### Paxlovid® Submission Survey Results Data

#### September 2023

Data gathered from the survey "Experiences with Paxlovid(R) as a Treatment for COVID-19," developed by Save Your Skin Foundation for CADTH and INESSS submission regarding Paxlovid® as a treatment for COVID-19



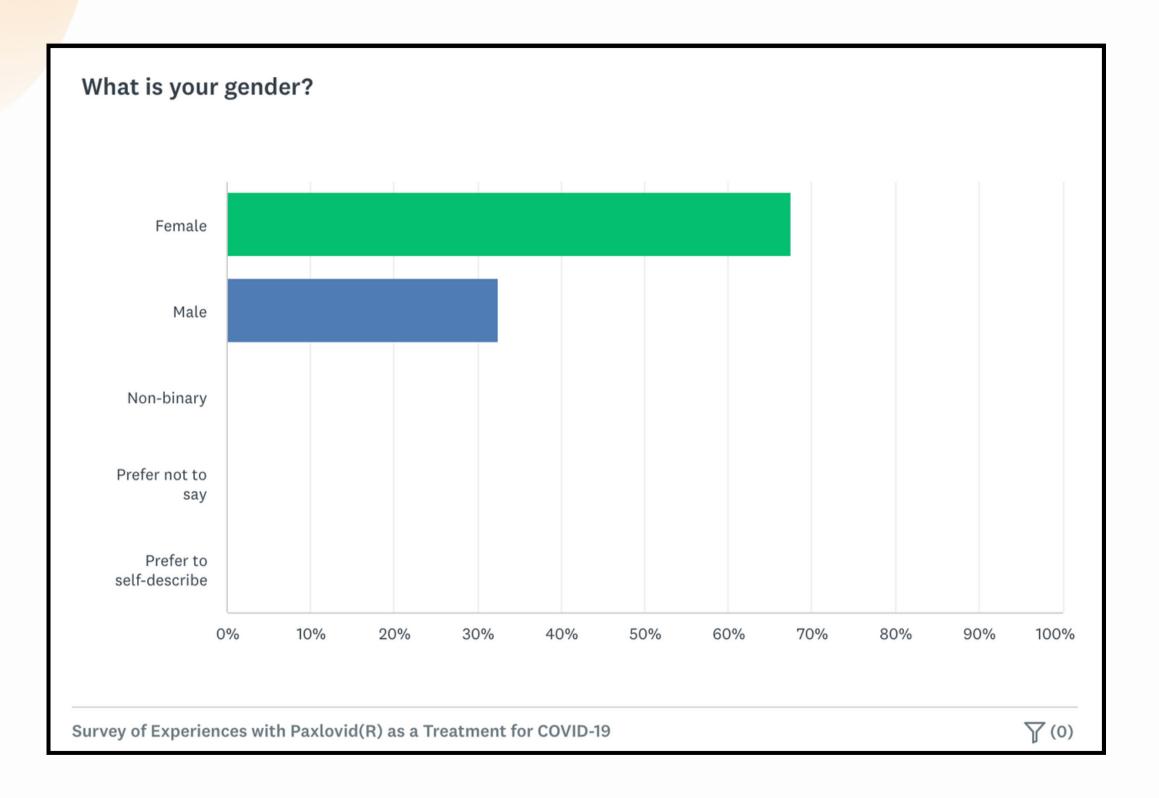
Save Your Skin Foundation developed this survey to gather patient experiences regarding the use of Paxlovid® as a treatment for COVID-19. The survey was open to everyone who has either experienced COVID-19, regardless of whether they received Paxlovid®, and others who wanted to contribute their opinion on the importance of accessible treatments for COVID-19. This information was used for Save Your Skin Foundation to prepare submissions for access to Paxlovid® to the Canadian Agency for Drugs and Technologies in Health (CADTH) and Institut national d'excellence en santé et en services sociaux (INESSS). This survey was endorsed and distributed by a variety of partner patient groups, to whom we are grateful for their support; a complete list of these organizations is available on the final page of this presentation.

Two versions of the survey were open from September 3-September 20, one in English and one in French. Data from both of the surveys was combined for the aforementioned CADTH and INESSS submissions. For this presentation, visual representations of the English results will be accompanied by description of the French data for each question.



