Comments on the ACD Received from the Public through the NICE Website

239 members of the public submitted the following comments to NICE, through the web comments system:

> I agree with the following statement from the Cystic Fibrosis Trust:
>
> Colobreathe (colistimethate sodium dry powder for inhalation, Forest Laboratories) should be recommended for the treatment of pseudomonas infections.
>
> The benefits over other treatments include:
>
> An alternate inhaled treatment option for patients who are contraindicated for tobramycin
> Treatment burden is reduced because the drug is administered by inhaler rather than by nebuliser.
> Promotes adherence as quick and easy to administer compared to the current nebulised form of colomycin.
> Treatment is more likely to be effective as patients will take a full dose because of more convenient inhaled delivery mechanism.
>
> There is a great need for further choice of treatments for CF to become available, particularly treatments that are quick and easy to use such as dry powder antibiotics. People with CF have a huge burden of care often having to do hours of treatments and physiotherapy a day. Each treatment that becomes available and is proven to be effective in treating infections and symptoms of CF is a huge step forward in helping people with CF to stay well.
>
> We are pleased that tobramycin dry powder will be recommended for people with CF. NICE should also recommend Colobreathe for the treatment of pseudomonas infections.

Additional comments from these individuals, and comments from other members of the public, are presented on the following pages.

Name	[redacted]
Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I am a 33 year old woman with Cystic Fibrosis whom works 40 hours per week and has done for over 15 years. Being able to reduce my treatment time would make a huge improvement to my live. Ensuring I receive adequate dosages also means I will keep infections to a minimum and less time off of work which will ultimately the NHS money and ensure that for as long as possible, I remain an active, tax paying member of society. Â I ask that you strongly consider the quality of life improvements that this product would bring to those actively LIVING with this disease.
Date	11/12/2012 5:03:00 PM

Name	[redacted]
Role	Carer
Location	England
Conflict	no
Notes	My son need all the options open to him. The more doors we open for his specialist to choose, then better chances he has. He deserves deserves a better, longer quality of life.
Comments on individual sections of the ACD:	
Section 4 (Evidence and interpretation)	QALY - More options will provide a better QALY outcome for carer - in delaying the total contraindiction point.
Date	11/13/2012 12:13:00 AM

Name	[redacted]
Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 2 (Clinical need and practice)	Any new drugs that will reduce the burden of treatment and improve quality of life is most welcome. Â Watching my 18 year old daughter struggle on a daily basis with her punishing regime Â of drug therapy, nebulised treatment & physio is something I would not wish on any parent. Â If this new drug could be of benefit and speed the drudgery for my daughter even by 5 minutes a day would be fantastic.
Date	11/12/2012 6:45:00 PM

Name	[redacted]
Role	Carer
Other role	Parent
Location	England
Conflict	no
Notes	Our child had cf and would benefit from this greatly .
Comments on individual sections of the ACD:	
Date	11/12/2012 8:22:00 PM

Name	[redacted]
Role	other
Other role	Parent of CF sufferer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 2 (Clinical need and practice)	While it is true that CF sufferers have problems with both respiratory and digestive systems, it is the respiratory problems which mainly affect both their quality of life and life expectancy. The digestive problems are often well controlled with modern enteric-coated enzymes which are easily and quickly taken. Anything which makes managing or alleviating respiratory

	complication easier or quicker therefore has a major impact on the lives of CF sufferers.
Section 3 (The technologies)	The fact that different patients respond to different medication in different ways is one reason why there should be as wide a range of treatments as possible available to patients and their medical advisors. As for cost, a better treatment for a CF patient can lead to cost savings for other treatments and procedures which could be necessary if health deteriorates. In the case of my son, and presumably many others, while he is kept well he can continue to work, thereby not claiming unemployment benefit, and contributing Income Tax and National Insurance from his wages.
Date	11/12/2012 6:33:00 PM

Name	[redacted]
Role	Patient
Location	England
Conflict	no
Notes	From my own personal perspective as a CF patient, i take both Colymcin and Tobramycin, in 4 weekly alternate cycles. The inhaled tobi is an unbelievable improvement, from what used to take 30 mins to administer, now down to just a few minutes is quite incredible. If colymcin could also be inhaled, this would be massively beneficial too. I also understand that the inhaled form of drug is more effective than the nebulised solution. I strongly urge you to give approval to this, as i know from personal experience how advantageous this would be, as cf patients do have so much treatemnt to fit into their day and any time saving equipment will be hugely welcomed. Many thanks. Andrew
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	As a cf patient, I curently take inhaled tobi and nebulised colymcin, in 4 weekly alternate cycles. It is difficult for me to provide a clinical opinion on this as i am not qualified to do so, suffice to say that time taken to administer oral antibiotics is a big issue and secondl the effectiveness of the treatment. From what i have been advised at the Royal Brompton, the inhaled drug is more effective than the nebulised, in addition to being massively quicker, which as a patient is significantly beneficial.
Section 2 (Clinical need and practice)	I completely agree with all the above. I also take Azithromycin (3 days per week) in addition to Tobi and Colymcin.
Section 3 (The technologies)	The tobi inhaler is just fantastic - i would go as far as to say that it is revolutionary and has reduced the time i take this drug from about 1 hour per day to about 5-10 mins, simply incredible. I am very grateful for this medical advance and for my GP to fund this. If Colistimethate can provide similar benefits, then it has my strong support.
Section 4 (Evidence and interpretation)	There is much analysis here and much to digest. I re-iterate my previous comments that inhaled tobi has been hugely beneficial to me, and further inhaled antibiotics, which are both time saving and effective must be beneficial.

