

## *Waterlupus* Summary Report

July 2019

### **Background:**

*Waterlupus* was a health hack undertaken by our research team at the University of Waterloo (<https://uwaterloo.ca/geographies-of-health-in-place/events/lupus-hackathon>) in the spring of 2019. Health hackathons are multidisciplinary events that bring together diverse stakeholders for a compressed period of time to focus on solutions to complex health challenges through a process of co-creation. In the context of SLE, our research – undertaken using a mixed methods approach - illustrates that affected individuals and their families experience considerable economic challenges, both direct and indirect. Indeed, our research shows that indirect costs are 4 times that of direct costs, and – unlike direct costs – are not related to severity of the illness. Furthermore, affected individuals often pursue a less satisfying working life, yet knowledge regarding interventions to improve the economic lives of these individuals is limited. Partial explanation for this state comes from the complex characterization of the illness, which is episodic, gendered, idiosyncratic, racialized, and often invisible. To effect change, we must look beyond individual and workplace solutions to focus on systems-level actions. *Waterlupus* was held to develop innovative solutions through a systematic process of engagement with a range of key stakeholders (lupus advocacy organization representatives, researchers, physicians, individuals with lived experience) and students over a period of 30 hours in Waterloo, Ontario.

Prior to *Waterlupus*, three webinars were held in order to provide background research results to the hackathon stakeholders and others.<sup>1</sup> Dr. Ann Clarke (April 30, 2019) presented the results of the quantitative surveys undertaken with lupus patients documenting both direct and indirect costs and their relationship with sociodemographic characteristics as well as illness severity. Dr. Francesca Cardwell (May 7, 2019) presented qualitative results from interviews with patients, physicians and lupus advocates. Dr. Susan Elliott (May 14, 2019) presented the results of a review of disability and employment policies across Canada and our ten provinces.

### **Hackathon Team:**

The hackathon research team consisted of the co-Principal Investigators Dr. Ann Clarke (Cumming School of Medicine, University of Calgary), Dr. Susan Elliott (Department of Geography & Environmental Management, University of Waterloo), and Dr. Elijah Bisung (School of Kinesiology, Queens University), as well as Dr. Francesca Cardwell and Emily Shantz (Department of Geography & Environmental Management,

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<sup>1</sup> The recordings of these webinars are available to the public on our website (<https://uwaterloo.ca/geographies-of-health-in-place/events/lupus-hackathon/pre-hackathon-webinars>).



University of Waterloo), and Whitney Steber (Cumming School of Medicine, University of Calgary). Dr. Jenna Dixon (School of Public Health, University of Waterloo) was also involved as a resource person. The research team partnered closely with the GreenHouse for Social Innovation at the University of Waterloo (<https://uwaterloo.ca/stpauls/greenhouse>). The GreenHouse team was an invaluable resource, given their experience in planning and executing successful hackathons, including those related to chronic disease (e.g., multiple sclerosis as well as dementia).

The *Waterlupus* Hackathon was held on May 24<sup>th</sup>-25<sup>th</sup>, 2019. A multi-stakeholder group of participants concerned with addressing the systems-level economic life needs of individuals with SLE attended, representing a number of different organizations, including Lupus Canada, the Lupus Foundation of America, Lupus Ontario, the Lupus Society of Alberta, and the Canadian Arthritis Society (Table 1). In addition, mentor participants with lived experience attended from Ontario and Alberta. Multiple lupus advocacy organization representatives also acted as mentors with lived experience. The students were self registered – the GreenHouse recruited students from both graduate and undergraduate programs across all 6 faculties (from Arts to Engineering, Environment to Science, Math to Applied Health Sciences) at the University of Waterloo. The innovative culture of the University of Waterloo – voted 27 years running as Canada’s most innovative university (see: <https://www.macleans.ca/education/university-rankings/canadas-top-school-by-reputation-2019/>) – serves as a jumping off point for young people committed to innovative solutions to complex problems. They gave up their weekend for some free food and a chance to change the world. They are, in a word, impressive to say the least.

