

SUPPLEMENTARY MATERIAL

The Impact of the COVID-19 Pandemic on Patients with Ulcerative Colitis: Results from a Global Ulcerative Colitis Narrative Patient Survey

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Supplementary Data

Patient Survey Questions

In which country or region do you currently reside?

Are you (gender)?

What is your age?

Q280. How would you describe your current overall health?

1. Poor
2. Fair
3. Good
4. Excellent

Q600. Are you currently living with or managing any of the following conditions, as formally diagnosed by a doctor or health care professional? *Please select all that apply.*

1. Ulcerative colitis (must select to qualify)
2. Rheumatoid arthritis
3. Diabetes
4. Depression
5. Psoriasis
6. Psoriatic arthritis
7. Crohn's disease
8. Lupus
9. Irritable bowel syndrome
10. Heart disease
11. Ankylosing spondylitis
12. Non-radiographical axial spondyloarthritis
13. Uveitis
14. Anxiety
15. Celiac disease
16. Chronic constipation
17. Eczema
18. Chronic anemia
19. Fibromyalgia
20. Hypertension or high blood pressure
21. None of these
22. Not sure
23. Decline to answer

Q605. Did you have an endoscopic procedure (i.e., a colonoscopy [a scope] or flexible sigmoidoscopy) in order to confirm your diagnosis of UC? *Throughout the remainder of the survey, when we say UC, please think about your experiences with ulcerative colitis.*

1. Yes (must select to qualify)
2. No
3. Not sure

Q608. Have you ever had a colectomy (surgical removal of all or part of your colon)?

1. Yes
2. No (must select to qualify)

Q615. Which health care professionals, if any, have you seen (either virtually, over the phone or in-person) in the past three years to manage your UC? *Please select all that apply. When thinking about managing your UC, please include all health care professionals involved in helping you live with and treat your UC, such as managing your medication, treating the inflammation of your colon, etc.*

1. Gastroenterologist
2. Nurse at a gastroenterologist's office
3. Nurse practitioner/physician's assistant at a gastroenterologist's office (not asked in Finland)
4. Someone else at a gastroenterologist's office
5. Internist (not asked in the US)
6. Nurse at an internist's office (not asked in the US)
7. Nurse practitioner/physician's assistant at an internist's office (not asked in the US or Finland)
8. Someone else at an internist's office (not asked in the US)
9. Gastroenterology surgeon (not asked in the US, Canada, or France)
10. Primary care physician/general practitioner
11. Rheumatologist
12. Dermatologist
13. Nurse in another type of practitioner's office
14. Nurse practitioner/physician's assistant in another type of practitioner's office (not asked in Finland)
15. Psychiatrist/psychologist/therapist (excluding therapists in Finland)
16. Nutritionist/dietician
17. Colorectal surgeon (not asked in Finland)
18. Other
19. None

Q625. Please indicate all prescription medications you have ever taken for UC. *Please select all that apply.*

1. Immunosuppressant
2. Anti-TNF biologic therapy
3. Other biologic or advanced therapy
4. 5-ASA
5. Corticosteroid
6. Another prescription medication for UC (varied by country)
7. Not sure
8. I have never taken any prescription medications for my UC

Q630. Please indicate all prescription medications you are currently taking for UC.
(Show only medications selected at Q625 series in same order; 7,8 anchored, exclusive.)

7. Not sure
8. I am not currently taking any prescription medications for my UC

Q635. You indicated that you have taken a corticosteroid for your UC. In the past 12 months, for approximately how many months have or had you taken corticosteroids for your UC?
If you have taken corticosteroids for 1 or more days within a 30-day period, please count as one month.

__ months (range: 0–12)

Q700. How old were you when you were first diagnosed with UC by a doctor? Your best estimate is fine.

__ years old (range: 0–current age)

Q710. Do you currently consider your UC to be in remission? When we say remission, we mean that your disease is controlled with few to no symptoms.

