

MyGut Privacy Policy

Last updated: October 19 2020

1. Personal Information: Our Commitment

Crohn's and Colitis Canada (CCC) recognizes the importance of protecting the personal information (including personal health information) that it receives and manages and the privacy of the individuals to whom it relates. CCC values the trust placed in us by individuals who provide or otherwise permit us to collect and use their personal information, and recognizes that maintaining this trust requires us to be transparent and accountable for how we treat personal information.

This Privacy Policy describes the personal information that CCC collects electronically through its application, MyGut (also referred to in this policy as the "App") and how we manage that information. This policy does not apply to any other collection, use or disclosure of personal information by CCC or any third party, including by individuals and healthcare providers, as described below.

Individuals registered to use MyGut ("Participants") may permit their healthcare provider ("Provider") access to their MyGut account, which gives the Provider access to the Personal Information in the Participant's account. The access permits Providers to use MyGut to collect personal health information ("PHI") from and disclose PHI to their Participant/patients. By consenting to their Provider having access to their MyGut account, Participants are consenting to CCC using their Personal Information to send an alert by email to their Provider when they add information to their MyGut account. CCC makes MyGut available for this purpose as a service to Participants and their Providers pursuant to terms and conditions to which all users of the App – Participants and Providers – must comply. Participants considering permitting their Provider access to their MyGut account need to consider the following. **CCC IS NOT RESPONSIBLE FOR THE COLLECTION, USE OR DISCLOSURE OF PHI BY AND BETWEEN PARTICIPANTS AND THEIR PROVIDER THROUGH THE APP. PROVIDERS ARE RESPONSIBLE FOR THE MANAGEMENT OF PHI THAT THEY COLLECT AND DISCLOSE THROUGH MYGUT. THE LAW GOVERNING SUCH COLLECTION AND DISCLOSURE, AND THE USE OF PHI BY A PROVIDER, IS THE LAW APPLICABLE TO THE PROVIDER.** Participants are not required to permit access to their MyGut account to their Provider and do so **AT THEIR OWN RISK**. Participants must direct any complaint or concern about a Provider's collection, use or disclosure of PHI through the App to the appropriate regulator, such as the Provider's professional college and/or the Information and Privacy Commissioner of Ontario. CCC WILL NOT INTERVENE IN NOR ADJUDICATE ANY DISPUTE BETWEEN A PARTICIPANT AND HIS/HER PROVIDER. CCC will terminate the access of a Provider on written direction from a Participant but such termination does not affect PHI collected and disclosed up to the date of termination.

CCC may amend this policy from time to time. CCC will post the date of any amendments above. Please confirm whether the policy has been amended prior to entering personal information into MyGut as by doing so, you will be understood to be consenting to the collection, use and retention of the information in accordance with the amended policy.

In this policy, "Personal Information" is information about an identifiable individual. This includes information such as name, age, gender, health indicators and status, personal email address and year of birth.

2. MyGut

MyGut is a mobile application through which individuals living with Inflammatory Bowel Disease (IBD) who choose to become Participants provide historical and current information related to their diagnoses, symptoms, treatment decisions, and daily activities to CCC or to CCC and their Provider. Participants disclose their information to CCC or CCC and Providers by entering it into the App. Individuals must register to use MyGut and agree to its terms and conditions of use. CCC uses Personal Information provided by Participants for the purposes described in section 4 below, which include research into IBD. Providers are restricted to

collecting information through MyGut for the purpose of providing healthcare to Participants, but as above, once collected, the Personal Information is in the custody of the Provider and its use within the Provider's control.

3. What information does CCC collect from Participants?

- a. CCC will collect the following information from Participants, one time only upon registration for a MyGut account: their email address; year of birth; gender; weight and height; highest completed level of schooling; and province or territory of residence. CCC will also collect baseline quality of life scores and baseline health status scores the first time the Participant completes the questionnaire. These questionnaires are also sent every two weeks and are listed in section C of this policy. Providers given access to a Participant's account may update his/her scores.

