https://doi.org/10.24095/hpcdp.40.7/8.03

Original qualitative research

Hacking systemic lupus erythematosus (SLE): outcomes of the Waterlupus hackathon

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Abstract

Introduction: There is a growing literature demonstrating the benefits of engaging knowledge-users throughout the research process. We engaged a multi-stakeholder team to undertake a hackathon as part of an integrated knowledge translation (iKT) process to develop nonpharmacological interventions to enhance the economic lives of people with systemic lupus erythematosus (SLE). The aims of this research were to (1) increase understanding of the economic challenges of living with SLE through stakeholder engagement at a research hackathon; (2) investigate possible interventions to improve the economic lives of individuals affected by SLE in Canada; and (3) document the outcomes of the Waterlupus hackathon.

Methods: Waterlupus was held at the University of Waterloo in May 2019, attended by lupus advocacy organization representatives, researchers, physicians, individuals with lived experience and students. We conducted participant observation with participants' understanding and consent; notes from the hackathon were qualitatively analyzed to document hackathon outcomes.

Results: At the conclusion of the 28-hour hackathon event, five teams pitched nonpharmacological interventions to address the economic challenges of living with SLE. The winning team's pitch focussed on increasing accessibility of affordable sun-protective clothing. Other Waterlupus outcomes include increased awareness of SLE among participants, and professional and informal networking opportunities.

Conclusion: This paper contributes to a limited literature on health hackathons. The successful outcomes of Waterlupus emphasize the value of hackathons as an iKT tool. Research about how knowledge-users perceive hackathons is an important next step.

Keywords: *integrated knowledge translation, systemic lupus erythematosus, hackathon, social innovation*

Highlights

- Waterlupus was an integrated knowledge translation health hackathon held in May 2019 in Waterloo, Ontario.
- Multiple end-users participated in Waterlupus, including lupus advocacy organizations' representatives, researchers, physicians, individuals with lived experience and students.
- The primary outcome of Waterlupus was the five innovative pitches aimed at improving the economic lives of individuals with systemic lupus erythematosus (SLE) in Canada.
- Additional outcomes included increased awareness of SLE, and professional networking opportunities among participants.

Introduction

Integrated knowledge translation (iKT) is an approach to doing research that involves a collaboration between researchers and knowledge-users; it has gained attention as an approach for enhancing the relevance of research outcomes.[1] There is a large and growing literature demonstrating the benefits of engaging knowledge-users as equal contributors throughout the research process,[1-3] and it is believed that iKT has potential to generate more relevant scientific outcomes (e.g. through engaging knowledge-users in research design), and to create better scientists (e.g. through improved communication skills).[4] Although health research is conducted to improve health systems and population health, major challenges exist in that findings often do not address problems identified by knowledge-users, and are often not applied in a timely manner.[3,5] While best practices in iKT are yet to be established,[1] hackathons are one possible approach to involve end-users in generating timely, useful and innovative health care solutions.

Understanding health hackathons

Health hackathons are events that bring together diverse stakeholders to focus on complex health challenges. The term "hackathon" combines "hack" (a solution reached through intense innovation) and "marathon" (an event of defined length and concentrated effort).[6,7] These events offer participants an uninterrupted period in which to work on a defined problem.[8] Hackathons champion the process of

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co-creation among stakeholders from a range of geographies and disciplines (e.g. health care, design, engineering, business; those with lived experience, end-users, scientists, health care professionals, entrepreneurs).[6] Hackathons are often forums where teams (either pre-established or formed at the event) can present innovative solutions to specific problems.[9] Many hackathons offer awards or prizes for the most promising ideas to help encourage solution development, and some offer funding opportunities to propel solutions forward.

While hackathons are well-established practices in software companies and are commonly associated with programming and computer science,[7-10] health hackathons first appeared in 2011 through the Massachusetts Institute of Technology (MIT).[7] MIT Hacking Medicine, a group that organizes health hackathons based at MIT, aims to accelerate medical innovation and energize the health care community. This group has organized more than forty events across nine countries and five continents (themes include reproductive, maternal, newborn and child health, diabetes, and Ebola), and offers its *Health Hackathon Handbook* online, detailing timelines, marketing, logistics, prizes and other organizational considerations.[11]

The first Canadian health hackathon was called Hacking Health, and was conducted in an attempt to narrow the gap between frontline health professionals and technology experts. It took place in Montréal in 2012, with over 200 health professionals and technical experts in attendance; 19 working prototypes were produced over this two-day event. Hacking Health have now conducted 58 events since 2012.[12]

