IBD BOOST
Living well with Crohn's & Colitis

The IBD-BOOST Survey

We are inviting you to take part in a research study. Before you decide, it is important that you know why we are doing the study and what is involved. Please read the following information carefully.

What is the purpose of the study?
The purpose of our study is: (1) to find out how many people with Inflammatory Bowel Disease (IBD, including Crohn's disease and ulcerative colitis) experience fatigue, pain and urgency, (2) to find out how many want help managing these symptoms. We will later be testing new ways of managing these symptoms (not part of this survey).

Why me?
You have been invited to participate in this study because you have a diagnosis of Crohn's disease, ulcerative colitis or another type of IBD.

If I take part what will happen?
If you agree to take part you will be asked to complete a survey which will take about 20 minutes.
Please complete the survey, even if you don't have any symptoms!

What happens if I am experiencing symptoms and want support?
If you complete the survey and want to continue taking part in the next stage of our study, then you might be offered a new way of managing these symptoms or you might not (we may not be able to include everyone). This is separate from this survey.

If you do not wish to participate further but want help for your symptoms, please speak to your GP or IBD team. More support and information can also be found at the Crohn's & Colitis UK website: www.crohnsandcolitis.org.uk .

What will happen if I want to withdraw from this study?
You are free to withdraw yourself from the study at any time without giving a reason. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information at www.hra.nhs.uk.

What if there is a problem?
It is very unlikely that this survey would cause you any harm. If you have a concern or a complaint about any aspect of this study, please speak to us and we will do our best to answer your questions. Please contact *[insert name]* on *[insert telephone number & email*]. If you remain unhappy, you can make a formal complaint through the NHS complaints procedure. Details can be obtained through the

Patient Advisory Liaison Service at your hospital or at London North West University Healthcare NHS Trust who can be contacted at LNWH-tr.PALS@nhs.net.

Will my taking part in this study be kept confidential?

King's College London (KCL) and the Pragmatic Clinical trials Unit Queen Mary's University of London (PCTU) are working in partnership with London North West University Healthcare NHS Trust (LNWUH).

LNWUH is the sponsor for this survey based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. KCL and the PCTU on behalf of LNWUH will securely collect identifiable information for the purpose of this study.

The research team will keep your name and contact details confidential and secure. The research team will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from LNWUH and regulatory organisations may look at your medical and research records to check the accuracy of the research study. LNWUH will only receive information without any identifying information unless you are a patient of LNWUH. The people who analyse the information will not be able to identify you and will not be able to find out your name, or contact details.

LNWUH and The research team will keep identifiable information about you from this study until the end of IBD-BOOST programme in November 2022. The research team will keep non-identifiable information about you from this study for 10 years after the study has finished.

Will you share my data?

The information collected about you will be used to support other research in the future, and may be shared anonymously with other researchers. If you have been approached via the IBD BioResource, we will also ask your permission to share your data to support future research on IBD. If you agree, we would like to pass on your survey responses to add to the information held on the IBD BioResource database.

What will happen to the results of the research study?

The results will be published in a scientific journal so that other people know about it. A summary of the results will be published on the Crohn's & Colitis UK website www.crohnsandcolitis.org.uk .

Who is organising and funding the research?

Professor Christine Norton is leading an experienced team of doctors, nurses and researchers. The study is being funded by the National Institute of Health Research (NIHR) through their Programme Grants for Applied Research.

Who has reviewed this research?

This study has been reviewed and given favourable opinion by North West - Greater Manchester West Research Ethics Committee (Reference: 18/NW/0613) and has approval from the Health Research Authority.

If you would like further information before deciding to participate, please contact:

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