Section 5 (Implementation)	The sooner the better, as always
Section 6 (Proposed recommendations for further research)	I postively welcome all further cf clincial research and indeed am pleased to advise that my company, The Big Yellow Self Storage Company, has chosen cf as our Head Office Charity and i liaise with the cf trust to ensure that all money raised is directed towards research projects.
Section 7 (Related NICE guidance)	This seems an awfully long way off - the sooner the better. I completely agree with all the above. I also take Azithromycin (3 days per week) in addition to Tobi and Colymcin.
Date	11/13/2012 11:42:00 AM

Name	[redacted]
Role	Carer
Location	England
Conflict	no
Notes	Please please please reconsider the recommendation for Inhaled Colobreath to be available to people with Cystic Fibrosis. My son is coping with this disease and life at university. The daily burden is huge and this Inhaler would make all the difference to his life. His compliance would be greater and he would stay more well - Thus saving the NHS money. If the research has produced this product, then it should be available.It is mind body and soul destroying to know that its there and would help my son, other sons and all people with CF. Please reconsider.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Colistimate should be avaialbe. Thise who thinkno t should try making up nebule, sterising equipmemt 2/3/4/ times a day, every day Christmas day, on holiday, when ill. This treatment is a life saver for all the family
Section 2 (Clinical need and practice)	The compliance using Inhaled Colobreath would be far more frequent and beneficial than nebulising.
Section 3 (The technologies)	Our child had cf and would benefit from this greatly .
Date	11/12/2012 6:35:00 PM

Name	[redacted]
Role	NHS Professional
Location	England
Conflict	no
Notes	I think that the dry powder colistimethate is a significant advance in treatment technology for cystic fibrosis patients and should be available for NHS patients. Nebulised colistin is our first line inhaled treatment for patients growing pseudomonas but patients find the nebulisation times too long and the proper care of nebulisers and compressors very onerous. I feel that the availability of the dry powder preparation would greatly enhance the quality of life of these patients and improve adherence to colistin therapy, which is often poor.

Comments on individual sections of the ACD:	
Section 2 (Clinical need and practice)	The device used in order to administer the antibiotic therapy is likely to be one of the most crucial factors affecting adherence to treatment and longterm outcome after pseudomonas infection
Date	11/6/2012 12:35:00 PM

Name	[redacted]
Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	My daughter is very ill with cystic fibrosis and has been battling with pseudomonas infection since the age of 5 she is now 18 and is starting to be assessed for transplant. Maybe with better help to fight the pseudomonas infection my daughters health could improve drastically!!! We need every chance we can get we don't want to lose the battle against cf we love our daughter dearly. Please help keep my daughter alive and at home with her family where she belongs!!
Date	11/12/2012 5:17:00 PM

Name	[redacted]
Role	Carer
Other role	Mother
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 2 (Clinical need and practice)	I am a full time carer for my daughter who has CF. She is colonised with psuedomonas and aspergillus and regularly grows other bacteria in sputum samples.CF is extremly invasive and significantly impacts on her life.She has a portacath (a permanet indwelling device in her chest, which also necessitates flushing every 28 days)as she needs regular intravenus antiboitics to treat psuedomonas. Her daily routine of medicines, specific CF diet, physiothereapy, nebulisers and inhalers is extremely time consuming and she naturally becomes exasperated from the amount of treatment and the time it all takes. Anything that will help reduce the treatment adherence time will be hugely effective as she is more likely to be encouraged to adhere to her treatments thereby promoting better health and hopefully reducing the requirement and frequency for IV antibiotics and hospital stays. She has periods of depression, as do I due to the intensity of the disease and it's implications. Please help her by recommending and supporting Colobreathe.
Section 3 (The technologies)	It is proven that these drugs target psuedomonas although the current delivery methods are far from efficient and practical as a nebuliser is needed to administer them. Also it is very time consuming to use and requires an extensive cleaning regime after each use. Standing on it's own this seems rather petty but in conjunction with all the other vital treaments i.e. physio etc it

	adds up to a substantial amount of time which is at the very least tedious and results in non compliance further resulting in worsening of symptoms then needing MORE treatment and medicines!
Section 4 (Evidence and interpretation)	When previously using nebulised Colistin over meny years my daughter developed a significant wheeze and cannot tolerate nebulised Tobramycin as it irritates her cough and throat causing lengthy coughing bouts and shortness of breath. She has recently been given the Toby Podhaler which has proven to be ABSOLUTELY AMAZING, in so much as it targets the psuedomonas - keeping it more controlled thereby limiting the lung damage.
Section 5 (Implementation)	If this were to be recommended the lives of many people suffering with CF, a chronic life threatening condition would be hugely improved. I believe it is vital to consider the long term rather than short term financial expenditure as it would most certainly encourage CF sufferers to adhere to their extensive treatment regime as it would be less time consuming and invasive.This in turn would reduce the exaserbation of lung disease and consequently hospital admissions.
Section 6 (Proposed recommendations for further research)	MAnnitol is another wonderful medication to help those with CF please recommend it's availibility on NHS.
Date	11/12/2012 8:11:00 PM

