HOUSE OF COMMONS

Health Committee

Oral evidence: End of life care, HC 805

Tuesday 20 January 2014

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Written evidence from witnesses:

- Cicely Saunders Institute
- National Council for Palliative Care
- Care Quality Commission
- Rowcroft Hospice
- Together for Short Lives
- Age UK
- National Bereavement Alliance and Children's Bereavement Network

Watch the meeting

Members present: Dr Sarah Wollaston (Chair), Rosie Cooper, Andrew George, Barbara Keeley, Andrew Percy, David Tredinnick

Questions 1 - 103

Witnesses: **Simon Chapman**, Director of Policy, Intelligence and Public Affairs, National Council for Palliative Care, **Dr Fliss Murtagh**, Cicely Saunders Institute, King's College London, and **Professor Sir Mike Richards**, Chief Inspector of Hospitals, Care Quality Commission, gave evidence.

Q1 Chair: Welcome to the Health Select Committee and thank you very much for coming this afternoon to start our inquiry into end of life care. Could you begin by introducing yourselves to those who are following this debate out of the room, perhaps starting with Dr Murtagh?

Dr Murtagh: My name is Dr Fliss Murtagh. I was previously a GP for about nine years but I am now a palliative medicine consultant at King's College hospital part time, and I work part time in research into palliative care.

Q2 Chair: Thank you. Mr Chapman.

Simon Chapman: Good afternoon. My name is Simon Chapman. I am the director of policy, intelligence and public affairs at the National Council for Palliative Care. We also lead the Dying Matters coalition. NCPC is the umbrella charity for England, Wales and Northern Ireland for those who want people to get the highest quality end of life care, and Dying Matters is an awareness and behaviour change coalition set up as part of the End of Life Care Strategy.

Professor Sir Mike Richards: Good afternoon. I am Professor Sir Mike Richards. I am the chief inspector of hospitals at the Care Quality Commission. In previous lives I was the national clinical director for cancer and then also for end of life care at the Department of Health. Prior to that, I was, for a short period, a professor of palliative medicine.

Q3 Chair: Thank you. Welcome. Can I start by asking each of you—we all know there are a number of issues that this inquiry needs to cover—to set out, in your view, what are the key areas that are going to make the most difference to those who need palliative and end of life care, perhaps starting with Dr Murtagh?

Dr Murtagh: Yes. I am happy to do that. I work at the Cicely Saunders Institute, which is a world-leading research institute. We are interested in building the actual hard evidence to underpin these kinds of decisions. We know very clearly what matters to people with advanced illness and their families. I would group those things into five areas: people want good pain and symptom control towards the end of their life; they want to reduce the burden that they are on their family and make sure their family has appropriate support; they want their preferences and priorities met in relation to information, decisions and place of care; they also want some chance for preparation and resolution before their death; and they want co-ordinated and continuous care so that their families do not have to explain the story again to the 16th person who has come through the door. Those are the things we know very clearly from evidence over the last 30 years, and even in the last five or 10 years the evidence says the same. The James Lind Alliance, which has recently published priorities for end of life care research, is focused almost precisely on those areas because they are what matter to people.

We also know the solutions to those problems because we know that good quality palliative care improves people's pain and symptoms. We know that it improves family quality of life and their satisfaction. We know it better addresses people's priorities and preferences, particularly advanced care planning if it is undertaken by skilled practitioners. Also, they have better emotional well-being and preparation. We know that palliative care delivers those things, but the problem is that about one in three people who die receive palliative care from a specialist team. Perhaps some more get some care from their primary teams but the quality of that is very variable. We know, too, that those who are older and those with non-cancer conditions are much less likely to get into receiving palliative care, and we know also that people do not get palliative interventions early enough to make the maximum difference.

I would also stress that we know very clearly that, if you do have home-based palliative care, you have twice the odds of dying at home, which is where the majority of people want to die. We also know that, if you have community-based effective palliative care, it reduces your emergency department attendances and reduces the unplanned admissions to hospital. That is critically important, because Martin Bardsley's review, looking at the cost of health and social care in the last year and three months of life, shows that 70% of all health and social care costs are due to acute admissions, mostly unplanned. That is what we have to change to deliver effective care.

I was quite shocked in my preparation for this Committee to discover that if you look at the total NHS spend on palliative and end of life care—this is data from 2011, which is the last time it was looked at in detail—even in the best case scenario, it is only about £450 million for the whole country. That is half the cost of running the hospital where I work in a year and that is distributed around the country. We are throwing peanuts in terms of resources to try and crack a problem which is really important in people's needs and it is not being addressed.

Q4 Chair: Can I clarify that figure? Is it £450 million across the whole country?

Dr Murtagh: Yes, across the whole country. That is data from the third annual report from the End of Life Care Strategy where there was a survey of all PCTs at that time looking to see the total cost on specialist palliative care and end of life care.

Q5 Andrew Percy: What does that figure include in the definition of—

Dr Murtagh: That is a very good question, because PCTs were just asked the question and nobody really did any validity checking to understand what they were putting into that pot or not.

Q6 Chair: It is referring to the PCTs, not the current situation.

Dr Murtagh: That is not the current situation.

Q7 Chair: We are going to return to commissioning later, but that would be your opening comment thing about what we could do.

Dr Murtagh: Yes, but I would say that, whichever way you cut the cake, the resources to deliver to this are tiny in comparison to the demand as people get older with complex care morbidities. So we should stop throwing the pebbles at this problem and start to think about how we can resource it effectively.

Q8 Chair: Thank you. Simon, would you like to answer next?

Simon Chapman: Yes. Fliss has given a very comprehensive answer, pretty much all of which I would agree with. Building on that, co-ordination is something that consistently people approaching the end of life and those caring for them tell us that they need; when they have the experience of well co-ordinated care it is wonderful, but when they do not it becomes extremely problematic. Allied to that is better working between services, so particularly making access to social care free and fast is really important, and round-the-clock access to care to enable people to be supported in the place that they want to be, all three of which will have an impact on hospital admissions as well, avoiding unnecessary admissions. There was some data from the National End of Life Care Intelligence Network a few years ago which recorded 89,000 admissions for people in the last year of life, of which 79,000 were emergencies. I think that is in relation to people with dementia—I can send clarity in relation to that afterwards—but that shows something of the importance of getting those things in place. Combined with that, research is really important, and I suspect we will be getting to that.

The big thing in palliative and end of life care is still the priority that is attached to it. I have been working in and around palliative care for about 12 years, which makes me the least experienced of the three of us on the panel, but throughout that time the thing we have consistently struggled with is lack of importance being attached to palliative and end of life care, to this important universal time of life, particularly within the NHS figures, if this is just quoted in relation to the difference between the voluntary sector and NHS spending. It would be good if a poor experience of care at the end of life could be seen as a never event within the NHS, and perhaps we could work out how that might be constructed in terms of identifying that somebody is dying and then making sure that they have a care plan in place, that it is being used, it is comprehensive and was not run up a few minutes before they died.

An episode of poor care for somebody at the end of life, letting someone down in their last experience, their last contact, with the health and care services should be seen as a never event and should be a matter for considerable soul-searching. It is not at the moment.

Q9 Chair: Thank you. Professor Sir Mike.

Professor Sir Mike Richards: I find myself in very close agreement with my two colleagues and with all that Fliss was saying about the specific areas that we need to do. I certainly find myself agreeing with her on the £450 million figure because I must have been responsible for that at the time as I published that report with the Department of Health. The other thing I do remember from that report is the wide variation between PCTs and the expenditure. I think—although I have not looked at it for four years—that it was about a tenfold variation between PCTs. But, actually, like Simon, I think the key priority is to raise the priority of end of life care—the profile. It is true that we need to do the same both in health care and adult social care. We also need to show how it can be done well. I am absolutely convinced that it can be done well, because over the past 16 months or so since we have been inspecting hospitals, care homes, GP practices and community health services, we have seen examples of it being done well. One of the things we need to be able to do is to raise the profile, measure what is good, publish what

is good and then drive improvement through shining a spotlight. That is certainly what we at the Care Quality Commission are doing.

Q10 Chair: Hopefully we will return to that later on this afternoon, but, before I finish, could you clarify for the inquiry what proportion of those receiving specialist palliative care are people with a cancer diagnosis and whether you feel there is a problem and a huge gap for those who do not have a cancer diagnosis? Should we be doing more and how can we go about it would be my question, Dr Murtagh?

Dr Murtagh: If we look at the minimum dataset, which is the best evidence we have about this, it does show that the majority of people who receive specialist palliative care have cancer. It depends which part of the services you look at as to the proportion. Taking them all together, it is, I think now, between 15% and 20% who have non-cancer. If you look at hospital advisory palliative care, it is markedly higher, whereas if you look in hospice in-patient beds it is lower. That does not reflect the demographics, as we know.

Simon Chapman: Fliss kindly referred to that and appendix 2 of our written evidence sets out the figures there, but, as she said, there is a range between about 28% of people in hospitals and about 12% to 13% in in-patient services. Again, we can make sure those figures are set out clearly before you, but certainly you are much more likely to have access to specialist palliative care if you have cancer than if you have a range of other conditions.

Q11 Chair: Would you agree with those who feel this is a huge gap in the service and that we should be doing more to extend specialist palliative care services to other diagnosis areas—

Simon Chapman: Yes, we would.

Q12 Chair: —particularly for people with, for example, dementia and other conditions?

Simon Chapman: Absolutely. It is not just, if you like, thinking about cancer. It is about people with all the complex co-morbidities that increasingly are going to be faced. There is an important issue about future-proofing specialist palliative care and making sure both that those working within it have the expertise to provide care for people with multiple conditions, but also, I think importantly, that people are being referred to specialist palliative care services. We might touch on this later, but one of the issues that still come up is the sense that dying, in some parts of the NHS, is still regarded as a professional failure as opposed to an inevitability. There is still too much emphasis on so-called heroic measures. Whether there is anything heroic about depriving somebody of comfort in the last year of life is a question up for debate.

Q13 Chair: What is the key barrier to that? Is it a lack of referrals or that referrals are being turned down because there is not resourcing? How do we improve the access? Where is that key barrier, do you think?

Professor Sir Mike Richards: I would say largely it is lack of referral. I completely agree with the overall figure of it being only 15% to 20% of all people seen by specialist palliative care who are non-cancer. It is worth remembering that, in the context of looking at the other way round, only about one in four of the population do die of cancer—when I say "only", I know it is still a very large number—so it is skewed. We see in the hospital sector, again, huge variation. In some specialist palliative care teams over half of all the referrals are non-cancer, but that is the exception and not the rule. So it can be done; hospitals can identify these patients and can refer them to specialist palliative care, but it is not always done.

Chair: Thank you very much. I am going to come on to Barbara and then Andrew.

Q14 Barbara Keeley: My experience as an MP is that spouses and families of people who have died after having dementia are often very disturbed at the end and they did not get that same support. It is tragic to see somebody who has not had the support that, say, a cancer patient's family would have had, not understanding the end, arguing with the treatment, thinking nobody cared and so on. The same is surely true of stroke and cardiac disease in some cases. There are two wards in my constituency where stroke and cardiovascular disease are the real killers, yet those patients and their families are not getting the support. What is going to make the change, in your view? Everybody is nodding and saying, "The numbers are these," and in some places, as you say, Professor Sir Mike, sometimes it is 50%, but how do we start to make it happen elsewhere for these other conditions?

Dr Murtagh: One of the challenges is that we do not necessarily know the best models of palliative and end of life care in the non-cancer conditions. There is an assumption perhaps that applying the cancer model will work. We do not know that. In order to discover the best ways, we need to do the research. Could I point out to you that 10p in every £100 spent on health services research is devoted to palliative and end of life research—10p, that is. It is not even a £1 out of every £100, but 10p; it is tiny. We have tried to work very hard at the Cicely Saunders Institute to identify how you identify the non-cancer patients earlier so that they get the maximum benefit from palliative involvement. We have various trials that we have run. For example, there is a breathlessness study which shows that, if you work with people to help relieve their breathlessness, not only do they get better mastery over the symptom but they survive longer in the non-cancer group, which is an unexpected finding. There are lots of things that need to be done to understand how you identify people early and how you deliver care. It may not necessarily be continuous; it might be in bursts of palliative and supportive care alongside their other services. We do not have the research to tell us the best ways to do it yet.

