

POSITION DESCRIPTION

Position: Link Worker Living with Lupus

Research Study Name: Social prescribing pilot for individuals living with lupus

Are you an individual living with lupus in Canada? If so, are you interested in serving as a link worker for a new, innovative social prescribing pilot?

Social prescribing is a holistic approach that supports people's overall well-being by connecting them with non-medical services in their community. Instead of focusing only on medicine or clinical treatments, social prescribing helps people find activities, programs, or supports that improve their daily lives. Examples of these activities include exercise groups, art classes, volunteer opportunities, food programs, and social clubs.

A growing body of research suggests that social prescribing can benefit our physical health and wellbeing, as well as build stronger social connections. However, one key limitation of the social prescribing programs implemented to date is that these programs do not explicitly focus on those living with lupus or any other autoimmune disorders. The gap is concerning, given the complex realities of living with lupus and the clear need for tailored, non-medical supports for those living with lupus.

To address this gap, a team of researchers from the University of Waterloo, Lupus Canada, individuals living with lupus and a rheumatologist have worked together to co-produce a social prescribing pilot.

There are three overall objectives of this research study: 1) Co-produce, implement and evaluate a social prescribing pilot for individuals living with lupus in Canada; 2) Evaluate the co-production process; and 3) Assess the pilot's impact on participants' wellbeing.

You, as a link worker living with lupus, will play an integral role in the design and implementation of the pilot.

As a research participant in this research study, this role includes a wide range of responsibilities – from developing personalized care plans to monitoring activities through tracker sheets. You and your partner link worker will provide direct support to five individuals living with lupus by connecting them with services and programs that address the participants' wellbeing needs. You will meet with each participant individually; the first virtual meeting will focus on completing a needs assessment, followed by regular virtual follow-up meetings. Please note that the frequency and duration of meetings will be determined by you, your partner link worker and the participant.

We anticipate an overall time commitment of approximately eight months. The first month will focus on link worker training, which will take approximately 6-10 hours and will be split across several virtual training sessions and asynchronous modules. Months 2–7 will be the active pilot

phase. During this time, we anticipate a 5-hour-per-week commitment, as you will meet VIRTUALLY with participants, suggest activities, complete tracker sheets, and meet virtually with the research team biweekly. During the biweekly research team meetings, you will be asked about what is working well in the pilot and what is not working well. The final month will include a 1-hour virtual focus group. The focus group will include questions about your overall experience with the pilot, what needs to be changed for future iterations and how this pilot impacted your wellbeing. You will also be invited to the post-pilot deliberative dialogues, where you can learn about the results of the pilot, share your experience and have a say in the next steps.

Please note, upon completion of the 6-month pilot, it is up to you, your link worker partner and your assigned group of participants to decide whether you would like to stay in touch.

As a small token of thanks for participating in this research study, you will receive \$675 and \$50/month for a smartphone data plan if you require one for the duration of the pilot.

While participation in the pilot may not benefit you directly, we hope that the findings from this study may benefit the broader community.

RESPONSIBILITIES:

Area of Responsibility	Tasks
Direct Services	• Complete an assessment of needs for individuals living with lupus; • Provide resource information, referral and supports as required; • Make referrals to appropriate internal and external programs and services; • Assist individuals living with lupus in navigation of services and systems by providing them with general information;
Planning and Program Development	• Maintain program utilization statistics through tracker sheets; • Ensure data entry is kept up to date; • Identify program improvement opportunities; • Adhere to policies, procedures;
Other Duties	• Attend virtual meetings as required; • As required and/or assigned.

CRITERIA:

- Identify as an individual living with lupus
- Reside in Canada
- Speak English
- Have access to a laptop and internet connection
- 18 years and older

SKILLS and EXPERIENCE:

- Ability to problem solve and make informed decisions;

- Great interpersonal skills;
- Excellent planning, writing and organizational skills;
- Computer literate with familiarity with Microsoft Word;
- Self-motivated and able to work as part of a team.

If you are interested in being a link worker for this research study, please complete this screening form: https://uwaterloo.ca1.qualtrics.com/jfe/form/SV_agErWdfVo9dwLrM

Please note our goal is to have a very diverse sample in terms of age, gender, ethnic background, educational levels. We encourage everyone who is interested to complete the screening form. If you are not invited to join the pilot, please know that this decision is not a reflection of you or the answers to the screening form. Because this is a pilot project, we have very limited space and can only include a small number of participants at this time.

This position works closely with the research team staff and other link workers.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board.

For any questions or for more information, email Satveer Dhillon (PhD Candidate at the University of Waterloo) sk8dhill@uwaterloo.ca