### Survey Demographics: Questions 1-4

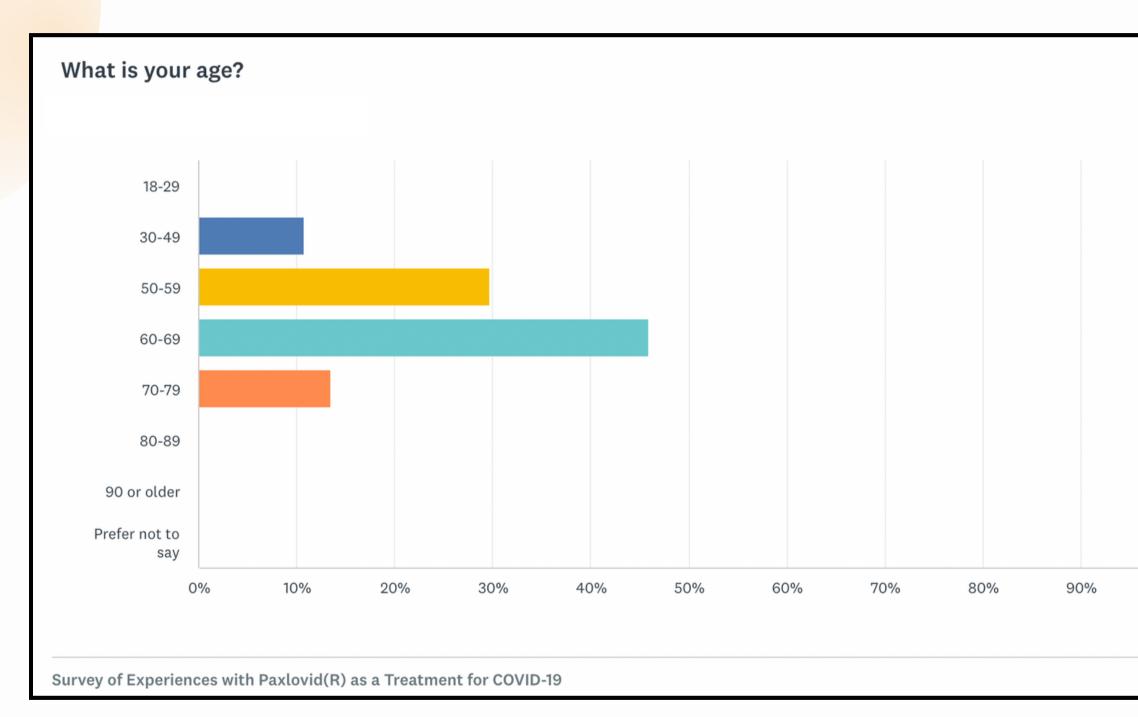




#### Question 1: Gender Indentification

100% of French language survey participants identified as female





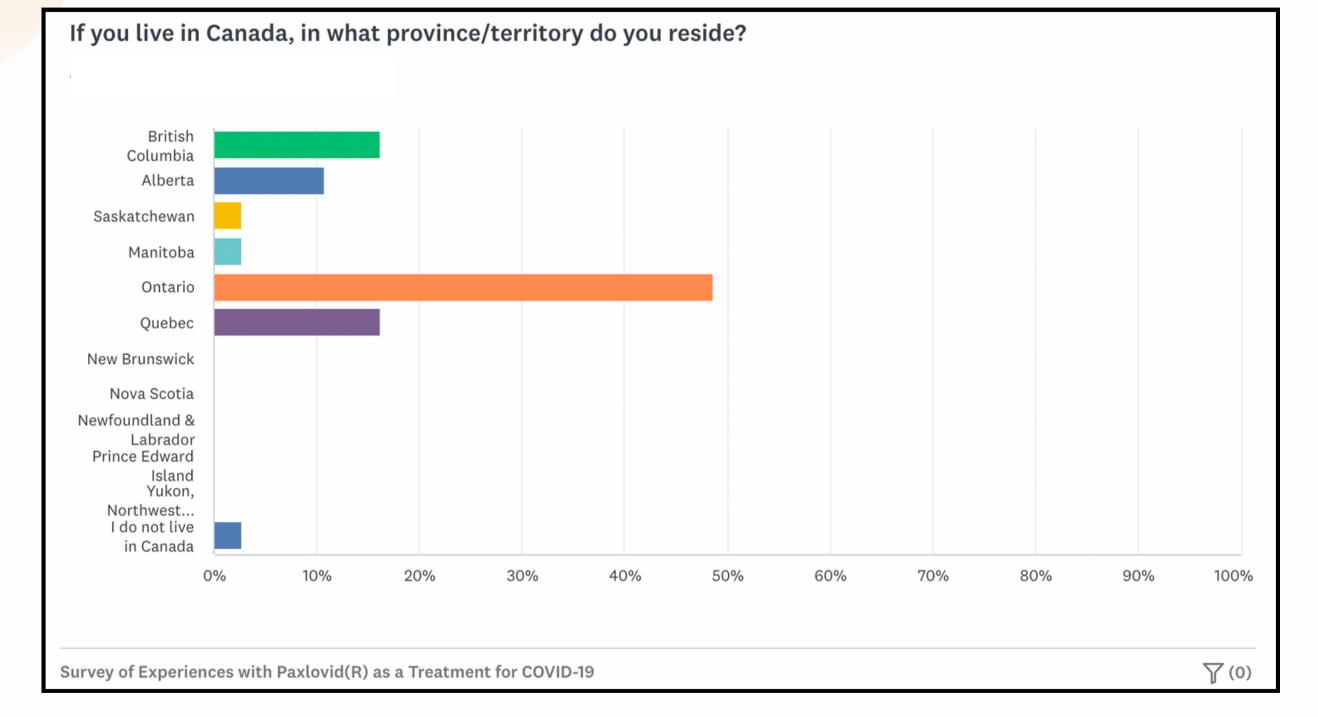
#### **Question 2: Age**

50% of French language survey participants were between ages 30-49 and the other 50% between ages 50-59

100%

了(0)





#### Question 3: Location

In question 3 of the French language survey, 100% of the participants reside in Quebec, other than the 1 participant who indicated in question 4 that they are in France.

In question 4, which asked participants where they were from if not Canada, all indicated that they were from Canada except for 1 participant from Italy.



## Participant Health Concerns and Risk Factors: Questions 5-7

#### **Question 5: Primary Health Concerns**

Survey participants across both the English and French language surveys listed the following as their primary health concerns:

- Cancer (various)
- Cancer treatment(s) side effects
- Multiple chemical sensitivity
- Follicular lymphoma
- Chronic psoriasis
- Autoimmune disease
- Chronic pain
- Cardiac issues
- Organ transplants

- Asthema
- Sleep apnea
- Irritable bowel syndrome
- Hypothyroidism
- Diverticulitis
- Fatty liver
- Diabetes
- Primary sclerosing cholangitis
- Scleroderma



#### Question 6: Secondary Health Concerns

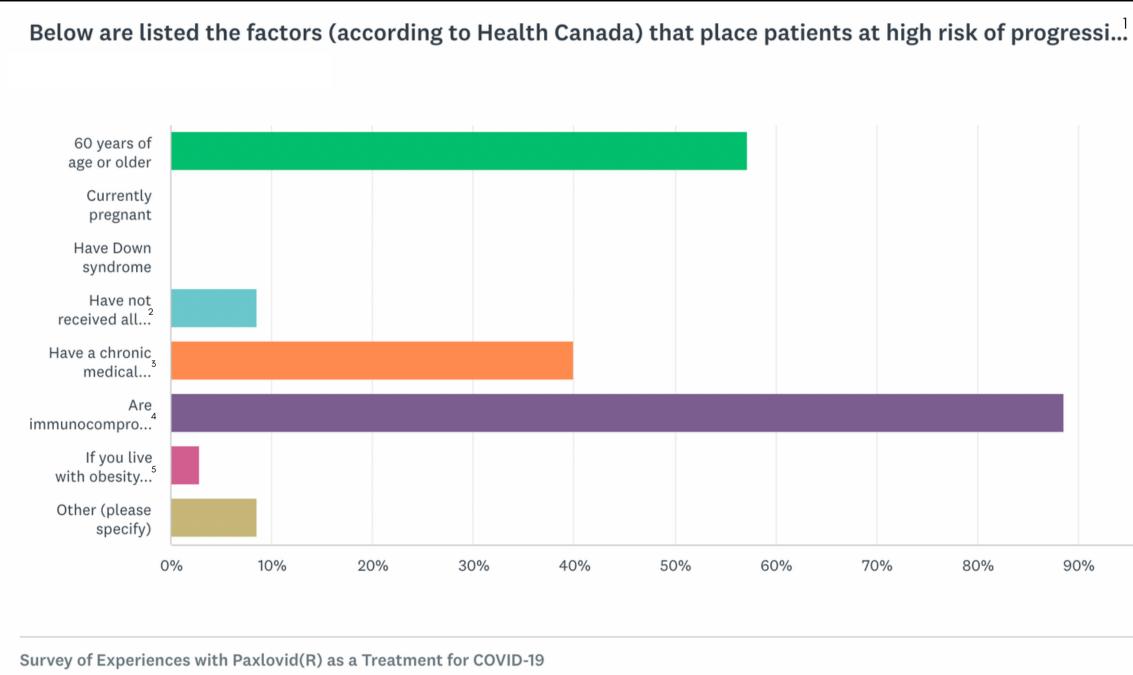
Survey participants across both the English and French language surveys listed the following as their primary health concerns:

- Cancer (various)
- Asthma
- Fibromyalgia
- Arthritis
- Long COVID symptoms
- Sarcoidosis
- Kidney stones
- Neuropathy
- Diabetes
- Lupus
- Atrial fibrillation

- Chronic pain
- Migraines
- Obesity
- Osteopenia
- Adrenal insufficiency
- Ulcerative colitis
- Autoimmune hepatitis
- High blood pressure
- Sjogrens
- Missing organs



#### **Question 7: (1) Risk Factors for High Risk of COVID-19 Progression According to Health Canada**



#### 100% of French language survey participants indicated that they were immunocompromised

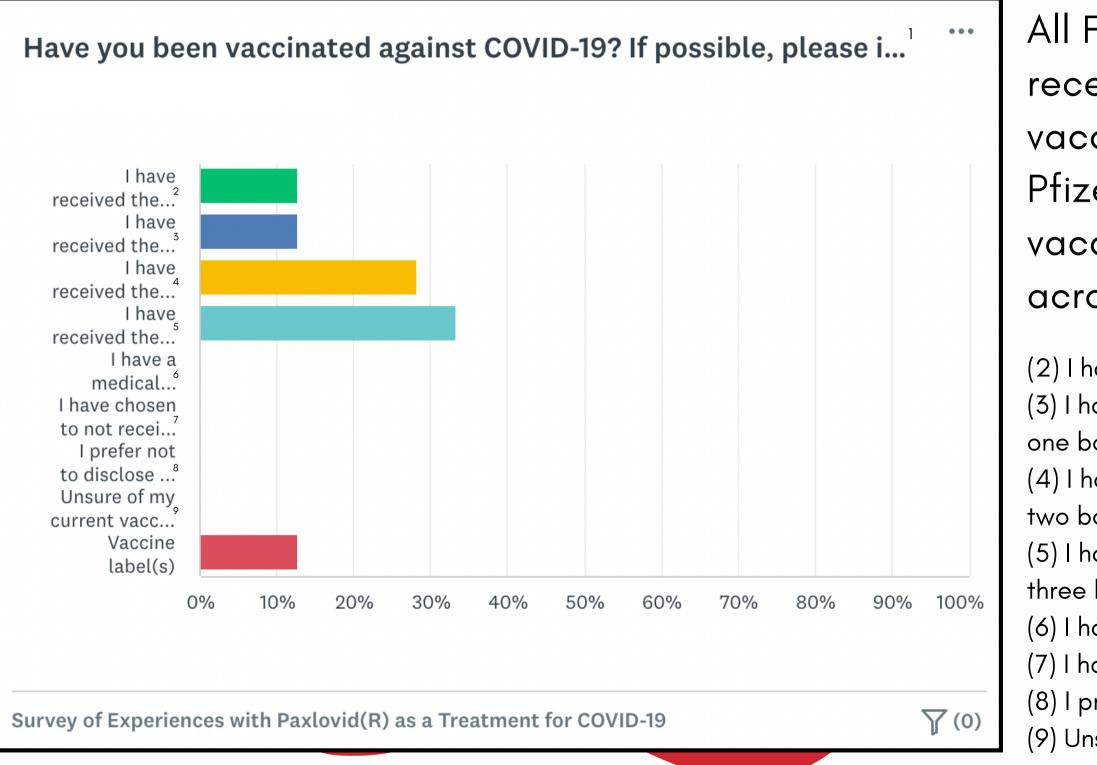
(2) Have not received all of your recommended COVID-19 vaccine doses (3) Have a chronic medical condition, such as: asthma (moderate to severe), dementia, diabetes, heart disease, high blood pressure, kidney disease, liver disease, lung disease, stroke (4) Are immunocompromised, including if you: have an underlying medical condition, such as cancer; take medications that reduce the immune response, such as chemotherapy; have had a solid organ or blood stem cell transplant (5) If you live with obesity (if you have a body mass index (BMI) of 40 or more)

