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Pàrlamaid na h-Alba

Official Report

HEALTH AND SPORT COMMITTEE

Tuesday 28 April 2015

Session 4

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HEALTH AND SPORT COMMITTEE

13th 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:

Janice Birrell (Scottish Government)
Paul Gray (Scottish Government)
Professor Craig White (Scottish Government)

CLERK TO THE COMMITTEE

Eugene Windsor

LOCATION

The James Clerk Maxwell Room (CR4)

Scottish Parliament

Health and Sport Committee

Tuesday 28 April 2015

[The Deputy Convener opened the meeting at 09:45]

Palliative Care

The Deputy Convener (Bob Doris): Good morning, everyone, and welcome to the 13th meeting in 2015 of the Health and Sport Committee. As usual, I ask everyone present to switch off mobile phones, as they can interfere with the sound system. I have apologies from our convener, Duncan McNeil, who is not able to be with us.

Item 1 is to take evidence from the Scottish Government on the current situation with palliative care to help the committee frame its inquiry into the subject later this year. I welcome to the committee Paul Gray, director general of health and social care and chief executive of NHS Scotland; and also from the Scottish Government Janice Birrell, senior policy and implementation manager, and Professor Craig White, divisional clinical lead. Good morning to you all.

Before I move to questions from members, do you want to make any opening remarks, Mr Gray?

Paul Gray (Scottish Government): Thank you very much. I have a brief opening statement.

I appreciate the opportunity to support the committee's interest in palliative and end-of-life care. It is a sensitive subject; we are talking about how we care for people at the end of their lives, so we will treat the committee's questions sensitively. If there is anything that we do not know but can provide, we will certainly do so as quickly as possible, to assist the committee.

I recognise that end-of-life care is not provided by the national health service alone. We greatly welcome the contribution of partner organisations, voluntary services and others, from which many have benefited.

Palliative care is a key dimension of high-quality care and services for people in Scotland who have progressive incurable conditions. A 2008 Audit Scotland review highlighted several areas in which focused action and improvement were required, and the publication in 2008 of the "Living and Dying Well" action plan provided everyone working in palliative care with a clear description of the required changes. Several improvements in education, national information systems, a single national policy for decision making on resuscitation, and the development of a set of national indicators were among the significant developments that came about as a result of that action plan, and were reflected in progress reports published in 2011 and 2012.

We are progressing plans to publish a new strategic framework, which will guide us, focus on the actions that will be needed to sustain the changes that have been made, and accelerate the pace and scale of improvement where that is needed.

The quality strategy measurement framework included a measure of the percentage of people spending six months at the end of life at home. The data have shown increases over time, but the increases are small. The data are now reported by hospital and health board, and across deprivation categories. We expect our strategic framework for action to outline the future requirements for an enhanced measurement framework, which we believe is important to support improvement.

That said, an increasing number of people's palliative care needs are now recognised and recorded on registers that are held by general practitioner surgeries. In 2008-09, 7,703 patients' palliative care needs were recorded; that figure rose to 12,050 in 2013-14. There has been a significant increase in the number of specialist palliative care nurses and doctors working in NHS Scotland in recent years and we now have a single, nationally agreed set of clinical guidelines for palliative care. We have learned from the successes of our national safety and person-centred improvement programmes. We have a new advisory group in place, with more effective links with GPs, hospice chief executives, nurses, palliative care specialists and the leadership of NHS boards, local authorities and national scrutiny and improvement organisations.

Earlier this year some of us met Kate Granger and her husband. All of you will be familiar with the hello my name is programme that Kate set up with her husband. Kate describes herself as a wife, daughter, sister, aunty, friend, doctor and terminally ill cancer patient.

Listening to Kate and her husband speak passionately about their campaign to improve the patient experience in hospital through getting the clinician and patient introduction right was hugely important to me. Indeed, that is one of the most important discussions that I have been part of since I took on my role. It is important that we work collectively to continue to build on what we have done during the past few years and drive forward further improvement. I welcome the committee's inquiry to that end.

The Deputy Convener: Thank you very much for those opening remarks, Mr Gray. We will move straight to questions.

Rhoda Grant (Highlands and Islands) (Lab): What pathway has now been provided for palliative care? The Liverpool care pathway was used, but I think that people pulled back and away from it because it was misused. My understanding is that there was then a bit of a gulf in respect of care and treatment. Do we have a recognised pathway for palliative care? Is it in use?

Paul Gray: You are right to say that we ceased the use of the Liverpool care pathway. We gave boards time to do that by the end of 2014. In fact, I checked with Professor White last night to ensure that we had ceased its use. As you say, there were times when it was not appropriate. Professor White will be able to give the committee more details about what we have in place now. I brought him and Janice Birrell to the meeting because they are the experts in the field. I will therefore turn a number of the questions to them, if that is all right with the committee.

Professor Craig White (Scottish Government): We convened a group of clinicians to provide advice on replacements for the Liverpool care pathway. We received advice that what was needed for care in the final days and hours of life was national guidance that focuses on four principles: informing people and communicating with them in a timely and sensitive way at the end of life; ensuring that significant decisions involve all aspects of the care team; ensuring that the focus is on psychological, social and spiritual care as well as physical care; and ensuring that the wellbeing of relatives and carers is factored into the care planning.

