

Online Supplemental Material: Sample Participant Comments

The text on each row of the table represents the comment of a different survey participant. Each comment is presented exactly as entered by the participant.

Sample Participant Comments
My tank is too heavy for me to go for a walk. Pulling the weight of the tank uses my oxygen and my SATS fall quickly. Likewise I cannot grocery shop.
If I had to continue using E-cylinders I would do far less
I only need oxygen for altitude (such as flying) or very strenuous exercise (e.g. aerobic). I have used liquid oxygen when I have been in Denver, CO in the past and find it provides MUCH better mobility, especially for fragile patients and folks who have pain and arthritis. For my trip in June 2016, I found NO provider offers liquid oxygen to patients due to severe Medicare reimbursement cuts. This is very disappointing. I am fortunate to have my portable oxygen concentrator (POC), which I purchased solely from my own funds but many patients cannot afford to purchase their own POC, which costs \$3000-5000 and have trouble getting insurer or Medicare to pay any or all of the cost of a POC. Using oxygen tanks and a large concentrator greatly restricts patient mobility and causes deconditioning of patients. This increases the spiral of dyspnea and increase exacerbation and general morbidity of patients. It is so disappointing to see patients who were happily using liquid oxygen and being mobile and exercising no longer able to obtain their supplies and being confined to shorter and shorter distances from their large, heavy concentrator and tubing (which trips them, creating additional hazards).
cylinder gives me better saturation than stationary concentrator and easier to titrate (4-5 l/m) up when needed both in/out of house. D tank in a shoulder bag is heavy but no POC goes up to the flows I require for in/out of house needs. I cannot manage an E tank getting it into/out of car. I do not have any friend/family assistance.
The tank and shoulder bag I carry weigh 5 pounds. For some people that is not a lot, but I am a small woman who has lost a lot of strength over my years with COPD. It is bulky and hard to manage while cleaning house, working in the yard, taking care of a pet or children, etc. I was disappointed that there was no choice of what type of device I could get. When my pulmonologist prescribed oxygen, the durable medical equipment company simply arrived with the concentrator and tanks. And that was that. This combination is a problem for travel--even for travel by car with an overnight stay. The concentrator is too large and heavy for me to take along, but the tanks don't last long enough to get me through the night.
I use LOX at home with a Smartdose unit. I travel a lot, and when I travel my provider gets me an electric concentrator and C tanks because I can't get LOX any place I've been in the last 18 months. I have a Smartdose conserver I use with the C tanks. I'll be in San Francisco next week for the ATS conference, and will be renting a scooter to get me to meetings because I would have to carry four C tanks if I were to walk to all the places I will have to go in the time I have between meetings. It would be easier with LOX and the large Smartdose, but I would probably still have to return to the hotel to refill after about 8 hours. For a situation like the conference there really isn't anything that will provide enough O2 for me to be gone for up to 16 hours without going to a refill. For daily living, LOX is much preferable to having to carry several tanks. I'm lucky in that I don't require O2 unless I'm walking fast and carrying stuff (including the tanks!).
I don't like my forced upon me portable, they took away my liquid oxygen on which I did so much better. I hardly have the strength to pull in the oxygen on the system I have now.
At first I had to use the medium and big tanks, It was impossible to even go to the grocery store, pushing a cart and dragging a oxygen canister behind me. the small tanks fits in the cart, that keeps me from needing help. the concentrator at home gives me total freedom, of the house. the hose goes far enough to go threw out and and the devise is on wheels.

Purchased poc for use outside home
the tanks are too heavy for my shoulders to carry
Portable oxygen keeps my life normal to at least some degree
i have a portable oxygen device but it's too heavy for me to carry so that is not a good thing, there needs to be more light weight poc's that can deliver continuous flow
My current Inogen portable concentrator makes it much easier for me to be able to enjoy my life outside of my home. For example enjoy my grandchildren.
my portable o2 tanks are very heavy and they don't give enough oxygen while moving around, I need 3 continuous and they only go to 2. must use wheel chair when I go out, because tanks do not give enough oxygen for me to walk
I love my liquid oxygen would hate to go back to the concentrator. This liquid means don't have to worry about no electricity or the heat that the concentrator puts out. Liquid is so much easier to use.
I would love to have a portable one that i don't have to carry extra tanks and swap out. I could do more with that.
Tanks too heavy have to put in my walker to transport too heavy for me to carry can't breathe with weight on me
I can only get delivery of portable tanks every 90 days. I have to be careful and ration trips away from home in order to conserve tanks. This means I miss out on many activities and even longer trips for medical purposes. It also panics me to not have extra O2 tanks on hand in case of a power outage.
It's too heavy, I would love a portable none tank version..
portable concentrator would enable me to go places
Liquid oxygen is the best
LOX is the only oxygen solution that allows me to be active in and out of my home and to exercise aggressively which keeps me well and out of the hospital. It allows me to exercise which allows me to live well.
Have a portable tank but too heavy to carry myself
The POC MADE IT EASIER TO ENJOY WITH MY DISABILITY. The previous cylinders hindered us due to the weight. If you can't breathe adding additional weight and cumbersome device hinders a person's life that is already hindered.
My comment is they cut me down to 5 cylinders per month. I was getting 5 to 10 per week. I tried to go do some of kind of exercise every day, Dr. appts., church and gym. Now I can only go once a week. So I chose Church on Sunday. My Dr. is trying to get me more bottles so I can go 3 days to rehab. Thank you for attempting to get this changed.
It's getting heavier and heavier every day to pack it around. But I will continue to do it
Use concentrator for around the house. Absolutely HATE the 'E' tanks that represent my portable unit. They are heavy, ugly and run out of O2 within 2 1/2 hrs My normal setting is 5 for activity. In the past, I was using a POC and then had to convert to 'D' tanks using 'home fill' system to fill extra tanks for all trips away from home. I always encouraged COPD patients to stay active. Now, I find that I am the one that has slowed down almost to a stop.
I would be more mobile and better able to be independent if I had a more efficient portable O2 system. The tanks are heavy and take extra oxygen to even carry them. I've always maintained that if you can carry those heavy tanks you don't need O2.
Would rather a poc instead of the M6 easier to carry lighter on my shoulders
My oxygen needs changed from being able to use a pulse ox cylinder to a continuous flow cylinder. I live in a climate that has extreme temperature fluctuations and it's hard to go anywhere with oxygen cylinders in my vehicle in the summer heat. I wanted to get a portable oxygen concentrator to use but 3L would not allow continuous flow.
I need a portable (battery powered) concentrator and/or liquid oxygen, paid for by Medicare, to increase