- b. CCC will collect the following clinical and healthcare information from Participants every six months:
 - Their most recent IBD diagnosis, and the year in which they were diagnosed with IBD
 - Their current and previous experiences with symptom flare-ups
 - Their use of cigarettes, tobacco and cannabis products
 - Information regarding the different types of healthcare providers which are currently involved in their treatment of IBD. Participants are discouraged from disclosing the names of their healthcare providers to CCC unless for the purpose of permitting a Provider access to the Participant's MyGut account
 - Information regarding their history of symptom onset and diagnosis of IBD, patterns and severity of symptoms, and any time spent in hospital
 - Information regarding their involvement in treatment decisions
 - Information regarding their current and historical medication prescription and usage

- c. CCC will collect the following information about outcomes from Participants every two weeks:
 - The nature of their current treatment
 - Their experiences with controlling IBD, and the usefulness of their current treatment
 - Their experience with physiological and psychosocial symptoms and side effects
 - Their current needs and their plans for future changes in treatment
 - Their health status scores based on the Harvey-Bradshaw Index, Short Inflammatory Bowel Disease Questionnaire (SIBDQ), and the partial Mayo disease activity index
 - Their utilization of hospital emergency departments and hospitalization events
 - Their quality of life scores based on the short inflammatory bowel disease questionnaire

- d. The following information will be collected as often as Participants wish to provide it:
 - Information regarding their daily schedules and activities such as sleeping, eating, physical exercise, and restroom usage

4. How does CCC protect Personal Information it collects through MyGut?

CCC employs safeguards to protect the information that Participants provide. We have security measures and tools in place to help protect against the theft, loss, unauthorized collection, use and disclosure and alteration of the information held in MyGut. Technical access controls are designed to allow only authorized individuals to access the systems that hold this information, and we train our employees to maintain the confidentiality of this information and the privacy of the individuals to whom it relates. CCC also protects Participant privacy by limiting the information that we collect and by removing their information from CCC's database when a Participant withdraws from MyGut as described in Section 7 below. Participant information is also stored in Canada and protected by Microsoft Azure's Privacy Policy and Terms of Use. As well as, Apple and Android's privacy policy and terms of use.

Notwithstanding the protective measures CCC has in place, no method of transmitting or storing information in electronic form is completely secure. As a result, CCC cannot guarantee the security of any information

Participants provide to us through or in connection with MyGut. In the unfortunate event of a data breach, we will inform the affected Participants. CCC may provide such notification by email.

5. How do Participants access or change their Personal Information stored in MyGut?

Participants may change the information in their profile in MyGut at any time. Upon written, verifiable request, CCC will inform individuals of whether it has their Personal Information in its records.

6. How do Participants withdraw from Participating in MyGut?

Participants may remove their Personal Information from MyGut if they no longer wish to use the App. Participants erase their information from MyGut by deleting their account. This functionality is available in the Account Settings menu. When a Participant deletes his/her account, CCC removes his/her Personal Information from CCC's active user databases, but the information may stay in backup storage for up to 30 days before it is completely removed or destroyed. Any information collected prior to withdrawal from MyGut may still be used by CCC in de-identified or aggregate form for the purposes described in this policy. Since the information is no longer linked to a Participant, CCC cannot extract it from its de-identified or aggregated information holdings.

7. Who can Participants contact at CCC if they have questions or concerns about MyGut?

CCC has a privacy officer responsible for overseeing its collection, use, disclosure and protection of Personal Information collected from Participants. Participants should contact mygut@crohnsandcolitis.ca with any questions or concerns about this policy, CCC's management of Personal Information, or CCC's management of their Personal Information in particular including any requests for access to or the correction of their Personal Information.

TO REGISTER AND BECOME A MYGUT PARTICIPANT YOU MUST ACKNOWLEDGE THAT YOU HAVE READ, UNDERSTOOD AND AGREE TO THIS POLICY.