



COUNT ME IN PRIVACY POLICY

Count Me In values your privacy. This Privacy Policy (“**Policy**”) provides important information about how Count Me In collects and uses your personal information. **Please make sure you review this Policy before using Count Me In’s websites or mobile applications. If you have any questions about this policy, please contact us at privacy@joincountmein.org.**

This Policy is effective as of November 11, 2020.

1. Who is Count Me In?

Count Me In, Inc. is a non-profit organization committed to advancing patient-partnered research. Its mission is to engage with individuals living with cancer and enable those patients to share their information and experiences with researchers to accelerate medical progress. For more information on the organization, please see <https://joincountmein.org/About>. We will refer to Count Me In in this Policy as “**we**”, “**us**” or “**our**.”

We have developed a website platform (the “**Site**”) and associated mobile application (the “**App**”) to enable users to learn more about us and upload, add, and share information. This includes the website at <https://joincountmein.org/> and the websites and corresponding mobile applications for our Count Me In projects listed below (“**Research Projects**”):

- Metastatic Breast Cancer Project, located at <https://www.mbcproject.org/>
- Angiosarcoma Project, located at <https://ascproject.org/>
- Metastatic Prostate Cancer Project, located at <https://mpcproject.org/>
- Esophageal & Stomach Cancer Project, located at <https://escproject.org/>
- Brain Cancer Project, located at <https://braincancerproject.org/>
- Osteosarcoma Project, located at <https://osproject.org/>

If you are a participant in a Research Project (“**Participant User**”), the Research Project will collect health-related information from you regarding your medical and health conditions, treatments, and diagnosis (“**Participant User Information**”). Some information is gathered from you prior to your participation to determine if you qualify, but most of the information is collected after you have qualified and under a written consent form that you are asked to sign in accordance with approved research protocols. Participant User Information may be uploaded to the Platform by persons conducting the Research Project.

We will refer to the Site and the App together as the “**Platform**.”

Please note that the Platform may link to other websites that are not affiliated with us or the Research Project (“**Third-Party Sites**”). We may offer those links as a convenience to you, but we are not responsible for the privacy practice of those Third-Party Sites. You should make sure

you review the privacy policies for those Third-Party Sites before providing them any of your information.

2. What is the purpose of this Privacy Policy?

This Policy describes the information we collect from users of the Platform, the purposes for collecting that information, how we use that information, and with whom we share that information. It applies to users who are Participant Users and those users who are not enrolled in any Research Project and are using the Platform for general informational purposes or because they are interested in participating in a future research project (“**General Users**”). We will refer to all users, including Participant Users and General Users, in this Policy as “**you**” or “**your**”.

Important Note to Participant Users: If you are participating in a Research Project, you may be asked to provide blood, saliva, and other types of samples to assist in research and development of treatments. We will obtain your separate, written consent to use these samples, and our and our research partners’ use of these samples and your Participant User Information will be governed by the terms of the consent that you sign and not this Policy.

3. If I use the Platform, am I agreeing to this Policy?

Yes. However, your use of the Platform is entirely voluntary and you have certain rights to control use of your information as described below. If you decide to use the Platform, you are agreeing that we can use your information as described in this Policy.

4. How do we collect information from you?

We collect information about you in two ways. The first is information you voluntarily provide to us when you choose to do any of the following, none of which is required:

- Register to use the Platform, such as when you download the Count Me In App or create a Count Me In profile.
- Use the Platform to provide us information about you, such as your experiences with cancer or in connection with Research Projects in which you participate. For example, the App will ask you to identify the kind of cancer you have and will ask you a series of questions about your cancer, treatment, medical condition, race, ethnicity, country, and zip code. Please note that you are not required to answer any question.
- Respond to surveys we may send to you.
- Communicate with us (*e.g.*, by email).

In all these cases, we only collect information that you have provided to us, except for information obtained through cookies and the tracking technologies noted below or that is generated through the Research Projects.

The second way we collect information is through certain automated technologies that are used when you access our Platform. An example is a “cookie,” which is a small piece of computer code that is placed on your computer or other device that can be used for various purposes, such as to recognize a user or to track their activities on a website. We describe automated technologies in more detail in Section 6 below. We collect various information through these automated technologies, including your Device Information as described in Section 5 below; your Location Information as described in Section 5 below; and how you use our Site and App,

such as the web pages you view, the links you click, the length of time you visit our Platform, and the web page or web site that led you to our Platform.