my mobility
I use a portable concentrator for anything outside my home. I don't have the strength to carry tanks.
Life would be easier if I had a portable oxygen concentrator with cont. flow of 1-6. then i would be able to go by myself an do the things i want to do such as pulm rehab, grocery store, hairdresser, going for walks, visiting friends an family an have a life an a purpose to live. I only leave my house for 3 Doctor appts an 3 family gatherings in a years time, if I'm not having a flare up at the time. Someone always has to go with me when i leave the house because of all the E-bottles i have to take with me an switching them in an out.
Why can't they have a lighter and more mobile O2 machine
I would like something even smaller to carry outside of my house because I am such a small person. It is hard on my to carry anything because I'm so little.
Would love a portable concentrater so I could get out more often.
Hard to carry, heavy,uncomfortable.
Not dependable, very slow to respond to deliver more oxygen, when in need, even in an emergency their equipment is old and dated
After years of using the clunky tanks Medicare approved the use of liquid oxygen for me. I was able to do more things outside of my home and my quality of life improved. 3 years ago I was informed that Medicare would no longer approve the liquid oxygen. Thankfully I was within the time frame to get approved for a POC. This little machine has been a great help in allowing me to go shopping, walking, visiting, and even having a part time job.
I am sure I need a stronger POC but then it would weigh to much and even though still considered a POC it would require a cart and to me that is not portable and limits your Maneuverability.
The heavy tanks make it impossible for me to go anywhere alone. I can not handle them.
The tanks are too heavy to move around without great discomfort. I am 80 yrs of age and need the excercise but find it impossible to excercise or walk without help.
Liquid oxygen provides the greatest amount of freedom for the patient. It is criminal that companies are phasing it out!
Tanks are too heavy to use as a back pack usage. I can only lay it on a stool next to the machine I am using at resp rehab. My concentrator is good at home b/c of the long tube A tank needs a better back pack or a cushion for the back pack as it can not be used as a carry along without causing more O2 depletion getting to the point of direction
I have a POC for outside activities. The weather hinders my going outside the home. Can't handle too cold or hot ...and lately it has been rainy. I am not physically strong and probably would've be able to go out much if I had to back to taking tanks again. Plus it makes me nervous carrying them in the car in case of an accident.
If I didn't have my portable oxygen concentrator I would not be able to be independent. I would have to rely on others to get my food and other necessities I need. Having any oxygen is limiting but with the portable at least I can do some things on my own. If I was completely housebound, I don't think life would be worth living.
my portable unit doesn't last long enough for me to go too far. It will only last 1.8 hours.
There are some of us who can still work and would GREATLY benefit from compact devices with at least 8 hours of service. The current system keeps people I'll and inside their homes instead of providing equipment that will allow better mobility, improve quality of life and reduce medical costs.
I have always had concentrators at home. I HAD portable oxygen tanks. I now have a a portable oxygen concentrator which weights less and the batteries Last longer.
Regulators leaking...supply hoses kink....tanks dirty looking..with a/c on tile floors temp inversion spits water thru tubing
Having supplemental oxygen has enabled me to live a healthier, more active life. Oxygen = freedom to do things I otherwise would not be able to do. I am grateful for my oxygen devices.

The oxygen concentrator for home use is fine, but the small tank for outside the home is cumbersome.
With liquid oxygen and the smaller portable, I am able to go places without being as sob. The concentrators and cylinders did not keep me oxygenated. Liquid oxygen works better. I am starting pulmonary rehab this month.
I felt like a old woman that was about to die when using cylinders with rolling cart. Hard to pick up and put in car and hard to get back out. I like to go to the beach and visit family out of town. Makes it hard to put so many cylinders in car to go off. I can go exercise easier with my portable that I can just put on my shoulder and go and use my concentrator when I am in my house.
Need a device that doesn't have to be carried, and if it does, doesn't weigh too much. Makes it very hard to walk very far carrying the tanks
My portable is too heavy to carry
I love my POC - but we really need to make these smaller, weigh less and last longer to give patients more independence.
3 years ago, purchased at own expense Inogen portable oxygen concentrator which means I can place it in a shopping cart to walk for 20-30 minutes. The battery recharges in the car, but runs 3 /2 hours. This is my main exercise and was prescribed by pulmonologist.
Love my Inogen One G3 - it is lightweight enough to keep me mobile - my other unit weighed about 12 lbs & that was virtually impossible for me to handle on my own
I prefer the portable oxygen machine compared to the tanks as I can plug in when getting low. I am lucky I work in an office & can still do that because I can't afford not to as I need the insurance. Medicare wouldn't give me as many benefits as my insurance I get through my job.
tanks are too heavy to carry, even putting them on a rolling walker does not help
Carrying my portable tank makes it very difficult to exercise,an makes it impossible to go anywhere outside of my county as I only get 2 tanks .cant go to gym to try an get stronger as 1 hand is holding my portable tank at all times
I am active at home on the concentrator, using the cylinders restricts time I spend outside my immediate home/yard. By the time I cart and get into a. While with a cylinder, I'm ready to be *done* ...so much energy is wasted!
I find the tank that I have to carry while moving around to be heavy and cumbersome. Wish I could get a portable concentrator.
Very restrictive and extremely difficult to use by myself.
Oxygen system at home limits me with a 30 foot hose. Can't go for walks outside because tanks are too heavy to carry and run out fast because I need to set it at 6 liters.
I had no quality of life prior to oxygen and pulmonary rehab. I was not strong enough to handle mobility and an E tank and had to rely on family to do anything with that size. The smaller tank allows me to walk my dog, get out into the community without anxiety and participate in my own life!
My current o2 system fills tanks that are too heavy for me to carry for any length of time. Wish I could get the portable concentrator.
If I didn't have the small tanks, I wouldn't be able to go anywhere as I can not lift the larger ones, without my oxygen levels dropping to the point, I'm useless.
Home concentrated is fine. Carrying several tanks limits outside mobility and travel.
its to hard to get the portable tank to use and the little washer keeps having to be replaced
I hate it...Ambient Air has to be clueless pulse delivery sux
Some of these questions cannot be answered simply. I would love to be able to go when and where I wanted, but it's such a bother to worry about having enough cylinders to get me through a trip or visit. I would love to have the option for a lightweight portable concentrator instead of the cylinders. My o2 supplier says that since Medicare won't pay for them, I can't get one, they're too expensive. Then again, I think about all the batteries and what they are doing to the environment with the disposal of them. I hope this has helped.

