

## **Arthritis Consumer Experts - Privacy Policy**

**Effective date: October 2, 2016**

Arthritis Consumer Experts (Arthritis Consumer Experts, or “we,” or “us”) is a non-profit making company founded to inform and educate people with arthritis and advocate on their behalf for improved treatment and care. Everything we do is provided free-of-charge to the public.

We have developed a mobile application (the Walk10Blocks app) to facilitate our Walk10Blocks research study (the “Study”). The Study is designed to help us and our research partners understand what motivates people who are sedentary or who have joint or brain health challenges to walk a minimum of 10 blocks each day.

### **We respect your privacy**

This privacy policy describes our collection of personal data when you participate in the Study available at [Walk10Blocks.ca](http://Walk10Blocks.ca), or otherwise use the Walk10Blocks app, our use and disclosure of such personal data, and the steps we take to protect such personal data. “Personal data” means any information relating to an identified or identifiable natural person directly or indirectly.

Your use of the Walk10Blocks app and your participation in the study are each voluntary. By using the Walk10Blocks app or participating in the Study, you consent to the privacy practices described in this privacy policy. The entity responsible for the collection and processing of your personal data in the context of the Study and the Walk10Blocks app is Arthritis Consumer Experts, #210-1529 West 6<sup>th</sup> Avenue, Vancouver, BC, Canada V6J 1R1.

### **Registering for the Study through Arthritis Consumer Experts**

In order to access the Walk10Blocks app functionalities, we ask you to create an account through the Walk10Blocks app. To create an account, you must provide a username, a password, your email address, gender, full name, signature, birth date, height, weight, and province/state, and diseases related with the purpose of the study. We will inform you of the purposes for which we are collecting, processing, using, and sharing your personal data and we will obtain your consent through an informed consent process. You must affirmatively consent to participate in the Study prior to finalizing the set-up of your account. To provide your informed consent, you will be asked to provide your first and last name, as well as your signature.

## **Information We Collect**

In addition to the data we collect in registration for the Study, we collect the following through the Walk10Blocks app and the Study:

### **Walking Activity**

The Walk10Blocks app will use the motion sensor built into your device to capture the number of steps and distance you have walked every 15 minutes. Data on your location (i.e. GPS coordinates) will not be gathered.

### **Walking Log**

The Walk10Blocks app will capture the information you to log the level of effort and activity related with a particular walking activity in the Walking Log screen of the app.

### **Surveys**

With your permission, we collect and process some data related to your health and physical activity that helps us better understand your walking habits. The survey will include questions on your demographics, walking activities, your neighborhood, and your experience using the app. Taking the surveys are very important in terms of the research. Although completing them is entirely voluntary, we encourage you to complete them when notified by the app.

### **Standard Log Information**

We automatically collect standard server log information, such as internet protocol address and details of how you used the Walk10Blocks app, including sessions, screens accessed, and use of the functionalities.

### **Other Information You Provide to Us**

We also receive other information, including personal data that you may provide to us, such as sending your comments or questions.

## **How We Use Information**

We use your contact information, including email address, to contact you for administrative purposes regarding your participation in the Study and your use of the Walk10Blocks app.

We use the information that we collect through the Walk10Blocks app and the Study to operate, maintain, enhance and provide all features of the Walk10Blocks app and the Study, to provide services and information that you request, to respond to comments and questions and otherwise to provide support to users.

Your data will be used for improving general health, medical and fitness management and for the purposes of medical research. Your data will not be used for advertising or other use-based data mining purposes. We will not access your personal contacts, other applications, personal photos or text and email messages on your iPhone.

With regard to our processing of personal data for the Study, our Walk10Blocks app and the necessary ancillary services aggregate user-provided and user-generated information, including personal data. We separate your account information (e.g., name or email address) from your Study data (including survey responses, walking activity, walking log) and combine your de-identified (i.e. coded) Study data (without your name) with those of other Study participants for research and analysis as described below under “How We Disclose Information.”

We use standard log files and other automatically-collected usage data that is essential for the Study and the Walk10Blocks app to function effectively, including to: (i) personalize the Walk10Blocks App and the Study, such as by remembering information so that it does not need to be re-entered; (ii) monitor and analyze the Walk10Blocks app and the Study; (iii) monitor aggregate Walk10Blocks app usage metrics; and (iv) track your activities on the Walk10Blocks app and in the Study. We do not use cookies, beacons or device fingerprinting.

## **How We Disclose Information**

Except as described in this privacy policy, we will not sell, rent, lease, give away, disclose or share your contact information, and will not disclose your information that we collect through the Walk10Blocks app and the Study to third parties without your consent. We may provide contact or coded study information to third parties if you consent to us doing so, as well as in the following circumstances:

When we work with third parties who provide services on our behalf, we take steps to limit the personal data provided to them to that which is reasonably necessary for them to perform their functions for the allowable purposes listed above. We require them by contract to agree to only process the personal data in accordance with our instructions and to maintain the security and confidentiality of such information by applying adequate technical and organizational measures.

To the extent permitted by applicable law, we may disclose your information if required to do so by law to comply with state and federal laws, in response to a court order, judicial or other government subpoena or warrant, or to otherwise cooperate with law enforcement or other governmental agencies.

We also reserve the right to disclose your information that we believe, in good faith, is appropriate or necessary to (i) take precautions against liability, (ii) protect ourselves or others from fraudulent, abusive, or unlawful uses or activity, (iii) investigate and defend ourselves against any third-party claims or allegations, (iv) protect the security or integrity of the Walk10Blocks app and the Study and any facilities or equipment used to make the Walk10Blocks app or Study available, or (v) protect our property or other legal rights (including, but not limited to, enforcement of our agreements), or the rights, property, or safety of others. We will notify you of any such disclosures.

