Interview with Matthew May

Transcript

My name is Matthew May. I work for DIA, which is a non-profit in the pharmaceutical industry. We're a global membership association who also provide conferences and trainings, and also are active in providing global thought leadership in various areas in medicines development. At the European, Middle East, and Africa Office in Basel I work as Project Manager focused solely on the work of EUPATI, the European Patients Academy for Therapeutic Innovation, where I'm responsible for the coordination of all of the content development and production to do with educational material within the EUPATI project. That's both for our patient expert training course that takes place over 18 months as e-learning and face-to-face, and also of the toolbox on the website that we have, which is a consolidated one-stop source of information in seven languages, and possibly more in the future, providing the public but also patient advocates and representatives, with information on medicines development.

When I first joined EUPATI back in 2012, a couple months after the project started, there were a number of very clear different stakeholder groups on the project. We could clearly see where everyone was coming from, as in what stakeholder group they were coming from, whether people were working for a patient organisation, whether they were working at an academic institution with an industry partner, and even from our advisor's perspective whether they were at a regulatory agency or an HTA or other non-profits.

As the project progressed, you sort of, slowly began to see these lines get blurred a little bit. We began to see all of us who came from a very specialist background, I myself, I'm a

chemist by training, very briefly worked in the lab in drug discovery and delivery systems, we began to actually do what we were hoping to teach of our students, of the trainees in the course: We became generalists. As we worked together and learned about each other's different areas, we would slowly bring in knowledge across the board, working together to pull the combined experience into a lesson, into a learning module, into an article or a presentation. In doing this editorial process and this content creation process, I think we've all actually benefited ourselves as becoming much more generalist educated professionals, which gives us a different perspective of how we do our jobs now.

What is more, as you see these teams that formed, the different work packages or subcommittees within different work packages of the project, you begin to see actually you're no longer solely representing your own company, or in my case my own organisation, but you begin to represent also the view of that stakeholder group as a whole. I myself sit on the EUPATI editorial board. We review all of the content that gets released to the public, which is all of our content because of course all of our content is publicly available, and on that board I'm not just representing myself as someone who knows about how medicines are made, but I'm also representing the NGO stakeholder group. My colleagues on that board will be representing not just a single pharmaceutical company, but the thoughts and viewpoints of pharmaceutical industry as a whole or as the patient community as a whole or as academia as a whole.

That's also necessary in such a project when one of our key, I guess unique points, is the fact of how neutral we are and how transparent we are, to make sure that we take into every single viewpoint without being biased in one direction or another.

HOW HAVE YOU BEEN INVOLVED IN PATIENT ENGAGEMENT AT DIA?

Within the DIA office, because of my extension of experience and work within EUPATI and really getting to know lots of different individuals but also the different organisations and what's important within the community of so I say the patient advocacy community, I have been responsible for all the patient activities within the European, Middle East, and African Office for the past few years now. Within DIA we do a number of activities and have done a number of activities over the past decade to ensure that patients remain a central part of medicines development. Within the European Office, over 10 years ago now we initiated a programme offering fellowships, sponsored attendance of patient advocates, patient representatives, to our largest meetings to ensure that they also had a platform and a means to attend and to network with the relevant stakeholders, but also bring a completely different viewpoint to the table that would stimulate discussion and future collaborations across the board.

This programme has also been replicated by our colleagues in North America, and takes place firmly as part of the core of the DIA annual meetings now. Over the past 10 years it hasn't just stayed static either. It's slowly evolved as times have changed within medicines development. For example, in Europe now we see patients just not attending our meeting as attendees, but they're there as equal stakeholders at the table, systematically involved as part of our programme as speakers and as panelists. We'll continue to do that in a number of other meetings as well.

DIA is a professional membership association with members coming from lots of different areas, lots of different stakeholders. As such, we recognise that an important stakeholder to have as part of our membership association is the patient community. DIA runs on a lot of different

communities based on individuals' professional specialisations, which allows people to network across regions, across companies, and across functions to drive guidances forward, to drive innovation forward, to drive collaboration forward, and to run off the back of each other's ideas.

The patient community has always been a little bit different for us, because of course the concept of a professionalised patient is relatively new and isn't always the way that patients work. Being a professional membership association, it didn't always fit truly together. As everything evolves, we of course have changed that as well, and there's now also a specific programme to allow patients to become members of DIA. If anyone's interested in that, they should also get in touch with us to work out how that happens. We offer a platform online and also at our meetings for patients to speak to each other, an idea that we also saw taking place within EUPATI, where you have people coming from lots of different disease areas, lots of different areas of the world to share ideas and really form one voice or one view to collaborate with others and also to collaborate with people from lots of different stakeholder groups.

Other areas that we've recently, I don't want to say "recently" here because actually it's been happening now for a number of years, is that we have people involved from the patient community in our own advisory groups within the organisation, whether that's at a board level, whether that's at a regional advisory level. We also have a systematic inclusion of patients in our programme committees within our meetings. That's to say we have someone who is there as part of the programme committee who's also providing insights for the rest of the programme committee into where the most valuable place for the patients to have a voice in the programme is, so that it's really impactful and really captures the imagination and the needs of all of the attendees

at a meeting.

HOW HAS DIA'S WORK CHANGED OVER TIME?

Over the past decade we've begun to do more thought leadership. That is to say we use our strength as a membership association, as someone who's involved with all these different stakeholders around the world, to bring together knowledge, to bring together insights to be able to transform the way that medicines development happens. In the area of patient advocacy, patients' interest, and patient engagement, we've been working in a number of different collaborations. For example, we've been working with the Clinical Trials Transformation Initiative.

We conducted a workshop with the Patient Centered Outcomes Research Institute, and more recently in the last year we've …… been working with the Tufts Center for Studies on Drug Development in a joint collaboration project to begin to look into the return on engagement with pharmaceutical companies on how they work with patient advocates and patient representatives. The idea here is that we recognise that patients have been an important part of medicines development for many years now. The question is always out there of, "Is there any quantitative data to show what impact is actually being made by including them at the various stages of medicines development?" The research that we did with Tufts has begun to address this.

You'll find the results of this study recently published on the DIA website, and you can look into the different areas we looked at. For example, we went looking into defining finally some metrics that are available for people to work out the return on engagement that's happening. We looked at then taking this metrics that have been developed and looking at specific case studies that have been submitted to us retrospectively. Of course, the metrics can be used going forward prospectively to define measures that can be used as

part of an engagement activity. Perhaps in the future we can even look further onto different areas already of retrospective research as we get more and more case studies coming in.

DIA insights and DIA thought leadership provide stakeholders with the tools and with the knowledge that they need to be able to advance their current working methods, advance the way that they're doing medicines, save money, and truly begin to see a return on engagement.

It's only by collaborating between the different stakeholders, and to collaborate we truly need to understand where each other is coming from and to have a knowledge that is suitable for us to engage with each other, that we can truly drive medicines innovation development forward, and make sure that in the end everyone in the world has access to a medicine that they need.