

# Crohn's Colitis Co-Care App – Privacy Policy

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Crohn's Colitis Co-Care App is owned and operated by Crohn's Colitis Cure or CCCure (ABN 85 154 588 717), based in Australia.

In this Privacy Policy, **we, our, us** or **CCCure** means Crohn's Colitis Cure (ABN 85 154 588 717). We respect your privacy and are committed to protecting your personal information.

We comply with the **Australian Privacy Principles (APPs)** under the Privacy Act 1988 (Cth) and the **New Zealand Information Privacy Principles (IPPs)** under the Privacy Act 2020 and align with the **EU General Data Protection Regulation (GDPR)**.

This Privacy Policy explains how we collect, use, share, and protect your personal information when you use the Crohn's Colitis Co-Care App (**App**). The App can be used in conjunction with the CCCare Platform or independently of it. If you choose to use the App with the CCCare Platform, the data you generate via the App will be linked with your clinical data held on the CCCare Platform.

By providing personal information to us, you consent to our collection, use and disclosure of your personal information in accordance with this Privacy Policy and any other arrangements that apply between us. If you are a carer or guardian using the App on another App user's behalf, you confirm that user has consented to the collection, use and disclosure of their personal information.

We may change our Privacy Policy from time to time by publishing changes to it on our website. We encourage you to check our website periodically to ensure that you are aware of our current Privacy Policy.

Personal information includes information or an opinion about an individual that is reasonably identifiable. For example, this may include your name, age, gender, postcode and contact details.

## 1. What personal information do we collect

We may collect:

- **personal details** such as name, contact information, date of birth, and gender;
- **health information** (sensitive information), including self-reported symptoms, treatments, medications, and wellbeing measures;
- **device and usage information** such as app activity, IP address, device type, and crash logs;
- **optional connected data:** If you choose to connect a third-party health platform (such as Apple HealthKit, Google Fit, Fitbit, Garmin, or similar), we will only access the data types you authorise (for example, steps, heart rate, or sleep). You can withdraw this permission at any time in your device or app settings.

We may collect these types of personal information either directly from you, or from third parties. We may collect this information when you:

- register on the App; or
- communicate with us through correspondence, chats (including with our AI chatbot), email, or when you share information with us from other social applications, services or websites.

If you do not consent to the collection of your personal information set out above, we may not be able to make the App available to you (but you will still receive your usual treatment course, as advised by your doctor). Please discuss this with your local IBD Care Service.

We endeavour to collect your information directly from you. However, in some circumstances we may collect your information from third parties, such as a service provider or from a publicly available record.

## 2. Why do we collect, use and disclose personal information?

We may collect, hold, use and disclose your personal information to:

- enable you to access and use the App and to personalise your app experience;
- operate, protect, improve and optimise the App, our business and our users' experience;
- enable remote monitoring, symptom tracking, reminders, insights and personalised care pathways;
- improve our services and support health research and quality improvement;
- communicate with you about updates, features, or support;
- send you reminders, technical notices, security alerts, and information requested by you;
- meet our legal, safety, and regulatory obligations;
- de-identify your personal information, which may then be used and disclosed for research purposes and/or on a commercial basis as described in this Privacy Policy;

We will never sell your personal information or use your personal health data for advertising.

## 3. To whom do we disclose your personal information?

We use your information only for the purposes outlined above. We may share it:

- with your treating team if you choose to share;
- with trusted service providers (e.g., secure cloud hosting, analytics) under strict agreements;
- with the CCCare Platform if you are using the App in conjunction with the CCCare Platform;
- with the CCCare Clinical Quality Registry and the global research database which CCCure is a partner to, **only with your consent**, and typically in **de-identified form**;
- with other persons, including government agencies, regulatory bodies and law enforcement agencies, or as required by law, or where necessary to protect someone's life, health, or safety;
- with our employees and related bodies corporate;
- with our professional advisers, dealers and agents.

We may also share or license **de-identified or aggregated information** (data that does not reasonably identify you) with research organisations, healthcare providers, or industry partners. This is always done to **improve care, advance research, and support the sustainability of CCCure which is a registered charity**. If you do not want your de-identified or aggregated information to be shared with such third parties, you can opt out of this at any time by contacting us using the details set out below.

<https://c-c-cure.org/contact>

## 4. Legal basis for using your personal information

For those in the EEA, under the GDPR, we are only permitted to use your personal information if we have a legal basis for doing so. We process the personal data listed in this Privacy Policy on the basis that:

- you have given us your clear consent to do so; and / or
- it is necessary in order to enter into a contract with you.