The University of Waterloo hosts Hack4Health, a hackathon that focusses on improving the lives of those living with degenerative neurological conditions, primarily multiple sclerosis and dementia. The inaugural event took place in 2015; four iterations of Hack4Health have since been completed. The involvement of those with lived experience of the disease and other speakers at the two-day events has enabled participants to generate ideas and create workable solutions for challenges encountered by people living with these conditions.[13] For example, the fourth Hack4Health saw two winning teams: one focussed on tackling social isolation through the creation of a baking social media app, while the other aimed to promote safe and independent cooking using a mat sensor that detects when a stove is left unattended (see https://uwaterloo.ca/hack4health/about-hack4health/hack4health-40-winners).

Health hackathons carry particular significance for addressing health challenges in resource-limited settings, where there is a need for cost-effective innovations that can positively impact health in an affordable and sustainable manner.[6,14] Health hackathons typically focus on social rather than technological innovation,[15] and can result in the development of small but realistic projects that can be refined and scaled up (e.g. funds raised, business plans created, start-up companies formed[6]). Olson et al.[6] reviewed the outcomes of 12 health hackathons (from 2012–2015) in the USA, India and Uganda, and found that one year post-event, 30% of projects had progressed, 25% of teams had begun pilot testing, and of these, 12% and 7% had piloted their innovation with care providers and patients, respectively. Notably, 15 new companies were formed and 22 patents were filed from the hackathons reviewed. The overwhelming majority (87%) of hackathon participants surveyed stated they would attend again, indicating both the potential for successful and innovative outcomes, and worthwhile participant experiences.

Hacking for SLE

In this research, we implemented a hackathon aimed to enhance the economic lives of individuals with systemic lupus erythematosus (SLE) and promote public understanding of the disease. SLE is a chronic autoimmune disease in which the immune system mistakenly attacks the body's tissues and organs, and can damage the skin, joints, blood vessels, brain, heart and muscles.[16] It commonly manifests as alternating periods of flares and remissions. Individuals with SLE are at increased risk of developing diabetes, heart disease and neurological and renal dysfunction.[17] SLE is among the leading causes of death in females aged between 10 and 44 years in the US.[18] Symptoms (e.g. fatigue, joint pain, sun sensitivity) vary based on the individual, and for this reason SLE has been called the "disease of a thousand faces."[19] While worldwide incidence and prevalence rates vary by sex, age and ethnicity (e.g. disease severity and frequency is estimated to be greater in people of African descent),[19,20] it is estimated that approximately one in every 1000 Canadians is affected by SLE;[19] and females are more frequently affected at a 9:1 ratio.[20] Women of child-bearing age (15–45 years) are most frequently affected; SLE is 8 to 13 times more common in females in this age range. Nevertheless, men, children and individuals above age 45 may all be diagnosed with lupus.[19] Those with SLE experience distinct physical, emotional and social challenges; like other chronic illnesses, SLE has been associated with the contraction of social networks and loss of identity.[21,22]

Previous research undertaken using a mixed-methods approach illustrates that affected individuals and their families experience considerable economic challenges, both direct and indirect.[23] A recent Canadian study estimated that direct costs (i.e. health care resources used by a patient with SLE) averaged over $10 000 per patient per year.[24] Other research shows that indirect costs (e.g. time missed from paid work) are four times that of direct costs, and—unlike direct costs—are not related to illness severity.[25] Despite all of this, knowledge about interventions to improve the economic lives of these individuals is limited.[24-27] Furthermore, affected individuals often experience a less satisfying working life.[26] This is partially explained by the complex characterization of the illness, which is episodic (i.e. with fluctuating periods of illness and wellness), gendered, idiosyncratic, racialized and invisible.[27]

For those with SLE, pharmacological treatment options remain limited and are often poorly tolerated or ineffective.[28] We must therefore look beyond individual solutions and focus on broader, nonpharmacological interventions. Bisung et al.[26] conducted a systematic review of existing nonpharmacological interventions to improve the economic lives of individuals with SLE. Four published and two ongoing studies were identified.[29-34] Of the four completed studies, all were conducted in 2005 or earlier. While the completed studies included individuals with SLE, SLE was not necessarily the primary focus; of the 979 participants across the four studies, only 9% had SLE, as each study primarily involved patients with rheumatoid arthritis or osteoarthritis. This is limiting, as arthritis is only one of the many manifestations of SLE that can impact individuals at home or in the workplace. The interventions studied included job accommodations,[29,31,32] vocational guidance[32], education,[29,31,32] support with transportation,[32] and skills training.[30] While three studies demonstrated positive effects on return to work and job retention,[29,30,32] the evidence remains dated, and comparison of effectiveness across studies is challenging due to variability in duration and study design.[26]

