Evaluate the value of Telehomecare for Mental Health

Project Information Sheet

The University of Toronto, Ontario Shores Centre for Mental Health Sciences, Lakeridge Health, Women’s College Hospital, and East Metro Youth Services (Toronto lead agency by the Ministry of Children and Youth Services) are partnering with the Ontario Telemedicine Network (OTN) on a project which aims to find out whether a solution called ‘Big White Wall’ (an online support community) may be of benefit to people who are having some difficulty coping or who are feeling anxious, depressed or have mental health related symptoms.

Your clinician believes that you may benefit from participating in the Big White Wall project (the Project). You are invited to take a few minutes to read this information sheet and decide whether you would like to participate.

You are being invited to participate in a project. This information sheet explains the purpose of this project and provides information about what is being studied including possible risks and benefits, and the rights of participants.

Please read this form carefully and ask any questions you may have. Please ask the project coordinator to clarify anything you do not understand or would like to know more about. Make sure that all of your questions are answered to your satisfaction before deciding to participate in this project.

Participating in this project is your choice. You have the right to choose not to participate, or to stop participating at any time.

ABOUT THE PROJECT

You are being invited to participate in this project because you have been referred to, or assessed by a staff member at your organization/university for a mental health problem. Mental health support and counselling is often identified as one of the most unmet needs among Canadians despite it being a recommended treatment for many mental health conditions. Modern solutions such as virtual care, which includes on-line, internet-based programs and tools, are rapidly entering the health care system to fill this gap.

The Big White Wall (BWW) is an on-line community that offers mental health support in a facilitated social network environment. The BWW offers 24/7 access to:

- Self-assessment tools to track symptoms for a wide range of mental health conditions over time
- Mental health educational materials
- A social network that allows communication between yourself and people who may have similar problems
- On-line courses that teach coping skills for common mental health problems like depression and anxiety.
People use the Big White Wall to obtain support and to share with others using the Big White Wall what’s troubling them, in a safe and anonymous environment. This is done with the guidance of trained mental health professionals known as ‘wall guides’ who monitor postings on the Big White Wall twenty-four hours per day, seven days per week. These individuals constantly review user activity and posted materials to ensure the content is appropriate and sensitive to all users. They will engage with users through instant communication to ensure that users feel like their material is being responded to. They may also participate in ‘talkabouts’ to guide user-generated discussion threads that are open to all users enabling peer interaction on a common experience or topic.

The BWW was developed in the UK and is now available in New Zealand, and the USA with over 35,000 users since it started. We are testing the use of the BWW in Canada to see if it can help people with mental health problems through providing support, education and self-management tools.

The project is funded through the Ontario Telemedicine Network. OTN provides services and technology to doctors, nurses, hospitals and other healthcare organizations and providers to help them give patients in Ontario better access to care. OTN is overseeing all parts of this project including providing you with a generic email account and activation code and access to the Big White Wall on-line support.

OTN received special funding from Canada Health Infoway, a federal government agency, to determine if technology can help a patient better manage their anxiety, depression or other related symptoms and in turn improve their health. Canada Health Infoway is an organization that helps to improve the health of Canadians by working with partners like OTN to speed up the development, uptake and effective use of technology across Canada.

For University of Toronto - OTN has collaborated with Women’s College Hospital (WCH) in Toronto. A project coordinator from WCH will provide you access to the Big White Wall.

Your organization/university is participating in the Project. The role of your organization/university is to identify participants suitable for the Project, to invite you to participate, to provide you access to the Big White Wall, and to work with OTN and its partners to ensure that all aspects of the Project are implemented as planned.

Your participation in the project and use of the Big White Wall application does not replace professional advice from your health care provider. The Big White Wall on-line support community used in this project is not an emergency service and if you are experiencing an emergency you should call 911 or go to the Emergency Department’
WHY IS THIS PROJECT BEING DONE?

The purpose of this project is to determine whether the use of an on-line community (the BWW) can improve mental health self-management and recovery among individuals seeking mental health care. In addition to this, we hope that this can help us understand the challenges involved in making this kind of on-line community available to Ontarians.

WHAT WILL HAPPEN DURING THIS PROJECT?

