The Scottish Parliament
Pàrlamaid na h-Alba

Official Report

HEALTH AND SPORT COMMITTEE

Tuesday 26 January 2016

Session 4

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HEALTH AND SPORT COMMITTEE
7th Meeting 2016, Session 4

CONVENER

*Duncan McNeil (Greenock and Inverclyde) (Lab)

DEPUTY CONVENER

*Fiona McLeod (Strathkelvin and Bearsden) (SNP)

COMMITTEE MEMBERS

*Malcolm Chisholm (Edinburgh Northern and Leith) (Lab)
*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)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Janice Birrell (Scottish Government)
Shona Robison (Cabinet Secretary for Health, Wellbeing and Sport)
Mary Scanlon (Highlands and Islands) (Con)
Maureen Watt (Minister for Public Health)
Professor Craig White (Scottish Government)

CLERK TO THE COMMITTEE

Jane Williams

LOCATION

The James Clerk Maxwell Room (CR4)

Scottish Parliament

Health and Sport Committee

Tuesday 26 January 2016

[The Convener opened the meeting at 09:30]

Interests

The Convener (Duncan McNeil): Good morning and welcome to the seventh meeting in 2016 of the Health and Sport Committee. As usual at this point, I ask the people who are with us not to use mobile phones because they interfere with the committee's proceedings. I also ask people to note that many members are using tablet devices instead of hard copies of the papers.

The first item on our agenda is a declaration of interests. I welcome Fiona McLeod as a new member of the committee. Before I invite her to declare any relevant interests, I record my appreciation for and thanks to—I am sure that I speak for the committee—Bob Doris, who has left the committee. I will feel a bit nervous this morning: Bob Doris was on my shoulder throughout his time on this and a previous committee. He was deputy convener for a number of years, so I feel a bit strange this morning.

I invite Fiona McLeod to declare any relevant interests.

Fiona McLeod (Strathkelvin and Bearsden) (SNP): I have no relevant interests to declare, convener. I am grateful to be back on the committee, even if just to cover for Bob Doris's paternity leave.

The Convener: Thank you.

Deputy Convener

09:31

The Convener: Agenda item 2 is the choice of deputy convener. Parliament has agreed that only members of the Scottish National Party are eligible for nomination as deputy convener of the committee. That being the case, I invite nominations for the position of deputy convener.

Richard Lyle (Central Scotland) (SNP): I nominate Fiona McLeod.

The Convener: We have no other nominations.

Fiona McLeod was chosen as deputy convener.

The Convener: Congratulations, Fiona, and welcome back to the committee. We look forward to working with you—albeit that it will be on a temporary basis.

Decision on Taking Business in Private

09:32

The Convener: Agenda item 3 is to make a decision on taking business in private. Do members agree to take in private item 7, on the evidence on palliative care, and to consider such evidence in private at any future meetings, if the need arises?

Members *indicated agreement.*

Health (Tobacco, Nicotine etc and Care) (Scotland) Bill: Stage 2

09:32

The Convener: Agenda item 4 is day 2 of stage 2 of the Health (Tobacco, Nicotine etc and Care) (Scotland) Bill. I welcome the Minister for Public Health, Maureen Watt; Dan Curran, who is the bill policy manager; Craig White, who is the divisional clinical lead; Lynne Nicol, who is the quality team leader; Ailsa Garland, who is a principal legal officer; and Meryl Skene, who is parliamentary counsel. I also welcome back to the committee Mary Scanlon, who is here for this agenda item.

Mary Scanlon (Highlands and Islands) (Con): Thank you.

The Convener: Members should note that part of the way through the debate I will pause proceedings to enable a change of Government officials. I shall introduce the other officials at that point.

Everybody should have a copy of the bill as introduced, the marshalled list of amendments and the groupings of amendments.

As all members know now, there will be one debate on each group of amendments. I will call the member who lodged the first amendment in the group to speak to and move that amendment and to speak to all the other amendments in the group. Members who have not lodged amendments in the group but who wish to speak should indicate that by catching my attention in the usual way.

The debate on the group will be concluded by my inviting the member who moved the first amendment in the group to wind up. Only committee members are allowed to vote. Voting in divisions is by show of hands.

The committee is required to indicate formally that it has considered and agreed each section and schedule of the bill, so I will put the question on each at the appropriate point.

Section 21—Incident which activates duty of candour procedure

The Convener: Amendment 3, in the name of the minister, is grouped with amendment 4.

The Minister for Public Health (Maureen Watt): Amendments 3 and 4 relate to outcomes of incidents that trigger the duty of candour procedure.

On amendment 3—which addresses an issue that was raised by North Ayrshire health and social care partnership in written evidence to the committee at stage 1—the duty of candour procedure can be triggered by

“an unexpected or unintended incident”

that results in the affected person needing treatment to prevent their death or injury. At the moment, however, the bill provides that treatment given to prevent death or injury would trigger the duty of candour procedure only where that treatment was given by a registered doctor. Amendment 3 will change that to ensure that the procedure is activated by an incident that results in the affected person needing treatment by a registered health professional. The definition of “registered health professional” is wider and includes not only doctors but nurses, midwives, paramedics, dentists and others, and amendment 3 reflects the reality that

“an unintended or unexpected incident”

in the course of treatment or care in health or social care settings could result in the intervention of any one of a number of health professionals to prevent death or injury.

Amendment 4 relates to outcomes of incidents that trigger the duty of candour procedure. One of those outcomes is the affected person requiring treatment to prevent certain injuries, and the amendment will add another category to the types of treatment that will trigger the duty of candour procedure. Section 21(4)(b) covers incidents that result in “permanent lessening” of one or more functions of the body, which is otherwise described as “severe harm”, and the effect of amendment 4 will be that the duty of candour procedure will be triggered if as a result of an incident a person requires treatment to prevent such harm. I am glad to have had the opportunity to lodge amendment 4, which does not reflect a change in the intended policy but corrects an omission in the bill.

For the reasons that I have outlined, I ask the committee to support amendments 3 and 4. I move amendment 3.

Amendment 3 agreed to.

Amendment 4 moved—[Maureen Watt]—and agreed to.

Section 21, as amended, agreed to.

After section 21

The Convener: Amendment 11, in the name of Rhoda Grant, is grouped with amendment 12.

Rhoda Grant (Highlands and Islands) (Lab): The bill outlines the use of the duty of candour in quite extreme circumstances, and I think that the previous amendments were helpful in highlighting just how extreme those circumstances are. The bill also sets out the bureaucracy and reporting process for the significant incidents in question, and amendments 11 and 12 seek to ensure that the duty of candour is not required in all circumstances. Patients must be at the heart of their own treatment and must, in order to have faith in the system, know what is going on. Although we have moved away from clinicians making decisions that they believed were in patients’ best interests and have instead put patients at the heart of that decision making, we need to go further. I do not want to set up another level of bureaucracy, but I want to ensure that patients are informed and able to make decisions for themselves. When an incident happens that is not of such extreme proportions, patients should at least be informed of what has happened so that they can make a decision for themselves.

Although the governing bodies of many professional organisations stipulate a duty of candour, we heard in evidence that that is not the case for all of them. As a result, amendments 11 and 12 seek to ensure that patients are informed about their own treatment and any adverse circumstances that might have arisen.

I move amendment 11.

Maureen Watt: Amendments 11 and 12 would require that “unintended or unexpected incidents” that

“did not or could not have resulted in”

harm or injury be reported to a person whose care has been affected. The result would be an unreasonable and unnecessary burden on health, social care and social work organisations. Furthermore, the amendments’ inclusion would depart from the principles that have led us to propose the duty of candour. The purpose of the statutory duty of candour for organisations is to require that organisations implement procedures for unintended or unexpected events that result or could have resulted in death or harm but for the treatment given by a health care professional.

We should focus on cases in which real harm has occurred or in which there was a risk that real harm could have occurred, rather than creating for organisations statutory requirements that would cover every case—even those in which no harm had occurred. Rhoda Grant’s amendments 11 and 12 would remove the focus on harm and require that everything that happens that is unintended or unexpected be judged to assess whether care has been affected. They would also require that incidents be reported to an affected individual, whether or not there has been a negative outcome to the event. Such a procedure would not be helpful to those receiving care or treatment, nor to the staff who deliver our health, social care and social work services.

The introduction of the statutory duty of candour must not become a box-ticking or form-filling exercise. The procedure that is proposed by amendments 11 and 12 is not proportionate. The additional procedure would result in the duty of candour for cases in which real harm has occurred becoming diluted and not having the desired impact on culture change, safety and learning.

For those reasons, I ask Rhoda Grant to seek to withdraw amendment 11 and not to move amendment 12.

Rhoda Grant: I do not understand what the minister is trying to say. She stipulated the circumstances in which the duty of candour would apply as death or real harm. Those are extreme circumstances. Amendment 11 would mean that

> "if an unintended or unexpected incident occurred in the provision of a health service, a care service or a social work service to the person and in the reasonable opinion of a registered health professional that incident—
>
> (a) affected the person's care, but
>
> (b) did not result in or could not have resulted in an outcome mentioned in section 21(4)"

that person should be informed of what had happened, given

> "an account of the incident",

told about what steps had been taken to put it right and given "any other information" that they require.

It would be very simple: "Something has gone wrong: here is what happened and this is what we have done." There would be no added bureaucracy or tick-box exercise. It is extreme for the minister to say that people are not entitled to very basic information about their own treatment.

I seek to withdraw amendment 11, but I will look at the matter again, in the light of the unintended consequences that the minister suggested it would have—although I believe those to have been overstated.

I am very concerned, however, that the minister does not believe that patients should have that kind of information on their treatment. That does not provide leadership to health service professionals.