In an attempt to effect change in the lives of people living with SLE, the Waterlupus hackathon was held, attended by a multi-stakeholder group of lupus advocacy organization representatives, researchers, physicians, individuals with lived experience and students, over a period of 28 hours at the University of Waterloo. The research presented in this manuscript was aimed at fulfilling three objectives: (1) to increase understanding of the economic challenges of living with SLE through stakeholder engagement at a research hackathon; (2) to investigate possible interventions to improve the economic lives of individuals affected by SLE in Canada; and (3) to document the outcomes of the Waterlupus health hackathon.

Methods

Waterlupus hackathon

The Waterlupus hackathon was held on 24–25 May, 2019, at the University of Waterloo in Waterloo, Ontario. Our research team consisted of three principal investigators, and four other researchers from the University of Waterloo, Queen's University and the University of Calgary. During the planning process, the research team partnered closely with two representatives from the GreenHouse, a community for social and environmental innovation at the University of Waterloo (https://uwaterloo.ca/stpauls/greenhouse). The GreenHouse staff has extensive experience in planning and executing successful hackathons, including those related to chronic illness (e.g. Hack4Health).

A multi-stakeholder group of participants concerned with addressing the economic needs of individuals with SLE attended the hackathon. Advocacy group participants included Lupus Canada, the Lupus Foundation of America, Lupus Ontario, the Lupus Society of Alberta and the Canadian Arthritis Society (n = 9). Participants with lived experience (n = 5) attended from Ontario and Alberta. Multiple advocacy organization representatives also acted as individuals with lived experience.

Members of the research team conducted stakeholder recruitment using multiple methods. Provincial and national SLE advocacy organizations were contacted by email to describe the purpose of the research and ask if their organization would be interested in participating. To recruit mentors with lived experience, one member of the research team who works as a medical doctor shared the hackathon details with her network. In addition, we consulted a list of participants from previous qualitative research undertaken by our research team. We contacted policy mentors (n = 2) based on their public health expertise. Finally, we used snowball sampling, asking potential participants if they knew others that might be interested in participating.

To provide a valuable interdisciplinary learning opportunity, student participants (n = 25) were recruited from both graduate and undergraduate programs across all six faculties (Arts, Engineering, Environment, Science, Math, Applied Health Sciences) at the University of Waterloo. First, summer classes were reviewed for themes related to health or social impact (e.g. Social Determinants of Health, Connections to Ethical Context, Social Research). Professors were asked if a representative could attend a lecture to describe the event, and provide an EventBrite registration link to students. Professors were also asked to post an advertisement on their course website. In addition, the University of Waterloo Federation of Students posted advertisements in preapproved campus locations. Finally, poster advertisements were distributed around the GreenHouse and the research team's personal and professional networks.

Before Waterlupus, three webinars were held to provide background research results to the hackathon stakeholders and others. All confirmed hackathon participants were invited to attend the webinars, and webinar links were provided at the hackathon as a resource. Webinar recordings remain available to the public (https://uwaterloo.ca/geographies-of-health-in-place/events/lupus-hackathon/pre-hackathon-webinars). The first webinar (held on 30 April, 2019) presented the results of quantitative surveys previously undertaken with lupus patients documenting both direct and indirect costs of SLE, and the relationship of these costs with sociodemographic characteristics and illness severity. The second webinar (7 May, 2019) presented qualitative results from interviews with patients, physicians and lupus advocates on the lifecosts (perceptions or experiences of economic and other costs) of SLE. The third (14 May, 2019) presented the results of a review of disability and employment policies across Canada at national and provincial levels. This data sharing was broken into three segments (i.e. three webinars) to make it manageable for a heterogeneous stakeholder group.

To kick off Waterlupus, one mentor participant spoke of her lived experience of SLE. This introduction engaged mentors and students, and helped participants gain a deeper understanding of the economic challenges related to living with SLE. GreenHouse staff then facilitated a "World Café," a method for conducting large-group discussions whereby smaller subgroups discuss questions in a comfortable, café-like atmosphere. During the World Café, student participants discussed a series of questions with lived experience mentors. In addition, members of the research team gave three short presentations (mirroring the webinars) of previous research to help contextualize the research problem, and answer any research-related questions. Based on their interests and initial ideas, student participants then formed teams, guided by the policy, lived experience and advocacy mentors.

