ELF Patient Organisation Networking Day:

James Chalmers: Q&A follow up

***From Janette**:*

Q: Teaching kids how to wash hands was good but all the focus now is on hand sanitiser in shops or schools and may reduce the amount of hand washing. How do we ensure the hand hygiene message is that hand washing is more effective and should be done wherever possible and that sanitiser is a poor relation if hand washing is not possible?

A: This is a great point. Initially in the pandemic the government messaging was quite clear that handwashing with soap and water was best, and sanitizer was there as the backup when you are out and about and don't have access to a sink. We need to keep making that point, and if you have a choice, washing with soap and water is best.

From Janette:

Q: Also how do we encourage the high number of people not wearing masks (both young and old) to reduce spread? Shops not enforcing it - saying it is guidance despite legislation existing… but police not interested - how can we recover the behavioural shift of "we're all in this together" that we had at the start?

A: This is a really difficult issue and my opinion is that it has to be done with consideration. Some patients with severe lung conditions really struggle with masks and I don't want them to feel stigmatised. On the other hand, many people who don't have health conditions feel they shouldn't have to wear masks and some people are actively protesting against wearing masks

I have a few suggestions

1) Educate- we should do more to explain to people why wearing masks is helpful, and that it is about protecting others rather than protecting yourself (young people don't wear masks because they feel invincible, but they might wear masks for the benefit of others)
2) Make it easier – large shopping centres or stores could provide masks at the front door, so those who are not wearing them because they forgot their mask can have one. Masks are cheap and easily available so no reason not to make it easier for people (hospitals already do this)
3) Make the rules more clear- mask wearing should be mandatory in many situations where currently it is "guidance" – the Spanish regulations are much more strict and compliance is therefore much better.

From Janette:

Q: Having regular meals, better sleep, and better adherence to respiratory meds are also likely to have contributed to the 'better' experience of many lung conditions not to

mention vastly improved air quality when traffic/air traffic was much reduced. how can we do more to sustain those too?

A: I agree. It is going to be hard to maintain the changes as we are all encouraged to get back to work, the traffic on the roads is going to increase. I hope some changes to home working will become permanent, and maybe some of the changes we have made to our lifestyle like sleep/adherence will also become more permanent as we recognise the benefits

From Ian Jarrold:

Q: Thank you James, an excellent presentation! What is your feel regarding the longer term effects of COVID-19 in people who have had it? Do you have a sense of the respiratory impact in survivors - will we see a large number of people with long term respiratory care needs? Also, cases in the UK are increasing but deaths are not - is that because we're better at stopping people dying from COVID, or the nature of who is now being infected - or both? Do you think there will be a 2nd wave?

A. Great questions. I am seeing a number of patients with ongoing symptoms like breathlessness and fatigue. Most people are recovering completely but maybe 10-20% of hospitalized patients seem to be having ongoing problems, and a small number of those who were not hospitalized are also being affected. The UK PHOSP study and the European Respiratory Society END-COVID19 projects are among those looking at post-COVID complications and will be able to more precisely quantify this problem.

The cases going up but deaths going down is seen all across Europe and reflects a change in testing strategy. We are testing more and more (most countries are seeing less than 1% positive tests) which means we pick the condition up in people who would have gone undetected in the past. This means people self-isolate and don't pass the disease on to more vulnerable groups, keeping the death rate down. At the moment the infections are primarily in young people who have a low risk of death and we need to keep it that way.

I don't really think about waves, I think we are going to see localised outbreaks, but not a widespread "wave" like we saw from March to May.

From Janette R:

Q: I've had a variety of clinical appointments during this period - some were impractical as a phone call - how can a physician listen to a chest, breathing etc - converted to a video call but still less than optimal. also had positive experience at a hospital on 15/5 with CXR and blood tests done and bone scan last week. many patients are very afraid of attending hospital appointments so longer term this may well impact their overall performance so home visits may be required or that primary care finally opens its doors in the UK. I'm involved in commissioning and know the rhetoric and the reality on the ground are quite a way apart. how can the methods of determining who will be seen or how be made more appropriate than at present and is there a role here for patients to express a preference?

A: That is very much my opinion. Remote consultations will suit some patients and not others, some patients will be fearful of attending hospital but many will want to come. I think we need to put a lot of the power in the hands of the patients here and be willing to be flexible.

From Gundula Koblmiller:

Q: Should we talk about spatial distancing than about "social" distancing?

A: I think the phrase social distancing is so widely known now that changing the name would probably cause confusion. I agree with the spirit of the question however, that we should put spatial/physical distance but not emotional or true "social" distance between us. We still need each other!