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Laidlaw Scholars Undergraduate Leadership and Research Programme

Leadership in Action Report

Bridging the Epistemic Divide: Translating Neurological Realities into European Policy

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Introduction

The gap between neurological research and actionable health policy is often vast, requiring dedicated advocacy to translate clinical realities into legislative priority. This summer, I completed my six-week Leadership-in-Action (LiA) placement with the European Brain Council (EBC) in Brussels, Belgium. Across the placement, I contributed to communications, outreach, and programming for a number of EBC's ongoing brain health initiatives. However, the centre of my placement, and the project through which I did the most directive leading, was the HEREDITARY Advocacy Workshop; a virtual event I conceived, designed, and led, held on June 30th, 2026, as part of the broader EU-funded HEREDITARY project.

The workshop convened 101 registrants across a three-hour programme, drawing researchers, policymakers, industry representatives, civil society actors, and patients from more than twenty countries. What follows is an account of what I built, as well as the meaningful discourse, arguments made, tensions surfaced, and moments when the workshop's premise was tested, and I believe, proven. This report draws directly on the workshop's outputs, and explores the leadership themes of decisive ownership under ambiguity, relational and cross-cultural facilitation, and ethical stewardship of a patient-centred advocacy space; and how designing and delivering this workshop entirely from scratch in the span of six weeks reshaped how I understand my own leadership capacity.

Project Objectives and SMART Goals

I structured my ownership of the HEREDITARY Advocacy Workshop around three goals.

1. Programme Design and Speaker Recruitment: To design a full workshop agenda spanning EU policy education, a multi-sector panel discussion, and a hands-on policy simulation, and to recruit and confirm speakers representing research, policymaking, industry, and patient advocacy, within roughly two weeks of active planning time.

2. Outreach and Registration: To drive registration from a genuinely cross-sector, international audience of researchers, policymakers, industry representatives, civil society organizations, and patients, reflecting the multi-stakeholder nature of the workshop's mission.

3. Delivery and Continuity: To execute a seamless virtual workshop experience on the day itself, and to design a post-workshop resource package that would allow participants, particularly researchers newly exposed to policy engagement, to translate the workshop's insights into ongoing action.

Challenges Faced

The central challenge of this project was a compressed timeline under high ambition. Although the HEREDITARY Advocacy Workshop was part of a well-established, EU-funded consortium project, the actual planning and logistics for this specific workshop had not yet begun when I had arrived in Brussels. I was brought in to lead the workshop into existence, which

meant I spent much of my six-week placement designing the programme and recruiting speakers before I could even begin participant outreach and social media content pushing registration, leaving only a couple weeks to build an audience for an event I needed to also be building from scratch.

This created tension for me when formulating the logistics, because the workshop needed a large, credible, cross-sector audience to fulfill its purpose, but I was recruiting in a very strained timeframe, so I had to be realistic about who would be able to participate, and in what capacity. In practice, I reached out to over 250 individuals and organizations across the research, policy, industry, civil society, and patient advocacy landscape. A number of highly credentialed invitees responded positively to the proposed workshop agenda and expressed warmth and interest for the cause, but had already committed to other events months in advance; a natural consequence of reaching out so late relative to their calendars. Rather than perceiving this as a setback, I used it as information: several of these contacts requested the workshop recording and/or materials because they were genuinely interested in the programming and outputs, and others expressed interest in future collaboration. This response reinforced that the workshop's premise was resonating even with people who couldn't reasonably attend, and it kept me motivated through a demanding final stretch of planning.

Ultimately, the workshop drew 75 participants, including panelists and speakers, reflecting the sectors the workshop was built to convene: researchers and academics from institutions across Europe and beyond, EU policymakers including representatives from the European Commission and national government bodies, industry and biotech representatives, civil society organizations and NGOs, HEREDITARY consortium partners, and patient advocates and patient organization staff; several of them living with the neurodegenerative conditions the workshop's research base addresses. Registrants joined from more than twenty countries across four continents, including several Global South and non-European participants, which gave the eventual policy conversation a breadth I had not originally anticipated but had deliberately made room for by holding the event virtually.