In addition to multiple unique workshops held by the GreenHouse and the research team (with names such as "Deep Dive into Research"), most of the time was spent as an interactive working period, during which teams and mentors discussed their "hacks."

At the end of the working period, five student teams pitched their solution ideas. Three judges (a research mentor, a research director from a lupus advocacy group, and a GreenHouse pitch expert) deliberated with the support of the other GreenHouse expert for about one hour before selecting a winner and runner-up. Judging criteria were based on previous GreenHouse best practices and included four categories: problem identification; problem–solution fit; impact, feasibility, and viability; and additional criteria (Table 1). No numerical scores were attached to the judging criteria, and the final decision was based on a group discussion and consensus by the judges.

Data collection and analysis

This research was granted ethics approval from the University of Waterloo Office of Research Ethics, and conducted with all participants' consent. Data was collected in multiple ways. First, during the World Café discussions, hackathon participants were asked to record their responses and related notes for each question presented; this was collected for thematic analysis.

During the World Café and throughout the hackathon, multiple members of the research team conducted participant observation. Designated notetakers were present to record the event proceedings, summarize plenary discussions, and document outcomes (e.g. pitches, judge feedback).

Members of the research team discussed and recorded the major outcomes immediately following the hackathon. The first author reviewed all notes in the following weeks, and consulted other members of the research team. All notes were recorded into NVivo 10 for Mac (QSR International Americas Inc., Burlington, MA, USA) for subsequent analysis. Themes emerged inductively (based on researcher and chart paper notes and hackathon conversations) throughout analysis. The first author led the analysis, and noted any differences between themes identified in the notes taken at the event for further discussion with other team members. To enhance consistency and reliability in thematic analysis, the authors discussed the results, and consulted other members of the research team to ensure agreement in interpretation.

TABLE 1
Waterlupus[a] hackathon judging criteria

Judging criteria	Considerations
Problem identification	Is the problem specific? Is it real? Do you have quantitative/qualitative data to support the problem?
Problem–solution fit	Does the chosen solution address the identified problem? Is the solution useful to the specific user?
Impact, feasibility, viability	What is the potential impact of the solution? Is it scalable? Is it feasible to implement in the timeframe suggested? Is it viable? Do you see it implemented successfully?
Additional criteria	Did the team deliver an interesting and captivating pitch? Was the team/their ideas well organized? Did the team follow the guidelines for the presentation?

[a] Waterlupus health hackathon event held 24–25 May, 2019, at the University of Waterloo, Waterloo, Ontario.

Results

Hackathon results are reported in three distinct sections: World Café discussions, intervention pitches, and additional outcomes of Waterlupus.

World Café discussions

The first day of the hackathon included a World Café to increase student understanding of the economic challenges of SLE through engagement with diverse stakeholders. This activity contextualized the research problem and previous research results, served as an icebreaker and provided an opportunity for student participants to engage with mentors before joining their teams. Participants were enthusiastic about the World Café, and the questions generated engaging discussion between mentors and students. The lived experience, policy and lupus advocacy organization mentors were split between 7 tables to ensure a range of perspectives in each discussion. Students were divided into groups and rotated through the tables following each question, while mentors remained seated.

The first question, "What does economic quality of life mean to you?", generated in-depth discussion, and several common themes emerged across the groups (Table 2). The most frequent theme identified (by 6 groups) was the impact of a reduced income on quality of life. Lived experience and advocacy mentors discussed the importance of having disposable income to afford life necessities (e.g. shelter, healthy food, medication), as well as activities for entertainment and pleasure (e.g. to take holidays or give gifts). The potential impacts on mental health related to a reduced income were discussed by 5 groups. Each group spoke of the stress and worry associated with limited financial freedom and accumulating monthly bills. Conversely, the positive "state of mind" experienced when expenses are managed was discussed by one group. The connection between economic quality of life and relationships/social support (e.g. family, friends, spouse) was described by five groups. Participants discussed the economic and emotional familial impacts of a reduced income; for example, increased reliance on a spouse or other family member to support dependants, guilt associated with inability to support family members, and the possible relationship stress when an individual does not feel supported or understood by family or friends. The potential for social isolation due to job loss or early retirement was also identified.

Other themes discussed included the need to access satisfying and accommodating employment to maintain an income, pension and the sense of meaning that comes from fulfilling work (4 groups), and the potential loss of identity when an individual is no longer able to work, experiences reduced personal independence or does not feel meaningfully engaged in society (4 groups). Finally, the direct relationship between income and accessing medical care (e.g. alternative care practitioners), and the accessibility of resources that can support financial planning were identified by 3 and 2 groups, respectively.