So thankful for the portable units, however wish they didn't weigh so much, a small portable concentrator would be nice but the flow levels don't go high enough, to 5 only, then the unit is too heavy to carry, and I probably will be beyond 5L soon.. Medicare won't cover a portable concentrator and portable tanks. Wish they would.

Wish for portable O2 generator or lighter bottles. Big ones are impossible for me to carry as I do not have enough strength. Is it true that the US medical care system is trying to kill off anyone drawing SS? We often feel like they are.

I. Don't go anywhere except dr appt, my small concentrator Is broke and using the cylinders makes me real anxious about running out before I get home to my large concentrator. Pulling around a cylinder is very hard for me it makes it even harder to breath.

I could not do what I do if I did not have my portable tanks. I weigh 106 lbs and an e cylinder is impossible for me to carry around

i have a torn rotator cup which gets agrevated while using the e tanks i have requested a portable oxygen concentrator so i can be more mobile

I do not want to be limited to one type of delivery system. I can go to restaurants, volunteer work, and fly with my POC which I purchased myself. Medicare needs to increase O2 devices and payments.

Portable Liquid oxygen has allowed me to have a life , attending family and friend events church, and volunteering (days when health allows) Unfortunately not every day is a good breathing day .

LOX allows me to be active and exercise, exercise allows me to live well and avoid hospital stays and frequent doctor appointments in spite of very severe COPD

Medicare tried to take my independence away from me by making me use oxygen cylinders. I bought my own concentrator.

its heavy as heck and makes walking more difficult

Bottles to carry are heavy and unreliable. Having a bottle small enough to carry means it will not last very long. So for me a trip to the store and out to lunch may mean as many as 3 bottles of air. To keep me as mobile as I would like to be I would prefer a portable concentrator. Medicare will not pay for one. I also live at 6000 feet elevation. The elevation limits my mobility with the oxygen also. I was diagnosed 3 years ago. Went through pulmonary rehab- it was great. I started on 2 liters of O2 24/7 My condition has deteriorated so that I am now on 3 liters resting and sleeping and 4 walking eating etc.

My portable liquid device is very convenient to use during exercise and other strenuous activities. I use it at a fitness center, walking outside and such activities as lawn mowing, etc. I use the large stationary liquid reservoir when sleeping. I have been told that my supplier, Lincare, will be phasing out liquid oxygen.

Trying to exercise while carrying a portable tank is very uncomfortable an sometimes impossible

Wish I had a small, lightweight portable concentrator. Using tanks when I go out is a problem because the pack is heavy, the tanks run out unpredictably, constantly changing tanks. Regulators don't work right. And sometimes they leak so I always have to get out the key and shut the valve. If I forget, my tank empties. It can leak and not be perceptible - can't hear the leak.

The tanks that I use are m6 ,D and E they get extremely heavy carrying in the oxygen bag or pushing on the oxygen cart provided for the d tank. It is very hard on me as I have no one to help me load or unload my tanks when I. Need or want to go somewhere. I see other oxygen systems in a bag ran on batteries that weigh like five pounds oh my goodness I would love to have that or even the other kind that is on a cart that you push around it would be so much easier to use lasts longer and no tanks to drag around and secure in my car!!

Would love a lighter portable device. Since my needs are pretty high and have to be continuous if it's out there I can't afford it.

I wish it was not so restrictive. Tubing keeps me from feeling freer. My portables are heavy and makes me tired. I want to go out less. They do not last long enough. Hard to manage E tanks too.

I love my oxygen concentrator. I would be in a bbc.co let to do most everything without it. My portable oxygen is to large. Needs to be much smaller to move around more.

Liquid oxygen feels the best to breath, and is much easier to carry and use than other oxygen systems
I SO want to get out more but I am in a wheelchair, and have COPD and severe scoliosis and not able to carry around bulky tanks.. I would love a power chair and a small mobil concentrator to be able to just get out and about on my block, area
I'd be lost without my O2 and not survive as I am... I'd be a recluse.
I have to always carry I or two extra if I'm going to a long movie. I have to have someone with me to carry them.
I currently use oxygen bottles when I go out. I would prefer the portable oxygen concentrators as they are easier to transport.
I have grown out of me POC. Therefore I am limited as to what I can do. My stationary concentrators work well. Have tried the canisters and they are very weildy. Would love to see something that would be like my POC but provide the levels I need. I am severe but I have not given up and get very frustrated that there is nothing to help me to continue living life!
It is so much easier and I fee safer using my. Oxygen concentrator. The e tanks were difficult in the car and I had. To bring several if I had an appointment that was. Going to take some time the concentrator can be charged in the car or. Where I'm going so I wouldn't have the extra worry of making sure I had enough oxygen with me and not worry about running out.
I am limited to leave my home independently by having a small tank or a portable concentrator which is necessary to travel by air.
Home conctrater works well but tanks to go out are hard to manage
I am a VA health care patient supplemented by Medicare. Until I reached stage 4 and required constant flow oxygen, I was able to use a portable concentrator. I am no longer allowed one. Having a portable made travel for doctor appointments so much easier. It is difficult for my wife to transport all of the eTanks required for me on those trips.
The heavy tank limits my activity. Pulling it uses the oxygen I need to breath
I would likely be dead or in a vegetative state somewhere by now without my oxygen. I use a high flow and am being considered for a transplant. I live alone and have to move my portable oxygen source myself in order to get out of the house. If I had to use a large, heavy cylinder, I would never be able to get out. An observation of anyone, even without lung disease, demonstrates that the more active one is the more oxygen they will use. If this were not true, runners would not get winded.
I use the E-series canisters which limits me how long I can be out so I have to compensate by shutting it off and conserving which is dangerous with my oxygen levels dropping. If you have a Dr's appointment and your waiting time is 1hr but you only have 2 and 1/2 hrs canister you learn to conserve (as mentioned above). I need continuous flow and longer hours but I can't tote a bigger canister.
If it were not for the portable M-6 cylinders I use I would not be able to leave my home. I am unable to transport the larger tanks. I am not able to lift the large cylinder up and down the stairs or lift into my car.
My portable doesn't last long & I couldn't get the concentrator. My concentrator is older & doesn't work well
I wish I were phsically able to handle the tanks in portable manner. It has seriously robbed me of a major part of life,,mobility w/o an escort.
Continuous mode would. Be better when active and walking , pulse is not good , cannot move a lot
The portable device is very heavy and cumbersome on my back. A portable O2 concentrator that could be worn on the side would probably improve my quality of life. Also, with the portable O2 concentrator I would not be limited to where I go based on time and geographics while constantly being worried I will run out of O2.
First, as far as walking, I walk 2 miles on the treadmill at rehab. 1 mile 2 different times. Can't take a normal walk and carry a tank. My oxygen delivery device is OK. As long as I can breath, I'm fine.

