

The All-Party Parliamentary Group for Children Who Need Palliative Care

Oral evidence: how the government is meeting its commitment to choice for babies, children and young people who need palliative care

Session 5: 7 March 2018

Listen to the meeting: <https://togetherforshortlives.podbean.com/e/childrens-palliative-care-voices-5-dr-renee-mcculloch-dr-simon-clark-and-dr-emily-harrop/>

Members present

Catherine McKinnell MP (Co-Chair).

Witnesses

- Dr Renee McCulloch (Chair, College Specialty Advisory Committee - Paediatric Palliative Medicine, Royal College of Paediatrics and Child Health). Dr McCulloch is also a Consultant in Paediatric Palliative Medicine and Guardian of Safe Working at The Louis Dundas Centre, Great Ormond Street Hospital for Children NHS Foundation Trust.
- Dr Simon Clark (Officer for Workforce Planning, Royal College of Paediatrics and Child Health).
- Dr Emily Harrop (Chair, NICE Clinical Guideline Development Group). Dr Harrop is also Consultant in Paediatric Palliative Care at Helen and Douglas House Hospices.

Examination of witnesses

Catherine McKinnell MP chaired the session

Catherine McKinnell MP:

So good morning everyone, thanks so much for coming, thank you for your time, it's incredibly valuable. I'm Catherine McKinnell, I'm an MP from Newcastle, I've been MP since 2010 and it's issue that I've been working locally with, there's a number of families that I have supported in terms of their experiences on an ongoing basis as well and which is what sort of led my interest in being part of establishing this group in parliament as well. So, I'm sure you've heard about the purpose of this inquiry and that the evidence will form part of recommendations that we will be looking to make on a cross-party basis to make sure we and give the best palliative care to children and treatment for, well so and the easiest thing to do would be for you to just briefly introduce yourselves and then I've got a few questions that I'd be grateful if you would be happy to answer, obviously you don't have to answer all of them and if you've got something to add, then great or if you're happy for us to move on to the next question, then that too. I'm happy to be led by you to be honest in terms of what you think is key and what you think we need to know and what you think the changes need to be and what is working well as well, as obviously there is a lot of good practice up and down the country so the idea really is to make sure that where that is in existence, that we get that across the board. So, do you want to start, do you mind if I call you Emily?

Dr Emily Harrop

No, of course, my name is Emily Harrop, I'm the consultant in children's palliative care in Oxford and the other role I've been asked to talk from the position of today is I was the deputy chairman of the NICE guideline development committee for the end of life care work for infants, children and young people.

Dr Renee McCulloch

I'm Renee McCulloch and I'm a consultant in Great Ormond Street Hospital in paediatric palliative care. I'm the chair of the Royal College of Paediatrics and Child Health specialist advisory committee for training in paediatric practice

Dr Simon Clark

My names Simon Clark and I'm a neonatal consultant in Sheffield, I would like to go on record and thank my colleague Dr Sharma, who is doing my duty and shift for me today to allow me to attend here. I'm here because I'm the college officer for Workforce Planning for the College of Paediatrics and Child Health.

Catherine McKinnell MP

Thank you and I do recognize as well that is incredibly valuable, the time that you are giving to this. So, I guess on our part we'll endeavour to ensure that that is put as equal good use as you would be out there in the field doing your day jobs. So, one of the actions that the government has stated that it will take, because they are they are they have made certain commitments in terms of end-of-life care choice is to ensure we have the right people with the right knowledge and skills to deliver highly personalized care. That is a government commitment. To what extent do you think that is the case? To what extent do you think we still have some way to go to making sure that that is available for all of those people that require it?

Dr Renee McCulloch

Well, I think that we do have some way to go to providing really equitable care. Care is very geographically determined. There is some really excellent service, a lot of it has been developed through the charitable sector. And, there is a lack of skill, knowledge, expertise across the whole of the workforce to deliver informed choice.

Dr Emily Harrop

So, you know, I would really, I would echo that, I think that the training opportunities are being looked at, and while there is some optimism there, but still it's very difficult. When we have good paediatric trainees who are willing to get experience that we can't accommodate. And I would say particularly thinking about the charitable sector as a source of some expertise that contributes to the bigger picture is the sustainability of that is critically vulnerable. We are losing 40% of our workforce to redundancy as I speak at Douglas House. We, as the first children's hospice in the world can't fundraise enough money and would only be sustainable through more statutory funding in the future.

Catherine McKinnell MP

So where are those redundancies focused in terms of, so I guess I should have, to what extent do you think we have a paediatric workforce, paediatricians who have the relevant skills, experience and training to be able to deliver that and to what extent in terms of the

more general workforce? I'm just interested in when you say redundancies, where they are focused. Are they medical support stuff, or...?

Dr Emily Harrop

So it's actually across the board. We've had to make the very difficult decision to stop offering any care above the age of 18, we used to be able to offer care to young people more robustly. We've not had to make actual personal redundancies to the medical team, people have taken a reduction in their hours. So as to guarantee the out of hours rota, we need a critical number of physical bodies to do that safely. But, we will lose nursing staff, who I'm sure will find jobs, because there is a shortage and we will lose support staff.

