Questions + answers from the
COPD Education Workshop

February 17th, 2018
The Villages, Florida
Dear participant,

Thank you for attending the workshop on COPD for patients and caregivers that was held on Feb 17, 2018 in The Villages, Florida:

Morning session: Oxygen therapy panel + COPD 101
Afternoon session: Breakout sessions
Closing session: Getting involved in COPD advocacy + research

We at UI Health appreciate your interest in the workshop. We were happy to receive many questions throughout the sessions, but we were not able to answer every question during the workshop.

We provided answers to your questions below grouped into 9 themes:

Theme 1: General questions about COPD (page 3, questions 1-4)
Theme 2: Ways to use oxygen (pages 4-7, questions 5-23)
Theme 3: Symptoms to watch out for (pages 8-9, questions 24-28)
Theme 4: Oxygen safety (page 10, questions 29-31)
Theme 5: Traveling with oxygen (page 11, questions 32-33)
Theme 6: Companion treatments (page 12, questions 34-35)
Theme 7: Equipment issues and maintenance (pages 13-15, questions 36-51)
Theme 8: Service issues and advocacy (pages, 16-17, questions 52-59)
Theme 9: Other (page 18, question 60)

Some questions have been edited for clarity and we were not able to answer every question. Questions marked with YELLOW would be better answered by others like a respiratory therapist or a peer who also lives with COPD. Questions marked with RED require more information or further research by the scientific community to answer.

Please discuss and clarify further specific medical and clinical recommendations with your trusted healthcare providers. We encourage to use the document as a general source of information and to use additional resources from the COPD Foundation and the American Association for Respiratory Care.
Theme 1

General questions about COPD

1. **What is respiratory therapy?**
   Respiratory therapy is a specialty that involves health-care professionals who receive 2-4 years of formal training at accredited institutions in evaluation and management of patients with lung disease, use of mechanical ventilation and equipment. For further information, please check out the website from the American Association for Respiratory Care (www.aarc.org).

2. **How do I know the questions I should be asking if I'm new to this?**
   Write down all general problems, concerns, issues regarding oxygen therapy and discuss with your clinician. The COPD Foundation has a brochure "Optimal Care for COPD" and other single topic Slim Skinny Reference Guides that can help you decide what additional questions you should ask your healthcare professional.

3. **How often should you be seeing your pulmonary doctor to be tested?**
   Regular visits with pulmonologist are recommended, this depends on how you do clinically and should be discussed with pulmonologist (if you have more or less symptoms/problems with your oxygen). Generally, a short term follow-up (within 1 month) is recommended after admissions for COPD exacerbations to ensure recovery and address any issues with oxygen. You should talk to your doctor about getting your oxygen needs retested around 3 months after you start oxygen.

4. **What will medicine do to help us oxygen users?**
   The scientific community needs to do more research to answer this question.
Theme 2: Ways to use oxygen

5. Is it a fallacy that once you're on oxygen you'll be on it forever and dependent?
No, oxygen cannot make you addicted. However, supplemental oxygen helps the body maintain a level of oxygen in the blood necessary for your body to function, if your body is not able to do it by itself. In that sense, your body will depend on the supplemental oxygen. In general, patients remain on oxygen for a prolonged period of time, i.e. years, but in some patients, the oxygen level in the blood can increase to levels above the threshold to meet criteria for supplemental oxygen, e.g. when you are put on oxygen during a COPD exacerbation but recover afterwards, these patients sometimes can come off of oxygen.

6. Why do I need oxygen sometimes and not at other times? (Sometimes I'm on it and off it, when I'm in and out of the hospital)
Please see the answer to the question above.

7. Why oxygen? Isn't there something I can do to stay off of it?
It is difficult to predict which patient will require oxygen during the course of their disease. Sometimes patients get started on oxygen for reasons other than COPD, like heart failure or pulmonary hypertension. General recommendations for your COPD care include: get regular check-ups with your pulmonologist, stop smoking, stay active, and get your vaccinations to stay as healthy as possible. These can help avoid COPD exacerbations and progression, all of which can cause you to need oxygen.

8. How much oxygen should I use per minute?
This depends on determination of oxygen needs. Your clinician would usually do testing of your oxygen needs at rest, with activity, and with sleep.
Theme 2: Ways to use oxygen, continued

9. **What number am I on and can I change it?**  
   Similar to the #8 above, please see the answer there.

   If you have a pulse oximeter at home to measure your saturation levels throughout the day, you can discuss with your doctor and respiratory therapist about how to titrate your oxygen based on your saturation readings. That way, you can have an action plan on what to do in different situations.

   An example of a guideline might be: if you find you often need to use more liters per minute than you were initially prescribed to maintain saturation you should call your doctor to make sure there isn't a bigger health concern that needs evaluation.