Name	[redacted]
Role	other
Other role	Grandparent
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	My granddaughter is a CF sufferer and if there is any way her life can be made easier by having a more effective way of taking a treatment when she is suffering with the pseudomonas infection, then she & her doctors should be able to have that choice.So I really support the statement from the CF Trust , which says that Colobreathe should be recommended for the treatment of pseudomonas infections
Date	11/13/2012 3:56:00 PM

Name	[redacted]
Role	Patient
Location	England
Conflict	no
Notes	I suffer with Cystic Fibrosis, and have been taking nebulised colistin for several years. On top of the various other treatments I have to take, administering this drug is time consuming and to be able to have it as a simple inhaler would improve my quality of life drastically. I do not see any reason that this drug shouldn't be approved immediately, it has been available for years and

	the NHS are wasting time by not approving it, whilst the lives of thousands of CF sufferers are being detrimentally affected by nothing other than simple bureaucracy. Also, many people with CF (like myself) cannot tolerate nebulised or inhaled tobramycin, and it is not fair that one drug should be approved when another of the same sort isn't!
Comments on individual sections of the ACD:	
Date	11/12/2012 5:04:00 PM

Name	[redacted]
Role	Carer
Other role	Volunteer support worker for people with CF
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 2 (Clinical need and practice)	My son has Cystic Fibrosis. Â He manages to maintain a full-time job but finds it difficult to keep up with all his treatment, which includes nebulised Coliston. He would very much welcome a product such as Colobreathe which would make his treatment much easier. Â As with all people with CF, if he complies with his treatment he is able to stay out of hospital much longer, thus saving the NHS money, and continue working, thus contributing to the economy.
Date	11/12/2012 7:11:00 PM

Name	[redacted]
Role	NHS Professional
Location	England
Conflict	yes
Notes	awarded educational grants Novartis and Forest
Comments on individual sections of the ACD:	

Section 1 (Appraisal Committee's preliminary recommendations)	Tobramycin nebulisation can cause significant side effects as the drug may be absorbed. Many patients grow Pseudomonas resistant to Tobramycin while resistance to Colistimethate sodium is unusual. The key study allowing the use of Tobi was based on comparing half dose Colomycin vs nebulised tobramycin in patients previously exposed to the former drug. It was key to compare Colistimethate sodium dry powder to Tobi rather than nebulised colomycin. There are very limited antibiotics and patients find adherence very difficult. The individuals who use the ineb and work need alternatives. Adherence as we have shown is poor and even those individuals who which to be adherent can find it difficult to use nebulisers to to lack of time and convenience. As a doctor I would suggest those prescribing try out all the devices. I did and was amazed as to how unpleasant an Ineb and other nebuliser devices are. Tolerance of various products is variable and we need to have as many products available as possible. Lung deposition of Colistimethate dry powder is excellent and the device is so simple. Infection control is also very important. Fungal and bacterial contamination occurs in all nebuliser devices and disposable systems are key.
Section 2 (Clinical need and practice)	So where is the evidence for azithromycin. What about phage killing and NTM?
Section 3 (The technologies)	Have the team tested the various devices. They are both very good but one is a lot simpler to use. I agree that cost of Colistimethate sodium dry powder for inhalation needs to be reduced
Section 4 (Evidence and interpretation)	I welcome the decision for TIP but do not agree that the most appropriate comparator for colistimethate sodium DPI would be nebulised colistimethate. This would have gone against all the literature and certainly I would have criticised Forest. Â I also feel that there is too much emphasis on the newer nebulisers as discussed above. Those who are adherent and wish to get on with their life should be able to reduce their infection risk and ease of administration. It is very hard to write the comments as the box is 5 cm long and 3 cm tall.
Section 6 (Proposed recommendations for further research)	So where is the evidence for azithromycin. What about phage killing and NTM?
Date	11/12/2012 7:57:00 PM

Name	[redacted]
Role	Patient
Location	England
Conflict	no

Notes	As a CF patient, I know from first hand experience how debilitating Pseudomonas infections can be and how difficult it can be to treat. Any treatment which makes the administration of the drug easier should be welcomed as being connected to an IV three times a day really does limit what you can do and when I have needed to do that, it has meant I needed 2 weeks off work.
Comments on individual sections of the ACD:	
Date	11/12/2012 4:39:00 PM

Name	[redacted]
Role	Carer
Location	England
Conflict	no
Notes	Parent to a child with CF
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I concur with the position and recommendation of the Cystic Fibrosis Trust that Colobreathe (colistimethate sodium dry powder for inhalation, Forest Laboratories) should be recommended for the treatment of pseudomonas infections. As a parent of a child with CF I strongly believe that we should have available to CF patients treatments that are effective and reduce the burden of care and improve quality of life. Repeated daily nebulizers (in addition to physiotherapy regimes and oral medications) for multiple medications place a heavy burden on time and effort for patients/carers to administer and manage the treatment. Providing an alternative solution that reduces this effort cost effectively improves quality of life and encourages/facilitates compliance which in turn reduces frequency of hospital submissions. It is the appropriate and correct position to recommend this solution on both moral and total life cycle cost effectivenss grounds.
Date	11/13/2012 1:02:00 PM