<p>Any cuts to Medicare that will restrict patents from getting out and especially partaking in pulmonary rehab programs would be devastating to any person requiring supplemental oxygen. I can not imagine living without being able to do these things. In my case. I would not qualify for a lung transplant without going to pulmonary rehab (which medicare does not pay for phase 3). Proven and preventative in keeping us healthier and out of expensive ER's and hospitals.</p>
<p>My portable oxygen allows me to live my life to the best of my abilities, without it I would be completely dependent on outside help.</p>
<p>I sm so blessed to oen my own concentrator and have service. I have difficulty lugging the big tanks as evidenced by a reduction in blood O2 by oximeter and decrease in the distance I can walk in 6 mins when I use the tank at my doctor's. I cannot imagine having to pull a heavy tank everywhwr I went. I could certainly stay in more often.</p>
<p>I am so happy with my LOX Marathon. My worst fear is losing it and my independence and being forced to use compressed gas. I must use continuous flow, so the POCs won't really work for me.</p>
<p>e tanks are heavy to lift into car, by the time i get my spare cylinder, the push-pull tank and myself into my seat to go anyplace, I am to exhausted to go. Not worth the trouble, so I just stay at home. Wish there was a concentrator that could push 4 liters for easier mobility</p>
<p>I'm not sure what size my tanks are but they are large. Changing out the tank and or just getting it into the car makes me exhausted to the point of not being able to continue without napping. On 8 liters I desat to 77 % when walking and my company will only give me four tanks.</p>
<p>oxygrn therapy is not a one size fits all. If allowing patients to maintain their quality of life is an important factor for CMS then patients needs should not be dictated by what Medicare will reimburse but rather by what the patient needs.</p>
<p>DME equipment providers are horrible to deal with. I think all those that need oxygen should be able to have insurance pay for a portable concentrator one easy to use & move around with. Mine was purchased by family that all put the money together to help me and made a huge difference in my attitude & ability to to go to rehab after a hospital stay that left me weak and just wanting to give up.</p>
<p>I could not live without it on 24/7 it gives me life home concentrator i HAVE TO HAVE more than any other meds. I also have a portable unit with witch I use outside the home and on a plane or car I could not lift large tanks into the car OR FLYWITH A LARGE TANK. so it lets me see my family shop and LIVE LIFE, Oxygen is my medicine for life and without it and its portability my life would be very limited to home only, never see my family or friends that live away from my area</p>
<p>If a person cannot get out of their home they slowly die. With the devices they have now if makes it so we can do more things for ourselves and don't require help to do daily things</p>
<p>It is very important for COPD patients to have access to portable oxygen supplies to stave off the need for more intense life shortening complications.</p>
<p>I have to carry it and it is awkward and clumsy. It feel off balance .I wish they had a better way to make it lighter and easier to carry .</p>
<p>My devices are working very well for me. I wish it was easier to use a portable unit. I use the big tank in the car and the smaller ones when I get out to walk. I probably will not fly again because what I have will not work on planes.</p>
<p>Portable pulse works well but gets heavy after a while so limits what I can do</p>
<p>tanks are too heavy to carry</p>
<p>Only real issue is that the portable concentrators only deliver up to 3 liters. I'm on 4 liters. I use a tank during rehab.</p>
<p>hoping for wireless delivery soon :-)</p>
<p>Your poll is confusing on 'current oxygen devise'. I use concentrator in home; M-9's for eating out; E tanks on wheels for longer daily trips. Since I am old and on heavy oxygen 24/7, I will gladly kill any government bureaucrat who tries to limit my bottle usage or mobility!</p>
<p>Without the portable refillable oxygen cylinders I would never be able to leave my home.</p>

I have to pay out of pocket for a Portable Oxygen Concentrator due to Medicare won't pay for a device that goes to 6L. I have trouble using E tanks. I cannot use my local O2 provider who has MUCH better customer service than Apria because they have no Medicare contract. NOT FAIR!!! Why shouldn't Medicare have to pay ANY provider for the device MY DOCTOR ORDERS???. Please help us!!

Having small portable oxygen tanks are most important to have in order to live a some what active life. Having to use a large tank would basically home bound a person on O2. M4,M6, and D tanks are imparitive for a functional life.

the mini o2 concentrator is head and shoulders better than cylinders. I dont bother with them too difficult to deal with

Provider Center Manager attempted to replace my liquid with a concentrator which does not meet my needs nor perscription. Things got extremely ugly. Contact with Corporate Officers / local media and threat of legal involvement backed provider down. Have seen uninformed, elderly and extremely ill who are unable to advocate for themselves loose liquid to corporate greed. Competitive bid has been devastating for liquid oxygen users. Mobility greatly restricted.

I had to buy my own portable concentrator . I use it when I go out because I have this device I have a better and easier life, we all should have access to a portable light weight machine like I have bought. the tanks do not last very long and they are to heavy and do not possess the high tech hardware that makes these so very good.

With arthritis in hips, knees and shoulders, I can carry or lift only a limited weight--less than the usual woman's purse. Without my POC, I would be unable to travel to other states and countries during these last 10-15 years of my life. I would be unable to visit friends in other states, go to cultural and entertainment events with local friends, or take care of my needs outside my home. Even the exercise needed to keep up lung capacity and base muscle tone would be impossible. Without a POC I would never leave my home and be subject to even greater chronic depression. It helps me feel more normal. I wouldn't want to live if I could only have the restricted lifestyle proscribed by oxygen tanks.

