

Privacy Policy

Sage Bionetworks Mole Mapper Study

Privacy Policy

Effective date: **20 Sept 2015**

Sage Bionetworks (“Sage Bionetworks,” “we,” or “us”) is a 501(c)(3) nonprofit biomedical research organization in the United States, created to enhance how researchers approach the complexity of human biological information and the treatment of disease.

In collaboration with researchers at Oregon Health Science University, we have developed a research study (“The Study”) to better understand skin biology and melanoma risks using the Mole Mapper mobile application (“MM-APP”). The Study is designed for users over 18 years of age.

We respect your privacy. This privacy policy describes our collection of personal data when you participate in the Study via the Mole Mapper 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 Mole Mapper App and your participation in the study are each voluntary. By 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 via the Mole Mapper App is Sage Bionetworks, 1100 Fairview Avenue North, Seattle, WA 98109, United States. Its representative in Europe is the foundation Sage Bionetworks EU - 271b Noorderkerweg, 1069LT Amsterdam, Netherlands.

Registering for the Study through Sage Bionetworks.

In order to participate in the Study, we ask you to create an account through the Mole Mapper App. You must affirmatively consent to participate in the Study prior to creating your account. 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 document and process. To provide your informed consent, you will be asked to provide your first and last names, as well as your signature. To create an account after consenting to join the Study, you must provide a password and your email address.

Information We Collect

In addition to the data we collect in registration for the Study, we collect the following data through the Mole Mapper App:

- **Data Imports.** The Mole Mapper App allows you to import data to the Mole Mapper App and the Study, including photos of your moles and mole characteristics like location and size. You may also give permission to import certain data that you may have provided to Apple Health app separately or that may be available through other third party applications. We are not responsible for the data practices of third parties from which you may elect to import data and you are advised to consult their privacy policies separately. You may choose not to import these data types and to still participate in the Study.
- **Health Surveys.** With your permission, we collect and process some personal data that is necessary for the purpose of the study. To better understand your evolving health, we will ask you to answer questions about yourself (e.g. gender, date of birth, residing zipcode), your natural hair/eye color, medical history, and melanoma status). You may choose to leave any questions that you do not wish to answer blank.

- **Standard Log Information.** We automatically collect standard server log information, such as internet protocol address and details of how you used the Mole Mapper App (e.g. history of page requests such as uploading data or signing in and date/time of request).
- **Other Information You Provide to Us.** We also receive other information, including personal data that you may provide to us, such as comments or questions you provide to us.

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 Mole Mapper App. We also add your name, contact information and your unique HealthCode to the OHSU-managed War on Melanoma Community Registry database operated and managed by the Study partner at Oregon Health Science University (OHSU)..

We use the information that we collect through the Mole Mapper App and the Study to operate, maintain, enhance and provide all features of the Mole Mapper 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 management and for the purposes of medical research. Your data will also be used by researchers from the War on Melanoma community registry to inform you of other melanoma-related research opportunities and events that may be of interest to you. Sage Bionetworks isn't involved in the development, maintenance and implementation of the War on Melanoma community registry and will not have oversight on communications to or from the registry. Sage Bionetworks will NOT use your data for commercial advertising. We will not access your personal contacts, other applications, personal photos nor text and email messages on your iPhone.

With regard to our processing of personal data for the Study, the Mole Mapper App and the necessary ancillary services aggregate user-provided and user-generated information, including personal data. We separate your account information (e.g., names or email address) from your Study data (including survey responses, mole photos and mole characteristics) and combine your 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 MM-APP to function effectively, including to: (i) personalize the Mole Mapper App and the Study, such as by remembering information so that it does not need to be re-entered; (ii) monitor and analyze the Mole Mapper App and the Study; (iii) monitor aggregate usage metrics; and (iv) track your activities on the Mole Mapper 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 Mole Mapper 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 Mole Mapper App and the Study and any facilities or equipment used to make the Mole Mapper 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 with those of other Study participants. The combined Study data will be transferred to [Synapse](#), a computational research platform, for analysis. Researchers from the Study team and its partners accessing data through Synapse 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 metadata (responses to survey questions and the mole measurements without the mole photo) will be added to a shared dataset available to qualified researchers on the Sage Bionetworks Synapse servers (www.synapse.org), and will be made available to qualified researchers who are registered Synapse users and who agree to using the data in an ethical manner, to do no harm and not attempt to re-identify or re-contact you unless you have chosen to allow them to do so. Due to the higher risk of re-identification, access to the mole photos will require proof of ethics approval for the intended use. The study team will have no oversight on the future research that qualified researchers who have secured ethics approval may conduct with the coded study data. For more information about our data practices in the context of the Synapse research platform, see the [Synapse Privacy Policy](#).

How is my Health app data handled?

You have the option to share data from your mobile device’s iOS Health app with the MM-APP. Unless you agree to share your data through and with the App, you will not be able to include it in the study. Once you agree to share your data through and with the MM-APP, such data becomes covered by this Privacy Policy. We are not responsible for the data practices of the iOS Health app outside the Mole Mapper App in any way.

Do Not Track

We do not track the Mole Mapper 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

Sage Bionetworks uses 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 Mole Mapper App or the Study.

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.

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.

Within the MM-APP, you are able to review the personal data we have collected through your use of the Mole Mapper App and participation in the Study.

If you wish to access, rectify, delete or block any other personal data we hold about you, you may contact the Study team at privacypolicy@sagebase.org. 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 Mole Mapper App by clicking on the “Leave study” link in your profile page. You also may contact us at MoleMapperStudy@sagebase.org to withdraw from the Study.

To opt-out of or withdraw from the registry please contact the registry personnel at 1-844-300-SPOT (7768) or WarOnMelanoma@ohsu.edu.

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 coded study data that you have already provided will already have been distributed and will not be able to be destroyed or deleted.

If you have questions about your rights and choices in relation to your personal data, or would like to request additional information, please contact privacypolicy@sagebase.org.

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.

Although you may access the Mole Mapper App or participate in the Study from a location outside of the United States, any personal data collected by us in connection with the Mole Mapper App or the Study may be transferred to, processed, and stored within the United States. Also, we may transfer your data from the United States to other countries or regions in connection with storage and processing of data, fulfilling your requests, and operating the Mole Mapper App and the Study.

By using the Mole Mapper App or participating in the Study, you will be asked to consent to the transfer of your personal data, including your mole photos, to countries outside of your country of residence, including to the United States.

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 Mole Mapper App or the Study for the first time after such material changes are made. Your continued use of the Mole Mapper 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:

privacypolicy@sagebase.org

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