

Around the World, People Living with Ulcerative Colitis Share Common Perspectives and Experiences

New Global Survey Offers a Glimpse Into the Impacts of this Chronic Disease

May 18, 2018 – A new global survey suggests that, around the world, people living with ulcerative colitis (UC) share remarkably similar and profound life impacts while living with the disease. UC, a type of inflammatory bowel disease (IBD) that can cause debilitating abdominal pain and bloody diarrhea, may impact people both physically and emotionally—leading people with the disease to adapt to a new reality where they may choose to alter their studies and/or careers, avoid relationships, and even delay or avoid starting a family.

In recognition of World IBD Day (May 19), Pfizer is sharing key findings from the global UC Narrative survey^{1,2} conducted by Harris Poll, which gathered data from 10 countries and included 2,100 adults living with primarily moderate-to-severe UC and 1,254 gastroenterologists (GIs). The survey explored several aspects of living with the disease ranging from physical symptoms to patient-physician communication to emotional health and intimacy.

Visit Pfizer.com/UCNarrative to learn more about the UC Narrative initiative, or scroll down to learn more about insights from the survey and ways people living with UC may be able to better navigate their disease management.

1. 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.



Ulcerative Colitis: Inside and Out Insights & Ideas for Empowering People Living with UC Across the Globe

As the global incidence of UC grows, so does the need for resources and support for those living with the disease. A 2017-2018 10-country survey of 2,100 adults living with primarily moderate-to-severe UC and 1,254 GIs revealed that UC may have short- and long-term impacts on everyday activities and life choices. The survey suggests that some people living with UC accept certain UC-related symptoms, like abdominal pain, as part of a new reality that they can't change.

“We must challenge the notion that ulcerative colitis means that people must give up their life goals or things they enjoy. Certainly, the disease is life-changing, but the more that people living with UC, caregivers and healthcare providers examine the way they share information and talk about goals, the better chance people living with UC have to thrive.”



– Luisa Avedano | CEO, European Federation of Crohn's and Colitis Associations (EFCCA) and Global UC Narrative Advisory Panel Member

[See full survey methodology and limitations below](#)

LIFE IMPACTS

LIFE, INTERRUPTED:

67 percent (n=1417/2100) of adults living with UC strongly (24%; n=512/2100) or somewhat (43%; n=905/2100) agreed that they often felt like they spend more time in the bathroom than anywhere else. Additionally, 65 percent (n=1365/2100) of adults living with UC strongly (22%; n=455/2100) or somewhat (43%; n=910/2100) agreed that they felt like their disease controls their life rather than them controlling their disease.¹

The survey found that on their worst day, adults living with UC said they take, on average, **10 trips to the bathroom (excluding trips to urinate)**, and on their best day, **4 trips**.¹

“A potential outcome of this level of disruption, both real and perceived, is that people living with UC may be giving up the things that are most important to them.”

– Luisa Avedano | CEO, EFCCA and Global UC Narrative Advisory Panel Member

IS IT REALLY REMISSION?

Adults living with UC who reported their UC was in remission (67%; n=1415/2100), meaning that their disease is controlled with few to no symptoms, **still reported using the bathroom quite often**, especially on their worst day, as compared to those who said their UC was not in remission.¹

In Remission
Best day = 3
Worst day = 9

Not In Remission
Best day = 4
Worst day = 12

EMOTIONAL HEALTH

Survey Findings

84% (n=1769/2100) of adults living with UC strongly (42%; n=873/2100) or somewhat (43%; n=896/2100) agree that UC is **mentally exhausting**.¹

Nearly one-third (30%; n=636/2100) of adults living with UC said they **wished their GI better understood** how UC affects their mental health—but 51% (n=645/1254) of GIs said they **never discuss the impact of UC on their patients' mental/emotional health**.^{1,2}

Community Perspective

“For me, the level of mental exhaustion expressed by patients is the most striking impact uncovered by the study. It's a difficult thing for most doctors to perceive or understand.”

“We need to encourage our patients to tell us how they are feeling.”



– Alessandro Armuzzi, MD
Gastroenterologist
Italy

Empowering Ideas

Use emojis or notes to **track how you are feeling** on a daily basis—and make a point to share it with your healthcare team during your next appointment. If you notice that you are consistently feeling sad—seek out a mental health professional.



RELATIONSHIPS

Survey Findings

32% (n=667/2100) of adults living with UC said that UC having less impact on their **sex life and personal relationships** was important to them.¹

55% (n=1154/2100) of adults living with UC strongly (19%; n=404/2100) or somewhat (36%; n=750/2100) agreed that they **don't feel comfortable talking about their sex lives and personal relationships** with their GI—and most GIs (96%; n= 1202/1254) didn't feel this is one of the top three topics important to prioritize during routine appointments.^{1,2}

Community Perspective

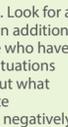
“I can relate to why people said it's so hard to talk about intimacy. When you don't feel good or feel good about yourself—it can really disrupt a relationship. But, having people who know what you are going through is actually a **critical part of dealing with UC**. Being open about UC can really free you.”



