Ceinwen Giles: What patients really want

In 2009 I was, like many of you, a working professional. I worked in international development for about 13 years and then in December 2009 it all went a little bit wrong. I was pregnant and I got very, very ill. I developed pre-eclampsia and then that turned into something called HELLP Syndrome which is a life threatening pregnancy condition. I had fevers, night sweats, I felt really sick and I eventually developed a really crushing back pain and I spent three and a half weeks in the hospital where they investigated me for all sorts of tropical diseases because I’d spent a lot of time in Sierra Leone and places where you pick up tropical diseases and what they eventually discovered was that I had stage four diffuse large B-cell lymphoma - and if you don’t know what diffuse large B-cell lymphoma is, because I didn’t, it’s a very aggressive form of blood cancer.

I spent five months in the hospital receiving chemotherapy treatment and they told me that if the cancer didn’t kill me, if the chemo didn’t kill me my chances of survival were 40% over five years.

So about a year after that happened just because bad luck really does come in threes I got meningitis. I know right, yes, really fab. So I spent another month in the hospital, four months recovering from meningitis because it had really badly affected my brain and it turned out that I got meningitis because my immune system had been damaged by the chemotherapy.

So as a result I now get monthly immunoglobulin infusions which are a blood product. So they take about four hours. I go to the hospital every month. They don’t make me feel great but they’re vastly preferable to getting meningitis again.

So I have a lot of complex medical conditions but what I wanted to talk about was how my experience of the Health Service and my work in international development have kind of influenced my thinking on what it means to be a patient and one of the questions I had in my mind was can development teach us anything about health care in the UK?

So if you’ll just bear with me for a second I wanted to give you an example of a project that I worked on in Vietnam about 12 years ago and I worked with a community of boat dwellers in Central Vietnam. They’re called the Sampeng Yang, they live on boats, they’re highly marginalised and I worked with an organisation that was working with the local government to distribute funds to the Sampeng Yang. What we discovered through our monitoring processes is that, although the project had been set out so that the people who lived on boats would use the money for small businesses, what they were really using the money for were televisions and motorcycles. I couldn’t really blame them for that because who doesn’t want a TV or a motorbike? But it wasn’t really creating long term change for anybody. Boxes were being ticked because the money was being spent but poverty wasn’t being reduced, people’s lives ultimately weren’t better in the long term.

So what we did was we went in and started working with the government and saying, “Right, how can you actually work with these people?” because to be honest with them they didn’t really know anything about the people who lived on boats and what their priorities were. The people on boats didn’t really understand what kind of businesses
they were supposed to be developing with the money that they were being given so we worked with them to develop a system where they could work together and design new outcomes and one of the things that they did was actually pool their resources so they created a floating health clinic which was something that nobody had ever thought was even possible. The government ended up buying into it, it was funded, they had government doctors working on that.

So I think in development certainly what we found is that failed products often lack in adequate understanding of the priorities of the beneficiaries and communities often aren’t trained in how to change but neither are the government officials that are supposed to be working with them.

This is really an example of what we call in health co-production but I think what we see very often is that health services often reflect the priorities of the provider and not the patient. I wanted to give you a couple of examples of how I’ve sort of come across this in the last couple of years, even though people-powered health and patient experience and patient engagement have really come to the forefront. I think very often as a patient you can feel like you’re a square peg that is being jammed into a round hole. You have to access the services that are available whether they meet your needs or not and I mentioned I have to go to an immunology clinic once a month and a few months ago I went there and they have a late clinic on a Wednesday. By late I mean it starts at 4:00, it ends at 8:00. So not really late, you still have to leave work early but it is helpful and I got there and they said, “Well we’re not having the clinics on a Wednesday anymore, we’re going to have them on a Tuesday or a Thursday because the doctor can’t do a Wednesday.” There always has to be a doctor on call.

So they did a survey of all of the patients who attend the clinic and all of us, there are about 20 of us that attend this on a regular basis said, “Well we would like it to be on a Tuesday.” So I re-did all of my appointments for the next six months so that I could attend on a Tuesday and that’s not just me, that’s me, my husband, my mother in law, my daughters, nursery providers, everybody around me who helps me go there on a Tuesday or Wednesday night. I came back the next month and they said, “Actually we’re not having the clinics on a Tuesday we’re going to have them on a Thursday” and I said, “Oh that’s really interesting because all of the patients wanted it on a Tuesday” and they say, “Yes well the doctors...” excuse me ... “the doctor doesn’t want to work on a Tuesday night.”

I then had this really interesting conversation with the nurse where I said, “Why is that you hold these late clinics?” and they said, “Well we hold them for the patients.” So I said, “Okay so now you’re holding the clinic on a Thursday night for the patients but none of the patients are going to attend” and she said, “Yes that is a problem.”

So there was a lot of back and forth and eventually I am pleased to say they are now being held on a Tuesday but when we talk about patient engagement and patient involvement is it really meaningful? Very often as a patient I tend to feel that we get asked questions but people don’t really want to know what the answers are.

I’m a trustee of a charity called Shine Cancer Support and we work with young adults with cancer and I think this kind of thing tends to happen a lot with younger adults with cancer because we don’t fit a model of what the cancer patient looks like and one of the
things that we recently found in a survey that we did was that almost 50% of people that we surveyed didn’t feel that they were adequately supported to preserve their fertility before they went for cancer treatment and we know that one of the reasons that this happens is that there are different priorities between the clinicians and the patients. The doctors really want to save the patients’ lives and of course that has to be a priority but the patients also want to have a life if their...you know, if their life is saved what was their life supposed to look like? If they wanted to have children and they’re not given any kind of choice in that process it’s really difficult.

So doctors and patients very often have different priorities when cancer is diagnosed but they don’t tend to talk to each other about it. Fertility I think is one of those issues that doctors can be quite shy about, patients are shy about and so in the end the outcome isn’t something that anybody really wants. If you’re not part of the solution you’re part of the problem. I think we have a lot of problems but patients would like to be part of the solution. It’s quite a heavy burden to walk around thinking that you have long term conditions and you are a drain on society. So engage us and make us part of the solution, yes and I think most patients would really welcome the opportunity to do that. So thank you very much. I will leave it there.