Please do not take away concentrators. I can now go to a ball game or out to dinner with my kids. I don't want to give this up when my Medicare kicks in. I have 3 diseases and have never smoked. Had some of these for 52 years. Bronchiectasis, Asthma, and COPD-Chronic Bronchitis. Thank you

The liquid O2 system has made my life better.

My home care delivery company informed me in March that I am limited to 30 tanks for a ninety day period. This is the first time since I have been on oxygen (same hom care delivery company), for four years that I have been limited. Needless to say that this has restricted me to staying home and not getting out as much. I feel that oxygen users are being punished due to the fact that society seems to think that all COPD patients were smokers....shame on us!!!

I use liquid oxygen in the house... M-6's out doors and E-tanks in house and out doors for nebulizer treatments with mask...I wish to continue with all this as is. If not I would not have any quality of life at all. I can no longer be out doors in high humidity....levels of humidity from the teens up cuts off my breathing ability. I use E-tanks with mask and nebulizer meds out doors if I need to keep a doctors appointment on humid days. (((to and from a car to the building where I need to be.)))) No local pulmonary rehab classes or support groups here in my area....I can not garden any more and I can't afford a gum not to mention those machines at this point are to hard for me.. I'm now walking with a walker.... A home pulmonary therapist would be helpful.

Too heavy for most physical activities. Had to give up gardening, gym, keeping up with friends.

I can not go far as my tanks are way to heavy and awkward.and you hve to take so many to go for very long. My concentrater I only had to take extra batteries

Without my oxygen concentrator I wouldn't be able to go for walks, I wouldn't be able to do my own grocery shopping. I wouldn't have quality of life.

I use the M6 tanks when I go out shopping or the doctors.I have the E tanks for exerciseing and in case of a power failure which we have quite often also use the E tank if we drive more than 2 houres because I would havw to carry to many M6 tanks in the car.I use a walker because it makes my breathing very

bad if I have to carry some thing and I can fit a couple of M6 in the seat of my walker when I go shopping or to the mall.I would never leave the house if I didn't have the M6 tanks they save my life.

This questionnaire is difficult because I do have liquid oxygen, which is the best, but it is being phased out, which is very bad. Liquid is extremely portable. I recently visited Disneyland. Could not get liquid in California and had to carry a PILE of canisters in an electric cart when one sweet Helios tank in a backpack would have done the job. Bad state of affairs!

I use the concentrator 24/7 but I also use a portable device -- Inogen -- when leaving my apartment. Medicare did not cover the cost of the Inogen.

Having very severe copd / asthma for a decade I utilize c size cannisters that fit in a backpack so I am able to be mobile. I can't lug the e size cannisters around as they are too heavy to lift. very severe osteoporsis also. I try to stay mobile by going to pulmonary rehab, and the gym to build muscle. I also take tricycle rides to build endurance. I have to use from 2-5 lt depending upon exertion. It's getting worse now as I'm experiencing an exerbation due to broncitis infection. I am very concerned that Lincare is not being paid by medicare. If this is taken away from me and i am forced to be sedentiary it will be a death knell for me. Please get them to pay.

The tanks make it very difficult to plan for a 8 hour event, because of the number of tanks it takes to sustain me which would be 4-6 large E tanks. Liquid oxygen was so much more portable. Quality of life has decreased.

I use the small C containers when I am out and the concentrator when I am at home. These work very well for me, allowing me to do almost everything I want. A portable concentrator would be better, but I cannot afford it. Medicare has already reduced the amount it will pay for, leaving me at risk of not having anything. If you change the available choices, I will be stuck at home, unable to do much of anything. Please take Medicare back to its full coverage for the best options available.

I currently use a back pack to get around with my oxygen. I'm concerned because my limit of outside access is lessening each time I'm sick. What happens when I can't carry the weight of my oxygen anymore? I can't lift the larger tank in and out of my car. This really will lesson my ability to do everything. Help I don't see a solution to weight issues!!!

I'm Stage 4 for 16 years and care for myself. The liquid oxygen & Helio system have enabled me to have freedom and better health since I can exercise and shop and have a social life also. When I had the heavy cylinders, I was exhausted just getting to my car and in or out, so I became a hermit for it was just too hard to function.

If I didn't have my portable concentrator, I would not be able to leave my home and engage in 'normal' activities. If I was housebound and unable to participate in life to some 'normal' degree, I would not want to continue living. Things are difficult enough now; without my portable concentrator, life would be intolerable and it would not be worth even trying to go on.

I am using the Simply Go , I first started with the large tanks and mostly stayed home all the time. Now i'm able to drive to rehab and walk on there treadmills 3 days a week. I do wish they would invent something smaller. The Tanks cannot be recharged we don' t want this.

With my Helios Marathon on my back I can be independent when I leave my home and be absent for several hours without worry if I am careful to change oxygen flow from continuous to pulse when I am at a meeting, sitting on a bus, etc. Because of arthritis, I would not be able to manage the push/pull of a portable concentrator or wheeled tank and would not be able to continue my current activity level or even do minimal daily self-maintenance activities such as grocery shopping, going out for a haircut, visiting the library, etc. without fear of running out of oxygen.

I don't like the cylinders they are too constrictive. Even the small ones to go out are not comfortable to carry. I would love to have the lightweight Concentrator for when I have to leave the house or just for moving around in the house. The large concentrator for sleep is perfect but not for going room to room with the tube always getting in the way or getting stuck under something.

I'm giving up my oxygen concentrator because of weight and difficulty wearing it over my shoulder. Went back to M-4 cylinders which are much easier to use. Plan on staying on M 4's thru Medicare and

buying a portable concentrator to have as a second option,. Wish the technologists could come up with a stronger but smaller battery in order to lengthen time plus ease of use.

I use refillable portables that enable me to drive & shop, attend short functions but am time constrained because portables only hold so many hours before needed refill. Cannot afford a portable that would allow me to travel or be away from home more then 5 or 6 hours.

The portable containers (BB) are so heavy for me to carry in addition to needing to carry extra cylinders for longer than about an hour. I am severe COPD and should be using 5 to 6 but most gauges only go to 5.

