

Social Prescribing Pilot for Individuals Living with Lupus: Research Study FAQ

Participant Role

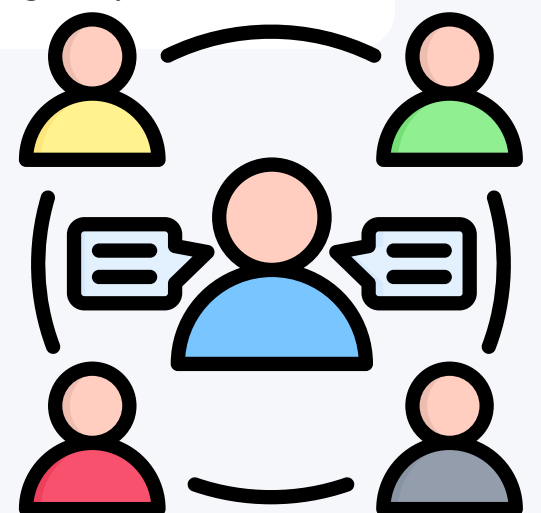
What is social prescribing?

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

It makes sure that the factors that contribute to health and wellbeing are being considered, so that we focus on "What matters **to** you?" instead of "What is the matter **with** you?"

What does the term "link worker" mean?

Link workers form the core of social prescribing. Also known as community connectors or navigators, these are individuals who work with participants to help address their non-clinical needs. This includes working together to develop a personalized wellbeing plan, having regular follow-up conversations with participants and connecting them to activities and or people (such as virtual classes or discussion groups).



Why is this pilot project important? And what is this pilot project about?

While there is so much research on social prescribing and the benefits to physical health and overall wellbeing, there has not been a social prescribing program implemented to date that explicitly focuses on those living with lupus or any other autoimmune disorders. We know this is a huge gap as people living with lupus have unique social, physical and emotional challenges, and there is a need to have tailored, non-clinical supports available for those individuals. In addition, who knows better what people with lupus need than other people with lupus?

To address this gap, a team of researchers from the University of Waterloo and the University of Toronto, Lupus Canada, individuals living with lupus, and a rheumatologist from the University of Calgary have worked together to develop this research study.

The main objective of the pilot is to create and implement the pilot and then assess the pilot's impact on participants' wellbeing using surveys, interviews and focus groups. Because it's a pilot, it is a very small study that we will be shaping as we move along, So it won't be a very big study. That's because this has never been done before! So we need to learn a few things before we can design a really big research project. So all the people involved in this project are really pioneers and have the opportunity to really shape what we are doing now and into the future for people with lupus.

Who is leading this research project?

A team of researchers from the University of Waterloo, University of Toronto, Lupus Canada, individuals living with lupus and a rheumatologist from the University of Calgary are all working together to create this pilot.

This work will form the basis of Satveer Dhillon's (PhD candidate in the Department of Geography and Environmental Management at the University of Waterloo) PhD thesis, and she will be the main point of contact for any additional questions (sk8dhill@uwaterloo.ca). Satveer's PhD supervisor is Dr. Susan Elliott at the University of Waterloo. Here is the link to her website (<https://uwaterloo.ca/geographies-of-health-in-place/>) if you'd like to learn more about her or the research and teaching that she does.

How long will this run for if I choose to commit?

The pilot itself will run for 6 months and will require approximately 5 hours per week of your time if you are a link worker, and we anticipate a time commitment of 1-2 hours if you are a participant.

And how many people will you be recruiting?

We will have 35 individuals: 25 as participants and 10 as link workers. However, we will maintain a waiting list just in case people are unable to continue their involvement.

Who can participate in this pilot?

Individuals who are 18+, live in Canada, have lupus, speak English, and have access to a laptop and internet connection are eligible to participate.

Will people be screened before being invited to the pilot?

Yes, all individuals who are interested and eligible to participate will be asked to complete a screening form. The purpose of the form is to screen for eligibility and to select a diverse group of participants.

Satveer will be reviewing the screening forms and shortlisting potential participants. She will then virtually meet with those individuals to see if they have any questions.

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

There may be additional research opportunities in the future. The screening form will include a question asking whether you would like to be considered for other upcoming studies.

How will this pilot project work?

After recruitment, link workers will receive specific training to ensure they are well-equipped to take on this role. After the completion of training, we will assign two link workers to work with groups of 5 participants. The training and all the activities will be virtual. The training will be conducted over a period of 4-5 weeks

Once the link workers are trained, there will be a virtual meeting with the 2 link workers and each individual participant. The goal of the first meeting is to complete the personalized wellbeing plan, pick a few activities (such as virtual cooking classes or art classes; online games; social support groups; etc) and decide how follow-up meetings will work. For subsequent meetings, only one link worker will be required to attend, both are more than welcome. It will be up to the link workers to create a schedule to distribute the workload to meet everyone's needs.

Has this research been approved?

Yes, this research has been given ethics clearance from the University of Waterloo Research Ethics Board. If you would like more information, please contact Satveer (sk8dhill@uwaterloo.ca).

Will this project help others living with lupus?

Our goal is to take the lessons learned and insights from this project and use it to improve future versions of the pilot. As a result of this pilot, we will have created tools that can be shared (e.g., the link worker training toolkit) and will know if we have had some impact on wellbeing so we can share all those measurement tools as well. Also, the data from this pilot projects, including the experiences of the link workers and participants, will contribute to the growing evidence base used to advocate for expanded support and funding for social prescribing.

I am interested, can you tell me a little bit more about how I can decide whether I should participate as a link worker or a participant?

It's great you are interested! To learn more about the differences between the two roles, we encourage you to watch both FAQ videos and review our "position" description documents.

The link worker role does have a slightly higher time commitment due to the training involved, which will take around 6 - 10 hours, and the regular meetings with the research team. We anticipate a 5-hour time commitment per week for 6 months. The participant role is a 1-2-hour-per-week time commitment for 6 months, in addition to any time you might spend on your activities.

What would be my role as a participant?

You will have regular virtual meetings with your assigned link workers. The first meeting will focus on creating a social prescribing plan that fits your wellbeing goals, followed by regular virtual follow-up meetings. Please note that the frequency and duration of meetings will be determined by you and the link worker. We do anticipate a time commitment of 1-2 hours per week. You will also be asked to complete a survey before and after your participation in the pilot. Finally, you will be requested to undertake a 1-hour Zoom interview at the end of the 6-month pilot period, where you can share your experiences and your perceptions about the entire process. 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 that participating in the study is not a substitute for medical advice.

Can I change my mind about participating in the study?

Yes, participation is voluntary and if you change your mind weeks or months in, you can always leave the pilot project by contacting Satveer.

What do I get out of this?

As a result of the social prescribing pilot, you may feel better connected to your community and to other individuals living with lupus, potentially resulting in improved wellbeing. Also, you will learn about fun virtual and in-person activities you can participate in even after the completion of this 6-month pilot!

As a participant, you will receive a small financial token of appreciation for your participation.

That's all of the questions I have for now... But what happens if I have questions later on?

Please feel free to reach out to Satveer (sk8dhill@uwaterloo.ca). She would be happy to answer any questions or concerns you may have.