Amendment 11, by agreement, withdrawn.

Section 22—Duty of candour procedure

The Convener: Amendment 17, in the name of Malcolm Chisholm, is in a group on its own.

Malcolm Chisholm (Edinburgh Northern and Leith) (Lab): I am a strong supporter of the duty of candour, but various concerns about it have been expressed by clinicians. The particular concern that amendment 17 picks up was expressed to those of us who visited Ardgowan hospice in Greenock in September. The visit was part of our palliative care inquiry, but we took the opportunity of asking the clinicians who work there about section 22. In summary, the concern is that some people might not want to be told about incidents. The clinicians at the Ardgowan related the concern particularly to people in hospices, but it could well apply to others.

10:45

I raised the matter as part of the evidence session on 22 September and I thought that the comment by Peter Walsh of Action against Medical Accidents was interesting. It might be helpful if I read out what he said:

> "The point about some people not wanting to know that a mistake has been made is a valid one. One must respect each individual's wishes. When the discussions took place in England about its version of the duty of candour, we made that very point. The way that it has been dealt with in England is that there is a requirement to tell the patient or service user or their family that there is something to report and to discuss, and they can simply say, "Thanks, but I don't want to know." Let us say that mum or dad has passed away: the family can say, "We're moving on and we don't want to know another thing." That is their absolute right, but it is not the right of any individual health professional or organisation to decide for them that they do not need the opportunity to know."—[*Official Report*, *Health and Sport Committee*, 22 September 2015; c 9.]

The last part of that is absolutely fundamental. We are clearly moving away from a paternalistic culture in which health professionals decide "whether" someone is to be told something, but there can be no objection in principle to a health professional asking whether somebody wants to know. The decision is then entirely the concern of the relevant individuals.

The approach that has been adopted in England is what I have tried to incorporate in amendment 17, which I will refer to when I find it—I cannot see it at the moment because the numbers are confusing me. The first subsection in amendment 17 states:

> "the responsible person must ask the relevant person".

The second subsection describes what has to happen, and states that

> "a written record is to be kept of the communications".

That will protect against any abuse of the requirement. Quite a lot of clinicians and members of the public might be concerned if people did not have the right to say that they do not want to know.

I move amendment 17.

Nanette Milne (North East Scotland) (Con): I support Malcolm Chisholm's amendment 17. I was particularly struck by the evidence that we received about the procedure in England. Having grown up through a very paternalistic health service, I think that the amendment is probably a step in the right direction.

Maureen Watt: Amendment 17 in Malcolm Chisholm's name would require that

"the responsible person must ask the ... person"

who has been affected by an unintended or unexpected incident that causes harm "whether" they wish

"the duty of candour procedure to apply to"

them.

It might not always be in the best interests of the individual to be told about what has happened, and organisations will be required to consider that carefully and to ensure that they do not take a one-size-fits-all approach to disclosing information. Additionally, not everyone will wish to know the details of what has happened: their not knowing should always be an option. The Scottish Government's guidance development group will consider such issues as part of its remit in taking forward implementation of the bill.

Although I acknowledge that the procedure should, as far as possible, take into account the preferences of those who have been affected by unintended or unexpected incidents, an undesirable effect of amendment 17 might be that, when an affected person does not want to be told about the incident, the wider duty of candour procedure might not apply. We would still want reporting and learning to take place in order to prevent the same type of incident happening again.

As members will be aware, under the bill the duty of candour procedure is a series of steps that are to be taken by the responsible person. Section 22 of the bill leaves the detailed steps of that procedure to be set out in regulations. Under section 22(2)(a), the regulations may make provision about

"the notification to be given by the relevant person"

who is affected, and section 22(2)(e) will allow the regulations to provide detail in

"an account of the incident"

that is to be given.

I intend that the regulations that will be made under section 22, which will set out the duty of candour procedure, will reflect the aim of amendment 17, to the extent that the purpose is to provide an affected person with an opportunity to decline to be told about what had gone wrong. However, it is important that in such cases the wider duty of candour procedure continues to apply to the responsible person so that lessons can be learned from such incidents even when someone does not want to know what happened.

Having set out that intention, I ask Malcolm Chisholm to seek to withdraw amendment 17.

Malcolm Chisholm: I thank the minister for that explanation. I am to an extent unsure whether she really is objecting to the substance of amendment 17. She says that she will ensure that the procedure is delivered in regulations, but I am not sure what her objection is to having it in primary legislation. I accept what she says about learning lessons from what has happened, but it does not follow that lessons will not be learned just because the person does not want to know. I am therefore not entirely clear that there is a fundamental objection to what I am proposing. It becomes a judgment about whether the provision should be in regulations or in primary legislation, and I do not understand the rationale for its being in regulations. I am happy to seek to withdraw amendment 17, but I am minded to lodge the amendment in modified or extended form again at stage 3, perhaps building in something about ensuring that lessons have been learned in order to cover concern about that.

Amendment 17, by agreement, withdrawn.

Amendment 12 not moved.

Section 22 agreed to.

Sections 23 and 24 agreed to.

Section 25—Interpretation of Part 2

The Convener: Amendment 6, in the name of the minister, is grouped with amendments 7, 8, 5, 9 and 10.

Maureen Watt: The amendments make changes to the interpretation section for part 2. Amendment 6 aims to assist with the interpretation of "provide" by adding a definition of "provide" that clarifies that providing

"a health service, a care service and a social work service means to carry on or manage such a service".

In relation to care services, the term "provide" is already defined in other legislation in a similar way; it is helpful to define it in the bill so that it is clear that the term operates in the same way.

Amendments 7 and 8 relate to the Care Inspectorate's written evidence to the committee at stage 1, in which it raised concerns that care service providers might opt for a different business model—for example, trading as an individual but employing others—to avoid the duty of candour. Amendments 7 and 8 will ensure that self-employed individuals who employ others or have arrangements with others whereby those others are directly involved in providing care services will be brought within the definition of a responsible person and will therefore be subject to the duty of candour.

Amendment 5 is a technical amendment to correct the name of an act that is referred to in section 25.

Amendments 9 and 10 will give the Scottish ministers the power to modify the definition of a responsible person in section 25(1). That will ensure that, if the definitions in section 25 do not cover a particular arrangement that it is envisaged should be subject to the duty of candour, secondary legislation can be laid to address that. Equally, the power will enable the Scottish ministers to exempt persons from the definition of a responsible person.

Amendment 10 makes the power that is conferred by amendment 9 subject to the affirmative procedure, which we consider to be appropriate, given that it is a power to amend primary legislation.

I ask the committee to accept the amendments. I move amendment 6.

Amendment 6 agreed to.

Amendments 7, 8, 5 and 9 moved—[Maureen Watt]—and agreed to.

Section 25, as amended, agreed to.

Section 26—Care worker offence

The Convener: Amendment 18, in the name of Mary Scanlon, is grouped with amendments 21 to 23 and 25.

Mary Scanlon: I am grateful for the committee's time in considering my amendments. I also thank the clerks for assisting me with the amendments.

Over my years as an MSP, I have met many families who have been left with the guilt that they should have done more to protect their parents when they were in residential care. I spoke to one such lady last night, which is why I am here. She has given me permission—I am sorry; this issue is quite emotive—to use her name and her mother's name. The woman's name is Mrs Blan Bremner and her mother was Mrs Doreen MacIntyre, who died some time ago in the Kingsmills care home in Inverness. Rhoda Grant will be familiar with that care home.

The family were concerned about their mother's care and treatment and decided to install a tape recorder in her room. They were shocked when they played back the recording. I have read the transcripts, which is why I find the matter so upsetting. Dr Ian McNamara of the Highland senior citizens network said:

> "Having listened to the tapes no one could be in any doubt that abuse of an older, vulnerable adult had taken place."

I appreciate that time is limited, convener, so I will be as brief as possible. Police Scotland was given the tape. It confirmed that

> "staff are behaving in an unprofessional manner and making inappropriate comments".

It also said that

> "insulting comments made by care staff were highly inappropriate, derogatory, insensitive and fell significantly below the standards any reasonable person would expect for the care of a relative"

but did not reach the

> "threshold set by Case Law to proceed to a criminal investigation."

Had the family installed a closed-circuit television camera, the situation would have been different.

I will give an example of how the staff treated Mrs MacIntyre. When the lady asked kindly for a hand to help her, staff gave her a round of applause and they laughed at and ridiculed her. The police stated that there was no evidence of assault by care staff and no evidence to meet the threshold for cruel treatment, which they stated is essentially a serious wilful neglect offence. They also stated that the conduct of the care by staff at the Four Seasons Health Care home required investigation by the relevant agency.

The family went to the Care Inspectorate. Its response was that it does not investigate alleged abuse. The family went to social work services, and the social care manager told them:

> "you have to move on from the issue as legally nothing can be done and it will affect your health."

The family are finding it more difficult to move on than the social work services appreciated.

10:00

The care home response was to send a letter that said that the two members of staff who had been suspended were no longer employed and that

> "Four Seasons Health Care bears no admission of guilt as a consequence."

I will come back to that when I speak to my next group of amendments.

I told the family about the bill because I thought that it would be an opportunity to look at what could be done. I am afraid that the family were not too impressed with the reference to "wilful neglect", and they pointed out the difference between neglect and abuse. To neglect is to pay little or no attention and to fail to care for or attend to properly, whereas to abuse is to hurt or injure by maltreatment, to assail with insulting or hurtful words or to use insulting or hurtful language and speak insultingly or cruelly. In my view, "abuse" clearly describes the experience at that care home—and it is not the first time that we have heard of such abuse in a care home in Scotland.