Leadership Skills Applied and Developed

Decisive Ownership Under Ambiguity

Designing this workshop meant making a large number of consequential decisions with very little precedent to draw on and very little space to course-correct. My academic and research background in Parkinson's disease research in and outside of the Laidlaw programme and biotech and industry work gave me credibility on the scientific reasoning, but I had no formal training in EU policymaking structures when I began building the programme for the workshop. I had to learn the policy landscape adequately and quickly enough from the policy team at EBC to structure a rigorous agenda, including an introductory session on the EU policymaking environment, several multi-stakeholder panels translating research findings into policy-relevant communication, and a hands-on policy simulation exercise placing participants directly into stakeholder roles. These roles included researcher, patient advocate, policymaker, legal expert, industry representative, etc., and participants were assigned to roles unalike to their real-life positions. This was designed in this manner to surface the real ethical and regulatory tensions

this field will keep producing, and from the perspective of a different stakeholder, in order to more effectively bridge the understanding of the implications of one field on another.

The substance of the day validated that structure. In his opening remarks, EBC's Executive Director, Frédéric Destrebecq, offered a concrete illustration of what successful science-to-policy advocacy looks like in practice: he described how the European Parliament's Public Health Committee had directly reached out to civil society actors to present the current state of brain health in the EU and to suggest how the EU should respond; a case, as he put it, of policymakers themselves asking the community to make its voice heard, rather than advocates having to force their way into the conversation. He also traced the decade-long path of the European Partnership for Brain Health, from an idea proposed by the research community to an officially launched programme in 2026 backed by roughly two and a half billion euros in Commission and Member State funding. The notion of patience and coalition-building translating over ten years into tangible resourcing set the tone for the workshop and demonstrated that this kind of structural change is achievable, but only through sustained, coordinated advocacy.

Communication and Adaptive Problem-Solving

Communication ran through nearly every part of this project, from translating dense scientific and policy concepts into outreach materials. Just days before the workshop, one of our panelists whom we were waiting on final confirmation from became unable to speak in their session due to travel constraints, although they remained registered to attend as a participant. Losing a speaker of that calibre and that close to the event created tangible pressure for me as the organizer, because the panel's value depended on maintaining balanced representation across sectors; research, policy, industry, and patient advocacy each needed a voice in that conversation for the discussion to achieve what it was designed to. Rather than filling that seat with whoever was available quickest, I intentionally identified and confirmed a replacement speaker with a comparable sector background, preserving the panel's cross-sector intergrity.

The resulting session, Session 2, " From Research Findings to Policy," delivered precisely the rigorous, multi-perspective exchange I had hoped for with this workshop. Christina Kyriakopoulou, a Policy Officer at DG Research & Innovation, described how the European Commission has shifted Horizon Europe toward an explicitly impact-driven model – a "pathway to impact" rather than impact as an afterthought – and detailed concrete mechanisms researchers can use to reach policymakers, including informal thematic project clusters that feed directly into what the Commission calls "feedback to policy," and short policy briefs that translate research evidence into structured, decision-ready recommendations. Danai Spentzou, an Accredited Parliamentary Assistant in the European Parliament, was candid about a structural imbalance: industry actors generally have far greater resources to get their messages in front of policymakers than individual researchers do, and she urged closer collaboration between researcehers and NGOs or foundations that already have that lobbying capacity. She also flagged a practical, often missed opportunity: EU public consultations, which researchers are frequenty unaware of, or learn about too late to contribute. Loredana Babeau-Simulescu, Executive Director of Biomed Alliance, named the deeper structural problem underlying both of these points: science-to-policy engagement remains, in her words, "largely a volunteer activity," and she argued that academic

incentive structures need to expand beyond publication counts to formally recognize policy and regulatory engagement. Otherwise, the researchers with the least time and support will remain the least represented in policy conversations. Yann Heyer, Policy Officer at the European Patients' Forum, grounded the entire discussion in evidence, citing European Medicines Agency data illustrating that in nearly half of cases where patients participate in the regulatory process, their input changes the recommendations ultimately given to developers.

