

The 'Telling My Friends: talking about having Crohn's or Colitis Resource

Summary Report 2019-2020

Background to the resource

The component parts of this resource were developed from the 'Being Me with IBD' study conducted by a multidisciplinary team of researchers and clinicians. The study was funded by [Crohn's & Colitis UK](#). It has been translated into Portuguese by [Doença Crohn/Colite, Portugal](#).

The research team was led by Prof Bernie Carter (Edge Hill University & Alder Hey Children's NHSFT) and Prof Pamela Qualter (University of Manchester).

The other team members were Prof Stephen Allen (Alder Hey Children's NHSFT & Liverpool School of Tropical Medicine), Dr Ali Rouncefield-Swales (Edge Hill University), Dr Lucy Blake (Edge Hill University), Prof Lucy Bray (Edge Hill University & Alder Hey Children's NHSFT), Kay Crook (St Marks & Northwick Park NHS), and Prof Chris Probert (University of Liverpool & Royal Liverpool University Hospital).

At the start of the study we created a short animation, hosted on YouTube that provided an overview of [The Being Me with IBD study](#). The aim was to share details about the study with the wider public as well as it being an additional way of young people learning about the study.

The animation and information sheets

The resource was developed in collaboration with members of our Young Person's Advisory Group, clinicians, teachers and other stakeholders. **The resource is evidence-based and free and downloadable from our website** <https://ehu.ac.uk/crohnsorcolitis>

Using all of the feedback and information gathered from the e-Advisory group, survey, interviews and events, with the help of an expert animator www.misttermunro.co.uk/ we created a short **two-minute animation** for young people, young adults, professionals and other people interested in understanding more about telling friends about living with Crohn's or Colitis.

We also created three information sheets:

1. [How to tell your friends about having Crohn's or colitis](#)
2. [How to support a friend with Crohn's or Colitis](#)
3. [Do you work with children or young people?](#)

CROHN'S & COLITIS UK Edge Hill University

Telling My Friends: talking about having Crohn's or Colitis

Young people with Crohn's or Colitis can find it difficult to tell their friends about their condition.

A free downloadable resource was developed with young people for young people.

This resource aims to help young people to make decisions about who to tell and when and what and how to share information about their condition with their friends.

It also aims to help their friends support them.

ehu.ac.uk/crohnsorcolitis

Alder Hey Children's NHS Foundation Trust | UNIVERSITY OF LIVERPOOL | MANCHESTER 1824 The University of Manchester

NHS London North West University Healthcare NHS Trust | NHS The Royal Liverpool and Broadgreen University Hospitals NHS Trust | LSTM LIVERPOOL SCHOOL OF TROPICAL MEDICINE Since 1888

The first of these (**How to tell your friends**) is aimed at helping young people with Crohn's or Colitis talk to their friends about their condition, if they wish to do so.

It provides advice and tips, with links to the animation and further resources available. There are signposts for an immersive app and a talking toolkit of resources at external sites.



The second (**How to support a friend**) is aimed at young people who are supporting friends who have Crohn's or Colitis. This provides information about the condition and how it may affect their friend.

It suggests appropriate ways to be supportive and contains links and signposts for more information.

The third (**Do you work with children or young people**) is aimed at health care and education professionals so that they can provide better support to young people living with Crohn's or Colitis.

It explains how the condition can affect young people's experience at school and how it can impact their education. It offers advice on how they can help students who are managing the condition, and links to further resources and information.



RCN Endorsement



The resource was endorsed by the RCN on 3rd June 2020. Receiving this endorsement means that the resources meet the Royal College of Nursing's quality criteria for professional standards and are fit for national and UK nursing practice.

Events and engagement

Engagement and tracking impact has been an important part of this work. We have used a range of PPI activities, including a pop-up event in a children's hospital, a patient and public involvement day, an online survey, blogs, social media campaign and other methods to enhance and measure impact.