The other big reason it does not happen is that the culture of our hospitals is around acute care and the acute care model. The fact that you can do things to people to cure them or get them better is the whole foundational model of how we think about health care and it is

not one that is fit for the current time. We all know that, so how do we change towards management of long-term conditions towards a decline, towards the end? How do we know when to shift from the very active interventional approach in cardiology, where they can do some amazing things, to introducing the idea that this is a condition from which someone is going to die? We need to think with them about their preferences and priorities in that light.

I would also point you to a survey we did looking at the public preferences. That shows very clearly that the public will prioritise quality of life over quantity, in distinct contrast to their professionals, who put quantity of life very highly. When you look at that discrepancy, you can then understand why it is that people themselves demand better quality, even at the cost of fewer months of life. That is quite a contrast.

Professor Sir Mike Richards: Going back to the question about stroke and heart disease, for example, with a lot of patients with established heart failure we know their prognosis is likely to be worse than the average patient with cancer, so we can identify those. There are lots of opportunities—and we need to make sure we maximise each—when we can recognise this. For example, when somebody comes into a hospital as an acute admission, are we asking the question about what is the possibility that this person is going to die in the next year? There are lots of different ways of asking that question, and others probably have more expertise in that than I, but how likely are they to die? If they are likely to die, are they aware of that? Is anybody else aware of that? What planning is being done with them for that? One of the ways that we can help with this in hospitals, where people come in often through the A and E department and may end up on an acute medical ward, is by asking how integrated is the specialist palliative care team with the acute medical ward? Are they there for the early morning ward rounds and able to advise on patients who really have a high risk of not recovering or not surviving many more months? Soon after people have gone into a care home is another opportunity. Most people who are going into a care home know that they have given up their own home. The thought that this may be the last place they are going to have as their place of residence before they die has occurred to them, so the good care homes will open those conversations with the patient. I do not think it matters so much what the diagnosis is, but are those conversations happening?

Q15 Barbara Keeley: Can I ask another short question? You asked the question whether the specialist palliative care teams are integrated and working together. What is your answer? Do you think yes or no?

Professor Sir Mike Richards: My answer is that we have now inspected over half of all the acute hospitals in England and we see wide variation. We see variation such that in some places the specialist palliative care team is extremely well integrated with other hospital teams, and, in one of the hospitals that we have deemed to be outstanding in this regard, the end of life steering group is not chaired by a specialist in palliative care but by a surgeon. But there is a whole-hospital approach to this and it is having an extremely good impact on the care given throughout the hospital. It is not surprising that that is also the hospital that has more than 50% of the referrals being non-cancer. So it can be done. It just is not being done equally at the moment.

Simon Chapman: Can I come back on that, accepting again and agreeing with all that Mike and Fliss have said? Part of the answer to the question is again about the priority attached to this by commissioners and this sense and understanding that palliative care is something for people with cancer rather than something that is applicable to everybody regardless of condition. Picking up on the hospital point, we know, for example, that less than a quarter of hospitals have round-the-clock access to specialist palliative care teams throughout the week, which again comes back to this lack of priority that is being attached to it.

The important thing in all of this is about fuelling demand. It is not just a priority within the NHS; it is about having a national conversation and discussion about end of life care and dying, making sure that this is something which is seen as an increasing political priority, which is why we and our voluntary sector colleagues are delighted that the Committee is putting some attention into end of life care. We need, as a society, to be much more aware of the obvious truism that we all die, but then to be more prepared for this universal life event than we are. We need to be more prepared to talk about it, to discuss it and to plan ahead for our own end of life and that of people who are close to us. That is the sort of thing that we are trying to do through Dying Matters, making sure that that public awareness—but, really importantly, behaviour change—leads to change of attitudes and to changes in the way people approach the end of life. It is really important.

Chair: Thank you.

Q16 Andrew George: In terms of the terminology which you are using—end of life care—I know, Dr Murtagh, you are suggesting that since that expression has been used it is only adding to confusion in terms of the understanding of what this process is. You clearly, in your evidence so far, prefer to err on the side of using the expression "palliative". Have you made any kind of advance in seeking to evangelise that point?

Dr Murtagh: It is also supported by Jane Seymour's evidence as well—from Nottingham. The difficulty I and many of my colleagues have with end of life care is that it is defined by the end of life, and we know from the data about prognostication how difficult it can be to predict when end of life is going to be. It allows for a lot of wriggle room, if you like. Professionals—clinicians—think, "Maybe it is not end of life yet," but we know, from the re-admission of someone or their complex co-morbidity, that the chances are they probably are relatively close to end of life care and to the end of their life. My difficulty is that it can only be defined retrospectively, in effect.

A patient said to me recently—and it made me think—"It is not the end of my life that I am worried about; it is about the bit till I get there." It does not make sense for patients to call it end of life care. It is hard for professionals to prognosticate anyway, so GPs do not put people into the 1% that they are trying to identify because they think, especially in non-cancer, that it is quite hard to tell. So, in terms of what it means, it is probably not very meaningful. Every single time palliative care has had a discussion through the 30, 40 or 50 years it has been around, it has been said, "We need a new name because nobody likes it," and every single time there is a proposal for a different name. It is actually that people do not want to grapple with the issues, whatever you call it. My suggestion would

be that we stick with palliative care—we all know it by the same name—and we bring that to the public, as you are doing with the dying awareness, and we make people more aware of the meaning of that word, what it might represent and that there will be a time in their life when they may want to think about saying no to the more technological interventions which can offer little benefit, and to go for more quality for the time that they have remaining and be supported to live as well as possible until the end of life. It is the living bit and living well that really matters, not the dying bit and not the end of life bit.

Q17 Andrew George: I get the point that you can only know in retrospect that someone is going to die or approximately when. You also contrasted the palliative model versus the acute model, as you called it. I am putting it in rather simplistic terms, but I think you were saying the palliative concerns itself with quality more than quantity and the acute is more concerned with quantity than quality of life. The question really arises what, therefore, is the difference between the provision of good pain relief and palliative care?

Dr Murtagh: I would say that that is similar to supportive care, and people sometimes say to me, "What is the difference between supportive and palliative care?" The difference for palliative care is that it is life limiting and life threatening, and time is in some way short. But I think people should have good pain control whether they are five years out, four years out or two weeks out. It may be delivered in different teams; it may be that the acute pain team addresses something which is curable, and it may be that the palliative team addresses something where someone has an advanced disease, but pain needs to be addressed equally to other metrics. Pain is not prioritised. It is as poor sometimes post-surgical as it is for palliative care. Those are the issues which we need to bring in alongside some of the acute interventions, and they have not had the priority; they have not had the emphasis.

Professor Sir Mike Richards: Can I have a go at this one as well? The first thing is that I honestly do not think that what it is called is the biggest issue. I can give you the reason why we went for the term End of Life Care Strategy back in 2008 because I was partly responsible for it. It was because palliative care was so heavily associated with cancer. This was to demonstrate that we were trying to get away from that. I would slightly disagree with Fliss on this—it is the first thing we have disagreed on—in that we need to ask ourselves the question whether this person is likely to be approaching the end of life. That is the question. We cannot be sure when it is going to be, but to what extent is this a likelihood, a possibility or very remote? That is a frame of mind that we do need to get into, but I do not think it is the be-all and end-all. With pain relief, of course it is different. You may have back pain for 50 years that needs pain relief, or other sorts of pain. Pain relief is part of palliative care but pain relief is much broader as well.

Q18 Andrew George: Can I try something else? I appreciate that this is about dancing on the head of a pin and perhaps this is a semantic argument—I do not know—but is there a point about the fact that the administration of the remedy or the treatment to a patient may hasten a death or shorten life? Is that the distinction between them?

Professor Sir Mike Richards: No. In fact, I think Fliss was referring to a study done earlier, a randomised control trial of people with lung cancer where one group were referred to specialist palliative care very soon after diagnosis and the others were only referred later on when the need apparently arose and the group that were referred early on lived longer. So that one has hit that one on the head, frankly.

Simon Chapman: Can I come in on this? There is a myth here which raises its head a little and which needs to be brought out and, as Fliss said, nailed. It is the sense sometimes, particularly in relation to the use of opioids, that doctors simply, on the quiet, increase the uptake of opioids by a little and they are quickly, mercifully and gently hastening the person into death. I bow to the experience of both my clinical colleagues here because I am not a clinician, but my absolutely clear understanding on this is that, if you are applying opioids properly through titration where you are increasing the doses in small increments, there is a very clear difference between the amount required to address the pain and anything required to achieve levels of fatal toxicity. This is quite a danger because the myth leads people to think that people have died wrongly, if you like, as a result of the legitimate use of opioids, and that leads to fears about use of opioids, which are really problematic.

Dr Murtagh: Could I emphasise Mike's reference to the Temel study? It was published in the *New England Journal of Medicine* in 2010. They were shocked to see—the research team did not expect this—that, when they gave early palliative care assessments and interventions to a group of people with advanced lung cancer, the people who had early palliative care lived longer. If you were developing a new chemotherapy drug and you saw that kind of survival improvement, you would be delighted and NICE would be very happy with it. But what they saw was that this approach stopped people dying sooner because they no longer had toxic chemotherapy interventions very close to the end of life which were harming them, and they did not have other technological interventions—they were not in hospital getting infections and so on. So more of them die at home, more of them are in the place that they want to be, and they have better quality of life but they live a bit longer. That study is being currently followed again in this country and we do not know yet whether it applies in other conditions and whether it also applies in a UK population because the health system is different, but I would be very surprised if we do not see something similar.

I would also say that the study that Irene Higginson has finished, an RCT published in *Lancet Respiratory Medicine* recently, shows that if you give the breathlessness service, supporting people in a complex way with managing their breathlessness, those with non-cancer lung disease actually live longer. So, again, you see this effect; people are empowered to take control and to make choices, and do not rely so much on the acute hospital-based care, they are more at home and they do live longer. It is an important consideration.

Q19 Andrew George: I am concerned partly by the evidence that you have already referred to, not just then but earlier, in relation to what sounds to be a significant variability in the delivery of end of life/palliative care across the country as a whole. I assume that this is

not caused by what we have just had, which is the potentially merely semantic argument about what is end of life and what is palliative. Do you think there is a need for greater clarity and greater, if you like, standards and clarification across the country as a whole so that acute providers and palliative services are clear about what the standards and protocols should be?

Professor Sir Mike Richards: One of the best bits of evidence around the variation geographically comes from something called the VOICES survey. This is a survey of bereaved relatives conducted a few months after a person has died and it is conducted on behalf of the Department of Health—now NHS England—by the Office for National Statistics. It takes a wide sample across the country of people who have died. It has given us really good evidence of variation. We know that there is variation between what relatives say about the quality of care delivered to their loved ones in the last three months, or even the last two days of life. There is a difference according to whether the person was dying of cancer or not cancer; there is difference according to geography. There are a whole range of differences. We can also see, not surprisingly, that people who die in hospices come out best; one would expect that. People who die at home or in care homes do relatively well. It is people who die in hospitals where the comments from relatives are much less favourable.

Q20 Andrew George: Are not the circumstances for those in acute hospitals likely to be that they are in more complex or catastrophic circumstances themselves?

Professor Sir Mike Richards: It may be; that is true, but it none the less shows us that there is a lot more that we could do there and there are variations geographically again. Because of the scale of the survey—I will put a plug in here that I would like to see the survey done on a much larger scale so that we could get down to the individual CCG or the individual hospital and really make comments on that—we are seeing, in population sizes of around a million, really quite marked differences in what relatives are saying about care.

Q21 Andrew George: But are you also confirming that hospices clearly provide the exemplar or blueprint which others should follow, or is that wrong?

Dr Murtagh: Only 4% of people will get to die in a hospice. The hospices do provide an exemplar and the data from VOICES shows that care in hospices is excellent at end of life. One of the troubles with the hospital-based services is that there is very little palliative care input in the acute hospitals. I can give you an example of King's, where I work. We see 1,300 referrals a year. There are 2.5 consultants, two doctors in training, four nurses and a social worker. We try and see that volume—1,300 a year. It is a huge amount. We work really closely with our community palliative care colleagues, and we try to ensure that people get out of hospital quickly and that they get excellent care for the dying, and so on, but it is an uphill struggle because the resources are so few. That is not different from any other big London hospital and it is even less in some of the district general hospitals. One of the things this Committee could usefully consider is improving the hospital proportion of palliative care to work with the community models that we know work really well.