100%

(0)

## **COVID-19 Vaccination Status** and Experiences: **Questions 8-13**

# Question 8: (1) Have you been vaccinated against COVID-19? If possible, please indicate which brand of vaccine(s) you have received in the comment box.



All French language participants have received their base COVID-19 vaccines plus at least one booster; Pfizer and Moderna were the only vaccine brands cited by participants across both surveys

(2) I have received the first two COVID-19 vaccinations(3) I have received the first two COVID-19 vaccinations plus one booster

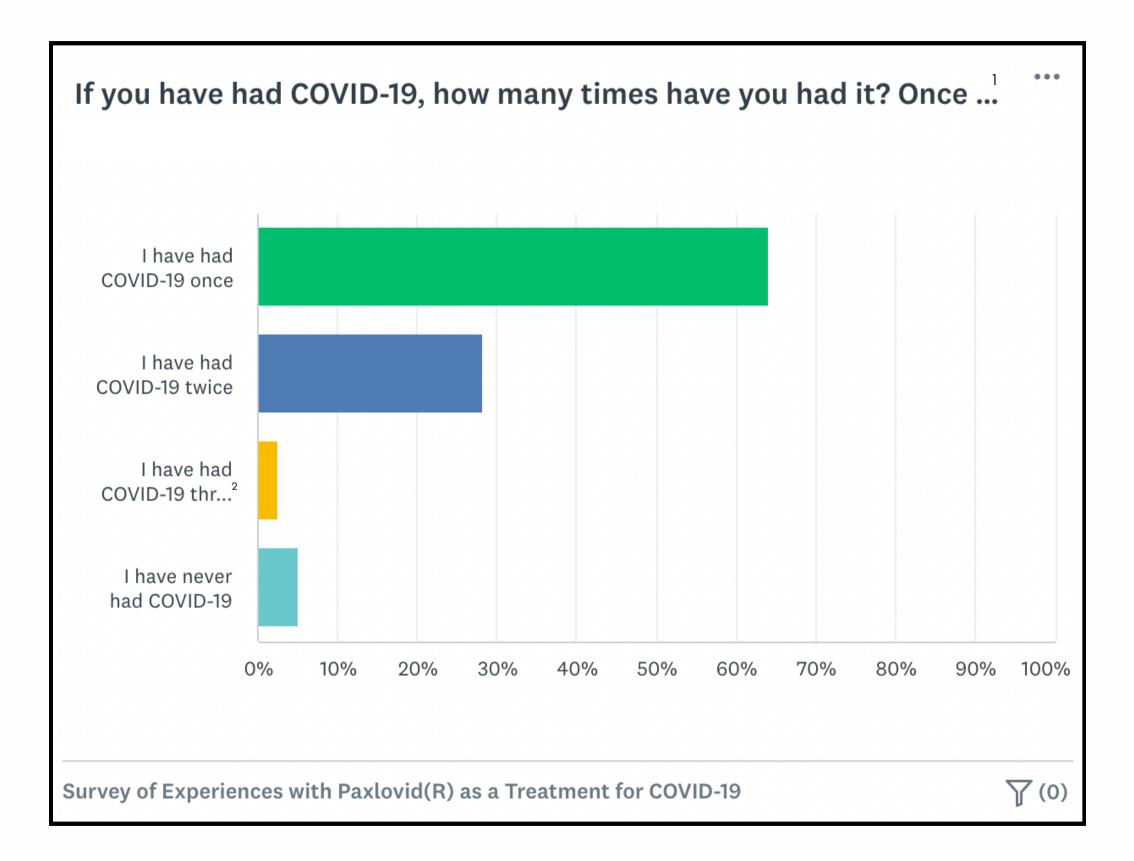
(4) I have received the first two COVID-19 vaccinations plus two boosters

(5) I have received the first two COVID-19 vaccinations plus three boosters

(6) I have a medical exemption from COVID-19 vaccination(7) I have chosen to not receive the COVID-19 vaccination

(8) I prefer not to disclose my vaccine status

(9) Unsure of my current vaccine status



#### Question 9: (1) If you have had COVID-19, how many times have you had it?

100% of French language participants have tested positively for COVID-19 twice

(2) I have had COVID-19 three or more times



#### Question 10: What kind of symptoms did you experience across your COVID-19 infections? Select all that apply.

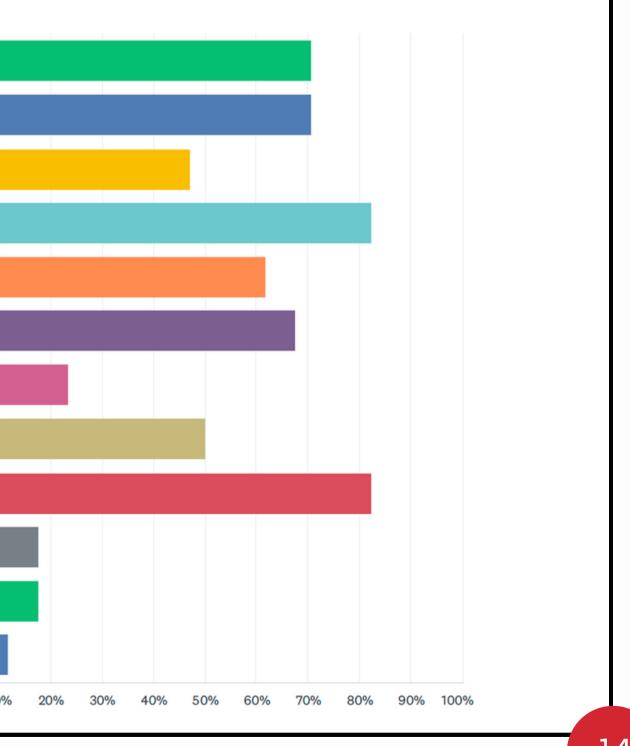
The French language participants expressed having experienced all of these side effects with the exception of congestion and vomiting

Other side effects contributed by participants in the comment section include phlegm buildup, dizziness, and increased heart rate

(1) Shortness of breath or coughing

Fever or chills Cough Shortness of breath or.. Fatigue Muscle or body aches Headache Loss of taste or smell Sore throat Congestion or runny nose Nausea or vomiting Diarrhea Other (please specify 0%

Q10 What kind of symptoms did you experience across your COVID-19 infections? Select all that apply. If you experienced something that is not on this list, please write it in under "other."



