Co-Production with patients and carers: What it is and why we should be doing it in the NHS

Innovate stage
Tuesday 12 September 2017
13:00 – 14:00

Speakers:

- Professor Jane Cummings, Chief Nursing Officer, NHS England
- Camilla Ball, Young Carers Health Champion, Blackpool Carers
- Helen Lee, Head of Quality Improvement and Experience, Lancashire Care NHS Foundation Trust
- Carol Munt, Patient Leader, The Leading Together Programme, Kent & Medway STP Public & Patient Advisory Group
- Dr Navina Evans, Chief Executive Officer, Consultant Psychiatrist, East London NHS Foundation Trust

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Jane:

So I wanted, before I just talk briefly about what we are doing nationally, I wanted to on behalf of everybody in the panel that Mark who was due to co-chair, best wishes and hope he's back and working with us again soon. I wanted to talk a bit about what Camilla is doing, she's going to talk later, but anyway, this week she's the @NHScurator. I don't know if you have looked at that, it is a Twitter account dedicated to us at the NHS, we have different people that act as the curator for a week and they tweet about their experience, about what they are doing and what's important. We have had all sorts of people, lots of staff, patients and others, that have done that.

Camilla has already been tweeting through expo and will continue to do that. I thought it was worth mentioning it now. Do you want to talk about what it means to you and how you are making it work so people can follow.

Camilla:

Well you actually touched on it quite nicely there. But if anybody is on Twitter and you are on it today if you could like the @NHS and follow the tweets throughout the week that would be great. Thank you.

Jane:

I wanted to talk briefly about some of the work we are doing nationally, I think it is safe to say that certainly throughout NHS England we really do value the co-production a. We just talked about this. You can write guidelines and all that but people are nervous about doing, how do we engage everybody, do we have a few people that are vocal, how do we really truly engage and make it real for people and make a difference.

It isn't actually, on one level it is quite simple but on one level it takes a lot of thought, commitment and work. But it is really important, because when you do develop services or you improve services or you change services actually doing that with the people that use them and will have a big impact on, it does make it that much better and it really does help. I do think though genuine partnerships and co-production can take lots of different forms. I don't think there is a one size fits all, it will depend on your local circumstances. And last year we worked with patient leaders and the coalition for collaborative care to develop a relatively simple model for co-production in the NHS. And that's about how people could genuinely promote equal partnership.

We have also worked with over 60 NHS organisations on the Always Events Programme, and we will hear more about that later. But that is really important, what is so vital, it is about what matters to patients and to people and so the you know what matters to them and then the standards and the way the work is done is developed at the very beginning with patients and people who use the services, so you really do concentrate on what's important rather than you know make others, doctors, nurse, managers determining what's important.

So we have been working with that with IHI, the Institute of Healthcare improvement and PICA Europe, I look forward to hearing more from Helen in a bit about that. Camilla is also going to talk a lot more about how we have been working with young carers and really engaging with them and having health champions in with the young carers which has been fabulous.

We have an involvement hub that we have set up and the involvement hub supports both patients and carers and staff to be able to access information, to be able to find out more on-line about the services and be able to get advice and support for how to do that. And earlier this year we also published some guidance for NHS commissioners, we did two things, one was guidance on Patient and Public Participation in commissioning, health and care, and the second one was around how to involve people in their own health and care, so promoting self-care, supported self-care and actually really putting, wrapping services around individuals rather than the old fashioned matriarchal, patriarchal society with doctors and nurses and therapists telling you what you need, rather than working with you about what you think you need and getting support to make informed choices.

And I think the other thing I I'm very proud of, is a few years ago we thought it is all very well talking about this but we need to put our money where our mouth is, so we actually committed to helping people with learning disabilities.

In my team we employ six people with learning disabilities, who take the lead and help us engage with people with learning disability out in the community, but co-leading different work stream, they actually lead the work.

Earlier this morning when I did a session on this stage around mental health and learning disability nursing we had one of our learning disability advisers here talking about the impact he has been able to have, and having a full-time job with NHS England what an impact that has had on him.

So actually working with people, who with lived experience has made a huge difference to the way we have approached that programme.

I also just wanted to point out that we have got lots of ladies in the room wearing lovely colourful sashes on, which from here looks at MAT experience, I know there is a session around better births and maternity, but really great to see that we have got people who have been through a maternity process, pathway and are actually there talking about what it means to them and what matters to them in terms of maternity experience. It is great that you are in the room. So thank you very much for coming. That's a little bit about what we have done and I shall now hand over to our next Helen isn't it?