Following this discussion, the students rotated tables, and the groups were asked "How has lupus affected your economic quality of life in the past, present or future?" (Table 3). After the hackathon,

TABLE 2
Themes emerging from the Waterlupus World Café[a] discussion, "What does economic quality of life mean to you?"

Subtheme	Number of tables where mentioned[b]
Impact of a reduced income on quality of life	6
Mental health impacts (positive/negative)	5
Relationships/social support	5
Need for satisfying and accommodating employment	4
Loss of identity	4
Relationship between income and accessing medical care	3
Accessibility of financial planning resources	2

[a] Small group breakout session at the Waterlupus hackathon event held 24–25 May, 2019, at the University of Waterloo, Waterloo, Ontario.

[b] A total of seven separate tables were involved in this discussion.

the research and the GreenHouse teams reflected on the similarities between the first two questions and discussed increasing variation in questions in future hackathon iterations. In this context, as often happens in qualitative research, themes in these discussions overlapped. Not surprisingly, the most common theme surrounded the impacts of lupus on employment (6 groups). Groups discussed uncertainty about sharing their diagnosis with or asking for accommodations from their employer, the need for accessible and flexible workplaces, challenges related to progressing in their career, and forced medical retirement. The resulting financial impacts were described by 4 groups (e.g. less security in retirement, reduced pension, difficulties finding health coverage). Other themes included the need to access quality health care and medication (3 groups); and the impacts on mental health (e.g. anxiety related to flares or future plans or career, lack of sleep, irritability from treatment) and the physical symptoms that can impact employment (e.g. inability to drive, organ damage from medication) (2 groups).

After the final rotation, groups discussed the question, "What ideas do you have to address some of these challenges?" (Table 4). Ideas varied more between groups relative to the previous two questions. Four groups described the need to increase access to resources, and the value of creating a tool or platform to facilitate access to relevant information (e.g. support groups, medical information following diagnosis, employment resources). One group spoke of the need for information to come from a credible source (e.g. medical professional) to reduce the spread of inaccurate information, and another group described the value of counsellors in sharing support and information with patients. Three groups discussed the need for medical interventions (e.g. lupus screening tools). Two groups each identified workplace-specific interventions (e.g. scale to subjectively rate symptoms for employers, flexibility in work schedule/hours), increasing workplace awareness (e.g. for improved accommodations), and interventions that went beyond the workplace (e.g. for policy change, increased research funding). The value in organizational collaboration (e.g. between advocacy organizations at the provincial and national levels), increased financial support for medical-related transportation, and increased physician education (e.g. to provide employment-related resources) were each identified by one group.

TABLE 3
Themes emerging from a Waterlupus World Café[a] discussion, "How has lupus affected your economic quality of life in the past, present or future?"

Subtheme	Number of tables where mentioned[b]
Impacts of lupus on employment	6
Workplace challenges and financial impacts	4
Access to quality health care and medication	3
Mental and physical impacts	2

[a] Small group breakout session at the Waterlupus hackathon event held 24–25 May, 2019, at the University of Waterloo, Waterloo, Ontario.

[b] A total of seven separate tables were involved in this discussion.

Intervention pitches

The primary outcome of Waterlupus was the interventions generated during the event: at the end of the hackathon, five teams pitched interventions to address the economic challenges associated with living with SLE. The winning team, called "Shine On," pitched their idea to collaborate with Lupus Canada (and other advocacy organizations) and Canadian clothing brands to increase accessibility of affordable sun-protective clothing suitable for different environments (e.g. work, school). SLE patients are encouraged to minimize their exposure to sunlight, as it may aggravate their illness. The judges thought this pitch was especially innovative, because it had the potential not only to change the lives of those with lupus, but also the lives of other sun-sensitive individuals, such as those on certain medications. It could also reduce UV exposure among the general population, and it had economic potential for the innovators. As one participant with SLE described, this innovation was attractive due to the stigma associated with their "lupus clothes," since, although available, sun-protective clothing is extremely limited and costly.

The runners up, "Team Purple," pitched their idea for a professionally moderated online social network to connect patients to relevant employment-related information and resources, and offer a space for meaningful social interaction with others impacted by SLE. This pitch was recognized by the judges for considering and applying mentor feedback, and for having a clear connection to economic quality of life. While it would be important for the platform to be professionally moderated in order to ensure credibility, the feasibility of this was identified as challenging.