Question 11: (1) Overall, how would you rate the side effect severity of your COVID-19 side effects? If you have had COVID-19 more than once and the side effects manifested differently, please note this in the comment box below. If you were hospitalized for COVID-19, please also include this in the comment box.



This question asked participants to rate the severity of their COVID-19 side effects on a scale from 1–5, with 5 being the most severe.

The French language participants rated the severity of their side effects as 3.5 out of 5.

In the comments section, three (3) participants reported being hospitalized due to COVID-19 symptoms and recovery times of between 3 and 8 months were cited by multiple participants

了(0)

#### Question 12: Of the symptoms you listed in question 11, what symptoms did you find affected you most in your day-to-day life?

Survey participants across both the English and French language surveys listed the following when asked which of their COVID-19 symptoms most affected their daily life:

- Congestion
- Cough
- Headaches
- Vision disturbances
- Difficulty breathing
- Difficulty swallowing
- Sore throat

- Fatigue
- Diarrhea
- Fever
- Body aches
- Elevated heart rate
- Dizziness
- Nausea





#### Question 13: Do you believe that any of your COVID-19 symptoms were exacerbated by your other health concerns? If so, which ones?

Across both English and French language surveys:

- 31.03% of participants said no, they do not believe their COVID-19 symptoms were exacerbated by their other health concerns
- 10.34% said they were unsure
- Examples of exacerbated symptoms cited by participants include: asthma, autoimmune issues and being on immune system suppressants, cardiac conditions, cancers (multiple)
- One response noted being positive for long COVID for 10 months
- Another response stated that they waited in the hospital to receive treatment for more than 4 hours without water, painkillers, or any other care

"My symptoms progressed and included neurological issues such as strong headaches and associated disturbances, as well as visual disturbances. These issues have persisted for 8 to 9 months after the initial infection"

"I was hospitalized due to a high fever, and that's how my COVID-19 diagnosis was made"

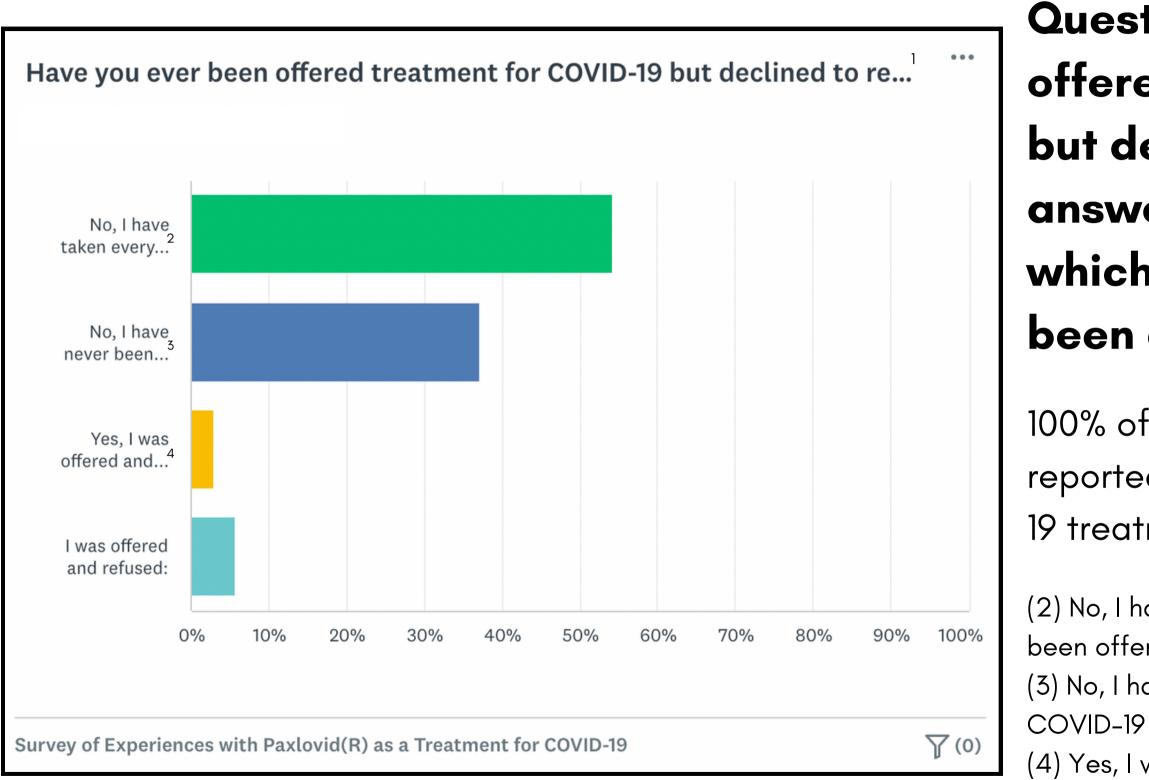
"During my second bout with COVID-19, I lost my sense of smell and taste. The first time, it took me 3 months to fully recover. The second time, it took about 2.5 months, but it felt worse than the first"

"I spent 10 days in the ICU"

"My symptoms continued for 6 months, and I was hospitalized three times during that period"

### Treatment for COVID-19: Questions 14-16





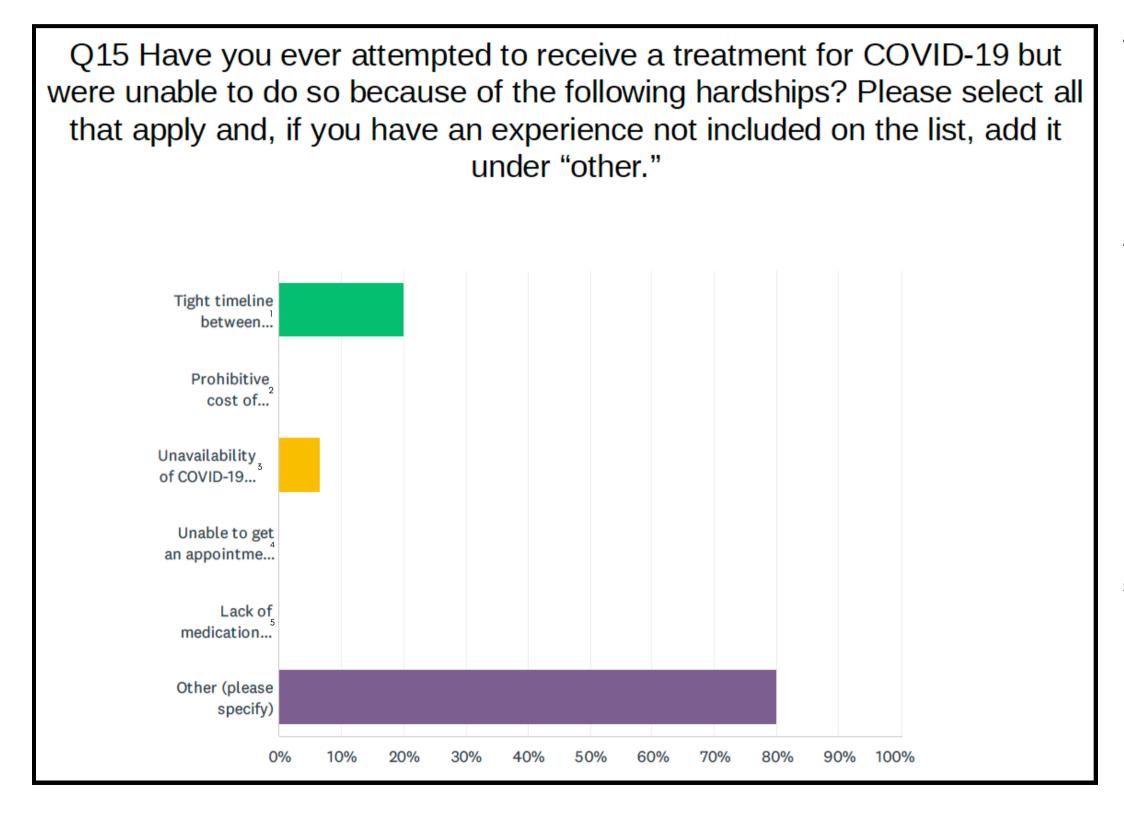
#### Question 14: Have you ever been offered treatment for COVID-19 but declined to receive it? If the answer is yes, please record which treatment(s) you have been offered and declined

100% of French language participantsreported that they have taken every COVID-19 treatment they have been offered

- (2) No, I have taken every COVID-19 treatment I have been offered
- (3) No, I have never been offered a treatment for COVID-19
- (4) Yes, I was offered and refused



#### Question 15: Have you ever attempted to receive a treatment for COVID-19 but were unable to do so because of the following hardships?