Q22 Chair: Before we come on to the Liverpool Care Pathway, can I clarify is this variation an issue that the CQC is going to be addressing?

Professor Sir Mike Richards: Yes, absolutely it is. We have made end of life care a priority. We have defined it as one of the core services that we always look at, both in the acute hospital and in community health services. It is also looked at in care homes and in general practice. It is absolutely firmly part of our approach. Wherever we go, whatever service we are looking at, we ask five questions. Is it safe? Is it effective? Is it caring? Is it responsive? Is it well led? We apply exactly that same approach to end of life care as we do to the other core services. In a hospital, for example, not surprisingly, we always look at the A and E department, the medical wards, surgical wards, critical care, maternity and so on. So end of life care we deliberately have made a core service in itself.

Q23 Chair: What marker are you using for effective? In effect, how are you measuring a good death?

Professor Sir Mike Richards: We look at a range of markers. There is no one marker for each of these, but for effective, for example, we look at the extent to which they have processes in place for pain relief and what they can tell us. Have they conducted audits of pain or other symptom control relief? We look at whether they have care plans, because there is a lot of evidence that care planning leads to better care. We look at access to specialist palliative care and whether the patient was seen by specialist palliative care. That is because, again, as Fliss has said, those who are referred tend to do better. We look at multidisciplinary team working and look at the audits that they conduct of outcomes, the National Care of the Dying Audit of hospitals being one of those. So it is how closely they are conforming to NICE quality standards—NICE quality standard 13. Some of the things in NICE quality standard 13 we would put into other ones of our key questions, but many of them fit into our effective domain.

Q24 Chair: Thank you. Simon, can you make it brief?

Simon Chapman: I have terribly brief points in relation to this. The first is that I understand why Fliss is an academic and Mike is a regulator. You used the word "variation" because they need to be more measured than I, as a member of a campaigning charity, need to be. But it does cover up and can be used to mask words or phrases such as unfairness, low quality care, inconsistency or lack of priority. I would urge the Committee to veer towards calling it as it is, or as the Committee sees it, in its report.

The second point I want to make, which backs all this up, is that work is under way at the moment to develop a pilot to enable individual outcomes data to be collected for people receiving palliative care at the end of life. This would make an enormous difference. If we were able to collect and measure data about the treatment or care that people receive through particular services, we would then be able much better to measure what the impact and effectiveness of those services is. Fliss is involved in some of that. That, again, would be terribly useful.

Professor Sir Mike Richards: Can I just reassure the Committee that we do call it as it is? We use four words—or five actually: outstanding, good, requires improvement and inadequate. These are exactly the same words as are used by Ofsted, as you may have recognised. In the first 62 trusts that we have rated specifically on end of life care, we have rated three as outstanding, 32 as good, 26 as requires improvement, and we have had one rated as inadequate. Those numbers are obviously building up all the time, but those, I think, are in our evidence to you.

Chair: Thank you very much.

Q25 David Tredinnick: I want to ask some questions about the Liverpool Care Pathway, but before I do can I take you back, Mr Chapman, to something you said earlier? You talked about an heroic measure, I think, did you? What is an heroic measure?

Simon Chapman: Yes, it is a phrase I mentioned. It was used in the context of doing your level best to keep somebody alive regardless of quality of life. That is what I meant in that particular context.

Q26 David Tredinnick: Thank you. What has been the impact on delivery of end of life care in hospital following the withdrawal of the Liverpool Care Pathway?

Professor Sir Mike Richards: Shall I take that one to begin with as it is specifically about hospitals? As Committee Members will know, a date was set by which the Liverpool Care Pathway should have been withdrawn. That was 14 July 2014. The first thing that we inquire about is whether it has been withdrawn. There was a hospital that we saw that had only fairly recently withdrawn it, but I can confirm that I have yet to come across a hospital where it has not been withdrawn. What we then ask is what people are putting in its place. Again, this is where we see variation. Some people, from very early on, when Baroness Neuberger's review and its findings were known, immediately set to and decided, "Right, what are we going to put in its place? Let's phase out the Liverpool Care Pathway." Others, who waited till the last minute, around July of last year, were still telling us, "We are just getting our plans in place." So, again, there is wide variation in what people were doing.

This reflects very much on our so-called well-led domain, when asking, what is the leadership of this service—not just the leadership of the specialist palliative care team but the leadership of what I would call end of life care throughout the hospital? At what level is this recognised? I have been to hospitals where it is very clear that those leading end of life care have direct access to the chief executive and the director of nursing, and others where that is not the case. Those where there is senior leadership and oversight tend to have made much more progress in moving on to what are now called the five priorities for care. Again, in that, as in everything else, there is wide variation.

Q27 David Tredinnick: But was the independent panel that reviewed the Liverpool Care Pathway right to call for its total withdrawal based on evidence that some staff only were not using it as it had been intended, using a one-size-fits-all or generic approach? Was that completely over the top and pandering to media hysteria?

Professor Sir Mike Richards: People have different views on that.

Q28 David Tredinnick: I am asking you for your view.

Professor Sir Mike Richards: The problem was that it had got such a bad name that it had to be phased out and a new approach found. Having said that, I would emphasise that where it was being used well—and there were a lot of places it was being used well—it had been a useful tool, if you like, or approach to making sure that end of life care was delivered well. That does not mean that it is the only way of doing it. That is now being replaced, but it is taking time and there has been a hiatus.

Simon Chapman: Can I come in on this as well? I would agree with what Mike said that, in the end, it did have to be phased out because there was a loss of public confidence in it and a blow to staff morale as well within all of this. This comes back to the point I made right at the very beginning about the priority that is attached to end of life care and was being attached to the Liverpool Care Pathway. This is precisely, as has been echoed in Mike's answer, about the leadership and importance attached to this within individual hospitals. The Liverpool Care Pathway was a pretty sophisticated, clinical audit-based tool, but it was designed as a prompt and it had become a crutch. As a matter of English, a prompt means reminding you of something that you already know, whereas a crutch is leaning on something that is broken or was never fixed in the first place. Too often, people at the top of hospitals—and this is a matter of governance for those hospitals, I would suggest—were content to let the Liverpool Care Pathway be used by staff who were inadequately trained in that competence and confidence in relation to it. I remember a conversation I had with a palliative medicine consultant shortly before it was phased out and she had received a telephone call from a colleague in an acute hospital saying, "Help. I don't know what to do now I don't have the LCP," to which it seemed to me that the obvious answer was, "Did you know what you had to do when you had the LCP, because it was not there to tell you what to do? It was there as a prompt and a reminder." It was because too many hospitals were content to see it as something that it wasn't that many of the problems came to pass.

Dr Murtagh: There was one major difficulty with the Liverpool Care Pathway, which was that it was about measuring processes. It did not measure outcomes. What I mean by outcomes is the difference made to people's health or well-being. That was a real problem for it because it did not capture whether the application of it was making that difference. As Mike says, in some places it probably was great and making a big difference, and in others it was not doing that and people died badly.

I would say there is a real need in palliative care to think about measuring the difference that we make and measuring the outcomes. That is work that is going forward nationally, led by Public Health England, and it is critically important. It is only if we show the difference made to pain management, breathlessness management and other difficult

symptoms, and improvements in emotional well-being and family support, that we can show these things are making a difference. When there are excellent models of practice, which I think you will hear about later from one of the hospices, where those things are in place, we need to see how they are making a difference and roll that out so that it happens everywhere and it is not pockets of excellence but it happens universally.

Q29 David Tredinnick: The Secretary of State for Health has made it quite clear that patients should be at the heart of the health service.

Dr Murtagh: Yes.

Q30 David Tredinnick: The implication is not clinicians.

Dr Murtagh: Yes.

Q31 David Tredinnick: The Leadership Alliance for the Care of Dying People—LACDP—has said in its report that the focus should be on the individual needs and wishes of the dying person and those closest to them. Do you subscribe to that view?

Dr Murtagh: Yes.

Simon Chapman: Yes.

Professor Sir Mike Richards: Yes.

Q32 David Tredinnick: In that case, carers of dying people and those who are dying might want to choose different approaches. I am mindful about what you said, Dr Murtagh, about toxic drugs at the end of life—I do not know whether those were your words—hastening death. I have a question about organisations like IFPA—the International Federation of Professional Aromatherapists—who are in my constituency. Just for clarity, an aromatherapy treatment is one "designed to help maintain physical, emotional and spiritual wellbeing by the correct application of pure essential oils". I have a centre in my constituency with various manufacturers, therapists and this international organisation. Should greater use be made of people like the aromatherapists? In the courses I have attended, for example, lavender—and there are very many different types of lavender, as you probably will be aware—when massaged, can give great relief from stress and pain.

Dr Murtagh: I am an academic and I would say that we need two sets of information in order to decide whether a specific intervention is useful or not. One is, what are the outcomes from it, so what difference is made to health and well-being? The other component of what we need to understand is what it does in terms of people's experience of care. We need both outcome measures and experience measures in palliative care which tell us what interventions are doing. If you can say to me that there is evidence which shows that whatever intervention improves outcomes and experience—

Q33 David Tredinnick: May I write to you through the Committee?

Dr Murtagh:—then fine, but at the moment we do not have that evidence.

David Tredinnick: Thank you. That is all, Chair.

Chair: Thank you. Andrew.

Q34 Andrew George: This is still on the Liverpool Care Pathway. It seems that following 14 July last year a lot of hospital settings would be left in a potentially rudderless situation without any parameter against which they can guide the process. Professor Sir Mike, you are perhaps in a better position to answer this as an overview, but to what extent are you satisfied that the acute setting especially, or those settings which were using the LCP, had an adequate alternative in place?

Professor Sir Mike Richards: I cannot say that I am satisfied. I have said that, to the best of our knowledge, the Liverpool Care Pathway has been withdrawn, as was planned and recommended, and the pace at which different hospitals have moved to replace it has been variable. Some hospitals are taking a very active approach based on the five priorities; some are taking a very active approach based on the NICE quality standards and are making good progress because of that. For others it has created a hiatus.

Dr Murtagh: In some places I would say it has also pulled the scarce palliative resource to focus on the last week or two of life when they needed to be doing more work in early identification and getting people home.

Q35 Andrew George: Are there any elements of the LCP which are worthy of carrying forward into any replacement national standard?

Simon Chapman: It depends what you mean by "elements", but the sorts of decisions that it was covering, in terms of things like access to pain relief or withdrawal of blood tests, are the sorts of things and decision making that should be part and parcel of a comprehensive and holistic approach to end of life care decision making anyway.

Professor Sir Mike Richards: As Simon indicated earlier, it is the difference between a prompt and a crutch. Some places are using several of the same questions but putting them in the form of questions and not a tick box with just a box to tick, literally. So there are questions such as, "Have you considered what the nutrition and hydration requirements of this patient are? Have you asked them? Have you communicated with the relatives about the fact that this person is approaching the end of life or is likely to die within the next few days?" But those are questions rather than saying it is a tick box, and then you can develop the individualised care plan for that particular patient.

Simon Chapman: Curiously enough, the clinical audit way in which it was set up had the unintended consequence of it not being particularly person-centred in that you had to prescribe either that something be done or not done or there was a variation. In my view,

the variation should be, "What is the variation from the care plan that I have agreed with my health care team?"

Q36 Andrew George: Professor Sir Mike, you were saying earlier that you and the CQC were going into hospitals and assessing this area of activity on the basis of a five-point assessment. Each of those five areas all sounded like subjective assessments and I wonder whether it is possible to establish an objectivised method of working out whether end of life or palliative care is being adequately provided in the acute setting.

Professor Sir Mike Richards: The five priorities are very good as principles. Do we recognise who is approaching the end of life? Do we communicate well with them? Do we involve them in decisions? Do we think about their family's needs? Do we plan their care? Who could be against any one of those? We are all signed up to those. You are absolutely right that the key point is: how do we objectively measure? That is why we do it according to, "Is this safe?" One of the points is how they are identifying and when they are identifying people, but also then getting into specifics about pain relief, nutrition and hydration, the care plan and about the access to the specialist palliative team; is it a seven-day-a-week palliative care team or not? There are lots of specific questions that we report on.

May I recommend that you read the section on end of life care in the Frimley Park hospital report? If you Google Frimley Park hospital and the CQC, it comes up very quickly. Their report on end of life care would show you how we go about it and also what a really good hospital is doing in this regard.

Q37 Andrew George: Has not the Cicely Saunders Institute immediately come up with an alternative?

