

### Responding to queries via email and social media

It sounds obvious, but it is important that enquirers understand what you are telling them and that any links you provide are correct. Avoid using jargon and double check your message before hitting send. When mentioning the Charity please use Crohn's & Colitis UK and not CCUK as not everyone will understand what this acronym means and is not how we externally talk about the Charity as acronyms reduce awareness.

If you require support from a fellow volunteer in responding to a query, as for example the query relates to an event they are organising, please do not forward the email onto them without first getting permission from the enquirer. You can also just copy and paste the content into a separate email/message. The key point is that their email address or other contact details should not be passed on without the enquirers explicit consent.

Where the supporter needs to contact the Charity, we can solve these issues quicker if you ask them to contact us directly instead of you contacting us on their behalf. If you are unsure which department to signpost them to please ask them to contact our Helpline Team via email at [helpline@crohnsandcolitis.org.uk](mailto:helpline@crohnsandcolitis.org.uk) or call 0300 222 5700.

Enquirers will find it a lot easier to find the information they need if you include links to the Crohn's & Colitis UK website or any relevant pages in message, as well as the correct numbers for the Helpline. You will find example text for signposting enquiries below.

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## Data Protection

Everyone in the UK has the right to have information about them (personal data) kept safe and only used for the purpose that they have supplied it. Crohn's & Colitis UK is registered as a Data Controller to hold people's data in accordance with rules laid down by parliament and any breach of this puts us at risk of serious fines.

### What does this mean for answering enquiries?

- Any other information given by the enquirer must not be disclosed to anyone outside our organisation without the enquirer's specific permission.
  - This also means it must not be copied into any other email account or system even within the organisation without it being clear why we have it.
  - A useful way of contacting a number of people with the same enquiry, or interest in the same event, is to put all their email addresses in as blind copied to the email account you are using. This means they will not have access to others' addresses and replies will always come back to you.
- Any information divulged must be kept only for as long as the enquiry is being dealt with. After that this information should be deleted to avoid accidental misuse of the data. It is good practice to let the enquirer know that their enquiry has been closed and will only be held on file for a month in case they wish to reopen it, after one month the record will be deleted.

You can find out more by reading our [Data Protection policy](#).

## Research Study & Advertising Enquiries

Occasionally researchers, hospitals and local companies contact Local Networks to request support with their studies or product/services development.

To make sure only appropriate and ethical opportunities get promoted by our Local Networks, and to increase the number of opportunities the Charity promotes, please pass these enquiries onto the relevant teams below and only promote opportunities that are listed on our website at [Research Involvement Opportunities](#) and [Patient Engagement](#).

If a researcher or academic contacts your network asking you to promote their take part in research opportunity please direct them to our [Information for Researchers](#) and forward their email onto [researchinvolvement@crohnsandcolitis.org.uk](mailto:researchinvolvement@crohnsandcolitis.org.uk), who will be happy to discuss this further with them. If the opportunity meets our criteria, we will list it on our website [here](#).

If a local hospital or Clinical Commissioning Group (CCG) contacts you to promote opportunities they have in local services, and example of this could be a focus group to develop a new pathway, please forward them onto [patientengagement@crohnsandcolitis.org.uk](mailto:patientengagement@crohnsandcolitis.org.uk), who will be happy to discuss this further with them. If the opportunity meets our criteria, we will list it on our website [here](#).

Once the opportunity is on the website, the Research or Patient Engagement Team will contact the network, so they can promote it locally on social media, at events and in newsletters.

Always refer to the guidance in the [Advertising Policy](#) before responding, which states the advertising we would not do. If you are at all unsure about a request, please contact the Volunteering Team or we would suggest that the Network declines to participate.

## Example content to use for common signposting enquiries

We have provided some example text you can include in your email response to signpost people to the relevant services or information.

### How to join the network's mailing list

As a Network do not hold or maintain a mailing list. This is because we only communicate via email or post to members of Crohn's & Colitis UK using contact data held centrally by the Charity. If you are a member of Crohn's & Colitis UK and live within the network's area, you will receive information about our events, as and when they take place.