The French language did not report any hardships when accessing treatment for COVID-19

Additional comments from participants included being afraid to wait at the crowded hospital (in case they might catch something else), pharmacists being unwilling to prescribe COVID-19 treatment, and miscommunication between their healthcare providers

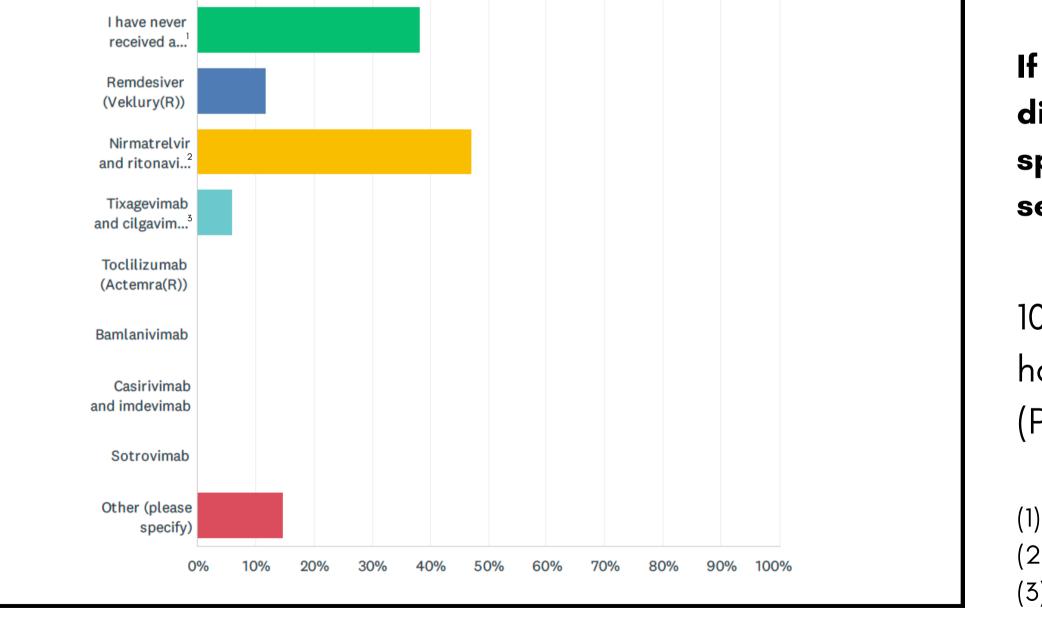
(1) Tight timeline between manifesting COVID-19symptoms and being able to take COVID-19 treatment(five days)

- (2) Prohibitive cost of COVID-19 test
- (3) Unavailability of COVID-19 test
- (4) Unable to get an appointment with doctor in time

20

(5) Lack of medication availability at pharmacy

Q16 Have you received a treatment for COVID-19? If so, please select all that apply. If you received these treatments during different COVID-19 infections, please specify this in the "more details" section.



#### Question 16: Have you received a treatment for COVID-19? If so, please select all that apply.

If you received these treatments during different COVID-19 infections, please specify this in the "more details" section.

100% of French language participants have received Nirmatrelvir and Ritonavir (Paxlovid®)

(1) I have never received a treatment for COVID-19

- (2) Nirmatrelvir and ritonavir (Paxlovid®)
- (3) Tixagevimab and Cilgavimad (Evusheld®)



### Access to Treatment for COVID-19: Questions 26-27

Please note that the next two questions in this presentation are the final two questions from the Paxlovid® survey, which were accessible by all participants regardless of whether they received Paxlovid®. This choice has been made to more clearly demarcate the general participant data from that related to Paxlovid®.



#### **Question 26: If applicable, please describe** your experiences with the COVID-19 treatmer you received that were not Paxlovid(R) in as much detail as you are able. Please specify which treatment you are discussing.

- 64% of responses indicated that this question was not applicable to them, either because they have not received a treatment for COVID-19 or because they have only received Paxlovid®
- Side effects from other treatments listed by participants include persistent cough for two months, ongoing headaches (since receiving Paxlovid®), long-term experiences of infection side effects, and feeling better for a week after receiving Remdesiver (Veklury<sup>®</sup>) only to be hospitalized again

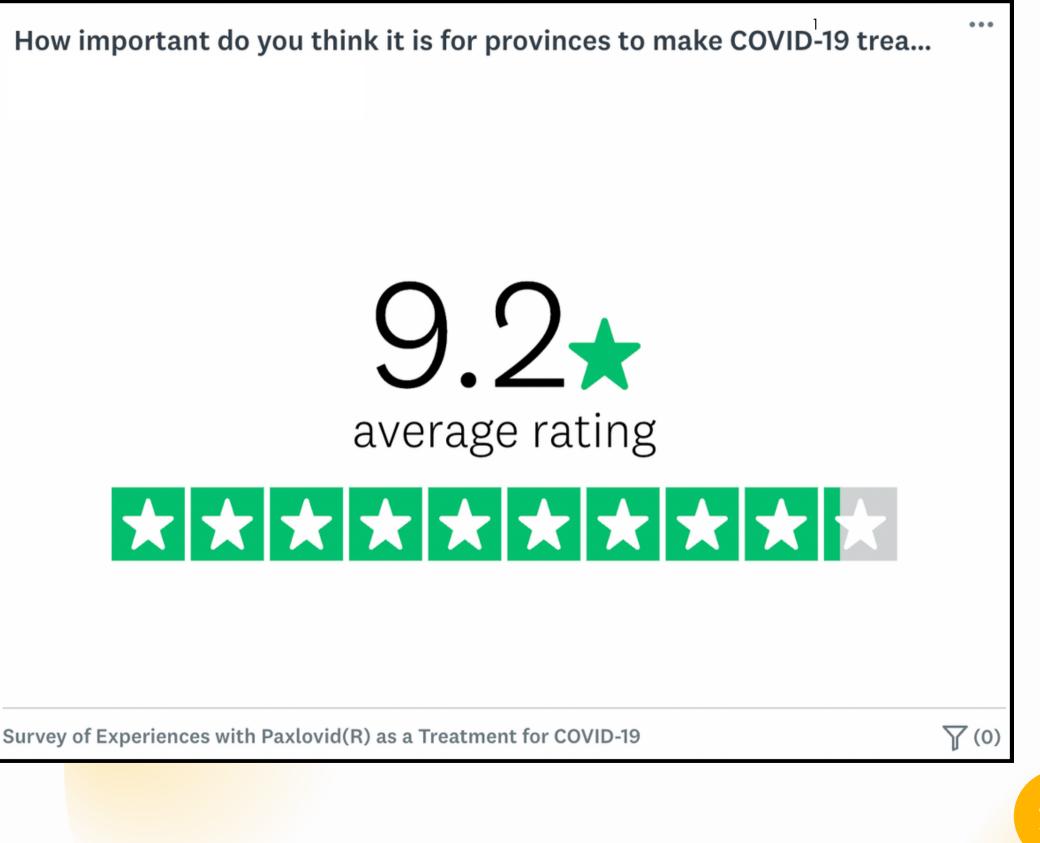
"Remdesivir was given during" first hospital stay, approx 1.5 months into covid infection. It wasoffered to me. Initially it seemed to work as I felt much better in 3-4 days and was releasedfrom hospital. But went downhill again a week later and was hospitalized again"

*"It helped me a lot but I had a* cough for 2 months I would say"

Question 27: (1) How important do you think it is for provinces to make **COVID-19 treatments** available to patients that are at high risk for progression to severe COVID-19?