5. What kind of information do we collect?

We collect various types of information:

- **“Personal Information”** is information that alone or in combination with other information may be used to readily identify, contact, or locate you. For example, your name, age, address, phone number, email address, clinical data, medical history, and treatment type are Personal Information we may collect through your use of the Platform.
- **“Device Information”** is information that relates to a particular computer, mobile device, or other device (*e.g.*, iPad) that you use to access the Platform. Device Information includes such things as an IP address (which is a number assigned by an internet service provider to the computer you use to access the Internet), a device ID (which is a number assigned to a mobile phone by the device manufacturer), or the type of operating system or web browser used to access the Platform.
- **“Location Information”** is information that can be used to identify your geographical location, such as where you are geographically located when you are accessing the Platform using a mobile phone. We will not collect Location Information from your mobile phone using a location-based service without sending you a separate notice to your mobile phone and obtaining your consent. Please note, however, that certain automated technologies such as cookies can identify IP addresses and other data to infer the location of a device that you may be using.

6. Do we use cookies and other tracking technologies?

Yes. We use cookies for various purposes, such as to make it easier for you to navigate our Platform, to enable a faster log-in process, or to allow us to track your activities on our Platform. There are two types of cookies: session and persistent cookies.

- **Session Cookies**. Session Cookies exist only during a session. They disappear from your computer or device when you close your browser or App or turn off your computer or device. We use Session Cookies to allow our systems to uniquely identify you during a session or while you are logged in to the Platform. This allows us to process your communications and requests and verify your identity after you have logged in and as you move through our Platform, and to optimize your experience in using the Platform.
- **Persistent Cookies**. Persistent Cookies remain on your computer or device after you have closed your browser or the App or turned off your computer or mobile device. We use Persistent Cookies to track aggregate and statistical information about user activity on our Platform (see **“Tracking Technologies”** below).

Disabling Cookies. Most web browsers automatically accept cookies, but if you prefer, you can edit your browser options to block them in the future. The Help portion of the toolbar on most browsers will tell you how to prevent your computer from accepting new cookies, how to have the browser notify you when you receive a new cookie, or how to disable cookies altogether. Visitors to our Site who disable cookies may not be able to browse certain areas of the Site or use the Platform.

Tracking Technologies. We use automated devices and applications, such as Google Analytics, to evaluate usage of our Platform. We also may use other analytic means to evaluate our

Services. We use these tools to help us improve our Platform, performance, and user experiences. We may also use third-party tracking technologies, such as tCell, to detect malicious code or attacks on our Platform. These entities may use cookies and other tracking technologies to perform their services. We do not share your personal information with these third parties.

7. Do you respond to Do Not Track signals?

Do Not Track (“DNT”) is a privacy preference that users can set in their web browsers. When users turn on DNT, their browser sends a message to websites requesting that they do not track the user. However, our Platform does not change its information collection in response to DNT browser settings or signals. For information about DNT, visit www.allaboutdnt.org.

8. How do we use your information?

We use your information, including your Personal Information, for various purposes:

- **Conduct Research**. We, and the research partners with whom we collaborate, use the information you provide about yourself, your medical condition, cancer treatment, and experiences to conduct research, but only if you are a Participant User that has enrolled in a Research Project and have executed a separate written consent with the applicable Research Project.
- **Provide the Platform**. We, and our vendors and service providers, use your information (*e.g.*, your profile information, user identification, and password) to provide the Platform, respond to your inquiries, and troubleshoot issues with the Platform, and for other customer service purposes.
- **Personalize Your Experience**. We use your information to tailor the content and information that we may send or display to you, to offer location customization, and personalized help and instructions, and to otherwise personalize your experiences while you are using the Platform.
- **Improve and Develop Our Platform**. We use your information to ensure our Platform is working as intended, to better understand how users access and use our Platform, both on an aggregated and individualized basis, to make improvements to our Platform, to develop new features and applications, and for other research and analytical purposes.

We do not use your Personal Information for marketing purposes, but we may share aggregate data from our cohorts to encourage participation in our Research Projects. This aggregate data does not identify you personally.

9. With whom do we share your information?

We may need to share your information, including your Personal Information, with third parties. The following are the categories of third parties with whom we may share your Personal Information:

- **Research Partners**. The purpose of the Platform is to facilitate the sharing of information from cancer patients with researchers involved in the various Research Projects; we only share such information, however, if you are a Participant User and have first signed a consent for such sharing with the Research Project. As set forth in the consent, the information you provide through the Platform is used by various persons involved in the Research Project such as the principal investigator and other clinicians and individuals involved in conducting research in a particular Research Project. In

addition, we will share your information with the third parties listed on the consent that you are asked to sign when joining a Research Project, which includes: the Broad Institute of MIT and Harvard, a leading nonprofit biomedical research institution, and its affiliated hospitals such as the Dana-Farber Cancer Institute, a leading cancer hospital.