1. Yes
2. No

Q715. How long has your UC been in remission? *Please enter a response in each row.*

1. Months (range 0–11)
2. Years (range 0–[show years only if answer to Q700 is > 0])

Q720. How long has it been since your UC was last in remission? *Please enter a response in each row.*

1. Months (range 0–11)
2. Years (range 0–[show years only if answer to Q700 is > 0])
3. My UC has never been in remission

Q725. Thinking about your UC today, how much do you agree or disagree with the following statement? *I feel that UC controls my life, rather than me controlling the disease.*

1. Strongly disagree
2. Somewhat disagree
3. Somewhat agree
4. Strongly agree

Q735. Thinking about the UC flare(s) you have had since the beginning of the COVID-19 pandemic in early 2020, did you experience more, less or about the same number of flares as you experienced in 2019? *When we say flare, we mean a period where you experience a dramatic increase in symptoms that is different from what you typically experience.*

1. Less flares in 2020/during the pandemic than in 2019
2. About the same number of flares in 2020/during the pandemic as in 2019
3. More flares in 2020/during the pandemic than in 2019

Q800. How has living through the COVID-19 pandemic impacted each of the following?
(Possible answers: *Negatively impacted a lot, negatively impacted a little, no impact, positively impacted a little, positively impacted a lot.*)

1. My emotional well-being
2. How controlled my UC symptoms are
3. My ability to perform daily activities
4. The expectations I have for my treatment plan (i.e., the prescription medication taken for my UC)
5. My ability to access the prescription medication that I need
6. How safe I feel taking my prescription medication for my UC

Q805. Do you think any of the following have made it easier to control your symptoms during the COVID-19 pandemic? *Please select all that apply.*

1. Working from home
2. Working in-person
3. Having less anxiety/stress
4. Having a less busy schedule
5. Having fewer social outings
6. Having virtual appointments with my doctor (e.g., telephone or video chat)
7. Communicating with my doctor via text, email, or online portal
8. Having more time to focus on my overall health
9. Feeling comfortable going into a hospital or office to receive care or treatment
10. Other
11. Nothing made it easier to control my symptoms during the COVID-19 pandemic

Q810. Do you think any of the following have made it more difficult to control your symptoms during the COVID-19 pandemic? *Please select all that apply.*

1. Working from home
2. Working in-person
3. Having more anxiety/stress
4. Not being able to get an appointment with my doctor
5. Not having access to virtual appointments with my doctor (e.g., telephone or video chat)
6. Being unable to get the prescribed medication I needed
7. My prescribed medication stopped controlling my symptoms as effectively
8. Having other priorities to focus on
9. Being hesitant to go into a hospital or office to receive care or treatment
10. Other
11. Nothing made it more difficult to control my symptoms during the COVID-19 pandemic

Q815. Please indicate which of the following you did before, during and/or plan to do after the COVID-19 pandemic. *Please select all that apply for each. (Possible answers: I did this before the COVID-19 pandemic, I did this during the COVID-19 pandemic, I plan to do this after the COVID-19 pandemic, I have never done or plan to do this.)*

1. Use symptom tracking or disease management apps
2. Use an online patient portal to contact my doctor's office or see laboratory results
3. Have virtual appointments with my doctor (e.g., telephone or video chat)
4. Rely on information from patient advocacy groups
5. Rely on patient support groups
6. Use social media to connect with other patients or learn about UC
7. Set goals with my doctor for managing my disease
8. Talk openly with my doctor about how my disease impacts my life
9. Communicate with a nurse at my doctor's office between appointments

Q820. How much do you agree or disagree with each of the following statements about living with UC during the COVID-19 pandemic? *(Possible answers: Strongly disagree, somewhat disagree, somewhat agree, strongly agree.)*

1. I am worried about my ability to control my symptoms once life goes back to normal
2. During the COVID-19 pandemic, I have felt more isolated and alone in managing my UC
3. Because of the COVID-19 pandemic, I feel more resilient when it comes to managing my UC
4. I became better at tracking my symptoms during the COVID-19 pandemic
5. The COVID-19 pandemic made it easier for me to talk to people about what it's like to live with UC
6. I was hesitant to make changes to my UC treatment plan during the COVID-19 pandemic

Q900. How satisfied have you been with your ability to access the health care you need during the COVID-19 pandemic?

