HOUSE OF COMMONS

Health Committee

Oral evidence: End of life care, HC 805

Wednesday 28 January 2015

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Written evidence from witnesses:

- Macmillan Cancer Support
- Royal College of Nursing
- Royal College of Physicians
- Department of Health

Watch the meeting

Members present: Dr Sarah Wollaston (Chair), Rosie Cooper, Andrew George, Robert Jenrick, Charlotte Leslie, Andrew Percy, David Tredinnick

Questions 104 - 242

Witnesses: **Adrienne Betteley**, Programme Lead, Macmillan Cancer Support, **Amanda Cheesley**, Long Term Conditions Nursing Adviser, Royal College of Nursing, **Carolyn Doyle**, Lead Nurse, End of Life Care, Royal College of Nursing, and **Dr Kevin Stewart**, Clinical Director, Royal College of Physicians, gave evidence.

Q104 Chair: Good afternoon and welcome to the Health Committee. Could we start with you introducing yourselves to those who are following at home?

Adrienne Betteley: My name is Adrienne Betteley. I am end of life programme lead for Macmillan Cancer Support and have a clinical background as a district nurse.

Amanda Cheesley: I am Amanda Cheesley. I am the long-term conditions and end of life care lead at the Royal College of Nursing. My background is also in district nursing.

Carolyn Doyle: I am Carolyn Doyle, lead nurse for end of life care for North East London Foundation Trust, and also interim service lead for community nurses in Thurrock.

Dr Stewart: I am Kevin Stewart. I lead national quality and safety programmes for the Royal College of Physicians, including the national end of life care audit in hospitals. I am a consultant geriatrician by background and I still do some of that in Winchester.

Q105 Chair: Thank you, and thank you very much for coming this afternoon. Could I start by asking for your views on the terminology? We have called this inquiry the "End of Life" inquiry, but others have commented to us that we should be using the term "palliative care". There is some controversy and perhaps lack of understanding both from users and from those working in the services as to which term we should be using. Perhaps you could give your views at the outset about what we should be calling this inquiry. Should we be calling it the palliative care inquiry or the end of life inquiry?

Adrienne Betteley: There is an awful lot of confusion out there. There has been a whole shift towards calling this end of life care, particularly following the end of life care strategy for England. That very much came about because people were thinking about end of life care just being those last days of life, but there is real value in thinking about that whole much longer journey when somebody knows they have a life-limiting illness. For me, palliative care is much more about the approach that should happen even if somebody is still having active disease, for instance, with cancer. I do not know the right or wrong answer as to whether the inquiry should be palliative, end of life or even palliative and end of life care.

Q106 Chair: Is the risk that we end up excluding people who could be brought into better care arrangements by focusing on end of life?

Adrienne Betteley: No, not necessarily so. I do not know whether any panel members would agree or disagree with that.

Dr Stewart: From our perspective, palliative care has a very specific reference to a medical sub-specialty. The messages we are trying to give are that end of life care is everybody's business in every setting. A description of end of life care implies a much broader time span and a much broader responsibility, if you like, so we would favour end of life care over, specifically, palliative care.

Q107 Chair: Thank you. Carolyn, do you want to add to that?

Carolyn Doyle: What Kevin is saying is absolutely right. We absolutely need it to be everybody's business. Very often when people think of palliative care they think of specialist palliative care, and specialist palliative care tends to be provided by specialist nurses or our hospices, whereas end of life care is everybody's business and therefore needs to be a core component for all our community nurses and social care, with all those people working together to get it right.

Carolyn Doyle: I would concur with all of that and, wider than the health and social care professions, this is something we are all going to do—we are all going to die—and we need to start talking about it as normal. Rather than its being a cancer diagnosis or another sort of diagnosis, we need to get more people feeling comfortable talking about end of life as something that will happen to us all.

Q108 Chair: The consensus seems to be that we stick with end of life. Moving that on, do you feel we should have a better definition of what we mean in terms of time scales?

We have heard some people refer to the last few days. Could you let us know your views on that?

Adrienne Betteley: There seems to be fairly general consensus that end of life care, when it is referred to in all the strategy documents, is the last year of life, and I think the RCGP and others would talk about end of life being the last year of life, which is fairly helpful, other than for people who might have something like motor neurone disease whose prognosis might be three to five years. That is where some of the confusion can arise.

Dr Stewart: On the priorities, the care document talked about people in their last days or weeks of life, or some such phrase. End of life care for us is certainly about that, but it is a little broader as well, because, if we are trying to get to a situation where the public are thinking about end of life care in advance of having to make really difficult decisions, pushing the time span out in terms of the mindset is helpful for us. The last year or six months, when we know somebody has a condition that is probably going to lead to their death within that sort of time scale, is probably sensible.

Amanda Cheesley: I would agree with that. The RCN, certainly in the work we are doing, which I know we will probably talk about in a bit, is concentrating on it being the last year. I would also add that it needs to be individual. Some people who know that they have a life-limiting illness may want to discuss that with people much earlier than a year, so when we talk about it in its wider context it is about ensuring that we are discussing things with people at a time that they wish to discuss them, which may be two or three years before they die; some people may not want to talk about it at all.

Q109 Chair: Some of the witnesses to the inquiry made the obvious point that you can only say retrospectively whether someone was in their last year of life, and whether or not that misses the opportunity to have conversations with people. How can we guard against that? In other words, we would like to tease out in this inquiry how we make sure that we start those discussions and bring in as many people who are felt to be at an appropriate time to start them.

Adrienne Betteley: I am sure there is general consensus that the most important thing of all is around prognostication and communication skills. There needs to be a lot more work done around better prognostication, so that somebody is then informed that they have a life-limiting illness. The way that is delivered, to make sure that the person actually understands it, is vital and there are huge gaps in people's confidence in having those really difficult conversations. There has been a huge amount of work done nationally around communication skills training, but it is only, very often, touching the specialists, and actually it is everybody's business. When I think back to my nursing career, I think I spent one day every year doing fire training, but in all of those years as a nurse I never had a single—not one—session of communication skills training.

Dr Stewart: I wonder if perhaps there are two levels of thinking we want to engender about this. One will be for folks who we are fairly certain are going to deteriorate—for people who find themselves in that situation—and the other is for the general public, to try to raise the level of awareness about the importance of having discussions when people are otherwise healthy. We have probably made some progress in that respect, but that is more about society, isn't it, and society's view of death and the taboo around death? Maybe there are two levels of discussion that we need to have: more specific ones with

individuals who we think are in those specific circumstances and then a broader, wider public discussion.

Chair: Thank you.

Q110 Andrew George: The Liverpool care pathway was stopped on 14 July last year. Can any of you tell me, from your knowledge and experience, how widely it was being used as a tool in terms of end of life care, and in what kinds of settings? Was it only in the acute setting or was it being used in other settings as well, in which case can you say more?

Carolyn Doyle: In south-west Essex we did not use the Liverpool care pathway, but we used an integrated care pathway for the last days of life, which was very much based on the Liverpool care pathway. That was used in our acute trust, our hospices and in some localities in our community, where we were assured that education around the use of the tool was absolutely embedded in practice. What we did not want, and what we absolutely shied away from, was that people had a tool that became a tick-box, and that they were more concerned with the piece of paper than the person they were dealing with.

Q111 Andrew George: My question was intended just to get an idea of the extent of its use. I will come on to the failings and perceived weaknesses and so on in a moment. I do not know whether, for example, the Royal College of Physicians or the RCN, or perhaps even Macmillan, had an idea as to how widely it was used. Were more than half of acute settings using it?

Dr Stewart: In our audit, we looked at 6,500 patients who died in May and June 2013, and of that 6,500 about 50% at that stage were on the Liverpool care pathway, or a similar sort of format, and about 50% were not. That was shortly before the LCP was phased out. That was in acute hospitals.

Adrienne Betteley: That information is available. When the national end of life care programme team were in place they used to monitor uptake of end of life care tools, including the Liverpool care pathway. As an estimate, I would imagine that something like 80% of acute hospital trusts used it. Most community—

Q112 Andrew George: Eighty?

Adrienne Betteley: That is purely a guess, but we could get that information for you. It was also very widely used in the community.

Amanda Cheesley: And in hospices.

Adrienne Betteley: Most hospices would use a variation of it, and also a lot of nursing homes. That was led centrally.

Q113 Andrew George: That was a preface to a supplementary, which is to what extent there were, as Carolyn was saying, variations—using it as a template against other systems of care. I wondered whether it was being used religiously as a gospel to follow or as

a template in which parts were useful, and whether it was more widely used across all sectors than the 80% you have quoted.

Adrienne Betteley: Its use was very variable in all settings. There were some aspects of it that were very positive. I remember being a district nurse before the Liverpool care pathway and after it, and I was very much involved in implementing it in Cheshire where I worked. It made a huge difference to things like anticipatory prescribing of medication, because we used to struggle to get GPs to get medication into somebody's home. If people were in the dying phase, we had the drugs prescribed and ready to use. However, it did in some areas become a tick-box. In the Neuberger report, if you read that, the detail shows that in most instances care was at its poorest in hospital.

Q114 Andrew George: We will come on to that in a moment. In relation to the decision of the independent panel, do you think it was right to call for its complete withdrawal just because there were concerns about its use in some settings but not in all?

Amanda Cheesley: Because of the huge amount of extraordinarily distressing and adverse publicity, the Liverpool care pathway became too toxic to continue to use.

Q115 Andrew George: It was a public relations issue rather than a substance issue.

Amanda Cheesley: That is something that Baroness Neuberger very clearly said; in those places where it was used properly, with proper education and training for the staff in its use, it was extremely effective. But despite that, because of the amount of publicity—and many people had horrific experiences; I would be the first person to acknowledge that—it would have been very difficult to reassure people that its continued use would be better than had been put forward in the press.

Q116 Andrew George: I will not pursue that further. No one would disagree with the view that it was not necessarily the substance, although there were examples of poor practice or poor implementation in certain circumstances; it was largely a question of reassuring the public and taking action. Are you not concerned that the withdrawal of the Liverpool care pathway has left a climate of deep uncertainty and everyone is finding their way forward? We are six months into the period since and nothing has replaced it so far. How content are you with the current climate of uncertainty, or do you not think it is uncertain?

Amanda Cheesley: Certainly, from our point of view, in some areas there is definitely uncertainty. There were a number of people who expected there to have been some greater influence from the centre in terms of what would replace it. One of the reasons why it was not replaced was that it could have been perceived to be the Liverpool care pathway in anything but name. I have been all over the country in the last six months, and there are some areas where people have worked very hard to use the five priorities of care that "One chance to get it right" suggested people use as a framework. They have looked at the sort of things they want to put in place, in order that their staff understand their role in talking to people about end of life care, and then recording them. It is about assessment, the recording and sharing of information and everybody being happy and in agreement with those decisions. There are some places that are behind that and are struggling. That is largely due to the fact that nobody knew what the content of "One chance to get it right"

was until it was published at the end of June, and the Liverpool care pathway was withdrawn only three weeks later. There had been some hope in some areas that there would be more in that report that enabled them to take something forward than there actually was.

Q117 Andrew George: Adrienne, in Macmillan's evidence it is suggested that the Liverpool care pathway is still being used, effectively, but not in its name. I am not suggesting that they have taken the top sheet off and are just carrying on using it, but, in the absence of the ability to use the Liverpool care pathway, is it not true that there are many settings that are still applying some of the framework of the Liverpool care pathway? Your evidence suggests that anyway.

Adrienne Betteley: Some of the fundamentals are basic good principles for care anyway, so it is fine that people are using those principles, around communicating that the person is dying and so on. But there are areas that I know have almost tweaked the original document, called it something else and that is what they are using. That is very concerning. But, irrespective of what—

Q118 Andrew George: Why is it concerning? Can you explain?

Adrienne Betteley: Because it potentially will remain as is—that it is a tick-box exercise. At the end of the day, no matter what tool is used or what guidance is in place, fundamentally, clinicians are not confident enough in dealing with dying people, and that is mainly due to lack of education.

Q119 Andrew George: Presumably if you put a new framework in place, will that not soon be seen as a tick-box exercise? How do you avoid a situation where any replacement for the Liverpool care pathway is not perceived as a tick-box exercise which fails to look at the human being? Is there any way of doing it? Are you confident?

