

Privacy Policy

OHSU Mole Mapper

Effective Date: **01 June 2016**

We will take steps to keep your personal information confidential, but we cannot guarantee total privacy. This is a low risk because we separate and/or de identify personal information that can directly identify you, such as your name or email from the study data to respect your privacy. Only the study organizers and some IT staff will have the key to associate your coded study data to your name and account information. However, certain skin features like tattoos or birthmarks may be unique to you and enable your re-identification despite our curation efforts (described below). So even though your name is kept separate from your coded study data, it is possible that someone could still figure out your identity. To reduce this risk, we recommend photographing moles at close range (~6 inches from skin surface) to minimize capture of secondary identifiable skin features.

Data de-identification

The Mole Mapper study data collected through the app will be encrypted on your phone, transferred electronically and stored securely in Synapse (synapse.org), Sage Bionetworks' data repository and analysis platform in the United States using secure Cloud services. We will separate your account information (name, email, contact information, etc.) from your study data (your responses to surveys and photographs of moles) to be analyzed.

We will use a random code number instead of your name on all your study data. This code cannot be used to directly identify you. Information about the code will be kept in a secure system. Only the study investigators, including War on Melanoma researchers and essential IT staff will have the key to link your coded study data to your name and account information.

We will NOT access other information on your iPhone for example, your personal contacts, other applications, text or email message content, or websites visited. We will never sell, rent, or lease your contact information.

Where will my data be stored?

Your study data (survey responses, photographs and measurements of moles) will be encrypted and transferred for data storage and analysis to Sage Bionetworks in the United States. We will combine your coded study data (without your name) with those of other study participants for analysis. For more information about Sage's data practices in the context of the Synapse research platform, see the Synapse Governance Overview [<https://www.synapse.org/#!/Wiki:syn2502577/ENTITY>]

How is my coded study data used in research?

Your study data (without your name) will be curated and added to the data of other study participants. Curation involves removing from the study data facial images, removing images that contain easily identifiable markings such as tattoos or birthmarks, verifying that they are useful (e.g. not too fuzzy and are pictures of moles), and if applicable are accurately labeled. Individuals performing curation will be under the oversight of the Principal Investigator

This study gives you the option to share your coded study data broadly, with qualified researchers worldwide for use in this research and beyond to benefit future research both academic and commercial. If you choose to share your study data broadly, your coded unnamed metadata (your response 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). Your mole photos will be available to qualified researchers who have received ethical approval to use the photos for their research. It is important to note that the Principal Investigator and Sponsor will have no oversight on the future use of the shared study data by other researchers.

We will create and collect health information about you as described in the Purpose and Procedures sections of this form. Health information is private and is protected under federal law and Oregon law. By agreeing to be in this study, you are giving permission (also called authorization) for us to use and disclose your health information as described in this form.

The investigators, study staff, and others at OHSU may use the information we collect and create about you in order to conduct and oversee this research study, store in a repository, and conduct future research.

We may release this information to others outside of OHSU who are involved in conducting or overseeing research, including:

- The Office for Human Research Protections, a federal agency that oversees research involving humans
- The National Cancer Institute (NCI)

Those listed above may also be permitted to review and copy your records.

We will not release information about you to others not listed above, unless required or permitted by law. We will not use your name or your identity for publication or publicity purposes, unless we have your special permission.

When we send specimens or information outside of OHSU, they may no longer be protected under federal or Oregon law. In this case, your information could be used and re-released without your permission.

Your authorization for the use and/or disclosure of your information will expire if you choose to withdraw from the research study subject to any time limitations imposed by applicable law or by December 31, 2060.

If you choose to withdraw from the research study, we will stop collecting your study data. At the end of the study period we will stop collecting your data, even if the app remains on your phone and you keep using it.

If you opt out of the Melanoma Community Registry you will stop receiving information about future educational events in your community or research opportunities, but information previously provided will not be deleted.