   Don’t wait until you "feel bad" to check your saturation or use your oxygen. Some patients will not feel short of breath but do in fact have a low saturation.

10. **What times do you need to actually use this oxygen?**  
    Similar to the question above. This depends on the determination of your oxygen needs. Clinician would usually do testing of your oxygen needs at rest, with activity, and with sleep.

11. **When do I use oxygen?**  
    Similar to question above. Please see answer there.

12. **How do I know when I need daytime oxygen?**  
    Similar to question above, this depends on determination of oxygen needs. A clinician would usually do testing of your oxygen needs at rest, with activity, and with sleep.

13. **Is it possible to do too much?**  
    Like any medicine, oxygen is a medical therapy and should be used at specific times and amount. Too much oxygen can be of no clinical benefit and even be potentially harmful. Please check with your healthcare provider to find out what the right prescription is for you.
Theme 2: Ways to use oxygen, continued

14. **What dictates increase/decrease?**
   Changes in clinical status, e.g. worsening of COPD (exacerbation) and/or underlying disease other than COPD that might warrant need for oxygen, e.g. heart failure, pulmonary hypertension etc. can change oxygen needs. Regular check-up with pulmonologist and primary care doctor and short-term follow-up after exacerbations of COPD are recommended.

15. **How is dosage determined?**
   See answers to questions #6, 8, 10 and 12.

16. **They don't talk about titrating oxygen when you leave the hospital.**
   This might relate to a few different things. This might relate to lack of communication between different provider teams (Theme: Service issues and advocacy, question #53) or relate to need to check for change of oxygen needs after hospital discharge (Theme: Ways to use oxygen, questions #5 and 14).

17. **Can I go out with oxygen?**
   Yes. It is encouraged to use oxygen the same way outside as when using it at home. If outside, you will need oxygen equipment that can be carried, e.g. compressed oxygen tanks, or portable concentrators. Your clinician and respiratory therapist can help determine which equipment is best fit for your needs.

18. **What are limitations of activity with oxygen?**
   Similar to question above. In general, it is encouraged to use oxygen when determined if there are oxygen needs with activity. If used during activity, you will need oxygen equipment that can be carried, e.g. compressed oxygen tanks, or portable concentrators.

19. **Do I have to sit up or lie down to use it?**
   You can use oxygen in any position (standing, sitting, lying down).
Theme 2: Ways to use oxygen, continued

20. **Are there patterns of numbers for how much oxygen to use?**

   There is no standard number of liters per minute of oxygen to use. It depends on your individual oxygen needs at a certain situation (at rest, with activity, and with sleep) but most patients are first prescribed between 2 to 4 l/min. The prescribed amount may increase over time. Your healthcare provider can help you determine your oxygen needs.

21. **How do you know how much you’re taking in on a pulse dose?**

   It is difficult to know how much amount of oxygen actually reaches the patient. In contrast to continuous flow, which provides a constant flow of oxygen, pulsed dosing only provides flow of oxygen when the patient takes in a breath. One way to test, if you receive an adequate amount of oxygen for your needs is to check your oxygen saturation with a pulse oximeter.

22. **Can you swim with oxygen?**

   Some water activities may be possible, however swimming may not be feasible as the oxygen delivery device may not be waterproof. Please check with your DME provider. You can also read about other oxygen users' experiences with this topic on the COPD Foundation's 360Social free online social network.

23. **Can I take a shower with oxygen on?**

   Yes, however some of the equipment may need to stay dry, especially if it has electrical components. Non-electronic devices are suggested for the shower. Please check with your DME provider. You can also read about other oxygen users' experiences with this topic on the COPD Foundation's 360Social free online social network.
Theme 3

Symptoms to watch out for

24. Oxygen saturation remains at 95% at night. When getting prepared for bed at times I get light-headed and sometimes pass out. What is the cause? Decreased oxygen, low blood pressure, other?
This could be an issue not necessarily related to low oxygen levels. It sounds concerning and we would recommend a full evaluation by your healthcare provider.

25. How to determine whether you have a COPD exacerbation, the flu, a cold or are just plain sick?
This should not be done by patient and caregivers themselves but together with the clinicians, because the conditions are oftentimes difficult to differentiate. This would require more work-up and can be done in a clinic or at a hospital. One useful approach that your clinician can give, is an action plan with some specific steps and symptoms to look out for to be able to quickly recognize significant and life-threatening worsening of your condition. You can find one example of an Action Plan here. Take this or any Action Plan to your doctor to fill out and make a plan best fit for your needs.

26. If oxygen saturation goes below 88% for a short time, how much damage are you doing to your body?
It depends on the situation in which your oxygen is low (e.g. at rest, with activity or sleep) and for how long the levels are low. In general, it is preferred to avoid severely low oxygen levels at any situation (at rest, with activity or sleep) for a prolonged period of time.
27. **What affect does oxygen have on other body functions?**
   Similar to question above, see answer there. All organs and body functions depend on adequate levels of oxygen in the blood. However, hyperoxia, i.e. from using too much oxygen, should be avoided in certain clinical situations, e.g. hypercarbic respiratory failure (high levels of carbon dioxide), etc. as this can worsen clinical outcomes.