Catherine McKinnell MP

And that is purely a funding issue as opposed to a demand issue?

Dr Emily Harrop

Purely a funding issue. No, its absolutely, demand has never been higher. It's purely a funding issue.

Dr Simon Clark

I think one of the, there are so many strands to these things that you've touched on. On behalf of the Royal College of Paediatrics and Child Health, I would like to categorically state that there is a lot of focus on end-of-life care, it is embedded within the curriculum. Many of us, I include myself in that, would consider ourselves to be experts in our area at delivering end of life care. And as a neonatal consultant, tragically I see a lot of babies who die because of prematurity and complications around the transitions they face as they make the leap from foetus to baby, which is a huge leap and if you don't have the right structures or you've got a congenital abnormality with your lungs, or you're extremely premature, then very sadly some of those children don't survive. So, there's a lot of doctors who have a lot of experience in that but I think the challenge that the system faces is that the draw and the pull of the acute care requirement is so high that releasing individuals to then further increase their skills into the more complex areas of palliative care into the longer term issues of palliative care as many of the children are surviving longer and there's an increase in the technology dependence of those children is particularly challenging when many units are overwhelmed and I use the word overwhelmed as that's how it feels, not necessarily the actual figures. When you've got, you know, children turning up in the middle of winter who are unwell, with their current illness and other things you've got someone off sick because actually they, it is winter too, we have a shortage of nursing staff and you are busy trying to hold the acute service delivery together. Then trying to say, well actually what we'll do is be imaginative and we'll let one of the doctors go and do palliative care. It is extremely important in a technologically advanced civilized society need we owe these children and these families that care, but the challenge that you face and in the former life I was the head of school of paediatrics in Yorkshire and Humber. I was very proud to have created a training post specifically for palliative care in the region and we recruited a doctor into that and they're currently in the process of training, which is really very exciting. But the machinations that I had to go through to be able to release the money in the business plans and, for want of a better word, haggling across the region about how we were going to do that was, you know, very high, I was slightly smug at the end of the process. [skips] but hugely.

Catherine McKinnell MP

So I guess you talked about being able to in those circumstances being able to release somebody to go on and deliver palliative care where its required, but to what extent do you think that situation in terms of resource is actually restricting family and patient choice?

Dr Renee McCulloch

I think we just need to take a step back and look at the trajectory of the children that we work with. There are, and this is part of the complexity of the sector and can be a bit confusing I think. The trajectory of children with life-limiting conditions is very varied, you have some children who are receiving very highly complex medical care for long periods of time. You have other children who have a very short end of life trajectory. You have other children who need a lot of input for what we would call enhanced supportive care. So, whilst they are continuing having a lot of active treatment

[skips]

Dr Simon Clark

Of course, if you do go to somewhere that doesn't have quite such a large neonatal unit there may be one doctor. So in fact, you can then have a service where you've got cover for most of the time but not all, but by and large most of the children have a paediatrician who takes the lead for the children with cardiac abnormalities and sees those children either in conjunction with or parallel to the paediatric cardiology service and that's grown up over the last number of years and what you're talking what they're talking about, about the children who have these diagnoses in conditions where we're as sure as we can be that life is not going to continue to the average age of the population or the expected time and we're not sure when that's going to happen. There is no one, you know, and actually the local paediatricians are working without that expert support coming and seeing them and discussing those cases and other things like that. So, the cardiology paradigm I think is really useful in terms of saying actually, while there are always challenges with how every service is set up that would be a great thing to aim towards, in terms of saying this would actually make the difference for those children.

Catherine McKinnell MP

So I guess what needs to happen here to make that to make that happen, and I know that's something that you're working on, are you?

Dr Renee McCulloch

Yes, we are working on that, we are working on that. And we kind of, have held up a flag and have been very much part of that saying, you know, we are looking at work in this area. We totally appreciate that this is not just about specialist work, every single paediatrician should know how to look after these children. But, as with any illness, as with any area of medicine, there are aspects where they need help. They need input with somebody who has that volume of expertise, they are seeing this all the time, this is what we do all the time and that's when you need to support your colleagues. We find that people are so helpful and willing. This is not about people avoiding being helpful. People are helpful and willing, when you can create a team around the child and you get the right structures in place, the right communications, it can work beautifully. I often go and see the GPs that I'm working with, because I will go and just say hi. I'm the one on the end of the phone that you are going to talk to, this is the team, this is the team who are going to help support you look after this child at home with your community nurses with, if there's a local paediatrician who can help,

brilliant. With support, people are really willing, but actually there is an enormous amount of work. The teams who are working in this area are overwhelmed, they're overwhelmed. We've got many single-handed consultants, nationally, who are totally overwhelmed, with actually being the only one who is holding up their region and that is not sustainable. It's not how it should be looking after our workforce. Now, what are we doing. What we've done is made sure that our level 3 specialist training is really clear. What we're trying to achieve with that through the syllabus. We've met with the dean of paediatrics in Health Education England and raised this. Its been raised at the college, so people are aware about the problem, what we don't have is an action plan.

