

Online Supplement

Patient-Driven Research Agenda: What Needs to be Studied in Those Living with COPD During the Coronavirus Disease 2019 Pandemic

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Supplementary Table S1. COPD & Coping with COVID Pandemic Survey

1. Do you consider yourself: *(check all that apply)*

- Patient with COPD, bronchiectasis and/or NTM
- HCP
- Caregiver
- Other option:

2. What is your age:

- Less than 40
- 40-49
- 50-59
- 60-69
- 70-79
- 80 or older

3. Do you consider yourself a:

- Female
- Male
- Other (please specify - optional)
- Prefer not to Answer

Activities- Your usual activities and personal care needs

How has the COVID pandemic affected your level of concern, worry or anxiety about each of the things you may need or want to do? *(Please select the best answer for each line)*

Issues	Caused me to be very concerned, worried or anxious	Caused me some increased concern, worry or anxiety	No change	Not applicable
Getting groceries or meals (a)				
Doing or getting personal care such as bathing or hair care or getting laundry done (b)				
Doing exercise or activity (c)				
Attending functions such as family celebrations, social gatherings, club meetings, religious services (d)				

Doing volunteering or working outside my home (e)				
Not being with ill or dying friends or family members (f)				
Doing online shopping for basic needs(g)				

4. Are there other concerns or worries about your usual activities and personal care? _____

Living Situations:

How has the COVID pandemic affected your level of concern, worry or anxiety about any changes to your living situation and/or taking care of your home? *(Please select best answer in each row)*

Issues	Caused me to be very concerned, worried or anxious	Caused me some increased concern, worry or anxiety	No change	Not applicable
Care of your home, inside or out, like cleaning, yardwork or repairs (a)				

Living arrangements: Having to move, or have family or others move in with me (b)				
Getting mail or online purchases delivered to my door & signing for them (c)				
Trying to do work or help others do work or schoolwork from home (d)				

5. Are there other concerns or worries when it comes to your living situation? _____

Health care use & Self-management:

How has the COVID pandemic affected your level of concern, worry or anxiety regarding **getting medicines, health care, oxygen and your other health care needs?** *(Please select the best answer for each line)*

Issues	Caused me to be very concerned, worried or anxious	Caused me some increased concern, worry or anxiety	No change	Not applicable

Getting medicine due to shortages or higher costs during this period (a)				
Having trouble getting to pharmacy or having medicines delivered (a)				
Concerns about risks of using nebulizer at home (a)				
Fear of going to doctor's office or office not open for sick visits (b)				
Learning to use and when and how to use telehealth (b)				
Cannot get tests I needed like pulmonary function or spirometry or CT scans (b)				
Do not know what visits or tests like spirometry or "elective" procedures can be safely delayed (b)				

Trouble getting my home health care services (c)				
Fear of going to emergency room when I need to do so (d)				
Fear of going to hospital for my COPD because of COVID risk (d)				
Fear of being alone if I am in hospital (d)				
Cannot get or continue my pulmonary rehabilitation program or after care (e)				
Don't know how to get or cannot find mental health services (f)				
Uncomfortable getting mental health services in person or by telehealth (virtual visits) (f)				

Trouble getting oxygen delivered or set up in my home (g)				
Fear that I or family or friends will get COVID (h)				

6. Are there other concerns and worries you have about health-care use and self-management? _____

Getting and interpreting data on risk, safety, suggested actions:

How has the COVID pandemic affected your level of concern, worry or anxiety **about finding and using information about COVID?** *(Please select the best answer for each line)*

Issues	Caused me to be very concerned, worried or anxious	Caused me some increased concern, worry or anxiety	No change	Not applicable
Where to find accurate information about my COVID risks & how to prevent getting COVID, now and in the future (a)				

Understanding information after I get it and what it means for me (b)				
Getting information from my doctor or office (b)				
Confusion when information and recommendations change over time or conflict (c)				
How to explain information and recommendations for me to people and friends without COPD (d)				
Getting too much information—overload (e)				

7. Are there other concerns or worries about receiving or interpreting data? _____

New Norm:

How has the COVID pandemic affected your level of concern, worry or anxiety when you think about what might be the **new “normal” following this COVID pandemic surge?** *(Please select the best answer for each line)*

Issues	Caused me to be very concerned, worried or anxious	Caused me some increased concern, worry or anxiety	No change	Not applicable
Knowing if I will ever be able to go out, or work or volunteer again (a)				
Not knowing what is safe to do (a)				
Not knowing how I will maintain friendships (a)				
Not knowing if a vaccine will be developed, if I will be able to take it or if it will work (b)				
Not knowing if I will get to do the “bucket list” I had planned (c)				
Not knowing if I will get to visit children, grandchildren and family members (c)				

<p>Not knowing what my life will look like in the future (c)</p>				
<p>Not knowing if I will recover from the stress, depression or anxiety caused by the pandemic (d)</p>				
<p>Feeling older people and their needs are being ignored (d)</p>				

8. Do you have other concerns or worries with the “New Norm”? _____

Coping strategies and abilities

Just a few final questions about coping during the COVID pandemic:

9. How much more difficult is it to cope during the COVID pandemic? *(Give us your best answer)*

- A lot
- A little more difficult
- No change
- A little easier
- A lot easier

10. Have you been able to identify ways to cope? *(Give us your best answer)*

- Yes, several ways to cope

- Yes, a few ways
- No, could not find ways
- No, have not even tried

11. Do you know where to find potential resources on how to cope? (check all that apply)

- I have no idea
- I have some ideas
- I need help finding ways

12. Do you think you need new coping strategies due to the COVID pandemic? (Give us your best answer)

- Yes, need new ones
- No, the old ones work
- I don't even know
- I don't use coping strategies

13. How well do you think you are currently coping? (Give us your best answer)

- Very well
- Pretty well
- Don't know
- Not coping well
- Coping very badly

Supplementary Table S2. All 25 topics with number of votes received

Daily Quality of Living

- Getting COVID-19 on top of my COPD or other chronic lung disease affects most of my thoughts or actions. (395)
- Doing the activity or exercise I need to maintain my health, breathing ability and well-being. (330)
- Wearing masks--when and which ones to try and what to do if I cannot breathe when wearing a mask. (328)
- Getting all or enough of my COPD or other chronic lung disease medicines due to shortages, costs or trouble having them delivered or me getting to the pharmacy. (223)
- Being able to recover from or get help for the stress, depression and/or anxiety caused by the pandemic. (166)
- Continuing to do volunteer activities or work outside my home that are important to the community and to my self-worth and health. (151)
- Getting the food/meals I need to maintain my health and well-being while not putting myself at risk. (137)
- Getting personal care support that I need due to my COPD so I can maintain my health and interact with others in person or by distance such as on social media. (78)
- Being able to pay my bills due to things happening since the pandemic started including higher costs, need for more help or losing income. (77)

Family, Friends and Social Concerns

- Being able to be with or attend family functions/celebrations or social gatherings. (326)
- Dying alone at home or in hospital with no one able to be with me or to allow me to say goodbye to family and friends. (151)
- Trying to explain my concerns about COPD and COVID-19 to family or friends. (84)