Helen:
We got involved a few years ago, there was a call out from NHS England to see if anyone would like to test the always approach. For us at Lancashire it was perfect time, we had just signed up to the quality-led strategy, it was a perfect opportunity to bring that to life in a really meaningful way, putting people at the heart of what we are doing. So we got involved with NHS England, working in partnership with the Institute for healthcare improvement and with PICA Europe, and for those not familiar our experience is that are so important for people who use healthcare services and their families and carers that they should happen every time and every interaction.

And for me, what always events have done for us at Lancashire care has really enabled that magic mix and that framework and that formula to enable people at the point of care and people who use our services and their families to come together to improve care together by truly understanding what matters to them. And I think for all of that true, genuine partnership to happen there has to be that true desire, there has to be that curiosity to really understand what really matters to people, that we don't know, we don't have all the answers in healthcare and we need to really find that out by engaging with people and asking what is it that matters to you, what would make the biggest difference to you in your care today.

And then it is about moving from, as Jane was saying, moving from doing for or to people, to doing with people. So kind of leaving our egos, our NHS badges at the door and our hierarchies and working in true partnership with people. Together, just looking at how things could be different, what other possibilities and how we can bring them to life. Always Events have enabled us to do, that they have given us that framework and have enabled that true partnership because people have been involved at absolutely every step of the way. From understanding what matters to them, to then saying OK then what are the change ideas what could be different, what could make the difference. Right through to testing those change ideas, to measuring them and to evaluating them, so that core design team of people using the services and families and carers a staff at the point of care doing the whole process together as equals.

I think what we have also found at Lancashire Care and they took about this in the toolkit developed by the IHI and NHS England is the real importance of having the leadership and the culture that will enable that to happen, because it doesn't happen overnight, it takes time to really understand what deeply matters to people.

But that time, what we found in Lancashire Care is it is time that is well invested, because by taking that time to deeply understand what matters to people and what the opportunities are for improvement we are actually paying attention to the things that will have the biggest impact and we're co-designing things that will work, because we have been designed by people using and providing the services.

What we found in our Always Events experiences is often we are blown away by the fact that it is small tweaks and changes in how we do things that have a massive impact for people using our services. And because one of the balancing measures when looking at the measures were some of the staff experiences and staff were saying understandably how they were quite anxious because of the time that this might take, but then when we have measured that and on reflection, staff have felt so empowered that actually they have connected back to their core purpose of why they came into their job that they are able to listen and respond to people and make the changes together with them.

And that ultimately has led to these changes being sustained because they are designed right, staff the can see that by doing things slightly differently it is having a fantastic outcome so why would they revert to the old way of doing things. I think the other thing that we found at Lancashire care is Always Events we are on a journey with it, but we are trying to hard wire that into the way we do things so it is not something that is an additional thing, that it is not an isolated quality improvement, that we co-design or we do things in partnership this week, but actually it is the way we do things, because it is the right thing to do, it enable, it gets the right results and why would we, our experience is why would you not do it, and Always Events has really helped us to bring it to life.

If anybody is interested in finding more about the Always Events then come and have a word afterwards and have a look on the NHS England website, there is lots of information toolkits and resources and NHS England are looking for people who want to be involved in the next wave, so if you are interested get involved because it has been a fabulous experience getting brilliant results.
So Camilla will talk to us about what she does.

Camilla:
I'm not sure what kind of things people know about what our young, what a health champion do, a young carer health champion what we do is we are a group of young carers that meet quite regularly where we will meet and discuss the kind of things that young carers are dealing with at the moment and the kind of issues that we are facing. We're quite lucky in terms of the NHS has produced the

health champions, where we can fight the rights of carers nationally and it's involved from the NHS England commitment to carers programme. So the kind of things that we have done, we have had the opportunity to meet with David Mower, which is one of the ministers, he has listened to the kind of things that carers nationally what they have to say, which then they will incorporate that into the carers' strategy.

We also have contributed to The Children's Society GP pack which is a pack that will be given to all GPs where they will help them know how to treat carers. Another thing we have done is presented at the Carer's Group, Respite.

Camilla:
Yes. This is the second year of the health champions. The first year went really well and we had a lot of positive outcomes and now the health champions from last year have become mentors like myself to help the next champions that are coming through. So I think the biggest thing for me is I could definitely talk for Britain about what kind of things it's done for me, so for me 100%, a few years down the line a few years before I wouldn't be sat here today, I wouldn't be sat here talking to you about the kind of things about what a health champion does so in particular the NHS have given myself as a carer the confidence to sit here and speak to you guys today.

