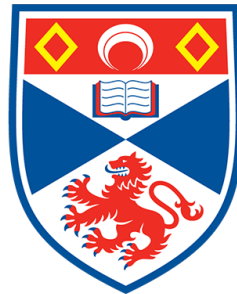


Laidlaw Leadership and Research Scholarship Programme

Lucy Knight Robinson



University of
St Andrews

Advancing Precision Medicine Access and Advocacy through Patient Engagement

Supervised by Vincent Raske and Silvia Bornengo, The Synergist



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1 Introduction

A true leader inspires a collective drive towards a shared purpose. This resonated with me long before embarking on the Laidlaw Programme. But is this the optimal approach or can we push this further to achieve higher efficiency? Conventional leadership theories typically focus on a single individual, but what if leadership traits could be instilled and nurtured throughout an organisation where instead of relying on a sole leader, numerous leaders work together seamlessly toward a shared objective? Does this achieve greater progress than an individual leader could achieve alone? My journey as a Laidlaw Scholar has highlighted the power of global collaboration, demonstrating how multi-stakeholder partnerships drive progress and address complex societal challenges. In this essay, I will delve into experiences and insights gained throughout.

2 Applying to the Laidlaw Programme

My journey toward understanding leadership began with a personal realisation. Having primarily engaged in academic essay and report writing, I approached the Laidlaw application process with a similar methodical mindset. However, before submission, feedback revealed its entirely factual nature and failure to convey the essence of leadership, requiring a deeper exploration of personal values, beliefs, and aspirations. I aimed to infuse it with a sense of authenticity: I considered what leadership truly meant to me, beyond factual analysis. Throughout the programme, I have tried to maintain this mindset of looking beyond facts, embracing an evidence-driven, critical and holistic approach.

3 Leadership Training

3.1 Discovering My DiSC Profile

The first leadership event involved examination of DiSC profiles. Anticipating alignment with the Compliance (C) - Dominant (D) style, I was instead categorised as Influence (I) - Steadiness (S). In evaluating my DiSC profile, which portrayed me as a casual and relaxed individual, I could not help but juxtapose these attributes with qualities I associate with myself. Whilst my work ethic aligns closely with CD profile traits, like diligence, accuracy, and logical reasoning, I began to recognise nuances of my personality that emerge in different contexts. Outside a professional environment, I tend to exhibit IS traits. Acknowledging these distinct personas, I came to appreciate the diversity in my personality, seeing these differences as complementary rather than dichotomous.

3.2 Effective Communication

Another critical aspect of the training focused on effective communication. Through various workshops, I learned the importance of clear and empathetic communication in fostering trust and collaboration within a team. Effective communication is not just about conveying information; it's about listening, understanding, and responding to team members' needs and concerns. I also recognised my lack of confidence in public speaking and have actively worked to improve this skill throughout the Laidlaw Programme. Speaking at the launch event for the following cohort taught me the value of preparation and stepping out of my comfort zone. The programme also emphasised authenticity in leadership, encouraging reflection on personal values and aspirations, helping me develop a leadership style true to myself rather than trying to fit into a predefined mould.

4 Connecting Science and Leadership

During my research project, I realised the intrinsic connection between science and leadership, with leadership skills intricately woven throughout the research process. I experienced the necessity of resilience, how researchers must bounce back from and beyond setbacks. Working

on a project related to Spinal Muscular Atrophy honed my data analytics and research skills, delving deeply into intricate details working on a protein level. However, when I embarked on my Leadership-in-Action (LiA) project, I was instructed to think “high-level”. Throughout my degree, I rarely approached anything from a high-level perspective. My training had always focused on meticulous and detailed thinking. In the context of my research on neurite outgrowth, the "bigger picture" meant understanding a biological process unfamiliar to most people. However, reflecting on my LiA project, I realised the importance of making research findings accessible and relatable, understandable to patients, caregivers, and non-specialists. My LiA project enhanced my ability to see broader implications, using clearer language and avoiding overly detailed specifics to make my work more meaningful to a wider audience.