Dr Stewart: The feedback we get from our fellows and members is that there is a lot of variability in practice. Some places have adapted really well to moving on to new systems and some are struggling. It is undoubtedly more confusing for a lot of folks out there, where previously there was something more straightforward that they could follow, but it is probably a more confusing clinical area than they thought it was. We hear that people have extracted good practice from aspects of care which were covered in the Liverpool care pathway, especially around some of the technical aspects of care, stuff around prescribing and medication, which in our audit we found were done quite well. The difficulties, which again we found in the audit, are around some of the softer skills—the communication, the understanding and the involving of patients' families; that was not done so well. Our feedback is that the new framework is likely to be more difficult to implement because it has broadened the subject matter, but it is something that people are drawn to and understand the principles of, so I do not think they will just reinvent the pathway. It will take them longer to get to the place we need to be in, and possibly they need to understand a bit more that this area is a national priority, and that we see it as a national priority that is everybody's business, which it has not necessarily been to date.

Q120 Andrew George: You all have a national perspective; even you, Carolyn, I am sure, have a national view. Since you are experts in this field, have you not picked up where in the country there is very good practice, and should that not be exemplified and evangelised around the country, as it were, during this period of hiatus until a replacement is in place?

Dr Stewart: That is certainly something we have been trying to do. We work quite closely with Marie Curie, who funded our audits, and one of the things we have been trying to do is highlight the areas of good practice, along with Marie Curie.

Q121 Andrew George: Where are the places of good practice? Can you name and fame these places?

Dr Stewart: Off the top of my head, I think there is pretty good practice in Essex, but I would say that because I am sitting next to Carolyn. As I understand it, Marie Curie highlight good practice in Bradford, Sheffield, Liverpool and somewhere else I can't—

Q122 Andrew George: Liverpool itself.

Dr Stewart: I can't quite remember. But it is focused on their long history of supporting hospices in those areas, and of course Marie Curie's nursing service has been very well written up and evaluated by the Nuffield Trust. There is good practice. I am sure we could all do more to highlight that, but you are absolutely right that that is what we should be doing.

Amanda Cheesley: As part of that, when the leadership alliance met, one of the things we had was a sub-group who were identifying areas of good practice where people were already anticipating not using the Liverpool care pathway. One of the difficulties is the argument about us having robust evidence about the effectiveness of those areas rather than just saying, "This appears to be really good practice, and the patients and families are supportive of this particular way of working." But certainly I would echo Kevin in that. I went up to north Yorkshire very recently and they are doing a great deal of work across the dales, York and Sheffield, and had actually developed some really nice guidance. What was really good was that they had been working across health and social care, so there were shared information sheets and ways of working, involving the social care staff. It was good.

Andrew George: Thank you.

Q123 Rosie Cooper: Before I ask my question, I would like to make a comment—a question on the last few questions. I am somebody who believes that the Liverpool care pathway, in principle, is absolutely required. You talked about problems with communication and horror stories, but the reality is that the tick-boxes that you are talking about were not adhered to either. You are supposed to review withdrawal of fluids every so many hours, and people are not supposed to be on it for more than—I think it was—24 hours, or whatever the actual detail is; the horror stories said that people were not hydrated and it went on for weeks. Those ideas of communication meant that the patient, where able, or the families were not

told. This is fundamental. If you get it wrong, you affect the patient and the family to an absolutely horrendous level. My question would be: if you believe that the Liverpool care pathway by any other design, name or practice is going on, how do we know that the abuses, the misunderstandings and the lack of education are not going on under our noses now?

Amanda Cheesley: Bluntly, we don't, unless somebody identifies that it is happening, or you happen to be one of the brave souls—patients or carers—who jump up and down and say, "This is what is happening to my mum," husband, wife or whatever. It is very difficult for anybody, whether they be the CQC or us as an organisation, to say that is going on. It is horrifically worrying that these things could be going on, but it would be quite wrong for me to suggest for a second that there isn't somewhere they might be going on, because there will.

Q124 Rosie Cooper: But if we address that question, we address everything.

Amanda Cheesley: I know.

Q125 Rosie Cooper: For me, that is what makes it really horrendous. If we get people's responsibilities right, and they genuinely believe it, the rest of this is humanity at its best.

Amanda Cheesley: Yes.

Dr Stewart: I absolutely identify with what you are saying. The issues around communication and understanding—the technical aspects around the communication skills required—are difficult. I have done this hundreds of times and I still find it really difficult. I have taught it hundreds of times and I still find it really difficult. The emotional aspects around it are really difficult, and what we found in our audit was that a high proportion of trusts do not offer any training at all; I think somebody said, "I have never been trained in this stuff." We are expecting people to do it as common sense, but the evidence is that people can be trained and people need to be trained. Trusts need to take the issue seriously. Only about 20% of trusts make training in end of life care mandatory, and 20% of trusts do not offer any training in end of life care. We have a long way to go. We have done quite well on some of the technical aspects, but we have a long way to go on some of the softer skills. The framework around that can create the atmosphere, but we have to do the technical bit around the training and the trust taking it seriously, with a trust board member with responsibility for end of life care, a report to the trust and an annual audit—I would say that, wouldn't I, since we run them? But the national clinical audit of end of life care to date has been funded by charitable donations. It has not been part of the national programme for audit. All those things will help us.

Q126 Rosie Cooper: Brain surgery and heart surgery are difficult and we train people for that, so there is no reason why not.

Dr Stewart: All these areas are important, but this area is obviously very important—very important to the public, to our patients and to clinicians.

Carolyn Doyle: It is more than just chalk and talk education. I am a nurse at heart, and it is far more about how you connect with other human beings. Sometimes we learn that from other role models and people that we witness throughout our career. It is not always about knowing the academic underpinning; it is about our staff having an opportunity to see that really going on for a person approaching the end of life, and their family and the nurse interacting with them, but they do not always get that opportunity. In a lot of the education we run, we try to give people a safe environment in which they can practise those skills. Sometimes that is not seen as hard academic learning, but nursing and caring is fundamentally about interacting with other human beings and giving people what they need when they are at their most vulnerable.

Q127 Rosie Cooper: Thank you very much for that. Now, my correct question. The inquiry has been told that health care staff in too many cases fail to offer specialist palliative care to people who are approaching the end of life. That is particularly true for conditions other than cancer—dementia, for example. Why does the NHS struggle to identify people in the last phase of life who would benefit from specialist care?

Dr Stewart: It is difficult. I know that sounds like a bit of a glib answer. In our audit, 23% of patients who died had cancer and 70-something per cent had COPD, heart failure, dementia, stroke or were frail elderly people with multiple problems. It is more difficult; it is less well defined. The course is more uncertain in non-cancer conditions. To date, we probably have not thought enough about non-cancer palliative care. That is changing now, but it has taken longer than it needs to change, to think about making decisions in a less certain environment. Recognising when somebody is dying is probably less certain in non-cancer conditions, and understanding the prognosis is less certain. It does not mean we should not try hard to do that, but it is more difficult.

Q128 Rosie Cooper: I can appreciate that it is less certain, but as a clinician directly involved with patients, looking at co-morbidities, or whatever it is, you will start to see the clock ticking; you will see it. I do not understand why that tick does not arrive in your head, or somebody's head, so that a person can be offered specialist services. Do you think the clinician does not make that connection, or do they feel that the services are not there or they are overloaded? What is the reason? I don't believe that you don't know.

Dr Stewart: I have been doing this long enough that, hopefully, I probably do know most of the time, but there are times when I do not, and there are times when I think I know and I have got it wrong. Most experienced clinicians will say the same to you. It is difficult. There will be clinicians who do not know—people with less experience and so on and so forth. But when that thought comes to you, it is quite difficult to broach the subject with the patient or with family members who might be thinking something different. It is almost easier for the system to carry on and do things than to take that step back and say, "Shall we look at the big picture here?" I recognise your frustration. It is just very difficult to do; it takes time, experience and some training—all the things that we have talked about.

Q129 Rosie Cooper: That little bit of extra difficulty would be of immeasurable help to the family and the patient in all probability.

Dr Stewart: Yes, absolutely. Where it is done well, all those things happen. We are making some progress, but we have an awfully long way to go; I understand that.

Carolyn Doyle: It is done well when we have a central person co-ordinating what is going on for that person; you have a named clinician who works with the family, builds a relationship with the family, and navigates and supports the person through the system. It does not work well when you have lots of different people dipping in and it becomes disjointed. For a good outcome, you need an absolute, good co-ordinator, a person who can navigate through the systems that are out there.

Q130 Rosie Cooper: Who would that person be?

Carolyn Doyle: Personally, I think primarily it should be the community nurse. However, in a way you almost need to have a conversation with the family and work in partnership with the family to enable them also to identify who they are building up that relationship with. I know I am sitting in an area where we are not going to have that many trained district nurses in the system, because lots of us are approaching retirement and will not be around for that much longer—I do not mean I am going to die.

Amanda Cheesley: Physically, you're going to be here.

Carolyn Doyle: I will be here physically, but I may not be here in a practitioner role. As a district nurse you have the life skills, the academic background and the humanistic skills to be able to connect with people and direct them through, and also to support your staff, because it is about good leadership too, and how you support your staff to get the skills to be able to go forward, which might be through role modelling, with them working alongside you and experiencing that.

Adrienne Betteley: Some of this is historical. Palliative care had its origins in supporting cancer patients, and there has been a big shift to broaden that to encompass looking after people with whatever condition, but there is still long way to go. I hear it said an awful lot, "Oh, you've got it right for cancer," but actually, no, we haven't got it right for cancer. I can speak from very personal experience; my mum died of cancer last year and there were huge issues around pain control and things like that. People are still not always referred to specialist palliative care; it is not always identified. We need a consistent approach to everybody who is in those last months or year of life.

Q131 Rosie Cooper: That is a really big sentence in the sense that you have just said, "People are still not referred to specialist care." The question I would ask you is how and why? How do we stop it, and stop it now, because that is ridiculous?

Amanda Cheesley: We have done a survey fairly recently of nurses and some of it is that clinicians—I use that in its widest sense—are sometimes very reluctant to admit that somebody may be approaching the end of their life. There is a whole ethos within health care about treatment, rather than actually talking to people about what they might like in terms of the best quality of life for the remainder of their life. Adrienne is right: palliative

care is still perceived by non-palliative care or non-specialist end of life or cancer nurses, doctors and people as being only for particular diseases. In particular, frail older people, people with dementia and people with coronary heart disease who are dying are often outwith the palliative care system anyway. There are not the same links as there are with cancer patients, so there is not the automatic thought, "Perhaps a palliative care team could give us some advice on this," and they are often sitting in specialties which are, again, outwith the system. If you have motor neurone disease or MS you are with the neuro services and sometimes those links are not made. I know it is not an excuse; it is just what is happening. In some of the rarer conditions we do not know enough about them as general jobbing workers, and therefore people do not always do the right thing. They often do not do the right thing.

Chair: Thank you.

Q132 Robert Jenrick: Can I follow on by asking about the different settings in which people face the last period of their lives? Following on from Rosie's question about people with dementia and care homes, of all conditions it seems that we are not particularly good at providing palliative care to people with Alzheimer's and dementia, especially in care homes. Why is that and what more could we do to give the staff who work in care homes more training, confidence and support to provide better end of life care?

Adrienne Betteley: Care homes have a very transient work force who are very poorly paid and are never, or not very often, allowed time to access education and, if they do, they have to do it in their own time. Those are some of the flaws within that care sector. It goes back to my point about education being fundamental to all of this, but it is also about giving care home staff the support to have that education.

Carolyn Doyle: In reality, we provide a lot of educational support for care homes. However, you can provide that education on a Monday, and the following Monday the staff members will have changed. That is fact. We know that staff working in care homes move jobs; they are transient, as Adrienne was saying, and it is hard to engage with them. They want to engage with us, but you almost need—and we have looked at this—a passport of education that people who work in care homes can take from one care home to another, because they learn those skills; those skills do not disappear. We are just not good at putting a system in place that supports them. I do not think we always value staff who provide care. We really engage with our care homes where I work, but across the board, if there was an incentive for everybody to work alongside care homes so that you become one team co-ordinating a person's care, people would get a much better package, and it would not be so fragmented. But I think staff in care homes feel undervalued.

Dr Stewart: We do not have a lot of evidence from care homes, but from my clinical practice I can say that I agree with everything that has been said. There are issues, probably out of hours and at weekends when staffing can be particularly difficult and there can be a number of agency staff. The pressures on care homes are probably to send people to hospital if there is a concern, especially on a Saturday night or whatever, rather than take a risk. They do not always feel they have the level of medical support out of hours. Often they do not have the level of experienced nurses present out of hours. All those things contribute to poor quality of care for a group of patients with dementia but who, of course, often have three, four or five other chronic conditions as well.