28. **What do I do if my oxygen levels are ok but my heart rate is way up?**
   Tachycardia, or elevated heart rate, might be due to multiple causes, e.g. cardiac problems, arrhythmias, deconditioning, anxiety, pains etc. We would recommend to check with your healthcare provider to determine if there are any other underlying medical problems.
Theme 4

**Oxygen safety**

29. **What are the dangers of having oxygen tanks around?**

There are potential fire hazards when oxygen equipment and tubing is close to flames, fire smoke, and fire sparks. No one should smoke near oxygen delivery devices. Other hazards include fall risks when tripping over oxygen tubing, for example.

30. **Can you light candles when you are wearing oxygen?**

No. Open flames, fire smoke, and fire sparks should be avoided when using oxygen and a safety distance to any oxygen equipment and oxygen tubing should be maintained to avoid fire hazards.

31. **How safe is oxygen?**

Similar to question #29. Please see answer to that question. In general, it is safe when used appropriately but there are risks of oxygen therapy, e.g. fire hazards and fall risks when tripping over oxygen tubing. Please also see answers to: question #13 (Theme: Ways to use oxygen) and question #27 (Theme: Symptoms to watch out for)
32. **Travel—air and sea; "how can I travel with oxygen?"**
You should plan travel in advance as you need to coordinate your travel plans with your DME company and airline. They may need special equipment for air travel and/or arrange delivery of equipment to the location of travel. It sometimes takes two weeks to get clearance from the airlines to fly with oxygen. Check with your airline as not all have the same policy for oxygen use during travel.

Your healthcare provider may need to provide additional information to the DME company or airline, which may require additional testing before you travel. The COPD Foundation has a Slim Skinny Reference Guide all about traveling, available for free download [here](#). Click on Slim Skinny Reference Guides and then English to see the topic list including “Traveling with COPD.”

33. **Can I rent a small machine to travel on a bus for a few days? I'm on oxygen at night only.**
A respiratory therapist or your DME provider can better answer this question. You may be able to rent a small machine for travel. You should contact your DME provider to check what type of equipment they can provide.
34. **Do all people use an inhaler and use oxygen, too?**
   Patients with COPD are often on inhalers besides oxygen therapy. Depending on the underlying severity of the COPD or other diseases that might require oxygen therapy, e.g. pulmonary hypertension, patients are usually also treated with inhalers, medications, and other therapies.

35. **What are the latest surgical procedures available?**
   You should discuss indications for surgical therapy as well as risks and benefits with your healthcare provider. Surgeries, e.g. lung volume reduction surgery in patients with COPD, are generally high-risk therapies and may improve outcomes in few, selected patients only.
36. There is widespread confusion on oxygen equipment and its use. This has been a long-standing issue in our support group. This is a complex issue and one way to address it includes tailored oxygen teaching and education specific to a patient’s needs. Different advocacy and research groups, including ours, are working on development of tools to assist in better teaching, management, and prescription of oxygen therapy and oxygen equipment. Would also recommend to look at further resources and educational material that is provided by the COPD Foundation (www.copdfoundation.org).

37. How and when do I use equipment?
   Similar to question above and relates to what type of oxygen equipment should be used. Please see answer above.

38. How do I order oxygen?
   Your DME company can arrange for delivery of oxygen or equipment. Your clinician and respiratory therapy can assist with contacting the DME company. Learn more about oxygen coverage and rights here.

39. Why can't I get a reading with my pulse oximeter?
   There are multiple reasons for why a pulse oximeter may not be able to read your oxygen level, e.g. oximeter malfunction, nail polish, movement, decreased blood flow to fingers where measurements are taken etc. We would recommend to bring the oximeter to your healthcare provider to demonstrate how you take measurements at home and make sure no other underlying medical problems are going on.
Theme 7: Equipment issues and maintenance, continued

*We believe questions in yellow are best answered by a respiratory therapist or other healthcare professional in your community. You can also view some similar questions and conversations with peers at www.copd360social.org. Some questions that have similar answers are grouped below.

40. What is the best machine and company to work with for oxygen?
41. Who's going to tell me about oxygen equipment?
42. Are all the pieces of equipment the same? How can I know which one is best?
   We do not want to make company and machine recommendations as each case is different and not the same fit for all. The important thing is to get devices appropriate for your needs with correct settings. Check with a respiratory therapy or advocates from the COPD Foundation. Depending on the area where you live, there may be only certain DME companies available due to the competitive bidding program. Besides respiratory therapists and resources from the COPD Foundation, your healthcare provider, like your primary care physician or pulmonologist, should be able to provide information on oxygen equipment.