The decision was taken not to introduce a national pathway, because one thing that we learned from the Liverpool care pathway review was that teams need to be able to tailor their local care processes to local systems and care facilities. Our guidance therefore provides a framework for local boards and partner organisations to develop their own approaches, and we have created a national mechanism for organisations to share their particular resources.

We have the national guidance, which was published in December 2014, and we are supporting people to share what works well through our national infrastructure. One of the problems was not being able to tailor particular care delivery to local circumstance.

Rhoda Grant: Can you give me an example of where it was not possible to tailor care delivery to local circumstances?

Professor White: Two examples come to mind. Colleagues in NHS Grampian developed a particular approach to care planning for palliative and end-of-life care, which, they advised us, provided greater levels of flexibility. They were less constrained by some aspects of the pathway concept. There are also examples in NHS Forth Valley. We would certainly be happy to pass to the committee the work that colleagues in those two boards and, indeed, all the boards have been doing on the replacement for the pathway, if that would be helpful.

Rhoda Grant: It would be helpful.

My concern is that, if there is no nationally recognised standard of care, we will end up with a postcode lottery in which there is a lot of flexibility and, depending on where people live, they may have excellent care at the end of life or, if there is too much flexibility, if circumstances do not allow or if the care is difficult to provide, they may not get care at all. That seems to happen quite a lot. My concern is that, if there is not something that says what standard of care people should have at that point in their lives, they may not get that care. How do you monitor, check and ensure that best practice is available to everybody?

Professor White: The guidance and the statement that were issued in December 2014 make very clear what good-quality care looks like with the four principles that I mentioned. We expect NHS boards to use that guidance as part of their local assurance mechanisms to monitor the quality of care through their on-going improvement and governance mechanisms. The local teams will design the monitoring of quality into their processes.

The Deputy Convener: Mr Gray, do you want to add something to that?

Paul Gray: It might be helpful to Ms Grant and the committee to know that the group that Professor White referred to has already met twice—in November last year and February this year. It will meet again on 19 May, 27 August and 3 December this year.

The group is supported by a stakeholder group that consists of policymakers, representatives of third sector organisations, senior and front-line NHS staff, and service users and carers. Through that group, we expect to get feedback on the efficacy of the implementation of the guidelines that Professor White has referred to.

I take Ms Grant's point that it is important that we maintain focus on ensuring that those guidelines are implemented. We are interested in consistency of outcome. We are not imposing a single approach across Scotland. Apart from anything else, there is clear evidence that services in more remote and rural areas are delivered differently, in ways that best meet the needs of the populations in those areas. It would be wrong of us to say that what works in Glasgow should work in Ross-shire, but we are very alert to the point that the committee is making about the need for consistency of outcome.

Rhoda Grant: Regardless of where you live, you should have the same experience of a high-quality service and support for yourself and your loved ones at that stage in your life. I suppose that my concern is that there does not appear to be a way of monitoring that outcome. I agree that we should be looking at outcomes rather than at how services are delivered. Obviously, if there are fewer staff, people will deliver care in a way that is different from how it would be delivered in a more urban area, where there are more staff and resources. The patient should not notice the difference, though. They should feel supported, cared for and comfortable in their final days. We seem to be hearing from organisations such as Marie Curie Cancer Care that the kind of palliative care that someone gets depends very much on their condition. We surely should aspire to give everybody at the end of life the same quality of treatment and care.

Paul Gray: I take your point entirely. Professor White could perhaps say a little more about how we will assure ourselves over time that the standards are being applied appropriately in all areas.

Professor White: One of the areas in the strategic framework for action that needs some further focused conversation is how best to capture this complex aspect of care. As the committee is aware from its previous work, palliative care is a dimension of care; it is not always a service as such, although clearly specialist palliative care is a service. We recognise the need to have discussions with all the groups that Paul Gray mentioned about the really quite tricky issue of how we capture a fairly complex set of outcomes that span quality of life and physical, social and psychological outcomes.

On the range of conditions, we have been doing a lot of work to discuss with colleagues who work with stroke, heart failure and dementia, for example, to ensure that they are included so that we can capture the outcomes across a wide range of conditions. We are also sharing the learning from some of the work that has been taking place. To reassure the committee, a central element of the strategic framework will be the need to improve our ability to describe the quality and consistency of care that is required.

On assurance and scrutiny, Janice Birrell and I have had discussions with colleagues in the Care Inspectorate and Healthcare Improvement Scotland to ensure that the end-of-life care standards and guidance that I mentioned are included in the existing programme for older people in acute hospitals and in the Care Inspectorate's work in care homes. Again, we are trying to embed that in a range of activities so that we get a comprehensive national picture across different providers.

10:00

The Deputy Convener: I have a brief follow-up question. You mentioned the Care Inspectorate and care homes. When there is a standard inspection of a care home for older people, does the inspectorate do a mapping exercise? Might there be elderly people in a care home who have not been screened as needing palliative care? From the cohort in a care home, does the inspectorate look at whether people have palliative care needs and whether those needs have been identified properly and are being met? Does the inspectorate inspect those matters?

Professor White: The Care Inspectorate has well-developed resources for care homes that it issues in advance of the self-assessment and inspection process, which prompts care homes to consider all the issues that you have mentioned. We would be happy to provide the committee with copies of those documents, which were developed after the living and dying well recommendations. The Care Inspectorate collects data of the sort that you mention. In the past few years, it has particularly focused on whether people in care homes have an anticipatory care plan that mentions what their end-of-life care needs might be. The data that the Care Inspectorate collects shows a modest increase in the number of people whom it reviewed in its care home inspection programme who had an anticipatory care plan—in 2012, the figure was 38 per cent and in 2013, it was 46 per cent. There are some encouraging measurements and processes that we want to build on and improve in future.