Amanda Cheesley: The other thing about care homes outwith that is that, by their very nature, many people who go there are frail elderly and have dementia, and there is almost an assumption that for some reason they do not need to talk about their end of life care wishes or preferences. It is not always something that is discussed when people go into a care home: "Who are the people who are important to you? What is important to you?" It is the old Marmite or marmalade analogy, but it is really important to know about who that person is and I do not think that all care homes have that ethos. I have been to some fabulous care homes that provide the most stupendous care for the people who live there; it is their home. They would not dream of sending somebody to hospital who did not absolutely have to go there. They give their staff training; they are doing the gold standards framework. They are absolutely out of this world. Sadly, there tend to be very few vacancies in those care homes, and very often people with dementia or frail older people are sent to care homes from acute settings because it is quick and easy to get them out, and their care home is not necessarily chosen as being the best place with the most appropriate care for their needs at that time. That is not a reflection on the care home itself; it is a reflection of the system—that the default position is very often either that you send them back to a care home which was not coping, or if they came from their own home, they are sent to a care home, because they cannot put a package of care together to keep somebody in their own home. For me—this is a big soapbox—it is iniquitous to send somebody to a care home from where their home has been for 60 or 70 years and they never see that home again. That is iniquitous, but it is happening.

Q133 Robert Jenrick: Dr Stewart, you raised the question of many care homes sending their residents to hospital perhaps unnecessarily, although understandably, because they do not have the confidence, or they are concerned about liability or they do not have access to support from doctors or community nurses. What more could we do there? We have all seen circumstances where a care home has perhaps unnecessarily sent a patient to hospital, effectively to die.

Dr Stewart: There are of course times when people come completely appropriately from care homes. There are models of good practice in different parts of country. The models of good practice that work best are where the care homes are well supported by local NHS teams, either from secondary or primary care, with community staff, where they know perhaps that there is going to be a routine medical review, not necessarily at the weekend, but on Monday morning, so there is going to be somebody to help. There is proactive planning, often led by—I would say this, wouldn't I?—a consultant geriatrician; it does not have to be a consultant geriatrician, but somebody with skills, experience and common sense who can help to set in place anticipatory plans. There are models of good practice that we know about, and where it works well, it works really well, but it is incredibly variable.

Carolyn Doyle: We saw that our care homes were sending people into hospital, very often inappropriately, so we joined ranks. Our commissioners bought into a partnership service. Macmillan nurses, Marie Curie, the local hospice, and our commissioners all worked together to set up a 24/7, 365-days-a-year service so that people in care homes, when they are concerned, have somebody at the end of the phone who will be able to give them advice. We also send our night district nurses in to support that community home if need be. The problem is that no one organisation could commit to that service on its own,

because it takes a huge resource, so you have to have a joining of hearts and minds in order to fulfil your role in that. It is working amazingly; it is working really well. I know that is going on in various other parts of the country as well.

Q134 Robert Jenrick: Thank you. Can I follow up with the other settings? Hospital is obviously the place where the majority of people end their lives, but it is also, proportionally, the place we get the most complaints about the end of life palliative care that patients receive. There are many reasons behind that. Clearly many people enjoy spending the last period of their life at home surrounded by family and friends, so it may be about more than just the quality of care they directly receive. The setting that receives the greatest feedback, to the extent that you can rely on the statistics, is hospices. What more could hospitals learn from the experience of hospices about how to carry out good quality palliative care and end of life care?

Dr Stewart: Our work was all in hospitals. The figure is that about 50% of people die in hospital at the moment. Our message has been that this is core business. Access to training, which we have already talked about, is incredibly variable and some hospitals do not offer that at all. Access to specialist palliative care in hospital, particularly out of hours, is limited. We found that only 20% of hospitals provided face-to-face palliative care support seven days a week. Most people provided it Monday to Friday, nine-to-five, and at weekends there is either telephone advice or nothing. One thing we can learn from hospices is the expertise of the palliative care team to support front-line clinicians in a hospital when they have difficult decisions to make, but that is not going to be there all the time. For us there is something about trusts taking this issue seriously and seriously reconsidering palliative care staffing seven days a week. There is definitely something about training and about the leadership of the trusts taking the issues seriously—the trust board. We know that the issues trust boards pay attention to are issues that front-line staff pay attention to as well. There are all those things. For us, as we said earlier on, this is everybody's business, across all sectors. It would be a mistake for us to say that everybody needs to be looked after in a hospice or everybody needs to be looked after by specialist palliative care, but this is core business for everybody; we all need some of those skills.

Q135 Robert Jenrick: The statistics show that half of all complaints to the parliamentary ombudsman featured poor communications as one of their themes. That takes different forms, whether it is communication to the patient or their family, not updating the patient about their prognosis or the inability to see a doctor or a consultant, maybe at weekends, which might happen to be the last few days of someone's life. What more can we do to tackle that particular problem in hospitals?

Dr Stewart: Again, we found that about three quarters of family members fed back that they had had a satisfactory experience and would recommend the trust to family or friends. About a quarter were unhappy and a percentage were very unhappy. We are very concerned about those people particularly, because this really is only one chance, isn't it? At the risk of repeating myself, some of it is about having the time, some of it is about having the skills and some of it is about having the emotional energy. We found that quite a lot of staff will not engage, because they are uncertain, and, if they do not have the skills and they have not had the background and training, they are likely to try to avoid having

the conversation. It is always difficult—I am sure you would feel the same—to try to answer a question that you are not really confident you know the answer to. That is the technical bit. We talked earlier about there also being an emotional bit: it is obviously very difficult for families and patients, but it is also difficult for staff. Thinking about death is something we all try to avoid, if possible. It is a whole combination of things. I am sorry that is not a straightforward answer.

Adrienne Betteley: I totally agree with everything you said, Kevin. Going back to your earlier point about the fact that death is a taboo in society, we need to take a public health approach. We have some great examples where organisations are coming together to take that public health approach and trying to encourage much more open discussions about death and dying, because that helps the individuals who are experiencing it, and also the professionals. Sometimes it is about facing their own mortality, which is quite challenging.

Going back to your question about hospices and what hospitals potentially can learn, although it is not something that we are involved in, there is a fantastic programme in the Republic of Ireland called Hospice Friendly Hospitals. They have taken some of the principles and tried to embed them throughout the hospital, but they have done an awful lot of education. I am sorry that is the word I keep using, but it is fundamental and that is where it is lacking.

Amanda Cheesley: To add to that, there is a huge issue still about information sharing. Going back to your bit about communication, people do not get the information they need about what people have expressed they want, such as, if you are going from home into a hospital, that you did not want to go there in the first place. We use IT and information sharing confidentiality as a reason to not do things. Having been involved in the painful process of NHS IT some years ago, we still do not have IT systems that talk to each other. It is not beyond the wit of man to have a care plan in my hand when I go somewhere and say, "I do not want to be here," and somebody saying, "Okay, we will get you out again." That is not happening. The communication has to be about properly held records that people have access to, so that absolutely everybody knows what has been talked about, who wants what and what is not going to happen. Then everybody is signed up to that. It is about good record-keeping, good conversations and good recording, hearing what people are actually saying to you rather than assuming that you have understood what they said.

Robert Jenrick: Thank you.

Q136 Andrew Percy: I am going to ask about district nursing. The BBC reported that from 2003 to 2013 the number of training places had reduced by 40%, and I think it is now down by 44%. Figures in our brief show that in the last year only five students took up graduate and postgraduate district nursing training courses in London universities. I looked into NHS England's response on this and they state that it is because district nurses have been replaced with other community roles. It seems a bit odd at a time when we are talking about moving care from hospitals into the community that we have fewer district nurses, yet we have more hospital nurses. It seems counterintuitive, although, obviously, the pressures we all know about exist in hospitals. That figure looks very concerning. Is it as bad as the figures suggest—that we have lost all these district nurses—or have they been replaced by other

roles? What is your perception about where we are at in terms of district nursing and other roles, and so on?

Amanda Cheesley: I think it is dire—absolutely dire. If you are replacing somebody with what is called a community nurse, you cannot just move out of hospital and become a community nurse. Well, you can; you can have a title. District nursing training gives you really good additional skills. I did a year and a half's training for my district nursing training. It incorporated end of life care and all sorts of good communication skills. This is not in any way to denigrate somebody coming straight out of the hospital into the community, but they absolutely do not replace a skilled and experienced district nurse. They are often at a relatively inexperienced level of their career. They often may be a band 5 nurse who is a couple of years post-qualification. You cannot compare them to somebody like Carolyn who has 30 years of experience and all of that expertise to share, both with the people that she is caring for but also with those people.

Part of the problem is also about the training. The reason a number of people do not take up training is that, often, they have to take a lower band in order to undertake it. You may be at one level of training in your hospital or the place where you are working, but most of the training is provided at a lower band. If you have a big mortgage you are not going to be able to do that. I am not going to go on about pay, but it is a factor in attracting people into undertaking that further qualification.

Q137 Andrew Percy: So a district nurse who is replaced with a community nurse—sorry, my words are not coming out very well.

Amanda Cheesley: I am having the same problem.

Q138 Andrew Percy: I am not very clever. You stated that the pay band is lower for a district nurse than a community nurse.

Amanda Cheesley: Vice versa.

Q139 Andrew Percy: But during training—

Amanda Cheesley: You may have to take a significant pay cut in order to undertake the training because you are under a training contract, which for some people is fine, but other people cannot manage to do that financially.

Q140 Andrew Percy: It looks very alarming. I think we talked about this last week in terms of the rapid decline in district nursing numbers. It looks pretty poor, which is why I went away and had a look, and saw that NHS England's line on it is that they have been replaced by other roles. In terms of somebody who is being cared for at the end of their life in the community, what difference do they see when it is a community nurse compared with a district nurse? What skills are lacking? It is all about patient outcomes, so what impact does it have in terms of the patient at the end of their life?

Adrienne Betteley: Can I give a practical example from personal experience? When my mum was dying at home in an area where I used to be the district nursing sister—I did a

12-month specialist practitioner degree course in district nursing following years of experience working in hospital—what would have been my old team of district nurses had all left and been replaced by very junior and inexperienced community staff nurses. There was a mix within the team, but the ones I was seeing on the coal face were very inexperienced. On one occasion I asked them to catheterise my mother because she had retention of urine and was in a lot of pain. They said, "No, just put a pad in; she'll be all right." Later in the evening I called out the evening service, and a very experienced, qualified district nursing sister did a full holistic assessment, catheterised 1,400 mls of urine and relieved my mother's agony. The difference in their whole approach is what makes the difference between a qualified district nurse and a community staff nurse.

Q141 Andrew Percy: But surely a community nurse should know how to catheterise somebody.

Adrienne Betteley: They should know how to catheterise but they may not even realise that the person needs catheterising. It is lack of experience and skills.

Q142 Andrew Percy: This may well be an area, when we come to write the report, that we have something to say on, but we need to be clear about what the impact is in terms of the patient. In that example, a community nurse should know how to do that as much as a district nurse. I want to be really clear on what the difference is in terms of training and what impact that has on the patient in their own home as to their outcomes.

Amanda Cheesley: There are two things. One is the requirement to have had a significant amount of experience at a certain level before you undertake the training, and the second is that the training incorporates very advanced decision-making skills, very advanced clinical decision-making skills and advanced communication skills at a level that is much more significant in terms of having difficult conversations and raising conversations. The assessment skills would have enabled the person to say, "This person's bladder is really full. They are obviously very uncomfortable; therefore we need to catheterise." They often are able to prescribe medication so they can alter medication there and then and sort it out, rather than going back to a doctor and saying, "Could you please prescribe this medication?", or whatever. They can actually initiate treatment very quickly, even to the extent of setting up an IV antibiotic—a drip with antibiotics in—if that is required. Those are the sorts of advanced decision, clinical and communication skills that you learn when you do that advanced training.

Q143 Andrew Percy: I would be sympathetic to that. Given that this rapid decline in district nursing numbers has been happening for more than a decade now, any evidence or datasets that directly link that with a poorer outcome or patient experience would be very helpful to us. Can you remind me what the Royal College of Nursing's—I will not say demand—request is on district nurses?

Amanda Cheesley: We want loads.

Q144 Andrew Percy: You want lots of them. You have a very clear position on this, don't you?

Amanda Cheesley: Absolutely. There needs to be much more emphasis on training people to have those advanced skills, and rapidly to try to address the significant decline— with further to come. There are an awful lot of district nurses who are in their middle to late 50s who are likely to be retiring in the not too distant future. It is about that whole succession planning.

Andrew Percy: It does seem counterintuitive, given that the conversations are all about moving care outside hospitals, to then have people being treated by nurses who are less well skilled at the very time when we need them to be better skilled. That is a comment, not a question, so I apologise, Chair.