Dr Emily Harrop

I think that's so important because it touches on burnout from two angles, there's the burnout that could affect a single specialist managing a patient who then are overstretched. But, actually it's really well known that people who are inexperienced and haven't have enough training being asked to care for dying children themselves. They face discomfort, burnout, you know sick leave etc will increase. So, I think there is both sides of that. There is supporting single handed specialists and there is giving the required support and education to those working at the level below so that they themselves don't become victims of burnout.

Dr Renee McCulloch

And, you know, a lot of the children who we look after, we're with them for a long. It's very different to adult palliative care. Some might even say is palliative care the right terminology for paediatrics, especially about that, because although we do end-of-life care and we palliate, which is to make comfortable, to look at the holistic care of the child. It puts some parents off from accessing your services, even though they are eligible because they've got a child with a life-limiting illness, they think we don't want palliative care because our child's not dying, we're fighting for our child, we want our child to go to intensive care. So, luckily for our team at Great Ormond Street, we're very integrated with the whole of the hospital, so we get involved with lots of different hats on. The nurses on our team are actually oncology nurses, so they meet all the cancer patients anyway. There are lots of different models like this that work, but actually, partly some of the things we do recalling enhanced or early supportive care, to get in, to give people palliative care services. And they know, when you meet somebody face-to-face its ok, its often just bullshit, you know 'I can't see palliative care doctors, what are they going to do, get me some morphine'. And then you meet them and they're like 'yeah actually, I do need that help, you have really helped us with making our child a bit more comfortable and actually this is great'.

Dr Simon Clark

Paediatric palliative care is about living, it's not about dying. And I think that

Catherine McKinnell MP:

You could rebrand it living well care

Dr Simon Clark

So I think that I was going to say I don't like the term rebranding, but there is a there is a branding issue. Together for Short Lives is a masterstroke of branding, because it doesn't say, it says its about living. And actually, paediatric palliative care is about making the most of what you've got and when I'm teaching my junior doctors and trying to get a little bit of focus out of them and a bit of light-heartedness in the education sessions. I talked to them in slightly colourful language about the fact that we all live in this functional denial about our

own mortality and that lunch is palliative care because you don't have lunch you've got 32 days. Because without any more fuel 32 days is it, that's the time that you've got probably on average if you don't have lunch next, or your next meal after that. But no one thinks like that, we all think that death is not something that's going to happen to us which is not entirely true but you know, generally. We all came to this meeting today not thinking that, actually at some point this is all going to be over for me, we're trying to make the most of everything that we've got and that's what paediatric palliative care is absolutely about and that's what all life is absolutely about is, this is the time that you've got enjoy it, do something constructive with it but enjoy it.

Dr Emily Harrop

It gets lost actually, even in ethical debates, when you call the paediatric helpline, and have a debate with a number of ethicists about active vs less active treatments. It was really good, but nobody actually, other than Laura and I would put their hand up and said active palliative care is an option. You know, it was ooh we're having a debate about whether this child should have a tracheostomy and ventilation or will die. You know that there was no idea that this child could have anything other, that palliative care would travel with him either way but there would be another active, other thing offered. It was really difficult to even introduce that into a debate, at post-graduate level which was sort-of disappointing.

Catherine McKinnell MP

Ok, so I wanted to, I mean this leads quite helpfully into, I guess the choices that need to be made between professionals and the individuals and their families and the government's end of life care choice commitment. They've set out a number of actions and for each one, it would be helpful if you could say whether you feel medics are being educated to carry them out and to ensure that they are delivered and how well you feel tertiary level children's palliative care services in England are actually taking these actions. So, the first one is hold honest discussions with children and their families about their conditions and the fact that they are life-limiting or life-threatening. To what extent do you think that?

Dr Renee McCulloch

I see this happening a lot, I think it is happening. Its not just a single conversation, it's a whole journey of talking and I think there's a lot of skill in it. It has to be done in the right way because otherwise, you pushed parents into an entrenched, very difficult position to manoeuvre out of, it has to be done very sensitively. People can always learn how to do things better, but I think it is happening and I think there is education focus on it, but there could be more, most definitely. We just set up some very interesting and very popular training at GOS which is called simulation, so you simulate really difficult conversations in intensive care, with our intensive care colleagues. That's gone really well, and I think there's always room to improve, but it is happening.

Dr Emily Harrop

It's also in line with the first quality standard from NICE, which is about, broadly about advanced care planning, but it talks about the active engagement of the child and the family in that process and spells out essentially the bits of quality you're describing and I think that'll be a really good thing for people to use to measure progress. You know, if they wanted to say are we achieving this? That first quality standard outlines an awful lot of the important bits of quality in that.

Catherine McKinnell MP

So, I guess one of the things and that's come out of evidence that we've taken in other sessions is that for some medical practitioners it is just not their strong point at all, the communication side necessarily and when there are particularly difficult conversations some... so I guess it's it doesn't always have to be one particular person within that team it can be.

Dr Simon Clark

We work as teams and I think one of the...

Catherine McKinnell MP

Because we have heard stories though, as well, of people who literally would not told they didn't understand.