- **Vendors and Service Providers.** We use various third-party vendors and service providers that assist us in providing the Platform. For example, we may use third-party vendors to store and authenticate account credentials, send email communications, ship test kits, and for hosting and storing information collected through our Platform. We may share your information with these vendors and service providers to enable them to provide these services to us. These service providers and vendors are required to only use your information to provide their services to us and in a manner consistent with this Policy.
- **As Required By Law.** We may be required, by law, to disclose your Personal Information to third parties, such as in the following situations:
 - In response to a request by law enforcement;
 - In response to legal process, such as a subpoena, a request for discovery in a civil proceeding, or in response to a court order.
- **Enforce Our Terms and Protect You, Us, and Others.** We may access, preserve, and disclose your Personal Information to enforce the Terms of Use for the Platform and protect your, our, or others' rights, property, or safety.
- **Merger, Sale, or Other Corporate Transactions.** A legal entity, such as Count Me In, may be involved in a business transaction where its ownership or assets are sold or transferred to another legal entity. This can happen in a merger with another legal entity, an acquisition by another legal entity, a corporate reorganization, or a legal proceeding (e.g., bankruptcy or receivership) where a trustee or other takes over control of the entity. In each of these situations, your information, including your Personal Information, may be sold or transferred as part of such a transaction as permitted by law and/or contract.
- **With Your Consent.** We may ask you from time to time to give us permission to share your information with other third parties not described in this section. In each case, we will describe that third party and the purpose for sharing your information.
- **Aggregate and De-Identified Information.** We may share aggregate or de-identified information about users and their use of the Platform with third parties and publicly for marketing, advertising, research, or similar purposes. This information will not identify you personally.

We do not rent, sell, or share Personal Information about you with other people or unaffiliated organizations for marketing purposes.

10. Can other users see my Personal Information?

Users will not be able to post content that is visible to any other users of the Platform. Your information will only be made available to us, our research partners, our service providers and vendors, and the other third parties listed in Section 9.

11. What rights do I have with respect to my information?

Participant Users can update their Count Me In Profile at any time. All users can also contact us to request access to, a copy of, correction, or deletion of their Personal Information by contacting us at privacy@joincountmein.org.

We will respond to any user request as soon as we reasonably can, and within the time and in the manner required by law. We may request additional information from you to verify the request. We may not be able to accommodate all requests; for example, we may be unable to accommodate a deletion request if we are required to maintain information under law or a legal obligation or if information is used as part of a study (only individuals who have signed a consent with a Research Project would be included in the study).

12. What kind of security does Count Me In use to protect my information?

We use reasonable safeguards to protect the Personal Information we collect from users. These safeguards encompass administrative, technical, and physical procedures and controls, including:

- encryption of personal health information in transit [at rest, on servers];
- threat and risk assessments;
- system monitoring;
- access control and login reports;
- privacy and security training; and
- secure destruction of records.

Access by our personnel and third-party service providers to the personal health information that we process and hold is governed by role-based access protocols and confidentiality obligations.

We require that all employees and third-party service providers having access to Personal Information sign agreements stipulating compliance with the provisions in this Policy and participate in privacy and security training.

However, we cannot guarantee the security of information we collect or any transmission of information over the Internet. For this reason, you should make sure that you keep your account on the Platform confidential, including any user identification or password. You should also notify us immediately if there has been any unauthorized use of your account.

13. Do you collect information from children?

We do not collect information directly from children under the age of majority, *i.e.*, under thirteen (13) years of age. If we discover that a child under the age of majority has provided us with Personal Information, we will delete such information from our systems. However, minors can join and participate in a Research Project with the consent of their parent or legal guardian as required by applicable law. If you are a parent or legal guardian providing personal information regarding your child, you represent and warrant that you have the right and authority to provide us such information.

14. Is there any transfer of Personal Information from one country to another?

This Platform is intended for use in the United States and Canada only. We store the information you provide on servers in the United States. If you are a user of the Platform, you agree to the transfer of your Personal Information to the United States and acknowledge that the laws in the United States may offer less protection to your Personal Information than the laws where you live.

15. Whom do I contact if I have a question or a complaint?

You may contact us at the addresses below if you have any questions or complaints about information practices or this Policy:

By email to: privacy@joincountmein.org.

By mail to:

Count Me In
415 Main St.
Cambridge, MA 02142,
United States
Attention: Data Privacy

16. Will you update or change this Policy?

Yes, we may need to update or change this Policy for various reasons, such as to comply with changes in the law or to cover new features, services, or Research Projects provided through the Platform. If we update or change this Policy we will:

- Post the changes to the Policy on the Site and in the App; and
- Notify Participant Users of any material changes to the Policy through the email address in their profile.

To make sure you are aware of any updates or changes, you should review this Policy periodically and make sure you have your most current email address in your Count Me In profile. We will post the effective date of any new policy.

New Uses of Personal Information

As a general practice, we will not use your Personal Information for uses or purposes that are significantly different from those described in this Policy. However, from time to time, we may desire or need to use Personal Information for uses not previously disclosed in this Policy. If this should happen, we will use reasonable efforts to notify you and obtain your consent to such new uses as required by law.