What is the Global UC Narrative?

- The UC Narrative is a global initiative created by Pfizer to engage the ulcerative colitis (UC) community to help identify how people living with ulcerative colitis are impacted by the disease.
- The first project in the UC Narrative initiative is a global survey of patients and gastroenterologists from 10 countries, including the U.S., that explores a range of topics that may influence a patient’s quality of life including day-to-day disease impact, disease management, goal setting and communication.
- The Global UC Narrative Advisory Panel, comprised of people living with UC, as well as leading gastroenterologists, IBD nurses, a psychologist, and patient organizations, including the Crohn’s & Colitis Foundation in the U.S., from 10 countries will work together to turn the insights gleaned from the survey into actions that can help identify real-world needs and concerns about living with UC.

About the U.S. UC Narrative Survey

- The UC Narrative U.S. preliminary findings represent a subset of the UC Narrative global survey, which was developed with input from the Global UC Narrative Advisory Panel. In addition to providing input into the development of the survey, the Crohn’s & Colitis Foundation recruited respondents (n=126/301) to complete the survey online.
- The preliminary U.S. findings from the U.S. surveys are being announced in collaboration with the Crohn’s & Colitis Foundation during the Crohn’s & Colitis Congress taking place in Las Vegas January 18-20, 2018. Survey results for all countries are anticipated in the spring of 2018.
- A total of 301 U.S. UC patients were surveyed online or by telephone between August and October 2017. 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 149 U.S. gastroenterologists were surveyed online between August and November 2017. To qualify for participation, physicians must have seen at least 10 UC patients per month, with at least 10 percent of those patients currently taking a biologic treatment for UC. 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 U.S. UC Narrative Survey Methodology.”

U.S. Findings Highlights

These preliminary findings suggest that people living with UC are suffering from symptoms that may impact their life choices; this is also reflected in the physician survey. Further, it appears that some patients accept these symptoms as their “new normal.”

- Among the 301 patients surveyed, 64 percent (n=194/301) reported that their disease controls their life rather than them controlling their disease.1
- Additionally, 63 percent (n=190/301) of patients indicated they often feel like they spend more time in the bathroom than anywhere else.1
- Many (69%; n=209/301) agreed they would be a “more successful person” if they did not have UC.1 Some patients (28%; n=85/301) indicated that they had changed their plans around deciding to adopt, not to have any/more, or delay having children because of their UC.1
- Of the 66 percent (n=198/301) of patients who said they considered their disease to be “controlled with few to no symptoms,” more than one-third (39%; n=77/198) reported averaging nine or more trips to the bathroom for any reason other than urination on their worst day, compared to 80 percent (n=159/198) making four or less trips on their best day), and 30 percent (n=60/198) reported experiencing three or more flares in the past 12 months.1
- GIs surveyed agreed that their patients would approach their personal relationships (65%; n=96/149) and career or education (50%; n=74/149) differently if they did not have UC.2

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i. Where permitted, members of the Global UC Narrative Advisory Panel were paid honoraria for their participation.
The survey also suggested that patients weren’t comfortable discussing some topics with their GIs, and that both patients and GIs wanted more educational and support resources.

- 34 percent (n=102/301) of patients wished that their gastroenterologist better understood how UC affects their mental health; however, more than 46 percent (n=137/301) said they don’t feel comfortable talking about emotional concerns with their gastroenterologist.
- 46 percent (n=139/301) of patients said it is important to them for UC to have less impact on their sex lives and personal relationships, yet 50 percent (n=152/301) said they don’t feel comfortable talking to their GIs about these topics.
- Only 55 percent (n=165/301) of patients said they had ever reached out, been referred to, or relied on information from a patient association.
- Forty percent (n=59/149) of GIs said having informed resources to provide to their patients would help them improve their relationships with patients; yet 45 percent (n=67/149) of GIs said they recommended patient associations as a source for information and support to less than half of their patients.

About the U.S. UC Narrative Survey Methodology

The UC Narrative U.S. patient survey was conducted online and by telephone by Harris Poll on behalf of Pfizer between August 23 and October 23, 2017, among 301 adults ages 18+ residing in the U.S. who have been diagnosed with UC, have had an endoscopic procedure to confirm their diagnosis, have not had a colectomy, have been to a gastroenterologist’s office 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. The research method and survey questionnaire were reviewed and received IRB approval from WIRB-Copernicus Group. Medication history was used as a proxy for disease severity, with “mild” patients capped at 20% of total completes. Data were not weighted, and are therefore only representative of the individuals who completed the survey. Patients who qualified for and successfully completed the survey were compensated for their participation.

The UC Narrative U.S. physician survey was conducted online by Harris Poll on behalf of Pfizer between August 23 and November 3, 2017, among 149 adults residing in the U.S. who are licensed to practice medicine, specialize in gastroenterology, do not mostly practice in a long-term care facility or hospice, see at least ten (10) UC patients each month, with at least 10% of these patients currently taking a biologic, and provided informed consent to complete the research. The research method and survey questionnaire were reviewed and received IRB approval from WIRB-Copernicus Group. Results were weighted by region and years in practice by gender to bring them in line with their actual proportions in the population of U.S. gastroenterologists. Physicians who qualified for and successfully completed the survey were compensated for their participation.

1. Mild patients were defined as those who have ever taken a 5-ASA, steroids for 3 or less of the past 12 months, or another medication for their UC, but have never taken a biologic or immunosuppressant, and have not taken steroids for 4 or more of the past 12 months. “Moderate to severe” patients were defined as those who have ever taken a biologic or immunosuppressant, or have taken steroid for 4 or more of the past 12 months. and years in practice by gender to bring them in line with their actual proportions in the population of U.S. gastroenterologists.

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