Dr Simon Clark

There's a ban on human cloning and we can't clone the doctors who are really good at it and just have them working all the time and we can't have people just working all the time so...

Catherine McKinnell MP

But there needs to be a system, doesn't there

Dr Simon Clark

You have to work in a team, the challenges that we face with a team, now I'll go back to the cardiology example. My colleagues put up with some of my shortcomings, in terms of the things that I am adept at as a neonatal consultant. There are stuff, there's stuff I don't shine at, as a neonatal consultant, because I am only human. But they think, you know, that as part of the team, if ever they don't want to go 'this baby's heart I'm - could you' and I'm just there, I can understand the heart. Because you know, that's one of the things that I think that I'm relatively adept at, they appreciate my input on and I have a good relationship with the service. I think I'm particularly good at talking to people about death and dying and that's also one of my areas of strength, I believe. But you are right, there will be people where that is more of a challenge and the difficulty that we have with the way that the system is set up is at 2 o'clock on Sunday afternoon, there may only be one doctor in the hospital. How you then manage that is difficult. I think we also must acknowledge that there are some families where that journey that Renee alluded to is extremely long and very difficult for them. Because whatever you do, save my child's life, and there's no other discussion about anything else because that's what we meant to be doing.

Sometimes that journey takes a long time to move that forward and while I don't doubt that it's really difficult for those families. It is of interest when I have had a member of the nursing staff in a room with me and I think I have been quite clear about what is going on and what the risks are as sensitively supportively as you can and then the family go back into the intensive care area and the nursing staff who were with me then listen to them talk in between themselves or even talking on the telephone and what they say is virtually the opposite of what I think I've said. Now, I'm not saying that happens all the time but I think there's an element of actually where this information is overwhelming, am I really going to acknowledge that this is what's happening or am I going to present a different face? Are they saying that so that they're talking to other family members who they're protecting from the information that I've given? Now, I don't know the answer to any of those things but it is, the

amount of talking in the amount of time cannot be underestimated, it can be a very very long, complex process moving from the first conversation through to actually this is about ensuring that the existence for your child is fulfilling and as comfortable as possible for as long as we think that is appropriate.

Dr Emily Harrop

They are also the hardest skills to teach, so we were looking through the research for the trainees in our areas about their confidence before and after delivered training in certain areas of palliative care. There were bits around symptom control and other things they felt better about afterwards. Communication and advanced care planning was thought much more to be an experience gained skill. Very difficult to teach in the time and constraints you have and it's something that the trainee I've brought with me today is doing a master's on, actually looking at that comfort and training for those types of conversations around the advanced care planning and general paediatric training. And I think it is an issue which we would need to dedicate significant time and effort to do it well, yet it's easy to tick a box and say ooh they had a lecture module online or something. Unless they have exposure to working with people doing that as an understood skill, it's really hard.

Catherine McKinnell MP

Do you think there are quite a lot of people and do you think potentially there are medical practitioners who don't recognize they actually need that? So, you think you're doing fine and actually, you don't realize what you don't know until you've done some training.

Dr Renee McCulloch

I've sat in on hundreds and hundreds and hundreds of these talks and sometimes, as Simon said, you just think we're not getting to the point here, there's a lack of alignment. I have to say, this is a really really complicated area, it's really complex. We don't really understand what influences parental decision making, we don't know if it's the right thing to do for some families to have this conversation. From my experience parents wanted to have all the knowledge they can and they really want to be part of the decision-making but then they have to live with those decisions they make and we have to be very careful about how we help them to do that and it's incredibly complex. We've got recent research, very qualitative data that is actually said some of the young people we work with, they don't want any part this conversation thank you very much we don't want to talk about that. Healthcare policy is we need to write this down, we want to know what you think. We need to understand more about this it's really the dynamic is so encouraging so modern medicine we expect parents to make really hard decisions. They don't know, of course they want to keep all their options open unless they have really been through some very open, honest discussions and they really know where they want to be, in my experience, probably the minority. The majority want to keep their options open.

Catherine McKinnell MP

So that takes me to the next government's commitment, which is make sure that the needs and wishes of children and their families are respected and reflected in the care they receive. And then the next one is treat children and their families as experts in their own care and to what extent is that happening?

Dr Emily Harrop

That is all obviously, is captured in NICE, so they should place a mandate for that to happen fairly easily. I think it is incredibly variable the degree to which that happens, depending on

the expertise there is, depending on the time people have in an individual service. There are ways suggested to try and evidence that within the quality standards and metrics, but I actually think they're very difficult to apply, even having been involved in them. In that I think it's very hard to evidence the extent to which somebody's actual preference in the moment was met and reflected, in that their preference may have changed, so it's quite challenging.

Catherine McKinnell MP

One of the ways, is part of the evidence that we've taken again, is through having a plan, so a care plan in place. So, I guess and obviously some when it's an acute situation, but it does seem to be the recommended practice that you have a plan, so you have that conversation and then you have a plan in place and then I guess you can measure against the there being some flexibility within that plan as well.