43. How often should service take place on the condenser?
44. How often should the technician come out (for a home visit)? And why?
   The frequency of service depends on your device. Contact your device manufacturer and ask how your device should be serviced. How often a technician should visit may depend on the service your DME provider offers. Ideally, they would come out every month or as needed. CMS has some information about equipment maintenance: https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/Home-Oxygen-Therapy-Text-Only.pdf

45. How often should you change your cannula? When it gets rigid?
   Every month? When you get sick or have an infection?
   This depends on the brand of cannula and how often you use it. You can change it once it becomes stiff or uncomfortable for you to wear. Generally, patients exchange the cannula according to their healthcare providers instruction. You might need to change it more often when you have an infection. You can find more resources from the COPD Foundation (www.copdfoundation.org) and the American Association For Respiratory Care (www.AARC.org).
46. **How often should you change oxygen tubing?**
Check with your manufacturer for recommendations. In general, most people change it every 3 to 6 months.

47. **Can tubing be maintained?**
Check with your manufacturer for recommendations. Tubing should be washed every week and replaced as discussed above.

48. **Can I soak my oxygen tubing and cannula in “ASO clean”?**
We are not familiar with this product, but there are other disinfectants that can be used. Some patients use a mixture of white vinegar and sterile water to disinfect tubing.

Some of the equipment may need to stay dry, especially if it has electrical components. Please check with your DME provider.

49. **What does the machine that makes oxygen cost?**
What are the advantages?

50. **What is the cost of oxygen?**
The costs of the oxygen delivery devices vary depending on the brand, model and other factors. The more sophisticated, the more it costs. One advantage of having an oxygen concentrator with home transfill system is not depending on cylinder tanks being delivered in order to have oxygen.

The cost of getting oxygen depends on your location and the company that provides your oxygen. Further resources for independent guidance on the different types of oxygen delivery devices include the COPD Foundation ([www.copdfoundation.org](http://www.copdfoundation.org)) and the American Association For Respiratory Care ([www.AARC.org](http://www.AARC.org)).

51. **Do you need to wait 5 years before you can get a new one or do you have to buy one?**
It depends on the type of insurance you have. For example, for patients with Medicare it may be difficult to change oxygen equipment between years 3 and 5 as Medicare will not pay additional money to the DME company for new equipment.
52. Do I have an advocate through my pulmonologist?
Yes. Your pulmonologist is your advocate, together with the rest of your healthcare team including nurses and respiratory therapists. Other resources include advocacy groups, e.g. the COPD Foundation.

53. Who do I call if I am not getting proper service?
You should contact your DME company and healthcare provider. You can also contact your insurance company or the Medicare patient line (1-800-MEDICARE). The COPD Foundation Information Line is a great place to report your issues as well. They are collecting information in order to inform CMS about the problems and advocate for change. Call 1-866-316-COPD (2673).

54. How can I prevent things (i.e. information) from getting lost between my primary care doctor and pulmonary rehab center?
This question seems to be related to the problem of lack of closed-loop communication between primary care physicians and pulmonary rehab across healthcare systems. Unfortunately, there are no standard solutions so far, but we identified this as a “hot spot”, i.e. a problem that should be addressed. Some research groups, including ours, are working on designing solutions to improve communication and transfer of information across and within healthcare systems.

55. How do you know what Medicare will cover, what you're allowed?
56. Does Medicare cover for portable oxygen devices?
57. Does Medicare/insurance cover oxygen?
Coverage will vary based on your needs and the type of insurance you have. You can learn about your rights within traditional medicare at Learn more about oxygen coverage and rights at here. Private insurances generally have similar coverage to Medicare and Medicaid.
Theme 8: Service issues and advocacy, continued

*We believe questions in yellow are best answered by a Respiratory therapist.*

58. **Who should you call if you have problems with Medicare?**
You can contact Medicare directly (1-800-MEDICARE) to report problems. You can also contact your healthcare providers in assisting to advocate for you as they may have more experience dealing with payers. You can report your issues to the COPD Information Line at 866-316-COPD (2673).

59. **I didn't realize I'd be limited on tanks. How can I know what I'm entitled to?**
You should discuss with your DME provider and if you have any remaining questions, the Medicare patient line may be able to provide additional answers. Additional resources include the COPD Foundation info line (1-866-316-COPD). Learn more about oxygen coverage and rights [here](#).
Theme 9

Other

60. **There is no independent and neutral review of oxygen equipment and companies.**

The scientific community needs to do more research to answer this question.

We agree that this is a gap in what currently exists. Some resources that may be helpful are the COPD Foundation (phone # 1-866-316-COPD) and the AARC (phone # 972-243-2272). The UIC team is looking at some options and more information will be provided when it is available.