

Facts & Fiction: Knowledge Gaps That Could Impact the Health of Those Living With UC

A 2017-2018 10-country survey of 2,100 adults with a history of primarily moderate-to-severe ulcerative colitis (UC)ⁱ and 1,254 gastroenterologists (GIs) tested patients' knowledge of UC and physicians' perceptions about their patients' knowledge. Here are the findings from the survey (see survey methodology below) that show there might be an opportunity to improve education and management of the disease.

THE FACTS:

Even if UC symptoms are under control, there may still be active disease or inflammation. UC patients typically experience periods of being symptom-free, alternating with periods of having active disease symptoms, also known as a flare.³



41% of those surveyed with a history of UC were either not aware or unsure that even if symptoms of UC were under control, there could still be active disease or inflammation.¹



68%ⁱⁱ of GIs thought that their UC patients understood this was false.²

THE FACTS:

It is important to keep UC under control to reduce long-term complications.⁴



86% of people with a history of UC knew that it is important to keep their disease under control to reduce long-term complications.¹



88% of GIs surveyed thought that their UC patients understood this somewhat or very well.²

THE FACTS:

Patients with UC are at higher risk for developing colorectal cancer than the general population because of inflammation in the colon.⁵



21% of people with a history of UC were not aware that uncontrolled inflammation of the colon is a risk factor for colorectal cancer.¹



72% of GIs surveyed thought that their UC patients understood that uncontrolled inflammation of the colon is a risk factor for colorectal cancer.²

More than UC

THE FACTS:

Up to 31% of patients with UC experience symptoms outside of the colon, including the musculoskeletal system, skin, liver, kidneys, and eyes.⁶



66% of GIs surveyed thought that their patients with moderate-to-severe UC understood that UC may be associated with other conditions outside the colon.²



30% of those surveyed with a history of UC were not aware that UC may be associated with other conditions outside the colon.¹

For more information, visit Pfizer.com/UCNarrative

The UC Narrative is a global initiative created by Pfizer to engage the UC community to help identify how people living with ulcerative colitis are impacted by the disease.

The Global UC Narrative Advisory Panel,ⁱⁱⁱ comprised of people living with UC, as well as leading gastroenterologists, inflammatory bowel disease (IBD) nurses, a psychologist, and patient organizations, from 10 countries, is working to better understand the clinical symptoms of UC, as well as the complex impact this disease has on individuals in their personal (social and emotional) and professional lives.

About the Global UC Narrative Survey and Survey Methodology

The UC Narrative patient survey was conducted online and via telephone^{iv} by Harris Poll on behalf of Pfizer between August 23, 2017 and February 9, 2018, among 2,100 adults ages 18+ residing in Australia (215), Canada (215), Finland (105), France (169), Germany (210), Italy (210), Japan (210), Spain (214), the United Kingdom (251), and the United States (301) who have been diagnosed with ulcerative colitis (UC), have had an endoscopic procedure to confirm their diagnosis, have not had a colectomy, have been to a gastroenterologist or internist's office^v in the past 12 months, have ever taken a prescription medication for their UC (excluding those who have only ever taken 5-ASAs), and provided informed consent to complete the research. Raw data were not weighted at the individual country level, and are therefore only representative of the individuals who completed the survey.

The primary goal of the survey was to characterize the experiences of UC patients who are believed to be living with moderate to severe disease or those who may be living with poorly controlled disease. The choice to focus on these patient types was based on the assumption that these groups (versus those with milder disease) were more likely in need of support and resources, which the survey could help better identify.

To achieve the goal of focusing on those with moderate to severe disease, self-reported medication history was used as a proxy for disease severity. Patients with "moderate to severe" disease were defined as those who have ever taken a biologic or immunosuppressant for their UC, or have taken steroids for four or more of the past 12 months. Patients with a "milder" form of the disease were defined as those who have never taken a biologic or immunosuppressant, and those who have taken steroids for three or fewer months of the past 12 months. The research excluded patients who have never taken a prescription medication for their UC or have only ever taken a 5-ASA to control their UC. More than 80 percent of total completes were from patients whose disease was classified as "moderate to severe," using this definition, with "milder" patients capped at no more than 20 percent of total survey completes. Results from the UC Narrative patient sample survey may not reflect the experiences of the broader UC population.