Dr Murtagh: No.

Q38 Andrew George: If you are focusing in that area of activity, I am surprised that you were not or may be able to say, "We will try this instead."

Dr Murtagh: Bear in mind that this is focused on the last few days, and much of our work is, more broadly, thinking about the last year of life, if one can tell, but perhaps more based upstream.

Simon Chapman: Hence the importance of the need to find a way of measuring outcomes and experiences for individual people. That is what would make a real difference, which is why Fliss and I have both alluded to it already.

Q39 Chair: May I clarify before we move on whether Frimley Park was the one hospital that you rated outstanding?

Professor Sir Mike Richards: It was the one adult hospital that we rated outstanding for end of life care. We have also rated Alderhey and Sheffield children's hospitals outstanding for end of life care. They did not get outstanding overall, whereas Frimley Park did.

Q40 Chair: Thank you. Dr Murtagh, can I ask if you have yourself an idea of what your preferred model would be as a replacement where you have identified very good practice?

Dr Murtagh: I am part of the palliative group in the London Cancer Alliance, a confederation of about half of London, and the various teams who were leading on implementing the priorities shared the different ways that they were trying to do that. There is no proscription about it, but there is a way of looking at the priorities and trying to identify whether they are being implemented.

Q41 Chair: Right. We heard informally as a Committee last night—one of the models presented to us was—about what happens in Wales. Are you aware that they—

Dr Murtagh: Yes, I am aware of that.

Q42 Chair: Do you have any thoughts about the model that happens in Wales?

Dr Murtagh: There is a real challenge to all of these things in that many look at processes. It is the challenge that Mike has in how he assesses quality when he goes and inspects. What you really want to see is what difference it made. The best way to capture that dying period is the post-bereavement survey, which is why VOICES has been so invaluable. Many individual organisations are doing their own post-bereavement surveys. They ask people after the death—usually a certain period of time afterwards—to reflect back on what was done well and what was not done well. Those are really useful ways of informing whether you are getting it right or not.

Q43 Chair: Is that a more useful way than having something which is inevitably going to be process-driven to a certain extent for the CQC?

Dr Murtagh: I think you need a bit of both.

Professor Sir Mike Richards: We need both. Because we believe that the processes are linked to outcomes, we do need to be measuring these processes. If you do not have syringe pumps, you are not going to be delivering good pain relief.

Q44 Chair: So you need to merge both. Is there any ongoing research that we can have an answer as to what is the approach we should be rolling out as best practice?

Dr Murtagh: That is a more complicated answer and it may take some time before we really know the best.

Q45 Chair: So we still do not know what is the best in terms of—
Dr Murtagh: Mike might.

Professor Sir Mike Richards: What we can say is that we will go on rating things and, hopefully, where they are outstanding we will try and distil those features that are outstanding. Although I mentioned Frimley Park as being outstanding, there are other ones that have some outstanding elements. There are hospitals that have trained-up nurses on every single ward of the hospital to be link nurses. There are hospitals that have very rapid discharge arrangements for when patients want to die at home, and by very rapid I mean within a few hours, not a few days, and there are places that have trained volunteers so that they can sit with people who are dying if the nursing staff do not have the time to do that. We are finding examples—and those are things just off the top of my head—of where we think there are outstanding elements of care. In a few months' time, I would hope that we would be in a position to bring those together and say, "Here are some very good ideas." It is not that we are going to say, "You must do things," but that these are things that our teams might suggest and, remember, our teams have experts on them. They have senior nurses and doctors, people who are experts in palliative care. It is a peer-review programme in that way, of being able to say, "What do we think is good?", and, "What do I want to take back to my own hospital?"

Dr Murtagh: It would be good to have that alongside the individual hospital-level VOICES data.

Professor Sir Mike Richards: Yes.

Dr Murtagh: That would be absolutely brilliant because then you could understand, "These are the processes that have to be in place to make it happen and here are the results that can be achieved." That is what we need to marry together.

Simon Chapman: The other thing that will in due course be able to be added into that is that the National Care of the Dying Audit of Hospitals is going to be repeated—funding is now in place for that—which is being done by the Royal College of Physicians. That audit will take place later in this year. It will be the first post-phase-out of the LCP audit.

Chair: Thank you. Let us go on to Barbara.

Q46 Barbara Keeley: Let us go on to preferred place of death. There are two different views here. The straightforward question is why are so many people not able to die in their stated preferred place? Is it solely about the availability of services, or there is also a suggestion here in some of the evidence we have that people then change their minds as death approaches about whether they want to die at home? What we have heard so far is that so many people want to die at home and, obviously, from the chart we have, the evidence is that

very small numbers of them are able to do so. But it seems too as if people start to want to prefer, for instance, hospices. Those are the two questions. Is it solely about services or is it also that, at certain points, people change their minds?

Professor Sir Mike Richards: In simple terms, I would say three things. We do not ask people where they want to die routinely. We ask some, but not all. We do not then plan and we do not co-ordinate. If we did all those three things, we would have a lot more people dying where they want to, but you are absolutely right that people do change their mind over the course of the illness and that is to be expected, and we should then be able to change the plan with them because that is what they want.

Dr Murtagh: Could I give you some more evidence about this? If you look at people in general, about two thirds would prefer a home death. It does vary slightly according to whether you ask people with advanced illness, their families or the public, but, in general, it is fair to say that about two thirds want to have a home death, but only about one in five do, so there is a big gap. We also know, though, that about 20% of people—about one in five—will probably or may change their mind. That is in the Cochrane review, so it is a very high standard of evidence. The trouble is that we do not know very much about that—about what makes people change their mind. I would say to you that the place is not at the top of people's list. If we go and ask the public or ill people—and this has been done—it is not at the top of their list. At the top of their list is to have it being free of pain, having other symptoms controlled, and making sure that they are not too much of a burden on their family and that the family have support. If they are in a situation where their family has loads of pressure, then they will change their mind and want to go somewhere. There is evidence in our report about place of death published by the Cicely Saunders Institute in 2010 that if you are older you are more likely to prefer hospice. That is about people being on their own at home, not having the appropriate support services or being too much of a stress for their family. As people get older, there is a greater preference for hospice because they see that as a place where the excellence of care can be delivered.

Q47 Barbara Keeley: Can I ask you—tied into my next question too, which is another question about quality—how do you stress-test this? I have seen examples whereby a planned death at home fell apart because of shortcomings of the GP, the district nurse services and, I have to say, sadly, a hospice nurse, who between them did not pull together the care and it all fell apart. You may think, in terms of planning, "I want to die at home and have a plan to do these things," but that may not work for you and you do not know, as the patient, do you? It is a difficult choice when there are so many unknowns. Clearly, if you are going to be on your own and are an elderly person, you do not have a family around you, but also how do you know if your family, as carers, could cope?

Dr Murtagh: Absolutely.

Q48 Barbara Keeley: With certain conditions, it just might be too much to ask. Those are my worries when we talk about it.

Dr Murtagh: You are absolutely right to have those worries and it does need to respond. It needs to be a flexible plan that can respond to those changing issues for people, but I

would draw your attention to Martin Bardsley's report. Out of all of the deaths in that report, only one in three had even one district nurse visit. That is a real issue. One reason for the inequity around the country is that district nursing provision in some places is scantily absent—there is none of it. I talked to some colleagues in Brighton & Hove and they have two commissioning group areas which abut: one service has district nursing and the other has very little. The kind of services that the palliative people have to deliver varies immensely because of that difference. I would say resources to support district nursing, which is so important for people in the last weeks and days of life at home, has to be a priority.

Q49 Barbara Keeley: My second question was really around—we have explored a lot of it—this issue of whether there is a definition of quality. It seems as if the CQC is working towards one. Professor Sir Mike, when you were talking about quality measures in hospitals, you mentioned, for instance, very rapid discharges of patients to die at home being a quality measure. But then if what happens later is not there, how can that hospital know that the team of a GP, district nurses and the hospice nurse will then do the job? They can do their bit fast, as you say, within hours, but how do they know what is beyond what they can do?

Professor Sir Mike Richards: It is because this is a co-ordinated discharge. When they are doing it, they have co-ordinated with the ambulance service, the community health services and the GP. They have put a package of care in place. This is usually for people who are only expected to live a further few days. They have ensured that there is a package there and they would not be sending the patient home unless they had got—

Q50 Barbara Keeley: Indeed, but I have known cases where that completely fell apart because the GP would not provide the pain control, the district nurses were overstretched and did not make it, and the hospice nurse was simply overstretched. When you have stretched community resources, you can have as fine a plan as you want but it can fall apart.

Professor Sir Mike Richards: But the best places—and I am not saying this happens everywhere as it certainly does not—are working with their commissioners, with the CCGs and this is planned with them. It is not just a reflection of the hospital; it is a reflection of the hospital and all the other services working together and planning out how often this is likely to happen, how it can be done and how it can be done rapidly. There are places that are doing it extremely well.

Q51 Barbara Keeley: Indeed, but if you are unlucky you end up in one that is not.

Professor Sir Mike Richards: That is true.

Q52 Barbara Keeley: That is a key point about district nurses. In other inquiries we have had it pointed out to us that we now have less than half the 12,000 district nurses we used to have.

Dr Murtagh: I would really urge you to read Martin Bardsley's report that looks at the last three months of life because it shows the proportionate costs of the different services: 70% is acute hospital unplanned admissions and the district nursing proportion is tiny; even the social care provision that he looked at, which was local authority provided, is very small, and yet we know that if that is provided it reduces the hospital admissions. He found it very hard to cost palliative care into that, but we know if you have good community palliative care your chances of staying and dying at home are doubled. We know that it can be done and we know what needs to be in place—good community palliative care but good district nursing and good GP provision. The GPs, of course, are really stretched; they do not have the time for the visits.

Simon Chapman: Again, at the risk of harping on about the point I made at the outset, Mike's point goes back to the priority attached to it by individual commissioners. But the point is well made. This is happening in some places and it should be happening everywhere, and would be, if this was seen as being something of sufficient importance.

Chair: Thank you. I know Andrew wants to come in.

Q53 Andrew Percy: Further to Barbara's point about people's choice of where to die, we have talked about home and hospices, and obviously we have talked about unplanned admissions to hospital. Have you done any work with regard to the role of community hospitals? One of the big demands in my area is that people get dragged off, particularly when they are acutely ill, to the district general hospital. Often when they are at the end of life they do not want to be in the district general but they would like to be at our local community hospital. They see that as dying in their own community then because they are not 35 miles away in Scunthorpe or 60 miles away in Grimsby.

Dr Murtagh: I can give you the names of two people who are doing work in this area. Sheila Payne, who was a professor at Lancaster, has done work in this area. She is now retired but is still involved there. There is also Catherine Evans, who works with us at the Cicely Saunders Institute, is currently undertaking work looking at those who are older with complex co-morbidities and the role of community hospitals in their care.

Q54 Andrew Percy: The system is kind of going the other way, though, since all the changes, and safety is now such a big issue. Admissions to community hospitals tend now to be via the district general, and if someone is very ill, which at the end of life they are, they never get back to the community hospital. Is there any work around how many people would prefer that setting as their end of—

Dr Murtagh: I do not know the evidence and that is why I am referring you to my colleague Catherine Evans, who can help you with this.

Andrew Percy: Maybe we can get something.

Chair: We will ask them informally and they can tell us their emerging evidence.

Could we go on a little bit further about the integration of health and social care and the cost of end of life? Barbara, did you want to carry on on that point about whether or not we should provide free social care at the end of life?

Q55 Barbara Keeley: Yes; it is a straightforward question really. There is a lot of campaigning round this and that will probably build up over the next few months. Should we accept that? What is the basis on which we should do that?

Simon Chapman: We would certainly urge you to accept it and we included that in our evidence. I am just trying to find the precise stat that we have on what we think it would save. It is not just about removing the means test for people approaching the end of life, which has also been supported both by the Palliative Care Funding Review and the Dilnot Commission—every committee that has looked at it so far has been made aware of the case for it—but it is also about the speed with which this happens. We have discussed already people having been discharged from hospital, but one of the barriers sometimes is access to social care. Making sure that that barrier is something that can be removed, and any boundary disputes between health and social care can be sorted out afterwards round the bedside of the person who is dying, would be a very efficient way of getting people out of hospital into the community settings that they want to be in.