Information about our users, including personal data, may be disclosed and otherwise transferred to an acquirer, successor, or assignee as part of any merger, acquisition, debt financing, sale of assets, or similar transaction, or in the event of an insolvency, bankruptcy, or receivership in which information is transferred to one or more third parties as one of our business assets, to the extent and in the way as prescribed by applicable law.

As described above in the “**How We Use Information**” section, we will combine your Study data, including survey response and walking activity with those of other Study participants. The combined data will be used by Arthritis Research Canada for analysis. Researchers from the Study team and its partners accessing data will analyze the data and report findings back through blog or scientific publications. This Study gives you the option to share your coded Study data more broadly, with other researchers worldwide, for use in this research and beyond to benefit future scientific research. If you choose to share your data broadly, your coded data (without your contact information) will be added to a shared dataset and will be made available to qualified researchers who agree to using the data in an ethical manner after being approved by Arthritis Research Canada, to do no harm and not attempt to re-identify or re-contact you unless you have chosen to allow them to do so.

## **Do Not Track**

We do not track our Walk10Blocks app visitors over time and across third party websites or online services to provide targeted advertising, and we do not specifically respond to Do Not Track (“DNT”) signals.

## **Data Security**

We use appropriate physical, managerial, and technical safeguards that are designed to protect the confidentiality, integrity and security of personal data that we collect and maintain against accidental or unlawful loss, theft and misuse and unauthorized access, disclosure, alteration destruction, or any other type of unlawful processing. We cannot, however, fully guarantee the security of personal data or other information transmitted to us through the Walk10Blocks app or the Study. It is your responsibility to ensure that you always keep your account password and verification code private and never share it with anyone. We also recommend that you use a password lock on the iPhone itself. Taking these precautions will help towards preventing unauthorized access to your personal information.

We take steps to ensure that your personal data is kept in de-identified format by removing personal data that reasonably can be used to identify you directly, such as name or telephone number, from the research study data. However, experts in re-identification may be able to reverse our processes and/or attempt to re-identify you if given sufficient cross-reference information. Total anonymity cannot be guaranteed. In the event we are aware of a security breach that involves your personal information stored by us, we will notify you immediately. By disclosing your email address to us you agree to receive electronic notice from us in the event of such a security breach.

Your Rights and Choices Subject to applicable law, you may have certain rights regarding the personal data we maintain about you. You may have the right to request access to and receive information about the personal data we maintain about you, or have your personal data rectified, blocked or deleted if it is incorrect, inaccurate or outdated. Following your request, we will accommodate your enquiry as required by applicable law.

If you wish to access, rectify, delete or block any other personal data we hold about you, you may contact us at [walk10blocks@arthritisresearch.ca](mailto:walk10blocks@arthritisresearch.ca). Please note that while any changes you make will be reflected in active user databases within a reasonable period of time, we may retain all information you submit for backups, archiving, prevention of fraud and abuse, analytics, satisfaction of legal obligations, or where we otherwise reasonably believe that we have a legitimate reason to do so, as permitted by applicable law.

If you would like to withdraw from the Study, you may do so within the Walk10Blocks app by clicking on the “Leave study” link in your profile page. You also may contact us at [walk10blocks@arthritisresearch.ca](mailto:walk10blocks@arthritisresearch.ca) to withdraw from the Study.

You can withdraw any consent you have provided to us for the processing of your personal data at any time and free of charge. Please note that if you withdraw from the Study, we will stop collecting new data from you, but the data that has already been de-identified may not be able to be destroyed and deleted.

## **Data Storage**

The Walk10Blocks research team is located in Arthritis Research Canada, a non-for profit research institute located at 5591 No. 3 Rd, Richmond, British Columbia. This institute, along with the researchers who will be using the data collected from the Walk10Blocks app, are affiliated with the University of British Columbia. As required by the University of British Columbia Research Ethics Review Board, all university-affiliated researchers must have full ownership of the data collected for the Study. Upon completion of the Study, de-identified data will be transferred, via a password-protected document, using the Arthritis Research Canada network. Arthritis Research Canada network uses a fully encrypted and secured site using 128-bit SSL encryption, which is also used by many major banks.

All of the research documents will be destroyed after 5 years following the end of the Study, in line with UBC requirements.

If you have questions about your rights and choices in relation to your personal data, the Study or would like to request additional information, please contact our email address at: [walk10blocks@arthritisresearch.ca](mailto:walk10blocks@arthritisresearch.ca).

## **Cross-Border Transfer of Your Information**

We may transfer your personal data to countries outside of your country of residence which may have different personal data protection laws than the country in which you initially provided the

information. In doing so, we comply with applicable legal requirements pertaining to the transfer of personal data to other countries and will protect that information as described in this Privacy Policy.

## **Changes to Our Privacy Policy**

We may change this privacy policy from time to time. Any changes will be posted on this page with an updated revision date. In the event that any changes to this privacy policy materially alter your rights or obligations under this privacy policy, we will make reasonable efforts to notify you of the change. For example, we may send a message to your email address, if we have one on file, or generate a pop-up or similar notification when you access the Walk10Blocks app or the Study for the first time after such material changes are made. Your continued use of the Walk10Blocks app or the Study after the revised privacy policy has become effective indicates that you have read, understood and agreed to the then-current version of this privacy policy.

## **Contact**

If you have any questions, comments or requests regarding this privacy policy or our processing of your information, please contact:

[walk10blocks@arthritisresearch.ca](mailto:walk10blocks@arthritisresearch.ca)

Arthritis Research Canada

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## **Updates**

We may update our Privacy Policy from time to time to clarify how we collect, process, store, use and disclose information. We want to be as transparent as possible about the changes we make to our Privacy Policy. Here is a summary of the changes we have made.