Dr Emily Harrop

So, you can, and we have tried to collect data using the advanced care plan document that meets with the guidance in in our region and I think you can show in a slightly two-dimensional way whether people have met their placement of life care of my child has died. Whether they have had the chance to meet their preferences for hospital escalation or not for other emergencies, but the little tiny bit misses is that sometimes when faced with a situation the parents will have changed their mind. So I know that in our data there's at least one family where it looks like they ended up in hospital when they've been writing for years we want to be at home, but I know what happened and I know that on that occasion, they said actually we just can't do it and wanted to be in hospital. But if you were to look at that and audit that, it would look like their choice hadn't been met. So I think, yes you can look, certainly you can collect data but the way that it suggested within the quality standard measurement is that you have to also capture the views of parents, whether that's by interview or other to make sure that you do capture some of those changes of mind and some of the fluctuations there is in people's choice.

Dr Renee McCulloch

And actually, we've got to think about what influences choice, because it's very easy to say hospice, home or hospital, but actually some of those aren't choices if you don't have teams to support them. We've been collecting data on all the conversations we're having, we have 200 new referrals a year, we have got a lot of parents on looking after a lot of children, unfortunately, who die. What we're seeing in our data that we haven't yet published is that people don't necessarily decide on place of death. They very clearly decide on where they want their care to be, but they think about where do I want to be, where do I want my child to be looked after. But the influences on that decision are huge, if you've got a child on various pain pumps or various other technology in hospital, that can't be delivered outside, then you're not going to choose. So, care planning has a very important place, but we don't know enough about it yet to be making sure. Yes, of course we should all be having conversations and we should all be enabling that dialogue. But, it's really difficult, I think it's really difficult.

Dr Simon Clark

The challenges as well also include, actually the fluctuations that do occur that have already been alluded to. So, I have one or two phone calls in my career about well what why hasn't this family followed the plan that you put in about what they were doing for their end-of-life care and in fact it's because the family had made a different choice than the one that was written down. You then think well how have I missed that, but you've given, you think you've given the choice and so get all the choices that are available to you and I think again that's another really important point. I'm trying to think how to phrase this, but I think from many

neonatal units there would be quite some significant logistics about moving a child from the neonatal unit to a home environment or a hospice for end-of-life care. Now, for neonatal medicine, I mean it's a microcosm of the bigger picture to some extent, there are some babies where you are as sure as you can be that they are so technology dependent at the moment, that you move from supplying all that technology to not, that the time that the family are going to have with that child will be really short. Through to some children, where you then remove that dependence the technology and you're not quite sure what's going to happen. But yeah, removing a child from our environment to another environment is a complex logistical issue that I think is you know when you're giving people the choice, we don't have a consultant on duty to do that. Someone then has to be a there to see the child at home and do the legal aspects following death if that's a death certificate or other things and that can be quite tricky for us because no one else may have looked after this child other than neonatal consultants and so there isn't anyone else who can then do the paperwork. But we're meant to be on duty on our unit and we're not and so there's lots of... all of those things of surmountable and we have done this. We have taken children home, but the level of organisation that it takes is really high and that's even with a fully commissioned paediatric transport service who will assist us in that.

Catherine McKinnell MP

So that's what, I mean, we've kind of covered offer meaningful choices including end of life, developed personalized care plans, coordinate care for children with life-limiting. But I guess the we haven't looked at, and that kind of touches upon it, is help to join up care and support from different professionals and organizations so where that connection has to come with social care, with community nursing.

Dr Renee McCulloch

Again, I think you're talking to people who are delivering quite a lot of this kind of care. But I do know that across the nation its very patchy and there will definitely be families who don't have any experience of anyone having what they would define as a meaningful conversation. Yes, of course, we do come across that and we do come across people who don't have plans, they don't have individualised care plans, yes of course that's all happening. As far as networks, the networks are not official networks, they are networks that have been developed. If you're working in the field, you'll know, like I said, I know exactly who I've got in Hounslow, fabulous team. If you work across one of those boundaries, you haven't got a hope of having a syringe or [inaudible 38:24] pump. We're talking very basic end of life care, so we have an absolute nightmare trying to support end of life care in some areas because we don't have anyone able to help us.

Dr Emily Harrop

We try to offer training, we have a nurse consultant who goes and tries to refresh people's skills, but we have to make sure that's good enough. So with some teams it is, if they're just not seeing this kind of care often, but if they haven't had the base skills in the first place, I don't think that would be safe. The top-up training is ok, if you've done it before but maybe not for

Catherine McKinnell MP

So is this where the difference lies in adult palliative care? Because you have Macmillan, you've got third sector organisations.

Dr Renee McCulloch

A lot of the hospices are great, and they will try and have outreach teams, but they're finding it very hard to recruit paediatric nurses. They don't have commission services or perhaps, we have tried to enable some pathways through some commissioners to facilitate outreach teams from the hospice, but sometimes they don't have the staff to help to go out, to man a 24/7 rota if something goes wrong with one of the pumps.

Catherine McKinnell MP

Just taking this all the way back, why do you think there's such a shortage of paediatric training places?

Dr Simon Clark

Well, nursing?