Strategic Communication and Outreach

The registration campaign ran across the EBC newsletter, the HEREDITARY consortium mailing list, the HEREDITARY LinkedIn and website, the EBC LinkedIn, and my own personal LinkedIn to extend reach further. I drafted these posts in collaboration with the EBC communications team, building toward the June 30th date with a countdown campaign that also gave early audiences a preview of the agenda as speakers were confirmed. The target audience was by design exactly who ended up registering and attending, and thankfully this was evident in the participant engagement; enough to fill the chat and Q&A sessions with substantiative questions and insights throughout, rather than a passive and uninspiring presentation.

Cultural Humility and Decentring My Own Instincts

Coming from a research and academia background with a bias towards speed and efficiency, my first instinct when the panelist dropped out days before the event was to prioritize expediency and confirm somebody new as soon as humanly possible. What stopped me was recognizing that expediency would have compromised the integrity of the panel session and the very thing the workshop existed to protect, which is balanced, authentic representation across sectors. The dilemma of balancing speed and quality of decision turned out to be the precise dynamic I designed the policy mock-up exercise to surface, and watching the conversation flourish live among participants confirmed I had succeeded in that endeavour. In the exercise, participants were split into breakout rooms and assigned real-world stakeholder roles, such as researcher, patient advocate, policymaker, industry representative, legal expert, etc. to work through an open-ended scenario involving AI-assisted clinical decision making in a stroke triage scenario. One participant reporting back described this shift candidly: her group's initial instinct, reading the scenario cold, was that the AI tool simply should not be used at all; but once the group began discussing it from each stakeholder's perspective, that position softened into a more structured compromise; a tighly monitored pilot, restricted to consenting hospitals, run as a formal investigator-initiated trial with clear documentation of how AI-assisted decisions were made. A second group, working through the same stroke triage scenario, arrived independently at a similar conclusion: rather than a binary yes-or-no, they called for urgent guidance from the European Commission to navigate the balance between innovation, safety, and fairness. Observing how participants move through positions in an ethically-layered scenario through different stakeholder lenses, and transcending from an instinctive "no" to a considered, multi-stakeholder "how" was inspiring to witness and reinforced the choice of prioritizing representation over speed.

Ethical Considerations

The most significant ethical responsibility I carried in designing this workshop was ensuring that patients were never reduced to a supporting detail in a conversation ostensibly held on their behalf. It would have been easy to build an agenda that centred researchers, policymakers, and industry with patient experience folded in as a single panel or closing remark. I designed against that from the outset, working directly with patients and patient advocacy organizations as collaborative feedback in shaping and honing the workshop's purpose.

A second, related ethical decision I had to advocate for was the deliberate inclusion of neuroethics as a core theme, both with Hugo's foundational session on the EU policymaking landscape and as a recurring thread throughout the policy simulation exercise. Neuroethics is the field concerned with the ethical, legal, and social implications of neuroscience and brain-related technologies: questions about cognitive privacy and neural data, informed consent, equitable access to emerging brain therapies, and the boundaries of using neurotechnology to predict or intervene in human cognition. I pushed for its inclusion because the HEREDITARY project itself sits directly at the intersection of these questions, and because the workshop discussion validated the importance of its representation in the programming. Hugo's session detailed EBC's own European Charter for the Responsible Development of Neurotechnologies, developed collaboratively in response to what he described as a grey zone in EU legislation around commercial and non-commercial uses of neural data, and now moving into an operational phase with pilot companies. Brain-related data is uniquely sensitive; it reveals not just as a diagnosis but predictive information about a person's future cognitive trajectory, and the policy simulation's AI-governance scenarios illustrated participants grappling with the implications of both innovation and protection in neural advancements. A workshop that endeavoured to train researchers and policymakers to engage confidently in the science-to-policy pipeline, without equipping them to reckon with these stakes, would have been incomplete.

