TAKING PART IN RESE ARCH/SHAPING RESEARCH FORM GUIDANCE

### INTRODUCTION

This guide has been prepared to support the completion of a taking part in research or shaping research form. The guide includes information on the audience you should be writing for, tips on how to make your writing accessible and a glossary of common terms you may use when describing the opportunity. The content is confidential. This guide is not designed to be read from start to finish. A navigation pane has been enabled to allow you to access relevant sections, as you require them.

We are happy to answer any questions. Please e-mail researchinvolvement@crohnsandcolitis.org.uk

### ABOUT US

We are the UK’s leading charity for Crohn’s and Colitis. Right now, over 500,000 people in the UK are living with a lifelong disease that many people have never heard of. Because of the stigma and misunderstanding that surrounds these diseases, thousands of people are suffering in silence. But they’re not alone. We’re here for them. We’re here to give people affected by Crohn’s and Colitis hope, comfort and confidence.

### AUDIENCE

The audience for our taking part in research and shaping research pages is people affected by Crohn’s or Colitis.

### ACCESSIBILITY

If your sentence length is over 25 words, it could probably benefit from being split up into two or more sentences.

If you’re using Microsoft’s ‘editor’ tool, your average sentence length shouldn’t exceed 20 words. We aim for a Flesch Reading Ease score above 60. Flesch Reading Ease can be checked via Microsoft Word or [online](https://goodcalculators.com/flesch-kincaid-calculator/). The [Hemingway app](https://hemingwayapp.com/) is also a useful tool to help make your writing clear and accessible.

### TERMINOLOGY

#### The diseases

Use “Crohn’s” and “Colitis” where possible. If you’re describing the specific condition write out “Ulcerative Colitis” or “Crohn’s Disease” in full. To avoid repetition, we sometimes use “Inflammatory Bowel Disease” (and then “IBD”). But we’re looking to move aware from “IBD” in public-facing communications as most people describe their condition as either “Crohn’s” or “Colitis” and IBD is too often confused with “IBS”.

#### Patient or person?

We almost always write about ‘people with Crohn’s and Colitis’ rather than ‘patients’. This is because people often tell us that they don’t want to be defined by their illness. If in doubt, avoid using the term ‘patient’.

#### Empowering language

In general, try not to describe people with Crohn's or Colitis as having things done to them, as if they are passive recipients of care and support. Instead, use empowering terms such as ‘people living with Crohn's and Colitis’.

When you want to include friends and family, use 'people affected by Crohn's and Colitis'.

Don’t use:

* Patients (unless you’re talking about a hospital situation, for example)
* Victims
* Sufferers
* People battling Crohn’s or Colitis
* People fighting Crohn’s or Colitis
* People struggling with Crohn’s or Colitis

Use

* People with Crohn’s or Colitis
* People living with Crohn’s or Colitis

People affected by Crohn’s or Colitis

### WORDS RELATING TO CROHN’S AND COLITIS

We have based this on the [NHS A-Z of health writing](https://service-manual.nhs.uk/content/a-to-z-of-nhs-health-writing). For any queries or for clarification, please speak to the Knowledge and Information team.

#### Abdomen and abdominal

It's okay to use ‘abdomen’ where it’s important to be medically accurate but we prefer tummy to refer to this part of the body.

For example, we’d state that an ostomy is an opening on the wall of the abdomen but we’d say that surgery may mean someone has scars on their tummy.

If users may not be familiar with ‘abdomen’ but are likely to hear their GP or another health professional use this word, we may add ‘abdomen’ after ‘tummy’.

For example: a dull ache in your tummy (abdomen).

#### Anus

We prefer ‘[bottom](https://service-manual.nhs.uk/content/a-to-z-of-nhs-health-writing#bottom)‘, as in ‘bleeding from your bottom’, to ‘anus’ or ‘[rectum](https://service-manual.nhs.uk/content/a-to-z-of-nhs-health-writing#rectum)‘.

You can add ‘anus’ in brackets after ‘bottom’. For example, in ‘enlarged blood vessels found inside or around the bottom (anus)’.

NHS user testing showed that people understand ‘bottom’ better than ‘anus’ but they do search for ‘anus’ in Google to seek medical information.

#### Chronic

The NHS has seen evidence that the word ‘chronic’ confuses people. Some people think it means ‘bad’ or ‘serious’.

We prefer ‘long-term’ or ‘ongoing’ if referencing symptoms. When referring to the chronic nature of Crohn’s and Colitis, we use the term lifelong.

#### Condition

We use ‘condition’ when talking about a personal experience, as disease can sound very negative. Disease may be used in formal and technical settings, such as a policy paper. We also use the word disease when it is the name of a condition such as Crohn’s Disease.

#### Death

In our information and storytelling, we avoid euphemisms and prefer to say “death”, “dying” and “died”. We don’t use words such as ‘deceased’ or ‘passing’.

