



**James
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Alliance**

Priority Setting Partnerships

Digital Technology for Adolescents and Young Persons with Inflammatory Bowel Disease Priority Setting Partnership - Survey 1

There are three sections to this survey

Section 1

This asks about who you are to help us understand your role and how you're connected with IBD.

Section 2

We would like you to ask questions about the use of digital technology in two broad areas. You may wish to focus on just one area or both:

- 1. Questions about digital technologies to support your condition and have the potential to improve IBD care.**

2. Questions about the use of digital technologies to improve communication with your healthcare team.

Section 3 (optional)

This asks for additional background information about you to help us understand who you are and to ensure that we have captured a range of different experiences. These answers will not be linked to your responses in sections 1 and 2.

Section 1: About You

It is important to know who you are and how you are connected to IBD.

Which of the following describes you best?

- I am an adolescent or young person with IBD
- I am a parent or have experience as a carer of an adolescent or young person with IBD
- I am a family member of an adolescent or young person with IBD
- I am a friend of an adolescent or young person with IBD
- I am a healthcare professional who looks after adolescents or young persons with IBD
- I am a member of an organisation or charity representing persons with IBD
- Other (please specify):

Section 2: Your Questions

Please write down up to three questions that you would like to see answered specific to the use of digital technology for IBD. This can be in the form of a sentence or a question. You do not have to fill in all of the sections if you don't want to.

Please focus on the use of digital technology for IBD in two broad areas. You may wish to focus on just one area or both:

1. Questions about digital technologies to support your condition and have the potential to improve IBD care. These technologies help your

healthcare team with making decisions about diagnosis, treatment and clinical care. They may also help you self-manage IBD, promote healthier ways of living and monitor your progress. *Examples include mobile apps that record your symptoms and disease activity or provide information.*

2. Questions about the use of digital technologies to improve communication with your healthcare team. These technologies help to improve the two-way communication between you and the health professionals who look after you. *Examples included instant messaging portals and video consultations that link you to healthcare teams.*

Please click here to view example questions. (<https://cypmedtech.nihr.ac.uk/wp-content/uploads/2022/01/PSP-Example-Questions-First-Survey.png>)

My first question/comment

My second question/comment

My third question/comment

Please write down any other questions/concerns in the box below if you'd like to.

Section 3: Additional Information About You (optional)

This question is optional but it is important to understand who is filling out the form to ensure that we have collected views from a range of people with varied experiences. These details will not be analysed in relation to the answers you have provided in the previous two sections of this survey.

What is your age?

- <16
- 16-25
- 26-39
- 40-59
- 60-79
- 80+
- I prefer not to say

Which of the following best describes your gender?

- Boy/man
- Girl/woman
- Non-binary
- I prefer not to say
- I prefer to self-describe (please specify):

What is your ethnic group?

- Asian or Asian British - Bangladeshi
- Asian or Asian British - Chinese
- Asian or Asian British - Indian
- Asian or Asian British - Pakistani
- Black/African/Caribbean/Black British - African
- Black/African/Caribbean/Black British - Caribbean
- Mixed/Multiple ethnic groups - Asian and White
- Mixed/Multiple ethnic groups - Black Caribbean and White
- Mixed/Multiple ethnic groups - Black African and White
- White - English/Welsh/Scottish/Northern Irish/British
- White - Gypsy or Irish Traveller

- White - Irish
- Any other ethnic group - Arab
- I prefer not to say
- Any other ethnic group (please specify):

Where do you live?

- England
- Wales
- Scotland
- Northern Ireland
- I prefer not to say
- Other (please specify):

Would you like to help us with the next step?

Once the survey has closed, we would like to get back in touch with the people who completed this survey for help with collating research questions into order of importance or urgency. Your contact details will not be analysed in relation to the answers you have provided in this survey.

If you would like to take part in this stage, please add your contact details below.

If you are under 16 years old and would like to take part in the next stage, please ask a parent or guardian to put their details below.

Name

Address

Email

Are the details above a parent or guardian's?

- Yes
- No

If yes, what is your child's name?

Thank you for completing the survey.

What happens after the survey?

We will look at all the questions that have been asked in the survey and check that they align with this project. For the questions that have not been answered already by research, we would welcome you to help us put these into order of priority. Please leave your contact details on the previous page if you wish to be involved in this part. Finally, we will come up with a list of the top 10 research priorities which will be publicised to researchers and organisations that fund IBD research.

Contact details

If you have any questions or would like any further information, please contact us using the details below.

Website: <https://cypmedtech.nihr.ac.uk/digital-technology-ibd-bsp/>

(<https://cypmedtech.nihr.ac.uk/digital-technology-ibd-bsp/>**)**

Email: cypmedtech@nihr.ac.uk (<mailto:cypmedtech@nihr.ac.uk>)

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