Name	[redacted]
Role	Public
Other role	Relative of CF sufferer
Location	England
Conflict	no
Comments on individual sections of the ACD:	

Section 1 (Appraisal Committee's preliminary recommendations)	My cousin suffered with CF all her life until her death 2 years ago at an incredible age for someone suffering with CF of 35. Â Her life expectancy when she was born was little more than 8 years. Â She fought every day to improve the care for CF sufferers and awareness of the illness. Â Her day to day life towards the end was made incredibly difficult due to the regular need for her nebuliser. Â A drug such as this that could be administered through an inhaler would have made her life much easier. Anything that makes life easier for sufferers of this terrible illness should be made as readily available as possible.
Date	11/12/2012 4:52:00 PM

Name	[redacted]
Role	Carer
Other role	grandparent to CF sufferer
Location	England
Conflict	no
Notes	At the age of 7 years my young grandson has had psudomonas twice and treatment is by intravenous anti-biotic under hospitalisation; we all love to see him improve with his treatment but he misses home and a large chunk of education. As Britains most common life-threatening disease CF sufferers need all the help available.
Comments on individual sections of the ACD:	
Date	11/13/2012 9:07:00 AM

Name	[redacted]
Role	Pharmaceutical Industry
Other role	Interim Medical Director
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 2 (Clinical need and practice)	Comment from Gilead Sciences UK Ltd. We wish to draw to the attention of the Appraisal Committee that a third inhaled antibiotic is licensed and available for prescription in the UK CaystonÂ® , (aztreonam lysine solution for inhalation) is a monobactam antibiotic indicated for the suppressive therapy of chronic pulmonary infections due to Pseudomonas aeruginosa in patients with cystic fibrosis (CF) aged 6 years and older. It may be used in repeated on/off cycles of 28 days duration. Cayston is administered by nebuliser using the ?e-flow rapid? device and has a significantly shorter administration time of only 2-3 minutes. The safety and efficacy have been extensively demonstrated in a large programme of clinical studies, including

	a long-term safety study. Â Cayston was shown to be non-inferior to inhaled tobramycin in an active comparator study. Although the addition of Cayston to the current, small range of available inhaled medications for the treatment of pulmonary exacerbations is comparatively recent, we consider that the omission of any reference to this product in the appraisal is an important oversight. Â We would anticipate an acknowledgment of this omission.
Date	11/9/2012 11:02:00 AM

Name	[redacted]
Role	NHS Professional
Location	England
Conflict	no
Notes	nil
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Why dry powder tobramycin but not colistin
Section 2 (Clinical need and practice)	Evidence may be emerging that Azithromicin may be associated with non tuberculous mycopbacterial infection so this strategy may fall in disuse.
Section 4 (Evidence and interpretation)	It should be stated that the microbiology of CF is changing rapidly with emerging pathogens especially aspergillus and non tuberculous mycobacteria. Â These often require multiple antibiotic regimes including nebulised treatment. Â Together with requirement for mucolytic therapies (Dnase and Hypertonic saline) there is simply not enough time in the day to administer all this nebulised treatment. Â We simply must replace nebulisation with dry powder devices or we will be forced to stop treatments as we try a guess which pathogen we should treat first. Â I do not think you have given enough emphasis on reduced treatment time that dry powder devices bring. Â You have also not mentioned the cost of the actual nebuliser devices in your analysis and the latest devices are not cheap and consumables produce a suprisingly large bill for the NHS. Â Nebulised treatment is largely frowned on in other areas of respiratory medicine where dry powder alternatives are available and the same should follow in CF
Date	11/12/2012 3:54:00 PM

Name	[redacted]
Role	NHS Professional
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 4 (Evidence and interpretation)	As a clinical psychologist with 22 years experience working with people with cystic fibrosis, much of my work is involved with difficulties associated with adherence to treatment. I am pleased

	to read that the committee did conclude that the use of dry powder inhaler system would improve quality of life and increase adherence to medication. Greater adherence to daily antibiotics reduces cost of other care such as admissions and added in therapies. The patients and families I work with are eagerly awaiting the availability of an inhaled device for colistin. Parents are keen that this device will reduce their time spent preparing and cleaning the device and people with CF are keen to be able to use something as normal as an inhaler rather than a nebuliser for colistin.
Date	11/9/2012 4:07:00 PM

Name	[redacted]
Role	NHS Professional
Location	England
Conflict	no
Notes	Provide a CF service for children in Basingstoke \and North Hampshire area.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It is sad that NICE have decided purely on the basis of cost that Colistimethate shouldn't be recommended. In real practice we get very little resistence to Colistine as opposed to Tobramycin on the basis of its mode of action. Also it is 1 capsule at a time as opposed to 4 capsules. Thus the compliance will decline with passage of time.
Section 2 (Clinical need and practice)	As above. Clinically Colistine dry powder is far superior to the Tobramycin dry powder system. Practically, the turbospinhaler is a much easier device to use than the tobramycin podhaler.
Section 3 (The technologies)	Though recommendation is a month on and month off, frequently patients are on it continuously, hence encouraging more resistent Pseudomonas to develop.
Section 4 (Evidence and interpretation)	Comparative study was done on the basis of EMA requirement for Colistin. May be it should have been more explicit as to what was the best study to do prior to marketting the devices. It would also have been useful to have someone with the knowledge and expertise of CF in the committee.
Section 5 (Implementation)	Cost can always be negotiated. If the company doesn't get licence/ NICE recommendation then we are likely to loose an important drug in the treatment of CF in UK. The Forrest are more likely to get European agreement
Date	11/4/2012 11:50:00 PM

Name	[redacted]
Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I have CF and sometimes have reactions to some mediciations. It is therefore important to me to have a number of options available.