However, when responding to a supporter about a death, we recommend reflecting the language they use. If somebody tells you that a loved one has passed away, it is appropriate to use this phrase throughout the conversation.

#### Fart

We use ‘fart’ and ‘farting’ when we're talking about symptoms. People understand ‘fart’ better than ‘passing wind’ or ‘flatulence’.

We use ‘wind’ for ‘trapped wind’ or bloating.

#### Flare-up

Lots of people living with Crohn’s and Colitis understand what we mean by ‘flare-up’ but you may wish to explain it the first time you use it.

For example: When your symptoms are worse or happening more often, known as being in a flare-up, here’s what you should do.

We always say ‘flare-up’, rather than ‘flare’. We might sometimes say ‘flaring’ but only if we’re already talking about flare-ups.

#### Gut

Use gut as an umbrella term for the digestive system (from the mouth to the bottom). Occasionally you may need to use specific terms for specific parts of the gut, such as when describing a particular type of disease.

Use bowel if you are specifically referring to the lower part of the gut that runs from the tummy (stomach) to the bottom (anus).

Use oesophagus if you are specifically referring to the upper part of the gut that runs from the mouth to the stomach.

See our information on [Crohn's Disease](https://crohnsandcolitis.org.uk/info-support/information-about-crohns-and-colitis/all-information-about-crohns-and-colitis/understanding-crohns-and-colitis/crohns-disease) or [Ulcerative Colitis](https://crohnsandcolitis.org.uk/info-support/information-about-crohns-and-colitis/all-information-about-crohns-and-colitis/understanding-crohns-and-colitis/ulcerative-colitis) to see how specific parts of the gut should be named.

#### Incurable

Avoid ‘incurable’. Instead, we say ‘there is no cure’.

#### Poo

We mostly use ‘poo’, rather than ‘stool’. We know that everyone can understand ‘poo’, including people who find reading difficult.

We don’t use ‘opening your bowels’ or ‘bowel movements’, preferring everyday language such as ‘having a poo’ or ‘needing a poo’ instead.

We sometimes use the words ‘stool’ or ‘bowel’ when people will hear their GP use them, but we will explain the term or phrase.

For example: a sample of poo, often called a stool sample

We don’t use the word faeces. When writing about the faecal calprotectin test, we can say ‘poo test’ to help with understanding where appropriate/necessary. It is often helpful to include the name of the test as well, so that people know what to ask their doctor for.

For example: poo test (faecal calprotectin test) or a poo test called a faecal calprotectin test

### WORDS RELATING TO HEALTHCARE

#### Brand names

We avoid brand names when talking generally about certain medications. For example, in a blog we’d use the names of medications such as adalimumab, rather than Humira, one name it’s sold under. This is so we don’t appear to be recommending one medication over another. This would also apply to medications such as ibuprofen. We’d use this over Nurofen.

However, in our patient information it can be helpful to explain the medication is ‘also known as the brand name…’. This is because it is prescribed by a brand name and people with the conditions could be more familiar with this name.

There might also be a need to refer to a brand name in relation to our corporate partners, who produce specific branded drugs. For example, Amgen produces Amgevita and Abbvie produces Humira, but they are both adalimumab.

#### Chemist

Use ‘pharmacy’, not ‘chemist’.

#### Drugs

Use ‘medicine’. When we say treatment, this encompasses surgery as well as medicine.

#### Flu vaccine

Use ‘flu vaccine’ to refer to the annual flu vaccination programme and when referring to a vaccine given to children.

You can sometimes use ‘flu jab’ for adults because people search for this but be aware that this excludes children as the child vaccine is administered via spray.

#### GP surgery

When writing for the public, use ‘GP surgery’ or ‘surgery’ rather than ‘practice’, because NHS research shows us that this is the word patients are more likely to search for and use.

#### Normal

We prefer to say ‘usually’ and ‘usual’, as we don’t want to make people feel they aren’t ‘normal’ in a health context.

For example, ‘if you are going to the toilet more than usual’ doesn’t make the toilet habits seem weird. If we say, ‘symptoms usually start for the first time between the ages of 10 and 40’, we’re not implying that having symptoms at 45 is abnormal.

#### Nurse

Use ‘nurse’ to mean any type of nurse, including IBD nurse specialists. You can also use IBD nurse specialist when you’re talking specifically about this role.

#### Sick

Use ‘feeling sick’ instead of ‘nausea’, but you may want to put ‘nausea’ in brackets afterwards: feeling sick (nausea).

Use ‘being sick’ instead of ‘vomiting’. Again, you may want to put ‘vomiting’ in brackets afterwards: being sick (vomiting).

Use ‘vomiting’ in phrases like ‘vomiting blood’.

Use ‘vomit’ as the noun. For example: blood in your vomit’.

#### Treatment v therapy

We use treatment to refer to both medicines and surgery. You can use a specific term, or treatment to encompass both. You may also use treatment if you’re not sure what kind of treatment someone has had or may have.

Therapy can refer to psychological interventions or complimentary options which are generally alongside or in conjunction with treatment.