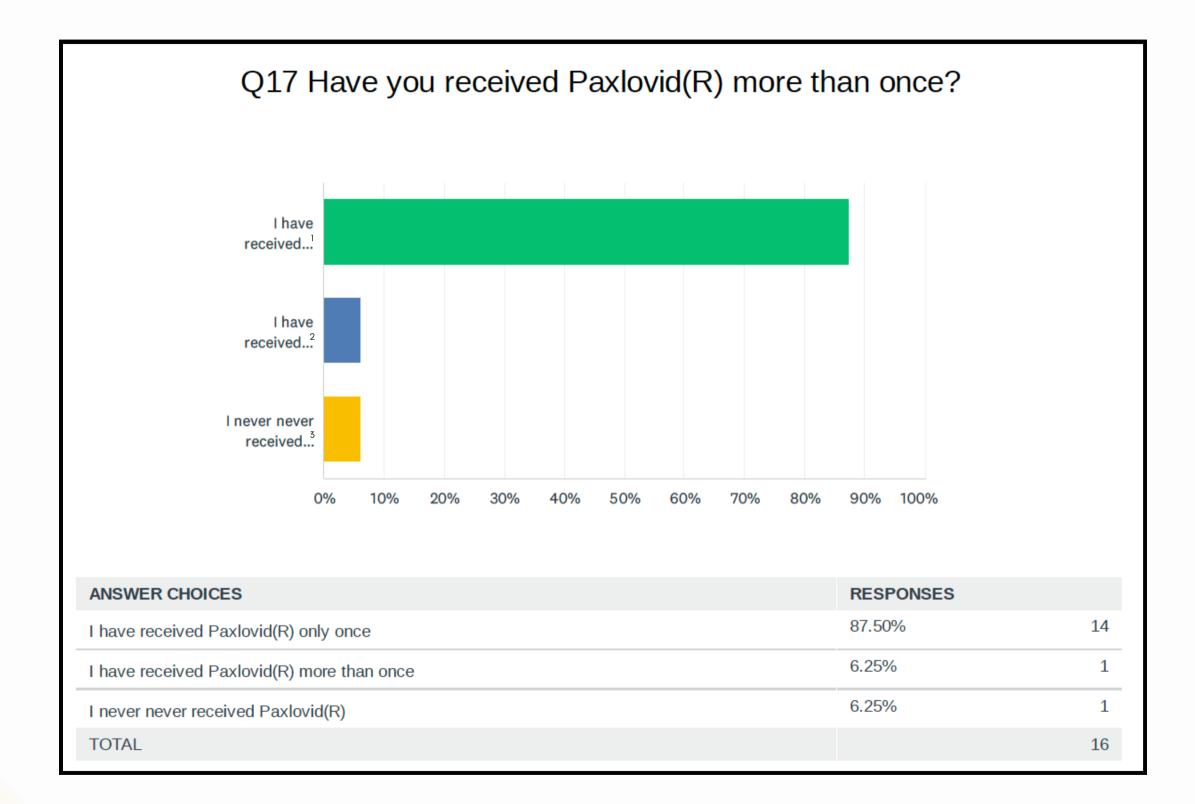
Participants were asked to rank the importance of accessible COVID-19 treatments on a scale from 1–10, with 10 being of the utmost importance.

French language participants rated this question an 8.5 out of 10.



# Questions Related to Paxlovid® as a Treatment for COVID-19: Questions 17-25

This section of the survey was only open to participants who have received Paxlovid® as a treatment for COVID-19.



#### Question 17: Have you received Paxlovid® more than once?

100% of French language participants reported that they have taken Paxlovid® more than once

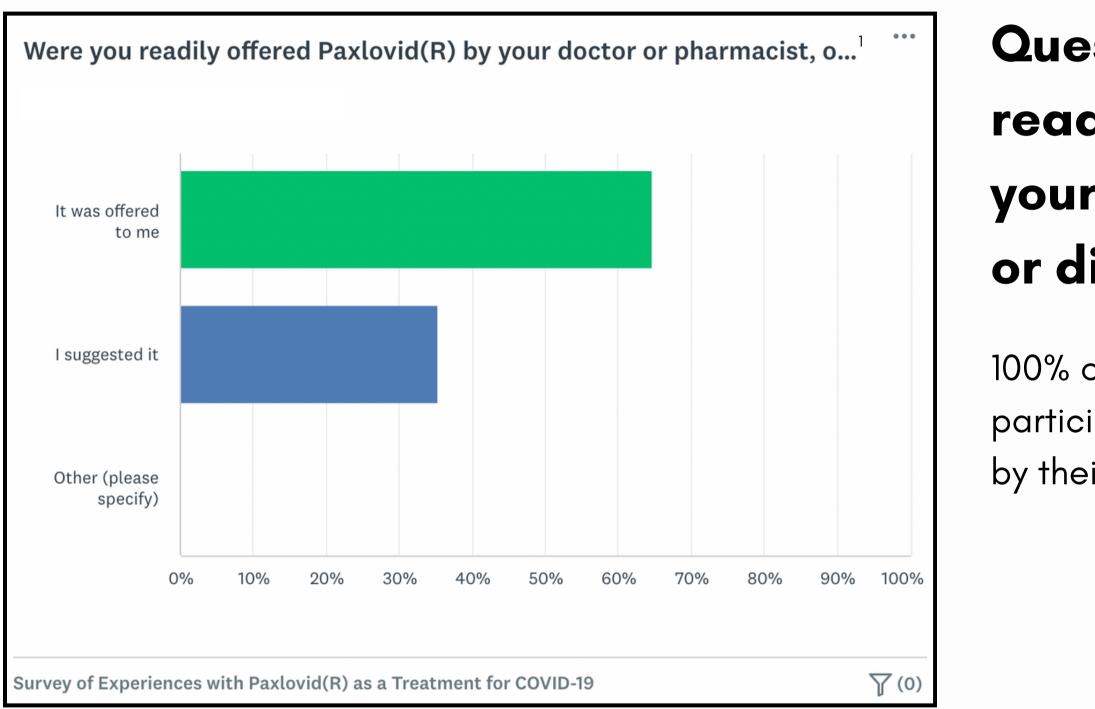
(1) I have received Paxlovid® only once
(2) I have received Paxlovid® more
than once
(3) I never never received Paxlovid®



#### Question 18: If you have had COVID-19 more than once, have you received a treatment other than Paxlovid® at a different time? If so, what treatment and when?

Across both the English and French language surveys, 100% of participants who have received Paxlovid® as a treatment for COVID-19 have only received Paxlovid®



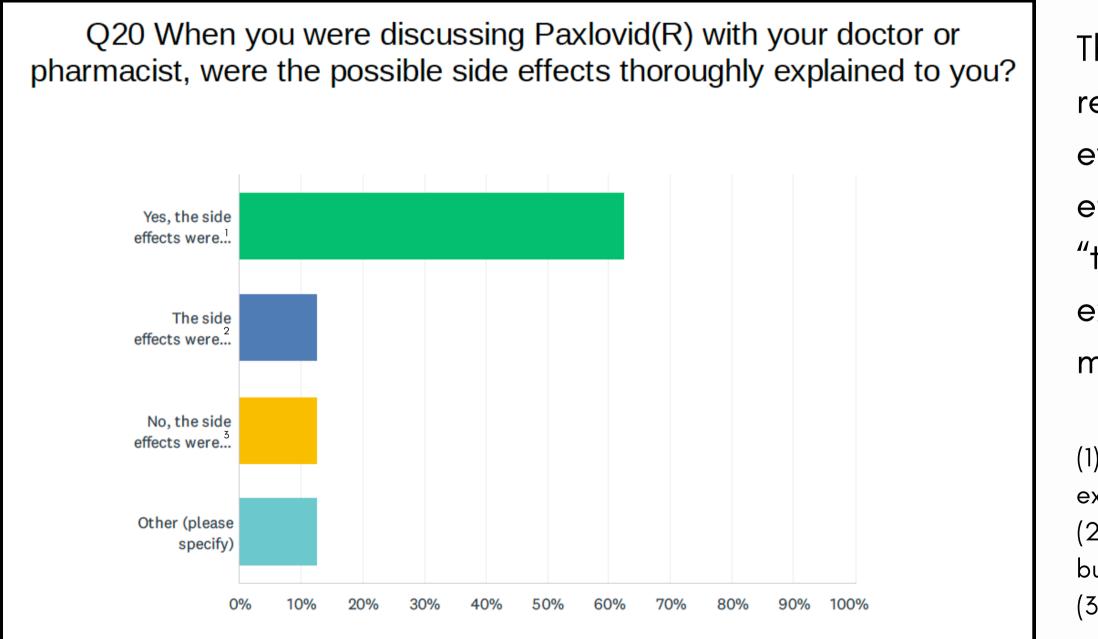


### Question 19: (1) Were you readily offered Paxlovid® by your doctor or pharmacist, or did you suggest it?

100% of the French language participants were offered Paxlovid® by their healthcare provider