Date	11/13/2012 8:55:00 AM

Name	[redacted]
Role	Carer
Other role	Nurse
Location	England
Conflict	no
Notes	My daughter really struggles with the high doses of colomycin and the cure is bad mind you the problem worse, please pleae make this available for people like my daughter, she made it to 21, something i never dreamed possible, please let her see more birthdays.
Comments on individual sections of the ACD:	
Date	11/12/2012 9:49:00 PM

Name	[redacted]
Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I am a CF patient and the main benefit of dry powder antibiotics to me would be that as it is quick to use and portable, I can take the antibiotic the correct amount of time after my pulmozyme (DNase). It is necessary to wait at least an hour after DNAse before taking nebulised/inhaled antibiotics as the antibiotics reduce the efficacy of the DNase. I have just been prescribed the dry powdered tobramycin inhaler instead of my colomycin nebuliser for alternate months. After just three weeks on this my health has definitely improved. Previously I was did not have enough time or energy (due to coughing fits etc) in the morning to take DNAse, wait an hour and a half (Hour wait + 30mins physio) then nebulised colomycin (15mins + 10mins wash and sterlise) before leaving for work, so I had to just take my colomycin in the morning then DNAse after work. This is not so effective and meant my lungs were not cleared properly all day. Now I do my DNAse and physio before work, then take my TOBI inhaler to work to do anytime during the morning. My health is much improved on this regime! For patients that need colomycin not TOBI, and for patients like me who only take TOBI alternate months, the opportunity to have colobreathe would make a massive difference to both our health (especially for patients that have to do many more nebulisers than myself), and in their quality of life as the majority of CF patients use pulmozyme so experience the same difficulties as me of fitting in the meds at the appropriate times with the right time gaps between them to allow them to work. Frances Lavender
Date	11/13/2012 3:14:00 PM

Name	[redacted]
Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 3 (The technologies)	He quicker the technique the more likely a child/person will use this.
Date	11/12/2012 8:54:00 PM

Name	[redacted]
Role	other
Other role	Grandparent of Afflicted Â Teenager
Location	England
Conflict	no
Notes	My Wife and I have an 19 years old Grandchild, who is currently ill with the pseudomonas lung infection bug. It is a further crucial stage of his Young life, one of a series of similar infections that blight sufferer's lives and make every day a battle. Doctors and Clinicians need every possible array of arsenal weapon to keep sufferer's alive. We agree with the C.F. Trust in their support of this treatment.
Comments on individual sections of the ACD:	
Date	11/12/2012 7:18:00 PM

Name	[redacted]
Role	Public
Location	Wales
Conflict	no
Notes	I have a six year old sister who has had the pseudomonus infection since last year. It is important to keep this at bay and if it flares up who knows how ill she will become. Cystic Fibrosis is such a temperamental illness and infection can make a sufferer seriously decline. I have experienced it and think it's really important that this treatment is offered.
Comments on individual sections of the ACD:	
Date	11/12/2012 7:07:00 PM

Name	[redacted]
Role	Patient
Location	England
Conflict	no
Notes	This. would make my life so much easier. Any help managing my CF is greatly appriciated and this would help.
Comments on individual sections of the ACD:	
Date	11/12/2012 6:42:00 PM

Name	[redacted]
Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	MY SON IS RESISTANT TO TOBRAMYCIN so we desperately need NICE to recommend Colobreathe for the treatment of pseudomonas infections. Colobreathe would ease this burden for my family.
Section 3 (The technologies)	My son has multiple resistant pseudo. Â He is resistant to Tobi he would benefit so much from having Colobreathe
Date	11/12/2012 4:44:00 PM

Name	[redacted]
Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I could copy and paste the CF Trust statement, however thought it important to stress adherence. It's incredibly important, and the burden of nebulisers seems to be poorly understood at times. It isn't just the time taken to nebulise (and the new models are quicker, but not quick) but also the cleaning and care involved. Dry powder inhalers, even if not quite as effective, are going to help with compliance and thus potentially be more effective in the long term.
Date	11/13/2012 2:28:00 PM

Name	[redacted]
Role	Carer
Location	England
Conflict	no
Notes	My daughter Freya is 10 months old and has CF.
Comments on individual sections of the ACD:	
Date	11/13/2012 3:55:00 PM

Name	[redacted]
Role	Carer
Other role	Mother of cystic fibrosis sufferer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I believe this would improve quality of life being quicker and so much easier to administer than a nebuliser: without the inconvenience of having the extra equipment to assemble, disassemble and wash all the separate parts, changing filters each time, mixing the medicine(having to use syringe/needle to do so then suitably disposal of these), having to use electricity

	or battery power, sterilising the equipment Â and of course being in a suitable place to do all this.
Date	11/12/2012 9:27:00 PM

