

## From Words to Action: Ensuring True Accessibility at Scientific Conferences



I want to talk about access and inclusion at scientific conferences and putting actions to words or values. Conferences are exhausting for anybody, but more so when at every turn there is an unnecessary barrier to your full participation that you must navigate. It is compounded when accommodation is promised and not followed through on — in the past, I've even encountered this in the critical 20 minutes prior to my presentation beginning.

Recently, one of my abstracts was accepted as a talk for an upcoming patient-centered research conference. Eager to share my work, I began looking into travel and accommodation, but I was disappointed by a lack of accessibility, and lack of information, when I went to check about the conference site and hotel room block — particularly given the conference purports to value patient research partners. As a wheelchair user, I felt alienated, frustrated, and, frankly, tired.

While the conference website did include a section with some accessibility information, it was apparent the conference organizers failed to prioritize access. Neither the conference site nor the discounted room block (same hotel) is fully accessible, and the hotel website contains no access information.?

Compare that to my recent experience at C-Path's Inaugural Global Impact Conference, I was heartened by the clear effort to ensure maximal accessibility. A few examples include a ramp that all speakers took to access the stage, people ready in the crowd to carry wireless microphones to audience members to ask questions, and a sign at registration encouraging attendees to request accommodations if needed. I also know the organizers aimed for independent accessibility wherever possible (that is, accommodations that do not require asking for help each time), but in the few instances where they could not work with the venue to achieve this, they ensured that help was readily available and easy to find.



Cole enjoys a networking break at #CGIC2024

For the conferences and venues that do not make these efforts, it feels performative to still claim, as conference websites often do, to value the participation of disabled people and apologize for the "inconvenience." What does that mean when you have planned an event without full accessibility, resulting in the creation of barriers??

The "inconvenience" of being unable to stay at the conference hotel may also be magnified for many disabled folks. Getting from hotel to venue and back each day can pose multiple barriers, such as inaccessible public transportation, poorly maintained sidewalks, or old cobblestone streets. Many disabilities come with fatigue, adding more difficulty to that daily trip and increasing the likelihood of needing a break in your room. Some disabled folks may also need more to survive the day — medical equipment, medications, items to manage symptoms, food to accommodate a medically-necessary diet that the venue can't provide, etc. For some, these added barriers alone may be insurmountable, or else may prevent them from being as alert, engaged, and present as they otherwise could be.

In my experience, the choices of conference organizers even after a venue is finalized can have a large impact on the ease of access. At one conference I attended last year, the location of hidden-away elevators was highlighted by large signs pointing the way, aisles around booths and posters were wide and navigable, conference volunteers brought hand-held microphones to audience members who wished to ask questions, and catered food was provided in to-go boxes with lids. In contrast, at another conference, only two-thirds of the conference rooms had elevator access, audience members asked questions via microphones placed at standing-height around the room, the food and drink stands were too high to be accessible and only heavy flat plates were provided, and the caterers' set-up blocked one of the two accessible restrooms.



Panelists engage in the session, "Lived Experiences in Action: Advocacy Update Across Rare Diseases" at #CGIC2024

Although a comprehensive list of best practices is beyond the scope of this piece, I encourage conference organizers to, at minimum, ensure that the venue and hotel comply with relevant access laws (e.g., the ADA in the US); this should include considering the space after event set-up. It is notable that, due to the limitations of such laws, full access and inclusion often requires going beyond this. Disability access consultants can be engaged to ensure the event is as accessible as possible. For the greatest success, accessibility for both visible and invisible disabilities should be discussed from the earliest planning stages and considered with each decision.

As more scientific fields recognize and lift up the importance of diverse perspectives, it is essential that we make our conferences and conversations accessible. Whether you yourself are disabled or an advocate, there are simple actions you can take to improve accessibility:?

- Become aware of these issues
- Expect more of the events in your field or that you attend
- Notice barriers during an event
- Ask organizers about access
- Communicate that a lack of access is unacceptable

Enough people speaking up will make a difference.?

This is a field that is supposed to be centered around the experiences of people with disabilities and chronic or acute conditions. We say we want to make the patients at the center of our research integral to its process. How can we do that as a field when our events create unnecessary barriers to inclusion for a large portion of those people?

## **About the Author**

Cole Ayasse, Ph.D., 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. They work to bring all their relevant experience to the table when planning or discussing research, and to promote research practices that center living experiences.

## **About C-Path**

At C-Path, we strive to be the ones stepping up to make those differences. This isn't just through the work we do every day to improve lives with the collaborative environments our consortia offer to industry, regulators, academia, and patient groups. We live it through the little things, including the AccessiBe integration on our website (check out the little blue figure on the bottom right), the detailed planning that went into the C-Path Global Impact Conference, and the efforts put forth by our DEIR committee, of which Cole is a member.