Another team, "Lup4Help," also pitched an online platform to create awareness, share stories and provide employment opportunities for individuals with SLE. A fourth team, "Purple Monarch," similarly pitched an online platform designed to provide information for treatment and symptoms, a social feature (e.g. to coordinate meet-ups) and financial and employment resources and opportunities. This platform was especially accessible (e.g. the group created the platform in multiple languages, which is relevant given that

TABLE 4
Themes emerging from a Waterlupus World Café[a] discussion on ideas for addressing economic challenges associated with SLE

Subtheme	Number of tables where mentioned[b]
Increase access to resources and information	4
Need for interventions (e.g. medical, workplace-specific interventions)	3
Need for increased awareness in the workplace	2
Need for broad awareness (e.g. for policy change)	2
Organizational collaboration	1
Financial support for medical-related transportation	1
Increased physician education	1
Need for communication from credible sources	1
Role of counsellors for support and resources	1

Abbreviation: SLE, systemic lupus erythematosus.

[a] Small group breakout session at the Waterlupus hackathon event held 24–25 May, 2019, at the University of Waterloo, Waterloo, Ontario.

[b] A total of seven separate tables were involved in this discussion.

SLE has higher prevalence rates among minority populations[35]), and was also user-driven, increasing feasibility. Finally, the fifth team, “Lupus@Work,” pitched an online platform to bridge employees and employers with respect to possible workplace accommodations. While this platform had the potential to be incredibly useful and was heavily informed by mentors’ lived experiences, it would require employer buy-in to be implemented successfully. Table 5 provides a detailed summary of each pitch.

Based on their pitches, the winning teams were awarded the opportunity to continue to work on their innovations in collaboration with the Workplace Innovation Program (WIP), developed and implemented by the GreenHouse with the support of Geographies of Health in Place (GoHelP) Lab (https://uwaterloo.ca/geographies-of-health-in-place/about) and the research team, along with other stakeholders (e.g. lupus organization representatives). The conclusion of the hackathon saw support and enthusiasm from advocacy and lived experience mentors, who will continue to support the winning teams throughout the WIP. The WIP guides students for 8 to 12 months in the development of their solutions through ongoing capacity-building exercises.

The winning teams moving forward in the program are focussed on two distinct ideas. Shine On are proceeding with their idea to develop fashionable and affordable UV-protective clothing, and are currently working with three mentors with lived experience and a local fashion designer to design templates for clothing that is comfortable, desirable for a work environment, and made from sun-protective fabric. Team Purple are moving forward with their idea to create an online space for individuals with SLE to share useful employment-related resources. They are in the process of exploring the market to understand what other online resources exist for individuals with chronic illness; they are currently consulting with another WIP team (unrelated to the hackathon) to explore whether there is any overlap with their project (developing a digital space for individuals with chronic illness to access disability-related resources).

While both teams generated initial ideas at the hackathon, participation in the WIP is iterative, and the teams are currently reviewing the literature, patents, current market and stakeholder feedback to determine how to best generate interventions that differ from what currently exists. In this way, these innovations will continue to evolve over the course of the program.

Additional outcomes

Additional outcomes of Waterlupus were also documented. A major outcome relates to increased awareness of the economic challenges of those with SLE. Not only did the webinars and hackathon increase awareness among participants (especially the students, many of whom had no prior knowledge of SLE), but the innovations have the potential to increase awareness of SLE and the associated economic challenges of living with the disease among employers, colleagues and the Canadian population more broadly. Indeed, multiple lived experience and advocacy mentors spoke of the students’ increased knowledge of SLE, and the potential for the innovations to continue to increase understanding of the economic impacts of SLE and other invisible and episodic illnesses.

The lived experience, policy and advocacy mentors also described the positive experience of spending extended time with students interested in SLE. During the informal working periods, students worked on their “hacks” with the mentor participants. Not only was this a productive time for the teams to receive feedback from mentors, but the mentors spoke of the energy and innovative ideas generated while engaging with students. Similarly, the educational opportunity provided to the students was positive, as they had the opportunity to work on a real-world problem and develop their skillset with a group of stakeholders that would otherwise be inaccessible in a university setting. Their participation offered an unbiased and future-oriented vision to this health and social challenge.

Finally, a very positive but unintended outcome was the feedback received from mentors, who genuinely appreciated the time they had to share their experiences. This provided professional networking opportunities and encouraged development of informal support networks, both for mentors representing advocacy organizations as well as for patients who connected across provinces.