Name	[redacted]
Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 4 (Evidence and interpretation)	I am an aunt of an 11 year old with cystic fibrosis whose daily treatment regime involves both physiotherapy and oral and nebulised drugs, lasting several hours. Pseudomonas aeruginosa is a bacterium that has caused recurrent infections. The amount of time taken to administer treatment has increased over time, and also involves fortnightly intravenous drugs every 3 months. The physical discomfort and disruption to education and family life cannot be underestimated for this child and its carers. The Cystic Fibrosis community can see that there is a great need for an increased choice of treatments for CF to become available, and in particular those that are quick and easy to use such as dry powder antibiotics. There are immense benefits to be had from such treatments to enable those with CF to remain well, and to live their lives with less impact from increasingly time-intensive treatment regimes. The Cystic Fibrosis Trust believes that NICE should recommend Colobreathe for treatment of pseudomonas infections, so that people with CF and their clinicians should have the opportunity to assess whether Colobreathe is the right treatment for them. I am fully supportive of this position.
Date	11/12/2012 10:08:00 PM

Name	[redacted]
Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 2 (Clinical need and practice)	As a cf patient and one which has to do 2x daily nebulised colomycin permenantly, to have an the oppotunity for a dry powder inhaler which could potentially be available is fantastic news! It is extreamly hard work to keep well and it takes alot of dedication and energy to adhere to all the required treatment, medication, physio, hospital appointments on top of working full time, and trying to spend quality time with friends and family as well as trying to enjoy life! It is essential that these new treatments can be made available to everyone helping to releive the burden of daily time

	consuming treatments. This would dramatically improve my quality of life making it easy as possible helping people just like me to get on with life whist keeping well and keeping on top of medication and ultimately keep well for as long as possible. This would help so many patients in so many ways and I urge this to be recommended for the treatment of pseudomonas infections.
Date	11/12/2012 9:19:00 PM

Name	[redacted]
Role	Patient
Location	England
Conflict	no
Notes	On a personal note the idea of quick and fast treatment is very very appealing. Â I have a busy work schedule and treatments which take hours, resulting in early 5am starts and late 12am finishes are not ideal and only impede recovery. Â Something fast and quick like this should be made available for all those who would benefit from it. Â J.A.Symington
Comments on individual sections of the ACD:	
Section 3 (The technologies)	Something fast and quick is greatly needed so patients with CF can live a more normal life, without treatments starting at 5 am and finishing at 12am to ensure we can go to work etc.
Date	11/12/2012 4:34:00 PM

Name	[redacted]
Role	Carer
Location	England
Conflict	no
Notes	My 7 year old son has Cystic Fibrosis, and after his 3rd case of Pseudomonas he is now on permanent nebulised Colomycin. Anything that is going to make his life more comfortable has got to be tried
Comments on individual sections of the ACD:	
Section 2 (Clinical need and practice)	My 7 year old son has Cystic Fibrosis and has had Pseudomonas 3 times. He is now permanently on nebulised Colomycin, so anything Â to ease his burden must be a good thing
Date	11/12/2012 4:50:00 PM

Name	[redacted]
Role	other
Other role	grandfather of 19year old Cystic Fibrosis sufferer
Location	England
Conflict	no
Notes	I agree with the following statement from the Cystic Fibrosis Trust: Colobreathe should be recommended for the treatment of

	pseudomonas infections. One of the benefits is that it promotes adherence as quick and easy to administer compared with the current colomycin;this is of particular relevance to young people like my grandson who is about to go into King's Hospital London for several days to help stop the infection or at least slow it down.
Comments on individual sections of the ACD:	
Date	11/13/2012 4:24:00 PM

Name	[redacted]
Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	As a parent of a child with CF then any medication which is proven to fight pseudomonas is a welcomed development. This type of infection reduces the quality of life of a person with CF and so prevents them from having a normal as possible. This affects there mental health as well as physical as it prevents them from doing every day things.
Date	11/13/2012 8:14:00 AM

Name	[redacted]
Role	other
Other role	relative of teenager with CF
Location	England
Conflict	no
Notes	My granddaughter becomes very poorly when the levels of pseudomonas in her lungs increases. If using an inhaler works efficiently it would save her a great deal of time and keep her lungs working for longer, which may one day enable her to work full time when she finishes her studies.
Comments on individual sections of the ACD:	
Date	11/12/2012 10:12:00 PM

Name	[redacted]
Role	NHS Professional
Other role	Clinical Lead for the Cheshire, Merseyside and North Wales Network of Paediatric CF Care
Location	England
Conflict	no
Notes	I have presented at educational meetings supported by Forest Laboratories and Novartis, and have received honoraria on occasion (Â£1-200 to cover expenses). Â I have received no funding from Respironics (Philips), but applied to the NIHR for a RfPB grant with them as an industry partner.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary	The Colobreathe study shows surprising clinical responses in both arms, which CF physicians would not have anticipated and