Q56 Barbara Keeley: Is there also an issue around the varying levels of the NHS paying for continuing care? I was quite astonished at the point where my local PCT became a CCG to see that we funded in my local authority area five times the level of continuing care per head of the population than one of our adjoining authorities did. That is an enormous variation, is it not?

Simon Chapman: It is. Some colleagues in the voluntary sector commissioned a report from APM about that, which again showed a real inconsistency in the way in which continuing health care is being applied. There is a lack of national guidance about how this should apply to end of life care and that again would be very useful.

Q57 Rosie Cooper: In your written evidence to the inquiry you mention that you have written to NHS England to ask why end of life care had been given only, almost, a cursory mention in the Five Year Forward View. You argue that it should be core business for the NHS. As the NHS says its main role is to improve people's health outcomes, do you think that there is a role for yourselves and others to help the NHS with the culture change that re-thinking their role in providing end of life care services might require?

Simon Chapman: Absolutely, and we have written to NHS England about that. A meeting is due next month in relation to it. It is worth remembering, is it not, that modern palliative care, in the hospice movement, grew out of a reaction to what was seen as a failure in the care of dying people on the part of the NHS 30 or 40 years ago? You can still see in terms of some of the figures we have heard about—the financial spend, for example—that the

voluntary sector is shouldering a great deal of the burden in relation to that. We talk about the rhetoric of a cradle-to-grave NHS, and one of the reasons that we had an End of Life Care Strategy in 2008 was in recognition that the cradle end had received rather more attention and focus than the grave end and that balance needed to be restored. That remains the case today. High-level aspirational statements—for example, the End of Life Care Strategy—say that the way we care for dying people is a litmus test for health and care services and a measure of society as a whole. If we genuinely mean that—and this is back to my priority point—the sorts of inconsistency that we have heard about that the CQC are picking up on in their inspections and that we have seen, for example, from the VOICES survey as well, simply would not be acceptable. That degree of inconsistency would not be seen as acceptable in any other area of health care.

Q58 Rosie Cooper: Why do you think we do accept it?

Simon Chapman: There is potentially quite a complex answer in relation to that, but, very briefly, part of it is the taboo that has grown up around death, dying and bereavement. It becomes self-fulfilling. If we think it is going to be a frightening and scary experience and it turns out to be that, then that is what we expected.

Going back to your question about whether there is a role for the NHS to work around culture change, the answer is emphatically yes. It is good that in the Five Year Forward View the NHS is recognising that it does not always own every problem or the answers to every problem and it is much more open to working with the voluntary sector. But I would challenge culture change because we need to be sharper than that. Culture change needs to be measured by attitudinal change but also behaviour change. In the end, we are after a different way of thinking and a different way of doing things.

Professor Sir Mike Richards: I would absolutely agree that we need to bring about culture change. I would re-emphasise the fact that at the CQC we have deliberately given priority to end of life care. That was a very deliberate decision that was shared across the CQC and it is across all the inspections that we do. But where we do see the culture having changed in some of the very best hospitals—the ones we have rated as outstanding—we hear it not just from the specialists. If you read the Frimley Park report, which I have referred to before, you will read about what the porters thought about the end of life care and what the health care support workers say about end of life care. They feel very positive about the care that is being given within that hospital and they mind about it. So it is possible to get that culture embedded in a hospital.

Q59 Rosie Cooper: I am wondering whether we have got into this position not just about the fear of death but the idea that social care is divorced from acute care and how you manage the end of life treatment of people. When they are on their own, not only are they on their own and it is dire, but it also does not cost you as much money and the consequences are just dreadful. Is it money as well as edges of culture?

Professor Sir Mike Richards: Money is a challenge but it is also about how we integrate things and how we integrate services. I have recently been to a hospital where the

hospital manages a GP service and that GP service looks after almost all of the care homes in that CCG. They have good medical care being given to the people in care homes. That may actually prevent people then being admitted to hospitals, but it also ensures they are getting good care in those homes. So there are new and interesting ways we can do this.

Q60 Rosie Cooper: I will end now, but the bits of this that I have seen are of somebody being admitted to a care home in the end stages of dementia and the first thing that happened was his GP, who had never ever seen this patient before, came in, looked at the medicines that were allocated and just said, "No, no, no," and just changed it all at a stroke. That kind of disconnect is terrifying.

Professor Sir Mike Richards: That goes back to this wide variation that we see.

Chair: Thank you.

Andrew George: I am conscious of time.

Chair: Yes, because we are near to a vote now.

Q61 Andrew George: I want to raise a further question on the issue of the cost of care. This is primarily to Mr Chapman and Dr Murtagh, if I may, in relation to a point which Barbara was raising earlier about the cost of continuing care. As far as I can see—and Barbara elucidated this point earlier—across the country as a whole, there seems to be incredible variability in terms of what hurdles one has to go through in order to enjoy the benefits of the state helping to bear some of the financial burden. There is an interrelation between this and the narrative, which I think the state is keen to advance, which is that people prefer to die at home, and, of course, it takes it, hopefully, off the public purse in that process. I want to get your commentary on where you think we are—whether you think there is satisfactory and clear guidance as to when continuing care cuts in and when it does not. It seems to me that there is tremendous inconsistency. Am I right in coming to that conclusion?

Dr Murtagh: Yes. Because I work in a hospital which is both a district general and a regional centre, we work with lots of different CCGs in terms of their continuing care. I can tell you that their approach to that varies—the bars that need to be leapt over. More importantly, what will then be provided or not varies.

Andrew George: Right, okay.

Dr Murtagh: So there is a variation in the bar but also a variation in what will be funded.

Q62 Chair: Just to clarify, briefly, would all members of the panel support having free end of life care—social care?

Dr Murtagh: Yes.

Simon Chapman: Yes.

Professor Sir Mike Richards: Yes.

Q63 Chair: Thank you. That is nice and clear. One final area to raise with you as a panel is about planning care and how we can improve discussion with people well in advance about their plans, and, for example, the use of advance statements and advance decisions. In Australia they have an electronic model encouraging all Australians to make advance statements, as we understand it. Are you aware of anything that we could be doing and recommending that could improve discussions?

Dr Murtagh: I would say that the reviews of evidence around what works, in terms of advance care planning, highlight the importance of having skilled facilitators of those conversations. That is much more important than a draft document. People give more weight to that. It is having a conversation with a health professional that they have seen before and they can trust that can then follow through. That is the best way to get good advance care planning—somebody who is skilled at doing it and whom an individual can trust. It is very difficult if care is so fragmented that you do not see consistently the same person. It makes a huge difference to the quality of the advance care planning and whether it can make any difference in terms of delivering to someone's priorities.

Simon Chapman: I completely agree with that and there was an episode—I can send you details—reported last August, an example of a well-intentioned attempt to do advance care planning that went horribly wrong because it was done in a tick-box process by somebody who had not been well trained. Beyond that, it is the identification of the person for whom this sort of conversation is important and what stage of life they have reached, and then that discussion and recognition that it is a process that continues over time as the person's condition or conditions develop. It is also about making sure that there is good information sharing in place. The accurately but very public-unfriendly named EPaCCs—Electronic Palliative Care Co-ordination Systems—are a way forward in relation to this. In London it is called Coordinate My Care, which is altogether a more public-friendly approach to it. These are being rolled out. Public Health England produced a report about that. The challenges that they face are, first, making sure that all organisations that might be involved in a person's care genuinely can access them—we have done some initial surveying which suggests that that is not always the case, although we have not published it yet—and making sure that those are offered to everybody, not just, again, as we have seen so often with the history of palliative care, largely to people with cancer. It is making sure that they are offered to all those who are identified as approaching the end of life.

Q64 Chair: So offer them to more people but make sure it is a skilled facilitator who is delivering it, otherwise it is a process that might not be helpful.

Simon Chapman: Absolutely, and then that the person themselves and their carers can access the plan as well and make sure that it is kept up to date.

Q65 Chair: And they can update it.

Simon Chapman: Yes.

Q66 Chair: Would there be anything that you would want to add to that, Professor Sir Mike?

Professor Sir Mike Richards: I would totally agree.

Q67 Chair: There is one final point on the controversial issue of "do not resuscitate" decisions. As the CQC, are you coming across any unlawful practices where these are being recorded in notes without consultation with families, and, if so, what action would you take?

Professor Sir Mike Richards: We always look at the "do not attempt CPR" records in every hospital that we go into. We do see variations in practice. We see occasions when they have not been signed off by a consultant. We see quite a number of cases where they have not recorded, at least, that they have been discussed with a relative, and those contribute to our ratings. We do absolutely take that into account.

Q68 Chair: If you came across practice where it is being recorded in an unlawful manner, would you consider that to be a matter for regulators or a matter for referral to the police? I ask this simply because it has been raised with us by someone who felt it had been done in their relative's case.

Professor Sir Mike Richards: It would depend on the circumstance. Normally, if something had been done deliberately wrong, we would take that and work with the police. If we think things have been deliberately falsified, there are examples, whether it is in terms of cancer waiting times or whatever, where we have worked closely with the police to investigate what is happening. If we think it is just poor practice, we can issue a warning notice that can demand that people put things right very quickly and we will go back in, re-inspect and make sure that they have improved their practice. If they are not doing that, then we will escalate our enforcement activity and we could prosecute.

Chair: Thank you. Does anyone have any final questions or any points you have not been asked that you feel are important to make? No. Thank you very much for your time this afternoon.

Witnesses*:* **Giles Charnaud**, Chief Executive, Rowcroft Hospice, **Barbara Gelb OBE**, Chief Executive, Together for Short Lives, **Stephen Lowe,** Social Care Policy Adviser, Age UK, and **Alison Penny**, National Bereavement Alliance and Childhood Bereavement Network, gave evidence.

Q69 Chair: Welcome to our second panel. Thank you very much for your patience. For those following at home, could you introduce yourselves and say in what capacity you are here and who you are representing, perhaps starting with Giles Charnaud?

Giles Charnaud: My name is Giles Charnaud. I am the chief executive of Rowcroft hospice, an adult hospice in south Devon serving the Torbay and south Devon area, so it Teignbridge and South Hams.

Barbara Gelb: I am Barbara Gelb. I am the chief executive of Together for Short Lives, which is the leading charity for children's palliative care.

Stephen Lowe: I am Stephen Lowe. I am social care policy adviser for Age UK.

Alison Penny: I am Alison Penny. I co-ordinate the Childhood Bereavement Network, which is the national umbrella organisation for organisations supporting bereaved children and young people, including those bereaved suddenly as well as those through an expected death. I also provide some project co-ordination to the National Bereavement Alliance, which is a newly-emerging organisation for those providing bereavement support for all ages.

Q70 Chair: Thank you. Thank you also for sitting in on the last panel. I will start with a similar question that I asked them. What would make the greatest difference to the people that you are representing that you feel absolutely should be included in our report? Could you tell us the main points that you would wish to make, perhaps starting with Giles?

Giles Charnaud: Thank you. I would like to have in the report that end of life palliative care can be done very well and is being done very well in various parts of the country. It is an issue that will affect all of us: 1% of the population per year are in their last year of life and we will all join that 1% of the population at some point; 79% of people would prefer to die at home; 50% die in hospital, and only 5% would wish to die in hospital. I come from a part of the world where we have a population which is what the UK population is going to look like in 2035: we have 24% of the population over the age of 65. I believe we have good co-ordinated palliative and end of life care services and the statistics around place of death tend to support that because we have much lower hospital deaths than the England average and much higher home and care home deaths. I agree with the previous panel that the way this can be done is by good co-ordinated services, both between the hospice sector and the NHS. It has to be both of those.

I disagree that only 4% of people die in hospices, because I think that does not take account of the impact hospices have on deaths outside the hospice. As a society, we need to get away from the impression that hospices are buildings and beds. We provide community-based services, hospice at home services and IPU services, but we also provide education services that support the non-hospice providers of palliative care and care homes, and, indeed, the hospital district nurses, that enable them to deliver end of life palliative care services better than they would otherwise.

Barbara Gelb: May I ask you to repeat the question? Was it just one thing?

Q71 Chair: It was just to ask each of you to give us your summary of the key points that you think will make the biggest difference to the group that you are representing today.

Barbara Gelb: Than you. Care co-ordination and integration of services are absolutely critical in children's palliative care. By that, I mean integration between health and social care, between the statutory and voluntary sector, and with education services. Where young people who are in transition are concerned—by that, I mean young people moving from children's services into adult services—we would like to see much greater integration with employment services, higher and further education, and leisure services where that group of young people is concerned, as well as housing.