Discussion

This paper documents the outcomes of the Waterlupus hackathon conducted at the University of Waterloo in May 2019. Not only does this paper report outcomes from the event, but it contributes to a limited literature about the use of health hackathons for social innovation. The Waterlupus hackathon was a useful iKT tool, generating innovative ideas to address a complex health challenge.

While the World Café itself did not generate the interventions, it was an opportunity for students to increase their understanding of the economic challenges of living with SLE by hearing from those with lived experience; it contextualized

TABLE 5
Summary of Waterlupus[a] hackathon innovations

Team name	Place finished	Target population	Problem identified	Summary of innovation
Shine On	1st	• Canadians with SLE, specifically those with sun-sensitivities • Other sun-sensitive individuals	• Sun-sensitive individuals must limit exposure to sun, which can impact quality of life • Lack of affordable everyday clothing for sun-sensitive individuals; UPF clothing exists but is limited to specialized clothing (e.g. athletic wear)	• Create accessible and affordable sun-protective clothing suitable for work and school • Develop clothing templates, approach Canadian clothing brands to increase accessibility of UPF sun-protective clothing
Team Purple	2nd	• Canadians with SLE • Presentation specifically identified users under age 45	• Need to improve economic quality of life of individuals with SLE, through reducing time it takes to access relevant resources • Need to reduce physical pain and emotional challenges of an SLE diagnosis	• Professionally moderated online social network to connect patients to employment resources • Ensure valid and relevant information, provide a positive community and meaningful interactions • Platform offers opportunities to organize threads and sub-threads, connect people and provide in-person meetups through message board and hashtags
Lup4Help	N/A	• Canadians with SLE	• Individuals with SLE often have to limit or leave employment following diagnosis • As a result, SLE can lead to reduced income and quality of life, and increased reliance on disability benefits • Need to increase social and economic impact	• Online platform to create awareness, share stories and provide employment resources • Aim to create job opportunities for individuals affected by connecting to flexible employers, and create awareness among employers • Aim to build a community to increase awareness and raise funds by organizing community events (e.g. marathons, camping)
Purple Monarch	N/A	• Canadians with SLE	• Continuously declining economic quality of life • Overwhelming for individuals with SLE to find resources and receive support • Current sources are limited or not user-friendly	• Online platform to provide resources to individuals with SLE • Tailored and curated financial assistance • Frequent updates on optimal care and specialist availability • Access to peer support and community building • Accessibility challenges identified (e.g. website provided in multiple languages)
Lupus@Work	N/A	• Canadians with SLE • Specifically focusses on those of working age	• Many with SLE cannot continue in employment following diagnosis, and those that do face stigma, fear disclosing their illness or are unable to access job accommodations to prolong their ability to work • With appropriate accommodations, increased productivity, improved interactions with coworkers, and long-term employment are possible	• Online platform to bridge employees and employers related to possible workplace accommodations • Engage variety of stakeholders (e.g. employers, employees, family members, advocacy representatives), and collaborate with software providers to create a prototype platform • Need to enable open discussion about workplace opportunities

Abbreviations: SLE, systemic lupus erythematosus; UPF, ultraviolet protection factor.

[a] Waterlupus health hackathon event held 24–25 May, 2019, at the University of Waterloo, Waterloo, Ontario.

the results of the previous qualitative and quantitative research; and it provided energy and momentum early in the event.

With respect to the interventions, the winning pitch and the runner up both offered solutions with the potential to positively impact the economic and the social challenges faced by individuals with SLE (e.g. workplace barriers, stigma, social isolation).[23-27] These innovations may also be beneficial for those impacted by other chronic diseases (e.g. accessible sun-protective clothing for other sun-sensitive individuals).

The two winning teams are currently moving forward with the development of their ideas in the WIP. In so doing, they will work through an iterative innovation cycle with both the research team and hackathon organizers from the GreenHouse to explore and develop their solutions. This involves following a multistage process that ensures teams identify and define a problem, conduct a needs identification and generate an implementation plan. In addition, in-depth training on a range of topics (e.g. giving an effective pitch) will be provided. Funding opportunities to move their projects forward and disseminate results will also be offered by the research team.

Documented successful outcomes from previous health hackathons include increased passion, community engagement and sustainable, culturally appropriate solutions;[14] generation of ideas and enthusiasm for innovation;[36] establishment of networks to inspire future work and collaboration;[14] and the start of new innovations, solutions and companies.[6] Waterlupus also had numerous successful outcomes. For example, multiple and diverse end-users (e.g. patients, advocacy representatives) were included, and provided their perspectives to ensure long-term and sustainable innovations that satisfy end-user needs. In addition, multiple participants expressed excitement with the energy generated at the event, and were impressed with the passion of both mentors and students. Finally, new professional and social networks were created, as multiple stakeholders reported connecting with individuals from different geographic locations. Multiple participants exchanged contact details, and every lived experience, policy and advocacy mentor expressed interest in receiving research results and updates with respect to the WIP teams' progress.