Catherine McKinnell MP

Yeah

Dr Simon Clark

Now, part of my problem with answering that is I'm trying to work out whether I'm going to answer that just as, perhaps, a member of the taxpaying public or as a member of the Royal College, being the college officer for workforce planning. There are choices that the government make and the information that they make those choices on are, sometimes cause me concern.

Catherine McKinnell MP

So, they're under estimating the needs?

Dr Simon Clark

So health education England have acknowledged, and I think I'm correcting in saying this, but I've sat in a meeting and listened to them say this and in fact it says it in this document. They have acknowledged that when they have gone out there and said oh how many nurses do you need? The hospitals have said I think we need this many nurses and the hospitals have said that probably because they've been under significant financial scrutiny and so they had to then say well, we don't want that any more nurses because that means we're not going to balance our budget next year. So they have probably underestimated the number of nurses that they need.

Catherine McKinnell MP

And do they only ask the hospitals?

Dr Simon Clark

No, they ask a whole load of people.

Catherine McKinnell MP

Yeah, but everybody's got squeezed budgets

Dr Simon Clark

So, everyone's got squeezed budgets, so everyone says well okay this is this is what we think our growth in staff is going to be. Because that's what the budget will allow for and so health education England then commission that number of places and then we've then discovered a gap has grown because the number of posts at the hospitals then advertise and try and recruit to is significantly larger than that and accounts for now there's thirty six thousand nursing vacancies. When you only need you to look at the amount of medical staff and nursing staff that we're importing from around the world, and in some specialties it's even worse. So in paediatrics something like, the exact figures are in the GMC document which I've also got here for the safe education practice in the UK, something like in paediatrics 37% of all paediatricians don't have a UK medical degree. Now that's fabulous, I don't have a problem with that, that makes us like Chelsea Football Club, you know because we're importing the best and the brightest from around the world. But the, idea that we meant to have a sustainable production of staff, the number that the GMC say that there is something like 58,000 doctors who don't have a UK qualification on the GMC register with a license to practice in the UK. The increase in training phases of medical students is going to mean that we are so self-sufficient in doctors with no attrition and no other retirements, I think it's by 2076, and so the scale of the problem is massive and they acknowledge that in this document and the difficulty is what we've done. This is me talking as a UK taxpayer now, not representing anyone in the next statement. If you do Workforce Planning by budget, you will always end up with not enough staff because you cannot see, and I'm now quoting Michael Portillo, you can't see the jobs that are going to be created. I don't know who he was quoting, he might have been quoting someone else. You can see the ones that are going to be destroyed, so when they say technology is going to make it better, we're going to need less people, we won't need this, we won't need that. I don't think there's a civilized healthcare service in the world that has got less nursing staff and less medical staff now that it had 10 years ago and 10 years ago they say we're going to radically change how we do. So, I think there's a mismatch and this document talked about we must do Workforce Planning based on what we can afford and that's the bit in this document that absolutely terrifies me. Because we've been doing that and the gap at the moment, according to this document, is in excess of 42,000 workers.

Catherine McKinnell MP

And, I mean, I'm just thinking in terms of Brexit, to what extent are they non-EU?

Dr Simon Clark

In paediatrics, about 6% of our doctors are European Union and then it's about 30% are non-European Union. Now, amongst the nursing staff, I genuinely don't know the answer to that. I think it might be similar in paediatrics in terms of the nursing background, so that's why that graph worries me about the number of the nurse training places.

Catherine McKinnell MP

I think in nursing it must be greater, no? The EU

Dr Renee McCulloch

I wonder if it wouldn't be greater.

Catherine McKinnell MP

I'm I just thinking of, like, my own experience recently, like the Italians, Spanish.

Dr Simon Clark

It may be, but I think actually there's a huge variation around the UK. So I have a feeling that in London and the South East, where Europe obviously is closer and potentially a trainline away, actually you might have a different density of European Union nursing staff than you do in regions like mine. Where, actually I'm struggling to think of, yeah, we've got nurses from quite a few places but, you know, not quite so many from Europe as from other parts of the world. So I think and I you know I have loads of sympathy for the people who are trying to do this calculation because apparently there's only so much tax revenue and I think we have to we have to accept that. Because I am talking as a UK taxpayer, but it's when we prioritise that spending as a civilized society and, for me, I think paediatrics it is the thing that's going to fix some paediatric nursing and paediatric workforce and health care workforce for the children is going to fix some of the challenges that we face in 5 years, 20 years, 25 years. Because if we have a group of well-educated healthy children, they'll grow up to be well-educated healthy adults. They'll stay in work longer, my retirement age has gone up to 68, I don't know what theirs is going to go up to. But also, they'll look after themselves, they'll be better educated. They'll make wise choices and if they get unwell, they'll utilize the services because they've been well-educated. They may even pay higher tax.

Catherine McKinnell MP

Ok, that was urm...

Dr Emily Harrop

Catherine, your point about inequity with adults is key though isn't it, if we just finish that bit. You mentioned, Macmillan and other services that might be available, but are less so under eighteen. I think so much of this comes back to inequity, whether geographic or whether age related and just because there may only be 49,000 families affected, doesn't mean they don't have any right. And I think that comes back to another campaign worked on by Together for Short Lives.