The Deputy Convener: Thank you for sharing that.

Dennis Robertson (Aberdeenshire West) (SNP): I have witnessed the experience of palliative care in Grampian, especially at Roxburghe house, with David Carroll. That is an example of palliative care working extremely well on behalf of not just the patient but the family and carers of the patient. It also recognises the needs of the staff. It is a very holistic approach. I am very impressed with the work that goes on in Grampian.

On the Government's living and dying well strategy, there are still a few issues on which I am not entirely convinced we are making as much progress as we could be. The issues are the move from acute care to the primary care sector and the integration of health and social care. Are you satisfied that we have the mechanism to measure what is happening in the primary care sector? Are you satisfied that GPs and specialist nurses are identifying the patients who require palliative care at the time of need, rather than much later in their condition? Perhaps Mr Gray wants to answer that.

Paul Gray: I have a couple of points, but I will let Professor White give an initial answer.

Professor White: Dr Carroll is a member of our national advisory group.

Dennis Robertson: I am delighted to hear it.

Professor White: Like Mr Robertson, we have benefited from learning from colleagues in Grampian. Interestingly, NHS Grampian was one of the organisations that did not use the Liverpool care pathway and had its own local approach. We have looked at some of the learning and the positive impacts that have been described.

On integration of health and social care, as the committee will be aware, the integrated joint boards are responsible for palliative care in hospitals and community settings. The set of indicators that has been published for integrated joint boards on health and social care includes measurement of some of the issues in relation to palliative and end-of-life care decisions.

Mr Gray has mentioned the increase in the number of people on palliative care registers. However, one of the themes that have emerged from some of the data is that, although there have been improvements against some of these measures, they have been modest. Again, the data from GP practices on people with non-malignant diseases—in other words, diseases other than cancer—show that, although there have been increases in the numbers going on to palliative care registers, they are not the sorts of increases that we want as we accelerate and scale up the change. People are being identified, but not as many as we would like.

Dennis Robertson: You say that

“not as many as we would like”

are being identified. What can be done to capture those who require palliative care on the register at that time of early need?

Professor White: Every year, the General Medical Council publishes “The state of medical education and practice in the UK report”, and last year’s report captured quite nicely the point that end-of-life care is one of the most challenging aspects of medical practice. The GMC receives a large number of questions from doctors about this area, and it noted that even experienced doctors say that they sometimes lack the support, the confidence or the skills to effectively communicate some of these issues. We therefore think that one of the key areas of improvement is to support not just doctors but all members of the care team in initiating conversations with people who have a wide range of conditions and to ensure that they feel confident and supported in doing so. Again, education and training will be a key dimension of future work, and we believe that both will improve matters.

Dennis Robertson: It—

The Deputy Convener: Just a second, Dennis—I think that Mr Gray wants to say something. I will, of course, let you back in later.

Paul Gray: In response to your question about primary care, it is worth mentioning to the committee that Professor Sir Lewis Ritchie is currently leading a national review of primary care out-of-hours services. One of the review’s task groups, which is chaired by the medical director of NHS Tayside and co-chaired by the Royal College of Nursing’s associate director for Scotland, will explore a range of groups that have been identified as vulnerable, including those with palliative care needs. Sir Lewis has met the Scottish Government’s palliative care policy team and has attended the recent meeting of the cross-party group on palliative care, which was hosted in Parliament on 15 March. I simply want to reassure the committee that the issue is being taken very seriously indeed.

Indeed, in the interests of being transparent with the committee, I must point out that we are not here to suggest that we have got this absolutely right. We are doing all this because we believe that we can improve, and the committee’s assistance in the review will be helpful to us. We believe that we are doing a lot of good things that could be spread more widely, but we just want to acknowledge that we know that there is room for improvement.

Dennis Robertson: On that very point, are we able to identify those areas, whether they be urban or rural, where resources and education need to be improved and then deploy the appropriate resources to try to redress the balance?

Paul Gray: I will bring in Professor White in a moment, but one of the things that I have been discussing with senior representatives of general practice is the importance of ensuring that the appropriate resources are devoted to this area. I am not going to say that we have a complete answer to that, but general practice and primary care are an absolutely central resource for palliative care. GPs are very well placed to have the kind of conversation that needs to be had with people who are coming to the end of their lives and with their families, because, generally speaking, they are familiar with them.

One of the issues that we are trying to tackle and which I should draw to the committee's attention is the willingness of individuals and families to have these conversations at the right time. That is in no sense a criticism of patients or families, but we need to provide a space in which they can have that conversation comfortably. Some people are more comfortable with that conversation than others are. It is up to us—it is our professional duty—to ensure that that conversation can be had. General practice is a critical part of helping us to do that.

Professor White: Our colleagues at NHS Education for Scotland are represented on the national advisory group. As part of the work to develop the strategic framework for action, we have been asking them to look at what has worked well in terms of educational resources and what might be required in the future to ensure that there is a range of educational programmes to reach a range of professions across different teams.

To highlight the point that was made earlier that these issues go beyond cancer, I note that our national improvement plan for stroke includes plans to roll out across the country some specific training resources on how best to assess and provide palliative care as a key dimension of care following a stroke. That is also led by colleagues in NHS Education for Scotland.