My oxygen supplier is considering no longer supplying liquid due to reimbursement cuts. I must have my liquid oxygen in order to continue being active. I love to work in my yard. I weed eat, blow leaves, cut grass and work in my garden. Even though I am on 4 to 5 liters continuous, I am still very active. I also walk 1 to 2 miles 6 days per week. In the winter, I use my treadmill. If I am deprived of my liquid, I am sure my life expectancy will be greatly shortened not to mention my daily quality of life.

I will lose liquid oxygen at the end of the month. It is clear from the available alternatives that my mobility will be seriously curtailed. I fear that will have a direct effect on my longevity. I am convinced that the mobility afforded to me my liquid oxygen over the past seven years has been a key component in my health and survival through medical problems.

They have me filling my own tanks and at first only gave me 1 tank that would only last 5 hours. I begged for another one and they gave it to me as long as I pay them 20 a month. These tanks are heavy and hard for me to lift. The other tanks I was getting before they changed me was easier to handle. Although I would use more than 6 a month, they told me that was my limit and I would have to come to the company and get more If I needed them....when I started doing that the owner got upset that I was using more a month. I will be finding another company....I cannot continue to do the home fill system. Thank you

Wish there was a continuous flow that weighed less then 10 lbs

Tanks are too heavy to walk around with.

Run out of oxygen only last an hour on 4L on a b tank. To heavy to carry get out of breath.

Just do rehab 3 times a week. End stage and feel liquid is the best source of oxygen for us with lung diseases.

I like the refill option I have with my concentrator. I am still limited to 3 bottles. The portable tanks are somewhat heavy to carry around. I use my wheeled walker with basket to carry the tank if I am out walking around a lot. At home I use 2-25ft tubing connected to concentrator, kind of unhandy but I can reach all areas of my home.

I have the home fill system and I am happy with it. The tank is light enough that I can put it in a back pack and off I go. I use them when I am exercising and I walk between 5 and 7 miles a day. If if weren't for the small tanks, there is no way I could walk that far every day.

I used liquid o2 while in CA. This area I live in now does not have liquid o2 available so I use concentrators. Both stationary and portable. Of course I preferred the liquid but I take what is available.

I don't usually have one unless I am extra ill. I need one but the doctor says I need to wait because I am too young to be dependant on it all the time. I have 28% breathing and would be angry if what little movement I can have was taken away by having to tote a big oxygen tank. I have neither the strength or the energy to be able to do that without a lot of help.

I am so lucky to still have my liquid. I don't have to worry about the electric going off and it only weighs 6 lbs. It can last for 7 hrs. on demand. Without it I would have to stay home and rarely go out. And because of the big O2 suppliers not carrying it, I can no longer travel to DC to let my voice be heard! I've been on oxygen 24/7 for 14 years only because it is the liquid form.

Lincare has been great - the B tank is perfect weight and size to carry around and gives enough time to get errands done. Please, Lincare, fight for us.

I am on lliquid oxygen which allows me to do many things that I wouldn't be able to do with the bottles

like walk up stairs and I am able to travel and not have a bunch of bottles and concentrator into hotels. I believe that congress should pay back all money's that have been stolen from Medicare and Social Secuurity and leave our benefits alone
I hate it. Live in appt and cylinder too heavy for me so I do not like going out anymore because I live in appt with steps.
I am very satisfied with my Concentrator and LOX. Without the LOX I would be house bound because I am not strong enough to handle tanks.
I would be home bound if I had to use a big tank everywhere I go. I am not big enough or strong enough to lift them into & out of the car repeatedly.
I have a concentrator for insdie and I have outgrown my POC. What is needed is a machine that extends my O2 supply for more than 1 hour. I need something that allows me to LIVE longer! I'm not ready to stay in my home and do nothing. That is not living - it's existing. I chose quality not quantity so I could do that. We need sometihgn better that is afforable to all of us.
I'm satisfied and happy with my liquid oxygen.
Being able to have a POC would greatly improve my quality of life. It would give me more mobility.
Would be nice to get more hours in a lighter weight canister, but I do fine with my backpack at this time. My company takes good care of me
I was recently evaluated for the Inogen portable concentrator. Was told I was not a good candidate because I could not maintain my numbers during walking test. I felt the testing was insufficient. The therapist & I were talking as we were walking. This was a pulse dose machine. It felt unnatural to me.
I have been leading a very active life packing around a small tank liquid of oxygen on my shoulder and I do not want my life restricted further by the lack of access to this liquid O2 technology. Liquid oxygen is highly condensed and I can carry the equivalent of two of those long green (15 lb) metal cylinder tanks in my shoulder bag which weighs up to 11 lbs when full. I am covered under a strong private insurance policy, but the impact of change in Medicare reimbursement, is causing all of us to lose access to this wonderful oxygen support system. There are a number of people with serious lung conditions that require 'high flow' oxygen as I do; liquid is the best answer to being able to stay active and live life fully. Going to a system of using compressed air tanks which are heavy and unwieldly to carry throughout your day or requiring pulling a cart everywhere you go is limiting and discouraging. Just imagine carrying an 18+ pound briefcase around with you, absolutely everywhere you go, 24 hours per day, no matter how far you have to walk, regardless of whether there is a hill to climb or a flight of stairs. Then add smaller, less functioning lungs to the mix. Access to liquid oxygen is a must for high flow oxygen users. Revise the reimbursement system to allow greater reimbursement for high flow patients or increase our out of pocket expense for it. Don't take away the access completely.
Liquid oxygen has made my and my wife's lives meaningful again
The cylinders are heavy and bulky. Too heavy for me to carry around.
I use my concentrator at home and while exercising, which I just started back. I use liquid oxygen for going outside, the Dr.'s Office etc... I do, however, have to pay for my oxygen refills which I get once a month and partial payment on my portable liquid oxygen Helios tank. When I was using the E Tank I had fallen numerous times. I no longer have that problem with the liquid oxygen. It last must longer than the small cylinders you get with the concentrated oxygen, and I would have to carry three small tanks of concentrated oxygen which would be heavier, to make up for the helios.
The M-9 tanks allow me to do anything i want to do restaurants shopping etc.. anything larger than that would restrict what i can do
The weight of the cylinders is awful. My shoulder is constantly in pain.
Please do not restrict our lives more by making us use these heavy tanks.
I use a walker and the bottles are too heavy and clunky, always in the way, heavy to pick up -- a portable concentrator would help me and I would go out more, I do not know if I will be able to get one or not, I have asked for one, but have not heard anything for several weeks now

