

STANFORD UNIVERSITY Research Information Sheet

Protocol Director: Dr. Ann Ming Yeh

IRB Use Only

Approval Date: December 14, 2020

Expiration Date: (Does not Expire)

Protocol Title: Positive Psychological Resources in Youth with Inflammatory Bowel Disease

The following information applies to the participating adult or adolescent. If the participant is a child or ward, the use of “you” refers to “your child” or “your ward.”

DESCRIPTION: You are invited to participate in a research study for adolescents and young adults who have Inflammatory Bowel Disease (IBD). The goal of this study is to better understand how psychological factors impact IBD health and quality of life. This study is interested in learning how characteristics such as positive mood, self-compassion, and mindfulness can affect one’s health. You will be asked to complete an anonymous online survey with questions pertaining to your emotions, thoughts, COVID-19 coping and IBD health. This information can help inform the development of psychological treatments that support the mental and physical health of individuals with IBD.

TIME INVOLVEMENT: Your participation will take approximately 15 minutes.

RISKS AND BENEFITS: The risks associated with this study are possible discomfort from answering some of the survey questions. You are free to not answer specific survey questions or withdraw from the study at any time. The possible benefits of this study include the creation of future psychological treatments that better support the mental and physical health of adolescents and young adults with IBD. We cannot and do not guarantee or promise that you will receive any benefits from this study. Your decision whether or not to participate in this study will not affect your medical care and/or membership in the Improve Care Now (ICN) network.

PAYMENTS: You will not be paid to participate in this study.

PARTICIPANT'S RIGHTS: If you have read this form and have decided to participate in this project, please understand your participation is voluntary and you have the right to withdraw your consent or discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled. The alternative is not to participate. You have the right to refuse to answer particular questions. The results of this research study may be presented at scientific or professional meetings or published in scientific journals. Your individual privacy will be maintained in all published and written data resulting from the study.

CONTACT INFORMATION:

Questions: If you have any questions, concerns or complaints about this research, its procedures, risks and benefits, contact the Protocol Director, Dr. Ann Ming Yeh at 650-723-5070. You can also contact Dr. Anava Wren with study-related questions at 650-723-5070.

Independent Contact: If you are not satisfied with how this study is being conducted, or if you have any concerns, complaints, or general questions about the research or your rights as a participant, please contact the Stanford Institutional Review Board (IRB) to speak to someone independent of the research team at 650-723-5244 or toll free at 1-866-680-2906. You can also write to the Stanford IRB, Stanford University, 3000 El Camino Real, Five Palo Alto Square, 4th Floor, Palo Alto, CA 94306.

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Authorization To Use Your Health Information For Research Purposes

Because information about you and your health is personal and private, it generally cannot be used in this research study without your authorization. This form is intended to inform you about how your health information will be used or disclosed in the study. Your information will only be used in accordance with this authorization form and the informed consent form and as required or allowed by law. Please read it carefully before giving authorization and then proceed with the one-time online survey.

What is the purpose of this research study and how will my health information be utilized in the study?

Inflammatory Bowel Disease IBD is a chronic inflammatory condition that can impact children and adolescents' psychological and physical wellbeing. There is preliminary evidence supporting the notion that positive psychological resources such as mindfulness can play a protective role for pediatric patients experiencing psychological distress and inflammatory processes, and help build resources that improve their overall wellbeing.

Investigators hope to examine the relationship between positive psychological resources (e.g., acceptance) and stress, mood, disease activity, and quality of life in a sample of adolescents and young adults with IBD. The purpose of the study is to examine the relationship between psychological factors and IBD-related outcomes through a selection of questionnaires among youth and young adults with IBD.

No personal health information will be collected. Interested and eligible participants will just complete the one-time online survey. The results of the study will be published but no information that would possibly identify any participants will be included.

Do I have to give my authorization?

You do not have to give your authorization. But if you don't, you will not be able to participate in this study.

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If you wish to participate in the study, please give your authorization by clicking, 'I agree' at the end of this form.

If I give authorization , can I revoke it or withdraw from the research later?

If you agree to participate first, you are free to withdraw your authorization regarding the use and disclosure of your health information (and to discontinue any other participation in the study) at any time. After any revocation, your health information will no longer be used or disclosed in the study, except to the extent that the law allows us to continue using your information (e.g., necessary to maintain integrity of research). If you wish to revoke your authorization for the research use or disclosure of your health information in this study, you must write to: Dr. Ann Ming Yeh, 725 Welch Rd, Palo Alto, CA 94304.

What Personal Information Will Be Obtained, Used or Disclosed?

The research team will may have used internally for recruitment only: MRN, DOB, name, email address, home address, telephone numbers, and IBD diagnosis. The information that the study collects will be limited to the least amount of information needed to accomplish the purpose of the research such as information about psychological state, thoughts, feelings, or behaviors related to COVID-19 and IBD. This one time online survey will collect demographic information but no identifiers will be collected, or disclosed.

Who May Use or Disclose the Information?

The following parties are authorized to use and/or disclose your health information in connection with this research study:

- The Protocol Director Dr. Ann Ming Yeh
- The Stanford University Administrative Panel on Human Subjects in Medical Research and any other unit of Stanford University as necessary
- Research Staff

Who May Receive or Use the Information?

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The parties listed in the preceding paragraph may disclose your health information to the following persons and organizations for their use in connection with this research study:

- The Office for Human Research Protections in the U.S. Department of Health and Human Services

Your information may be re-disclosed by the recipients described above, if they are not required by law to protect the privacy of the information.

When will my authorization expire?

Your authorization for the use and/or disclosure of your health information will end on December 31, 2045 or when the research project ends, whichever is earlier.

Please print a copy of this page for your records.

If you agree to participate in this research, please indicate this to the researcher by clicking 'I agree' and proceed to complete the survey.