In my book, many of the problems that arise from poor care standards are not simply neglect—they are abuse. I lodged the amendments to seek clarity on the issue, given that the bill is a unique opportunity to put in place something to help to protect elderly, frail and vulnerable people.

I move amendment 18.

Dennis Robertson (Aberdeenshire West) (SNP): I thank Mary Scanlon for lodging her amendments. There are standards of professional conduct for people who are registered to provide care and, if they fail to meet those standards, they can be held responsible and criminal charges can be brought against them. Such matters are usually dealt with under the standards of professional conduct that already exist for registered social care and social work organisations. I am not sure that the amendments would assist with dealing with the issue any more than the standards of professional conduct that exist for registered organisations already do.

Rhoda Grant: Nobody who listened to Mary Scanlon could help but be horrified by the experience that she described. Sadly, it is all too common in some care homes—we have seen care homes have their licences removed because of such cases.

If I was the daughter of the person who was named, I would not be happy if all that could happen in such cases was the removal of professional registration. Such abuse needs a legal sanction, so I am minded to support Mary Scanlon's amendments.

Richard Lyle: I would be concerned if what Mary Scanlon described happened in any care home. However, there are many care staff in many care homes who deliver an excellent service. I remember a care home that my father-in-law was in, which he said was not a five-star hotel but a seven-star hotel. I take the point that there may be deplorable situations that should be dealt with under the law, but I must put on record the fact that many care workers in this country are delivering an excellent service and working hard to help elderly people.

Nanette Milne: I hear what Richard Lyle says; we would all agree that there is excellent care in many cases. Nonetheless, there are cases such as the one that Mary Scanlon told us about. I remember her telling me about it some months ago. It really is an appalling thing and the law should be able to provide a means for dealing with such abuse, in addition to wilful neglect and other practices.

Maureen Watt: The care worker and care provider offences in part 3 are committed when there is ill treatment or wilful neglect of individuals who are in receipt of care. As the committee knows, the expressions "ill-treatment" and "wilful neglect" are established in law and cover a wide range of harmful behaviours, including what we would understand by the term "abuse".

As has been made clear previously, those offences are intended to deal with—among other things—the sorts of abuses that occurred during the breakdown of care at the Mid Staffordshire hospitals. On that basis, adding the term "abuse" would not broaden the range of behaviours that the offences cover, as we are content that such behaviour would already by caught by the bill. The term "ill-treatment" is distinct from neglect and covers a range of behaviours, including behaviour such as that described graphically by Mary Scanlon.

The amendments would mean a departure from the wording of existing offences in relation to those receiving mental health care and treatment and in relation to adults with incapacity. That could cause confusion and cast doubt over the width of the existing offences. Throughout the Government's processes of consultation and engagement on the provisions, there have been many comments on the wording of the offences, and we have sought to reassure stakeholders that the terms "ill-treatment" and "wilful neglect" are familiar to the police and the prosecution service. For those reasons, I ask Mary Scanlon to withdraw amendment 18 and not to move the other amendments.

Mary Scanlon: I appreciate Dennis Robertson's point. The care workers would be registered with the Scottish Social Services Council. Until a few weeks ago, one of them was still working in the national health service, at Raigmore hospital in Inverness. In the example that I gave, the workers were suspended, they left and there was no investigation, so the police, the Care Inspectorate and social work services could do nothing. Rhoda Grant is right to say that there have been quite a few examples of that in and around Inverness and it is all too common.

I should have said this earlier, but I was so focused on the issue that I did not mention it. Two, three or 20 poor care workers do not take away from the commitment that 99 per cent of our care workers have. They are not always the best-paid workers either, so I should have put that on the record. Like Richard Lyle, I have nothing but respect for well-managed, excellent care homes. Thankfully, most of them are well managed with excellent staff, so I hope that, by citing the example that I gave, I did not give the impression that it was true of every care home. I wholeheartedly agree with the points that Richard Lyle made and I cannot speak highly enough of care staff.

Because I am a bit of an outsider at this meeting, I am not au fait with all aspects of ill treatment in the bill. I am not sure that the bill goes far enough but, having said that, I am grateful for the responses from the committee members and the minister. I felt that the provisions needed probing because people are asking how much better the bill can make the situation and whether it can ensure that people who do not have the commitment to caring that we expect are not put in charge of their family members. Having heard what I have heard today, I will withdraw amendment 18 and not move the other amendments, but I might consider lodging them again at stage 3.

Amendment 18, by agreement, withdrawn.

The Convener: Amendment 19, in the name of Mary Scanlon, is grouped with amendments 20, 24 and 26.

Mary Scanlon: My comments on the amendments follow on from the good point that Dennis Robertson made about professional conduct. I have described the poor experience of care standards, and it is worth noting that the tape-recorded evidence related to only two care staff. With a camera installed in the room, the evidence would have been much clearer and the position on a court case and prosecution would have been different. The staff were suspended and were no longer employed by Four Seasons Health Care, but they were instantly able to gain employment elsewhere in the care sector, because there is a national shortage of care staff.

One of the care workers got work with NHS Highland at Raigmore hospital; I am not sure whether he was still employed there after the family and I raised the matter with the NHS. Nevertheless, the ease with which that individual found further employment and had further opportunities to continue his unacceptable practices angered and continues to anger the family in question.

With the amendments that I have lodged, I want to examine what can be done to protect others from care workers who do not live up to their job descriptions. The issue is relevant to the particular case that I have described and to successful prosecutions.

This was a very difficult case. There was tape-recorded evidence, and the police said that the comments that had been made were inappropriate and so on. However, no charges were brought, no investigation was carried out, no one picked up the matter and the care workers just walked away and got jobs elsewhere. The amendments that I have lodged in this group are probing ones.

I move amendment 19.

Maureen Watt: Amendments 19 and 24, in the name of Mary Scanlon, would remove the option for ill treatment and wilful neglect offences to be tried under the summary procedure. That would most likely result in fewer cases of neglect or ill treatment making it to court, as the Crown Office and Procurator Fiscal Service would proceed with only the most serious cases of ill treatment or neglect, for which solemn procedure would be appropriate.

For the existing offences of wilful neglect and ill treatment under mental health and adults with incapacity legislation, nearly 80 per cent of the prosecutions have been dealt with under summary procedure. Removing that option would severely limit the procurator fiscal’s discretion in dealing with less serious cases.

Amendments 20 and 26 seek to require the Scottish ministers to make regulations to prevent convicted care workers from working in care roles. I thank Mary Scanlon for giving me the opportunity to set out my intention to lodge amendments at stage 3 on the issue. First, I will set out the background. The Protection of Vulnerable Groups (Scotland) Act 2007 requires employers and regulators to refer individuals who have harmed a protected adult to Disclosure Scotland for the purposes of considering them for listing as unsuitable for regulated work. In addition—and more specifically in relation to the offences in part 3 of the bill—a court may, when convicting an individual, refer that individual to Disclosure Scotland if it thinks that it might be appropriate for the individual to be considered for listing. Disclosure Scotland will then consider whether the individual should be listed as unsuitable to work with vulnerable adults.

In standard and enhanced disclosures under the Police Act 1997 and PVG scheme record disclosures under the 2007 act, a conviction for ill treatment or wilful neglect under part 3 of the bill would be disclosed to a prospective employer. Given the seriousness of such offences, I intend to lodge amendments at stage 3 to ensure that they continue to be disclosed even when, as a result of the passage of time, the convictions would otherwise be spent.

I am therefore satisfied that sufficient safeguards are in place to ensure that unsuitable people are not employed as care workers. For those reasons, I ask Mary Scanlon to withdraw amendment 19 and not to move amendments 20, 24 and 26.

Mary Scanlon: I would obviously be concerned if fewer cases were getting to court as a result of my amendments, because that is certainly not my intention. However, I have to say that I am delighted with the minister’s tone and response; I had hoped that the issue would get a good airing, because this is an area that we are all concerned about. I am grateful that the minister is giving the provisions further consideration and will lodge amendments at stage 3. As a result, I will seek to withdraw amendment 19 and not to move the other amendments in the group.

Amendment 19, by agreement, withdrawn.

Amendment 20 not moved.

Section 26 agreed to.

Section 27—Care provider offence

Amendments 21 to 24 not moved.

Section 27 agreed to.

Section 28 agreed to.

Section 29—Power to order offence to be remedied or publicised

Amendment 25 not moved.

Section 29 agreed to.

Sections 30 and 31 agreed to.

The Convener: I thank the officials for their attendance and suspend the meeting to enable new officials to join the minister.

10:16

Meeting suspended.

10:19

On resuming—

The Convener: I welcome the officials from the Scottish Government bill team who are now accompanying the minister—Angela Bonomy, sensory impairment national delivery support adviser; David Wilson from the directorate for legal services; and Meryl Skene, parliamentary counsel.

After section 31

The Convener: Amendment 1, in the name of the minister, is in a group on its own.

Maureen Watt: The Scottish Government recognises that the provision of communication equipment and the associated support that is required to use it are key requirements of children and adults who have lost their voice or have difficulty speaking. Communication equipment ranges from low-tech equipment such as picture symbol books to high-tech equipment such as dedicated voice output aids.

Individuals who use communication equipment, service providers and organisations that represent service users tell us that provision across Scotland is inconsistent and inequitable and does not always meet the needs of people with communication difficulties, particularly in the case of those who require high-tech devices. The majority of them told us in response to a call for written evidence that there is a need for the bill that we are discussing today.

The aim of amendment 1 is to provide a more explicit duty on Scottish ministers to provide or secure the provision of communication equipment and associated support. That will consequently raise the profile of the service, bringing it to the forefront of service delivery. It is expected that health boards, which will discharge the duty on behalf of Scottish ministers, will review their current services, systems and processes and consider the service as a priority.