Dennis Robertson: Finally, when I had discussions with David Carroll at NHS Grampian, one of the things that he highlighted was that there are occasions when a patient and a family have made the decision that the person would like to die at home, but then, in the last few days of that person's life, they change their mind and wish to go to a hospice, rather than a hospital. Are we able to meet that request? Do we have the facility to accommodate the wishes of the patient at that time?

Professor White: We have been examining the work that is done by hospices to provide advice out of hours and to link with colleagues in hospitals and other services where there is a changing situation.

We have also been looking at the learning from the work on hospice at home. We presented on the work in Strathcarron hospice and Ayrshire hospice on hospice at home at the cross-party group that Mr Gray mentioned. That approach can offer greater flexibility to change arrangements, deploy resource and allow people either to go home or to let us plan for a change in the care setting. We are looking at where that is working in Scotland, working out why and trying to spread that learning and design it into the future system.

Dr Richard Simpson (Mid Scotland and Fife) (Lab): My question follows on from Dennis Robertson's point about where people wish to die. In my experience, people wish to die in different places for all sorts of reasons. I should declare my membership of Strathcarron hospice—I was previously the chair and a founder member of the hospice, so it is an area of particular interest to me.

One of the areas of concern in delivering hospice at home for those who wish to die at home is the provision of appropriate aids and equipment. The situation is often quite short term, but there is still the need for an appropriate bed, for example—it is difficult, but it can be provided, whether it is a mattress or a whole bed. Getting the right aids and equipment tends to be a rather slow process, but there is a need for speed if someone wishes to die at home.

Are you looking at the supply of aids and equipment in particular to support the hospice at home concept?

Paul Gray: I will let my colleagues answer in a second, but there is an important point that I want to address first. The questioning of the committee is causing me to reflect on two things coming together—the ability not just to meet the need quickly but to respond quickly to a change of choice. The flexibility and agility with which we can respond to that is critical.

Craig White or Janice Birrell may have more to say on the specifics of aids and equipment. As Dr Simpson says, it is not something that can wait a couple of weeks.

10:15

Professor White: Two points come to mind. As Dr Simpson will be aware, such issues often come up when general practices are reviewing things after someone has died. It might be concluded that something was not provided in time or that something had negatively impacted on the family's care experience or bereavement reaction.

We have been discussing how we can capture the learning from general practices across the country and how we can link that with the strategic commissioning arrangements for integrated health and social care in the plans that the integrated joint boards will be submitting.

Although we have not specifically discussed equipment today, we can flag that up as being important for having responsive, flexible provision when needs change. Sometimes the health service has the equipment and sometimes local authority occupational therapy services have it. One of the benefits of integration is that we can take a look at the local provision and commission a service that can be responsive and can change when it needs to.

Dr Simpson: That is an interesting comment. Services in Forth Valley were integrated 25 years ago. Three years ago, the committee was considering health board provision and efficiency savings. We were told by people from Tayside that they were about to merge their equipment. Let us hope that all boards will do that.

I have a further question. One of the four principles that are guiding you—

The Deputy Convener: Before you move on, Dr Simpson—and I will of course allow you to ask your other question—Colin Keir has a supplementary on that specific point.

Colin Keir (Edinburgh Western) (SNP): It has been very interesting to hear about the care-at-home aspect. There are of course difficulties with certain neurological conditions. With conditions such as Huntingdon's disease, it is very difficult to provide the person who has the condition with one-to-one positioning with a carer or nurse at home. Taking that into consideration, as well as the care-at-home aspect that is coming in, I take it that it is realised that it is not one size fits all and that something somewhere within the plan will kick in to make available what is required for those people.

Professor White: A key principle of anticipatory care planning would be to have a tailored individual conversation that takes account not only of the condition but of the preferences of the person living with it. As I mentioned before, there is a need to take account of the views of relatives and unpaid carers.

Colin Keir: I am thinking about when the priorities for funding come in. Will there be some sort of acknowledgement regarding funding generally, when all this is being sorted out—that it will not all be placed in one area, thus putting pressure on others? I am trying to think of a better way of putting this, but I am thinking about the differences between those people who require a more focused palliative care set-up and others.

Professor White: That relates to the point that we were discussing earlier about ensuring that palliative care, as a dimension of high-quality care, is considered across a wide range of conditions. It is also about improving our ability to describe how that is provided across a wider range of conditions so as to give assurances that everyone who needs that care will receive it when they need it.

Paul Gray: Referring to Mr Keir's question, I draw the committee's attention to the primary care direct enhanced service, which came into effect here on 1 April 2012. I can provide the committee with as much detail as it wants. I will not do that orally, for want of time, but I can give the headline that the direct enhanced service recognises that palliative and end-of-life care are integral aspects of the care that is delivered by any health or social care professional to those who are living with and dying from any advanced progressive or incurable condition.

That does not concern just the last months, days and hours of a person's life; it is about ensuring quality of life for patients and their families and carers at every stage of the disease process, from diagnosis onwards. That is not condition specific. If your concern, Mr Keir, is that we may fund care in relation to some conditions but not others, we are saying that, through the direct enhanced service, we are looking across the range of conditions.

I am not a clinician, but one thing that I have learned is that people who are dying rarely have only one condition. There might be one significant presenting condition, but there will be other underlying comorbidities. It is important that the package of care is tailored to the individual, as Professor White says. We have provided some funding for that to ensure that there is progress.