<p>The tanks do not allow me to travel and it is awkward to carry around. It does allow me to go to the store, Dr's appts, etc.</p>
<p>I need a smaller more portable device. Because of other crippling diseases I CANNOT ever lift the other devices than a portable one I would have to go get from the supplier. My quality of life is already SEVERELY LIMITED AND GETTING WORSE. Why can Medicare pay for Viagra so men can have sex and not pay for things like portable breathing machines so very ill people can have some kind of decent life? Shame on whoever makes the rules for Medicare. May they all have COPD and /or be handicapped severely in their own lives or families!</p>
<p>Tanks are kind of hard to use have to have someone with me to pull it</p>
<p>It's getting harder and harder to handle tanks as I get older and my arthritis gets progressively worse.</p>
<p>I currently have a portable concentrator for use outside the home. Small tanks would be a nice addition that would be more convenient at times.</p>
<p>Would love a poc. It would make things easier</p>
<p>I find it difficult to carry my portable oxygen concentrator due to its weight. Also had great difficulty flying accross country because airline required 5 batteries for concentrator.</p>
<p>The tanks are way too heavy for me. I can't get around with them</p>
<p>my liquid oxygen and marathon allow me to get out of the house and do things that require limited walking and mobility. I would be house bound and tethered to a fifty foot cord without my liquid oxygen.</p>
<p>I purchased a SimplyGo Mini with the large battery and weighs about 6 lbs. It is easier to carry and lasts longer than the heavier oxygen tanks that I used to carry and that would run out of oxygen when I was away from home. I have a backpack to use when going for walks that takes the pressure off my shoulders. I also use the SimplyGo (weighs 10 lbs) with a luggage cart as it is too heavy for me to carry. I use that one at the rec center pool when doing water aerobics and also for camping with my CPAP machine. The large heavy oxygen tanks made me stay home as they were too hard to manage and ran out of oxygen. I have a EverFlo Q for the house which is on ~20hrs when home.</p>
<p>I am having trouble getting the proper device to give me continous oxygen on my portable tanks. The device I have now is a pulse device and can get only two liters per minute of continuous oxygen which is not enough for me. Everytime I call my supplier nobody can advise me and they end up disconnecting my call.</p>
<p>I believe i will be changing portable oxygen from the pulse to a regular tank. It should not be so difficult to get what is ordered and needed.</p>
<p>I would love to be able to go for a walk or garden some, but because of the restrictions with my oxygen, I can not.</p>
<p>Non of what I am able to do now with liquid oxygen was I capable of doing packing and loading a heavy green cylinder around. Plus having to pack extra, it kept me homebound. The liquid oxygen allows me to fill and go without being heavy or cumbersome. I can be gone I hours, adjust my flow rate to 6 liters continuous.</p>
<p>I need supplemental oxygen beyond my at home concentrator, without this freedom I have no reason to continue. To be housebound would be a death sentence for me. Small cyclinders run out too soon and large cycliders are beyond my capability to transport me. I need a portable concentrator to improve my quality of life. improve my life and give me a reason to to go on.</p>
<p>currently , the house I live in can not support the wattage usage for the oxygen room concentrator. The energy required blows fuses in my house. Its an old house with the original fuse box . We rent and the landlord wont upgrade the electrical system , in this house..so I need to rely on the liquid O2 for my O2 needs. I use 3 lts at rest and 4 ltrs to move. The past year I had an admission which has contributed to my decline in lung function. I have been on O2 for over 8 years now. To be isolated to the house is like being a dog tethered on a leash or a bird stuck in a cage. We literally lose our independance and socialization..which in itself contributes to terrible depression. We need options in order to be able to</p>

leave our homes and try, as best we can, to maintain some sort of normalcy in our lifestyle, and to maintain a quality of life. We all deserves such basic needs .

I cannot travel with canisters the way I would with a portable concentrator.

Cylinders are difficult to tote along. The smaller more portable ones don't last long enough. I'd be able to be much more active in my life with a portable concentrator and hope to one day have one.

any of the cylinders well mostly the E-tank is too big for me to use by myself its to hevey for me to pick up and push family member has to help do that and its not fair to them wish my insurnace payed for a portable but they dont

I use a condenser at home. I like my small 'puffer, ' i.e. M7, and find it very helpful to deliver oxygen for trips outside my home. I also use it to go to different levels of my home and to go out in the yard. I have been able to drive myself to events within a 60 mile radius of home. It is the Rheumatoid Arthritis that is so hindering, now that my breathing problems have been so wonderfully eased with the oxygen.

If I had to use tanks of oxygen I'd become a recluse. I am active ONLY because I have the mobility that liquid oxygen gives me.

I would not have been able to retain the health I have now if I were not able to get out..The B tank is heavy enough but I still can enjoy life, exercise, garden, fish...do art work. If I had to use anything heavier I would be a statistic.....

I don't know what I would do if I didn't have my M6 tanks. I can put an extra M6 tank in a tote bag when I go to my doctor, dentist, go shopping, or go to lunch with my friends. I know then I can quickly change to a new M6 tank if I'm running short. I don't have to drag them on a cart as they only weigh about 5 pounds. I'm a little 83 year old lady and I can't imagine dragging and coping with an E tank on a cart! It would be simpler to just stay home which is self-defeating. The M6 tanks allow me to live life.

Before I went on Medicare, my Health Ins provider would only cover a floor concentrator at home and the small O2 tanks as portables. Once I went on Medicare, Inogen help me apply for and obtain a portable Oxygen concentrator. This is much more convenient that carrying a supply of tanks with me everywhere. My only complaint with that would be that the unit is a little heavy for me (I am 5' & 118lbs) and the unit weighs about 8 + lbs. Other than that I Have been quite happy with it all, AND Medicare's coverage of it for me.

I don't walk but I do exercise. The problem with walking has to do with my ankle and also that the oxygen concentrator that is portable Weighs about 9 pounds. That makes it very hard for me to walk. The concentrator is better then the canister because I can plug it in my car and charge it up as I need to. I wish that they would make all concentrators in the 5 pound range. The other thing that I wishes that they were special glasses that you can purchase at your regular doctor to hold the cannulas like what you see in the magazines

I currently use an Easy Pulse POC outside the home & participate in Pul. Rehab. transitioning to a Life Fitness class at the same facility. For the Life Fitness class I must bring my own O2 & have been using my POC. After my last hospitalization in April, Dr. has recommended I use tanks with constant flow during exercise & sent order to O2 Co. (Lincare) who has indicated that can't provide them (unless I pay \$10 per tank upon delivery) as Medicare won't pay for both the POC for everyday activities & tanks for exercise. I plan to pursue this in order to stay active & increase my endurance & energy & can use any support I can get.

