University of Wisconsin-Madison & Columbia University Consent to Participate in Research

Invitation
We invite you to take part in a research study titled "The Tick App". The study is a collaboration between Dr. Maria Diuk-Wasser from Columbia University and Dr. Susan Paskewitz from the University of Wisconsin – Madison. We are inviting you because you are a resident or visitor of a high-risk Lyme disease area (Northeast and Midwest of the United States).

The purpose of this consent form is to give you the information you need to decide whether you want to participate in the study. We invite you to read through the question and answers related to this study. If we address all your questions that you might have about this study, and you have no further concerns, then you can decide if you want to be in the study. This process is called "informed consent," and by signing at the end, you agree to participate.

Why are researchers doing this study?
The purpose of this study is to better understand exposure to ticks and tick-borne diseases. This research is being done because Lyme disease is the most common vector-borne disease in the United States. Our behavior can influence the chances of being bitten by a tick and the information provided will help us design integrated control strategies to prevent diseases transmitted by ticks. Funding for this study is provided by the Centers for Disease Control.

What will happen in this study?
If you decide to take part in this study, you will be asked to share your daily activities with us and other information related to tick exposure. We ask you to complete the enrollment survey that will take less than 10 minutes to complete and complete at least 15 tick diaries that should take less than a minute to complete each day. It asks if you or a household member encountered a tick and what you did that day. After mailing your submissions, data will be entered in a secure database and the forms will be shredded.

In the fall, a post-season survey will be available that will take less than 5 minutes to complete. In the post-season survey, you will be asked about the past spring and summer, if you are willing to participate in the following season and how we can improve the app. Answering "Yes" to participation in the next year gives us permission to retain your address so we can contact you. You may skip any question on the questionnaires that you do not wish to answer. If you participated in a backyard assessment, we will connect that information with your submissions through the Tick App. Lastly, you may be approached to participate in a focus group on the app experience and separate information will be provided for this.

Will being in this study help me in any way?
You may benefit from the educational material on the website, as well as from sharing your experience and perspective with researchers and peers who value your input. Your participation in the study may benefit other people in the future by helping us learn about the risk factors for tick borne disease and helping us design better methods that prevent tick bites and tick-borne disease.

What are the risks?
We believe there are no risks associated with this research study; however there is a risk that your information could become known to someone not involved in this study. To the best of

our ability your answers in this study will remain confidential. We will minimize any risks by keeping data on HIPAA compliant servers and by de-identifying demographic characteristics from your survey responses. That means that any personal information that could identify you would be decoupled from your answers and both databases will be linked by a code; that code will only be available for the researchers involved in the study.

Potential stressors (fear or anxiety) may appear as a result of participating in this study as you become more aware of the risk of tick-borne diseases. Information regarding tick-borne diseases and best practices to prevent tick exposure are included on our website (www.tickapp.org) to help you take control when feeling unsure in a particular situation.

Who can access my information?
Members of the UW-Madison and Columbia University research team. After the study, data will be labeled in a way so that no one can identify which answers came from you. This data will remain securely stored, it does mean that we cannot remove your answers at a later time as we cannot identify which data is yours.

Will being in this study cost me anything?
If you print the forms, print costs are yours. If you mail the surveys and diaries, we ask you to provide the stamps.

What if I don't want to participate now, or after enrolling?
Participation is voluntary and you may discontinue participation at any time without penalty or loss of benefits. If you already submitted information and you want this removed, you need to contact the research team.

What if I have questions?
If you have questions about this research, please contact the lead researcher for your region, Midwest region (IA, IL, MI, MN, WI) Dr. Susan Paskewitz (608) 262-1696 or smpaskew@wisc.edu, North East region and other states Dr. Maria Diuk-Wasser (212) 854-3355 or mad2256@columbia.edu. If you have any questions about your rights as a research subject or have complaints about the research study or study team, contact UW Health Patient Relations at 608-263-8009 or the Columbia University Human Research Protection Program (HRPP) at (212) 851-7040 or askirb@columbia.edu.

Agreement to participate in the research study
If you sign the line below, it means that:

- You have read this consent form.
- You acknowledge that you are 18 years or older.
- You have had a chance to ask questions about the research study, and the research team has answered your questions.
- You want to be in this study.

_____
Printed Name of Participant

_____
Signature of Research Participant Date

_____

Signature of Person Obtaining Consent Date

****You will receive a copy of this form****