This decision reflected the same principle underying my approach to patient inclusion: the ethical stewardship in advocacy work is not passive in any regard. It required me, as someone responsible for designing the programme, to actively insist that certain considerations be present.

Collaboration and Team Dynamics

None of this was accomplished alone, and the EBC team's investment in the workshop's success influenced both the final product as well as how I understand collaborative leadership. My colleague Laura co-designed the logistics of the policy simulation exercise with me and assisted with speaker outreach. My colleague Michaelis reached out to his own policy contacts in Greece to help expand the workshop's reach. My colleague Hugo put together and delivered the workshop's foundational session on the EU policymaking environment, anchoring the rest of the day's content with real command of the material, from the EU legislative process to the Charter for Responsible Neurotechnologies. The collective effort towards this initiative did not go unnoticed, and I credit my colleagues for the success of the workshop as much as I credit myself.

Outcome and Reflection

Feedback at the close of the workshop affirmed that the effort behind it had landed well, both in real time and afterward. As the session closed, an Observa researcher wrote that she had found the workshop "very interesting, inspiring, and clarifying" despite having to leave early for another commitment. A patient advocate living with young-onset Parkinson's closed the day by telling the group she would be open to exploring how her lived existence could contribute to the HEREDITARY project going forward; a direct and tangible continuation of the patient-researcher relationship I was attempting to foster in the space.

The exchange that resonated with me most, however, occurred earlier in the Zoom chat during the panel discussion itself. A patient advocate wrote: "I am a person with Parkinson's and I continue to be struck by the large number of young researchers who have never met a person with the illness they are researching. There is a lot of ecosystem work necessary for PD." To which I responded: "As a young researcher researching PD with two affected faily members, I completely agree with this insight. Part of the motivation for creating this workshop is to increase that awareness and centre patient realities and lived experiences in both research and policy outputs, since it can often be an oversight in academia." The overarching theme, which I hope I have conveyed in this report thus far, is that patient experience must sit at the centre of research and policy, and being given the opportunity to express my own reasons for pursuing this work was a really memorable moment for me during the workshop. My research in Parkinson's disease is not abstract to me, and being able to say that candidly to someone living with the condition and directly impacted by the research in my field was one of the most meaningful exchanges of my entire placement.

The discussion amongst participants during the workshop surfaced the sharp, structural questioning I wanted to invoke. One representative from EUpALS pressed the panel on exactly when registration in the European Transparency Register becomes mandatory for engaging policymakers, prompting Danai to clarify the distinction between bilateral meetings, co-organized events, and open public gatherings. Loredana Tuicu pushed the conversation further still, inquiring on what a citizen engagement model would need to look like to reach not just current patients bit the "asymptomatic majority," which is people not yet aware they are at risk. I was extremely grateful for the attendees' continuous engagement with the panel discourse and actively stress-testing the frameworks the panel described, because that is how we make structural and institutional progress.

Resource Package

The post-workshop resource package I created and referenced in this report was designed to help researchers, policymakers, and stakeholders to continue engaging with EU brain health policy beyond this workshop alone, and can be found publicly at this link should you have interest in the cause: https://www.braincouncil.eu/3d-flip-book/hereditary-advocacy-post-workshop-package/

Conclusion

I came into this placement with fluency in Parkinson's pathology and not at all about how the EU turns evidence into policy. Constructing this workshop meant closing that gap with very little room for error.

What I take from it isn't a single insight so much as a working method: make the call, protect the aspects that matter even when it costs you time, and trust the people around you to carry pieces of the vision you can't achieve entirely on your own. I saw this method vindicated in the room itself, with a patient and researcher recognizing each other's stakes without either having to perform it.

I left Brussels having done something I wasn't formally qualified to do when I arrived. Having achieved everything I set out for myself and more, and having influential actors in every sector of brain health stay engaged in a programme I designed for all *three* hours and express commitment to staying involved after, is what I will carry with me into whatever comes next in my career and advocacy journey.

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