Telling people about undertaking the study

Right from the start of the study we have been keen to share what we have been doing. We created a short animation about the study to help promote the work we were doing. We also wanted it to be a supplementary way of explaining the study to potential participants.



<https://www.youtube.com/watch?v=wX8Qcev0YyU>

Pop-up event at Alder Hey Children's Hospital

At our event at Alder Hey Children's Hospital in May 2019, we engaged with children, parents, people with IBD and hospital staff. As the event took place in the large atrium, it was seen by approximately 100 people from across the region who were attending or working there.



We used a series of activities to work with children, their parents, members of the public, clinicians, researchers, and other hospital workers to talk about Crohn's and Colitis and our study.

We worked with an illustrator to create a visual record of the day, based on feedback given. This provided important information that was used to help create the resources.



Patient Involvement in Research Day with CCUK (2019)

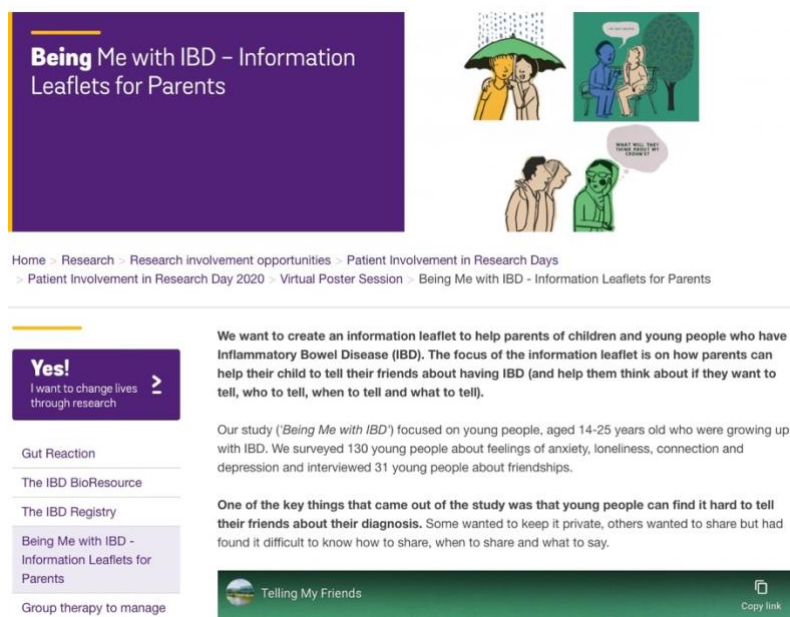
In September 2019, a patient and public involvement day was arranged by Crohn's & Colitis UK (CCUK) in Manchester as part of their education/support events. This engagement activity had attendees from all over the UK, with a potential reach of up to 500 people. We engaged with young people, parents and carers, but also with policy makers, professional health practitioners, third sector organisations and the general public.

We presented the findings of our study. We also engaged with people attending, to gain their ideas about the underpinning ideas (storyboard images, content, language, colours, etc.) we were using in development of our Telling Friends animation. We gained feedback about key content for information sheets. One young man offered to be part of the voiceover of the animation and has provided ongoing advice. The most significant impact outcome from this event was requests about further participation or involvement.

Patient Involvement in Research Day with CCUK (2020)

Due to Covid-19, the 2020 the Patient Involvement in Research Day was held online and the Being Me with IBD team contributed a virtual poster that explained the findings of our study. Via this virtual poster we asked delegates to provide feedback on our ideas for developing a parent information leaflet to support parents of children and young people who have Inflammatory Bowel Disease (IBD) who want to help their child to tell their friends about having IBD. We asked the delegates to respond to these questions:

- What do you think is the key content that we should include in our leaflet?
- What tips would help parents support their child trying to tell their friends about their IBD?
- How do you think a parent could bolster their child's confidence about telling their friends?
- Do you have any other comments about the study?



Being Me with IBD blog

In 2019 we started a blog called **Being Me with IBD: growing up and getting on with my life**. The aim was to raise awareness of the study and the issues experienced by young people with Crohn's or Colitis.