– Rasheed C.
Living with UC for 10 Years
Canada

Empowering Ideas

Many patient advocacy groups have developed **“discussion guides”** to help navigate difficult conversations with romantic partners. Look for a local resource to help. In addition, talking to other people who have been through similar situations can give you ideas about what to say. Finally, if intimate relationships are being negatively impacted—**speak with your GI or nurse. They want to help.**



MISSED ACTIVITIES & EVENTS

Survey Findings

Surveyed adults living with UC estimated missing, on average, **anywhere 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



Community Perspective

“I was amazed that most people aren't actually missing more events; it definitely suggests how resilient so many UC patients are. However, in looking at many of the other findings around the impact of UC, I have to wonder if sometimes they are **pushing themselves so they don't let down friends and family**.”



– Ailsa Hart,
BA (Hons), BMBCh,
FRCP, PhD
Gastroenterologist
United Kingdom

Empowering Ideas

Develop a **simple word or phrase** to let your friends and family know when you'll need to cancel plans. You won't need to explain, and they'll know the situation. **Recognize that you aren't letting anyone down** if you need to cancel last minute – and that if you aren't feeling well, you should focus on yourself.



LIFE JOURNEY IMPACTS

Survey Findings

68% (n=1436/2100) of adults living with UC strongly (29%; n=615/2100) or somewhat (39%; n=822/2100) agree that if they asked they would be a **more successful person** if they did not have UC.¹

51% (n=638/1254) of surveyed GIs strongly (8%; n=95/1254) or somewhat (43%; n=543/1254) agreed their patients would **approach their school or career differently** if they did not have UC.²

Community Perspective

“It's heartbreaking to know there are patients who are questioning their ability to be successful. I think **some people may be settling for living a life that is less than what they deserve or can achieve.**”



– Alexandra Sechi, RN
IBD Nurse
Australia

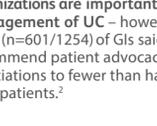
Empowering Ideas

Make sure you are familiar with your company's or school's policy on absences and disability due to illness so you know how to manage any paperwork before you need to take time off.



CONVERSATIONS ABOUT CARE

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



84% (n=1049/1254) of physicians strongly (24%; n=303/1254) or somewhat (60%; n=746/1254) agreed **patient advocacy organizations are important to the management of UC**—however, **48%** (n=601/1254) of GIs said they recommend patient advocacy associations to fewer than half of their patients.²

46% (n=957/2100) of adults living with UC strongly (17%; n=364/2100) or somewhat (28%; n=593/2100) agreed that they **worry that their GI will see them as a difficult patient and it will affect the quality of care they receive**.¹

“The UC Narrative survey gives us important new perspectives that build on previous research about the quality of life impacts of UC. One of these is the fact that it shows people living with UC that they are not alone. There are thousands of others having the same experiences, looking for resources and support. People living with UC must be empowered to speak up and encouraged to find help and hope!”

– Luisa Avedano | CEO, EFCCA and Global UC Narrative Advisory Panel Member

- WITH YOUR GI:**
- ✓ Set goals
- ✓ Be honest
- ✓ Ask more questions if you have them
- ✓ Find trusted sources
- ✓ Build your support network

Visit www.efcca.org for more information about ulcerative colitis. Visit www.Pfizer.com/UCNarrative to see more results from the UC Narrative global survey and more tips for living with UC.

About the UC Narrative
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,¹ comprised of people living with UC, as well as leading gastroenterologists, IBD nurses, a psychologist, and patient organizations, from 10 countries helped develop the survey methodology and questions. The Global UC Narrative Advisory Panel will work together to turn the insights gleaned from the survey into actions that can help address 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.

About the European Federation of Crohn's & Colitis Associations
The European Federation of Crohn's & Colitis Associations (EFCCA) is an umbrella organization representing 34 national patient associations. EFCCA aims to improve the quality of life for people with IBD and give them a louder voice and higher visibility across Europe and beyond.

About the Global UC Narrative Survey and Survey Methodology
The UC Narrative patient survey was conducted online and via telephone¹ 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 in the past 12 months,¹ 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.

The UC Narrative physician survey was conducted online and via telephone¹ by Harris Poll on behalf of Pfizer between August 23 and February 9, 2018, among 1254 adults ages 18+ residing in Australia (80), Canada (80), Finland (17), France (154), Germany (152), Italy (157), Japan (151), Spain (151), the United Kingdom (153), and the United States (149)¹ who practice as a gastroenterologist, internist with a gastroenterology focus, gastroenterology internist, or gastroenterology surgeon,² 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, and provided informed consent to complete the research. Physician results in the United States (U.S.) were weighted by region and years in practice by gender. In all other countries, physician results were weighted by age and/or gender to ensure alignment with the actual proportions in the population of gastroenterologists in each country.

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 multi-country 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 be 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.