

What Is the Global UC Narrative?

- The UC Narrative is a global initiative created by Pfizer to engage the UC community to help further identify how people with a history of ulcerative colitis (UC) are impacted by the disease.
- The goal of the UC Narrative is to help improve outcomes for people living with UC internationally by identifying common barriers to better care and work toward finding solutions to overcome these barriers.
- The first project in the UC Narrative initiative was a global survey fielded in 10 countries among 2,100 adults with a history of primarily moderate to severe UC¹ and 1,254 gastroenterologists: Australia (215 adults with a history of UC; 90 gastroenterologists), Canada (215 adults with a history of UC; 80 gastroenterologists), Finland (105 adults with a history of UC; 17 gastroenterologists), France (165 adults with a history of UC; 154 gastroenterologists), Germany (210 adults with a history of UC; 152 gastroenterologists), Italy (210 adults with a history of UC; 157 gastroenterologists), Japan (210 adults with a history of UC; 151 gastroenterologists), Spain (214 adults with a history of UC; 151 gastroenterologists), the United Kingdom (251 adults with a history of UC; 153 gastroenterologists), and the United States (301 with a history of with UC; 149 gastroenterologists). The survey explored several aspects of living with UC, including day-to-day disease impact, disease management, goal setting, and communication.
- The Global UC Narrative Advisory Panel, comprised of adults living with UC, as well as leading gastroenterologists, inflammatory bowel disease (IBD) nurses, a psychologist, and patient advocacy 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 UC Narrative Global Survey

- The UC Narrative global survey was developed with input from the Global UC Narrative Advisory Panel, which brought together physicians, patients, advocates, and nurses to turn the insights gleaned from the survey into actions that can help identify real-world needs and concerns about living with UC. 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.
- The UC Narrative global survey findings were first announced in collaboration with European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA) in advance of World IBD Day, which was on May 19, 2018. World IBD Day, which is coordinated by EFCCA each year, raises awareness about ulcerative colitis and Crohn's disease, both of which are known as IBD.
- A total of 2,100 adults with a history of primarily moderate to severe UC were surveyed online or via telephone between August 2017 and February 2018. Patients self-reported that they had been diagnosed with UC and had their diagnosis confirmed by an endoscopic procedure, did not have a colectomy, had visited a GI office in the past 12 months, and had taken prescription medication for their UC; patients who reported taking only 5-aminosalicylic acid (5-ASA) medications were excluded.

- A total of 1,254 gastroenterologists were surveyed online or via telephone between August 2017 and February 2018. To qualify for participation, physicians must have practiced as a gastroenterologist, internist with a gastroenterology focus, gastroenterology internist, or gastroenterology surgeon, did not primarily practice in a long-term care facility or hospice setting, saw 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, and provided informed consent to complete the research. Patients and physicians who qualified for and successfully completed the survey were compensated for their participation. For further information about the methodology, see below: “About the UC Narrative Global Survey Methodology.”

Global Findings: Highlights

The UC Narrative global survey findings have shown that UC may have short- and long-term impacts on everyday activities and life choices of people around the world. The survey suggests that these impacts may be exacerbated by the willingness of some people with a history of UC to accept symptoms, like pain and cramping, as part of a new reality that they cannot change.

- The survey found that on their worst day, adults with a history of UC said they take, on average, nearly 10 trips to the bathroom (excluding trips for only urination), and on their best day, nearly four trips.¹
- Among the 2,100 adults with a history of UC surveyed, 65 percent strongly (22%) or somewhat (43%) agreed that they felt like their disease controls their life rather than them controlling their disease.¹
- Additionally, 67 percent of those surveyed strongly (24%) or somewhat (43%) agreed that they often felt like they spend more time in the bathroom than anywhere else.¹
- 48 percent of adults with a history of UC reported experiencing three or more flares, meaning the period of time where they experienced a dramatic increase in symptoms that is different from what they typically experienced in the past 12 months.¹
- Of the 67 percent of adults with a history of UC who said they considered their disease to be “controlled with few to no symptoms,” 40 percent reported averaging nine or more trips to the bathroom for any reason other than urination on their worst day, compared to 78 percent making four or fewer trips on their best day; and 41 percent reported experiencing three or more flares in the past 12 months.¹

Findings from the survey suggested that UC’s impact extended to mental health and intimacy, leading people with the disease to alter their careers, avoid relationships, and even delay or avoid starting a family, yet these topics are not always addressed at doctor’s appointments.

- 84 percent of adults with a history of UC strongly (42%) or somewhat (43%) agreed that UC is mentally exhausting.¹
- 30 percent of adults with a history of UC wished that their gastroenterologist better understood how UC affects their mental health; however, 51 percent of gastroenterologists surveyed said they never discuss the impact of UC on their patients’ mental/emotional health.^{1,2}

- 32 percent of adults with a history of UC said it is important to them for UC to have less impact on their sex lives and personal relationships, yet 55 percent of those surveyed strongly (19%) or somewhat (36%) agreed that they didn't feel comfortable talking to their GIs about these topics.¹
- On average, adults with a history of UC estimated missing between five and 33 events (e.g., days of work or school, social events, travel plans, or child events) in the previous 12 months.¹
- 68 percent of adults with a history of UC strongly (29%) or somewhat (39%) agreed they felt like they would be a "more successful person" if they did not have UC.¹
- More than half (51%) of gastroenterologists surveyed strongly (8%) or somewhat (43%) agreed that their patients would approach their career or education differently if they did not have UC.²

Gaps in communication and education resources identified by the survey highlighted some reasons why it may be difficult for some people living with UC to address aspects of their new reality.

- 46 percent of adults with a history of UC strongly (17%) or somewhat (28%) agreed they worried that if they ask too many questions, their GI will see them as a difficult patient and it will affect the quality of care they receive.¹
- 60 percent of adults with a history of UC strongly (17%) or somewhat (43%) agreed that patient advocacy organizations are important to the management of UC.¹
- 84 percent of gastroenterologists strongly (24%) or somewhat (60%) agreed that patient advocacy organizations are important to the management of UC, but 48 percent of gastroenterologists said they recommended patient associations as a source for information and support to less than half of their patients.²

About the Global UC Narrative Survey and Survey Methodology

- The UC Narrative patient survey was conducted online and via telephoneⁱⁱ 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 officeⁱⁱⁱ 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 telephoneⁱⁱ by Harris Poll on behalf of Pfizer between August 23 and February 9, 2018, among 1254 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)^{iv} who practice as a gastroenterologist, internist with a gastroenterology focus, gastroenterology internist, or gastroenterology surgeon^v, 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.^{vi} 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.

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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 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.

ⁱⁱⁱ 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.

^{iv} 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.

^v 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.

^{vi} Physician results were not weighted in Finland due to the 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.]