Dr Simpson: We have 54,000 deaths a year. Have we done an estimate of how many of those are likely to qualify for or need palliative care? If not, can we do so? There are 12,500 on the GP register now, and that increase, as part of DES, is worth while. However, where are we likely to be heading in the long term? That would give us a clue about what the situation is.

Paul Gray: I was thinking about this issue yesterday, as I was preparing for this meeting. We want to be certain that anyone who dies in Scotland has available to them the care that they need at the end of their lives, as far as that is within our gift. Some people die by accident and some die suddenly, and clearly those deaths cannot be anticipated. However, for those whose deaths we can reasonably anticipate, without giving a hostage to fortune, I would like to get the figures up to close to 100 per cent. That is what we ought to be aiming for.

Some people might not want to engage in the conversation, which will make that harder. Others might not want the provision, which is all right—that is a choice that individuals can make. However, we should be doing our best to have the conversation with everyone, if we can.

Dr Simpson: I do not know whether Mike MacKenzie would like to ask a supplementary question.

The Deputy Convener: I think that he does.

Please bear in mind that there is a stack of other committee members wanting to come in on other subjects, Mike. However, you may ask a supplementary question on the point that Richard Simpson was asking about.

Mike MacKenzie (Highlands and Islands) (SNP): I am a wee bit disappointed in Mr Gray's answer to Dr Simpson, because I think that the question gets to the nub of the issue. It is surely possible for you to make some kind of estimate or reasonable assumption of what would be required, so that we could all put our hands on our hearts and say that provision is not patchy, as Rhoda Grant has suggested, and that the opportunity to access good-quality palliative care is there for all who might need it. Can you put a number on that?

Professor White: One of the things that I mentioned earlier that makes the situation challenging is that the World Health Organization defines palliative care as being care that improves someone's quality of life and prevents and alleviates suffering and as involving an assessment and management of care across physical, psychological, social and spiritual needs. Those things should be a dimension of high-quality care for everyone.

As we talk to colleagues, we are increasingly becoming aware of the numbers of people who are going to be living with dementia, and we have good data on other conditions. Linking back to the plans around the strategic framework, we would expect to be able to start to describe and quantify the situation, with some sort of measurable aims.

As the committee will know from some of our other improvement programmes, you start to get improvement when you have an aim—when you can say how much you want things to improve by and by when. For example, we hope to start to be able to say that, by X date, Y number of people who are living after a stroke will be identified as having particular needs.

We are absolutely committed to improving our ability to measure and present to this committee and others something more definitive in terms of numbers of people. It is likely to take some further time to get that right, though. We expect it to be in the strategic framework for action.

One of the challenges is that the question is like asking how well we are providing psychological care across the NHS.

Mike MacKenzie: Let me try to help you, then. A charity wrote to me recently suggesting that 11,000 people in Scotland are suffering needlessly and that those people should be provided with palliative care but are not. Do you agree with that statement?

Paul Gray: It is difficult to agree without seeing the detail.

Mike MacKenzie: Is it in that ball park?

Paul Gray: I am saying that there are 54,000 people dying in Scotland each year, and we know that 12,700 of them have a plan. There is therefore a gap between 12,700 and 54,000. Some of those 54,000 will die suddenly and some will die by accident, so there will be no opportunity for a conversation. Some of those 54,000 will die, one might say, of natural causes without the need for a plan but, in my view, many ought to have that conversation. I want to get as close as is reasonably possible to the 54,000.

The Deputy Convener: I am being a little bit naughty here after denying Dr Simpson another question but my question is on the numbers, so I ask everyone to bear with me briefly.

There must be some modelling work on the numbers. Mike MacKenzie makes a reasonable point. The problem is that he could have said 15,000 or 8,000—he could have chosen any number. Unless the Scottish Government has suitable modelling work, we can all just choose a number.

Earlier, I think that you said 7,703 people had registered palliative care needs in 2008-09 and that the number went up to 12,050 in 2013-14. Do you know whether that is because we are getting better with an existing cohort who need palliative care or because we have an ageing population and more complex illnesses are developing so the burden is becoming greater? Why has that increase happened and where should the number rest at? More importantly, is the Scottish Government doing the modelling work that sits behind that or are we leaving it to the new integration joint boards? Who is pulling it together?

I am being really naughty now, Richard, and asking another question.

Dr Simpson: You are the convener. It is the convener's prerogative.

The Deputy Convener: That information must all push into strategic commissioning because it is about individual human beings getting the services that they need at the time that they need them. I do not want to argue about the numbers; I want reassurance that the Government is getting a grip on the numbers and that that will feed its way into local strategic commissioning.

Paul Gray: I will say yes and then will let—[*Laughter.*] No, genuinely. It is an absolutely fair point. If the integration joint boards are responsible, the issue must come into their commissioning plans. I agree with that entirely.

I also say yes to the point that we need to understand the situation nationally. Although there is local delegation on delivery, we need to understand it nationally.

Professor White will say a bit more.

Professor White: Professor Scott Murray at the University of Edinburgh has been undertaking some analysis of the figures on the change in the palliative care registers, particularly on the conditions that people are living with. We have some historical data from the direct enhanced service that Paul Gray mentioned and, I believe, some data that is about to be published and that we hope will influence the further conversations on how to make improvements.