recommendations)	probably reflect the treatment naÃ¯ve population recruited. Â Treatments are only efficacious if they are taken and this needs to be the focus of this review. In summary 1.The appraisal has not taken into consideration factors that are important for CF patients and the CF teams that care for them (illustrated in the two expert statements from patients). 2.It has given too much credence to a comparison which is not significant (either statistically or clinically) 3.It has resulted in a recommendation that will led to a monopoly that will result in continued inflated pricing of the Tobramycin dry powder device
Section 2 (Clinical need and practice)	The review mentions the importance of addressing adherence, but does not give this adequate consideration in the document. For CF physicians, sustaining these long term treatments is the biggest challenge we face in maintaining the health and well-being of our patients with chronic airway infection. Â We require a varied armamentarium to achieve this and have anticipated the development of dry powder delivery devices as an important step forward in addressing this challenge.
Section 3 (The technologies)	I feel very uneasy that the NICE review recommends that one DPI device remains available for the UK CF community. Â This essentially represents a monopoly and is disadvantageous to both patients and the NHS. Â We have already seen how the availability of two Tobramycin Solutions for Inhalation (TOBI and Bramitob) has driven down the price of this therapy.
Date	11/11/2012 4:17:00 PM

Name	[redacted]
Role	Carer
Location	England
Conflict	no
Notes	My son is now three years old and has spent 18 months of his life needing Colomycin administered via a nebuliser. For a baby and toddler anything which can ease the burden of administering medications through a nebuliser is life-changing. Toby would cry so much during the twenty minutes it took to administer a dose that I found it too distressing to continue. he therefore was not benefitting from the therapy prescribed. NICE must allow this formulation to be made available for my son and all those others living with CF.
Comments on individual sections of the ACD:	
Date	11/12/2012 11:37:00 PM

Name	[redacted]
Role	Carer
Location	England
Conflict	no
Notes	The following is our current experience of nebulisers: I am never confident that the dose dispensed from the current nebuliser is accurate, times of dispersal are erratic: it is fiddly to make up, we get cut by the metal on the vial, I cannot leave anyone else to make the product up, I have to be there to mix it AM and PM; nebulisers require thorough washing and routine steaming or boiling with sterilised water. Â The need for all this plus the pumps, leads, filters and chambers we also have a water steriliser and a steamer. Â It is cumbersome treatment to the point we dont go away and ensure we do not make arrangements that mean we are away from home AM and PM. Â When we have had to go Â away and just one element of the kit has been missed, which has happened, treatment can be missed for days. Â It is life limiting for a condition that is already burdensome. Â a diagnosis of pseudomonas is bad enough but the ensuing upheaval of a nebulised treatment compounds it, an inhaler would be so fantastic and enable my 13year old to get on with her life despite pseudomonas rather than the treatment overburdening her.
Comments on individual sections of the ACD:	
Date	11/13/2012 12:30:00 PM

Name	[redacted]
Role	Carer
Other role	Parent
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	My daughter is 14 years old. Â She has had repeated pseudomonas infections since the age of 8. Â The burden of the treatment regime for CF sufferers & their families is immense. Courses of nebulised colistin last for months at a time to eradicate an infection, & involve preparation of the drug, twice daily nebulisers & the sterilisation & care of the equipment each time. This compromises the lifestyle of a young child & their carer, but particularly compromises the lifestyle of a teenager or young adult. It is a huge responsibility for those leaving home for the first time, either short term for a holiday or long term for University. Adherence to treatment would be greatly increased if the burden was reduced with the benefit of inhaled colistin Â (ie:Colobreathe) & the consequence would be a direct improvement in health & recovery from each pseudomonas infection. This in turn would enhance CF sufferers chances of a longer & healthier life & a greater chance of maintaining lung function.
Date	11/12/2012 7:17:00 PM

Name	[redacted]
Role	Carer
Location	England
Conflict	no
Notes	the life of a person with cystic fibrosis is hard enough, this drug will help ease the daily burden of treatments currently available
Comments on individual sections of the ACD:	
Date	11/13/2012 11:18:00 AM

Name	[redacted]
Role	Carer
Location	England
Conflict	no
Notes	I have a 15 year old daughter with Cystic Fibrosis who is treated regularly for damaging lung infections caused by pseudomonas.
Comments on individual sections of the ACD:	
Date	11/13/2012 11:09:00 AM

Name	[redacted]
Role	NHS Professional
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 4 (Evidence and interpretation)	I think it is important not to underestimate the importance of compliance with medication here. This is something that is not assessed in randomised controlled trials where compliance is alway abnormally high, not reflecting the real-life situation we face as CF clinicians. Simplicity of treatment is paramount in some individuals, even when it comes down to 4 capsules twice a day vs. 1 capsule twice a day. A significant minority of patients will only engage with the simplest of treatment regimes, and it is often these patients who take up expensive inpatient time because of exacerbations relating to non-compliance. I feel strongly that having an alternative simple inhaled antibiotic regime for such patients, and those unable to tolerate tobramycin DPI or suffering side effects from long-term aminoglycoside use, is worthwhile. I accept that the colistimethate DPI has undersold itself by failure to properly measure patient preference but I hope that common sense, and perhaps some financial negotiation, may lead to a change in recommendations. The simpler colistimethate DPI is something CF clinicians and patients have been eagerly awaiting for many years.
Date	11/12/2012 7:00:00 PM

Name	[redacted]
Role	Public
Location	England
Conflict	no
Notes	I have relatives with cf and am a uk taxpayer
Comments on individual sections of the ACD:	
Date	11/12/2012 8:03:00 PM