The blog was designed to complement our work on Twitter to engage health and research professionals in the study. A secondary audience was anticipated to be young people with IBD, carers and/or patient groups, supporters/charitable donors, third sector organisations and the general public. As such, its reach is international and by December 2020 over 465 unique visitors accessed the site. The URL link for the blog is <https://blogs.edgehill.ac.uk/ibd/>

The research team have been contributing with posts about the study itself, the background to the work, contributions to initiatives such as Children's Mental Health Week, alongside insights into our on-going research practice. So far, we have created ten posts and will continue to build this aspect of our work.

The most significant impact outcome for this activity has been through requests for further information.

Covid-19 and disruption to formal academic dissemination

With the completion of the animation towards the end of 2019 and the information sheets in early 2020, a series of strategic presentations to clinical and academic colleagues were severely disrupted. Abstracts had been accepted for presentation at:



- **British Pain Society (April 2020, London).** Juggling symptoms: dealing with, concealing and underplaying pain by adolescents and young adults with Inflammatory Bowel Disease (IBD). The original poster abstract was selected to be one of the top six oral presentations at the Annual Scientific Meeting. This meeting was postponed.
- **CCUK Education Event (April 2020, Cambridge).** This invited presentation was to be part of the first Young People and Family Education Programme where we were to present our research and also be part of an expert panel. Meeting cancelled
- **Authenticity to Action: Celebrating Public and Patient Involvement in Health and Social Care Education Conference (April 2020, Preston).** Title of presentation: Animating research: making research something that moves people. This invited keynote aimed to explore the journey about co-developing outputs from research with stakeholders. Conference cancelled.
- **COMET Communication and Medical Ethics Conference (July 2020, Aalborg Denmark).** Two papers were accepted "I don't want to make a fuss...be defined by it": young people's decisions about telling their friends about their IBD and Developing and using animations to disseminate research findings and improve communication about chronic conditions. Conference cancelled but opportunity to submit powerpoint or video of presentation or present the following year in Italy.

Evaluation of the 'Telling My Friends' animation and information sheets

The animation was launched ahead of the information sheets.

We have gathered feedback through an online survey on the resource website, via Crohns and Colitis UK and from Crohn & Colite (Portugal), as well as directly from professionals and practitioners through conversations and emails.

What do you think?

We really want to know what you think about our 'Telling my Friends' resource, [please fill out a short survey](#) and let us know.

We have had some responses to the blogs and very positive feedback via 'quoted' tweets and direct tweet messages, particular in response to the co-ordinated month of twitter activity about the resource.

Feedback via Twitter has been positive with people living with IBD responding to our tweets and emphasising the importance of the work and the need for mental health and well-being to be addressed within consultations.

To date we have had feedback from children, parents and health professionals.

Most of our feedback from young people and parents has come via social media (Twitter, Instagram) directly to our professional Twitter accounts or via the charities we have closely engaged with (e.g., Crohn's and Colitis UK and Crohn e Colite, Portugal).

Feedback from children, young people and parents has been equally positive with some young adults posting tweets that state that they wished the resource had been available when they were younger and struggling with the challenges of making friends.



Typical feedback from young people and parents

It's really helpful and clear – I'm going to share with my friends.

It's hard to know what to do – as a mum I think I should know how to help her – this [resource] is going to help start a conversation with her and that's a good thing.

When I was first diagnosed I couldn't tell anyone – something like this would have helped a lot.

Feedback via the survey has come from healthcare professionals including an IBD consultant, an IBD dietitian, and a behavioural scientist. We have also gained direct feedback from key professionals in various networks when we have been in contact explaining the resource with a view to them recommending and/or distributing through their networks, such as the School and Public Health Nurses Association (SAPHNA).

Feedback from professionals indicates high levels of positivity about the resource which is seen to “fill a gap” about a topic that is not adequately considered or covered. The resource has made many professionals think more clearly about the social impacts of IBD on the children and young people they care for and some plan to weave social support and friendships into clinic appointments or support offered in school.