If you are currently not a member you can join Crohn's & Colitis UK (*SEE TEXT BELOW*) or you can find local events within your area on our webpage: [www.crohnsandcolitis.org.uk/events](http://www.crohnsandcolitis.org.uk/events)

### How to volunteer

Our 50 Local Networks operate across the UK bringing local people affected by Crohn's and Colitis together and raising awareness of the conditions with members of the public. From educational talks to social events, we help give people the comfort and confidence to live freer and fuller lives. And together, we can make our voice heard. There are plenty of ways you can give your time and it's very flexible to getting involved. If you would like to find out more about volunteering with us please call 01727 734472 or email [volunteering@crohnsandcolitis.org.uk](mailto:volunteering@crohnsandcolitis.org.uk). You can also enquire here: [www.crohnsandcolitis.org.uk/get-involved/volunteering/local-network](http://www.crohnsandcolitis.org.uk/get-involved/volunteering/local-network)

You can also find out about all of the Charity's other roles here:

[www.crohnsandcolitis.org.uk/volunteer](http://www.crohnsandcolitis.org.uk/volunteer)

### How to become a Crohn's & Colitis UK member

You can join online at [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk) or call the Membership Team on 01727 734465 for an application form.

### How to update membership details

To update your Crohn's & Colitis UK membership details please contact the Membership Team via email at [membership@crohnsandcolitis.org.uk](mailto:membership@crohnsandcolitis.org.uk) or you can call them on 01727 734465.

### How to Fundraise

There is plenty of information on the Crohn's & Colitis UK website on how you can fundraise: [www.crohnsandcolitis.org.uk/get-involved/fundraising/organise-your-own-event](http://www.crohnsandcolitis.org.uk/get-involved/fundraising/organise-your-own-event)

If you wish to fundraise for our Local Network please let the fundraising team know when setting up your JustGiving page to make sure the money is then allocated to our network.

You can contact the fundraising team on 01727 734485 or by emailing [fundraising@crohnsandcolitis.org.uk](mailto:fundraising@crohnsandcolitis.org.uk) for a fundraising pack and help with your ideas.

### How to get a Crohn's & Colitis UK t-shirt

Currently Crohn's & Colitis UK t-shirts are only available to registered volunteers or those fundraising for the Charity. To enquire about getting a t-shirt as a volunteer or a fundraiser please email [helpline@crohnsandcolitis.org.uk](mailto:helpline@crohnsandcolitis.org.uk)

## How to access Information & Support

Crohn's & Colitis UK's website has a wealth of reliable information that may help to answer your questions: [www.crohnsandcolitis.org.uk/about-crohns-and-colitis](http://www.crohnsandcolitis.org.uk/about-crohns-and-colitis)

Crohn's & Colitis UK's helpline is a confidential service providing information and support for anyone by Crohn's and Colitis.

Our team can:

- help you understand more about Crohn's and Colitis, diagnosis and treatment options
- provide information to help you to live well with your condition
- help you understand and access disability benefits
- be there to listen if you need someone to talk to
- put you in touch with a trained support volunteer who has a personal experience of Crohn's or Colitis and understands what you are going through

Contact them by:

Telephone: 0300 222 5700

*Monday to Friday - 9am to 5pm*

Email: [helpline@crohnsandcolitis.org.uk](mailto:helpline@crohnsandcolitis.org.uk)

Live Chat: [www.crohnsandcolitis.org.uk/livechat](http://www.crohnsandcolitis.org.uk/livechat)

## How to access support for Young People and Families

The Crohn's & Colitis UK website has information on local family events and support available for young people and families: [www.crohnsandcolitis.org.uk/support/support-for-families](http://www.crohnsandcolitis.org.uk/support/support-for-families)

## How to deal with Research Study Enquiries

Thank you for your enquiry. We advise you to contact the Crohn's & Colitis UK Research Team who review all research studies for potential addition to the website and/or promotion by Local Networks. The Crohn's & Colitis UK website has lots of useful information about research: [www.crohnsandcolitis.org.uk/research](http://www.crohnsandcolitis.org.uk/research), or you can contact the team on [research@crohnsandcolitis.org.uk](mailto:research@crohnsandcolitis.org.uk).

## How to deal with Patient Engagement Study Enquiries

Thank you for your enquiry. We advise you to contact the Crohn's & Colitis UK Patient Engagement Team who review all studies for potential addition to the website and/or promotion by Local Networks. The Crohn's & Colitis UK website has lots of useful information about Patient Engagement, including tools for hospitals: <https://www.crohnsandcolitis.org.uk/get-involved/patient-engagement>, or you can contact the team on [patientengagement@crohnsandcolitis.org.uk](mailto:patientengagement@crohnsandcolitis.org.uk)

Created: Feb 2020  
Next review: Feb 2021