

# Active listening to the patient is the way forward

## My journey in patient involvement

When I moved to industry, my mission to do my part in trying to improve peoples' health as the people themselves would define it stayed the same as it was previously in academia and clinical practice. In my industry role, I'm driving the idea that active-listening to representative patients at key points during medicine development can help us understand which outcomes are most meaningful to the patient and their communities and may help us to be more efficient in how we do our work.

How we do this in an environment that is evolving alongside patient activism, regulatory, technologic and scientific advances, requires collective discussion amongst all interested groups. We also must be acutely aware of differences in the regions where we work to ensure that we are respectful of culture and compliant with laws and regulations. I believe patients (including the person with a diagnosis, caring for someone with one, a family member or close community members) should have their experiences and preferences considered and integrated with what science tells us, before decisions are made that will affect them.

In clinical practice, before I joined industry, it was clear to me that shared decision-making helped our health care team, along with the patients, make the distinction between what could be done and what should be done to try to achieve the *patients'* goals. Goals of care were often articulated as sunsets, weddings, births, graduations, days in the park. We learned that we should make no assumptions about what they

wanted based on our own goals or those of other patients in our practices. Working with patients individually facilitated very personalized care.

People living with illness are experts in how they live their lives with their illnesses and they can easily gather a lot of information through the internet and social media. However, they may not have the experience or background to contribute their expertise in a manner that allows it to be incorporated into the development and understanding of new medicines and other therapies.

## **EUPATI's role in this story**

I see EUPATI as a flagship collaborative program that is educating, empowering, and enabling patients about how to do that.

The program offers several avenues to build on their knowledge and to explore where and how deeply they would like to become more involved, whether it is with industry or academic sponsors of research, regulatory authorities, health technology assessment bodies, or elsewhere within their healthcare system. The program is building on resources that should help patients to provide their insights in ways that will move us all toward our shared goals.

The stories of participants on the EUPATI website and told at the live meeting in Dublin last April outline the work they are already doing to better inform the way therapies are developed. The stories of patients, families, partners, friends, scientists and health care professionals are also quite compelling to me – and underline that we have a long way to go toward more systematic patient involvement across our health ecosystem. That can only be achieved through appropriate collaboration, commitment, and connection.

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