The other thing it does for us is that as carers it gives us the I influential background and we get to meet inspiration people like all of you guys today and people take us seriously about the kind of impacts we have on our health and the impacts on other carer's health. The other things that it does is it helps us create our own support network, so meeting other carers in the same situation as myself as well as adults that are going through the same kind of things that is really so impactful and we can't thank the NHS enough for that.

The last thing that I want to leave with you today is that as the health champions, as we are trying to create an army so trying to build an army of people that are supporting all of these carers and so if I leave you with one thing is if you can think about carers, at least once a day or once a month then at least we have done something. Yes. That is it.

Carol:
I know it's early in the day, a round of applause. Now, unfortunately Nadia, you have to follow that.

Navina:
I am Dr Navina Evans. I am fortunate that I am a clinician, a consultant psychiatrist and very lucky to be a Chief Executive of an NHS Trust. It's a huge privilege.

I will go anywhere and I will speak at any invitation about the involvement and the benefits of really good engagement with our patients/carers and service users. It's made a huge change to the way I work, to my working life and to our organisation. So thank you for hearing and listening to my story which is what I am going to tell you now and I hope that I will be able to share more with questions.

In our Trust we made a decision many years ago, it wasn't me, it was the previous Chief Executive and previous Chair that if we really wanted to take service delivery and service improvement to another level we had to engage differently with patients/service users and carers and thought long and hard about how to do this. I think that is the wisest decision our previous Chair and Chief Executive ever made in the organisation. We have developed what we call People Participation. The most important thing for us is that it has the support and it is led by the most senior people in the organisation and that is the Chief Executive, me and the Chair. The People Participation Committee is a subcommittee of the board; it's chaired by the chair of the Trust.

I am accountable to patients, my appraisal, feedback; I am directly accountable to that committee. I have to listen sometimes to some very uncomfortable things that I am really grateful that people will share with us, senior leadership owning this is very, very important in our organisation. The next thing for us is that we have had to focus massively on culture change.

I see one or two faces from my Trust here and it's not been easy. We are afraid, we worry, we are afraid to say we don't know, we are afraid to say we got it wrong, we are afraid to say actually this was just terrible and once we got over that and started to say it I am amazed at the reactions we get from our patients/carers and service users.

To focussing on that culture change has been really important and we have done that in many way, some with using methodology and others around social movements and things like that. We also have a quality improvement initiative programme which we are rolling out in the organisation, we are using a formal methodology, and we have a partner with the IHI to do this.

But what is key around our quality improvement work is the involvement of patients/carers and service users in the work. We have trained over 100 patients, carers and service users, so they are part of the quality improvement teams. Our service users are employed in the organisation as People Participation leads, as peer support worker, as members of staff and their input has been really, really important and I can honestly say that in the parts of our Trust where things work well I can guarantee it's where patient involvement is the strongest.

In the parts of my Trust where we struggle it's where it's the weakest. And we have a lot of variation where that is concerned. I want to give you another example, a personal example of where working with service users has been really helpful.

We had a patient who was very unhappy with some of our services, she wrote letters of complaint and wasn't satisfied with the responses on a number of occasions and I am really grateful to her because she could have gone to the Ombudsman, she could have, it could have gone further, but what she decided to do was to offer us some help in she started to do some work with us, using the quality improvement project to start off with in our complaints team and now we have patients working in the complaints team ;they help me to respond to complaints from patients/carers and service users.

They also come and help us; patients and carers help us around learning lessons and they sit and listen to many of the SI learning seminars and give us our perspective on how we could do things differently.

Our Trust has a long way to go, but we did rather well with the CQC ratings and one of the things that CQC really pointed out was that the benefit of patient/service user and carer engagement and what that has brought to the organisation.

So I can say that every day I am humbled by the involvement that the patients and their carers, in my organisation give me, I am amazed by the effort and the input, I am amazed when we say something has gone wrong and what people say to us is right, we just want to help you make it better and we want to help you so it doesn't happen again.

And that is really humbling and I don't really understand why, but I don't want people to stop doing that for us.

For me personally, patients and carers are my eyes, my ears and my conscience. I will go anywhere to talk about this.

Carol:
I am sure there must be some questions that you want to ask, so if you are please go ahead. Yes, please, have you got a microphone coming across to you now. Microphone in the second row, in the middle, please.