1. Not at all satisfied
2. Not very satisfied
3. Somewhat satisfied
4. Very satisfied

Q902. Thinking more broadly about your experiences both before and during the COVID-19 pandemic, which of the following challenges, if any, have you ever experienced in accessing the health care you need? *Please select all that apply.*

1. Difficulty with my doctor and I understanding one another due to language barriers
2. Difficulty with my doctor and I understanding one another due to cultural differences
3. Financial difficulties in paying for the care that I need (not shown in France)
4. Lack of high-speed internet access or Wi-Fi at home
5. Lack of access to a computer, tablet, or phone
6. Lack of privacy at home to conduct virtual appointments (e.g., telephone or video chat)
7. Lack of transportation to appointments

8. Lack of conveniently located medical care
9. Lack of a caregiver to help me
10. Difficulty getting time off work to go to appointments with my doctor
11. Difficulty getting an appointment with a specialist for my UC
12. Other
13. I have never experienced any challenges in accessing the health care I need

Q905. Which of these challenges became worse during the COVID-19 pandemic? *Please select all that apply. (Only show items selected at Q902, in the same order.)*

1. None of these

Q910. How many times have you seen or visited (whether in person or virtually) a doctor for your UC since the start of the COVID-19 pandemic in early 2020? *Please enter a response in each row.*

1. In-person appointment(s)
2. Appointment by phone where your doctor can hear you but not see you
3. Appointment by video where your doctor can hear you and see you

Q915. Thinking about your last in-person appointment during the COVID-19 pandemic with the doctor that you see for your UC, how satisfied were you with each of the following? *(Possible answers: Not at all satisfied, somewhat satisfied, satisfied, very satisfied.)*

1. The overall quality of care I received
2. Length of appointment
3. Quality of communication with my doctor
4. My ability to be open with my doctor about my experiences
5. Discussion of my disease management goals
6. Discussion of my symptoms and flares
7. How easy it was to schedule the appointment
8. My doctor's ability to physically assess my symptoms

Q920. Now, thinking about your last virtual appointment during the COVID-19 pandemic with the doctor that you see for your UC, how satisfied were you with each of the following? *By virtual appointments, we mean the process of providing health care from a distance (as opposed to in-person) through technology (e.g., telephone or video chat). (Possible answers: Not at all satisfied, somewhat satisfied, satisfied, very satisfied.)*

1. The overall quality of care I received
2. Length of appointment
3. Quality of communication with my doctor
4. My ability to be open with my doctor about my experiences
5. Discussion of my disease management goals
6. Discussion of my symptoms and flares
7. How easy it was to schedule the appointment
8. My doctor's ability to physically assess my symptoms
9. The technology platform that I used to access my appointment

Q930. Which type of appointment with the doctor you see for your UC would you prefer for each of the following circumstances? *(Possible answers: Strongly prefer in person, slightly prefer in person, no preference, slightly prefer virtual, strongly prefer virtual.)*

1. Regular check-ups with the doctor I usually see for my UC
2. When I have a flare
3. When my doctor and I are discussing changes to my treatment plan
4. When I would like to discuss my disease management goals with my doctor
5. When I would like to discuss emotional impacts of my disease with my doctor
6. When I need a refill on a prescription medication for my UC
7. When meeting with a new doctor for the first time

Q1005. Have you and your doctor discussed and/or made any changes to your UC treatment plan since the beginning of the COVID-19 pandemic in early 2020? *As a reminder, when we say, "treatment plan," we mean the prescription medication you use for your UC.*

1. We discussed and made changes to my treatment plan
2. We discussed but did not make changes to my treatment plan
3. We did not discuss or make changes to my treatment plan

Q1000. You indicated you are currently taking prescription medication for your UC. How satisfied are you with your current UC treatment plan?