## 5. Disclosure of personal information outside of Australia or New Zealand

Some service providers (eg, data storage providers) may be located outside Australia or New Zealand. If we transfer information overseas, we take reasonable steps to ensure your data is protected in line with the APPs and IPPs, and the GDPR. In the case of restricted transfers outside of the UK/EEA, we will ensure that these are covered by an appropriate transfer mechanism.

## **6. Using our App and cookies**

We may use 'cookies' or other similar tracking technologies on our App that help us track your App usage and remember your preferences. Cookies are small files that store information on your computer, TV, mobile phone or other device. They enable the entity that put the cookie on your device to recognise you across different websites, services, devices and/or browsing sessions. You can disable cookies through your internet browser but our App may not work as intended for you if you do so.

## **7. Data Security**

We may hold your personal information in either electronic or hard copy form. We take appropriate measures to protect your information from misuse, interference and loss, as well as unauthorised access, modification or disclosure and we use a number of a number of physical, administrative, personnel and technical measures to protect your personal information, including:

- Encryption in transit and at rest.
- Multi-factor authentication
- Role-based access controls.
- Security monitoring and audit logs.
- Secure destruction or de-identification when data is no longer required.

However, we cannot guarantee the security of your personal information.

## **8. Links**

Our App may contain links to websites operated by third parties. Those links are provided for convenience and may not remain current or be maintained. Unless expressly stated otherwise, we are not responsible for the privacy practices of, or any content on, those linked websites, and have no control over or rights in those linked websites. The privacy policies that apply to those other websites may differ substantially from our Privacy Policy, so we encourage individuals to read them before using those websites.

## **9. Accessing or correcting your personal information**

You can access the personal information we hold about you by contacting us using the details set out below. Sometimes, we may not be able to provide you with access to all of your personal information and, where this is the case, we will tell you why. We may also need to verify your identity when you request your personal information.

If you think that any personal information we hold about you is inaccurate, please contact us via <https://c-cure.org/contact> and we will take reasonable steps to ensure that it is corrected.

You also have rights under the APPs and IPPs, and the GDPR to:

- access a copy of your personal information;
- request corrections to your information;
- delete your account and your personal information (subject to legal retention requirements);
- restrict the processing of your personal information in certain circumstances;
- object to the processing of your personal information in certain circumstances; and
- request the transfer of your information to another organisation.

You may also withdraw your consent to us processing your personal data at any time by contacting us via <https://c-cure.org/contact>

## 10. Making a complaint

If you think we have breached the Privacy Act, or you wish to make a complaint about the way we have handled your personal information, you can contact us using the details set out below. Please include your name, email address and/or telephone number and clearly describe your complaint. We will acknowledge your complaint and respond to you regarding your complaint within a reasonable period of time. If you think that we have failed to resolve the complaint satisfactorily, we will provide you with information about the further steps you can take.

You can also raise a complaint with your local privacy regulator if you are not satisfied with our response by contacting us via <https://c-c-cure.org/contact>.

## 11. Retention & Deletion

- Identifiable App-level information is retained only as long as necessary to provide our services or meet legal obligations (generally up to seven years after your last use, or until age 25 if collected when you were a minor).
- You may delete your account at any time within the App. Personal data stored in the App will be securely erased within 30 days unless required by law.
- If you have clinical data recorded in the CCCare Platform as part of your treatment at a participating hospital, that information forms part of your official medical record. Deleting your App account will not remove this clinical data, as hospitals and registries are legally required to retain health records for defined periods (for example, at least seven years, or until age 25 for minors).
- Where possible, CCCare may de-identify linked data for research or benchmarking if you withdraw from the App, but your clinical record remains governed by your treating hospital's obligations.
- De-identified or aggregated data may continue to be used for research, quality improvement, or benchmarking to improve care and support the sustainability of the CCCare Platform.

## 12. Children's Privacy

We recognise that many children and young people live with IBD.

- If you are **under 16**, you must have the consent and supervision of a parent or legal guardian to use the App.
- Parents/guardians may exercise rights of access, correction, or deletion on behalf of their child.
- If we learn that we have collected information from a child under 16 without parental consent, we will take steps to delete it.

## 13. Breach Notification

If your personal information is involved in a data breach likely to cause serious harm, we will notify you promptly and inform the relevant regulators (OAIC in Australia and OPC in New Zealand or the relevant data protection supervisory authority if outside AU/NZ).

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## 14. Contact Us

For further information about our Privacy Policy or practices, or to access or correct your personal information, or make a complaint, please contact us via <https://c-c-cure.org/contact>

You also have the right to complain to:

- The **Office of the Australian Information Commissioner (OAIC)** – [www.oaic.gov.au](http://www.oaic.gov.au)
- The **Office of the Privacy Commissioner (New Zealand)** – [www.privacy.org.nz](http://www.privacy.org.nz)
- Or your relevant local authority if outside AU/NZ.

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