disagreement, a guardianship order needs to be applied for. That needs to be done through the sheriff courts, and the process is very time consuming. It can take anything from three months to 12 months. They are the main body of code 9s.

A number of code 9 patients are delayed in hospital because the specialist facilities that it has been agreed that they need simply do not exist in the community. It may be that, among the category Bs, there are some who should not be in hospital. We do not exactly know that, because they are not clinically ready for discharge, so the doctors have not decided that they are clinically ready to leave. That needs to be looked at. However, those people will be in hospital for valid reasons. There may be long-term rehabilitation. We do not break things down by reason as such, but they will be captured in the revised data that we plan to collect, which almost brings the two together.

We will start to collect data that captures anybody who is in hospital for more than six months. Doing so on a snapshot basis is not ideal. I agree with Dr Simpson that that is not an ideal approach, but until we have absolute real-time data on everybody who is in hospital, that is about the only way that we can capture data. We will capture it in line with the review recommendation.

12:45

Shona Robison: We also have some work under way to see how we can speed up the adults with incapacity issue. There is obviously a delay in the courts, and we are trying to understand what part of the process is causing the delay and whether it is something to do with the role of mental health assessment and so on. We are looking at what more we can do to make that process a bit quicker.

Dr Simpson: That is very welcome. I had experience of a patient with alcohol-related brain damage, whom we moved from the acute sector, where he was extremely expensive in terms of resources but it was not doing him any good, into an alcohol unit while waiting for a guardianship order. However, waiting for that order took six months and cost £60,000. I therefore very much welcome what the cabinet secretary is saying.

I just wanted to illustrate that this is a highly complex area. England has not got it right and I am not yet convinced that we have got it right. I very much welcome the cabinet secretary’s agreement to carry out a review within a year, because I think that we need to look at the issue very closely. One of the important things that Mr Slater said was that if the specialist facilities exist in the community, someone will be moved into them and will have to pay for that; if the facilities do not exist in the community, the person will be kept in the health service and will not have to pay for it. We will therefore always have some degree of inequity, and solving that will be a significant task for the cabinet secretary.

Bob Doris: I apologise to my colleague Dr Simpson, because there are many words that I would use to describe him, but the word “irritant” does not spring immediately to mind.

I want to follow up on some of the convener’s questioning on dispute resolution. The most obvious example of dispute resolution occurs when a patient or a family disagrees with a clinical opinion. They have a right to a second clinical opinion as part of the process, but—I do not necessarily expect you to have the figures to hand for this—how routinely does that happen? How confident are patients and families about asking for a second opinion?

Of course, when a second opinion is requested, we would want to ensure that the second opinion would not be given by a clinician in the same clinical team as the clinician who gave the first opinion. There could be conflict in such a case. For example, if the senior clinician said that a person was good to go, it would be quite a big thing for a junior clinician to say that, in their view, the person was not good to go. We would hope that such cases do not eventually go to ombudsmen and the like and that the process will work, but I wonder whether we need a more nuanced approach to how we build in capacity and perhaps advocacy provision for individuals and families so that they feel confident about asking for a second clinical opinion. That issue might become more important as we go forward.

Shona Robison: I am very clear that patients and families should be aware that that aspect is part of the process, and I will make sure that that happens. It should be laid out from the start, as should the whole process from second opinion to medical director and, beyond that, ombudsman. Brian Slater can confirm whether there is guidance around the second opinion process—I am not sure—but best practice would suggest that the clinician who gives the second opinion should not be from the same team as the clinician who gave the first opinion. However, we will take note of that point and ensure that, in practice, there is distance between the first and the second clinical opinion.

Brian Slater: It is in the guidance that a person is entitled to a second opinion that must be from a competent medical professional. The process is the same as that for any other clinical decision and applies not just to eligibility for hospital-based complex clinical care: people in general are entitled to a second opinion.

The panel spoke to key stakeholders about whether the second opinion should come from somebody from another health board, for example. However, they were very clear that it should not because, in a very small country such as Scotland, health professionals from different boards will all know one another, so the second opinion process should be contained in the same health board. However, I take Mr Doris’s point that the two opinions should not come from the same clinical team so that a junior doctor is not put in the position of overthrowing a senior doctor’s decision.