Chair: Thank you. I know three members would like to come in very briefly—Robert, Andrew and then Rosie. We will start with Robert, just a very short question.

Q145 Robert Jenrick: While we are on the topic of patients being at home, can I ask about a very specific issue that was raised in the course of the inquiry? Obviously a lot of people would like the opportunity to spend the last period of their life in their own bed, for a lot of reasons; often they are comfortable and there is a sense of security and memories. An issue that has been raised with us is that a lot of patients are not able to do that because they are recommended by hospitals and doctors to have a hospital bed, and there are waits for those. If they do not live in a large house, they cannot even get it through the door and upstairs, and sometimes it is put in the front room of a small terraced house, which is pretty undignified and takes all of the potential security and dignity away from what might have been just making the decision yourself to die in your own bed even if, to a medical practitioner, that is not an ideal scenario but is what people actually want. Do you have a view on that and what we might do to change that culture?

Carolyn Doyle: You are absolutely right. Sometimes the issues around getting a hospital bed are contentious and they are not always necessary. If you have discussions—the majority of the questions that we have been asked seem to come down to having those open and honest discussions with people—people can absolutely die in their own bed, in their own bedroom with their partner, and do it their way; and we should be striving to ensure that that happens. We get fixated on people having to have a hospital bed. There are risks if you do not have a hospital bed and the proper equipment; you may develop pressure ulcers and things like that, but if you give people all the information and allow them to make those choices, then, absolutely, we should be supporting them. We should not be turning their homes into mini hospitals, because they want to be in the place they feel most safe with their families. I came from a trust, a long time ago, where we used to put divan beds on blocks—we did not have hospital beds in people's houses—or we got a double overlay. You had to be creative. I suppose that brings us back to what Amanda was saying about having a district nurse, because as a district nurse you build up the confidence to be able to say, "Hang on a minute, we can take this person home. We don't need a hospital bed. We can adapt their own bed." They know the risks and we know the risks, and we are willing to take them. I think we get sidelined.

Chair: Thank you.

Q146 Andrew George: Because of time, I will direct this at Amanda. In relation to your earlier comments, on top of nursing, it is also about integration with other community services, particularly GPs or other doctors who are able to prescribe things which nurses cannot prescribe and administer high-end drugs for pain relief and other things. There are many examples where patients who are in their homes or nursing homes do not get support, or are living in great pain because of the failure of intervention of doctors, even though nurses are available. Is that not true—that it is not just nursing?

Amanda Cheesley: It is true and I think there is still a misunderstanding with a lot of people. I have to say, going back a very long time, that Harold Shipman did a grave disservice to the management of people's pain in that there is still very real anxiety for some people about giving high doses of very strong opioids, and therefore they do not necessarily prescribe the right doses. Some nurses are able to prescribe those medications, but there are still places where people are definitely dying in pain because of inexperience in what sort of doses and medication can be safely prescribed. The other thing is making sure that those drugs are in the house in anticipation of a potential deterioration in somebody's condition so that you are not rushing around at two o'clock in the morning trying to find things.

Q147 Rosie Cooper: Going back to Andrew's question and the different attitudes to training, you mentioned that you probably need to take a lower band to train to be a district nurse. I wonder, on the record, if you would contrast the NHS's financial approach to training district nurses with that of nurses doing masters degrees.

Amanda Cheesley: No.

Q148 Rosie Cooper: A nurse doing a masters degree is doing extra training for a future role, but I do not believe that they lose pay for taking time out to do it.

Amanda Cheesley: No.

Q149 Rosie Cooper: Yet if you want to train to be a district nurse you take a lower band. Why does the NHS not make up the gap?

Amanda Cheesley: I cannot answer that question. I do not know.

Q150 Rosie Cooper: Does my question make sense?

Amanda Cheesley: It does, absolutely. Often the district nursing training is usually wholly funded by a trust or a clinical commissioning group. To do a masters degree, very often the nurse may well pay a component part of those modules themselves and therefore there is a negotiation between them having time off for study leave, a part payment, and them doing those modules, whereas the district nursing course is one year out of the workplace per se. The way that it is funded has always been different actually, but in answer to your question, I do not know why.

Q151 Rosie Cooper: To address Andrew's end result, that is, if we want more skilled people in that role out there in the community—

Amanda Cheesley: You have to pay for it.

Q152 Rosie Cooper: If that is where you are going to focus, this is the question we need to look at.

Amanda Cheesley: Yes.

Rosie Cooper: How do we get those nurses trained without them losing pay?

Q153 Charlotte Leslie: I am sorry for having to nip out and come back in again a bit late. I want to talk about the competence of the work force that exists. Where there are specialist palliative care teams, how integrated are they within acute medical wards? Are they doing ward rounds? Are they in A and E? How are we using our specialist palliative teams?

Dr Stewart: Is the question about hospitals?

Charlotte Leslie: In acute settings, yes.

Dr Stewart: In some places, they are very well integrated, but in many places they are not. Some of that is traditional, because palliative care services have often traditionally sat in hospices, which are either completely funded by voluntary charities and other sectors, or part-funded. I would say that only in the minority of organisations is palliative care integrated in the day-to-day working of the acute hospital. In most places it is not. Of course, we said earlier that only 20% of trusts provide face-to-face palliative care seven days a week. Whatever happens Monday to Friday in most places, it is not happening on Saturday and Sunday.

Q154 Charlotte Leslie: Is there any desire to learn from any—I hate this phrase—best practice spreading? Is that going on, or is it quite a static situation?

Dr Stewart: There is best practice in some places. but the recommendation that there be seven-day-a-week, face-to-face palliative care services in hospitals as standard has been there for some years and has not really been taken forward, we think, because this area has not been a priority for trusts. Trusts have lots of priorities, don't they, but we do not think this has been an important enough priority for them?

Q155 Charlotte Leslie: Some of the evidence to this inquiry has already suggested there should be more dedicated palliative care units within hospitals. Is that a suggestion you would support?

Dr Stewart: I do not think that is the whole answer, because we think that risks moving away from "This is everybody's business." For us this is everybody's business—the generalist physician, the specialist physician, the generalist nurse in hospital, in the community and in palliative care. We need to go to specialist palliative care for advice and

support, but our view would be, if they are embedded within hospitals, that is for advice and support for the work force and for managing some very difficult situations as opposed to managing all patients.

Q156 Charlotte Leslie: One thing that seems a bit ironic—correct me if I am wrong—is that sometimes hospitals suddenly focus on palliative care when their mortality rates do not look so good, and entire wards are turned into palliative care units overnight when someone comes in and advises. Is that something you have found frustrating—that it becomes a sort of excuse for statistics that perhaps could be better?

Dr Stewart: That is not something I have found. If you have found it, that is good, but it is not something that I have found. It is not something that we hear at the college.

Adrienne Betteley: I would totally agree with what you say about it not being the answer because, at the end of the day, you might well put 10 specialist beds into a hospital but actually it is almost—excuse the pun—like creating a bit of heaven for the few, isn't it, whereas what you really want is good end of life care across a whole hospital trust? It has to come from the leadership, as you have already said a few times, Kevin: we need that trust board buy-in. There are some examples: NHS Improving Quality have had a really good programme that is about transforming end of life care in acute hospitals, and one of the principles of that is getting buy-in at trust board level and having a lead person who is responsible. That is fundamental.

Amanda Cheesley: I would agree with all of that, and just add that I do not think it matters altogether where the palliative care team sits. It is about having access to their expertise as and when it is needed, wherever it is needed.

Q157 Chair: Thank you. A final question for this panel is about "Do not attempt cardiopulmonary resuscitation" orders. We have received evidence that 80% to 90% of people who die in hospital die with one of these orders in place, but there seems to be a great deal of variation in both how they are interpreted and how that impacts on people's care and also how they are recorded. That seems to be the subject of a number of complaints. Could you comment on how you think we should be recording them differently? Do we need a national database or more consistency and a clear message about how people with those orders in place are treated?

Dr Stewart: I am not sure we need a national database, bearing in mind we have already alluded to IT issues.

Q158 Chair: Yes, but do you know what I mean?

Dr Stewart: Yes, I know exactly.

Q159 Chair: In some countries people can record these decisions and adapt them themselves.

Dr Stewart: Generally speaking, "Do not attempt resuscitation" orders are used more now than they were in the past, and that is a good thing because it means that people are being engaged more than they were in decisions about one aspect of their end of life care. Where they are used well, they can be incredibly helpful and they can help open up the broader discussion about wishes in the last days and weeks of life. Where I work in the south of England, there is a standard format for recording DNACPR orders across community and hospital settings and it seems to work well. Quite often we see folks coming into hospital with an order in place; the GP has had the discussion, the family have been involved and the family will draw our attention to it. Where it works, it works well. We probably need to promote models of good practice. It has the same disadvantage that any sort of document has to it—that there may be a temptation to go through the process of ticking the boxes as opposed to doing the underlying requirements as well as they should be done. But I do not think it is a problem with the documentation; I do not think it is going to be solved by a national database, sorry.

Q160 Chair: There is nervousness, isn't there, among some patients and families that once one of these orders is in place they might be written off, if you like, and other aspects of their care might not be advanced or investigated because they have that label? Do you think that is a concern? Are they right to be concerned? Is there any evidence that it affects their care?

Dr Stewart: It is a concern for patients and their families. I have been working on this sort of area for a long number of years and it is less of a concern now, as members of the public become more aware of what it means and what it does not mean. I think we have probably become slightly better at explaining what it means and does not mean.

Q161 Chair: Have you come across any evidence in hospitals that those patients who have "Do not attempt resuscitation" orders on them have less good care in other aspects?

Dr Stewart: No.

Q162 Chair: Have you come across any evidence of that at all?

Dr Stewart: No. We have a big database and we have not found that, and I am not aware that it has come out in work anywhere.

Q163 Chair: Do other members of the panel want to comment on that issue about recording and consistency?

Amanda Cheesley: Kevin is right; there are inconsistencies and there are misunderstandings about what it applies to. There are nuances with it as well, because it may be that you do not want be to be resuscitated in some circumstances, but if, for example, you inhaled a pea, you might want to be resuscitated. I know that is a bit flippant, but it is important that people recognise that there are nuances. A lot of clinicians struggle with initiating the conversation about, "If such and such happens, do you want to be resuscitated or not?" We have done some very recent guidance: the RCN, the

Resuscitation Council and the BMA only in October launched some new updated guidance for clinicians around how to have those conversations, with examples of paperwork and things. But it is also something that has had some recent bad press, with Roy Lilley's mother and the nurse who did not know her going in and just initiating it: "By the way, do you want to be resuscitated?" That is absolutely not the way to do it. If you have an opportunity to build up trust with somebody, it is a conversation you can have. There are times when it is very challenging, particularly for people in A and E or in ITU when it may be a very traumatic event and you are asking those questions. Sometimes it is about the planning and the communication.

Q164 Rosie Cooper: I understand that, but, for clarification, a DNACPR notice cannot just appear on somebody's notes. Do you actually document who you have spoken to and who you have agreed that with?

Dr Stewart: Yes.

Q165 Rosie Cooper: Always.

Dr Stewart: On our standard format there is a requirement to say who was involved in the discussion and if nobody was involved in the discussion to state that, and state why they were not involved in the discussion and so on and so forth.

Q166 Rosie Cooper: For what percentage of DNAs would you say there is no discussion?

Dr Stewart: Off the top of my head, I cannot tell you. There will often be logistical issues about contacting people, finding who the next of kin is, and so on, but in practice, most people will understand the need to get involved in a discussion very quickly, if not with the patient themselves, as the patient is often not competent to be involved in discussion, with a family member, and we will try really hard to get a family member. Sometimes it is very difficult logistically to do that.

Chair: Thank you very much for coming this afternoon.

Witnesses: **Rt Hon Norman Lamb MP**, Minister of State for Care and Support, Department of Health and **Dr Martin McShane**, Director for People with Long Term Conditions, NHS England, gave evidence.

Q167 Chair: Thank you very much. I am sorry to have kept you waiting.

Norman Lamb: No problem.

Q168 Chair: Thank you for your patience. Would you mind introducing yourselves to those who are following this at home?

Dr McShane: I am Dr Martin McShane. I am the medical director for long-term conditions in NHS England.

Norman Lamb: I am Norman Lamb, the Minister for Care and Support.

Chair: Thank you.

Q169 Andrew George: The Liverpool care pathway has been brought to an end. Since that time nothing is currently replacing it—not as a formal tool to replace the Liverpool care pathway. Who do you think should be taking the lead in finding a tool which could be universally applied through this particular area of care?