**Table 1: *Waterlupus* Participants**

<b>Participant Group</b>	<b>Number of Participants</b>
Research Team and Resources Persons	7
GreenHouse Team	2
Advocacy Organization Mentors	9
SLE Mentors	5
Policy Mentors	2
Students	25

**Hackathon Weekend:**

To kick off *Waterlupus*, one of the mentor participants spoke of her lived experience of SLE. This introduction engaged both the mentors and students, and helped participants gain a deeper understanding of the economic challenges related to living with SLE. To this end, the GreenHouse also facilitated a ‘World Café’, whereby student participants discussed a series of questions with the lived experience mentors. Participants were enthusiastic about the World Café, and the questions (e.g., What does economic quality of life mean to you?) generated engaging discussion between the mentors and student participants.

In addition to a number of unique workshops held to support the hackathon teams (e.g., Deep Dive into Research, Policy Overview), the majority of time on May 25<sup>th</sup> was used as an interactive working period, during which the teams discussed their ‘hacks’ with the mentors. Not only was this productive for the teams to receive feedback, but the mentors spoke positively of their experiences engaging with enthusiastic and innovative students. A very positive but unintended consequence was the feedback received from mentors who genuinely appreciated the time they had to spend together to share. At the end of the working period on the 25<sup>th</sup>, five teams pitched their solution ideas. Three judges (one research mentor, a research director from a lupus advocacy group, and a GreenHouse pitch expert) deliberated for almost an hour before choosing the winner and runner up.

### **Results and Impact:**

The hackathon had both direct and indirect impacts. With respect to the pitches, the winning team *Shine On* pitched their idea to collaborate with Lupus Canada and Canadian clothing brands to increase accessibility of affordable sun protective clothing suitable for different environments (e.g., work, school). The runners up, *Team Purple*, pitched an online social network to connect lupus patients to relevant information and resources. *Lup4Help* also pitched an online platform to create awareness, share stories, and provide employment opportunities for individuals with SLE, while *Purple Monarch* similarly pitched an online platform designed to provide information for treatment and symptoms, a community feature (e.g., to coordinate meet-ups), and financial and employment resources and opportunities. Finally, *Lupus @ Work* pitched an online platform to bridge employees and employers with respect to possible workplace accommodations. Not only did the webinars and hackathon increase awareness amongst those who attended the event (e.g., especially the student participants, of whom many had previously not heard of SLE), but the innovations also have the potential to increase awareness of SLE and associated economic challenges of living with the disease amongst employers, colleagues, and the general population.

In addition to the five pitches, additional positive outcomes are many. First, the mentor participants described the positive experience associated with spending a weekend with excited and innovative students. Similarly, mentors described the unique experience of attending an event with other mentors from across the country. This provided professional networking opportunities, particularly for mentors representing lupus advocacy organizations. Finally, mentors also reported the benefits associated with the informal support networks generated amongst participants at the hackathon.

### **Next Steps:**

Two student groups are moving forward in the Workplace Innovation Program developed and implemented by the GreenHouse for Social Innovation with the support of the GoHelp Lab (<https://uwaterloo.ca/geographies-of-health-in-place/about>) and lupus research team, along with other key and willing stakeholders (e.g., lupus organization representatives). Indeed, the conclusion of the hackathon weekend saw tremendous support and enthusiasm from our mentors and patients. The Workplace Innovation Program will involve the students for the next 8-12 months in the development of their

solutions. In so doing, the innovation teams will work through an iterative innovation cycle with both research and organizational mentorship to explore and create their solution. This includes in-depth training in how to organize and undertake meetings, how to develop a business plan, how to give an effective pitch, etc. Funding opportunities to move their projects forward and disseminate their results are also offered. In the medium term, the solutions developed will support the economic lives of those affected by SLE. In the longer term, the development of these solutions will also serve to increase public awareness of SLE in Canada.

The research team will also of course publish this work in peer reviewed journals to report the direct and indirect outcomes of *Waterlupus*, including the innovations and ideas generated by event participants as well as the development of a Performance Measurement Framework that will assess the success of the hackathon as an integrated knowledge translation (iKT) initiative.

### **Acknowledgements:**

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