1. Very dissatisfied
2. Somewhat dissatisfied
3. Somewhat satisfied
4. Very satisfied

Q1010. How much do you agree or disagree with the following statement? If my treatment makes me feel good enough, I don't see a need to consider other treatment options, even if they might make me feel better than I do now.

1. Strongly disagree
2. Somewhat disagree
3. Somewhat agree
4. Strongly agree

Q1020. Aside from prescription medication, which of the following, if any, are you currently doing, using, planning, or taking to help manage your UC? *Please select all that apply.*

1. Surgery
2. Complementary (non-medication) therapies (e.g., acupuncture, homeopathy, massage, yoga, meditation/relaxation) (Note: Homeopathy not shown in Japan)
3. Psychological therapy
4. Exercise
5. Diet/maintaining a healthy weight
6. Over-the-counter medications
7. Other
8. Nothing

Q700B. Are you the parent/legal guardian of any child/children who is/are...? *Please select all that apply.*

1. 2 years old or younger
2. 3–5 years old
3. 6–9 years old
4. 10–12 years old
5. 13–17 years old
6. 18 years of age or older
7. I am not the parent/legal guardian of any children
8. Decline to answer

Q300. Which of the following are true of/for you? (*Possible answers: Yes, no, decline to answer.*)

1. I am an essential worker (non-health care) and worked during the COVID-19 pandemic (in France [employees in essential sectors, “indispensable to the functioning of the country,” such as waste collection, grocers, food distribution, public utilities, etc.])
2. I am a frontline health care worker (e.g., nurse, doctor, paramedic) and worked during the COVID-19 pandemic
3. I worked primarily from home during the COVID-19 pandemic
4. I plan to primarily work from home following the COVID-19 pandemic
5. I reduced my work hours or had my hours cut due to the COVID-19 pandemic
6. I was laid off, furloughed, or lost my job due to the COVID-19 pandemic
7. I was not employed before the COVID-19 pandemic

What is your marital status?

1. Never married
2. Married or civil union
3. Divorced
4. Separated
5. Widowed
6. Living with partner

Including yourself, how many people age 18 or older live in your household? (range: 1–5)

How many people under the age of 18 live in your household? (range: 0–15)

Household size: Size of household (net)

Which of the following best describes your employment status?

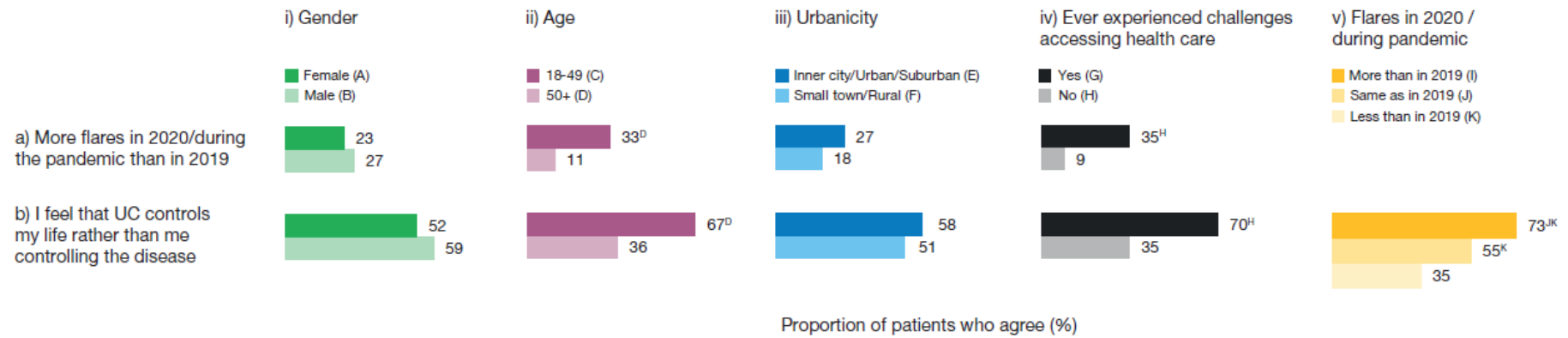
1. Employed full time
2. Employed part time
3. Self-employed full time
4. Self-employed part time
5. Not employed, but looking for work
6. Not employed and not looking for work
7. Not employed, unable to work due to a disability or illness