Dr Renee McCulloch

Yeah, and it's not impossible to get systems that are workable. I think it shouldn't be impossible. I think with formalised networks, we can do this really really well. But we have to up our game now, we've been talking in these terms for far too long. I've worked in the service for nearly 20 years. I know that because my oldest child is 20 and I started working in the hospice in Oxford when I was pregnant with him. And I'm still having conversations that I had 10 years ago. We've just got to come together as a wider sector and start to say this has to happen now. Because actually, what we're seeing is just an increasing body of work because we do have survivorship of complex illness. We've got graduates out of neonatal units, out of every area of medicine who are living with really difficult, challenging conditions. We've got to enable the parents to carry on working and supporting their families because it's almost a social crisis as well actually. Because, we've got to be caring in our society, it's really really important.

Dr Emily Harrop

Back to Nelson Mandela, isn't it, you judge society by the way it treats its most vulnerable, and these are the most vulnerable.

Dr Renee McCulloch

They are the most vulnerable, but I have to say, children, you know, visit the choices document. I think there's something about children after the government summary at the end, it's in the appendix and I just think it's actually, this is today when we're not able to support, as Emily says, the most vulnerable people. This is today that we're not able to even look after some children with cancer, cancer is supposed to be well-funded, but sometimes we can't look after those children with cancer very well either in England because we don't have the resources.

Catherine McKinnell MP

So ok, this is to all three of you, in turn. If you could recommend one thing to government health education England or some other stakeholder, but I presume the first two would probably cover it. That would make a significant difference to make sure that we have the medical workforce to deliver the care that I know you all have ambition for, and it seems to me that there is a fairly clear idea of what's required. The challenges arriving there and it being uniform across the country, what would be that one recommendation were you able to give one.

Dr Emily Harrop

I'm very clear, I think that we need to have a proper commitment from government. We can't just look at the medical workforce, we have to look at the whole of the workforce, the social and healthcare workforce. We need to have a commitment to fund a group that looks at the different specifications of what these children need. Not just specialist specification but looking at the core areas that need to be funded such as respite care, we need to look at the whole trajectory. We need in that group, to be planning, such as the adults have done with a very useful document, we could very easily do something like that with paediatrics.

Catherine McKinnell MP

So would you say to mirror what has happened for adult palliative care for children?

Dr Emily Harrop

I want to take some of their, some of the good bits and grow it into paediatrics. I don't think we can mirror adults because we're so different. So I want to take elements of that and grow it, but with this has to come training and education, planning and commitment and, of course, funding.

Catherine McKinnell MP

So it's three things?

Dr Emily Harrop

It's complicated, I could probably do it with one thing but it completely supports...

Dr Renee McCulloch

I don't want to just say money...

Dr Emily Harrop

I don't want to just say money either, but it does touch on money, I'm really sorry. I think for all the time I spent working with NICE and I feel all the time I spent trying to look at what was going to come out of the palliative care funding review, for me there's something about demystifying the way that money is due, does that make sense? And, you know, you have a way of commissioning a service if it's highly specialized which is NHS England, you have a way of commissioning something through the CCGs if it meets certain another criteria, you have statutory and third sector partnerships for other areas and you surely have a little bit of what my service does that is only for us, to fundraise, the nice extras that would be the life and breath of a hospice and that there needs to be some sort of structure. Which is something I've spoken to you about when you're working on, where we can approach each of those bodies, who can otherwise say I won't fund you because you're too specialist, I won't fund you because you're not specialist enough. And say actually, of the service we look to provide, which is a holistic service, you might have a liability for some of this part and to have some kind of code we can use is...

Dr Renee McCulloch

We can't just, the problem that's happened in the past is we've just looked at specialist service specification. We can't do that, we've got to look at the whole of the services that these children require.

Dr Emily Harrop

We were told it wasn't specialist, that description we wrote at the summit we heard apparently was too woolly and not specialist enough.

Dr Renee McCulloch

That's why I think we need to break it down, so people are really clear about who's paying for what, and what level. Because at the moment its just a big, kind of, splat and its just not clear. And everybody's saying not my problem.

Dr Emily Harrop

It's so easy to push it away if it's not clearly your liability.

Dr Renee McCulloch

We do need that but we need support to do that properly, to do it not just in our own time, as we've all done so many things for this sector. We need it to be properly funded so we get proper delivery at the end of it. Not just funded from all those in the charitable sector who are supporting, you know, services as well. That's what we need, we need a proper commitment from government to support us going to the next stage, which is actually a significant platform because we really need to up the ante.

Dr Emily Harrop

And even within the third sector, you know, I mean we only get about 12% statutory funding, I know there are areas of the country where the commissioners take a different view and

they may get a third of their overall cost funded and that's not right. You know, it's at the whim of individuals which is probably not ethically appropriate

Dr Renee McCulloch

So at the GOSH specialist service, so GOS. We get, a third of our funding comes from charity, to run the Great Ormond Street service that spans most of London. A third comes from some of the money we are able to raise by doing some visits and things like that. And the rest of it, in fact less comes from what we can actually bill for, because we can bill for very little. And the rest is just supported by the hospital because it's a valued service, but we're not commissioned and that's just becoming a massive issue.