Question: I thought I would go ahead and ask the first question which no one wants to ask. Just for some background information I work in the voluntary sector, I spend 20% of my free time working in the voluntary sector.

I am a liaison officer for the London region and we are struggling to engage with our commissioners. I know my experience is not unique because it's a national voluntary organisation, we have helplines and officers across the country and we are being met with shut doors and we are not asking anyone, we are happy to give our time freely and it's quite a frustrating situation which I understand you are trying to address, but when one looks at CCGs, you look at the leaders which is NHS England and my day job is working at NHS England Policy and Strategy and I think it's fantastic that you employ people with learning disabilities and you want your staff group to reflect the patient group that you are serving and that is excellent and I admire that, but that has not been my experience in NHS England and so, as a board member, my question to you is how does NHS England ensure that it leads by example to other commissioners and that all the directorates are representative of the patient group that they serve. So how does the board assure itself?

Jane:

It's, I guess it's a work in progress, there is no doubt about that. Certainly through all of the national priority works and the next steps to the Five Year Forward View I know that in each of those national priority areas there is if not already in place a plan to put in place much better engagement with people with lived experience. I think that is fairly clear.

If Claire Murdoch was here she would talk about the mental health plan and what they have done for some of those. You can see we have people in the room working with us on the Maternity Programme, so I think there is, we are getting there, it's there are lots of people, we treat over a million people every 24 hours, as you know.

The one thing we have done as part of the board is our chairman has recently asked Lord Victor Adebowale, which is looking at patient involvement and patient participation.

So Victor is setting that up at the moment. It will add on from the work that Jeremy Taylor's work has done. He is a member in terms of National Voices.

That will report to the board on how well we are engaging and we are in the process of creating a dashboard that looks at how we can engage and report on that so I think we have moved it on and I would expect, you know, that will continue to improve and increase and the other piece of work we are doing, which absolutely we are talking about in the next session is work that we are leading with four of the STPs where we are, my team are working with STPs specifically looking at patient and public engagement and how we can set them up as exemplars for others.

Greater Manchester is one of those areas and we have someone from Greater Manchester in the audience. So we are moving on that and there is more work to come. That is particularly around carers but there is more work to come.

Carol:
Does that answer your question enough? Yes. Fourth row in on the middle.

Question: My name is Tom Griffiths, I am a committee developer by back ground, I have been asked to help a local trust deal with co-production so the answer to the first of your statements is yes, yes, yes. Thank you to you for some good examples.

My question is about a clash of cultures between making co-production work with your eyes and your ears and your conscience and your whole heart, with managerial cultures about project plans and this that and the other and Gantt charts and all of that and psychiatric and clashes of cultures. How do you deal with that?

Carol: I think that is one for you.

Navina:
It's something that, we deal with all the time. We have been doing this for years in our Trust and it's still something we have to face and deal with. I think that the one thing is it's got to be genuine and it's got to come from the leadership of the organisation and I don't think it can be delegated to, we will have a people participation or a patient involvement, my heart sinks when I go to organisations and I see oh, look, there is a someone there who does patient involvement, the someone who does patient involvement should be here. That is what I think.

Carol:
Does that answer the question for you? Do you want to say anything about? Clash of cultures?

Helen:
I think it's about doing the right thing. As Carol said before people and Navina said people want to help the NHS to be the best it can be and to do that we all need to leave our egos at the door, our management speak at the door and we need to get together as peers and people who want to make it bet together look at how we can do that. To me it's as simple as that.

Carol: Gentleman at the back?

Question: I'm a Learning Disability adviser in Jane's team, the thing that really interests me is the talk about the young carers, because I heard you in the talk, you have a Twitter page and a path through GPs, we are wondering what else are you doing to spread awareness and to give services more information about this topic, thank you?

Camilla:
Yeah OK, so literally we will be anywhere. So we have the Twitter page and we have the hashtag #NHSthinkcarer and we also have the big deck chair, I don't know if you have seen it, feel free if you are free at any point today sit on the deck chair and we can tweet about it.

Because we are all from different areas across the country we meet up and we speak about all the different kinds of things that are going on and the problems that young carers are facing and then we will go back into our own areas and then champion the kind of things and raise awareness anywhere and everywhere we can get in, that will be GPs, whether it is schools, whether it is meeting up with other carer centres, anywhere and everywhere we can get, that's where we will be. If anybody has any ideas, please come and see us at the end, or come and see us at the deck chair and we can get them sorted. You are welcome.

Carol:
One of the things you didn't mention is the fact you have organised respite for young carers, do you want to say something about that it would be useful.