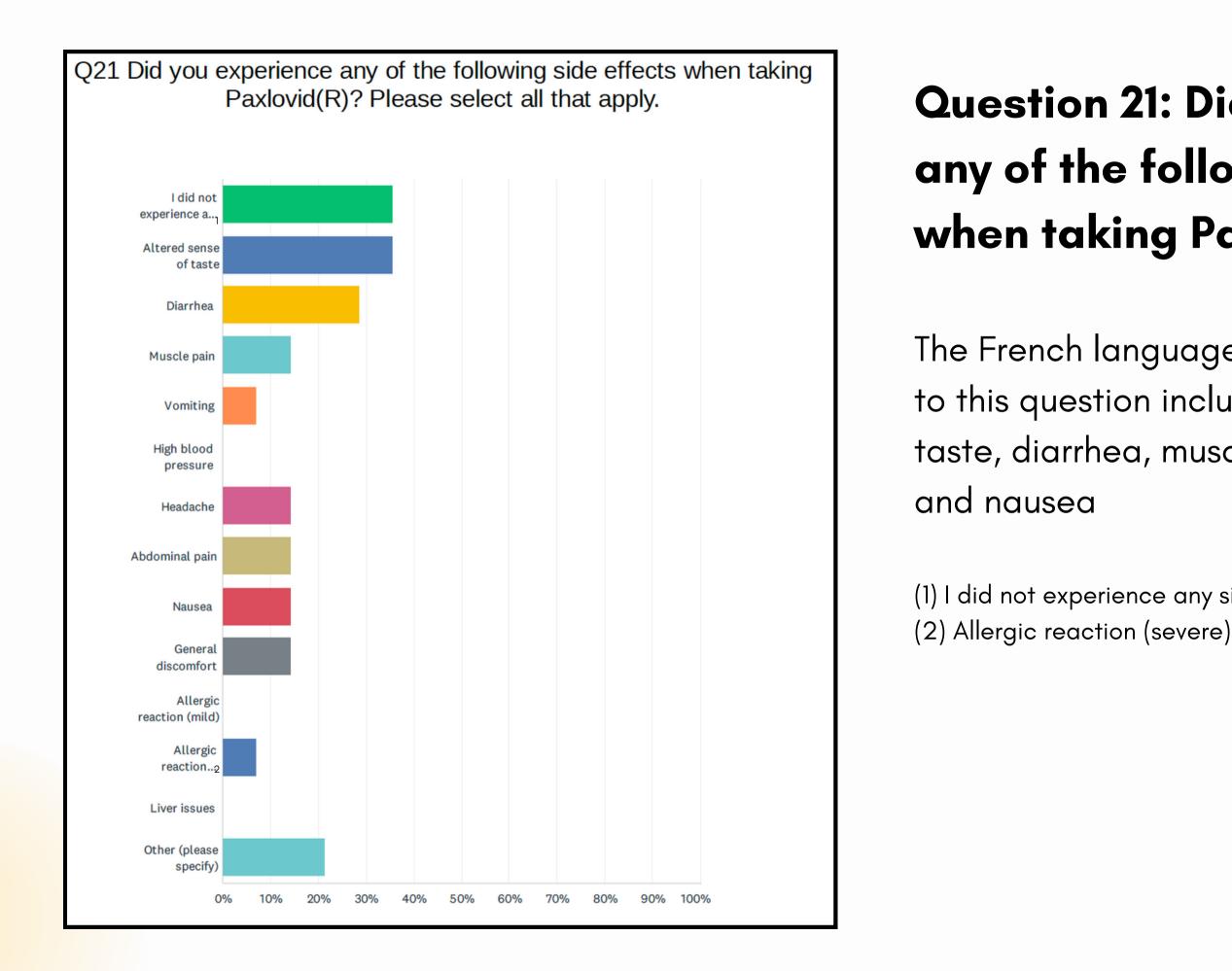
# Question 20: When you were discussing Paxlovid® with your doctor or pharmacist, were the possible side effects thoroughly explained to you?



The French language participant responses to this question were evenly split between "yes, the side effects were explained to me" and "the side effects were somewhat explained, but I could have used more information"

(1) Yes, the side effects were completely explained to me
(2) The side effects were somewhat explained, but I could have used more information
(3) No, the side effects were not explained to me



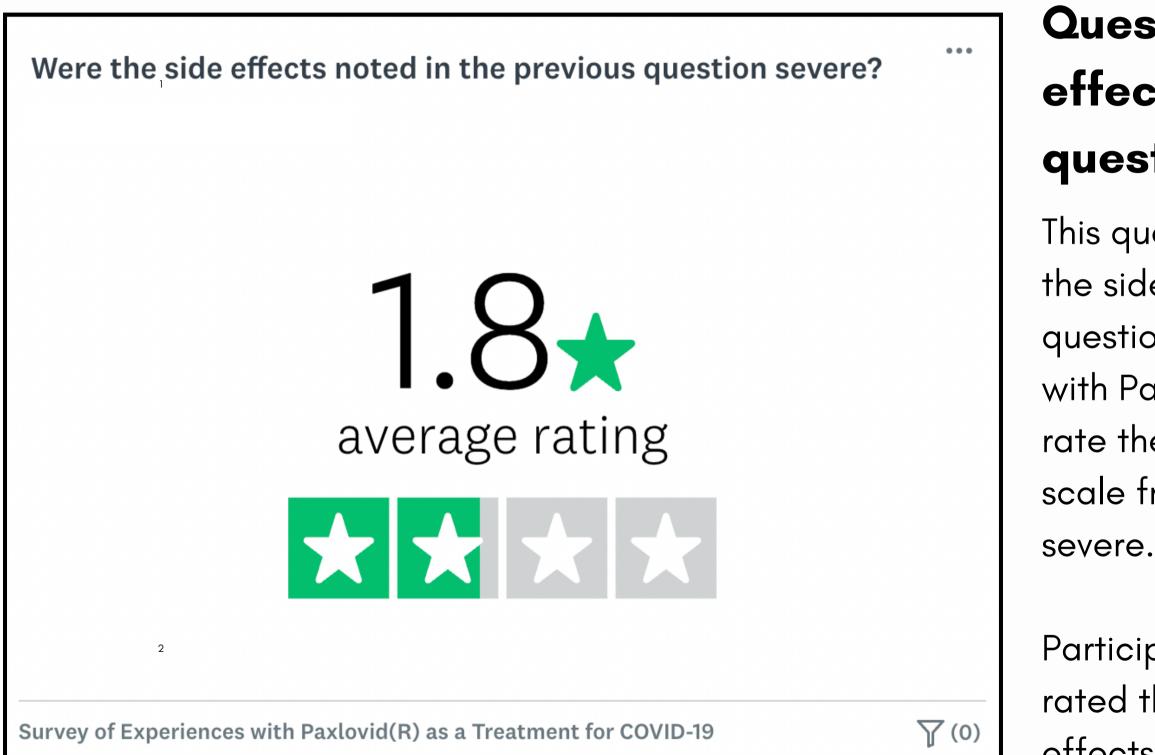


#### **Question 21: Did you experience** any of the following side effects when taking Paxlovid®?

The French language participant responses to this question included altered sense of taste, diarrhea, muscle pain, headache,