Norman Lamb: We have the five principles of care. At the heart of that is that it must be very much personal to the individual, that there is a care plan developed for that person. One of the findings of the Baroness Neuberger review was that we need to move on from a one-size-fits-all approach, which the Liverpool care pathway had become. I regard the Liverpool care pathway as an important advance in end of life care, and its purpose and intent was absolutely right; but through the work of the review there was a clear recognition, and I think quite a consensus, that there were flaws in that one-size-fits-all approach and that the principles of care actually create the best sort of framework. I was at a hospital last week in Burnley where, as I arrived, they were doing the training. They seemed to be very positive about the approach that is now being taken. I am not sure that there is a need for anything additional to that. Training is completely critical. There is quite a consensus behind the approach that is now being taken.

Q170 Andrew George: Dr McShane, do you have anything to add?

Dr McShane: We need to realise the steps that it takes—it was interesting listening to the discussion which happened just before—in recognising that someone is at their end of life.

Norman Lamb: Or may be.

Dr McShane: Or may be, yes, but it is then focusing on communicating with the person themselves and the individuals who are most important to them. It is about involving them in the decision making and identifying their needs, and that then creating a personal care plan which is about that person—their needs and their wishes—and that it is done with them and the people most important to them. As a set of principles, it is more difficult to turn it into a tick-box.

Q171 Andrew George: That is very helpful in fact. You do not anticipate that the Liverpool care pathway is dead, and that you need to find—

Norman Lamb: It is dead.

Q172 Andrew George: You accept that it is dead and it is clear now to me—perhaps it was clear to others before—that you are not proposing to replace it with another tool of a similar kind of dimension.

Norman Lamb: No.

Q173 Andrew George: You are looking at the five principles as one useful set of priorities for people to look at. But in terms of filling the gap that has been left with another tool, that is not what you are proposing.

Norman Lamb: No. It is a different approach, but I do not think there is a continuing gap. Bee Wee, the national clinical director, led the across-the-system response to the report, and what was remarkable was that everyone came together to agree the approach that should now be in place. Then the training takes place to make sure that those principles are properly applied in individual providers.

Q174 Andrew George: Okay. There are some settings where certainly the evidence that we have been given, from Macmillan and elsewhere, suggests that the Liverpool care pathway is being used in all but name. Obviously there was a lot of good in the Liverpool care pathway—I do not think anyone is arguing that there was not—and, in fact, in the absence of anything else that is currently available, it is still effectively being used as a very useful source of guidance, not in totality but certainly the frameworks and many of the elements of it.

Norman Lamb: It should not be used.

Q175 Andrew George: It should not be.

Norman Lamb: Absolutely not. We have been very clear about this. If clinicians and other health care workers, and indeed their employers, follow the principles, they will be on the right track. I commissioned the review by Baroness Neuberger and her team, and I wanted them to remain in place as a panel to monitor what happens over the first year of this new approach, so they are there ready to look at and monitor how things are going. It would be wholly wrong for a hospital, for example, just to re-badge their approach or their use of the Liverpool care pathway, call it something else, and carry on as before. It is not what everyone came together to achieve.

Q176 Andrew George: Do you think this is an area where it is the Department that needs to provide the leadership, not the royal colleges or any other organisation, in terms of what replaces what has gone?

Norman Lamb: As I say, Bee Wee, as the national clinical director within NHS England—one of Martin's colleagues—led the whole-system response. There was a lot of work over the course of a year after the Neuberger review reported, and they came up, as I say, with a consensus approach about how end of life care should be approached from here on. The whole system is united on this, and, as the national clinical director, Bee Wee very appropriately, in my view, took the lead on that.

Q177 Andrew George: There are the NICE quality standards for the five priorities for care, which you have described, the actions for end of life care and a new end of life narrative. At the moment we have a number of pieces of guidance coming out. Can you understand that there are a lot of care settings that are rather confused about what they should be doing at the moment and what they should have in place, given that up to 80% of, certainly, acute settings were using the Liverpool care pathway?

Norman Lamb: I do not think they need to be confused. If they read the outcome of the response to the Neuberger review, it is quite clear and provides them with the route map for improving care, where that is necessary, and for getting those principles embedded in practice. I do not know whether you want to add anything.

Dr McShane: There are a number of things. First, we need to go back to the origins of the end of life care strategy from 2008, a 10-year strategy which set out some clear principles about addressing the key changes that were required. We have made quite a degree of progress in delivering that strategy.

Secondly, it is interesting, to echo what was said before, that this is not one person's business; it is everyone's business. The ambitions for end of life care, which involve a wide group of people, including social care and ambulance—I have the list of everyone who is involved in the ambitions for end of life care—are to pull together the work which was done. There was an immediate response to the Liverpool care pathway. It has been addressed. There has been an audit. NHS IQ have been into 27 trusts around the country to look at what they were doing about it. It has raised the profile of end of life care once more, and we have delivered "One chance to get it right". Personally, as a clinician, I find those five things to remember to do quite clear.

Norman Lamb: The principles.

Dr McShane: The principles. At the end of it, there is a product which is about the person rather than a process. That is incredibly important. The Liverpool care pathway came out of the hospice movement and was linked to a clear purpose, but in the invariable way we sometimes have of doing these things, we focused on the process and disconnected from the purpose. Now we have reconnected to the real purpose of end of life care.

Norman Lamb: Just to repeat, the Neuberger review specifically said that the one-size-fits-all generic protocol, as the LCP has come to be seen, intended to be applicable to all dying patients in any setting, is the wrong approach. To replace one generic protocol with another one is not learning the lesson of what went wrong in some settings, while recognising that this is an evolution and that the Liverpool care pathway in itself marked a significant improvement overall in end of life care.

Q178 Andrew George: But you will acknowledge that there will be some settings where care providers are still uncertain, and are still struggling at the moment to readjust and find a satisfactory tool to manage.

Norman Lamb: I come back to the fact that we should not be having a generic tool.

Q179 Andrew George: No?

Norman Lamb: No. That is the approach that the review—

Q180 Andrew George: Or an approach, okay. I will take the word "tool" away and say an approach, but they are struggling to readjust since July last year.

Dr McShane: Communication about the ambitions is really important—to get that clear message across about recognition, communication, involvement, identification of needs and, from that, developing a person-centred care plan. It is a message we have to keep repeating.

Norman Lamb: The role of HEE is critical in this in leading the training of staff to ensure that people understand that there is not confusion. I have to say that in the hospital I was in last week there was no sense of confusion at all. There may be some people who express confusion, perhaps because they have not fully read, understood and embraced it, but I do not think there needs to be confusion about the approach that is now being taken.

Q181 Andrew George: But in terms of your approach to those circumstances, it seems that the Department issued a number of detailed documents and guidance, and that is what you are going to provide to those care providers. It is going to be documents and guidance and leaving it to them to interpret.

Norman Lamb: The other element of this, of course, as Martin just mentioned, is the Care Quality Commission. They have identified end of life care—this is in itself really important—as one of the key strands of activity that they will absolutely look at and rate in its own right in hospitals or in any other provider. Monitoring and assessing the quality of what is now being provided will be clear for all to see.

Chair: Thank you. Rosie has stepped out for a minute, so do you want to carry on with your question about community nursing?

Q182 Andrew George: Yes. I think, Minister, you were here earlier and you will have heard Amanda Cheesley describing some of the difficulties and challenges, in response to my colleague Andrew Percy, in relation to the falling numbers of district nurses and the facilities, which are simply not in place, to ensure a framework of support if we are going to have the management of more end of life care at home, or at least in the community. What assessment have you made about whether the health system is able to satisfy the mantra, which it often repeats, that people should have the right to die in dignity at home, wherever possible?

Norman Lamb: First of all, in a way, we are talking here about ensuring that individuals' preferences and priorities are respected, so that they can die where they want to be, and indeed—*[Interruption.]*

Chair: Because we are a little way from the Chamber, shall we leave it there and return to that point when we come back?

Suspended for a Division in the House.

On resuming—

Q183 Chair: Minister and Dr McShane, we will start because we have quite a lot to get through and we are quorate. I am going to go back to Andrew's question. I do not know whether you want a quick, nuggety refresher or whether you are happy to start again.

Norman Lamb: I think I had said a sentence about district nursing.

Chair: Do you want to start again?

Norman Lamb: Yes. The starting point is about respecting people's wishes so that the system can deliver what people want. We know from the surveys that have been undertaken that the majority of people want to die at home. You then ask the question: as the system and work force are currently designed, do they meet that particular shift? The answer clearly is no, they do not. There are clearly work force implications and there is no doubt—it goes back over the last decade—that there has been a decline in the number of district nurses. My view is that the fact that within the system the incentives are not really aligned—that you have payment for activity for acute care and then block contracts for community care and for mental health—distorts where the money goes. It means that our agreed priorities and intentions—I think there is agreement across the political spectrum—about shifting towards better out-of-hospital care, better support for people at home, including at the end of life, to respect people's wishes, are undermined by a payment system that is distorted. That is what needs to change as a matter of priority. That is my personal view.

Q184 Andrew George: You are doing some kind of blue-sky talking or thinking. In terms of where the Government are, where the Department is, the Government have asked themselves the question and these are generally the desires—being closer to home—and you do not have the facilities to fulfil what the desires are at present, so—

Norman Lamb: The work force does not meet those needs at present.

Andrew George: I understand that. We have concluded that too, and it seems that a lot of other stakeholders have also identified insufficient district nurses, an insufficient infrastructure, to enable that to happen. What will the Government do? Having asked the question, the answer is no, and we all agree it is no, what can you do?

Norman Lamb: I mentioned that the incentives need to change because that—

Q185 Andrew George: That is your personal view.

Norman Lamb: It goes beyond that. There is quite widespread recognition that that needs to reform, and indeed Monitor are doing work on how you reform payment systems to achieve better results. But then there is Forward View, which comes from NHS England

and maps out what needs to happen; it talks about new models of care, out-of-hospital care and achieving that sort of shift; it recognises the work force implications of that and the need, therefore, to train the work force, and indeed to try to make it attractive for people to choose district nursing and community nursing as a career option as well—a point you were making in the earlier questioning. I do not know whether Martin wants to add anything.

Dr McShane: I would pick four themes out of that. One is around the financial incentives. We have set a clear steer across the system that there should be more flexibility in contracting arrangements and payment arrangements in health care systems.

Q186 Andrew George: That would be powers for the CCGs to commission differently.

Dr McShane: Yes. That is already happening in places. The second point is the new models of care from the Five Year Forward View—the multispecialty community providers, or the primary and acute care alignment. Again, people are picking that up. I was in York recently, and they are already implementing a new model of care where, just in this last month, a geriatrician and a GP have started going into care homes, reviewing the patients and looking at their care plans and, as a result, to date they have reviewed 73 patients, stopped 140 medications and put in place 41 advance decisions, the DNACPR plans, with proper guidance and communication with relatives and the care homes.

The third thing is around IT and communication. The only way we will get the sort of continuity of information that people are seeking in order to manage the complex needs that people have around end of life care, and complex care needs, is to make sure that the information can be shared between providers, preferably, I would say, between the individual and, with their permission, their carers if they so wish. End of life care is one of the key themes in the National Information Board priorities.

Then, to echo the education and training points, I know that Jane Cummings, for instance, has championed the compassion in practice agenda, but her team are also working with The Queen's Nursing Institute and Health Education England to get increased community placements. Also, we are looking at how we can support local health communities to plan their work force requirements better by using modelling tools that help them to do that. I have been working with my colleagues in the nursing directorate around that agenda as well. They have recruited a leader within the nursing directorate, a specialist nurse adviser for district and community nursing, because they take this agenda very seriously. It is high on the radar and there is a lot of activity to address it, but I do not think we can underestimate the challenge.

Q187 Rosie Cooper: The Cicely Saunders Institute told us that those who are older and those with non-cancer conditions were less likely to be receiving palliative care. The National Council for Palliative Care also provided evidence that people with cancer accessed 75% of all specialist palliative care services, although cancer actually causes about 30% of deaths. What action will you take to ensure that specialist palliative care services are offered

to everyone with a life-limiting condition, other than just those with cancer, within the next five years?