If you consent to participate in this project, you will be asked by the project coordinator at your organization or the clinical staff at university of Toronto or to sign this consent.

For University of Toronto - Your name, telephone number and email address will need to be shared with the project coordinator at Women’s College Hospital so that they can contact you to set you up on the Big White Wall solution.

There are additional components to this project, namely:

- Registering on the BWW as a user.
- You will be able to access the on-line support through the internet on a personal computer or mobile device.
- You will be provided with a generic email account by OTN and an activation code to link to the BWW. The generic email account serves to limit identifying information about you being transmitted to and stored in the UK. Once logged in to the BWW you assume an online identity which is anonymous to other users of BWW and to the ‘wall guides’ monitoring the BWW.
- You will receive personalized email notifications from Big White Wall. If you do not want to receive these emails, you have the ability to turn off the email notifications within your Big White Wall profile.
- Completing a questionnaire prior to getting access to the Big White Wall (University of Toronto Students only).
- Completing a questionnaire upon completion of your time on the Big White Wall. You may do this over the phone with the project coordinator, or request that the questionnaires be sent to your email address.
- Providing consent for your name, email address and telephone number to be shared with the project coordinator at WCH. You may also contact the project coordinator directly.
- Upon registering on the BWW, you will also be asked questions about socio demographic information. This is to help Big White Wall to improve their solution offerings to people from various backgrounds. Demographic information collected include:
  - Gender
  - Ethnicity
  - Education
  - Household income
  - Marital status
  - Age at which first experienced mental health problem.
You will have access to BWW for a minimum of 3-month period. Once this 3-month period is over you may be able to extend this time depending on the number of spaces remaining for the project use. You will receive notification prior to your access expiration. You may contact the project coordinator if you are interested in continuing after 3 months and she will inform you if this is possible.

Please note, as this app is online, you will incur normal charges as per your internet services provider for the time spent online

**HOW MANY PEOPLE WILL TAKE PART IN THIS PROJECT?**

Up to 1000 people will participate in this project across 4 participating health care sites in Ontario; 3 of which include a research component. The maximum length of time you will be in the project is 3 months. The entire project for all participants is expected to take about 12 months to complete and the results should be known in 2 years.

**WHAT ARE THE RESPONSIBILITIES OF PROJECT PARTICIPANTS?**

If you decide to participate in this project, the clinical staff will collect your contact information and pass it on to the project coordinator.

A direct link to the on-line questionnaires can be sent to your email address. You can complete them at your leisure from anywhere you can access the internet. You may also complete them over the phone with the project coordinator.

**WHAT ARE THE RISKS OR HARMS OF PARTICIPATING IN THIS PROJECT?**

There are no known major risks to you from participating in this project. If you were recruited from a waitlist, participation in the project will not affect your position on the list or time to services. If you are currently receiving help for your mental health problems, you will continue to meet with your health care provider as planned. There is a risk that you will be distressed by something you encounter during your use of the BWW. The BWW is monitored by trained therapists called ‘wall guides’ who are available to respond if something problematic is experienced on the site. Once your access to BWW expires at the end of your participation, there is a risk that you might miss having access to it if you found the program beneficial. Since this is a trial project, we are unable to offer patients continued use of the BWW beyond their participation. If you require additional mental health support after your participation, please contact your health care provider for advice.

Please note that the BWW on-line support community used in this project is not an emergency service and if you are experiencing an emergency, you should call 911 or go to the Emergency Department.
You will be told about any new information that might affect your willingness to continue to participate in this project as soon as the information becomes available to the project staff. You will be able to maintain anonymity on the site through a unique non-identifiable user ID.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS PROJECT?

You may or may not benefit directly from using the BWW. Based on the results of previous studies involving this and other similar on-line communities, we hope that many people will experience benefits in a range of outcomes. Your input will also tell us how this and similar on-line communities can be used to help people like yourself who are experiencing mental health problems.

CAN PARTICIPATION IN THIS PROJECT END EARLY?

You can choose to end your participation at any time. If you choose to withdraw, your choice will not have any effect on your current or future receipt of health care services. If you choose to withdraw voluntarily from the project, you are encouraged to contact the project coordinator by telephone about your decision. If you withdraw your consent, the information about you and your mental health problem(s) that was collected before you left the project will still be used. No new information about you will be collected without your permission.