5 LiA: Synergistic Solutions in Healthcare

5.1 Global Collaboration and Multi-Stakeholder Partnerships

Globalisation and the digital age have significantly improved our ability to solve complex social issues (The Synergist, n.d.). As a not-for-profit based in Brussels, Belgium, The Synergist unites stakeholders from various sectors to collaboratively address societal challenges. My LiA project involved working with The Synergist on their multi-stakeholder From Testing to Targeted Treatments (FT3) programme, which aims to make precision medicine (PM) an accessible reality to all patients who could benefit at the right time.

In May 2024, as part of my LiA project, I had the privilege of helping to facilitate various thought-provoking sessions at the Patient Engagement Open Forum (PEOF) in Baveno, Italy. Patient engagement is the process of involving patients in their own healthcare, ensuring their voices are heard and their needs are addressed. The PEOF addresses global healthcare challenges, serving as a dynamic platform for global leaders in healthcare to co-create (come together/collaborate to create) innovative solutions for pressing issues. The forum emphasises

the need for systemic changes and collaborative efforts for meaningful progress towards better patient outcomes.

Attending the PEOF was invaluable yet challenging. I learned to work under extremely tight deadlines and high pressure in a new environment. At this flagship event for The Synergist, my role as a new team member required that I quickly adapt to the high standards set by the organisation. This triggered self-doubt and imposter syndrome, and I questioned whether I could meet the high expectations placed upon me. Despite these challenges, the experience ultimately proved to be a sink-or-swim moment which reinforced my belief that I could handle such high-pressure situations.

5.2 Promoting Early Patient Engagement in Research

At the PEOF, I helped to facilitate and synthesise insights from a session on research funders' critical role in promoting early patient involvement in the research process, paramount for ensuring research addresses real-world needs. Traditionally, patient involvement has often been an afterthought, but early integration of patient perspectives can significantly enhance research relevance and success. Involving patients from conception and planning through to clinical trials and post-launch activities ensures research is aligned with actual patient needs and concerns. The session aimed to co-create guiding principles for funding agencies to foster sustained and meaningful early patient engagement, highlighting the necessity of systemic changes in funding structures to support patient-driven research. Being part of this session, I demonstrated determination in managing multifaceted responsibilities in a fast-paced environment. This experience also honed my social and cultural intelligence, enabling me to navigate and build relationships effectively in a diverse, international setting.

5.3 Developing Advocacy Roadmaps for Personalised Healthcare

Another session I helped facilitate centred on developing advocacy strategies to enhance access to personalised healthcare. Unlike traditional methods that use a one-size-fits-all model, PM customises therapeutic interventions based on a patient's unique molecular profile, taking individual variability into account to reduce reliance on trial-and-error prescribing. This approach not only minimises ineffective interventions but also enhances patient outcomes by decreasing adverse drug reactions, reducing the need for high-risk invasive procedures, and promoting treatment adherence (Baird et al., 2023). However, the benefits of PM are not yet fully realised, and access remains inconsistent due to systemic barriers like regulatory hurdles, inconsistent healthcare budgets, and inadequate infrastructure.

The session aimed to empower advocates by providing a modular advocacy roadmap to identify access barriers and offer strategies for effective advocacy. Participants worked collaboratively to test and refine one of the modules, equipping PM champions (for example patient organisations and other healthcare system stakeholders) with the tools to navigate regulatory environments, healthcare budgets, reimbursement processes, care practices, workforce training, and digital infrastructure. This work has not only expanded my grasp of PM but also illuminated its profound impact on patients' lives, moving beyond cellular processes to tangible improvements in healthcare outcomes.

Building on the workshop, one of my roles at The Synergist was to further the advocacy roadmap by developing an evidence module. Many PM Champions have expressed uncertainty about specific evidence needed to convince powerholders to implement PM. To address this, I mapped out evidence requirements, methods to collect this evidence, best practices and strategies to effectively package evidence to craft compelling arguments. This required meticulous planning and coordination across multiple domains, reinforcing my ability to lead projects that drive meaningful change in healthcare policy and practice.

