## Crohn's and Colitis Research survey 2019 for the IBD BioResource







To help our research we want to know what drugs you have been treated with for Crohn's or Colitis. Please provide details below. Although the form looks quite complicated most people will only have received one or two drugs in each section (or none at all), so filling it in is not as bad as

The first section is for infusion / injection -based treatments. The second section is for immunosuppressant tablets (methotrexate can also be as an injection)

N.B. Estimates of dates are fine! If you haven't received these drugs or you are not sure please leave the row blank.

	Drug treatments						
IBD Drug name	Start date (approx)	Stop date (approx) if stopped	Are you currently on this drug?	Was the treatment effective? (Choose one of the options from below that best describes your response to the drug)  1 = Yes it worked / is working with no loss of response  2 = No didn't work  3 = Only ever worked partially  4 = Unable to assess (e.g. unable to tolerate)  5 = Worked well for less than 1 yr then lost response  6 = Worked well for more than 1 yr then lost response  7 = Don't know	Did you have any significant reactions to drug injections/ infusions?	If yes, did you have to stop the drug / switch to an alternative?	While on this drug (answer separately for each drug), were you also taking it in combination with an immunosuppressant such as Azathioprine, Mercaptopurine or Methotrexate? (Choose one of the options from below)  1 = Yes  2 = No  3 = Only for first months then stopped the immunosuppressant 4 = Initially on drug (a/b/c/d/e) without immunosuppressant but then had immunosuppressant therapy added later on  5 = Don't know
a. Infliximab	M M / Y Y	M M / Y Y	Y N	1	Y N	Y N	1
Infliximab (if given a 2nd course)	M M / Y Y	M M / Y Y	Y N	1	Y N	Y N	1
b. Adalimumab (Humira etc.)	M M / Y Y	M M / Y Y	Y N	1	Y N	Y N	1
Adalimumab (Humira etc.) (if given a 2nd course)	M M / Y Y	M M / Y Y	Y N	1 2 3 4 5 6 7	Y N	Y N	1
c. Vedolizumab (Entyvio)	$\left[\begin{array}{c} M & M \\ \end{array}\right] / \left[\begin{array}{c} Y & Y \\ \end{array}\right]$	M $M$ $M$ $M$ $M$ $M$ $M$ $M$ $M$ $M$	Y N	1	Y N	Y N	1
d. Ustekinumab (Stellara)	M M / Y Y	M M / Y Y	Y N	1 2 3 4 5 6 7 6	Y N	Y N	1
e. Golimumab (Simponi)		M M / Y Y	Y N	1	Y N	Y N	1





IBD Drug name	Start date (approx)	Stop date (approx) if stopped	Are you currently on this drug?	(Choose described describe	ne treatment effice one of the open of the	otions from the set to the dream working with the effects are sets than 3 m and or Adalian after start to after surge sess than 1 years than 1 more than 1 deals if a bit / particular the start of the effects than 1 years than 1 deals if a bit / particular than 1 deals if a bit / bit	rug)  th no loss of  th had to st  tonths  mumab at t.  ting  try (had few  rear but the  year but the	significant side effects with drug?	Were you able to stay on drug (e.g. at reduced dose)?
a. Azathioprine	M M / Y Y	M M / Y Y	Y N	13		_	2d 7		Y N
Azathioprine (if given a 2nd course)			Y N	1		_	2d 7		Y N
b. Mercaptopurine		/	Y N	13		_	2d 7		Y N
Mercaptopurine (if given a 2nd course)			Y N	1 <u></u> 3 <u></u>		_	2d 7		Y N
c. Methotrexate		$\left[\begin{array}{c} \mathbb{N} & \mathbb{N} \\ \end{array}\right] / \left[\begin{array}{c} \mathbb{N} \\ \mathbb{N} \end{array}\right]$	Y N	1		_	2d 7		Y N
Methotrexate (if given a 2nd course)			Y N	13		=	2d 7		Y N
d. Tofacitinib (Xeljanz)		M M / Y Y	Y N	13	. —	_	2d 7		Y N
Oral steroids	Have you ever had either of the listed oral steroids? (i.e. taken by mouth)	Approx. how many courses of each steroid by mouth have you ever received for your IBD? (If none enter 0)	What was approx. du of longest you ever ha (in weeks)	course	Did you have any side effects?	you:  a = Int ad  b = Mc  c = Pr  d = Wc  e = Sk  f = Inc	fection required fection required fection fect	ance (e.g. anxiety, eping hat affected your se that affected your	d / or depression) elf-esteem
a. Prednisolone	Y N				Y N	a	· Ш	d e	f
b. Budesonide (Entocort, Budeno Cortiment)	falk,				Y N	a	b D C	d e	f
			<u> </u>		1				





Appro	eximately what percentage (%) of steroid courses that you took fell in the following durations
	Duration Percentage (%)
	Less than 2 weeks
	2-8 weeks Total % (should add up to 100%)
	8-12 weeks
	More than 12 weeks
Have yo	cal history  ou required any surgery for your IBD? \( \sum_{\text{N}}^{\text{N}} \)  you have had surgery for ulcerative colitis, indeterminate colitis or IBD-Unspecified (IBD-U) please go to <b>Section 1</b> below you have had surgery for Crohn's please go to <b>Section 2</b> overleaf
SECT	ION 1: surgery for Ulcerative Colitis / Indeterminate colitis / IBD-U
Have yo	bu had your colon (bowel) removed?
If	yes, what was the reason for surgery? (choose one of the options from below)
	a = Acute severe colitis – i.e. you were admitted for a sudden severe flare which did not adequately respond to medication, hence needed urgent surgery
	b = Longstanding active colitis – usually a number of medications were tried over a period of months or even years, but without adequate response (+/- dependent on steroids) - hence ultimately requiring surgery
	c = Concern about pre-cancer ('dysplasia') e.g. based on results of biopsies
	d = The actual finding of a cancer either before surgery or on histopathological examination of the removed bowel after surgery
	e = Not sure
	ION 2: surgery for Crohn's disease
	for an abscess or fistula +/- with a 'Seton' suture /stitch left in place)
Ye	ear of first surgery on your bottom ?
H	ave you required more surgeries on your bottom since then?
Have yo	ou had surgery on your <b>abdomen (tummy / belly, bowel / gut)</b> for Crohn's
lf	yes, what is the total number of surgeries you have had on your <b>abdomen</b> for Crohn's disease?
W	/hen was the last surgery on your abdomen? / / /
De	o you have a stoma present?

continued overleaf...





Surgery on your abdomen (Tummy, belly, gut) for crohn's	Year of surgery	Reason for abdominal surgery (choose one of the options from below)  a = Narrowing (blockage, stricture, stenosis, scarring) in the gut  b = An intestinal perforation / internal abscess / internal fistula e.g. connecting bowel to bladder  c = Gut inflammation that was not getting better with medication or would only respond to steroids  d = Severe 'perianal' disease i.e. fistulas/ abscesses around your bottom, requiring a stoma bag  e = Simply to reverse an existing stoma  f = Don't know		
1st Surgery	Y Y Y Y	a b c d e f		
2nd Surgery	Y Y Y Y	a b c d e f		
3rd Surgery	Y Y Y Y	a b c d e f		
4th Surgery	Y Y Y Y	a b c d e f		
5th Surgery	Y Y Y Y	a b c d e f		
If you have an email address, please provide this below:				