The project staff may decide to remove you from this project without your consent. If you are removed from the project, the project coordinator and/or clinical staff will discuss the reason(s) with you.

WHAT ARE THE COSTS OF PARTICIPATING IN THIS PROJECT?

There is no cost of participating.

ARE PROJECT PARTICIPANTS PAID TO PARTICIPATE IN THIS PROJECT?

You will not be paid to participate in this project.

HOW WILL MY INFORMATION BE KEPT CONFIDENTIAL?

The information you provide to Big White Wall will be limited. The data collected such as your age, education level is used to recommend what portions of the Big White Wall may be most helpful to you and is kept separate, and behind firewalls. This minimal information collected will be stored on an encrypted server in compliance with applicable laws.

Your organization/university will provide OTN with minimal information about you only to allow OTN to set up your generic email account and activation code.

OTN will keep minimal information about you, securely, for the purpose of creating a generic email account and emailing you the email account and access code to your personal email. This information will be kept by OTN for 15 years. OTN is required to comply with provincial
privacy legislation. OTN is also required to ensure any third party vendors (such as Big White Wall) also comply with this legislation. OTN uses a variety of physical, administrative and technical methods to protect patient information including assessing, monitoring, reviewing and updating our practices regularly to ensure the ongoing privacy and security of that information. OTN is required to conduct privacy and security assessments as a requirement of the funding we receive from Canada Health Infoway. We are required to provide the findings of this assessment to the participating health care provider organizations and to ensure that all organizations involved in the Project are fulfilling their privacy and security obligations.

Agreements are in place with Big White Wall, and all participating organizations requiring them to fulfill their privacy and security obligations.

You have the right to have any health information about you that is collected, used or disclosed for this project to be handled in a confidential manner.

If you decide to participate in this project, the project staff will collect only the information they need for this project. You have the right to access, review and request changes to your personal health information.

The following people or project team may come to your organization/university to look at your personal health information to check that the information collected for the project is correct and to make sure the project followed the required laws and guidelines:

- Members of the project team at your organization/university
- Representatives of WCH (for university of Toronto and Women’s College only)
- Representatives of Health Canada and other regulatory bodies.

Access to your personal health information will take place under the supervision of your organization/university clinical staff.

“Project data” is information about you that is collected for the project, but that does not directly identify you. Your project data will include information about your use of the BWW and results of questionnaires you complete on the site. These results will not have your identifying data and will be sent by BWW to OTN. Your data will be added to the project data from all other project participants and sent to OTN after project completion for analysis. Any project data about you that is sent outside of your organization/university will not contain your name or address, or any information that directly identifies you. Project data that is sent outside of the hospital will be used only for the purposes explained in this consent form.

The project staff and the other people listed above will keep the information they see or receive about you confidential, to the extent permitted by applicable laws. Even though the risk of identifying you from the project data is very small, it can never be eliminated.

When the results of this project are published, your identity will not be disclosed.
BWW will be provided access to de-identified, aggregate data around things like how often you used the on-line community so that they may improve their product. They will not be given any information that can be used to identify you personally. Your organization/university may also be provided de-identified, aggregate data to help them to identify if a solution like the Big White Wall is useful for other patients/students.

You have the right to be informed of the results of this project once the entire project is complete. If you would like to be informed of the results of this project, please contact your organization/university lead.

**DO THE ORGANIZATIONS INVOLVED HAVE ANY CONFLICTS OF INTEREST?**

There are no conflicts of interest to declare related to this project.

**WHAT ARE THE RIGHTS OF PARTICIPANTS IN A PROJECT?**

You have the right to receive all information that could help you make a decision about participating in this project. You also have the right to ask questions about this project and your rights as a participant, and to have them answered to your satisfaction, before you make any decision. You also have the right to ask questions and to receive answers throughout this project.

If you have any questions about this project, you may contact the project coordinator or clinician at your site.

**WHAT DO I DO NOW IF I'D LIKE TO PARTICIPATE?**

If you are interested in participating, please contact a clinic staff or the project coordinator at your site.