Dr McShane: This harkens back—I am sure it has been referenced—to the seminal *BMJ* article which showed the three trajectories towards last years of life care. Cancer, as was alluded to earlier on, is the easiest one to identify in some ways; it is kind of predictable. There is the see-saw descent—that is the only way I can describe it: a crisis, then a little bit of further deterioration, crisis, then recovery, but a little bit of further deterioration—that happens with the sort of cardiovascular, respiratory and endocrine conditions which bring about terminal illness. Then, finally, there are the easiest to categorise under neurological, the slow inevitable decline you have in conditions such as motor neurone disease or multiple sclerosis, things of that nature. Cancer and, in effect, the neurological conditions are relatively easy to identify and predict, but the complex care ones—cardiovascular, endocrine and respiratory—are more difficult. One thing we need, which is evidenced by the work that has been done on care planning, is a situation where professionals are instituting and refreshing care plans with patients, and involving carers and people important to the person much earlier on and engaging in that conversation: "If you are at the end of your life"—not "you are at the end of your life"—"what would matter most to you?" This is why I have taken the approach, certainly as the lead for long-term conditions, that we need to get this right for any condition. Our approach should be driven not by a condition but by the needs of the person. That to me is about recognition, care planning, communication and working with people on what matters to them. That then will change the nature of the conversation. I have just come from a meeting I was holding today on exactly that—the work that is being done, for instance, led by Isabel Hodkinson, in Tower Hamlets, on exactly that agenda and reframing it. It is a really difficult one, because it means we move away from what has been a traditional medical approach to one that is far more about the person.

Q188 Rosie Cooper: I asked the previous panel this question and went on to ask why the NHS struggles to identify people in the last phase of life. I do not know whether you were here at that point.

Dr McShane: Yes.

Q189 Rosie Cooper: Clinicians will have in their own mind that the person is now moving into a late phase of their life. The response we got was essentially that it was about education. Clinicians and professionals knew that this was in the near future but found it very difficult to engage with families in the conversation you have just described as the "What if?" conversation. How can this go from being something we believe should happen to something that is happening on the ground and makes a difference?

Dr McShane: We are thinking about trying to do it in the way we do things now, and we need to step outside that and ask what we need to change about our approach that would make this normal—which would make this the way we approach it. The Dying Matters coalition has done a lot of work over the last year about changing societal attitudes towards death and dying. If we can move the conversation to, "You have a lot of things happening to you, but what matters to you most? What would matter to you most if you

reached a situation?", that is different from waiting until someone is dying and then rushing in and saying, "We now need to talk to you about dying."

Q190 Rosie Cooper: Absolutely, but how do you get that out there now? From being something that you are talking about in the Department of Health or NHS England—however it goes—how do you get it down to consultants, registrars and district nurses? How do you make it happen?

Dr McShane: Doing it will lead to a change in attitude, which will lead to the thinking about it. We are trying to get people to actively think about a form of conversation with people—

Q191 Rosie Cooper: How are you going to try and make them do it?

Dr McShane: By changing some of the levers, incentives and drivers around the system. It goes back to the tariff consultation. Also, if as is planned, and as is happening across the country, we introduce an IT-enabled care planning process, it completely transforms the nature of the conversation, because you cannot upload a care plan to be accessible to everyone unless you have the permission and collaboration of the person the care plan is about.

Norman Lamb: It is a training issue as well, to embed as we train clinicians the critical importance of communicating with the individual and with the family. That is one of the things embedded in the five principles, but whether it is through training at the start of a career or continuing professional development, we have to overcome the resistance among some clinicians to actually talking about this. There are some GPs who would probably still find it difficult to talk to someone about the fact that they may be approaching the end of life, but it is also fair to say that this is still an inexact science and we cannot make accurate predictions about what will happen at that time.

Rosie Cooper: Absolutely.

Q192 Charlotte Leslie: The Five Year Forward View only mentioned end of life care in a very cursory way. Why is that? Is it no longer a priority?

Norman Lamb: It is his organisation, not mine.

Dr McShane: It did not mention a lot of things, I would say, and a lot of people have said, "Oh, it didn't mention this or that." I think it was setting out a direction of travel, a view; it is not just NHS England but all the major statutory bodies—Public Health England, the CQC, Monitor and the TDA. Everyone was involved in establishing the vision in the Five Year Forward View. Now that everyone has said, "Yes, that looks like a good idea," we are at the stage of, "How do we make that real?" From a compass, we now need to draw up the map into the future.

My policy agenda is older people and end of life care. I lead a programme of work on that within NHS England. This is incredibly important because, in terms of hospital utilisation, people under the age of 40 use about 1 million bed days a year in England and people

above the age of 85 occupy 7 million bed days in England. We really need to understand that we have become victims of our own success; we have done well to keep people well and we should be keeping people well until end of life, but also preparing for end of life proactively. That has not been the nature of the system, or the culture of the system, entirely. There are leaders who have been promoting that for a number of years and there are pockets of excellence. We need to build on that and spread it.

Q193 Charlotte Leslie: There is quite a striking trend that, when asked, the public prioritise quality of life over quantity, but when health care professionals are asked they see quantity and length of life as more of a priority. Do you think there is a massive culture change so that the NHS sees itself, therefore, to be more in line with what the public want?

Dr McShane: This is one of the things where, working with the Coalition for Collaborative Care—a wide-ranging group of leaders across health and care and communities—we are endeavouring to make that cultural change, to putting the person centrally and asking, "What matters most to you?" If you ask that question, as I heard this morning, you get some striking revelations. Maybe the glycosylated haemoglobin is not the most important thing to someone; but just being able to get up and answer the front door is something they would really like to be able to do.

Norman Lamb: One of the most exciting things happening here is the EPaCCS, which I am sure you are very familiar with. In London I think it is known as Coordinate My Care. The evidence appears to show that, where it has become embedded and is used so that people can express their own preferences and priorities, you suddenly get about 75% of people who are part of it dying where they want to die, instead of being stuck in hospital where they do not want to be. In terms of driving a change of behaviour in the system and respecting people's wishes—about not resuscitating or not receiving treatment, or whatever it might be—this is incredibly powerful in changing behaviour.

Q194 Charlotte Leslie: In terms of the culture and then going to statistics, in a recent audit of palliative care the Royal College of Physicians found that training in caring for dying people was only mandatory for 19% of doctors and 28% of nurses in trusts. Why is the number of health care staff receiving training for end of life care so low?

Dr McShane: I would make a distinction between mandatory training and training. Mandatory training is what you have to tick the box for, as I have recently experienced; but that has not been all my training this year. Hidden beneath this, there will be a lot of professionals who take professional pride in being able to deliver high-quality care, and have undergone training in end of life care. However, we need to look at better surveys—the VOICES survey has been incredibly helpful—and the way we get feedback and listen to it, in particular from carers, and learn from that to improve the care. You can overload the system with mandatory training and it then becomes something burdensome and almost self-defeating.

Q195 Charlotte Leslie: However it is done, the general consensus this afternoon has been that there is not enough and it is not widely spread enough. Is the Government going to invest more in palliative care and end of life care training for generalist staff?

Norman Lamb: The mandate to HEE is helpful in this regard, but I completely accept the premise of your question that, overall, this has been a neglected area of care, traditionally, within the NHS. It is changing. Improvements have been made, but there is a long way to go. The recognition that we need to train the general work force—as Martin said, all of the different people who may be involved—is very clear to me.

Q196 Robert Jenrick: Can I ask a few questions about the funding of palliative care? We have heard in the inquiry that, in 2011, £450 million was spent on palliative care across the whole country. We have not been able to establish whether those figures are accurate or what the latest figure is. Are you able to provide any more accurate figures for us?

Dr McShane: Yes. The problem is that that is taken from a paper about PCT investment in specialist palliative care. The estimate is that somewhere shy of about £4 billion is spent on end of life care and palliative care across the country, because, speaking as someone who has been both a GP and a hospital doctor, you have to take into account all the work that generalists do—we have heard about the fantastic work of community nursing and community provision—plus the generalist end of life care that is provided on hospital wards and in care homes; and then the specialist teams supporting generalists when they are struggling with issues in end of life care. It is always one of those statistics that you need to approach with caution, but work that has been done recently would estimate that it is somewhere shy of about £4 billion. Some of that also comes from local authorities. About three quarters is direct NHS, about another 10%, I think I am right in saying, comes from the local authorities, and the rest comes through the hospice sector.

Q197 Robert Jenrick: Would you be able to provide the Committee with a breakdown of those figures, because it is important that we get out into the public domain exactly how much money is being spent and how it divides up?

Dr McShane: I am sure we can. I have had a privileged view of the report in which I think it will be contained, and which is due to be published shortly.

Q198 Robert Jenrick: Thank you. In terms of the funding, one of the issues we have heard on a number of occasions, and in some of the written evidence as well, is about the siloed nature of commissioning and the difference between, as you have just said, the funding of palliative care that is provided through hospitals and GPs and that which is provided through hospices. Is there anything you would like to say about that and how we could try to improve it?

Norman Lamb: There is work under way to try to develop a tariff for end of life and palliative care. If we can get there and do it in a way that does not create new distortions, it would be an advance on where we are at the moment. It has to be done quite carefully. My understanding is that in 2015-16 a number of areas will be ready to trial this new approach.

Dr McShane: We established eight pilots to look at it and try to establish what things cost, to track where money was being invested and used, and why. Having got that information, we have been working on a payment system, based on the Australian payment system, which looks at the various different stages. The plan is to go forward and trial looking at that in those eight pilot areas.

Q199 Robert Jenrick: When are those trials going to be conducted?
Dr McShane: Soon; 2015-16. They are commencing in the coming year, so sort of road testing to see whether there are unintended consequences. Does this actually work?

Norman Lamb: There will be a shadow format, as I understand it, in 2015-16, so that we learn the lessons on how it would work and then it can be, hopefully, rolled out beyond that.

Q200 Robert Jenrick: When would you anticipate rolling it out—2016 or 2017?
Norman Lamb: Depending on the lessons we learn from it—

Q201 Robert Jenrick: Presuming it is successful.
Norman Lamb: The anticipation would be that we could be ready for that.

Dr McShane: The note I have is, "Within the next three years."

Q202 Robert Jenrick: That is quite a long time away.
Dr McShane: It is a recognition of the commissioning cycle, which is an annual cycle, and also of the work that has to be done to be able to implement something like a new currency.

Norman Lamb: We have to make sure we do not end up with unintended consequences. It is a bit of a cautious approach, but everybody is agreed with the direction of travel.

Q203 Robert Jenrick: One thing we have heard has been the argument that social care should be free at the end of life, and we have had written evidence that the threshold of £23,250 is arguably so low that it puts off a lot of people on quite modest incomes and people with quite modest savings, to the point where perhaps they do not want to go into a hospice or take social care for fear of the pressures it is going to put on their family, for fear of their relatives' reaction that their inheritance—I do not mean that in a negative way, but what someone wants to hand over to the next generation—is not going to be available. The logical outcome of that is that a far greater cost ends up being borne by the NHS, as the statistics seem to show that social care or palliative care is considerably cheaper than ending your life in hospital. What is your thinking on that?
Norman Lamb: I have been very clear that I am terribly keen on this, if it stacks up. Your Chair will recall, I am sure with great affection, the deliberations we had on the Care Bill

last year. It is a very attractive proposition. It was set out in the White Paper that the concept had a lot of merit. We hoped that we would get data from the eight pilots. The data falls short of what we need to make the judgment and, of course, we have to be able to convince the Treasury.

Q204 Robert Jenrick: How does it fall short? Is it inconclusive?

Norman Lamb: It is inconclusive. Following the Care Bill, I convened a round table bringing together interested parties to discuss this. Many of the groups believe that there is compelling evidence, and there is now engagement between those groups and officials, and I think there was a meeting—possibly today; I am not sure. That work is continuing. The objective will be to get it concluded in time for the next spending review. That is the hope, but we have not reached a conclusion yet, which for me is very frustrating because, on the face of it, the point you make is very powerful: if we can remove some of the tensions in the system and make it easier for people to make just the right decision, we may well end up saving a hell of a lot of money. Of course, care in a hospital at the end of life is free, so we have this ridiculous situation where we are providing free care for a place where people do not want to be. If we could provide free care to enable them to be where they want to be, that is obviously an attractive proposition. But we have to be able to convince the Treasury on the cost.

Q205 Robert Jenrick: That is the frustration; it seems a very strong argument but the evidence we have heard so far is anecdotal, and whether better quality data can come into the public domain—

Norman Lamb: That discussion is continuing with the groups who believe that they have the evidence to win this argument.

Q206 Chair: Can I follow up one point on that? I heard that the reason it was inconclusive was not that the evidence was poor; it was just that the pilots were poorly designed. Is that correct—that they were not designed in such a way that you could get meaningful data?

Norman Lamb: You have heard something that I have not heard, but that is not to say you are not right.

Q207 Chair: It is just a comment that I heard.

Dr McShane: I have been involved in part in this. This speaks to the agenda of our inability to link data up and track outcomes across the whole system to how money is invested and what activity by people has taken place; population assessment and diagnosis, if you like, of how money is being spent and what outcomes we are getting is holding us back in our ability to deliver best value off the back of the taxpayer's pound.