The breadth of the proposed duty is deliberate. It provides flexibility to determine who might receive communication equipment and what type of equipment might be provided, and it allows for responses to future technological developments.

In addition, under the existing powers of the National Health Service (Scotland) Act 1978, Scottish ministers will issue directions to health boards in the near future to help to support the discharge of the duty. The directions will need to be considered carefully. They must contain the correct level of detail to address the operational issues and deliver person-centred care. We know that that is a cause for concern among a number of our stakeholders and we thank them for bringing their concerns to our attention.

The directions will be developed in consultation with stakeholders. Discussions are under way with the Royal College of Speech and Language Therapists to develop a Scottish Government-funded programme of operational improvement work, which will build on the recent right to speak strategy and lay strong foundations for the introduction of directions.

I also highlight the on-going work on voice banking, which is an important development in augmentative and alternative communication. The Scottish Government will fund the Euan MacDonald centre to pilot voice banking in three NHS sites from April this year. We thank Gordon Aikman for bringing the research work to our attention and we look forward to the findings of the pilot.

The financial implications of the duty are expected to be cost neutral as it will not lead to an increase in demand. Any future directions are likely to incur modest financial costs for health boards and local authorities. To be clear, I add that the more immediate operational improvement work with the Royal College of Speech and Language Therapists and the voice banking pilot are being funded by the Scottish Government.

Loss of voice and the need for voice equipment affect only a small number of people, but the loss has a huge impact on their lives—imagine if we in this room had difficulty in communicating and could not convey our message. I therefore feel that legislating is the right thing to do, and I know that a number of people agree.

I move amendment 1.

Nanette Milne: The principle of this amendment on the provision of communication equipment and the associated support that is required is excellent. I was glad to hear what the minister said about guidance to health boards, because I was quite concerned when I saw the number of suggested amendments coming in from the Royal College of Speech and Language Therapists in response to the minister’s amendment. I hope that the issues have been taken care of.

Another issue that has been raised and which concerns me a bit is funding. I cannot find it on my iPad, but the Convention of Scottish Local Authorities made a late submission in which it expressed concern about whether there will be enough funding to cope with the likely demand for such equipment. Will that be looked at in detail? I am happy with the principle of the amendment, but there might be some detail to be sorted out. I presume that that can be done later in regulations or guidance.

Dennis Robertson: Will the proposal remove the duty on the Department for Work and Pensions to provide similar equipment through the access to work programme? I rely on communication equipment; although I have my own voice, I rely on speech-activated equipment all the time. Will the proposal remove the requirement on the DWP to provide such equipment for people who are in work?

Rhoda Grant: I welcome amendment 1, which is very important. It is very important for people who are faced with a devastating illness and who know that they will lose their voice and not be able to communicate properly to have something to hold on to that will be a comfort to them and to be able to take proactive action in mitigation of that. I am glad to see this amendment and I am glad that the minister paid tribute to Gordon Aikman, who has brought the issue to the fore. He has probably given an awful lot of people who would not have had such assistance access to it. I was unaware of things such as voice banking until that point, so I am grateful to him and to the minister for bringing it to my notice.

Maureen Watt: In reply to Nanette Milne, I say that we have taken the view that, in terms of what we put into the bill, less is more. We do not want to be too prescriptive, because technology moves on and, in a couple of years, something might replace voice banking, for example. We did not want to restrict ourselves.

The answer to Mr Robertson’s question is that this duty would not remove the duty on the DWP. The duties are complementary.

On funding and local authorities, the funding comes from the Scottish Government through health boards, but how that is worked out will be addressed as we develop the direction of travel with the legislation.

Amendment 1 agreed to.

Section 32—Regulations

Amendment 10 moved—[Maureen Watt]—and agreed to.

Amendment 26 not moved.

Section 32, as amended, agreed to.

Sections 33 to 35 agreed to.

Long title agreed to.

The Convener: That ends stage 2 consideration of the bill. I thank the minister and her colleagues.

10:29

Meeting suspended.

10:33

On resuming—

Subordinate Legislation

Public Bodies (Joint Working) (Integration Joint Board Establishment) (Scotland) Amendment Order 2016 (SSI 2016/2)

The Convener: For item 5, we have two negative instruments before us.

There has been no motion to annul the first instrument that is before us and the Delegated Powers and Law Reform Committee has not made any comments on it. There are no comments from members. Does the committee agree to make no recommendation on the order?

Members *indicated agreement.*

Health Boards (Membership and Procedure) (Scotland) Amendment Regulations 2016 (SSI 2016/3)

The Convener: There has been no motion to annul the second instrument that is before us and the Delegated Powers and Law Reform Committee has not made any comments on it. There are no comments from members. Does the committee agree to make no recommendation on the regulations?

Members *indicated agreement.*

The Convener: We have reached item 6, on palliative care, ahead of schedule, and I think that the cabinet secretary may have had some travel problems. We will therefore suspend the meeting at this point, get a coffee and stretch our legs. I ask members not to go far, so that we can proceed quickly to our business when the cabinet secretary arrives.

10:34

Meeting suspended.

10:46

On resuming—

Palliative Care

The Convener: Agenda item 6 is an evidence session on the Scottish Government's strategic framework on palliative care and its response to the committee's report on palliative care. I welcome the Cabinet Secretary for Health, Wellbeing and Sport, Shona Robison, and her officials Janice Birrell, senior policy/implementation manager, and Professor Craig White, divisional clinical lead and chair of the national advisory group for palliative and end-of-life care.

Cabinet secretary, when you previously appeared before the committee, it was remiss of me not to give you the opportunity to make opening remarks. You have that opportunity today before we move to questions.

The Cabinet Secretary for Health, Wellbeing and Sport (Shona Robison): Thank you very much for giving me the opportunity to discuss the important issue of palliative and end-of-life care. I very much welcome the committee's report "We need to talk about palliative care". This is an important time for palliative and end-of-life care in Scotland, as we have seen unprecedented public discussion of end-of-life issues, and we need to build on that conversation. I was struck by the comprehensive way in which the committee assembled the written evidence and was informed by the oral evidence that was presented to it. I also commend the committee for meeting service users during its visits to Rachel house and Ardgowan hospice.

I firmly believe that, as part of delivering person-centred health and social care, it is vital that we listen to and learn from people who use the services. With more adults in Scotland living with long-term conditions that involve specific palliative care needs, and with more children with life-shortening conditions living into adulthood, I fully recognise the need for robust and effective action to address the changing needs.

On 18 December, I had the privilege of launching the Scottish Government's "Strategic Framework for Action on Palliative and End of Life Care" at the Marie Curie hospice in Edinburgh. I was deeply grateful for the opportunity to speak to patients and staff there to hear directly about their individual experiences. I also pay tribute to the hard work of all the charities, the members of the public, the representatives of the health and social care sectors and the many others who helped to develop the framework. I am extremely pleased to tell the committee that the strategic framework has received a positive response around the world, with positive recognition coming from members of the World Health Organization and the Altarum Institute in the United States.

The vision that is set out in the framework is that by 2021 everyone in Scotland will have access to good-quality palliative and end-of-life care that is tailored to their symptoms and life circumstances. We are committed to ensuring that people can access high-quality palliative and end-of-life care regardless of their age, diagnosis, socioeconomic background or where they live.

The new health and social care partnerships and the independent hospice care and voluntary sectors will in local areas across Scotland play a central role in meeting the growing and changing need that I referred to. Only by focusing on local capacity and local solutions can we deliver the best care and support for all who are at the end of life, their families and their carers.

I recognise that significant improvements have been made in the delivery of palliative and end-of-life care in recent years; the committee heard about them from Professor David Clark of the University of Glasgow, who is a world-leading authority on the subject. Scotland has a good reputation for its palliative and end-of-life care—indeed, the number of doctors and nurses who work in specialist palliative care services in Scotland has increased—but I fully understand that we can still do a great deal to improve the provision of palliative and end-of-life care. I recognise that that will not be an easy task; it will require a great deal of hard work and commitment by many individuals and organisations across health and social care, the independent hospice care sector and the voluntary sector.

The framework outlines the Scottish Government's 10 commitments for action to support effective implementation over the next five years, and we have also committed £3.5 million to supporting national improvements and building capacity. The framework's 10 commitments, which provide a clear direction for improvement, are designed to improve palliative and end-of-life care in ways that are sustainable and which can be applied in many settings. Training and education are a key priority that we have identified for targeted action, and we have to ensure that medical, nursing and care staff are supported to recognise when time is becoming short and when sensitive conversations with people and their loved ones can make an enormous difference.

I am happy to report that work to fulfil the commitment has begun. NHS Education for Scotland is recruiting three regional practice education co-ordinators to work across the NHS and social care services on establishing an integrated and collaborative approach to palliative and end-of-life care education provision across health and social care partnerships.

We agree with the committee's finding that there is a need to improve the information that we have. That is why we have committed to improving the way in which information is recorded, shared and accessed across the sectors, which includes the capturing of end-of-life care preferences for where people would like to be cared for when time becomes short. It is recognised that those preferences and what it might be possible to provide might well change—that depends on an individual's clinical condition—but we need to get better at anticipating and recording care needs and at having an open discussion with people about what matters most to them.

It is important for staff across the sectors to be supported in improving the delivery of palliative and end-of-life care and, as part of the strategic framework, we will support clinical and cost-effectiveness evaluations. I note that a review of hospice funding is also being planned as part of the implementation process.

That has been a run-through of some of the key elements of our response. I am happy to answer members' questions.

The Convener: Thank you, cabinet secretary. Nanette Milne will ask the first question.