It is asking too much of an 86 year old woman to use an E tank to keep a doctor's appointment.

I use the OxyGo portable, it makes traveling easier.. Using Oxygen is not easy, but without it I would not be able to maintain my healthy lifestyle, limited as it may be I also use a oxygen concentrate at night and for exercising at home. I am not on medicare, but hope when the time comes they make it easy for me to stay healthly and active with the equipment I need.. For the record I was never a smoker.

I would not be able to do as much as I can now if I had to carry or lug around a larger oxygen container. I can manage the weight of the M6 tanks on my shoulder to go to different meetings for the groups I

belong to. If I had to use a bigger or heavier tank I wouldn't be able to get around like I do now. I can even travel with the M6 tanks to local restaurants, movies, shopping malls, etc.

Portable, liquid, supplementary oxygen is absolutely necessary for me to continue living an active and productive life. For me, not to be able to use liquid oxygen would, in effect, be a death sentence. Being mobile equates with freedom and freedom is what every human being wants and needs. It is pathetic that the U.S. Congress does not care more about oxygen-dependent people. We're not all homebound with nowhere to go. Some of us exercise on a daily basis, make trips and otherwise participate in society.

I use a treadmill at home 4-5 days/week, too hard to drag the tank. I often don't get out of car if I am unsure I can get into my destination because it is too much work to get the E tank out of my car, walk to the door, discover the person is not home or there is no seat at the cafe, and then have to turn around walk back to the car and try to get the tank put away and the cannula stretched back to the front seat. I often drive places without getting out of the car.

Lox would make it easier to exercise and do more outside because of the mobility factor.

Portables would be so much better. Sucks to have a 2-3 hit time limit.

The portable tank is too heavy for me. I need my daughter to take it outside if I want to sit on the porch. It takes up a lot of my energy while pulling it around. By the time I've reached my destination I am out of breath and my oxygen saturation has gone down below 87. The Dr. says it's suppose to be between 91-94.

I do only use 2L for resting and sleep but need 6L for any activity. Wrestling around an E tank is hard for me and one E tank does not last long enough for me to do much of anything. The weight of trying to use a double carrier for them would not be a viable solution to that. I don't think it is an exaggeration to say losing my liquid O2 would not only impact my quality of life but would actually shorten my life.

Liquid Oxygen is way more better than a Concentrator

service is okay...the tanks are extremely heavy and walking while carrying them makes walking much more difficult.

I am desperately trying to not move to my daughter's home in Va because liquid oxygen is not available. I may as well die without liquid oxygen.

Cylinders are cumbersome for a 100 lb. woman to deal with. I use a portable concentrator my niece has for me to use when I visit her home. Easy to use and light weight. At home, my Perfecto is fine for my needs. So far the service is very good, and the service provider is doing a fine job.

I could NOT handle a cylinder larger than B/M6.

being limited to large tanks would be extremely restrictive (playing golf for example). suppliers should be forced to furnish smaller tanks (m6's, etc

I also have a portable device, if I couldn't get out I would be depressed and need more mess at least I can live a fairly normal life with my devices. Exercise is a big issue so being Mobil with a device is very important to my quality of life

I love liquid wouldn't want it any other way very easy for us to use in home and away.

I am satisfied with my current delivery device. I think it would be crazy to go back to making people lug around the large tanks. We have a hard enough time with out lugging around heavy tanks. Perhaps the ones who make the decision should try to lug around those tanks while breathing thru a straw and then they might just understand. Thanks for your time.

the oxygen company I was with lost their bid with medicare and though the portable concentrator works best for me the company I am with now seems to be having problems getting medicare's approval. when I used one I was actually able to get around more even going places with my family. the doctor's office is the only place I can go now. my quality of life is '0'. Thank you; God bless you. Sincerely with Respect.

I only use the devices at night to sleep and, occasionally on a 'bad-breathing' day. I do not carry the cylinder because I feel that it is too heavy and causes more breathing problems for me. I leave it in the

car for use when I return and am breathing hard.

i am mild to moderate copd. continuous flow 2 lpm. overnight oxygen only and 'with activity'. I do not engage in 'activity' that requires me to use oxygen (walking etc. my choice - which is not necessarily good for me). I had occasion back in 2012 to have to use the portable tanks to visit my husband who was in the hospital for 3 weeks. I brought it with me but didn't hook it up. Carrying the portable tank around was worse for me than going without. We travel around new england several times a year. My original concentrator was a very heavy and bulky to bring with us on overnight trips. To obtain a portable concentrator I had to reserve one two weeks in advance which they wound up giving me a pulse only concentrator in spite of my instructions otherwise. Finally found the perfect concentrator - O2 Concepts - weighs only 20 lbs and is continuous flow for my. It is not really suitable as a portable to go out to the store, but it allows me the flexibility to go to the next state on a whim to see the grandkids which tremendously improves my life. Don't let the insurance companies dictate the quality of our life.

The small tanks are perfect to use because they are not heavy. They allow me mobility that I would not otherwise have. I could not lift the large tanks at all.

Given my high flow oxygen needs, desire and ability to exercise and to be mobile, I have found the liquid oxygen system to be the best at supporting me to live the fullest life possible in the face of serious life threatening health issues. To be limited by pulling a double e tank cart (2 tanks) through my day to support me as I carry out my activities would be physically difficult and taxing on my oxygen saturation levels. Not to mention the impact on my back due to lifting the tanks in and out of the car a few times a day. The liquid oxygen technology is available and access should not be the limiting factor in the ability to live an active life for high flow users of oxygen.

The Helios I use is light weight and easy to carry around at one time I had cylinders and they were so hard to handle.

I am worried that my current supplier will stop providing LOX and I will have to revert to using cylinders again which are too heavy. I won't be able to do much away from home if I have to carry heavy cylinders. Please get Medicare to cover LOX for those of us who need to maintain a good quality of life.