Children and young people's palliative care is different from adult palliative care in that it is not only about end of life. We would very much like to see this inquiry embrace that understanding of children's palliative care as being a whole journey from the time of diagnosis right through the trajectory of the illness itself to end of life and then death, and also post-death to bereavement support for the family. That journey can be very long where some children and young people are concerned. It can be many years. Diagnosis may take place at a very young age, and because of the advances in medical science these children and young people are living longer and longer. We would like that to be addressed and to be understood within this inquiry.

Integration is absolutely critical. We hear from families time and again that there is not the integration. What this means for families and parents is that they themselves have to navigate their way through the complexity of the poor communication between different agencies, and that is exhausting. Parents have to give up their jobs and full-time employment. In some cases, where there are two parents, both parents have to do that in order not only to care for the child but to navigate their way through the system. These children may have up to 35 or 40 professionals working with them. That lack of co-ordination is a critical problem in children's palliative care. That is the first key area.

The second key area relates to awareness and understanding. There were conversations in the last session about language and definitions in children's palliative care. We are very conscious that the generalist professionals—the GPs, who may only see one such child throughout their whole career, and education and social care staff and the generalist professions within the hospitals, the nurses—may not really understand children's palliative care and may not understand the very particular needs of this group of children. We would like to see much greater attention paid by Health Education England to the

training needs of generalist professionals so that they can better understand the needs of this relatively small group of children. We are talking about 40,000 children and young people up to the age of 19 in England. That is a relatively small group. However, when compared with the number of children who have diabetes in England and Wales—just using comparative figures—the figure for England and Wales is 43,500 children with life-limiting and live-threatening conditions, and there are 29,000 children and young people with diabetes in England and Wales. From where we are sitting in the children's palliative care world, we see that the services for children with diabetes are much better developed and there is greater integration.

Those are some of the highlights of points from me. That is not comprehensive.

Q72 Chair: No, it is not an exclusive list but they are your key points. It was really just the key points you felt. Stephen, do you want to add to that?

Stephen Lowe: We are concerned with older people, obviously. The evidence I am drawing on is feedback from a number of local Age UKs that offer services to people at the end of life and their carers, our national information line and our Dignity in Care Commission. From that evidence there are five key points I would like to draw out.

First is the extent of support for care homes. There is huge variation in the extent to which people who are at the end of life who are care home residents remain in a care home or are referred to hospital. That is probably a good indicator of the training and skills of staff in a care home but also of staff confidence and the extent of support for decision making, particularly where you have support for decision making by nursing staff in care homes, who are often quite professionally isolated. We would like to see the NHS providing support to people in that situation. An example would be the scheme in Croydon whereby the NHS funds nursing support for nursing homes to develop good practice. That kind of confidence building for professional staff would make a big difference.

In terms of end of life care in hospitals, we have numerous problems with this, but it does seem, in many ways, that hospitals are not the ideal setting for end of life care because people are not in a setting where they are dealing with staff who know them; they are in a situation where there is often lack of privacy, a busy environment that does not help with communication and where staff are taking rapid decisions without much knowledge of the person. So hospital is never going to be the ideal place for end of life care. Where we think there is scope for improvement is in communication, both with patients themselves and with their families. It does seem that problems that stem from lack of communication, not taking account of people's rights, not consulting people or the family about decisions, tend to be concentrated in hospitals. More focus on communication and respect for individual rights would be important in hospitals.

On our information line a lot of the problems we get are related to NHS continuing care, not only variations in whether people can get it but also in what they are offered. They are often offered only care in care homes, are not given a choice of care homes and are not allowed to top up the NHS package. Where people say, "We would prefer care in our own

home," they are told they cannot have it, and if they want care at home they get it from social services and will be treated as withdrawing from NHS continuing care.

The only other point I would like to make is regarding dementia care. Obviously, people need to be making decisions well before they reach their final, last years of life. Decision making about future needs should be made at an early stage as part of the mainstream process of assessment of people with dementia rather than just being seen as an end of life issue, because somebody who knows that their ability to make decisions and their mental capacity are declining is going to have to make decisions.

Q73 Chair: We will come on to that later. You had one final point you wanted to make.

Stephen Lowe: The last one was about the evidence base for funding for end of life care. From our evaluations of our local projects, there is perhaps some evidence that volunteer support at the end of life can save money for the NHS and social services.

Q74 Chair: That is great. If you could send us that evidence, that would be lovely. Those would be your five key areas.

Briefly, Alison, did you have any key points you wanted to make?

Alison Penny: Yes, briefly. Overall, we would like bereavement and the support needs of those after a death to be seen as a public health issue. One of the difficulties is that bereavement sort of falls between various stools. Yes, it is an end of life care issue; yes, it is a mental health issue; and, yes, in relation to children and young people it is an education issue. It is all of those and more. If we took a public health approach, that would allow four key things to be improved, one of which would be around a social response to people who are bereaved. We hear many stories about people crossing the road to avoid having a conversation with someone who has faced the death of someone close. I have worked in this field for 10 years and I still find it difficult to write cards of condolence; it is a very difficult conversation to have. That is why some of the work that the Dying Matters coalition is doing around a national conversation about death, dying and bereavement is really important.

In terms of children and adults, going back to some of the aspects of their continuing life after a death, so going back to school or to work, we would like to see better support from employers and from schools in acknowledging what has happened to pupils and to employees. That might be training in schools and in work settings, and specific policies as well.

We are concerned about the cumulative financial impact of bereavement on families. We would ideally like to see some sort of review that could look at some of the unintended consequences, for example, of the run-on of benefits under universal credit, which is great in terms of continuing benefits for three months after death, but under the housing benefit regulations it means that the under-occupancy charge is going to kick in much sooner for

bereaved families who will be facing that three months after the death of somebody close, which is a real concern to us. We are also concerned about the rising cost of funerals and changes to bereavement benefits. So there is a whole suite of financial impacts that are likely to have an effect on the health of bereaved people.

Finally, there should be something about clarity in responsibility for commissioning and providing bereavement services. At the moment, there is a great range of provision, which I think is right, but we need more clarity about where families can get the support that they want, how they can access it and where is the sustainable funding and commissioning for those services.

Chair: Thank you very much. Rosie.

Q75 Rosie Cooper: We have been told that a third of all deaths are people aged 85 and over, yet only 15% of people gaining access to specialist palliative care are of that age. Are attitudes towards older people and a focus on curative treatments implicated here? Is there an ageist agenda as well?

Stephen Lowe: There might be, but also it revolves around the definition of what end of life care is. It is often unpredictable when older people will die because they often have a multiplicity of conditions. They are not on a single pathway where you can say they have a life expectancy of six months or something. Also, what happens to people is that they become increasingly frail and their resilience, in the event that they have a health crisis, declines, so a relatively minor crisis or illness can lead to a person's death.

One of our projects run by Age UK Oxford, which provides volunteer support at the end of life, has renamed itself. It no longer calls itself "End of life support". It calls itself, "Support for people with life-limiting conditions which are likely to shorten life in the foreseeable future". Partly, as a result of that name change, that has led to a big increase in referrals because people are identified as fitting into that category even though they would not be identified as being at the end of their life. So it is to do with that identification of, I suppose, people at risk because they are frail, as opposed to having a diagnosis which says, "This person has," say, "three months to live," or something.

Rosie Cooper: Okay.

Giles Charnaud: I would argue, for my part of the world, that that is not the case. It is where that person is—physically where they live. We run hospice at home services. In the last six months, 34% of our patients who were cared for through our hospice at home services were over the age of 85; 24% of our patients who are referred to the hospice are over the age of 85. The biggest change we have in place of death is actually with the 85-plus. Of those that die in care homes and homes within south Devon, 57.7% of deaths over the age of 85 are in care homes or homes compared with an England average of 48.4%; 2.3% of the deaths are within a hospice compared with 1.8% in England on average. It is how you set up the services to meet the needs of those people as against the services discriminating against the elderly.

Q76 Rosie Cooper: To go back over the question, it was about gaining access to specialist palliative care. It is not about places and about where, so I agree with you, but I just cannot get it straight in my head what other issues would prevent older people from receiving dignified pain-free end of life care that they and their families would expect. I cannot follow just saying that you have a multiplicity of conditions and you are expected to die.

Giles Charnaud: I would argue that, again, it will be mainly around what are the community-based palliative care services available in the area. For us, part of the reason that hospice at home has such a high level of people involved who are over the age of 85 is that our hospice at home feeds through from our community team. The community team will have the first intervention in the last year of life and then at end of life will hand over to hospice at home teams.

Q77 Rosie Cooper: I will stop now because in my head there is a definite disconnect. The question is about a third of all deaths are people aged 85 or over and yet only 15% of people are getting access to that palliative care at the end. It is only 15%, so I do not quite see where that gap comes. I totally accept that, if you have a hospice at home, that works and is fantastic because they are getting it, but what is happening in other areas to those who are not? Are they just left?

Giles Charnaud: Those areas are where you have this sparsity of provision, that there is an inequitable element of provision across the country. Our hospice is unusual in providing in-patient care, community-based care, hospice at home care and outpatient care. Those combinations enable you to pick up the needs of most people.

Q78 Rosie Cooper: So you think it is the provision and that there are not other issues that are causing this or any other reasons other than that the service is not there for them to get to.

Giles Charnaud: I do not believe so. If you get the services right, you should be able to provide it.

Rosie Cooper: Thank you.

Q79 Barbara Keeley: You were with us earlier when we talked about conditions such as dementia and I raised stroke and cardiac disease also being identified for palliative and end of life care, and it seems that they are not. Would you tell us, maybe in addition to or in agreement with what you heard earlier, what you see as the barriers to better recognition of the need for palliative care for things other than cancer?

Stephen Lowe: I suppose we assume that there is an element of discrimination built into this, but we do not really have the evidence of what is happening and how that works. We basically do not know really. But we agree that there is an element of discrimination and that people are not getting the services.

Q80 Barbara Keeley: Do you see it as strong as discrimination? We heard earlier that people are not asking the questions, that there is not identification at an appropriate enough point that a cardiac or a stroke patient may actually be on a trajectory to dying. You think it is stronger than that, do you?

Stephen Lowe: I suppose that lack of identification is the issue itself and you have to ask why not—whether there is a reason for that in terms of the nature of the person's conditions—or whether it is just a cultural thing where people do not really look and whether it is just accepted for older people.

Giles Charnaud: There is a combination here related to the ease of predicting the last year of life perhaps with some diseases. The disease trajectory for cancer is easier to predict than the disease trajectory for heart failure. Traditionally, cancer has received the bulk of palliative care services because people are better able to say, "This is non-curative and this is near end of life." For other diseases, that is much more difficult. It does not mean that we should not be doing it; we should be doing it. There is an element where, with the other diseases, perhaps there is more that potentially could be done. The other element is that we are not having the honest conversations as to those other diseases in saying, "Actually, you are potentially in the last year of life. Is it worth continuing or would it be better to refer you to palliative care services?" It is going to take a while to get people's confidence to having those honest conversations.

Alison Penny: Quickly, while we are on equity of provision related to particular conditions, thinking about the elements of end of life care which are relevant to families following a sudden death, it is really helpful when the End of Life Care Strategy, for example, looks at the needs of those bereaved suddenly as well as those bereaved through an expected death. We know there is inequity in provision of bereavement support between those where the death has been expected and there has been support either from a hospice or a palliative care team, but those who are bereaved suddenly do not receive such good support and it is harder for them to seek it out. So there are differences in provision according to the nature of the death, whether it was sudden or expected as well.

Barbara Gelb: Could I pick up on the point of inequity as well? In terms of children's palliative care generally, there is tremendous inequity across the country in terms of the way that services are commissioned and funded. The process is very much complicated because there are three different bodies that commission care for children with life-limiting conditions. They are the clinical commissioning groups for general children's palliative care, NHS England for specialised palliative care for those children with the most complex needs, and then local authorities for social care. Where local authorities are concerned, we are extremely concerned that the provision of social care respite, if you like, or short breaks for families, is very much at risk. This is going to place families under huge pressure if the availability of short breaks is further decreased. Already it is not hugely available and is inequitably available, so to speak. A lot of the respite breaks are provided by the voluntary sector, but we are concerned that, with further cuts in public spending on the horizon, short breaks will be under further pressure and this is going to lead to family breakdown.

Chair: Thank you. Andrew.