(1) I did not experience any side effects

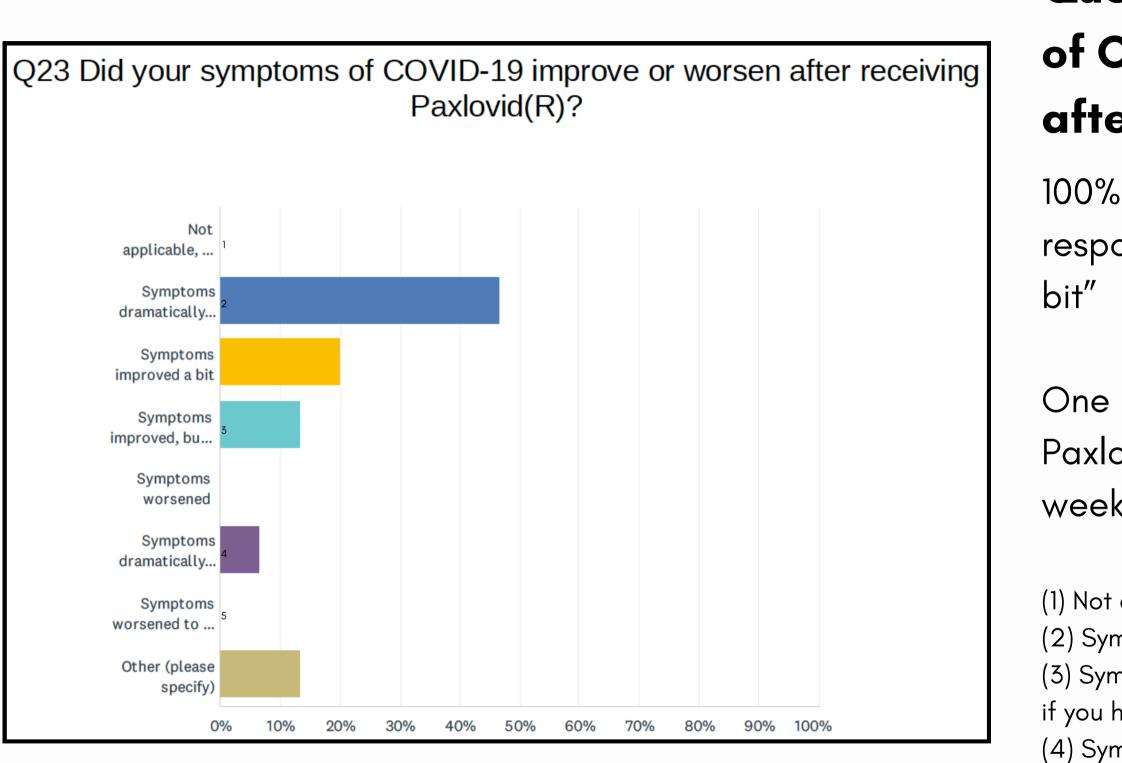




#### Question 22: Were the side effects noted in the previous question severe?

This question asked about the severity of the side effects participants cited in question 21, which were those associated with Paxlovid®. Participants were asked to rate the severity of these side effects on a scale from 1–5, with 5 being the most severe.

Participants in the French language survey rated the severity of their Paxlovid® side effects as a 2 out of 5.



#### **Question 23: Did your symptoms** of COVID-19 improve or worsen after receiving Paxlovid®?

100% of the French language participants responded that their symptoms "improved a

One participant noted that after taking Paxlovid® their symptoms improved for one week before dramatically worsening

(1) Not applicable, did not experience symptoms (2) Symptoms dramatically improved (3) Symptoms improved, but seemingly on a normal timeline (as if you had not received the treatment in question) (4) Symptoms dramatically worsened (5) Symptoms worsened to the point of hospitalization

# Question 24: Did you experience any hardships that barred you from accessing Paxlovid®?

Was the treatment readily available to you? Hardships could mean having to travel long distances; the tight timeline between symptom manifestation and receiving Paxlovid®; the cost of lack of availability of COVID-19 tests; or not being able to get Paxlovid® from the pharmacist, for example.

Across both the English and French language surveys:

- 50% of participants reported experiencing no hardships to accessing Paxlovid®
- 25% reported that their pharmacist refused to prescribe it to them
- Others reported hardships in the form of restrictive pharmacy hours, the lack of medication delivery service, and the tight timeline between symptom manifestation and prescription
- Due to lack of availability, one participant had to drive over an hour to another city to access Paxlovid®

"It was difficult to get the Paxlovid due to the Pharmacy hours of operation, lack of delivery service"

"Could not get it from the pharmacist due to my kidney and liver issues. Needed to see a doctor for a prescription. Had to get to doctor asap despite being very sick. Forced to make a quick decision because the treatment window was almost over. Had to find a pharmacy that would deliver asap."

"Pharmacist initially refused to prescribe, but then changed his mind and called back"

"My husband had to drive me to another city an hour away to get the medication"

#### Question 25: How important is/was it to you and your family members or caregivers that you received Paxlovid®?

Across both the English and French language surveys:

- 58.82% reported that it was very/critically important that they received Paxlovid® to treat their COVID-19 infection
- 29.41% reported that Paxlovid® helped to alleviate their COVID-19 symptoms
- 17.64% reported that they had specifically wanted to avoid hospitalization and felt confident that they were able to because they had received Paxlovid®
- 11.76% felt reassured that they would be able to manage their symptoms after receiving Paxlovid®

"Very important. The Paxlovid option gave me and my oncologist reassurance when I was travelling."

"Because it was advised by the physician, I took this drug. My breathing difficulties were advancing at the time that COVID was evident."

"Incredibly important. Given how quickly and severely my symptoms came on, I'm certain I would have ended up hospitalized without it."

### **Key Takeaways**

Across both the English and French language surveys:

- On a scale from 1–10, with 10 being "critically important," participants on the English survey rated access to Paxlovid® as a 9.2; the French survey rated this as an 8.5
- Survey participants with comorbidities noted that their COVID-19 symptoms exacerbated their other symptoms, as per these patient quotations:
  - "Was receiving targeted therapy at the time, obinutuzumab, I couldn't shake off the symptoms, developed pneumonia"
  - "Long covid I was positive for 10 months. I had covid soon After my last [chemo]"
  - "I'm already on pain meds, so they make me tired and COVID added on to it"
  - "Probably. What might have increase[d] the symptoms are the asthma, the sleep apnea (not able to wear my CPAP machine), obesity"
  - "Coughing as I have one lung"
- A participant highlighted the challenge of going to the hospital to receive Paxlovid® rather than the pharmacy, given the overwhelm on the medical system from COVID-19: "Because of the asthma, I had short breath and the pharmacist refused to give me the medication, but recommended I go to the hospital to receive the medication via IV and to be monitored. I didn't go as the ERs were so overflowing"
- Survey participants rated the side effects of Paxlovid® as a 3.2 (3.5 on the French survey) out of 5 on a scale where 5 indicated highest severity, whereas they marked the side effect severity of Paxlovid® as a 1.9 (2 on the French survey). This significant decrease demonstrates that participants found the side effects related to Paxlovid® were more manageable than those associated with COVID-19, which can be a meaningful difference to those with comorbidities (as seen above).

35

# Thank you to our partner organizations who shared this survey to their networks:





EQUAL AND FAIR CANCER TREATMENT FOR ALL





AWARENESS. SUPPORT. EDUCATION.



SENSIBILISER. SOUTENIR. ÉDUQUER.



Canadian Skin Patient Alliance Alliance canadienne des patients en dermatologie







saveyourskin.ca | sauvetapeau.ca | info@saveyourskin.ca

#### LA FONDATION Sauve ta peau