Nanette Milne: Good morning. I was delighted with the Government's response to the committee's report, given the amount of work that went into it. It is good that there is mutual thinking on the issue, and I am sorry that I will not be in Parliament to see the progress that will be made. However, I know that there is a lot of work ahead.

I will pursue the conversations that are had with the people in question. From what I have heard from witnesses who have given evidence and so on at various meetings that I have attended over the past couple of years, it seems that we as a country still do not talk about death, about planning for it and about end-of-life and palliative care. I am concerned about an issue that I think Marie Curie first raised with me—that healthcare professionals find it difficult to talk to their patients about the matter. I fully understand that. When I was a young doctor, we were thrown in at the deep end without any training at all to speak to patients about the fact that they were dying. That was not easy, and I am sure that a lot of mistakes were made because we had no training in that.

It is important to change the culture on that early so that, once someone is diagnosed with a terminal condition, the plan is openly and freely discussed with healthcare professionals. Will you give more detail about what the framework will do to drive the new culture of openness in the community?

Shona Robison: The training and the support for healthcare professionals are a key part of the framework, but the wider conversation about how we as a society deal with such issues is more challenging. As a society, we have found that conversation difficult. Perhaps it is a bit easier now than it was a decade or a couple of decades ago, but it is still very challenging.

That is why we have been looking at extending the views of informal carers for the evaluation of services—VOICES—survey so that it is Scotland-wide and at using opportunities in working with the Health and Social Care Alliance Scotland, the Scottish health council and others to really keep the conversation going in the public arena about end-of-life and palliative care, dying in general and the fact that people should be able to express their preferences and the family should be encouraged to talk about that. None of that is easy. When it comes to an individual having that conversation, the theory is one thing, but the practice is another. The support for newly qualified staff in particular is important.

Anticipatory care planning is important, as it gives a focus for the discussion. If there is an anticipatory care plan, there is something to talk about with the person and the family, and in some ways that can make things a lot easier, as there is already a focal point.

Professor Craig White (Scottish Government): As the cabinet secretary mentioned, NHS Education for Scotland and the SSSC are making good progress. In fact, the interviews for the posts that were mentioned are taking place today.

One advantage of NHS Education for Scotland and the SSSC being involved is their existing involvement in curriculum planning and training across the professions. Since the framework was developed, organisations have started to share their local training needs analysis with NES and the SSSC. For example, just in the past week, NHS Tayside has shared with us surveys that it has done of medical and nursing staff, who were asked to rate their confidence in such issues, and that will inform the needs analysis that the three new postholders will do across the country.

In talking to stakeholders, we have heard that initiatives such as the good life, good death, good grief initiative, which the committee's inquiry report referenced, are important in designing future approaches around the public conversation. The learning from the good life, good death, good grief initiative needs to be scaled up across the country so that we reach more people. In turn, that will mean that, when people need to have conversations, they will be less concerned by some of the barriers that have been reported.

Nanette Milne: Is it the plan for training and support to start pretty early at the undergraduate level for nurses and particularly doctors? I presume that, once they are in post, there must be on-going training or support—I do not know what it would be called. I feel that that has to be introduced early and progressed so that nurses and doctors continue to develop confidence in raising the issue with people. The issue has to be introduced early, when a decent amount of anticipatory care can be planned.

Professor White: Absolutely. There is early inclusion in the curricula and particularly in the practice-based aspects of health and social care professionals' training. As you said, the aim is to help people in the professions to realise that such conversations do not just belong where there is recognition of the end of life or deterioration. One wants to have the conversations earlier as part of the care and support planning.

11:00

The Convener: It is important to talk about the subject. I thought that the chief medical officer's annual report was very good on the challenge that we face. As a committee, we have flagged up education, training and so on, which will assist in some ways, but we are dealing with a much deeper problem in the professions—the pressure to do something even when it will make no difference. The CMO highlighted the issues around that. When it comes to palliative care and the end of life, it is important that people have the opportunity to understand the consequences of decisions about whether to take intensive treatments. The committee touched on that in the context of access to new drugs, particularly in relation to cancer and the end of life.

Members may remember that the clinician at Ardgowan hospice, who deals not only with cancer—in relation to which it seems to be easier to talk about these things if there is an inevitability about the situation and a timescale that can be applied—but with respiratory illness, said that having such a discussion with a patient who has a respiratory illness would be seen from the clinician's point of view as abandoning that patient and sending them home. We are dealing with deep-seated issues in the culture of the national health service. Education and training are all very well, but the chief medical officer has suggested that we need to do something more. Do you agree?

Shona Robison: The CMO's report was very good and quite challenging in some ways, as it reflected some of the on-going debates. We are in a different place from where we were years ago, as people can now live for a long time in a palliative care situation and their needs and requirements will change over that time. That is why the anticipatory care plan is so important, because the discussion about someone's wishes should happen not at an end-of-life point but when they are more able to have the discussion, which I hope would involve their family, about their expectations of their care pathway—it might be over quite a long period—and, at the end of that, their end-of-life choices. There should maybe be a focus on those issues and more priority given to that discussion, in addition to recognition of the importance of the right medication or intervention, which will always be clinical judgments.

Part of the debate that the chief medical officer has sparked off is about whether there is overmedicalisation of people's care. That is sometimes about the expectations of families and patients. If people hear about a drug or something that could enhance the time that they have, it is a natural instinct for them to want to access such a treatment.

Clinicians have to have a conversation with the patient about, for example, what the expectations are, what the treatment would do, what the likely outcome would be and any side effects. There are sometimes quite dramatic side effects, which in an end-of-life situation might not always be in the person's best interests. Those discussions are always difficult, which is why it is best to have them as early as possible in the process.

Professor White: I know that the committee has previously heard evidence about the importance of considering the issue across a wide range of conditions and not only as something that relates to the end of life. The chief medical officer asked some of the clinicians and the people who work in clinical lead roles, such as me and my colleagues, to advise her on themes. We advised her on some of the issues that relate to palliative care and the committee's inquiry report.

That advice very much informed some of the thinking about the conversation that the chief medical officer wants to have with doctors about realistic medicine and how we build on the good work that is being done to put people and families at the centre of conversations about anticipating future care needs. To go back to Nanette Milne's point, that might raise issues about confidence and skills for doctors. Both issues are linked in the conversation that the chief medical officer initiated in her report.

The Convener: That also highlights that there is now evidence that intensive care does not lead to better outcomes. The chief medical officer has cited some American studies on stage 4 cancer in which people who opted for hospice at home had better outcomes than those who opted for intensive care. We are going to have to have a debate about support for education and training that will encourage not the clinicians but the individuals concerned to make that choice. There needs to be discussion with the individual about their options and the fact that it is not just about intensive treatment. I do not know that education and training of the workforce will help to change that dynamic.

Shona Robison: Ultimately, it will always come down to clinical judgment in discussion with the patient and their family. Sometimes people will choose a different option if they are made fully aware of the side effects and what to expect, for example. It is about having the full range of information about the options and what they will entail, and having the discussions early enough to make a proper and informed choice.

Some of the practical issues that can cause panic or a failure of pain control leading to a last-minute hospital admission at the end of life need to be overcome to make sure that, at that stage, people are still able to make their choice and that the choice to have their end-of-life care at home is supported and sustained. I am sure that the committee has, as I have, heard of cases in which that was the active choice, but because of a lack of confidence in what to expect at the end, or because of pain-control issues, for example, people have ended up in hospital when they would not have, had the pathway been delivered as it should.

Those are the things that we want to get in about, with implementation. How can we ensure that the person's wishes are delivered, that the professionals and the patients are confident that they will be supported in their choice, and that the families are involved? I cannot stress enough that the families have to be involved in the discussion. In end-of-life situations families can, understandably, become quite upset and distressed. We have to make sure that everybody is clear about what the choices are.

Janice Birrell (Scottish Government): We are already working closely with the living well in communities work stream; a specific strand of that work is linked to anticipatory care planning. Two new clinical appointments have been made to that work that is hosted by and based in Healthcare Improvement Scotland. Wider work is looking at emergency care and treatment planning; we are ensuring that the anticipatory care planning work is linked to and has an oversight of the wider emergency care and treatment planning. That is out for consultation. I am happy to share with the committee the hyperlink to that work. Earlier discussions will have been had with a patient, but that work aims to establish the crisis points and to ensure that emergency care and treatment plans are in place for those times. The work very much links to the wider anticipatory care planning, but takes on board what the key preferences are when times become a bit difficult.

The Convener: I want to focus on the implications of a person's earlier decisions before an emergency arises. What is the likelihood that such a discussion would take place? What would that discussion look and sound like? Is there any consistency across the board or guidelines about that, or is it simply a case of doctor knows best?

Janice Birrell: In NHS Lanarkshire, a consistent approach across the care homes setting on anticipatory care planning has been piloted over recent years. I think that all but one care home in the Lanarkshire area use the same anticipatory care plan. Data demonstrate that inappropriate hospital admissions have declined over that time. Work is on-going to fit with the local infrastructure in order to ensure that a care lead is identified and that, in discussion with families, clear plans are put in place. We are trying to spread and share such work.

The Convener: In evidence, the question has come up whether death at home, or closer to home in a residential setting, is a better death than dying in hospital. We have not measured that. We know that more people are dying at home and it is said that that is better. Do we know about the quality of those deaths and the impact on individuals and their families? I do not think that we do.

Shona Robison: I suppose that that view is based on people's preferences being delivered. You are right about the need to look at the quality of the experience and the need to make sure that what we think is the better solution—given that we know all the challenges in busy hospital wards, including ensuring privacy and dignity, although that is delivered in most cases—is the better solution. Craig White will say a bit about the quality of people's experiences.