5.4 A Holistic Approach to PM Value

I worked on mapping evidence for new ways to measure benefits of healthcare technologies suggested by the International Society for Pharmacoeconomics and Outcomes Research (ISPOR). Health Technology Assessment (HTA) uses specific methods to gauge the value of a health technology over its lifetime (O'Rourke, Oortwijn, and Schuller, 2020). However, many HTA organisations primarily rely on established metrics like cost-effectiveness analysis. Recognizing this approach's limitations, ISPOR proposed a framework for a more patient-centred evaluation, transitioning to value-based care that considers patient experiences and broader societal impacts (Neumann, Garrison and Willke, 2022). In my role, I identified HTA bodies already integrating these ideas and compiled case studies showing how they apply to PM to create informational materials for PM advocates.

5.5 Global HTA Fragmentation

Additionally, PM implementation faces significant challenges due to lack of harmonisation in value assessments across different geographies and HTA bodies. Consequently, PM adoption varies not only between countries but also within countries, primarily focusing on objective dimensions like cost-effectiveness while neglecting subjective patient experiences and long-term societal impacts (Beccia et al., 2022). Therefore, I mapped the HTA process for Germany, England, Taiwan, India and the US (representing Bismarck, Beveridge, out-of-pocket, National Health Insurance and mixed healthcare models respectively), showing how each stakeholder interacts from policy to healthcare delivery. This enhanced my awareness of global issues like funding sources for healthcare innovations, their potential long-term impacts, and who stands to benefit from them, including implications for healthcare systems like the NHS.

6 Collaborative Leadership and Personal Growth

Before my LiA project came to an end, I delivered a presentation to The Synergist team on collaborative leadership, contrasting leadership methodologies of The Synergist and the Laidlaw Foundation, and reflecting on my personal growth. Leadership development is interwoven into The Synergist organisational fabric and culture, promoting collective empowerment through mutual respect, curiosity, open-mindedness, and a culture of continuous learning and adaptation, essential in navigating an ever-evolving landscape. Feedback is not only welcomed but viewed as integral for growth. However, I learned collaborative leadership necessitates continuous assessment of collaborators' needs, maintaining real-time responsiveness, and balancing personal and organisational ambitions. Additionally, potential differing opinions complicates the process. Despite these challenges, the benefits of collaborative leadership frameworks demonstrate their importance in fostering effective and inclusive leadership. Embracing collaborative leadership has not only enhanced my ability to lead but also deepened my understanding of the complexities of fostering a truly inclusive and empowering organisational culture. This has reinforced my commitment to continuous learning and adapting my leadership style to support and uplift those around me.

My LiA also taught me to think on a global level, highlighting the vast variability in health systems worldwide and complexity of discussing equitable access to PM when some countries lack basic healthcare infrastructure. As one of the participants aptly noted at PEOF, “Accessibility is not the same as availability and it is certainly not the same as affordability”. This emphasises the need for policies that address barriers to care and promote health equity for all. Leaders must embrace cultural sensitivity and lifelong learning to navigate global health challenges effectively, fostering international collaborations to address healthcare disparities and promote more inclusive and equitable healthcare.

7 Conclusion

My journey as a Laidlaw Scholar has been nothing short of transformative, shaping my aspirations and preparing me for a future dedicated to healthcare research and leadership. The international experiences provided by the scholarship have broadened my perspective on global healthcare challenges and reinforced the importance of global awareness in research and patient care. I have learned to balance detailed scientific inquiry with high-level strategic thinking and improved my ability to communicate complex topics in accessible ways. I have learnt that genuine leadership transcends individual roles, not confined to hierarchical structures but emerges from a synergy where every individual contributes to and benefits from a unified vision.

Looking forward, I am committed to giving back to the Laidlaw programme. Through mentorship, I aim to guide and support future scholars as they navigate their own paths of discovery and growth. Through this journey, I have come to understand that leadership is not just about guiding others but also about empowering and inspiring them to make meaningful changes. The essence of leadership lies in co-elevating, fostering an environment where collective efforts lead to greater progress and impact.

8 Acknowledgements

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