In light of the impact of Covid-19 and the turn to remote working and a high proportion of virtual clinics, clinicians see the value in the resource being played within virtual ‘waiting’ rooms.

Typical feedback from health care professionals

Really good - very simple and offers a number of approaches which emphasizes that there is no 'correct' way of telling friends but a number of options that you can choose when the moment feels right.

I was positively surprised with the quality and attractiveness of the resource. The animation is great – I love the touches of humour, sensitivity and practical tips that are shared very simply but effectively. The colours and style of the animation and leaflets are appropriate for the age group and I really like them.

I am conscious about moving into a virtual clinic setting and these videos will be helpful.

Reach

Our intention is for the resources to be used as widely as possible. They are hosted on the Edge Hill University website, as well as on the Crohn's & Colitis UK website and also on Figshare (Edge Hill University Repository).

The resource and our work has been picked up by self-help groups and by Ampersand Health, which has extended its reach further into the adult population. A blog was posted on Ampersand Health website promoting the resource: <https://www.ampersandhealth.co.uk/new-resource-developed-to-help-young-people-tell-their-friends-about-their-crohns-or-colitis/>

To coincide with **World IBD day** (which focused on work) on 19 May 2020, we released a series of over 30 tweets on Twitter about the resources; these were scheduled to run from 19th May to 15th June as part of more intense focus on sharing the information sheets/resource. These tweets each created between 200 and 800 impressions with the average #BeingMewithIBD tweet creating around 300 impressions.

Key organisations such as Crohn's & Colitis UK have also shared or retweeted posts, thereby increasing the reach further.

The Being Me with IBD study blog has had over 465 unique visitors by December 2020. We have promoted the resources frequently on Facebook and Twitter and in partnership with organisations such as Crohn's and Colitis UK. A Facebook post which promoted our animation and resources has been viewed by 6.4K people, shared 68 times received 8 comments and was 'liked' by 110 people.

Thus far we have contacted five NHS Trust hospitals with requests to share and/or display the resources. To date, we have had three positive responses. Feedback has been very positive, and in one trust the animation has been shared on patient information screens across the Trust. In order to broaden the reach further, we have contacted a number of key organisations that support young people and their health, including SAPHNA (School and Public



NEW resource developed to help young people tell their friends about their Crohn's or Colitis

Edge Hill University and Manchester University have led the development of a new resource, available freely online, that helps young people tell their friends about their IBD. The package includes a helpful and accessible animation and three leaflets with information for young people with IBD, their friends, and education professionals working with them.



Young people with IBD want to be able to fulfil their work-related hopes and aspirations finding ways to manage their symptoms, their treatment and juggle hospital appointments. @CrohnsColitisUK #BeingMeWithIBD @EHU_CYPF #worldibdday2020 ehu.ac.uk/crohnsorcolitis



9:00am · 19 May 2020 · TweetDeck

Health Nurses Association), Lancashire School Nurses Network and Merseyside School Nurses Network, Merseyside School Nurses Network are using the suite of resources in the School Nurses Toolkit which is given to every school nurse working in Merseyside schools. Furthermore, SAPHNA are developing their website and have plans to promote our study and resources in their underdevelopment research section.

Workshops and other events are planned to take place following the release of restrictions due to COVID-19.

To reach a wider audience, we wrote a piece for The Conversation which has accrued over 8000 reads, with readers from the UK, France, the United States and other countries.

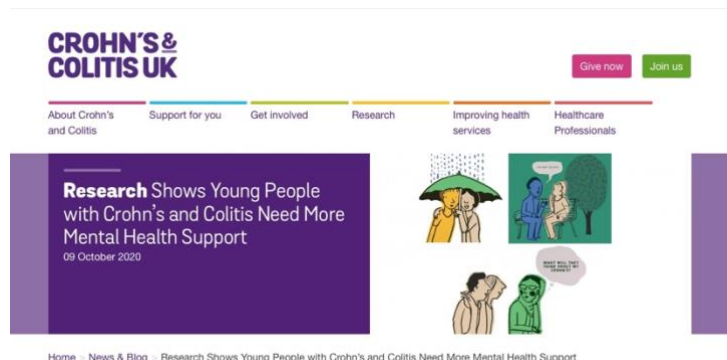
It was also shared on via the Crohn's and Colitis UK which would account for more reads.

