

## Appendix - Survey questions used for the study (In English and Mandarin)

**Table 1 Survey questions about demographic features**

English version		中文版问卷	
Question	Answer choices	问题	供选答案
Date of birth	Fill in date	出生日期	填写日期
Sex	Female	性别	女
	Male		男
	Prefer not to answer		
What describes you best?	I have IBD	您是否有 IBD?	我有 IBD
	I do not have IBD		我没有 IBD
What type(s) of IBD has a doctor ever told you that you have, even if the diagnosis changed later? <i>Please check all that apply</i>	Crohn's Disease (also called ileitis, regional enteritis, terminal ileitis, granulomatous colitis or Crohn's colitis)	医生曾告诉您您有何种 IBD, 无论此后诊断有无改变? <i>选择所有适合的选项</i>	克罗恩病（也称为回肠炎，局限性肠炎，终端回肠炎，肉芽肿性结肠炎或克罗恩结肠炎？）
	Ulcerative Colitis		溃疡性结肠炎
	Indeterminate Colitis (not clearly Crohn's disease or ulcerative colitis)		未定型结肠炎 (没有明确克罗恩病或溃疡性结肠炎)
When did the health care provider diagnose you with Crohn's	Fill in date	您的医护人员什么时候告诉您您有克罗恩病？	填写日期

disease?			
What was your smoking status when you were diagnosed with IBD?	Current smoker at the time of diagnosis	当您被诊断 IBD 时，您的吸烟状况是？	在诊断时是吸烟者
	Former smoker at the time of diagnosis		在诊断时不再是吸烟者
	Never smoked at the time of diagnosis		在诊断时和之前从不吸烟

IBD: Inflammatory bowel disease.

**Table 2 Survey questions about family history**

English version		中文版问卷	
Question	Answer choices	问题	供选答案
How many brothers and sisters do you have?	Dropdown menu to choose from 0-9, and 10+	您有多少个兄弟姐妹?	下拉菜单中以下选项中选择: 0-9, 10+
How many children do you have?	Dropdown menu to choose from 0-9, and 10+	您有多少个孩子?	下拉菜单中以下选项中选择: 0-9, 10+
Do any of your relatives have inflammatory bowel disease including Crohn's disease, ulcerative colitis or indeterminate colitis?	Yes	您是否有血亲患有克罗恩病, 溃疡性结肠炎, 未定型结肠炎?	有
	No		无
	I do not know		我不知道
How many of your blood relatives (parents, grandparents, children, grandchildren, brothers/sisters, uncles/aunts or cousins) have inflammatory	Dropdown menu to choose from 0-5, and 6+	您有几个血亲(子女, 兄弟/姐妹, 叔叔/阿姨和表兄弟姐妹)患有炎症性肠病(IBD)?	下拉菜单中以下选项中选择: 0-5, 6+

bowel disease?			
What is the relationship of relative #n to you? <sup>1</sup> (Ask for each affected relative)	Mother	您和您血亲#n 的关系是?	母亲
	Father		父亲
	Grandparent		祖父母
	Brother/Sister		兄弟/姐妹
	Son/Daughter		子女
	Grandchild		孙
	Uncle/Aunt		叔叔/阿姨
	Cousin		表兄弟姐妹
	Other		其他

<sup>1</sup>If participants indicated that they have relatives with IBD, they were asked this question for each of the relatives that had IBD (for up to 5 relatives). IBD: Inflammatory bowel disease.