Professor White: As the committee will know from its other debates on spreading quality improvement and safety initiatives, we have learned through other work, including the Scottish patient safety programme, about the best ways to spread reliable care processes to make healthcare safer. We have been learning how we can use the work that Janice Birrell mentioned in regard to NHS Lanarkshire to support health and social care partnerships in implementation in their local systems. That will reduce variations in when and how the conversations take place. You are absolutely right that we want to be able to measure that. The committee's inquiry report identified, as you know, an urgent need to measure, and to describe the quality of, care.

We have been supporting work in NHS Lothian on how to ask people about their experience of care and how to use the VOICES framework that has been mentioned to ask bereaved relatives for their reflections on the quality of care. It is important that we are, rather than waiting for a survey once every year or two years, looking at how data can be made available—again, learning from our work on safety—to teams every day and week so that they can continuously improve the quality of care.

There is variation, but as the cabinet secretary said, we want to accelerate progress on consistency in the care process so that, in keeping with the vision, by 2021, everyone, irrespective of their condition, will know when, how and with whom such conversations will take place.

Dennis Robertson: We heard evidence from Dr David Carroll from NHS Grampian. He said that although having the conversation is fine, the conversation must be continued, because patients—and sometimes their families—may well change their minds about the care that they want: they may even wish to end their life.

That brings me to the HIS in-year response. You suggest that HIS is looking at the methodology for inspecting what is going on at present. Do you have a timeframe for that?

11:15

Shona Robison: You are right to note that an anticipatory care plan is not produced once and then frozen in time. People's needs change, which may lead them to a different conclusion about the care that they want, including end-of-life care. There must be an on-going co-ordinated conversation so that everybody is clear about the person's wishes.

Craig White can talk about the timeframe.

Professor White: I think that Dennis Robertson is referring to Healthcare Improvement Scotland's work on improving outcomes—

Dennis Robertson: Just the HIS methodology.

Professor White: There are three elements of that work. The first concerns our commitment to support HIS and others in their work in meeting the commitment to improve the quality of palliative and end-of-life care.

Last week, Janice Birrell and I met representatives of HIS, Scottish Care and the Care Inspectorate, as well as the two new clinicians who have been appointed to lead in anticipatory care planning work. In terms of a timescale, the work is under way. We have asked HIS to submit a report describing how its existing work can support the commitments to palliative and end-of-life care and—importantly—how that links in with on-going work on the national care standards, and with the inspection process for strategic plans for health and social care partnerships on which HIS and the Care Inspectorate are currently working. That process is happening and we are linking it to our on-going review of the outcomes of the work and the guidance that health boards have been given on their local delivery plans. We have invited health boards to submit details of how the strategic framework will be implemented. We have tried very much to link the work with all the existing programmes of work and with the annual monitoring and governance mechanisms in boards and partnerships.

Rhoda Grant: I have a quick supplementary on the difference between hospital and community palliative care, particularly in an emergency situation. The committee did not take a lot of evidence on that, but it seems that there is a different set-up in hospital, where things happen very quickly. There is a huge intervention, and then staff realise that they cannot really help somebody.

We need a different kind of palliative care to assist the families of people who were hale and hearty half an hour ago and suddenly become ill. Has any thought been given to how that happens, especially in a busy intensive treatment unit or emergency department?

Shona Robison: Yes. Interestingly, I recently inquired into what happens in an emergency department. I visited the accident and emergency department at Ninewells hospital a few months ago and saw for myself that even in a busy A and E department there is good practice to ensure that a quiet area is provided to give people dignity and peace at the end of life.

As you can imagine, that is quite challenging, but the boards have assured me that they make such arrangements even in busy A and E departments, when it would be stressful to move the patient and their family somewhere else. Obviously one would not, ideally, want someone to have end-of-life care in A and E, but if the clinical judgment is made that it would be better not to move someone at that stage, when they are very much at the end of their life, there is good guidance on how that can be done in a dignified manner. As I said, I saw for myself how it is done at Ninewells.

Professor White: One of our commitments is to provide health and social care partnerships with guidance on commissioning. As the committee may be aware, the partnerships will be responsible for commissioning palliative care in hospitals, as well as in community settings. We will make sure that some of the issues that have been mentioned by the cabinet secretary are clearly reflected in the guidance on commissioning, so that people who present at accident and emergency departments receive high-quality palliative and end-of-life care.

The work around transforming urgent care—which is led, as you know, by Sir Lewis Ritchie—is also relevant. Sir Lewis and I will meet later today to discuss the issue that has been raised and will ensure that the work can take into consideration issues such as people presenting at urgent care services, and the need to look at the most appropriate care setting.

Rhoda Grant: My main question is about children. I visited Rachel house hospice as part of the committee’s inquiry. It struck me that palliative care for children is quite different from palliative care for adults; it quite often deals with children—from very small babies—with life-limiting conditions, who might not see adulthood. Would the definition of palliative care be different for them?

Looking further ahead, as care gets better and people learn more about those life-limiting conditions, I expect that some of those children will live into adulthood. There seems to be a gap in the definitions. I notice that, in your report, you talk about ages 0 to 25, but such cases can sometimes last up to the 30s. Families facing such situations depend on children’s hospice services, which give them huge support, but after that the families can feel cast out, I guess, because the adult support for life-limiting conditions is not on the same scale.

Shona Robison: I think that there is recognition—there certainly is in our response—that the needs of children and young people can be very different from those of adults. You touched on something quite important, which is that through the development of medication, technology and new ways of supporting children and young people with life-limiting illnesses, such children and young people are now, thankfully, living much longer than was previously the case. We need to make sure that the transition from children’s services to adult services is as smooth as possible, and that the needs of children and young people are recognised as being quite distinct from those of adults. I hope that that comes through in our response.

Craig White or Janice Birrell might want to add a little bit in response to the question about definitions.

Janice Birrell: I think that there is a specific definition for children and young adults in the summary of the wider evidence. We have been working with the Children’s Hospice Association Scotland and have been at a number of meetings at which we met the transition team that has been appointed to CHAS. That team is currently testing different models of respite care for a number of young adults who are used to coming together to meet within CHAS, in order to determine how those young adults might best be supported. In recognition of the fact that one size does not fit all, different models will be tested. CHAS is doing work on provision of short breaks to give support to individuals and their families.

Professor White: I will talk about definitions and transition issues. As chair of the national advisory group, when the framework was being presented, I was keen to seek assurances from experts including clinicians and the chief executive of CHAS that our framework and the evidence summary accurately reflected the issue around definitions. The medical director of CHAS confirmed that the Government's commitment to the 0 to 25 age group is very much in keeping with its service model.

On anticipation and transition, we expect that the children who are living longer with the sort of conditions that CHAS clinicians see will also benefit from the commitments that we have made for adults as they transition from CHAS services to adult services.

Richard Lyle: I welcome the Scottish Government's announcement that £3.5 million is being allocated to the framework. As regards the Scottish Government's response to the committee report, under the heading, "Where is palliative care provided?" the impact of home care visits being limited to 15 minutes is a concern of numerous people and has been raised several times. The committee recommended that the Scottish Government investigate the issue. In your response, you comment:

> "Local authorities allocate care on the basis of an individual's assessed needs. It's clear that no-one should have a 15 minute or shorter visit when it is not appropriate."

You add that a short visit might be appropriate if a medicine is being dispensed, for example. You go on to state:

> "The Scottish Government have developed a new joint inspection regime to ensure that people get the level of support, through free personal care, that they have been assessed as needing, and that the quality is no less than the people of Scotland deserve."

You also state that you will implement inspections, which will

> "include the commissioning processes by councils that determine the volume and length of visits needed to deliver safe, compassionate care services for Scotland's older people."

I have a sheltered housing complex behind where I stay. On occasions when I am leaving my home or coming back I see care workers visiting clients. That happens several times a day but they are different workers, and some arrive on foot and some by car. That could be organised better. What inspection regime do you intend to develop in order to get away from the constant comments that people are only getting 15-minute care visits?

Shona Robison: That is a big area. People should get the care package that they require according to their needs—it should be needs led. As you have outlined, a lot of work has gone on to try to improve the quality and the inspection regime around all those issues, including how councils commission services.

We are moving into new territory in the world of integration. The health and social care partnerships have had their shadow year, and from 1 April they will move into full integration. That will make a big difference. For example, the joined-up nature of people working in multidisciplinary teams gives us the opportunity to get away from a situation in which someone's living room can feel like Sauchiehall Street, with lots of different people coming in. Big improvements have already been made in that regard, but integration helps us to take that to the next level.

Through reform of primary care, integration also gives an opportunity for the right professionals to be spending the right amount of time with the patient. You can see how important that will be in an end-of-life or palliative care situation in which the person's needs are more complex. Reform of primary care should free up general practitioners to spend more time with the more complex cases. It is about making sure that packages of care—care in its total sense—are joined up and multidisciplinary, and that communication is good so that we minimise the number of different faces that a person will see and so that there is more continuity of care. There is a big opportunity there if we get integration and the new models of primary care right.

The framework is important and implementation is critical. A lot of big changes are happening or will happen in palliative and end-of-life care. Getting the changes right could make a huge difference to the quality of care that people receive through their lives and at the end of their lives. We need to get that right.

11:30

Richard Lyle: I certainly agree, and I hope that the many aspects that have emerged in the past year or so will make a difference to people's lives and the care that they will receive. Given that this particular work will be carried out by local authorities, are you confident that we can monitor what is happening locally?

Shona Robison: Inspections are moving to a whole-system approach, and we are trying to reflect the work of inspectors as the service changes and becomes more integrated. Instead of looking at just one element, we want to take the approach that we take when inspecting older people's services of looking at the whole range of services and getting a picture of all of them, not just the hospital element.