Norman Lamb: Do you think there was an issue?

Dr McShane: Linking health and social care data is always very difficult and then, of course, because of the means-testing in social care there are different thresholds between different local authorities in how much money people might be personally spending. That was a complexity around it.

Q208 Chair: There was great complexity around it in terms of demonstrating whether there was any financial saving, but what is more important to the wider public is whether or not there was an improvement in quality. In other words, were more people able to die in the place of their choice? Were they happier with their care overall when they had access to free social care?

Dr McShane: I cannot answer that question because I do not think it was part of the pilot.

Norman Lamb: If it would help, I am happy for us to do a note as to whether there are lessons to be learned from—

Q209 Chair: Yes, to explore the reasons why. Why was it an inconclusive pilot and what did it explore around the patient experience, which is probably the question that most of the public would—

Norman Lamb: I will commission a note on it.

Chair: Thank you.

Q210 Robert Jenrick: Just to be clear about the pilots, the set of pilots you have done were inconclusive, so you are commissioning new pilots.

Dr McShane: No. The pilots were designed—I need to be clear about this, if I can—to understand how money was spent, just actually knowing what the bill was, where, for what—

Norman Lamb: Including self-funders.

Dr McShane: Including self-funders.

Q211 Robert Jenrick: How do you resolve this? Are you doing new pilots?

Dr McShane: Off the back of that, having that data and knowing the baseline, if we now implement currencies, what difference would that make to the way money gets spent and the outcomes people have in the system? First of all, we had to get the baseline established—what is happening now—because we did not have that data. Now, having got that baseline picture established, we can move on to ask, "Now if we put changes in place, what impact do they have?"

Q212 Chair: In other words, these were not pilots of people receiving free social care at the end of life.

Norman Lamb: No; it was to understand them.

Q213 Chair: It was just to understand the background costs, but it was a very complex process trying to tease out what the exact costs were. That is why it was inconclusive.

Dr McShane: Yes.

Chair: Thank you for clarifying that.

Q214 Robert Jenrick: Can I ask one quick question about hospices? We have been hearing about how important the role of hospices is. Hospices still heavily rely on charitable funding, but, as we know, they also rely to a lesser or greater extent on Government funding through the NHS. Some of the statistics we have received suggest that half of hospices have seen their statutory funding from the NHS reduced or frozen in 2014. Is that something that you recognise and, if it is, is it wise?

Dr McShane: I recognise it for the NHS; we have had flatline funding. Wherever the NHS has to make investments, it has to make them on the basis of the money it is given. One of the issues, though, is that we also need to recognise that there is a change in emphasis. I previously worked in a local health community and redesigned palliative care with the hospice. With the hospice, we actually moved care away from a hospice setting into care homes and people at home. Figures I have just got from colleagues where I used to work are that 1,700 people received care through the redesigned care approach, and 93% of them died at home.

Norman Lamb: In that particular locality.

Dr McShane: In that particular locality. We also have to recognise that, with best intentions and endeavours, some people have set up hospices that may not be part of the service need within the community.

Chair: Thank you.

Q215 David Tredinnick: Minister and Dr McShane, I apologise for being late, having been detained elsewhere in other meetings. In an earlier session I raised the use of some complementary therapies in helping people towards end of life care—in fact aromatherapy. I have in my constituency the International Federation of Professional Aromatherapists headquarters and several manufacturers and therapy schools, so it is something I know a bit about. I have received a briefing note from St Wilfrid's hospice in Chichester, Sussex—funnily enough, where my late mother worked as a nurse—about the complementary therapy service they offer. They are using a range of therapies, and I want to list them and ask you whether you see a wider rollout of therapies, given what you were saying earlier on, Minister, about patient choice, in patients having what they want. The briefing from St Wilfrid's hospice says that complementary therapies and their valuable place in palliative care are well recognised: "Most hospices, including ours, offer a range. At St Wilfrid's we offer aromatherapy, reflexology, reiki healing, Bach flower remedies,

acupuncture and hypnotherapy, tai chi and yoga. Therapists work in all areas of the hospice and the day centre, and in-patients and patients and carers have unlimited access to these treatments." This is a major hospice, the largest in west Sussex, and it is probably reflective of a trend. Would you like to comment on the work that these additional caring services provide at hospices?

Norman Lamb: As your note points out—I think it said—most hospices provide a range of complementary therapies, and going back to what I said earlier about the paramount importance of respecting the individual and what is important to them, the view in the hospice movement, which I endorse, is that, if these therapies are seen as important to people, they can absolutely play a role. They are well established within the hospice movement.

David Tredinnick: Thank you very much.

Q216 Chair: Before we move on to the area of research, can I clarify and follow up a point that Robert raised about funding? Although I accept that it is difficult to tease out how much of it comes from communities and how much of it is generalists undertaking palliative care work, there is a real interest in how much is going into specialist palliative care. We heard from witnesses who would like to be able to extend specialist palliative care services into the community, for example, so it would be very helpful for us to understand how much is currently being spent on specialist palliative care; we know that it was £450 million in 2011. Certainly the evidence we are hearing is that the hospices cannot do any more; they have reached the limit of their charitable fund-raising capabilities, and in some cases that is being constrained. It is a limiting factor for them in being able to provide a greater service within hospitals, so that we have best practice everywhere, and especially rolling it out within the community. It is a major constraining factor for them. Are you able to talk a little bit more about specialist palliative care funding—the budget to them?

Norman Lamb: You answered the question earlier, Martin; I do not know if you have anything else to add. I am certainly happy to do a further note for the Committee about levels of funding if that would be helpful.

Chair: Yes.

Dr McShane: The figures that we have taken from the 2011 report reflect the nature of investment in specialist palliative care. The other thing we are trying to change is the relationship between specialism and generalism.

Q217 Chair: We do not have an update to that figure from 2011.

Dr McShane: I do not have one to hand at the moment, no.

Norman Lamb: But we can explore that and come back to you.

Q218 Chair: Would you recognise that picture from hospices—that they really have reached the limit of their fund-raising capabilities and that that is a constraining factor on what they do now?

Norman Lamb: From my point of view, they do extraordinary work to raise money in their communities, and I can quite imagine that there are limits to that. To reinforce the point that I think Martin was making, we have to get the specialists out of the hospital and to work much more collaboratively, whether in hospices or with GP practices and community teams, supporting people in the community. That is very much part of the sort of model of care that the Forward View envisages.

Chair: Thank you.

Q219 Andrew George: This follows on from David Tredinnick's question. If we are basing future policy on evidence, it seems that the oft-repeated figure—in this inquiry, at least—is that as little as 10p in every £100 spent on research in health relates to end of life and palliative care. If the Department and NHS England are going to support evidence-based policy making with regard to the management of end of life care—after all, we all die and increasing numbers of us over the years require some form of clinical or state-supported care intervention during that process—what do you think the Department can do to make sure that we gather the evidence on which to guide us in our future policy making?

Norman Lamb: There was a session this month, wasn't there?

Dr McShane: Yes.

Norman Lamb: It involved NHS England and Public Health England looking at the evidence that is available, and the research work that is under way. We certainly very much support them.

Dr McShane: Over the last year there has been, with the James Lind Alliance, an extensive consultation with people, both professionals and people with an interest in end of life care, about what are the priorities for research. Out of the large number of recommendations that came back, 10 key questions that we think should be addressed were identified by that workshop earlier this month. We go through the National Institute for Health Research funding process, and there is already somewhere in the region of about £5 million being invested directly, such that you could say, "That is about end of life care." But I think we also have to recognise that some of the research that goes on is pertinent to end of life care—on cancer, care planning and other issues—but it might not specifically be said to be attributable to end of life care. The DH works closely with Government and charity, and industry as well, to try to take this agenda forward. We now have clarity about what people want us to do research into. We have research that is ongoing, but it will also feed into the ongoing stream of research that we need moving forward.

Q220 Andrew George: Can I go back to the questions I was asking earlier and your response, Minister, that of course you do not wish to adopt a one-size-fits-all approach in response to the withdrawal of the Liverpool care pathway? In those circumstances, if you have these five priorities for care at the end of life, it also seems that if you have good research you can exemplify those very good examples of where there is very good practice and share it. But rather than those places themselves telling everyone what a good job they

are doing, you need to make sure that it is robustly peer-reviewed as part of a research programme, so surely it has become even more important to put some priority into research in this area, given that there is still a lot of uncertainty out there.

Dr McShane: I do not know if you have seen the 10 priorities, but they echo exactly what you have just said. They are about addressing and supporting the priorities for end of life care. We need to be a little bit careful with the statistic that was quoted because it also covers fundamental basic science research; it is not just about clinical research.

Q221 Andrew George: It may be an exaggeration perhaps—I do not know—but certainly the Cicely Saunders Institute, the Association for Palliative Medicine, and the National Council for Palliative Care all believe that this is an area which needs to be given a great deal more priority.

Norman Lamb: They are right.

Q222 Andrew George: It seems to me that while you are talking about your 10 priorities—

Norman Lamb: Have you seen those, incidentally?

Q223 Andrew George: No, I have not.

Norman Lamb: We can provide them if you do not have them.

Q224 Andrew George: That would be helpful. It seems to me that that needs to be shared and the priorities need to be pursued very vigorously. How you are going to up the investment in this area is still unclear.

Norman Lamb: We recognise that it is a priority to do that work, and the fact that we have met and identified what the priorities for further research should be is indicative of that recognition. Of course, you also need good quality research proposals coming forward, but the fact that we have set out what the priorities need to be will, hopefully, encourage good, robust propositions to come forward.

Andrew George: Thank you.

Q225 Chair: Can I return to an area that you touched on earlier about advance care planning? Responding to the House of Lords report on the implementation of the Mental Capacity Act 2005, the Government indicated that people should have greater powers to put in place lasting powers of attorney and advance decisions to refuse treatment. Do you agree that there is still a great deal of misunderstanding out there in the wider public about which of those is the most appropriate? There are concerns about the costs, for example, of lasting powers of attorney. How do we make this much more straightforward for people? You talked about Coordinate My Care and proposals like that, but what kind of things do you think would make the greatest difference to make this the normal or easiest thing to do?

Norman Lamb: First of all, you are absolutely right, and we recognise this very readily both in our evidence to the House of Lords inquiry but also in our response: we are still a long way short of really embedding an understanding of the Mental Capacity Act and the mechanisms we can use under that to, in a way, give power to people, to put people in control as much as we are able to. This does not happen overnight. It will take some time, and again training of the work force is critical to that, both the initial training but also the ongoing continuing professional development. Do you want to add anything, Martin, from a clinician perspective?

Dr McShane: Yes. It represents a shift to recognising far greater autonomy and involvement of individuals in decisions about their own care, from the 20th century paternalistic approach which was that doctor knew best. I must admit that I have been trying to work out the lexicon around this and I am not sure it is entirely helpful: an advance care plan could lead to an advance statement and an advance decision to refuse treatment, and I think we are confused. Simplifying that and making sure that it is a proper proactive care plan—"What matters to you, and what would you do if?"—is to my simple mind a way of clarifying the components in supporting people, ensuring that they have the mental capacity, and that that is recorded, and properly appreciated and valued.

Norman Lamb: We also need to make sure that the mechanisms are fit for purpose, as it were. With DOLS, for example, under the Mental Capacity Act, there is a very bureaucratic process, and there has been a lot of work done following the Supreme Court judgment to try to reduce the number of forms that practitioners have to go through in order to get a DOLS in place. We also have the Law Commission looking at the whole mechanism for DOLS, and hopefully their report might inform us in improving the way the system works. The fact that you have the court and local authorities both involved in the production of DOLS does not really make much sense to me. It would be more sensible, in my view, just to have one organisation that has responsibility for that.

Q226 Chair: Evidence to this inquiry suggested that care providers were looking for more leadership on this issue, and more engagement from NHS England to support them. What is actually going to make the difference to change the behaviour? We have heard a lot about the fact that we would like, in an ideal world, to move away from a paternalistic structure, but how are we going to make that happen so that this really does start?

Dr McShane: I work with the Coalition for Collaborative Care, and this month we published guidance for CCGs on care planning. Incorporated within that will be the support for advance care planning.

Q227 Chair: Thank you. Finally on the issue of lasting power of attorney, do you feel that the cost of putting in place a lasting power of attorney puts people off? Is there any way we could make it less expensive?

Norman Lamb: It may be an issue; there is felt to be a complexity to it and lawyers—I say this as an ex-lawyer—often charge quite a lot of money.

Q228 Chair: You acknowledge that it is a very expensive process. In other words, there are a lot of people who would like an LPA who just cannot have one because it is expensive.