Dr Emily Harrop

When you're in the hospital, people ask you if you're income generating, it's very to be income generating when you're dealing with palliative care, it's much easier for certain other areas of practice than it is for us.

Dr Simon Clark

But that actually just belies the whole, I'm going to go with farce, sorry, of the financial discussions with the National Health Service. Are you income generating, in order to generating an income, your service has to see some patients who then won't be seen in a different institution, who then, that institution doesn't get paid for it. So in fact what you're doing is moving money from one place to another.

Dr Emily Harrop

Its income spreading, it's not income generating.

Dr Simon Clark

And in fact what you're doing is then sucking the money into this institution rather than that institution and across the service. And, so I really worry about those conversations that are happening in hospitals. For me, I think as the officer for Workforce Planning, I think we need to think about actually how we workforce plan and there are lots of ways of doing that and I've split them into three categories. You either workforce plan for your current infrastructure, you workforce plan for what you can afford or you workforce plan for what you think the need is and I don't like workforce planning based on what you can afford, because the evidence that I have seen so far is that that always under-delivers on the staff that you need. And there appears to be somewhere between 5 and 25 years' worth of evidence that, from the United Kingdom.

Catherine McKinnell MP

Is it not deliberate?

Dr Simon Clark

Um, I'm going to take the 5th amendment. Because I promised my wife I was going to be as calm and considered. You and I could have a private conversation about that if you like. So the thing that I think that we should then think about doing, is doing a workforce plan based on a combination of need and current infrastructure. And, I've done that on the back of an envelope. I did that on the back of an envelope because it was the piece of paper that was close to hand, not because I'm slapdash or casual about these things and I take my

calculations are really very seriously. There are approximately 50 hospices in the United Kingdom. There are approximately, I think it's 200 inpatient units in the United Kingdom and you could look at the number of children who've got palliative care needs. That's about 50,000, you can do a lot of very complex calculations about the time required this, that and the other. The number I ended up with, in terms of actually if we were going to do this by need, I think it's probably, I've reserved the right to recalculate this, about 196 palliative care consultants. Now that's based on not precise facts, now the problem with that is, that's a mile away from where we are.

Dr Renee McCulloch

We've got about 15.

Dr Emily Harrop

I was going to say, isn't that a factor of 10 out.

Dr Simon Clark

Yeah, now you know that could be an over estimate, because actually there might be something about networking and having people with expertise in other things and you could probably get away with less than that. I think a more conservative estimate based on currently looking at networks and potentially emulating something like paediatric cardiology, is you might need somewhere around 40 to 60 true palliative care consultants. As in, who've been through growth, but you probably need then a host of other folks. In sticking with the cardiology analogy, a bit like myself who does some scanning and talking to the cardiologists, who actually then provides care in the local centre and is the liaison, those aren't in that figure of about 40 or 50. I've then done some songs based on how much it costs to do that. The magic number I came up with is about £7.5 million and that would account for going well actually, if we got 15 doctors every year to training proper palliative care to the college curriculum and about half of those were already consultants to bring consultant experience so they've trained in a post-consultant and about half of those were doctors coming through the current training program.

So actually, we ended up with generating a range of consultant experience, we could probably move forward with that. Now I fully accept that actually that's something that I have built having had conversations with individuals, I have not since checked this with anybody else, other than the fact that I've done a lot of calculations and I don't have a lot of conversations with individuals and sometimes your ballpark estimate is irritatingly accurate. But, I think that it's going to need that and that needs to be over and above what we've currently got. It can't be, you know, we need to then acknowledge that actually, if we're going to have consultants move from what they're doing now to be in palliative care, we've got to be able to replace those. We've got to have additional doctors in the training scheme who can then do palliative care, we can't just pool the doctors in the training scheme into palliative care, because we need the ones who are in the scheme to be the consultants of the future and replace some of the consultants who are going to take on these, these other roles. So, it's over and above what we've got at the moment. I just reserve the right to be completely wrong about these figures, because I'd like to do some more comprehensive modelling, you know, with multiple other partners rather than, you know, just using publicly available figures.

Catherine McKinnell MP

And that's just the, sort of, doctors that we're talking about.

Dr Simon Clark

That's just the doctors.

Catherine McKinnell MP

That's not even touching on the nurses and social care/health care. But no, but that's really helpful, I didn't actually expect, because I was going to say how many, earlier, how many do you think, but I didn't think you would have those kind of figures. But, no I know they're not, I'm not taking them as read.

Dr Simon Clark

I think everyone else is slightly more risk-averse when it comes to doing sums, I tend to be slightly bolder with sums, because I particularly like Mathematics.

Catherine McKinnell MP

Yeah, but I think that's really helpful and I think actually it's a good place to, kind of, end. In, I think we've covered an awful lot to be honest and I've certainly got a much clearer perspective from you of the challenges in terms of workforce and the challenges from both a numbers perspective, a resource perspective but also the challenge within that of making sure that this actually gets the priority and the focus that it needs. So, a huge thank you for your time today.