Sometime biologic medicines are referred to as biological therapy, but we would use the term biologics (or biologic medicines) and refer to it as a treatment.

### OUR GENERAL WRITTEN STYLE

This section is according to the [Observer style guide](https://www.theguardian.com/guardian-observer-style-guide-a).

#### Abbreviations

Always spell out an abbreviation in full first, follow it with the abbreviation in brackets and then use the abbreviation for the rest of the document. For example:

‘People affected by Crohn’s and Colitis, the two main forms of Inflammatory Bowel Disease (IBD), include family, friends, and children of those with the conditions.’

When we are using an abbreviation, we don’t use full stops in between the letters such as GP, not G.P.

There are some widely understood abbreviations such as MRI, GP, and NHS which we don’t spell out and this maybe be audience dependant. If in doubt, spell it out or consult a colleague.

#### And/or

Writing and/or like this affects readability, causes difficulties for screen readers and is ambiguous in meaning. We avoid using it.

#### Contractions

We use contractions like we’re, I’m and it’s.

This helps maintain our friendly, warm brand style and makes content easier to read. Use contractions when it makes your writing reflect how you would say something and would look stilted to without contractions.

However, we avoid should’ve, could’ve, would’ve and they’ve, as they can be hard to read. Contractions may not be appropriate when emphasising an important piece of information such as “you should not suddenly stop taking steroids”. We should avoid negative contractions.

#### Dates

Our style is: 21 July 2016 (day month year; no commas).

Dates do not always need the day adding, but if they do, it must come first.

Thursday 21 July 2016

We don’t use the letters –st, -nd, -rd or -th with dates (1st, 2nd, 3rd, 4th, and so on).

Should you have occasion to say 2016 out loud, such as on video or in a presentation, pronounce it ‘twenty sixteen’, not ‘two thousand and sixteen’

When referring to events, use the date to avoid confusion, even if in brackets such as ‘Next Thursday (20 November).’

#### e.g.

We don’t use e.g. as it can be read aloud as ‘egg’ by screen readers and prevents a natural flow when reading. You might use ‘for example’, ‘such as’, ‘like’, or ‘including’ – whichever works best.

#### etc.

We don’t use etc., try ‘and more’ or ‘and similar’.

#### Fractions and percentages

For percentages, use the % symbol.

For example: 50%.

However, it's often better not to use a percentage. Instead of 50%, for example, you could say ‘1 in 2’ or ‘half’.

We avoid using fractions, preferring to explain them in terms of numbers, as above.

For numbers less than 1, use 0 before the decimal point such as in 0.25.

#### i.e.

We don’t use ‘i.e.’. It means ‘that is’ or ‘which means’ and you can usually write your sentence in another way.

#### Numbers

All numbers should be spelt out if they begin a sentence.

Hyphenate numbers such as twenty-one and ninety-nine. For example, thirty-five members could attend a webinar.

Use commas for 1,000 and over.

Spell out million and billion.

We spell out numbers from one to nine except in the following situations:

* If they are part of a time (1am, not one am)
* If part of a fraction (1 in 5)
* If followed by a unit of measurement (2mg)
* If referring to ages, using years as a unit of measurement

We use numerals for 10 and above.

For money use:

£1 to £999,999

£1 million

£1 billion

If the number needs to be precise, write it out in full, using commas and full stops: £1,458,222.78

### SPELLING

Where a word has alternate spellings that are also correct, we have listed below which we use when writing for Crohn’s & Colitis UK

|  |  |
| --- | --- |
| We use | Instead of |
| adviser | advisor |
| among | amongst |
| best placed | best-placed  |
| coordination | co-ordination |
| dietitian | dietician |
| evidence-based | evidence based |
| flare-up | flare or flare up |
| focused and focusing | focussed or focussing |
| fundraising | fund raising or fund-raising |
| further/furthest | farther/farthest |
| healthcare | health care or health-care |
| healthcare professional | health professional |
| inpatient | in patient or in-patient |
| lifelong | life-long or life long |
| long-term (when used as an adjective) | long term |
| multidisciplinary | multi-disciplinary |
| people | persons |
| phone or telephone | never 'phone |
| older people | OAPs or old people |
| outpatient | out patient or out-patient |
| side effects | side-effects |
| undiagnosed | un-diagnosed |
| wellbeing | well being or well-being |
| while | whilst |
| workplace | work place or work-place |

### SIMPLIFICATIONS

Keeping it clear and simple is in keeping with our brand tone of voice

|  |  |
| --- | --- |
| You could try | Instead of |
| suddenstarts suddenlyshort-term | Acute |
| differentother | Alternative |
| more than | Exceed |
| carry onkeep goinglast for a long time | Persist  |
| help withease | Reduce |
| happen | Occur |
| ask forspeak to | Seek |
| hospitalcommunityname of the specific location | Hospital or community *setting*Primary or secondary care, unless with medical or policy audiences |