To go back to Mr MacKenzie's related point, the key point is that we want all the care processes in Scotland to identify need at the point at which it emerges. There is a real need to set some challenging improvement aims on that. We have some good mechanisms for identifying need and some good work has been done, but the measurement framework that must be in place has to set some bold aims for increasing the numbers of people who have a conversation and have their needs documented early on following diagnosis.

The Deputy Convener: I will not push the matter any further other than to say that today's session is a scoping exercise for an inquiry that we will have later in the year. If I or one of my colleagues were to ask a similar question later in the year, would you be in a position to provide the modelling work that was being done in a particular health board area or integration joint board to say that we need to have X more beds in hospices, Y more beds in care homes and Z more specialist professionals in the area? When do the numbers feed into structural change?

I am not asking you to answer those questions now—this is a scoping exercise—but will you be in a position to answer them as our inquiry rolls out?

Professor White: We have data on the partnerships and the variation in some of the figures on bed days at the end of life, so the data framework that is in place to support integration will be able to answer some of those questions.

On the other issues, we are gathering examples of, for example, the financial resources and the saved bed days from hospice-at-home services from teams that are looking at identifying palliative care needs in people who are living with liver disease. We are starting to bring together disparate sources of data precisely because we realise that we need to improve our ability to describe the national picture.

The Deputy Convener: Okay. Thank you for that.

10:30

Nanette Milne (North East Scotland) (Con): I notice that one of the priorities for implementation in the progress report on the strategy is the electronic palliative care summary. What progress has been made in ensuring that existing electronic systems, particularly the key information system, effectively communicate a patient's end-of-life care goals and information in a way that supports their care in all acute and community settings? What plans, if any, are in place to ensure that the key information summary system can cope with the increasing clinical complexity of communicating advance care planning decisions, especially in emergency situations?

Paul Gray: That is an important point. If the committee is content, I will write to you about it, because I asked yesterday for some more information on what we are doing.

Recently, I had cause to engage with someone over the availability of the key information summary to the Ambulance Service, which I know is planned and being rolled out this year. That prompted me to ask for some wider briefing on progress on e-health in this area. It might be helpful to the committee if, rather than giving you a patchy answer, I write to you about that.

Nanette Milne: I would be happy with that. The matter has been raised with me by a palliative care organisation, and I would be interested to know more.

Paul Gray: In terms of timing, convener, when would it be helpful for the committee to have that advice?

The Deputy Convener: I am turning to our clerks, because I am not sure when the timetable for our inquiry is going to roll out. It would be helpful if we had it by the summer recess.

Paul Gray: We will get it to you before the summer recess, then—by the end of June.

The Deputy Convener: Thank you. Nanette, do you have another question?

Nanette Milne: I might have another question later, but I will see how it goes.

Richard Lyle (Central Scotland) (SNP): Good morning. We have all had situations in which friends or relations have walked into the doctor for, they think, a normal, routine discussion and have found out through later tests that they have cancer. Is that one of the problems that you find and one of the reasons for the patchy data? Is it difficult to identify where people have such conditions?

Paul Gray: That is one of the issues. When a person approaches a GP or another qualified clinician with a presenting issue, it may turn out to be less serious or more serious than the individual anticipates. It is also important to stress that, if someone has cancer, they do not automatically die. In that sense, the need for palliative care may not be the first consideration.

If I have understood your question, the point is that we should be doing all that we can to ensure that, when the point is reached where there is a diagnosis that the person is unlikely to survive the condition, we ought to be ensuring that measures are put in place to have an anticipatory care plan and to have that discussion. I do not know whether Professor White wants to follow up on that, but have I understood correctly the point that you were making?

Richard Lyle: I had a situation where the mother of a friend was diagnosed with cancer and she was told that she would live only for six months, but she lived for three years. I also had a friend who was diagnosed in October of one year and died in April of the next year. There is a wide variation between people. Some cope with it, live with it and get on with it; others, unfortunately, have an express route into palliative care. That is the point I was trying to make.

Paul Gray: Again, that speaks directly to the issue of ensuring that the anticipatory care plan is tailored to the individual, so that we do not simply say, “A person has this condition; therefore they are likely to survive for X length of time; therefore this is what we will do.” Every individual is different. As already mentioned, a person may have one major condition but have other underlying conditions that affect the likelihood of their lifespan being long or short. That is why the input of the GP and other qualified medical practitioners is hugely important.

Richard Lyle: Before Professor White comes in, I have my main question.

We are being told that there is currently no available data on the total spent on the provision of palliative and end-of-life care because of its cross-cutting nature and the utilisation of many different staff. Do we honestly know—or can you tell us, or are we even trying to ascertain—what level of funding is currently required for palliative and end-of-life care in Scotland? I think that Mike MacKenzie brought that up earlier. What is the future prediction? If we are looking at this issue, we need to know whether there is sufficient funding for people to get the care that they deserve. What are you commissioning with regard to arrangements that are currently in place between NHS boards and independent hospices in Scotland?

We all know that those services do a wonderful job. We have all attended the different events, and we mentioned all the cancer charities—we have all been along and tried to help them as much as possible. I know that we are tackling the problem, through drugs and so on, to ensure that people live longer, but are we actually, physically facing up to the fact that, at some point, we are going to have to up the funding for the care if we do not have the correct data? Where are we?

The Deputy Convener: I will ask Professor White to come in, as he was going to make an additional comment before we move the discussion on.

Professor White: My comment is related to Mr Lyle’s comment about conversations about prognosis and how long someone might live.

