

Crohn's and Colitis UK Readers Panel

Why we have a Readers Panel

At Crohn's and Colitis UK we provide information and support for anyone affected by Inflammatory Bowel Diseases (IBD), especially Crohn's Disease or Ulcerative Colitis. We have a wide range of publications on a number of topics, and we are an accredited member of the Information Standard scheme. This means we have been through a rigorous assessment to make sure the information we produce is clear, accurate, impartial, evidence-based, and up-to-date.

As we write or review each of our publications we consult with our medical advisers and other professionals. We also need to know what the people who will use our information - people with IBD, their families and friends - might think of it. This is why we have set up a Readers Panel made up of Crohn's and Colitis UK members and other volunteers.

The role of readers on our Panel

The main purpose of the Readers Panel is to provide feedback on the clarity and coverage of our information sheets and booklets from a reader's point of view. So we ask, for example:

- Is this information clear and easy to read?
- Are any sections unclear or confusing? If so which and in what way?
- Are the style and tone appropriate for the intended audience?
- Does the information use jargon or medical/scientific terms without sufficient explanation? If so, where?
- Does it cover the points you would expect?
- Has it left out anything important, something that you feel should be included? If so, what?
- Do you feel this leaflet or booklet will be useful for people looking for information on this topic? If not, why not?
- Are there any other changes or improvements you would like to suggest, based on your expectations or experience as someone with IBD?

This is not a writing, editing, or proofing role, so we don't ask our readers to comment on the grammar or punctuation, or the typing errors, unless they affect the sense.

How the Readers Panel works

If you join our Panel we will contact you by email and send you a draft of the information sheet or booklet we are seeking comments on, together with a Reader Comments sheet. You would then read the draft, answer the questions, add any other comments you would like to make, and send it back to us at Crohn's and Colitis UK. We will let you know when we would like it back by - usually it's within 2-3 weeks. We also ask you to let us know as soon as possible if you can't send back any comments, so we can ask someone else.

Readers Panel Agreement

If you would like to join our Panel, please complete this Readers Panel Agreement and Conflict of Interest Declaration and return it to publications@crohnsandcolitis.org.uk. Thank you.

About you

To help us send you the most appropriate publications to review, we'd like to know a little more about you. The information you provide will only be used for this purpose.

When reviewing our information you may wish to provide a quote to help us give emphasis to the patient's voice within our publications. If you decide to do this, your first name, age, condition and diagnosis date will appear alongside this quote. We will always ask for your consent to share this information for each quote you provide before including it in a publication.

Name:

Email address:

If you are not the person with IBD, but a relative or friend, and still wish to be a member of our Readers Panel, please state your relationship to the person with IBD here:

If this is the case, please answer the following questions on behalf of the person with IBD.

Which condition do you have?

- Crohn's Disease
 Ulcerative Colitis
 IBD unclassified/indeterminate
 Other - please specify:

Approximately how long ago was it diagnosed?

Are you on (or have you had within the last year) any of the following medications?

- | | |
|---|---|
| <input type="checkbox"/> Azathioprine or Mercaptopurine | <input type="checkbox"/> Infliximab (Remicade) |
| <input type="checkbox"/> Steroids such as Prednisolone | <input type="checkbox"/> Adalimumab (Humira) |
| <input type="checkbox"/> Methotrexate | <input type="checkbox"/> 5-ASA drugs such as mesalazine (Asacol, Pentasa, Salofalk) |
| <input type="checkbox"/> Vedolizumab (Entyvio) | |
| <input type="checkbox"/> Other - please specify: | |

<p>Have you had surgery for your IBD within the last 5 years?</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>
<p>Are you:</p>	<p><input type="checkbox"/> Male <input type="checkbox"/> Female</p>
<p>Which age group are you?</p>	<p><input type="checkbox"/> 16-20 <input type="checkbox"/> 21-35 <input type="checkbox"/> 36-59 <input type="checkbox"/> 60+</p>
<p>Do you have any children under 18? If so, please share their ages. If any of them have IBD please also tell us which condition it is:</p>	
<p>Do you work as a health professional, or in journalism, PR, marketing, advertising or research? Have you any other professional qualifications or experience that you feel could be relevant to the Readers Panel role? If yes, please give details:</p> <p>If you work, but not in the areas mentioned above, please give details of your occupation:</p>	
<p>Membership</p>	
<p>If you are a Crohn's and Colitis UK member, please share your membership number (if known):</p>	

Please continue to the Conflicts of Interest Declaration on the next page.

Conflicts of Interest Declaration

We ask all reviewers to complete a Conflicts of Interest Declaration.

Under our Conflict of Interest Policy a conflict of interest might exist if a reviewer has any financial or personal relationships or other interests that may inappropriately influence or bias his or her actions. These include:

- Financial relationships - such as employment, consultancies, grants, royalties, honoraria, paid expert testimony or stock ownership or options
- Personal relationships - such as a mentor, former student, fellow or relative
- Academic, political, or religious interests

<p>Thinking of your role as a reader, where you are being asked to comment on information about IBD and its treatment, do you have any conflict of interest as defined in Crohn's and Colitis UK's Policy?</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not sure</p>
<p>If you have answered Yes or Not sure, please give brief details of the relationship or interest:</p>	
<p>Full name and/or Signature:</p>	<p>Date:</p>