8. Retired
9. Student
10. Stay-at-home spouse or partner

Q1320. Which of the following best describes the location where you live?

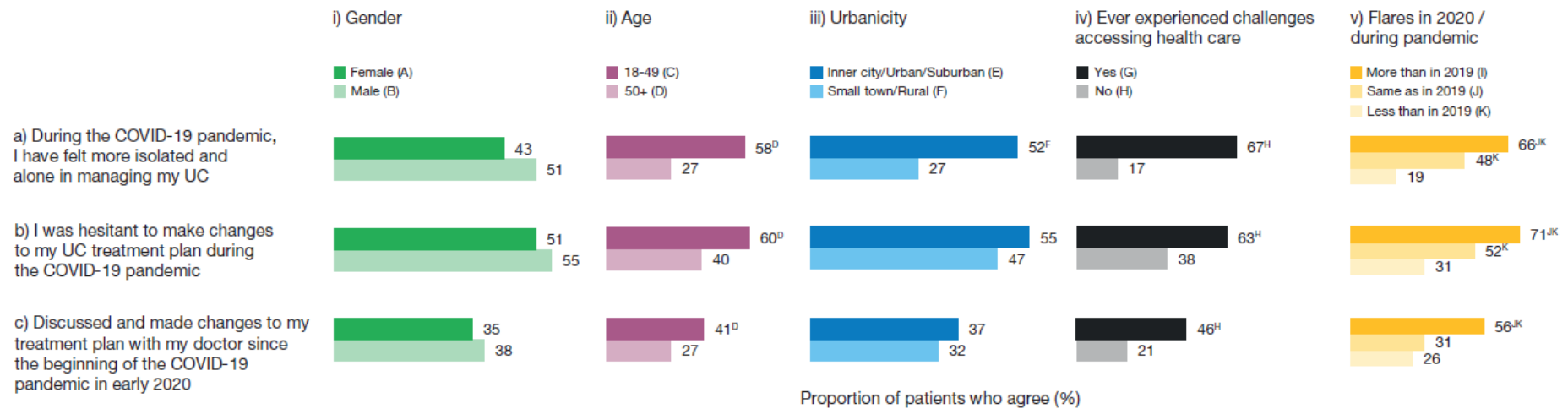
1. Inner city (not shown in Japan)
2. Urban (in Japan: “Capital area/designated city [> 500000 people]”)
3. Suburban (in Japan: “Core city [> 200000 people]”)
4. Small town (in Japan: “Other city/town/village”)
5. Rural (not shown in Japan)

Fig. S1 Proportion of patients who a) reported having more flares in 2020/during the pandemic than in 2019 and b) reported feeling that UC controls their life rather than them controlling the disease.