There were interesting data published in *The New England Journal of Medicine* in 2010 that showed that, with early consideration and provision of palliative care, although people received less aggressive treatments—because that was their wish—they actually lived longer. There are complex relationships in relation to those discussions, but it is important to link the early consideration of palliative care with the more general outcomes of treatment decisions and with lifespan. The study also showed that people were significantly less depressed if they had early access to palliative care.

I will pick up on the funding question, if I may. As the committee knows, one issue is the distinction between palliative care as a general principle or a dimension of care provided by everyone, and specialist palliative care. We can describe the funding that goes to specialist palliative care services because they are dedicated services, with dedicated nurses and doctors, and dedicated funding goes from NHS boards to hospices.

Boards are also able to describe the funding that they are allocating to palliative care initiatives. There is some wonderful work going on in NHS Lothian, for example, which is able to describe the amount of money that it is investing to promote early identification across a range of conditions and to train its clinicians in having the conversation.

One of the challenges is that some teams that are focused on people’s quality of life will not know that what they are doing is palliative care. They are having conversations about what patients would like to happen, but the team will not recognise that that bit of the care that they are providing is palliative care. There is the challenge of allocating or describing resource to that more general provision.

If it is helpful, we can provide the committee with some further information around boards and what they have been investing in.

Richard Lyle: It said that—

The Deputy Convener: Mr Gray wants to come in.

Paul Gray: I am sure that the committee remembers that you commissioned an NHS board budget survey. You asked each board for an estimate of spending on palliative care services as defined by the Scottish Partnership for Palliative Care and details of funding agreed by each board for hospices. There will be information in preparation for the committee that should assist with that particular aspect of the inquiry.

The Deputy Convener: Richard, I will let you back in, but I need to ask whether your question is specifically on this issue. Dennis Robertson has been waiting patiently to ask a supplementary.

Richard Lyle: Yes, it is. I could only see the statistic for 2006-07, which is £59 million. What is the figure now?

Paul Gray: That is why we are awaiting the boards' responses on this issue. That will be the best way to determine it. We can provide more data but, as Professor White said, there are a range of palliative services provided by boards that they do not define as palliative care. When the boards have completed their returns, the committee will have the latest and most up-to-date evidence in front of it to help with this consideration.

Richard Lyle: Thank you.

The Deputy Convener: It is fair to say that Richard Lyle has hit on an important point. When we get the data in, we have to make sure that it is gathered consistently. One part of the country could show low expenditure but might not be capturing all the spend. Another part of the country could show significant expenditure but could be mopping up everything that remotely counted as palliative care. How can the Scottish Government make sure that we can compare different parts of the country?

Paul Gray: You are right to point out that there could be differences. There are no absolutes, but one of the things that we will do this year through the various groups that we have mentioned is ensure that, as far as possible, there is consistency of definition.

Another point that is worth making is that palliative care is not always a drug or an adaptation; it might be ensuring that there is someone to talk to. We absolutely understand the point that the committee makes and we will make sure that, as far as possible, there is consistency. However, sometimes the palliative care that is needed is the GP or the practice nurse talking to the patient. There is no prospect of every such conversation always being recorded. Palliative care is also provided by voluntary sector partners, friends, family and colleagues. All those things come into the mix. From the standpoint of the NHS, we take the committee's point that, when we provide palliative care and it is so categorised, it ought to be recorded consistently.

The Deputy Convener: I call a very patient Dennis Robertson.

Dennis Robertson: Before Mr Lyle asked about funding, Mr Gray talked about the care plan for each patient. Obviously, there is a person-centred approach, which is to be commended. You mentioned comorbidity in relation to many people who are coming to the end of life. If a patient loses their capacity, what support is there for the family? The person might have had an early conversation and might have expressed a wish to die at home. However, their capacity might then be affected by dementia, for example, and they might say something contrary to their first expressed wish. Do we have the specialist provision to cope with people in that situation and to support carers and families?

10:45

Professor White: One of the core elements of the GP contract is that practices are expected to have in place a protocol to identify carers, to assist with some of the scenarios that you mentioned. We have noted that the number of powers of attorney that are in place in Scotland has increased significantly over the past five years. If someone makes their wishes known before they lose capacity, and if a power of attorney is in place, care teams can ensure that the person's wishes are reflected through dialogue with the person who has the power of attorney.

Dennis Robertson: Is a conversation to advise families and carers about power of attorney held at an early stage when a person goes into a care home or a similar situation?

Janice Birrell (Scottish Government): As far as anticipatory care planning is concerned, it is not a one-off discussion that is had; there should be a continuing and live process throughout the patient-clinician interaction. A patient or a person can develop an anticipatory care plan in discussion with their clinician, but that needs to be revisited over time. Care planning is an active element of the care. It involves checking that the plan is still current and that it is consistent with an individual's condition.

Dennis Robertson: I am aware of that aspect of care planning, primarily through David Carroll, but my concern is about capacity. How do we ensure that a person's initial wishes are followed through if they lose capacity? What happens if the family use the power of attorney to go down a different route?

Paul Gray: I will frame my response by referring to three situations that I can anticipate; there will undoubtedly be more. The first is the simple situation in which there is a clear anticipatory care plan that is consistent with the person’s wishes and was made when they had capacity. That can be followed through.

There is also the situation in which the person has capacity, makes an anticipatory care plan, loses capacity and appears to change their mind. That is more difficult, because it requires an assessment to be made of whether the person’s capacity is so diminished that the change of mind might be overlooked. Without going into individual cases, it is difficult to comment on how that might be handled.