**Table 3 Survey questions about disease extent**

English version		中文版问卷	
Question	Answer choices	问题	供选答案
What part(s) of your gastrointestinal tract have you ever been told are involved in your Crohn's disease? <i>Please check all that apply</i>	Terminal ileum (the very last part of the small intestine, right before the colon or large intestine starts)	您曾被告知克罗恩病累及您消化道的哪些部位？	末端回肠（小肠的末端部分）
	The ascending colon (sometimes referred to right side or right-sided disease)		升结肠（或称右半结肠）
	The transverse colon		横结肠
	The descending colon (sometimes referred to as left side or left-sided disease)		降结肠（或称左半结肠）
	The sigmoid colon		乙状结肠
	The rectum		直肠
	The entire colon (sometimes referred to as pancolitis)		全结肠（或称泛结肠）
	Upper GI (esophagus, stomach, first part of		上消化道（食道，胃，小肠的起始部分）

	small intestine)		
	I do not know		不知道

**Table 4 Survey questions about surgical and medication history**

English version		中文版问卷	
Question	Answer choices	问题	供选答案
Have you ever had surgery for your IBD?	Yes	您为 IBD 接受过外科手术治疗么？	有
	No		无
	I do not know		不知道
Have you ever taken any of the following medication(s)? <i>Please check all that apply</i>	Steroids (Bethamethasone, Budesonide, Dexamethasone, Fludrocortisone, Hydrocortisone, Methylprednisone, Prednisolone, Prednisone)	您使用过以下哪种 IBD 治疗药物包括生物制剂？	类固醇 (bethamethasone, 布地奈德, 地塞米松, 氢化可的松, 甲基强的松, 强的松龙 fludocortisone, 强的松)
	Mesalamine or 5-ASA (Apriso, Asacol, Canasa, Ipacol, Lialda, Mesacol, Mezavant XL, Pentasa, Rowasa, Salofalk)		美沙拉嗪或 5-ASA (Apriso 以前, 美沙拉秦片, 是一种溃疡性直肠炎用药, ipacol mesacol mezavant XL 公司, 颇得斯安, 氨基水杨酸, salofalk)
	Sulfasalazine (Azulfidine)		柳氮磺胺吡啶 (Azulfidine)
	Mercaptopurine or 6MP		巯嘌呤或 6MP (巯基嘌呤)

	(Purinethol)		
	Methotrexate (Trexall or Rheumatrex)		氨甲喋呤 (trexall 或甲氨蝶呤胶囊剂)
	Azathioprine (Imuran)		硫唑嘌呤 (依木兰)
	Infliximab (Remicade)		英夫利昔单抗 (Remicade)
	Adalimumab (Humira)		阿达木单抗 (Humira)
	Certolizumab (Cimzia)		Certolizumab (Cimzia)
	Natalizumab (Tysabri)		那他珠单抗 (Tysabri)
	Ustekinumab (Stelara)		Ustekinumab (Stelara)
	Golimumab (Simponi)		戈利木单抗 (Simponi)
	Vedolizumab (Entyvio)		vedolizumab (entyvio)
	Cyclosporine (Restasis)		环孢素 (停滞)
	Tacrolimus (Hecoria)		他克莫司 (hecoria)
	Thalidomide (Thalomid)		沙利度胺 (thalomid)
	Exclusive Enteral		专用肠内营养 (使用



	Nutrition (using a feeding tube)		鼻饲管)
	Total Parental Nutrition (TPN), receiving nutrition through your vein		全胃肠外营养 (TPN)
	None of the above		以上均无
When did you take steroids (Bethamethasone, Budesonide, Dexamethasone, Fludrocortisone, Hydrocortisone, Methylprednisone, Prednisolone, Prednisone)? <sup>1</sup> <i>Please check all that apply</i>	Now, currently taking it	您何时服用过类固醇 (bethamethasone, 布地奈德, 地塞米松, 氢化可的松, 甲基强的松, 强的松龙 fludocortisone, 强的松) ? <i>选择所有适合的选项</i>	现在正在服用 诊断为 IBD 之前
	Within 3 months of IBD diagnosis		诊断为 IBD 后的头三个月内
	3 months to 1 year after IBD diagnosis		诊断为 IBD 后的三个月到一年间
	Greater than 1 year after IBD diagnosis		诊断为 IBD 一年之后
	Before IBD diagnosis		诊断为 IBD 之前
	Took for non-IBD condition		非为治疗 IBD 而服

<sup>1</sup>This question was only asked for participants who indicated that they had ever used steroids.

#