The same can be said for palliative and end-of-life care. When we inspect those services, we will have an opportunity to look at the whole system, which I think makes more sense and, indeed, is the direction of travel as far as inspection is concerned.

Professor White: We have secured agreement in principle from three health and social care partnerships—Glasgow City, East Ayrshire and Western Isles—to test out how our commitments can be implemented and discussions are going on with other health and social care partnerships. Yes, inspections are important, but in order to get continuous quality improvement, we want care staff to have access to information that can influence day-to-day improvements, including the number of staff who are involved with somebody's care, the length of time they are there for, what they do and whether the individual's needs have been met. The teams need those data to look at as part of our approach to improvement. Inspection is part of that work, but as a result of other quality improvement work, we have found that if we allow teams to have these data as part of our commitment to improving measurement they can start to identify variations such as too many people being involved in a person's care or people not getting all the time that they might want. That will allow action to be taken without people having to wait for an inspection further down the line; indeed, we empower the staff to improve as they go along.

Richard Lyle: Thank you.

The Convener: As far as education and training are concerned, we all know that someone who is being cared for at home will see carers, home helps, social workers or whoever three times a day, every day of the week. They are the people who provide the care, while those who are being cared for might see their doctor or nurses perhaps only once a fortnight. The question is, therefore, what are we inspecting? Are we inspecting the basic principles of continuity of care?

Shona Robison: We are inspecting quality.

The Convener: Absolutely. I think that you are right, cabinet secretary; at some points, care can be too busy. That said, a perhaps more important issue from my experience is how the individual receiving personal care relates to the person who is delivering it.

There is also the issue of care workers not getting the professional support that clinicians and nurses get with regard to resilience. Carers might have been trained to lift, handle and so on but in the main they have not had the training and education to understand palliative and end-of-life care and what they are dealing with in that respect. Instead, they use their instincts and personal experience in order to provide empathy or whatever.

Care workers could also be caring for people for a long time, and that brings us to the issue of attachment, which has been recognised for nurses and clinicians. Care workers, however, get no support when the person they are caring for dies. For that workforce to be the workforce that we need it to be, it needs to be considered in the hierarchy of clinicians, nurses and whoever. After all, the people who are delivering care day in, day out are not those highly trained and highly paid people, and I hope that the strategic framework reflects the fact that those who deliver care need education, training and support.

Shona Robison: I agree. The work on the SSSC that Craig White has mentioned should help with that, but we need to monitor the situation and ensure that that level of care is recognised. If a care worker has a wealth of experience in delivering palliative and end-of-life care, we need to look at opportunities not only to recognise that in their skill levels, but to support them.

You are right to say that people get attached to the individuals in question—after all, they might see them every day—but the question is: what support do those staff get in an end-of-life situation?

Professor White: Absolutely. That issue came up in the meeting that I referred to earlier with colleagues in Healthcare Improvement Scotland, the Care Inspectorate and Scottish Care. There was an agreement last week that Scottish Care, as a representative organisation, would be involved in the work that we want to support in health and social care partnerships. That was for the reasons that you said—so that the whole range of care workers is involved and the issues around providing high-quality care that matter to them are taken account of.

To pick up on the convener's point about outcomes, the measurement framework that we want to develop needs to link with the health and wellbeing outcomes that are part of the integration work and legislation. We also want to develop specific indicators for palliative and end-of-life care that relate to quality outcomes.

The Convener: Will you monitor the continuity principle and measure how many different care workers a person has had over a week or a month?

Professor White: We want the partnerships that we will support and that will test the local work to develop and test out measures. Certainly, at those meetings we will be happy to keep an eye on that work and make sure that they are doing it as part of their monitoring. We do not want to impose from the centre how or specifically what they measure. Because the need for measures has been identified by Scottish Care at the meetings, it is already on the list of things that we are looking to discuss with partnerships.

The Convener: I suppose that I am pressing you to recognise that continuity of care is a priority and a principle that applies when a person is receiving end-of-life palliative care within the national health service. Why would it not be a priority and a principle that is insisted upon and measured if a person is receiving end-of-life palliative care in any other setting?

Professor White: It is a fundamentally important aspect. I am sure that work on the VOICES survey that I talked about, and which Janice Birrell may also remember, covers that point too, so we would have multiple points at which to monitor continuity of care.

Shona Robison: We can keep the committee informed of that work as it is taken forward and tested out. We will make sure that we home in on that issue in the feedback to the committee about continuity of care.

Janice Birrell: One of the models that I have seen involves sending a note—to the individual, their family or their carers—of who is going to see the person every day. It can be seen at a glance whether the same or different people are going in every day, or whether the same three people are going in daily over the period of a week. That is a model; I am not sure whether it is replicated across the country, but as an at-a-glance mechanism it is quite simple to use. If the individual does not have the capacity to understand the note, someone else can see who is coming and say whether it is who they thought it would be.

The Convener: I think that that approach is possible. It could also help in the development of the workers, who could take pride in being part of a palliative care team that can go in in specific cases.

Janice Birrell: Absolutely.

The Convener: There is all sorts of potential in that model, and opportunities to release potential. There are carers out there—

Shona Robison: With a lot of experience.

The Convener: —who are very good at providing care and who do it now, but whose potential might not be recognised.

Dennis Robertson: I have a supplementary on that point.

The Convener: I will give you a supplementary but it will test the patience of the committee.

Dennis Robertson: I know what the convener is saying and I understand the responses, but surely if we are looking at care being patient-centred, the most appropriate people should go in at the appropriate time for that person's care, because what is appropriate will change. The continuum of what is needed changes quite often. At one point a nurse with a very good specialist background might be going in, but if the person suddenly recovers, they might go back to receiving social care.

Shona Robison: That is about making sure that the person's needs are kept under review. If there is a requirement for more intense support—if someone's care needs change—of course their care should change.

I think that what the convener was saying—which I agree with—is that, where basic care needs are being met, the continuity of people involved in that care is very important. Relationships are formed and people get to trust folk, and that is very important in a personal care situation, where the person is quite vulnerable. We want to make sure that, through the testing and the work that was mentioned, we hold on to continuity of care as a key aspect of care. How we measure it can be taken forward. Janice Birrell outlined one simple way of identifying whether there had been continuity. We will take that work forward and I am happy to keep the committee informed.

Malcolm Chisholm: I will move on to a couple of other points, but I want to focus on the health and social care partnerships too, although some of the issues have been dealt with already.

I was pleased to see in the strategic framework that the first two commitments on the Scottish Government's list of 10 commitments relate to health and social care partnerships—we have heard today about the work of Healthcare Improvement Scotland.

The recommendations refer to the provision of expertise, guidance and so on. We know that health and social care partnerships have a great many commitments to deal with, and I am sure that everything will happen in due course, but to what extent is palliative and end-of-life care on their radar at present? The Scottish Partnership for Palliative Care recommended that all health and social care partnerships should have

> "an identified lead for palliative and end of life care"

and that partnerships should ensure that palliative care is included "within strategic and operational plans".

To what extent are you looking at those plans in terms of the attention that they give to palliative care? The plans are in place, but to what extent are the partnerships focusing on that area at the start of their existence?

Shona Robison: You raise an important point. As you know, the partnerships are required to produce a strategic commissioning plan by 1 April that covers all their functions, including responsibility for palliative and end-of-life care in hospitals and communities.

You may remember that the legislation sets out the requirements for engagement as part of the strategic planning process so that the third sector and the independent sector—all the right people, including local communities—are able to be part of the engagement process.

We will provide guidance specifically to support the partnerships in developing the content of their strategic commissioning plans with regard to palliative and end-of-life care services. Officials—with Craig White and Janice Birrell as the key contacts—are in the process of meeting each health and social care partnership to discuss progress on palliative and end-of-life care as well as other issues.

It is early days, but we have made it very clear to partnerships that we expect to see a focus on palliative and end-of-life care in the commissioning plans. We want to see a coherent plan laid out for how the partnerships will take that work forward and how they will involve all the providers in the third and independent sectors. The partnerships can articulate and lay out what those local plans look like. Craig White has been more involved with that aspect.

Professor White: Janice Birrell and I are in daily contact with the Scottish Government's integration team, which is linking up and meeting with the partnerships. We want to maintain the high levels of awareness that have resulted from the committee's inquiry and the publication of the framework.

As I mentioned earlier, the local delivery plan guidance that the chief operating officer of NHS Scotland issued last week encourages NHS boards to have those conversations with partnerships in their areas in order to keep palliative care a high priority and to look at how their future plans will address the issues. The chief social worker adviser, Alan Baird, and I attended a meeting with all the chief social worker officers, and I met the health spokesperson for the Society of Local Authority Chief Executives. We have been doing that work to ensure that the various stakeholders and leadership groups that will influence commissioning in the local plans are not only aware of the framework but have the opportunity to connect. They have our contact details so that we can connect them with the third sector organisations and the areas that are a bit further forward with some of this work.

11:45

Malcolm Chisholm: In commitment 7 of the framework, the Scottish Government commits to working with stakeholders to

> "Seek to ensure that future requirements of e-Health systems support the effective sharing of individual end of life/Anticipatory Care Planning conversations."

We had some discussions on that topic with some of our witnesses. There are questions in relation to what is recorded. We had some issues around just how many different summaries there seem to be: emergency care summaries, palliative care summaries, key information summaries for anticipatory care plans, and so on. Also, who would that information be shared with? I am not really sure where e-health has got to, but to what extent will it be possible for that information to be widely shared and to have the necessary information on the record?

Shona Robison: I will let Craig White talk about some of the details around that but, in essence, the key people will require access to information. For example, we talked earlier about the possibility that someone who planned to stay at home could end up being admitted into an acute setting. Even with the best-laid plans, sometimes these things happen. It is important that information is available to the staff within that acute setting about the needs of the person, particularly if they are in an end-of-life situation. Craig, do you want to say a little bit about where we have got to with the palliative care register and so on?