A third situation is that the person’s wishes might be known by the family but there is no anticipatory care plan and the person appears to change their mind. A conversation would have to be had with the family, the relevant clinicians and the individual concerned, to the extent that they could participate.

There is not a straightforward answer to your question other than to say that, in every case, a conversation involving all parties would take place, as far as that was possible.

Dennis Robertson: You are confident that you will recognise when such situations arise.

Paul Gray: Yes.

The Deputy Convener: Does anyone have anything to add?

Professor White: We would want to pick up a change in care preference; that relates to Dr Milne’s point about such information being available to all members of the team across all settings. As part of the work on key information summaries, NHS Lothian carried out interesting work on the importance of teams being able to access such information quickly, in order to provide care in accordance with a preference that might have changed. Clinicians need to know where in the system to go to get information about whether a preference has changed, so that they can have the conversation. That is another key part of having the right information available for teams.

The Deputy Convener: We have five minutes left. I will come to Richard Simpson shortly, but Nanette Milne indicated that she wanted to follow up an issue.

Nanette Milne: I will return to the issue of patients who did not get cancer drugs. Scotland opted not to have a cancer drugs fund as England had, and my understanding is that a number of people went from Scotland to England to access those drugs. What has the Government been able to do for the people who do not get those drugs at the end of life? Has that had any impact on palliative care?

Professor White: I am aware of the changes that were made to the individual patient treatment request system for requests to boards for the provision of certain drugs. I do not have information on the specific links with palliative care, but I am happy to provide the committee with that detail in writing as a follow-up.

Nanette Milne: It would be interesting to know what has happened.

The Deputy Convener: Our two Richards—Richard Simpson and Richard Lyle—will close the session.

Dr Simpson: One of the principles is that there should be a multidisciplinary discussion in creating an anticipatory care plan. The other side of that coin is whether it is stated in guidance that there should be a single named person as the point of contact. In my clinical experience, that would not necessarily be the GP. It might be the nurse, the physiotherapist, the OT or anyone else—it might even be one of the carers—but it is important to have a single person who co-ordinates what is often a complex team. I have had cases in which up to 16 individuals have been involved. I also wonder whether the need to give both the patient and a named person control together over a situation in which control is important psychologically is now clear in the guidance.

Professor White: In the national advisory group, we now start every meeting with a story from a patient or relative about care. We have heard some relatives say that they have had to take on the role of co-ordinating the agencies, which adds to the carer’s burden.

The guidance for the last days and hours of life emphasises the importance of families knowing which nurse or doctor is in charge of the care. I would need to check the position in anticipatory care planning with my colleagues who are working on that, but I would be happy to follow up and provide the committee with an assurance that the principle of who should be contacted is reflected in that work, as I agree that that is crucial.

Paul Gray: To respond to Dr Simpson’s question, principle 4 in the guidance is that

> “Consideration is given to the wellbeing of relatives or carers attending the person.”

Very simply, causing carers to run around trying to co-ordinate services is not giving due consideration to their wellbeing. I want to be very clear about that.

Richard Lyle: I have two comments. You have conveyed the idea that none of us likes to discuss our death or how and when we will die. None of us knows when we will die. I made a will 20 years ago, and my family know how I want to be buried and how I want to be treated if I go into a care home.

We all know that, if a member of our family or a friend goes into a care home, it can be hard to get power of attorney. Talking to an 82 or 92-year-old about death is difficult. I had to ask my mother-in-law and father-in-law how they wanted to be buried, and they did not want to discuss it. I discovered only after one of them died how the other wished to be treated.

We have to prepare, and Paul Gray said earlier that he had prepared for today's meeting. Knowing him as I do, I am sure that he is also starting to prepare for the committee's inquiry. What is the Scottish Government doing now to prepare for the future in palliative care?

The Deputy Convener: In effect, Richard Lyle is saying, "In the last two minutes of the committee session, tell me everything that the Scottish Government is doing in palliative care."

Richard Lyle: Your time starts now.

The Deputy Convener: We are timing you. Perhaps you can make some general comments, Mr Gray.

Paul Gray: I will keep my answer brief—again, we can write to the committee in detail. Richard Lyle asks a fair question. A couple of years ago, the Scottish Government did not have a national clinical lead or a senior policy officer for palliative care. We have now put in place that resource to ensure that we have a co-ordinated approach. We have also set up the groups that Professor White described and invested in ensuring that the out-of-hours review, led by Sir Lewis Ritchie, is briefed on the issues connected with the subject. I am happy to give a fuller account, but we are not simply talking about that work—we are doing things and putting in resource.

The Deputy Convener: One of Richard Lyle's key points was on the committee's forthcoming inquiry, which can—as we hope that it will—feed into some of that work.

Time has now defeated us, but it is worth pointing out that, when we took evidence a few months ago in a round-table meeting, professionals pointed out that Scotland's palliative care provision is of a very high standard in comparison with provision in other places. However, we have to go far further.

Both those things can be true at the same time, and it is in that environment that we are keen to hold our inquiry in order to drive change in the sector. I put it on record—as I am sure all the committee members do—that the palliative sector, including the third sector, does an exceptional job day in, day out.

I thank you all for your time. Your evidence has been useful in informing our scoping exercise for the forthcoming inquiry. As previously agreed, we will now move into private session.

10:56

Meeting continued in private until 12:11.

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