Interview with Dominique Hamerlijnck

Transcription

I’m Dominique Hamerlijnck. I’m one of the patient advocates from the Dutch Lung Foundation. We do quite a lot of different projects, and usually it goes two ways. We are asked for a specific project because they know we are interested, or we have sort of general call saying who would be interested in being involved in a specific project.

I started in 1980 when my primary care physician asked me to talk to some medical students on what it’s like to live with asthma. It sort of developed from there, and the main change happened when I worked for the Asthma Foundation as the leader of patient involvement. From there, it developed because then I got really, really interested in what we could do. It goes from being giving advice, or advising on projects, applications, but also going to EMA. We were asked to advise on a big EU project, research project, even before the first application was given. It was really wonderful because the primary proposer, he was really interested and he completely changed the proposal because of what we told him would be possible for patients with severe asthma.

We looked at all the proposals. We had a patient group of about 12 people, and we talked together on advising on proposals, and we helped each other. I learned about as much from my fellow patients as I learned from the researchers because everybody sees different things. Like with informed consent, we all of us have a language sensitivity that’s different, and it really worked very, very well.

We saw the proposals. We saw the informed consent. We helped them develop patient information leaflets on specific aspects of what the patients involved in the trial would go through. We helped them contact patients, because they had a lot of problems in getting enough patients included in the research. And for the first time we were involved in the work packages. Two of us were added to the work package and followed every discussion between the work package, participants, as patients as well. So we were really deeply involved in the project from beginning to end. That was really good.

The Dutch Lung Foundation invested when they made a special group of people who are experienced in being experienced in the disease. There’s not a real English word for it. They gave us some training in communications, and how to communicate in a way that connects instead of repels, so that you’re not telling a doctor they do everything wrong, but more find a way of talking together. We had a few of those. I think what was really educational is, we worked on a project where we as patients developed what questions would be interesting in giving advice on the research proposal. That really got all of us thinking about our role as patient advocates, and things like EUPATI, or going to EMA, just reading stuff is so educational. Then you see different aspects and that really helps.

HOW HAS THE EUPATI TRAINING IMPACTED YOUR ADVOCACY WORK?

It’s a good example: I was invited to a clinical trial development group which sort of is a consortium of the Dutch government, the Dutch clinical trial organisations and the pharmaceutical industry, and they are trying to get patients involved. And they had an open meeting, and because of EUPATI, I noticed I was talking differently with them. Had a different kind of input and could be more patient in what I was saying. This worked really well because I knew there was this wealth of information that I had in my backpack, but I didn’t have to tell everything from the get go. That I think EUPATI helped me in.

WHAT ARE SOME OF THE CHALLENGES AND BARRIERS THAT YOU ARE FACED WITH IN YOUR PATIENT ADVOCACY WORK?

One of the barriers, because I also work with HTA and cost effective analysis modelers and researchers, is that you have to find a common language. You have to find a way to be interested in what they tell you and make a translation, but also translate what you’re saying so that you find a common ground. That is a difficult thing to achieve. I feel that’s a barrier, but once you’ve achieved it, you get into the real conversation. Then you get influence. Then people start listening. When I started in the 1980’s, we could do very little. We could talk to some doctors. We could do maybe talk to some medical students, but all these little steps helped. It is an incremental system, and we’re in the forefront. Patients being patients is really important, we’re getting there, but it is still slow process. Ten years ago we couldn’t do what we do now.

We’re in the forefront, so we are the select group of usually high educated, highly vocal and interested, and out-there patients. It’s important to get us to be more involved in different areas, but also how can we involve less vocal, less educated people, and develop a form of patient advocacy that fits them.