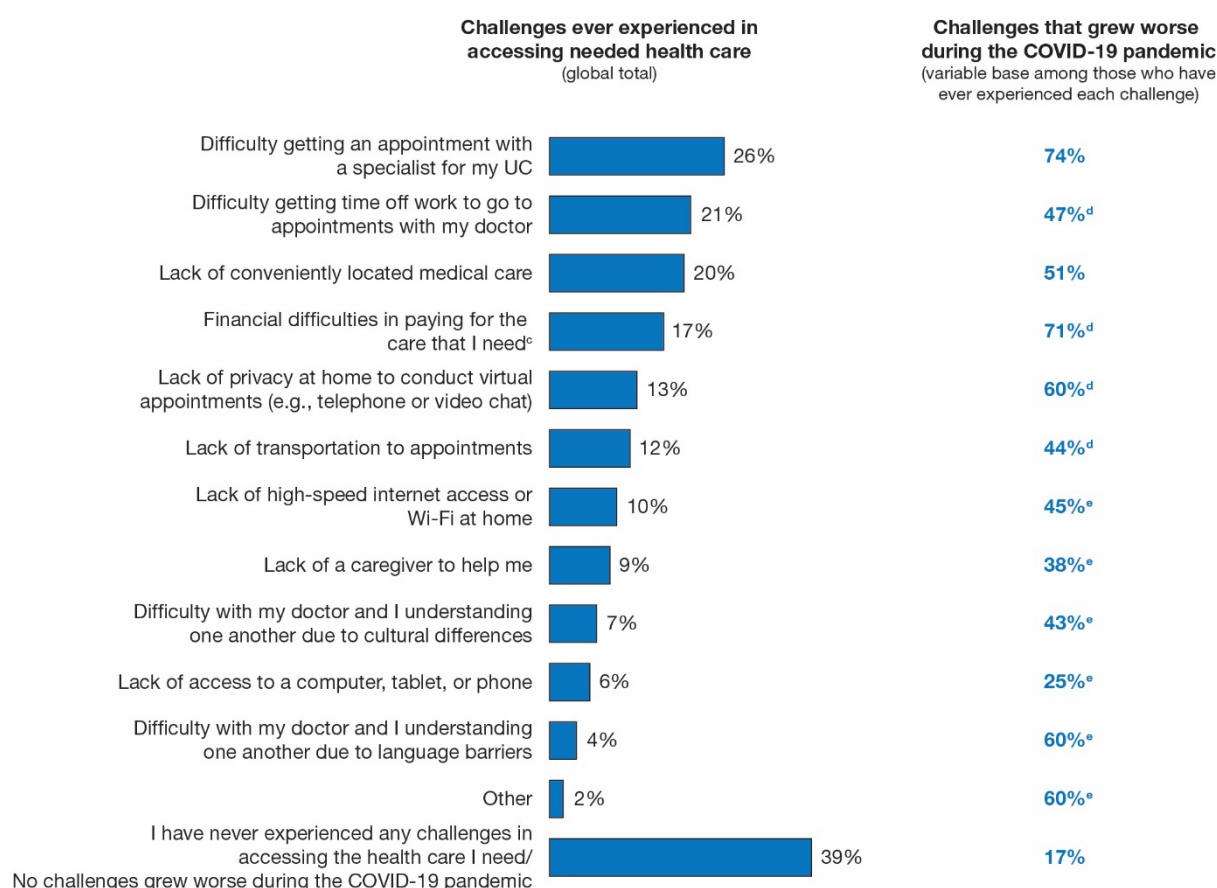
Rows that contain superscript lettering are significantly more likely to agree with this statement/select this item vs counterpart subgroup category(ies) at a 95% confidence interval, and the letter shown indicates the counterpart subgroup category. *UC* ulcerative colitis

Fig. S2 Proportion of patients who a) felt more isolated and alone in managing their UC during the COVID pandemic, b) were hesitant to make changes to their UC treatment plan during the COVID-19 pandemic, and c) discussed and made changes to their treatment plans with their doctor since the beginning of the COVID-19 pandemic in early 2020.



