

Getting to know Adrian Kielhorn, an Alexion R&D Leading Voice

November 1, 2023



Alexion's leadership in rare disease is driven by the many individuals whose expertise, creativity and tenacity fuel our commitment to advancing innovative science. Adrian Kielhorn is a Senior Director of Global Health Economics and Outcomes Research (HEOR). We spoke with him about his passion for problem solving, what motivates him, and what makes working in rare disease unique.

Can you explain the role of the Health Economics and Outcomes Research (HEOR) team?

Fundamentally, the HEOR team focuses on measuring how treatments help improve the lives of patients, often over an extended period of time. This is really important in rare disease, where so little is known about the true burden of disease on patients and caregivers. So, to really understand the value of a medicine, we need to understand what life looks like before a rare disease diagnosis.

This is hard to measure just by conducting clinical studies, which are driven by quantitative metrics, so we have to do additional qualitative research – interviewing patients and asking open-ended questions that prompt conversation – to get a better sense of how life has changed since symptoms began.

How did you get involved in a career in health economics and outcomes research?

...So, when I was studying at University of Hannover [Deutschland], one of my professors was involved in developing and validating a quality-of-life measurement tool which was brand new at that time. And I really liked this area between medicine and economics and how to evaluate the benefit of innovations by developing tools that could help measure changes in quality of life.

...I like doing new things. So, I got attracted to this area, started working for him as a part time research assistant, which ultimately led to my career working in the pharmaceutical industry.

What led you to a job in rare disease?

I was drawn to rare disease because I believe that communities affected by rare conditions most need our help. A lot of the health economics tools that we develop for big or more common diseases, they don't really work in rare diseases. So, you have to adapt them, you have to come up with new ways... this is really a challenge I like working on.

...Rare disease...is really the ultimate area to be in [for] me because there are so many tools that we need to develop from scratch. It's really a challenge that I like every day, to find ways to capture what's important to patients with rare diseases.

What about your current work excites you?

One area I'm particularly excited about is trying to develop effective solutions for patients and make a real difference when it comes to addressing health equity challenges. To do that, first we need to understand barriers to care that patients are facing, such as limited access to providers or transportation to appointments.

Qualitative research helps us understand these challenges. We're engaging patients in ways that go beyond checking a box on a form to better understand the socioeconomic, demographic and cultural considerations that affect their healthcare experience. This is particularly important in

marginalized groups where specific barriers may prevent them from participating in clinical trials. Our hope is that this research will help us create clinical trials that better reflect the populations affected by certain diseases.

Do you have any advice for someone considering a career in rare disease R&D (research and development)?

I am lucky to work in rare disease because it combines the professional challenges that interest me with an opportunity to advance understanding about diseases that are not well understood.

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