The UC Narrative physician survey was conducted online and via telephone^{vi} by Harris Poll on behalf of Pfizer between August 23, 2017 and February 9, 2018, among 1,254 adults ages 18+ residing in Australia (90), Canada (80), Finland (17), France (154), Germany (152), Italy (157), Japan (151), Spain (151), the United Kingdom (153), and the United States (149)^{vi} who practice as a gastroenterologist, internist with a gastroenterology focus, gastroenterology internist, or gastroenterology surgeon,^{vii} do not primarily practice in a long-term care facility or hospice setting, see at least 10 patients with UC each month (or a minimum of five patients with UC per month in Japan), with at least 10 percent of these patients currently taking a biologic medicine for their UC (physicians were asked to think about their experiences treating patients in their practice whose UC was moderate to severe throughout the survey), and provided informed consent to complete the research. Physician results in the United States were weighted by region and years in practice by gender. In all other countries, physician results were weighted by age and gender to ensure alignment with the actual proportions in the population of gastroenterologists in each country.^{viii} UC Narrative physician sample survey may not reflect the experiences of all gastroenterologists.

For both patient and physician data, for the global, 10-country total, a post-weight was applied to adjust for the relative size of each country's adult population within the total adult population across all countries surveyed. The unweighted sample sizes reflect the total number of patients and physicians who completed the survey in each country, while all reported percentages are calculated based on the weighted global total described here. Proportionate weighting for combining multicountry data into a single total is a common practice because it relies on externally recognized population data to achieve a global total that more accurately represents the real-world relative to the adult populations surveyed. There are limitations to this approach; when countries surveyed have widely varying population totals, the data from smaller countries may get weighted down within the total, thus reducing their share of voice when grouped together with the larger countries.

In the United States, the research method and survey questionnaires were reviewed and received institutional review board (IRB) approval from WIRB-Copernicus Group. Language referencing data of those who agree with the statement includes those who indicated both "strongly agree" or "somewhat agree" within the survey.

i. Patients with "moderate-to-severe" disease were defined as those who have ever taken a biologic or immunosuppressant, or have taken steroids for four or more of the past 12 months. Patients with a "milder" form of the disease were defined as those who have never taken a biologic or immunosuppressant, and those who have taken steroids for three or fewer months of the past 12 months. The research excluded patients who have never taken a prescription medication for their UC or have only ever taken a 5-ASA to control their UC. More than 80 percent of total completes were from patients whose disease was classified as "moderate-to-severe," using this definition, with "milder" patients capped at no more than 20 percent of total survey completes.
ii. Language referencing data of those who agree with the statement includes those who indicated both "strongly agree" or "somewhat agree" within the survey.
iii. Where permitted, some members of the Global UC Narrative Advisory Panel were paid honoraria for their participation. Pfizer provided travel and accommodation, as well as a modest compensation, to Advisory Panel members who represent patient advocacy organizations for time spent developing the survey and attending meetings to review the survey findings.
iv. Telephone interviews were conducted among patients in France, the United Kingdom (UK), and the United States (U.S.), and among physicians in Australia and Canada.
v. Managing physician varied by country: in Australia, France, Spain, the UK, and the U.S., patients must have visited a gastroenterologist's office; those in Canada, Finland, Germany, Italy, and Japan must have visited a gastroenterologist or an internist's office.
vi. Gastroenterologists in the U.S. also were duly licensed in the state they practice, did not practice in Vermont, were board certified, and were not associated with Kaiser Permanente.
vii. Medical specialty varied by country: in Australia, France, Spain, the UK, and the U.S., all physicians were gastroenterologists; in Canada, Germany, and Italy, gastroenterologists and internists with a gastroenterology focus qualified; in Finland, gastroenterologists, gastroenterology surgeons, and internists with a gastroenterology focus qualified; and in Japan, gastroenterology internists, gastroenterology surgeons, and internists with a gastroenterology focus qualified.
viii. Physician results were not weighted in Finland due to smaller sample size.

1. Data on file. Pfizer Inc., New York, NY. [UC Narrative Patient Survey, 2018.]
2. Data on file. Pfizer Inc., New York, NY. [UC Narrative Physician Survey, 2018.]
3. Loftus E. Progress in the diagnosis and treatment of inflammatory bowel disease. *Gastroenterol Hepatol.* 2011;7(2 suppl 3):3-15.
4. Higgins PD. New keys to maintenance treatment in ulcerative colitis. *Dig Dis (Basel, Switzerland).* 2010;28(3):483-489. doi:10.1159/000320406.
5. Flores BM, O'Connor A, Mess AC. Impact of mucosal inflammation on risk of colorectal neoplasia in patients with ulcerative colitis: a systematic review and meta-analysis. *Gastrointest Endosc.* 2017;6(86):1007-1011.
6. Levine JS, Burakoff R. Extraintestinal manifestations of inflammatory bowel disease. *Gastroenterol Hepatol.* 2011;7(4):235-241.