Shona Robison: Yes. We will take up that point and ensure that it is understood in practice. We can issue that guidance as a letter.

Bob Doris: It is maybe just a cultural and a confidence thing among the medical profession. Of course, it could be a fine judgment call whether clinical need would be met in hospital or whether capacity exists in the community. When it is a grey area and there is clinician disagreement, erring on the side of caution and using the hospital bed so that the full clinical support network could be accessed would seem to make sense. However, that decision would need to be taken in a way that is not seen to undermine the decision of a senior clinician in the same environment.

Shona Robison: We will take that point away with us.

Rhoda Grant: I have a question on the appeals mechanism. After a clinical decision is made, a patient can ask for a second opinion and, after that, they can go to the medical director. All those people who gave opinions would be employees of the same NHS board. What if there was a conflict between treatment and funding and someone was moved out of care as a cost-saving exercise? The ombudsman cannot look at clinical decision making; they can look only at whether the NHS board has followed the complaints process correctly. There is no independent opinion other than that that does not have a financial burden attached to it. How would you sort out that to ensure that a decision is looked at and is above suspicion of being made for a financial saving?

Shona Robison: There is no big cost saving to the NHS, so that driver is not there. It is clear in the guidance that the decision making is clinical decision making. Indeed, it says that no account of financial considerations should be taken in making decisions.

Part of a clinician’s duty is to look at a patient’s needs. I have full confidence in clinicians doing exactly that. They will not take account of any other considerations, because the guidance is clear that they should not do that. That is why it is in the guidance. I emphasise that decisions are absolutely clinically based and that no other considerations should be taken into account.

As I say, as part of the review 12 months down the line, we can check and probe the matter, to ensure and reassure ourselves that no other issues are being brought into decision making. However, the guidance could not be clearer on that.

Rhoda Grant: How would you “check and probe” decision making? The ombudsman cannot do that. They cannot look at or assess decisions that are based on clinical judgments. The issue is one of natural justice. We all hope that people will use the guidance properly. However, it is about not only being fair but being seen to be fair.

Shona Robison: We could, for example, look at a sample of the cases in which a second opinion was requested or that went to the medical director and see whether there was anything different in how the decisions were made, whether the outcomes were different from those elsewhere or whether there was anything that stood out as strange. It would be difficult to say that someone could not be cared for in hospital if they could not be cared for anywhere else in the community. To make a different decision, the clinician would have think, “Where is this person going to be cared for?” If any decisions looked out of kilter, if you like, we could certainly look at those cases, and we could perhaps also look at a sample of the cases that involved a second opinion or went to the medical director.

As we have said on a number of occasions, given that there is no big cost saving to the NHS, the money is ploughed back into integrated resources. It is not as if a health board will make a saving that it could use to offset financial pressures elsewhere. The system will not operate that way.

Brian Slater: I emphasise that, as part of a clinical decision, a multidisciplinary assessment is made. Clearly, the expertise of caring for people in the community has a big say in that. You would think that if the multidisciplinary team, who are experts in community care, are saying, “We cannot care for this person in their own home” or “We cannot care for that person in a care home,” the clinical decision will be influenced by that, which will affect the judgment on whether someone can be cared for in a hospital.

It is reasonable to say that, with all the continuing care funding, the specialities that these people are in are among the delegated functions, so the funding for older patients, whether they are in a care home or a hospital, will be delegated to the IJBs. I emphasise that we are not talking about transferring money from one statutory body to another. It will fall under the chief officer’s remit to make decisions on that budget.

The Convener: As there are no other questions, I thank the cabinet secretary and her colleagues for their attendance.

Meeting closed at 12:55.

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

Available in e-format only. Printed Scottish Parliament documentation is published in Edinburgh by APS Group Scotland.

All documents are available on
the Scottish Parliament website at:

www.scottish.parliament.uk

For details of documents available to
order in hard copy format, please contact:
APS Scottish Parliament Publications on 0131 629 9941.

For information on the Scottish Parliament contact
Public Information on:

Telephone: 0131 348 5000
Textphone: 0800 092 7100
Email: sp.info@scottish.parliament.uk

e-format first available
ISBN 978-1-78568-731-0

Revised e-format available
ISBN 978-1-78568-745-7

Printed in Scotland by APS Group Scotland