Q81 Andrew George: Can I say to you, Sarah, that I have to leave at quarter to five, so I hope that will not cause a problem with the quorum?

I have a very specific question in relation to the hiatus or the limbo that has been left since 14 July and the suspension or the withdrawal of the Liverpool Care Pathway. This is a very direct question to Mr Charnaud. Given the situation we have at present, what contribution can the hospice movement offer to the acute sector in seeking to fill what is not a complete vacuum but is certainly a lot of uncertainty and variability in terms of palliative and end of life care?

Giles Charnaud: The Liverpool Care Pathway itself was not the problem; the problem was its implementation within various environments. The amount of education and training at both undergraduate and postgraduate level that clinical staff—and by that I mean the full range of clinical staff—have in end of life care is very limited. Hospital staff, from our experience, are more nervous about opening conversations about the potential of end of life because they believe they will get the backlash from families because of the Liverpool Care Pathway media stories. We are now facing a situation where there is a greater referral of patients to palliative care teams within hospitals, which is potentially overloading them. Other acute staff are stepping back from that end of life care provision as a defence mechanism and there has been nothing coming in to fill that vacuum you have rightly identified. Hospices are ideally placed to provide education around palliative care provision and end of life care provision. It is not just to hospitals—it is to care homes; it is to primary care. For me, it is not about how we can get in another pathway. It is about how we can educate the entire work force that end of life care is a core component of how we deliver health and social care. It is a Cinderella service. It has been on the sidelines. Whatever we bring in will not work unless the education is there to give people the confidence to implement whatever comes in with confidence. That is not going to happen until we get to a stage—we are very lucky where we are that we are quite well integrated with primary care and the acute sector—where we have that better integration between hospices and—

Q82 Andrew George: We will accept that it is better to have an educated rather than an uneducated soil on which to place this tool, but I suppose I am asking whether the hospice movement is beavering away at present at coming up with an alternative tool, or is it simply waiting and seeing what happens elsewhere and making no contribution to that narrative at the moment?

Giles Charnaud: The only way I can answer that is that we never used the Liverpool Care Pathway in our hospice because our staff intuitively know the delivery of good end of life care. So I do not think it is the place of the hospice to come up with that tool. If a tool is going to be implemented within the national health service, it should be something that is driven by the NHS with hospices inputting into it. The reason we did not implement it was because our staff are well trained in delivery; they are specialists. If you have that confidence in training, the need to rely upon a tool diminishes. The danger with a tool is that it just becomes a tick-box exercise.

Andrew George: Thank you.

Q83 Barbara Keeley: I am going back to the question we asked the earlier panel about people being able to die in their stated preferred place and whether that is about services or the thought that people will change what they feel and start to prefer hospices rather than being at home. Could you give us your perspective on that question of resources or other issues being the major ones in people being able to die where they want to?

Giles Charnaud: Okay. We have about 3,400 deaths in the area, which is 1.2% of the population, so it is higher than the national average, yet we achieve a rate of deaths in hospital which is 43.1% compared with the national average of 50.7%. So we have a higher rate of deaths within care homes.

Q84 Chair: Can you say those figures again, please?

Giles Charnaud: The number of deaths in south Devon is about 3,400, about 1.2% of the population annually against a national average of 1%. The percentage of deaths that occur within hospital of all ages is 43.1% against a national average of 50.7%. In care homes and homes it is 47.8% against a national average of 41.3%, so we are doing better, and in a hospice it is 7% against 5.6%. Those are figures based on the National End of Life Care Intelligence Network for 2010-12 data.

The reason I think we are able to provide care in people's preferred place of care is because of the range of services we are delivering and the integration we have with the hospital and primary care. If we start with the IPU unit, we have three consultants in palliative care in south Devon and they all do on call both for the hospice and for the hospital. One of them is a hospital-based consultant and two of them are hospice-based consultants. So we have an overlap there already with the hospital. The community team, which is clinical nurse specialists, social workers, doctors, physios, OTs, complementary therapists, bereavement support workers, art therapists and music therapists work with primary care. The clinical nurse specialists attend the Gold Standards Framework meetings, which is the tool that they use to identify people potentially in the last year of life. They also work such that they are covering seven days a week, and that is important. Then they integrate with the IPU team, so they refer to the IPU team as well. That is integrated.

Then we have a hospice at home team that is 24 hours a day, seven days a week, is nurse led and that integrates with those other teams. So we are able to support people in their own homes or their care homes. That does not mean we are there 24 hours a day. It depends on the patient's needs. All those, and particularly the hospice at home team, support places like care homes to enable them not to panic and send their patient to hospital. We have care home facilitator educationalists who work with the care homes and the hospice at home teams will support the care homes. That gives other people the confidence to provide the care so that it does not just fall on what we call the specialist palliative and end of life care services.

There is a statistic that greater than 40% of people who die in hospital have no medical need to be there, and, of those, 25% will spend over a month in hospital. If we can keep people out of hospital—15% of emergency admissions are in the last year of life—economically it should make sense. The main reason they are there in hospital with no medical need is around carer breakdown and lack of other services. So when we developed a 24-hour, seven-day-a-week hospice at home service, we developed that from an initial service which had been running for many years which was only 9 to 5. That was developed on the basis of a primary care GP saying in his area, in Dartmouth, that most emergency admissions occur at night and at weekends because the doctor on call does not have the continuity with the patient, the family is panicking and therefore the only alternative is a blue light.

In answer to the question, the way you can provide that care is by having that level of flexible services whereby you can move patients through seamlessly, but also integrating that with other elements such as primary care. It is very important that our clinical nurse specialists are part of the GSF meetings. It is very important that we are linked to the hospital through the consultant body. We should not have these statistics because we have a huge elderly population in a very socially economically deprived part of the world, which has huge rurality as well. We are the seventh most sparsely populated county in the country. The only thing I can say as to why this has been achieved is that it is because of those services and the education.

Barbara Keeley: It sounds impressive.

Q85 Chair: Thank you. Does the panel want to come in at that point before we move on to commissioning?

Barbara Gelb: Thank you. In terms of children and choice of place of death, of the 5,000 children that die per year, 2,500, we are advised, have life-limiting and life-threatening conditions. We could get hold of the exact figures for you, but the majority die in hospital. A percentage—and a growing percentage—die in hospices.

In terms of choice of place of death, the common understanding until quite recently was that families' preferred choice of place was at home, and this has now been challenged following a piece of research by Professor Myra Bluebond-Langner, which was published last year.

The extent to which families have choice is a postcode lottery because it depends on the extent to which community children's nursing teams are available to provide care in the home and the extent to which hospice provision is available within that region. Community children's nursing is an area that we would certainly like to see much greater investment in and we see that as quite imperative to enable that spectrum of choice to be available for children and young people with palliative care needs.

One final point relates to advanced care planning, which, in the case of children and young people, is very patchy in England. There is an excellent exemplar in Scotland where one form is used universally across Scotland. In England that is not the case. Forms are

developed regionally, regions are reinventing the wheel, and there is no leadership being provided, as far as we can see, from the Department of Health in terms of policy directives around advanced care planning, which we would very much like to see, as well as engagement from NHS England in the implementation of advanced care planning. That will have a tremendous bearing. The implementation of advanced care planning more universally in England will have a tremendous bearing on facilitating choice for this group of children and young people.

Q86 Chair: Thank you. Do you have anything to add?

Stephen Lowe: I would add to the point that a lot of hospital admissions are coming from care breaking down. We ran a number of pilot projects, which were evaluated, for older carers of people near the end of life. One point from that evaluation was the importance of ongoing support for older carers, who are likely to be around the same age as the person they are caring for and may themselves face decline or crises in health, and having somebody to contact if they have a crisis in order to prevent the care relationship breaking down.

Chair: Thank you.

Alison Penny: I would like to echo the value of 24/7 support where families and carers can ring up if they are worried about breathing having changed or who is going to help them get the kids to school and deal with the additional pressures that they might be facing alongside caring. That is the key thing. That allows for, hopefully, families to look back on the experience as a story that makes sense, where they felt safe and held, rather than a story of chaos, which we sometimes do hear.

Chair: Thank you.

Q87 Andrew Percy: My apologies for popping in and out. I had a local council leader here. We received written evidence to the inquiry which talks about a focus on care in the last year of life as not being appropriate for children and young people. Could you explain why that might be the case?

Barbara Gelb: Could you repeat the question?

Q88 Andrew Percy: Yes. I am trying to find out where it is exactly, but in the written evidence we received we were informed that a focus on the last year of life is not deemed to be appropriate for children and young people. Whereas the majority of adults only need palliative care towards the end of their lives, the palliative care needs of children and young people are much more protracted. So this focus on being the last year is the issue, I guess.

Barbara Gelb: Yes. That was probably our submission, from Together for Short Lives.

Q89 Andrew Percy: Yes, I think it is yours and we quote you later.

Barbara Gelb: Just to elaborate, focus on the last year of life is really important in children's palliative care, and also we are urging that the inquiry focuses on the whole journey for this group of children, which in many cases is several years—many years. With the advances in medical science, a child can be diagnosed at a very young age and live with the condition which will deteriorate over a period of anything up to 20 years. We are asking that there is an understanding within this inquiry that palliative care for children is not just a year. With this group of children, being at the edge of end of life comes and in many cases it goes and comes back again. In not the majority but a lot of these children, it can happen many times during the course of their lives that the family and the clinicians think that they are right at the end of their lives and then they rally round. End of life for children and the kinds of conditions that these children are living with is very complex.

Q90 Andrew Percy: Your evidence is that it is patchy because of a lack of specialist children's nurses and also you mention the rurality factor.

Barbara Gelb: Yes, they are community children's nurses who are in fact generalists, but generalists with an understanding of the specialism of children's palliative care. That is a huge issue which I have highlighted and I am delighted to have the chance to highlight it yet again. It is a tremendous concern that we have. Yes, the postcode lottery means that in the more rural and isolated areas there is a greater paucity of services, and where they are regional hospices provided by the voluntary sector those families living in the rural areas have much greater distances to travel, or indeed, if the services are community based, the staff have much greater distances to travel to reach those families.

Q91 Andrew Percy: I apologise if you covered this while I was out of the room, but could you explain how palliative care for children is commissioned and then give your views—some of you have already provided them in evidence, I think—on joint commissioning?

Barbara Gelb: Children's palliative care is commissioned through three levels, if you like: through the clinical commissioning groups for generalist palliative care; through NHS England for the very complex end of palliative care for the children who are very poorly and have very complex symptoms; and then finally through local authorities. That is a very complicated system, not least because NHS England has not defined clearly enough what does and does not sit within the specialised commissioning. Further, there is a lack of adequate co-ordination and partnership between the CCGs and the local authorities. We see joint commissioning as a tremendous opportunity for enabling integration of children's palliative care services, and at present it is an opportunity lost. Health and wellbeing boards develop the joint strategic needs assessments for all children and young people, and we are told that in around 40% of cases children's palliative care is not addressed within that joint strategic needs assessment. We would welcome a much greater emphasis and much greater monitoring of joint commissioning of children's palliative care.

Alison Penny: Talking about children's bereavement services as well, 85% of services are in the voluntary sector and the majority receive a proportion of their funding from either

the local authority or the CCG, or both, and sometimes that is through the health and wellbeing board. I know you have just concluded your review of CAMH services, but some of the issues that are faced by bereavement services are to do with the interface between community-based bereavement support and then statutory CAMH services as well. Anything that can be done to improve joint commissioning of children's emotional well-being services across all tiers is really welcome.

Q92 Andrew Percy: Thank you. Coming back to the specialist commissioning, this is not clearly defined. At the moment what happens when someone falls between the gaps? Who is picking that up or is that need not being picked up?

Barbara Gelb: Both are happening. In some cases it is not being picked up and in other cases it is being picked up by charitable funding. The children's hospices are currently getting an average of 14% of their funding from the clinical commissioning groups—just 14%. They do also get a tranche of funding from central Government at present, and we are very much hoping, expecting, anticipating and lobbying, quite frankly, for that to be continued because that provides an additional percentage—about another 12%, I think—on top of the 14% from the clinical commissioning groups.

Q93 Chair: I have a question about the interface between the funding that is coming from the voluntary sector and the funding that is coming from bodies such as clinical commissioning groups and NHS England. Giles, are you able to set out the funding challenges facing the hospices and where you see we need to be moving to if we are going to be able to expand the roll-out of the kind of service that you have outlined, particularly hospice at home and I know other services you provide such as oedema services?

