

## Meet the Team — Q&A with Clinical Outcome Assessment Scientist Cole Ayasse

Can you tell us about your current role and responsibilities at C-Path?



I am a Clinical Outcome Assessment (COA) Scientist in the COA Program at C-Path. I support the consortia that are part of the COA Program, and I also support programs, consortia, and working groups across C-Path.

COA is an umbrella term for any measure that describes how a person living with a condition feels, functions, or survives. COAs rely on reporting from patients themselves, caregivers or another close observer, or clinicians, or on measuring the performance of patients in a specific task. A measure that asks someone to rate the severity of their pain would be an example of a patient-reported COA.

I frequently work on projects that are trying to solve measurement problems, or that aim to build evidence for the appropriateness of a

COA in a specific population or context. An example of a potential "measurement problem" is that, in a condition where RCTs repeatedly fail to demonstrate a treatment effect, one might ask whether those treatments are actually ineffective, or whether common endpoints are not capturing their effect.

What inspired you to pursue a career in science, and how did you get started?

Looking back, the initial spark came from being drawn to logical problems and solutions. I like being able to take apart a question and methodically construct an answer. Early on, I found it difficult to narrow my interests to one specific field of study. I took any opportunities that I could as an undergrad to gain experience in research that interested me, which resulted in everything from supporting psychophysics experiments in bats to initiating an interdisciplinary social psychology and applied statistics project. What do you enjoy most about working at C-Path?

I love that C-Path is so genuinely focused on improving people's lives and doing well-designed, meaningful, collaborative research. C-Path really walks the talk. As a zebra myself, I also have a personal appreciation for the amount of work C-Path does in rare diseases. My tethered cord diagnosis was delayed by decades due to initially normal results on more common testing, and I repeatedly encounter difficulties navigating access to the right treatment or support due to under-recognized clinical presentations. I have seen how accurate and complete characterization of disease progression and variability, one component of C-Path's work in rare diseases, can have an impact beyond the goal of treatment development.

Can you share some of your professional background and any key experiences that have shaped your career path?

The first course that introduced me to neural action potentials fascinated me, and that led to several years in cognitive neuroscience research, where I enjoyed the challenge of designing experiments to answer questions about cognition, which presents some unique measurement difficulties. My research was (comparatively) less applied though, and I began to realize that I wanted to do research where I could see direct applications toward improving people's lives.

After completing a post-doc, I somewhat stumbled into the COA and psychometrics field; I have said that without being sure of exactly what I was looking for, I accidentally found my dream career. I sought out opportunities to connect with people with similar backgrounds, and I discovered that a lot of my research experience and quantitative knowledge transferred. I worked for three years in pharmaceutical consulting as a COA-focused psychometrician/statistician before coming to C-Path. Personal experience has taught me the importance of ensuring those with lived experience have a voice in the clinical trials and pharmaceutical space, which makes it easy for me to feel aligned in values and mission.

How do you stay motivated and continue to grow in your role, and what advice would you give to others looking to advance in their careers?

I think if you can find a way to combine enjoyment of (most) day-to-day tasks with an alignment of mission and/or values, a lot clicks into place.

## **About the Author**

Cole Ayasse, Ph.D. (he / they), is a Clinical Outcome Assessment Scientist at Critical Path Institute with four years of experience in patient-centered outcomes and 14 years of experience in research and analysis. He is active in disability advocacy and in patient-led community networks. As a disabled scientist, they work to bring all their relevant experience to the table when planning or discussing research, and to promote research practices that center lived experiences.