Camilla:
I'm really lucky, I was supported by our local carers' centre called Blackpool Carers' Centre, they supported me from a very young aim. I then got the opportunity to be a young carers' champion, from that I raised awareness anywhere I could get in, to schools, speaking to carers about the kinds of things that I deal with and just showing that you are not on your own, you are not the only carer, there are other carers out there and everybody is out there to support you.

So now I have then become the respite co-ordinator at Blackpool Carers' Centre where I give young carers the opportunity to have the respite that they deserve. Whether it be a chat, they can come in and have a but you or it might be going to the local park and just giving them that chance to be a child again.

Carol: Gentleman here. Who is wandering around with the microphone.

Question: I'm from south Asian action, one question around co-production and how consistent across any NHS organisation, some are doing well and some are not, is there scope for a joined up approach to look at NHS England and Public Health, NHS London transplant and other organisation that is one question.

The other one is directed more around we have had race equality mental health action plan and then over the years that seems to have died down in terms of the equality issues. Is there scope for, I know we have horizons but on a grass roots level there is a lack of equality when it comes to particularly black and ethnic minority communities facing and working within the mental health systems.

Is there scope for national policy to further look at that. The statistics speak for themselves.

Carol:
Can I just say, I'm going to answer that from a very simplistic point of view as a patient;I don't think we can reply or expect the NHS to do this. If we do we are not co-producing, if not the only way we are doing this is if the NHS sets it up and either makes it mandatory or whatever. This has to be a joint effort.

The joint effort only comes about if you have patients who are equally up for talking with health professionals and you have health professionals passionate about working with patients. That is a huge ask, I fully appreciate that, which is why I will go back to what I said when I gave my talk at the beginning, we have to empower people to do it.

That is not necessarily something that can be handed over to the NHS, it is something that needs to be operated at a local level probably to start with and then at a reasonable level. Then let's look at the national level. Co-production has to start from the roots up t can't, in my mind, and correct me please, somebody correct me if I'm wrong and I will tell you I'm not.

But you know! I sincerely believe this has to start from grass roots, from people who have a passion to actually make it want to happen and it is a little bit like doing the lottery, yeah doing the lottery is great, you might win a fortune but on the other hand if you want to raise money for your local club, get out there and do some fundraising, don't sit there waiting for the lottery ticket to come up. The same thing with co-production if you want it get on and do it.

Question: I represent a group called TIDE, together in dementia every day, a network for carers of people living with dementia. To pick up your last point, what TIDE does is give carers a voice, so they can speak up and get involved, however, voices have to be listened to.

Organisations have to be ready to listen and not only to listen but to take action in response to what they hear. And I think our experience all too often is that particularly at a national level thing Public Health England, the Department of Health and NHS England don't listen, they expect carers to join a working group as a one-off event, they are not prepared to pay travel expenses, they don't recognise that carers may have caring responsibilities and may have to arrange alternative care.

It is not just about sitting down together and having a nice chat, it is resourcing and it needs recognising that carers are equal partners in care. And I'm not confident that organisations have really got that yet.

Jane:

Obviously I can't, you have got your experiences and you will have lived those and you will know. What we did in 2014st we published the commitment to carers strategy which set out in a bit of detail how we were going to approach this, what we were going to do, in NHS England, we have also got a policy around paying travel and expenses, so there is one and we have done it and we have sorted that, we have also done some work recognising caring responsibilities that people have and we have done that with our learning disability teams and with others.

I think that with all of these things there is often, with an organisation as big as the NHS, there is often quite a lot of variation, and one of the things that I think we all, and I mean all of us, have a duty to tackle is actually reducing that variation and not actually going to the level of the you know the worst, but really driving to get to the level of the best, and one of the things that we have, as I said, one of the pieces of work we have done with the four STPs which is the session that the team have put on next at 2.15 we are working with four STP we are working with themes too how we can best support carers and how they can within that organisation best support carers, we know that you know there are absolutely tens of thousands of carers providing more than 50 hours of care every week and so it is a vitally important piece of work we do and we are progressing it. I hope, I really genuinely hope that the description you have given is not something that is everywhere.

That is not the messages I get back from people that we have been engaging with. If we need to talk with the team afterwards and learn lessons from where you are from then we will do that.

OK I think we are now, yeah, somebody is telling me that we have come to the end of the session.

Carol:

Can I leave you with one thing to take away, co-production is a posh word for saying if we talk to each we can achieve things. Please bear that in mind. It is not an impossible task. Thank you very much for coming.