Giles Charnaud: Thank you. I will start by saying that end of life care—palliative care—is very complex and it is not something, in my belief, that can be standardised. The last time this Committee met to talk about palliative care, I believe, was in 2004 and the Department of Health came—and it is in the National Audit Office report of 2008—and said that they were confident that the HBR PbR system was going to come forward with a tariff for palliative care providers for full cost recovery, and it would be implemented by 2008-09. We are now into a second palliative care funding review, which is in its sixth year and is going to take another six years to come to anything, and, in my opinion, will not come to anything usable because it will just be totally bureaucratic. It is mortally flawed by the fact it is saying it is not going to look at any more funding and it is mortally flawed by the fact it is not looking at social care because that is the remit of the Department of Health and this is an NHS England-driven study.

Currently, our hospice is funded at the rate of about 29% of our non-trading expenditure. The national average for a hospice of our size is 35%. I have had negotiations with the CCG and we will go up to 35% at the beginning of next year. But 35%, being the average, is the middle ground of mediocrity, in my view. That means that 65% of the funding has to come from voluntary contributions. We are reliant upon £1.8 million-worth of legacy income a year in order for us to balance our budget if we get the other parts of our funding in place, such as retail; we get that coming in. Last year we had a £1.1 million deficit. This

year is looking at an £800,000 deficit. If that continues, we will run out of money in three to four years' time.

Is it right that, for this sort of work, we are relying upon 65% of that funding coming from voluntary contributions? It is not that hospices are not working hard to get that. They are generating voluntary funding at the rate of about £16 per head of population. Macmillan generates a rate of about £2.50 because they are dealing with bigger populations. £900 million from a population of 50 million is a huge amount for hospices to generate and it is an unsustainable system. The Palliative Care Funding Review will not come forward with things fast enough and there needs to be an interim solution, but it gets bounced between CCG responsibility and central responsibility.

Q94 Chair: What is the model that you think the Palliative Care Funding Review should have been going down?

Giles Charnaud: The model that the Palliative Care Funding Review should have been going down was potentially doing what they are trying to do but recognising in the meantime that there should be an interim solution which increases the funding to palliative care providers that is ring-fenced, a minimum level that is ring-fenced in CCGs and they can only use that for palliative and end of life care provision. Then try and find a tariff, which, in my view, is chasing the un-findable. But to continue, 11 years on from the first review, to believe that we can do this is nonsensical. The problem is that, even if we do manage to achieve it in six years, I do not think the services are going to be there to apply it to.

Q95 Chair: Thank you. Barbara, would that be your view as well?

Barbara Gelb: Yes, in a word—in a nutshell—absolutely. We welcome the concept of a per-patient system, but we do not have any confidence whatsoever that this system is going to work because there is no additional funding available. We are extremely concerned about the apparent or anticipated exclusion of short breaks and bereavement services, for all the reasons I cited earlier, and I cannot impress upon you hard enough how critical short breaks are to this group of children and families.

Q96 Chair: You would like that to feature.

Barbara Gelb: I would like that to feature. It is hugely important. These families are caring for their children 24 hours a day seven days a week, and short breaks are their only break. We hear from families that just using the local hospice for 15 or 16 hours to get a night's sleep so that they can keep going is totally imperative to their daily lives. Families will break down and local authorities will find themselves in the position of having to take these children into care, and there are not the resources available. It makes good economic sense to enable funding for short breaks.

Chair: Thank you. I know we are going to be particularly talking about bereavement next, so it might make sense for Barbara to lead on to bereavement to give Alison a wider opportunity to talk about the issues.

Q97 Barbara Keeley: Indeed. I would just like to say that that point is recognised. My party's commitment on ring-fencing for carers' breaks was made last week and you make a very good point on that. It is not often recognised how there can be carer breakdown if they do not get breaks.

We understand that there might be some issues around children and young people accessing support services and that perhaps more of them than people think experience bereavement during their time at school. Can you say how easy it currently seems to be for them to access that and possibly how it could be improved?

Alison Penny: We know that about two thirds of local authority areas are covered by an open access bereavement service. That is one that would see children who are bereaved through any cause of death, so those through expected and sudden deaths. But even where those services exist, their funding is often very fragile and vulnerable. Services also report that, if their profile were higher and they were seeing all of the children and young people that could benefit from their services in a local area, they would not be able to cope with demand. We know that services face difficulties with waiting lists and that also if a service is based in a particular town within a local authority area it may be more difficult for children and families who are on the edges of that community to be able to access the support.

Some children get excellent support in schools, often in the first year following their bereavement, particularly in primary school, if the school is aware of what has happened and is able to provide acknowledgment and ongoing support. But at transition to the next class the information does not always go with them. Similarly, on the transition from primary to secondary school the information again may not go with them, which can be difficult, particularly around anniversaries or some of the other difficult points of time.

In terms of the numbers, there is a real issue around the data on the number of children who are bereaved, so the services in your constituencies all struggle to plan appropriately. We collect data annually on the number of children who are affected by parental divorce but not the numbers who are affected on parental death, which seems extraordinary and makes it very difficult for services to plan in that way.

In terms of services being available within the community, obviously, as I have said, there is that gap of those local authority areas that do not have an open-access service. In those circumstances, children often will be able to access support if the death was in a hospice but they may not be able to access support if it was a sudden death.

Q98 Barbara Keeley: Can I add a follow-up point? You mentioned parental death, but in briefings we have heard that children can suffer quite substantially from grandparent

death if the grandparent was very significant to them. Presumably it is quite a bit more if you take grandparents into account.

Alison Penny: Yes, absolutely. About 3% or 3.5% of children of school age have been bereaved of a parent or sibling and about the same number have been bereaved of a grandparent. By the time young people are coming towards the top end of secondary, about three quarters of them will report having been bereaved of somebody close to them. That is their own definition, whether that is a grandparent or a teacher.

Q99 Chair: The figure we were quoted was one in 10 children in schools have been bereaved, but, as you say, it depends what you are counting.

Alison Penny: Yes. I can send through the estimates we have if that would be helpful.

Q100 Chair: That would be helpful.

Alison Penny: Of course it is difficult sometimes to read off which are the significant relationships for an individual child or a young person. People who have been involved in caring for them more widely may be important as well.

Chair: Thank you. I do not know, Barbara, whether you want to continue on with communication.

Q101 Barbara Keeley: Clearly, end of life and palliative care could be better understood. The situation would improve if communication between health and social care staff and people approaching the end of their life and their carers was better. We have heard examples. But people say they do not have enough information to make informed choices about their care and to challenge decisions made on their behalf. We heard quite a bit from Giles earlier about the good work that is being done there, but how much is that a factor—just this straightforward question of, yes, people do not plan it and it is not worked through? Is there just a lack of information? Could we just be kicking off something where providing more information and getting people thinking about this planning is a key factor?

Alison Penny: I do think planning is incredibly important and it is also incredibly difficult to think about what are the points at which people might already be thinking about these things. We have just launched a campaign encouraging parents with young children to think about writing wills, appointing guardians and those sorts of things. Only one in four parents with children under 18 had an up-to-date will and only 50% had appointed guardians. Even those things around care of the children are really difficult for people to think about or to put in place, so then also their decisions about their own preferences for care and treatment. There are great emotional barriers to people thinking about these things, but there is more that could be done at particular points, when people are taking out financial products or when there are story-lines on the television that include people facing some of these decisions. Those are some of the moments either for an individual or for a social response. Again, the Dying Matters coalition does a lot of work around that, but there is definitely more room for improvement.

Giles Charnaud: We are talking about one of society's great taboos, are we not—the discussion around death? There was a study that showed that 23% of people would actively turn a conversation about death to a conversation about sex, politics or religion—the other three taboos—out of preference. That, to a degree, is what we are up against. I also think that we have not done well in terms of health and social care professionals—unless they are absolutely within the palliative care field—having those conversations about services available. People just do not want to really engage with it. Some of the work we are doing in south Devon is how we change or reframe the conversation such that it becomes a conversation about how life-affirming palliative and end of life care is, both to the patient but also to the family, and changing the perception of hospices. The last thing we want hospices to be seen as by the public is that place you go to die which is better than going to the hospital. It becomes part of the community; it becomes a community asset. As I put in my written evidence, it does more than it says on the tin. We do quite a lot of stuff as to which people could say, "Why is the hospice doing that?" There are quite a lot of events which are deliberately very vibrant. We do quite a lot of work with secondary schools, both in terms of educating them about hospices but interacting in supporting people. On Friday, I am mentoring five year 12 students from Torbay Academy, along with several other people from businesses, because that is a good way of us interacting.

Again, it is going to take a while, but we have to change people's perceptions and attitudes towards end of life care, towards the last year of life, toward dying. We are making some really good progress, but, to go back to the earlier question, that will all just disappear if we do not get this funding issue sorted out because the places that are doing this will have to cut back as it is getting very hard to raise that 65% from voluntary income. Economically, it makes huge sense to support these, because if we can get it right, if we can get society to accept that we are all at some point going to join that 1% of the population that is in their last year of life at some point, the knock-on ability for people to cope with life going on is so much better, as is the ability for people to get back to work and for families to stay together. A bad death will affect two or three generations badly.

Q102 Chair: Thank you. I wonder, Stephen, whether you wanted particularly to raise the issue about dementia care.

Stephen Lowe: We are running a series of six pilot projects called My Life, My Decision, which are running in association with Compassion in Dying. They have on their website a number of fact sheets. Basically, the project is about helping people to make advance decisions to refuse treatment and advance statements and care plans, and understanding what a lasting power of attorney is and the difference between a lasting power of attorney applying to finance and applying to care matters, because there is quite a range of avenues or approaches that people can take and they do not understand them and are not told about their existence. These projects have not been running long enough to be evaluated yet, but they seem to be getting very positive feedback and there is a real demand for them. That is a model that we would hope to roll out more widely in the future.

Barbara Gelb: I very much echo what Giles has said. There is a lack of understanding and awareness, as I said earlier, about children's palliative care. It is an important part of the role of Together for Short Lives. We have built our website very much as a "go to" place for all professionals—generalists and specialists—working in children's palliative care right from the point of diagnosis and referring families. We are working with the royal colleges and Health Education England to promote this awareness because we are very aware that, as a sector, we are not reaching all the children that we should be reaching.

Q103 Barbara Keeley: The final question, to follow-up on that, is that some of the evidence to us in this inquiry suggests that there should be more dedicated palliative care units in hospitals to reduce the number of vulnerable people dying on busy wards and to improve the opportunities for staff to develop their knowledge and competence. Is that a proposal that members of the panel support? Do you think that would help?

Giles Charnaud: Personally—and it will come as no surprise because I come from a hospice, although I used to work in the acute unit in south Devon—I would say no because only 5% of the population want to die in hospital. Where we have been successful is in developing the community-based services that maintain people in their own home but also having other services that can be referred into, such as the hospice in-patient unit. We have found that the complexity of patients that are coming into the IPU in the hospice has increased because we are looking after the majority of less complex people at home, and that is the way it should be. If, as a result of this inquiry, what happens is that we increase the number of palliative care units in hospitals and think that is going to improve end of life care in the hospital, we will have missed a trick because that is not where people want to be. We need to increase the quality of care everywhere.

Barbara Gelb: Where children are concerned, we do want families to have the choice, so we very much applaud Sheffield children's hospital. We heard earlier they got an outstanding for their inspection with the CQC. They are clearly able to provide excellent palliative care, making that hospital a very real choice for families in their region. We want families to have the choice, and we think it is really important—particularly with children's palliative care, where children may be admitted to hospital and may die unexpectedly through a spate in hospital—that the generalist professionals really understand the needs of this group.

Alison Penny: We are unlikely to entirely eradicate people dying in hospitals. Therefore, we would support better training and support for staff in acute hospitals—even for expected deaths—simply because families talk about such an immense variation in the openness of conversations that they feel comfortable in having with them and the response that people get on the ward and beyond. Those are the things that people remember and take with them into their journey into grief. So, yes, absolutely, we would want better training and support.

Stephen Lowe: Repeating what I said at the beginning, hospitals are never going to be a good place for people to end their lives, but we could do a lot to improve the communication skills of professionals and have respect for people's rights to be involved in decisions about themselves.

Chair: Thank you. I think I speak for the Committee in saying that we have found your evidence really helpful this afternoon. We are very grateful to you for coming and for staying so much longer. Thank you.