Professor White: Yes. I will mention two areas that I have been involved with and then Janice Birrell can describe some of the specific conversations that we have been having with e-health colleagues about future systems.

Following the agreement to dismantle the quality and outcomes framework in relation to GPs from 1 April, we have reached an agreement with the British Medical Association and general practices that they will continue to maintain some of the disease registers that include palliative care, which are linked very much with the key information summary.

I have also asked that some of the clinicians working in community and hospital settings identify some of the issues that they encounter—not just things that work well with the key information summary but areas that need improvement, which is crucial information as we design the future e-health systems. Janice has been leading on that work in relation to e-health. Perhaps she could comment a bit more on the future commissioning of the new systems.

Janice Birrell: NHS National Services Scotland has been invited and commissioned to do a specific and rapid piece of work to make sure that, in its current state, the key information summary is being used and accessed. NSS will also look at how best practice could be spread because we know that, while in certain areas of Scotland the electronic key information summary is accessed quite frequently, it is more challenging in other areas.

Beyond that, a group has already met to start thinking through what the requirements might be around sharing the appropriate pieces of information across the health and care settings electronically. The group will consider what information about an individual and their care preferences it is appropriate to be able to access. Some of that information is captured on the anticipatory care plan and the electronic key information summary.

That piece of work has already started and colleagues in e-health are pulling together a multidisciplinary team that will include colleagues from health and social care integration to start teasing out what the requirements might be.

In the future, it might be that the key information summary is not the platform that is identified; it might be that more than one platform that is already in existence could be used. We are not yet clear about what the outcome of the exercise will be, but the work has started.

Malcolm Chisholm: We had a discussion about the palliative care register. Is it important to get more people on the register? There seemed to be different views about that, but it was unclear to us why so many people did not seem to get on the register, particularly if they had conditions other than cancer. Is that fairly crucial in terms of what you have been talking about, or is it not as central as some people might think?

Professor White: I guess that it goes back to one of the issues that we were talking about earlier: the need to have available the key elements of information that would allow conversations to take place. If key pieces of information about a person’s condition, medication, circumstances and care preference are available quickly, clinical and care staff can have the conversations that they are not able to have if it takes a long time to get the information or if it is not there at all. We have been told that, where the information is available on the register or is accessible and updateable in a secondary care setting, there is an improvement in conversations with people who are living with such conditions.

We did some work with NHS Lothian, where we found that medical staff were taking up to an hour and a half to locate information in different systems. The key information summary was not accessible, and there were information technology problems. We supported Lothian with some improvement work and it reduced that time to less than five minutes. The board subsequently reported a huge impact on the quality of care because staff could have an informed conversation with people who were on the register or whose information had been uploaded. We want to continue to support that link between e-health and point of care.

Malcolm Chisholm: I have one last question, on funding.

Cabinet secretary, you spoke about a review of hospice funding, and the committee raised issues in its report about the funding of the children’s hospice. However, there is a more long-standing issue that relates to the contribution that NHS boards make. We found it difficult to get information about that; it may be that there is not a common way of calculating the contribution, which makes it difficult to compare boards. The impression seems to be that some boards, if not a majority, are not contributing the 50 per cent that was agreed or required many years ago. Can you comment on the current situation and say what the review might involve?

Shona Robison: There are a few issues there. First, Craig White and Janice Birrell have had regular meetings with CHAS. I am sure that you are aware of this, but NHS Tayside commissions services from CHAS on behalf of the 14 boards in Scotland. There have been a number of joint meetings with NHS Tayside and CHAS, and we expect that the review of that agreement will be concluded by the end of the current financial year. We have had positive updates on how those discussions are going.

Secondly, on hospice funding more generally, we felt that it was important to announce the review of hospice funding as part of the implementation to address the disparity between children’s hospices and adult hospices, and to pick up on some of the wider issues such as the need to ensure that there is equity in the contributions. The review, which I would like to be concluded by the end of this year—and certainly no later—should pick up on all those issues.

Professor White: We are fortunate to have a hospice quality improvement forum in which many of the chief executives of the adult independent hospices meet. Through that group, and through discussions around our commitment to support clinical and health economic evaluations, we want to address the level of funding. We learned from the committee's work that it was very difficult to compare the position in different parts of the country because of the differences in the way in which data, including financial data, were collected.

You will know Professor David Clark from his report. My colleagues and I worked with Professor Clark on the framework. We have asked him and his team to complete a mapping exercise of specialist palliative care services across the country. That work will be available in April. We want to link that with financial data to have an accurate description of service and to evaluate models with our health economics colleagues.

Janice Birrell and I have visited several models of care. For example, I visited Strathcarron hospice, which is collecting financial data on its hospice at home service. That is part of our commitment to support health economic evaluation. We want to address some of those issues that your report highlighted.

The Convener: Do you think that that debate will encourage different models? There has been discussion about the number of empty wards in hospitals and the cost to boards if that increases, which means that they may consider providing palliative care wards in some of our general hospitals.

Shona Robison: We need to look at a range of models. There is scope for new thinking in the shift of focus to primary and community care, such as in the community hub model that we have been talking about, which brings together a range of professionals. The Clackmannanshire hub is already up and running and has some in-patient beds, some of which may well be for palliative and end-of-life care. In the north-west Highlands there is an agreement with a care home that is supported by a GP and nurses to provide palliative and end-of-life care in commissioned beds.

There are various models and it will not be a one-size-fits-all approach, because it might differ between more remote and rural areas, and more urban settings. We need a wider range of choices and, to ensure that the capacity is there, we will need more hospice at home and more community-based end-of-life palliative care beds. That is particularly the case when things happen that might not require someone to go into an acute bed but might mean that they need additional support that could be difficult to deliver in the home environment. There will need to be an expansion of those types of service and there will probably be a range of models.

The Convener: I am just flagging up the issue that increased contributions from health boards do not necessarily equal increased finance for specialist palliative care provided by hospices. The debate has tended to be around that point and whether the requirement has been met to fund 50 per cent of the running costs of hospices. Even if we get a greater focus from the health service and health boards, that will not necessarily equal money going into hospices; rather it will be for funding a broader model.

Shona Robison: The hospice movement will always have a key role to play, no matter what other services are developed—the hospice provision will always be a critical element. The point that I am making is that we will need more provision and there are models to be tested out. It will not be one size fits all and we will need greater capacity in all settings.

Janice Birrell: I saw one unusual setting, which was a mental health ward in a hospital, and hospital at home delivered the specialist palliative care element of that care package. I am not sure how the board captured that and fed it into its specialist palliative care spending under that budget heading. The care was delivered beautifully, but it was not clear how that spend was captured. That is where it gets quite complex. I think that the committee recognises that palliative care and specialist palliative care will be delivered across many settings. The difficulty is how you report those pockets and how they are funded.

12:00

The Convener: I do not disagree. I have identified an anxiety within the hospice movement. We are embarking on change. One particular value of hospices is that they are very well regarded in delivering such services. As any progress is made, having an Ardgowan or St Margaret's hospice badge—even if it is a badge of partnership—will be important for palliative care that is being delivered under different models in communities. It is also important to have those discussions with the hospices to say that they are part of the future.

Shona Robison: Absolutely, and I would want to reassure the hospices that their role is critical. However, we need to look at how we expand services and what the options are for different models. We also need to harness some of the opportunities that are presenting themselves. If we get the new primary care model right, GPs will have more time to spend with patients who need it, perhaps in palliative, end-of-life care situations. We need to look at it in the round.

Professor White: Linked to the theme of measurement, we have been talking this week about how we support the hospices to better use the data that they collect, so that they can describe the services that they provide. On enabling more people to access palliative care, we want to use the expertise in Scotland on data linkage so that, when someone is cared for by a hospice, we get the data on what care is being provided and can link that to our other information systems.

The committee will be aware of the work that was done by Marie Curie, based on English data, about the approximately 11,000 people in Scotland who might benefit from palliative care each year. For us to take that work forward in Scotland we have to have data linkage between hospices and other systems. This week, we think that we have identified a way to start—with speed and urgency—to link the data from the hospices and plug it in more effectively.

Fiona McLeod: I am aware that time is moving on, but I want to return to an earlier point. Rhoda Grant was talking about young adults and the support that we give them as they move through life. Janice Birrell mentioned respite that was available for young adults with long-term or life-limiting conditions who are living longer with those conditions. I know that you are doing some pilot work with Marie Curie, CHAS and Leuchie house. Do you have any timescales for reports on those pilot projects?

Janice Birrell: The first pilot was held towards the end of last year. I have not seen any of the outputs from that evaluation. A group of young men went to Leuchie house to trial a short respite break. I was at the meeting before the break took place and I know that Leuchie house was very keen to tease out what was required and what should be in place to help support that short break.

CHAS has been doing work to link in transition teams and has done some work in Highland to see how transition might look for young adults there. The CHAS team is looking at the current cohort but also at plans for youngsters who are coming up to that age when they need to transition on. That team has been in place for only a year and has done a huge amount of work in a short space of time.

Fiona McLeod: Can you keep the committee updated on that?

Janice Birrell: Yes.

Shona Robison: On my recent visit to Leuchie house, I was very impressed by the level of care needs that the team can manage. It is a great environment and they do a lot of activities and provide a very good-quality respite opportunity, but I was struck by the high level of need that they can manage, which is not the case in many other respite places. I was very impressed.

Fiona McLeod: Thank you.

The Convener: I thank the cabinet secretary and her colleagues for that very interesting session.

12:04

Meeting continued in private until 12:32.

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