Rows that contain superscript lettering are significantly more likely to agree with this statement/select this item vs counterpart subgroup category(ies) at a 95% confidence interval, and the letter shown indicates the counterpart subgroup category. *UC* ulcerative colitis

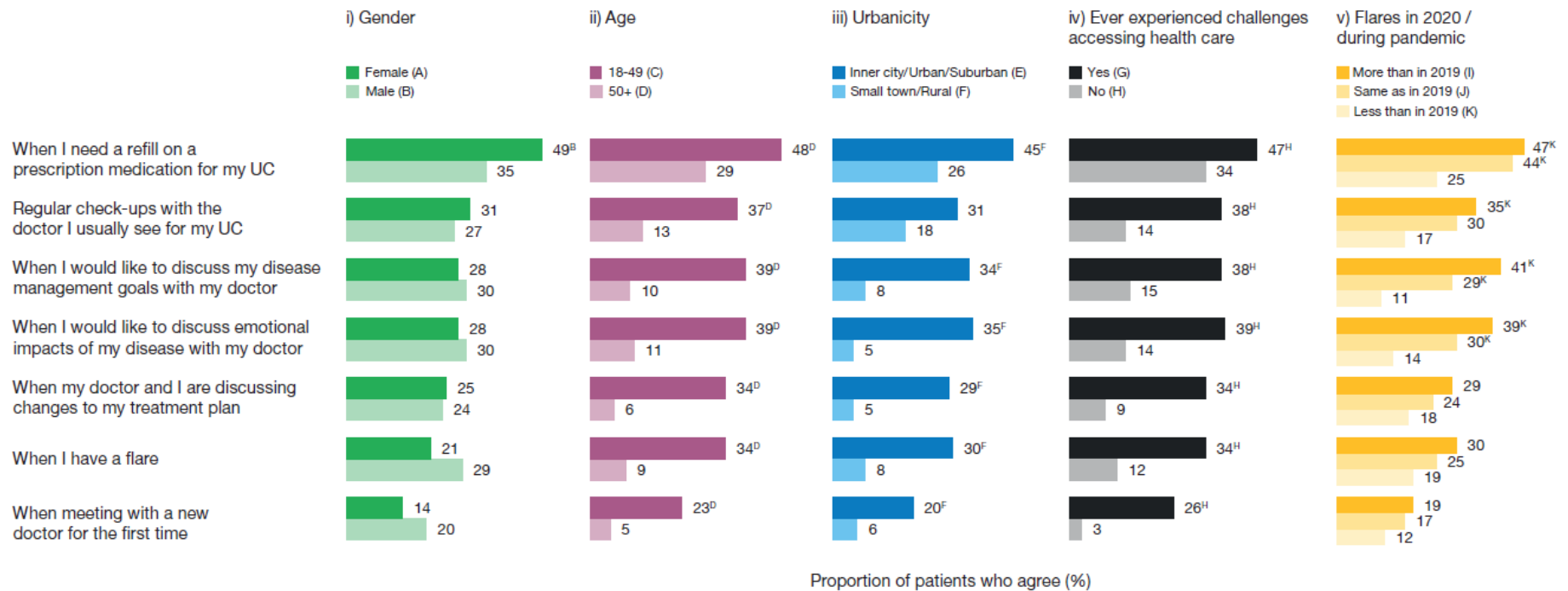
Fig. S3 Patients ever reporting challenges in accessing health care for their UC^a and challenges that worsened during the COVID-19 pandemic^b.



^aQuestion: “Thinking more broadly about your experiences both before and during the COVID-19 pandemic, which of the following challenges, if any, have you ever experienced in accessing the health care you need? Please select all that apply.” ^bQuestion (for patients who reported ever experiencing a challenge): “Which of these challenges became worse during the COVID-19 pandemic? Please select all that apply” (the base varied for each item and ranged from $n = 20$ –151). ^cItem not shown in France. ^dSmall base size (< 100); results should be interpreted as directional only. ^eVery small base size < 50 ; interpret with caution.

UC ulcerative colitis

Fig. S4 Proportion of patients who would prefer virtual appointments with their doctor, stratified by subgroups of interest.



Rows that contain superscript lettering are significantly more likely to agree with this statement/select this item vs counterpart subgroup category(ies) at a 95% confidence interval, and the letter shown indicates the counterpart subgroup category. *UC* ulcerative colitis