<https://theconversation.com/i-dont-want-my-friends-to-know-young-people-on-growing-up-with-crohns-or-colitis-143639>



Linked to World Mental Health Day (10th October 2020) Crohn's & Colitis UK promoted findings from the research

[<https://crohnsandcolitis.org.uk/news/research-shows-young-people-with-crohns-and-colitis-need-more-mental-health>]. Based on this and one of our papers, the Mirage News featured research by Professor Bernie Carter and partners which has found that [young people who experience severe Crohn's and Colitis symptoms are more likely to experience poor mental health](#), with 107k readers; it was also featured in the [Medical Express](#) with 1.8m online visitors and [the Health News Digest](#) with 2k.



Publications

Qualter, P. & Carter, B. Supporting young people with Crohn's and Colitis: New research offers insights. (Invited commentary) British Journal of Child Health.

Qualter, P., Rouncefield-Swales, A., Bray, L., Blake, L., Allen, S., Probert, C., Crook, K., Carter, B. (2020) Depression, anxiety, and loneliness among adolescents and young adults with IBD in the UK: the role of disease severity, age of onset, and embarrassment of the condition. Quality of Life Research. Published 30th September 2020. <https://link.springer.com/article/10.1007%2Fs11136-020-02653-9>

Carter, B., Rouncefield-Swales, A. & Qualter, P. (2020) 'I don't want my friends to know' – young people on growing up with Crohn's or colitis. The Conversation. Sept 2nd 2020, 11.55am BST. <https://theconversation.com/i-dont-want-my-friends-to-know-young-people-on-growing-up-with-crohns-or-colitis-143639>

Rouncefield-Swales A., Carter, B., Bray, L., Blake, L., Allen, S., Probert, C., Crook, K., Qualter, P. (2020) Sustaining, forming and letting go of friendships for young people with Inflammatory Bowel Disease (IBD): A qualitative interview-based study. International Journal of Chronic Diseases. Article ID 7254972, 10 pages, 2020. <https://doi.org/10.1155/2020/7254972>. Published 5th Sept 2020.

Carter, B., Rouncefield-Swales, Bray, L., Blake, L., Allen, S.J., Probert, C.J, Crook, K., & Qualter, P. (2020) "I don't like to make a big thing out of it": A qualitative interview-based study exploring factors affecting whether young people tell or do not tell their friends about their IBD. International Journal of Chronic Diseases. Published 11th June 2020. <https://www.hindawi.com/journals/ijcd/2020/1059025/>

Significance/impact

The research informed resources have been developed to increase understanding of how Crohn's or Colitis can affect the social and emotional life of young people, including the importance of friendships during the key transition periods of adolescence and young adulthood (see papers listed above).

The resources provide insight for professionals which can enable them to better support young people and help them to consider how they can share their diagnosis with friends if they wish to. This has built a strong foundation for future research into exploring friendships, loneliness and the impact of sharing a diagnosis.

The resource is currently being used at: Alder Hey Children's NHS FT, Royal Liverpool University Hospital, St Marks Hospital (a specialist bowel hospital) with other hospitals about to commence its use.

It has been distributed and being used widely in Portugal within health and education settings. It has been disseminated to Brazil and feedback is awaited.

Plans are in place for it to be used as part of the School Nurses Toolkit.

Prof Bernie Carter was invited to be a member of the CCUK Pain Collaborative – an international network of people with IBD and academic and clinical experts in pain and IBD. The aim of the Pain Collaborative is to advance the understanding and management of pain in people with IBD.