While SLE disproportionately impacts working-age females,[20] the innovations generated at Waterlupus were not necessarily designed to be age- or gender-specific. The hackers did, however, draw on previous research results (e.g. qualitative interviews, primarily with females impacted by SLE), and on the feedback from lived experience mentors at the event (who, with one exception, were all female). In this sense, the teams' innovations implicitly considered age and gender in that they were intended to improve economic (which often means employment) outcomes for individuals with SLE. For example, a professionally moderated online social network to connect patients with employment-related resources is relevant to females and males impacted by SLE, but may be used more frequently by females of working age (15–64 years) because they are disproportionately affected. Exploring how innovations can be developed to suit different subpopulations affected by SLE—for example, by increasing the number of languages available in an online platform or by creating sun-sensitive clothing that goes beyond athletic-wear and is suitable for both females and males—is certainly an avenue for future work.

Multiple challenges emerged in the execution of Waterlupus. First, using the term "hackathon" in the advertisement may have attracted students expecting a software hackathon, or deterred other potential participants assuming who assumed the event was a traditional hackathon. Second, a larger number of students was anticipated, based on previous hackathons held by the GreenHouse. Waterlupus was the first hackathon the GreenHouse had conducted during the summer term, though, when there are fewer students on campus available for recruitment. Other factors beyond the research team's control, such as seasonably pleasant weather, could also have deterred students from participating. The students in attendance, however, were extremely engaged and the research team were impressed with their commitment.

Third, throughout the recruitment process, by the questions that the research team were asked about SLE, it was evident that lay understanding of SLE is limited. The lack of awareness of the disease and its associated challenges may have reduced interest in the event. Fourth, with respect to the pitch outcomes, geography likely influenced the results. If this hackathon had been held outside of Canada, the pitches may have focussed on different economic challenges. In Canada, the health care system is publicly funded, offering universal coverage for medically necessary services.[37] While health care access challenges do exist in Canada in the context of SLE (e.g. appointment waiting times, accessing specialist care),[23,38] alternative economic challenges to accessing health care may have been identified elsewhere (e.g. in the US).

A primary criticism of hackathons is that they can develop short-lived excitement, yet lack a pathway to generate sustainable solutions with long-term impact.[14] Similarly, and outside of the hackathon literature specifically, there have been calls for researchers to consider the success of iKT beyond the short-term timelines of any one research project, as an avenue to build long-term partnerships and inspire innovative thinking.[2] In consideration of these criticisms, one of the primary outcomes of Waterlupus is the formation of WIP teams that are provided a pathway to continue their innovation beyond the short term with lupus organization advocacy groups, members of the research team and the GreenHouse. By moving these teams' solutions forward and involving multiple stakeholders in the process, we aim to go beyond awareness-raising to attitude, behaviour and, ultimately, social change.

Conclusion

This paper describes what is, to our knowledge, the first iKT activity focussed on the co-production of knowledge to improve the economic lives of individuals with SLE and increase public understanding of the disease. Waterlupus generated feasible and actionable nonpharmacological intervention ideas, established partnerships and facilitated networking and leveraged expertise between those living with SLE, advocacy organizations, policy makers and student participants. While these successful outcomes emphasize the value of hackathons in the iKT toolbox, the next step of this research involves increasing our understanding of how the hackathon participants themselves (e.g. knowledge-users) perceived the hackathon as an iKT initiative. Not only will this increase our understanding of how Waterlupus itself was valued, but acknowledging the perspectives and voices of knowledge-users is an important step in ensuring that future iKT science, and hackathons specifically, can help meet their needs.

Acknowledgements

We would like to thank Lupus Canada and the Canadian Institutes for Health Research (CIHR) for their generous financial support of this research. We are also sincerely grateful to the Lupus Society of Alberta, all the participants at the hackathon and in particular those innovative young people who gave up their weekend to work with us on this complex problem.

Conflicts of interest

There are no conflicts of interest to disclose.

Authors' contributions and statement

SE, AC and EB conceptualized the work; FC, SE, AC and EB acquired, analyzed and interpreted the data; FC drafted the paper; FC, EB, AC and SE revised the paper.

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