Norman Lamb: I do not think that, to secure it, an individual necessarily has to go down that expensive route, but people often want to use a lawyer and of course then they are faced with a large bill. It is not just a question of putting people off; it excludes it for some people and that is something that we need to consider further. I accept that.

Q229 Chair: Exactly. Have you done any work on what percentage of people from different financial backgrounds are able to take out LPAs, and what support is available to those who cannot afford to use a legal route?

Norman Lamb: I am not aware of any work having been done so far, but it is a very legitimate issue to raise and it deserves consideration. I accept the premise you put.

Chair: Thank you.

Q230 Rosie Cooper: Can I make a suggestion?

Norman Lamb: By all means.

Rosie Cooper: When a person is doing a lasting power of attorney, if they do not use a solicitor, which costs a fair amount of money, and do it as an individual, if there is a mistake on that form—any mistake, however small, such as leaving a letter off, or whatever—that form is returned to you and you have to start the process again, but you have to pay the full fee again. That is horrendous. That is why people go to lawyers.

Norman Lamb: It makes the point that this deserves review and consideration, in my view.

Q231 Rosie Cooper: Absolutely. I have just done them all. One of my friends is very good at this stuff and I would have made a million mistakes. It is the same form—I have done it—for health and wellbeing as well as financial matters, and if you made one mistake you had to pay it all again. Anybody else would have to go to a lawyer to do it. If you could do that, it would be absolutely great.

Now I come to the bit I was going to do. We have had conflicting evidence about this, even in the previous panel today, but some evidence to the inquiry suggests that we should have more dedicated palliative care units in hospitals to stop people dying in acute ward settings, and also because they may increase the skill set, the knowledge and competence of those providing care for people at the end of their life. What would your view of that be?

Norman Lamb: I heard the evidence earlier in response to, I think, the question you put to the earlier witnesses. I was very sympathetic to the answer that was given, that there is a potential danger of unintended consequences, of de-skilling other people. Martin used the phrase earlier that it is "everyone's business". Of course there is an absolute role for specialists, but in informing and working with generalists, the objective should be first of all for people not to be in hospital if they do not want to be there or do not need to be

there, but when they are in hospital, for the staff in that hospital, wherever they are, to be skilled in managing their care, with the support of specialists within the hospital.

Dr McShane: I was talking to Jane Cummings about this. She had recently been to the Chelsea and Westminster where she found exactly the points that were echoed earlier about leadership from the board, the spread of training and education throughout the whole trust and implementation to make it a core purpose of the care system within the trust. In another hospital she had been to, a senior sister on a ward had deliberately set out to create a room, which they called "The Bluebell Room", for people they recognise are at the end of their life. It is slightly larger than a single room, so their relatives can stay with them; it is peaceful, a bit off the main thoroughfare of the ward, and people can have peace and comfort. To me, as someone who has worked and prided myself on paying attention to people at the end of life, if you say, "We will put it over here," it will give an excuse for people to say, "That is the palliative care team's job. They can do it," whereas it is fundamentally core to everything we do.

Norman Lamb: Absolutely.

Q232 Andrew Percy: I want to ask about the role of community and cottage hospitals in end of life care. I have raised it with previous panels. In my area a lot of people do not want to be taken to the district general hospital, but they do not always want to die at home either; they would like to die in the local community hospital. But those facilities often are not there because of fear; if someone is very ill and at the end of life, they would rather have them in the district general with access to consultants and all the rest of it 24/7. What is your view, or vision, on using community or cottage hospitals for this purpose?

Norman Lamb: I will give a view to start with and then hand over to Martin. My own dad died in a community hospital, Kelling hospital in north Norfolk, near Holt. The quality of the care he received in the last fortnight of life, after having been in the acute hospital where it was pretty awful, was just fantastic. It was highly personal. In north Norfolk there is no hospice so, in a way, it is used as somewhere that people who are not able to be at home can be without having to go to a more distant acute hospital. But, again, I come back to the driving principle that, as far as possible, we should be respecting people's wishes about where they want to be. The majority of people, if possible, want to be at home.

Q233 Andrew Percy: Do you not think, though, that very often the current system almost drives away from having those facilities available in community hospitals? In my local community hospital, it has been a case of trying to remove medical beds, and discourage people—apart from, obviously, for surgical procedures—from being in that hospital. We are trying to get an end of life care suite at the local hospital at the moment, but it is almost like the commissioners do not necessarily understand it, or that the whole system is driven towards taking out of community hospitals the kind of beds that you need to support.

Norman Lamb: In a way, we have paid the price for that; if you look at delayed transfers of care this winter, the main cause and the main increase is within the NHS, and it is because there may not be a step-down bed available. I am sorry to repeat myself, but the distortion of the incentives within the system is part of the problem; money keeps getting

sucked into acute hospitals but away from those step-down facilities that can help to get people out of hospital or prevent them from going there in the first place.

Dr McShane: Yes, we should use facilities within the community and assets to best effect. It goes back to, "Why would anyone be admitted to a district general hospital?" It is because there is lack of communication and lack of continuity of information available at the right time to the people who are dealing with them. If we get that right, we afford people more choice and we get them the best possible care. I would just put in a plug, and echo what was said earlier: we also have to remember that there are four times as many care home beds in England as there are hospital beds. I had meetings last year with the big care home providers, and some in the care home sector are doing fantastic work in this area, but we need to recognise it, value it and work purposively. The Five Year Forward View sets out that intent as well. The new models of care—I mentioned two of them—actually talk about models of care for care homes and for smaller hospitals.

Q234 Andrew Percy: The problem is that we always end up in an argument about who pays and that never seems to be resolved. In my constituency, in my home town of Goole, we have a brilliant care home that has all the facilities, but people who want to die there cannot find the funding, or they have to fund themselves or whatever, and go through their local authorities. Just on this, you said, Martin, "Why would anybody want to be admitted to a district general hospital?" Surely if we are going to look at using community hospitals in this way, we have to address that. That lead has to come from on high because following Keogh and all the rest of it, in a local hospital such as mine in Goole, if I had a relative at the end of their life who wanted to die there—a lot of family members want to keep them at home as long as possible, as happened with my granddad, but at the end of the day do not feel able to care for them at the very end of life—what would happen in my situation is that my granddad would have to be dragged off to Scunthorpe hospital 35 miles away because there are no direct admissions, as there aren't at an awful lot of community hospitals, only then to be assessed and discharged.

Dr McShane: Let me quickly give you an illustrative example of how that could change. This comes from the Coordinate My Care experience in London, where over 18,500 people have now had care plans in place and in use. An elderly man who had advanced prostate cancer fell over at home; he banged his head and was confused, so the ambulance was called. The ambulance service was made aware that he was on Coordinate My Care and they could access his care plan. His care plan said, "If I cannot be cared for at home, I wish to be admitted to this hospice." The ambulance staff rang the hospice at two o'clock in the morning and said, "We've got this guy's advance care plan. Have you got a bed?" "Yes, bring him here." "It is going to take us four hours." "Why?" "Because we are going to take him to A and E first just to get his head stitched up and then we will bring him to you." That is what the ambulance staff purposely did, and he died three days later in the hospice. The problem is that we do not have continuity of information available, just like that, to all the services that respond to people at the end of their life. It is one of the things I am passionate about and am working within NHS England to promote; if we are going to start anywhere, let us start there.

Q235 Andrew Percy: I am sceptical, because it seems to be that the drivers at the moment are still all towards your district general hospitals. For all the warm words around having to move care elsewhere, I do not see any evidence of that happening in my area, despite what everybody keeps saying about it.

Norman Lamb: But we are seeing that where the EPaCCS, known as Coordinate My Care in London, has been introduced. We have this objective of getting 70% of CCGs having it enabled in their area by April. We then need to move on to embed it and make it part of standard practice. Where it happens, it is not just rhetoric; it actually is changing behaviour and people's wishes are being respected in a way that perhaps has not happened traditionally. That, for me, is an incredibly powerful way of changing the way the system works.

Andrew Percy: I have one more question, but I know Rosie is keen to come in so I am happy to come in later.

Chair: Just finish your point and then I will come to Rosie.

Andrew Percy: I have finished on this and was going straight on to ambulances.

Chair: You can ask a question on this point, Rosie.

Q236 Rosie Cooper: I spent a lot of time last year berating Liverpool Community Health trust but I now want to say something really positive about it which may help.

Norman Lamb: They have won you round.

Q237 Rosie Cooper: Liverpool Community Health trust runs two intermediate care wards which would almost read across for a community hospital. They now are working with GPs, so in a case such as you suggested the GP would contact that ward directly, there would be certain levels that would have to be met and, that agreed, they would go straight there and not to A and E. It is working, but they have to get out there and publicise it a lot more. The problem that overrides that is that the acute trust would rather the person came to A and E so they got the tariff for looking after them before passing them out. That is a really big hurdle.

Norman Lamb: The commissioners have to be strong on that and resist the desire to get more income through the tariff.

Q238 Rosie Cooper: But the powers that be should also be helping them divert patients.

Norman Lamb: I agree. Martin even has a tag saying "Liverpool" here.

Q239 Rosie Cooper: They are working really hard. Some of the things are yet to come out in an NMC inquiry, but the new interim team are doing a really great job.

Norman Lamb: Good. I am pleased to hear it.

Chair: Praise indeed. Over to Andrew.

Q240 Andrew Percy: I meant to come in earlier with this, but I was outside so I apologise. In terms of ambulance services, what is the vision for how ambulance services will help support people at the end of life? I have had situations where we know people are at the end of their life, yet, despite all the planning that goes in by the family, when something starts to happen they ring 999, the ambulance service turn up and, potentially, that person is then subjected to resuscitation or, in some cases, taken to hospital. What are we doing to skill up paramedics and ECAs in terms of end of life care, and, if we move to a more community-based system, which will involve ambulance crews also delivering more care at home, what is the vision for their role in all of this?

Norman Lamb: I will start by referring to a horrific case that I had to deal with in Norfolk where an ambulance crew turned up at a care home because someone had lost consciousness and, because of an anxiety not to be criticised, they resuscitated, but there had been a clear instruction not to. It ended up with a very frail older person having a traumatic death in an A and E department covered in bruising rather than the natural, calm and peaceful death that she was experiencing until the ambulance crew turned up. The problem with all of this is that it is not just the dying person, but the person left behind, the loved one, who then lives with that awful experience for the rest of their life; we have a responsibility to them as well. I do not want to sound like a record stuck in a groove, but where EPaCCS are in place and the ambulance service shares the record and are able, as they travel to the location, to understand what that individual's wishes are, it enables them, for example, to take the person to the hospice rather than to the A and E department. Again, that sharing of information is critical to getting ambulance services understanding what the patient's priorities are.

Dr McShane: I would totally endorse that. My colleague Keith Willett has been doing a lot of work around urgent and emergency care and bringing local systems together. Too often, we try to treat each component individually from the centre and direct hospitals to do this and the ambulance to do that, whereas actually what is needed is working together in local areas, co-ordinating and aligning the purpose of the different organisations. Keith has done a lot of work—the Five Year Forward View again; I am sorry to labour it, but it does set out that vision about whole-system management—with the ambulance service around paramedics, their training and "See and treat." Over the years we have gone from the ambulance service being seen as a taxi service to being seen as a mobile treatment service. On a significant number of their call-outs now, they arrive, they treat and they leave and they have no one in the back of the ambulance when they leave, because they have dealt with the problem or they have activated support. Again, we need continuity of information about who can be accessed to bring in support and care. My elderly mother lived near me for a while after a very bad stroke, so when the alarm went off I was activated to go and sort out the problem. It is about people knowing who to contact. I was desperate to avoid an admission to hospital because I knew that would do her no good.

Q241 Andrew Percy: Have any changes to paramedic training been identified as a result of what you have described?

Dr McShane: I cannot answer that specific question, I am afraid.

Norman Lamb: We will try to get a note for you if you would like.

Q242 Chair: Do colleagues have any further points they want to raise? Is there anything either of you would like to raise that you have not been asked that you want to comment on before you leave?

Norman Lamb: No, I do not think so. It is great that you are doing this; it has been a long neglected area and there are quite a few different things happening, whether it is the review that followed the Liverpool care pathway, the review of choice at the end of life or getting the tariff system sorted out so that it facilitates people's own choices. All of these things are very positive. We have the potential to achieve better care for people, but we have to ensure that the momentum and the attention are maintained, because it is so easy to neglect this area. I made the point earlier that for the loved ones left behind it is critically important, and making sure people have access to bereavement counselling is also very important.

Chair: Thank you very much for coming this afternoon.