Name	[redacted]
Role	Carer
Other role	I am the father of a CF patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 2 (Clinical need and practice)	There is an urgent need for improved treatments to improve quality and extend life for CF patients; the prposed drug will help with this considerably.
Section 3 (The technologies)	Because of the possible adverse reactions, there is a need for a new alternative to tobra mycin. The new drug will help with this need.
Date	11/12/2012 7:31:00 PM

Name	[redacted]
Role	Carer
Location	England
Conflict	no
Notes	I have a young daughter that was re-diagnosed with this today. Although I know she is too young for this treatment at the moment the fact that she may be denied something that could help in the future is extremely upsetting for my whole family. This infection can be hard to get rid of, sometimes not at all, and treatment takes months if not a year so anything that can help is invaluable.
Comments on individual sections of the ACD:	
Section 2 (Clinical need and practice)	There is a need for a faster acting drug which will hopefully cut down treatment time
Date	11/12/2012 9:02:00 PM

Name	[redacted]
Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I struggle with treatment times now I have so many nebulisers to take a day as my health gets worse. This is exhausting. By doing it as an inhaler will cut so much time out of my already full day with treatments alone. It will also benefit my health as I sometimes miss nebulisers if im out or struggle to fit it in. As bad as it is if im unwell and tired sometimes I dont do it

	because it takes too much effort as well as the cleaning washing all the little bits of the neb afterwards. If im out I can take the inhaler in my bag with me. The idea that this could become availiable makes me so happy thinking how much easier it will be, as im sure it will do for others like me. Please do not take this away from us, we have enough to do as it is.
Date	11/12/2012 7:01:00 PM

Name	[redacted]
Role	NHS Professional
Location	England
Conflict	yes
Notes	I am a lung transplant physician with background training in and ongoing involvement in the care of patients with CF. I chair the Association of Lung Lransplant Physicians-UK and in this role I have received eduactional grants and speaker honoraria from both Forest Labs and Novartis, among other pharma companies.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The recommendations lose sight of a an unavoidable outcome of this decision: a a significant switch from nebulised TOBI to TOBI podhaler, driven by the patients and their carers for the sake of ease and speed of administration, which promotes adherernce and may improve outcomes of chronic pseudomonal infection. Exclusion of Colobreathe is inappropriate however: 1. the clinical trial evidence used to endorse the Podhaler is not superior to that available for Colobreathe. 2. EMA required new agents to be compared with older drugs within their licensed indication. Nebulised Colistin is a traditional cheap and effective first line therapy in most UK CF centres but it is not licensed for this indication and could not have been used as a comparator for Colobreathe when the Freedom study was first planned and approved in early 2000's. 3. Us clinician need choice of alternatives. TOBI is not as clean as it is first set out to be. Several patients can't tolerate it due to bronchospasm, some have developed oto- and nephrotoxicity on it and can't use it again, and a third group simply do not show benefit Â from it. Restricting access to the only alternative will be to patient detriment.
Section 4 (Evidence and interpretation)	If a majority of patients switch to TOBI podhaler, as they will undoubtedly do, its chronic use will increase the background resistance to tobramycin and limit the useful shelf life of this antibiotic when no new effective antipseudomonal antibiotics are being developed at present (this was seen in most of the original TOBI trials). In contrast, resistance to colistin remains amazingly minimal despite its heavy use in CF. Many clinicians use alternate month colistin and TOBI nebs but this was not considered in the appraisal. I have made use of this fact, applying colistin for IV therapy of pseudomonal infection, nebulised therapy for eradication of first isolate, and for long term suppression of pseudomonas over 7 years in a transplant population including a large cohort of CF with good clinical and

	microbiological efficacy, tolerability and safety (BTS 2008, ERS 2012, manuscript in prep). Lung transplant recipients endure a huge treatment burden and patients and doctors were looking forward to having access to Colobreathe and TOBI podhaler to simplify treatment.Does a patient discount scheme allow Colobreathe to dominate TOBI nebs or even the podhaler? Negotiated with Forest yet?
Section 5 (Implementation)	General point: if we, as a clinical community, are not mindful of the implications of ongoing regulatory restriction of access to new "expensive" therapy based on hypothetical cost effective models (which do not capture real life expense; related to the burden of admissions from exacerbations and length of IV antibiotics in the case of CF), we run the risk of driving Pharma companies away from the UK. They simply will not consider the UK a viable site for conducting clinical trials and may no longer seek approval of new molecules in the UK. Our patients are the only losers in this scheme.
Date	11/11/2012 1:35:00 PM

Name	[redacted]
Role	Carer
Location	England
Conflict	yes
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Sadly, my 23 year old daughter lost her life to CF 4 years ago. I know she would want me to support all attempts to improve medical treatment as she had to undergo many tedious, tiring hours of treatment including twice daily nebulisers. As colobreatthe is an alternative, quick medication this relieves CF patients of having to prepare and administer a nebulised treatment when they are exhausted after doing 30 minutes of physiotherapy 2-3 times each day.
Date	11/12/2012 8:26:00 PM

Name	[redacted]
Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 2 (Clinical need and practice)	I have Cystic Fibrosis. I spend several hours a day administering my medication, having rigorous physiotherapy and exercise sessions to keep healthy. I take my Colistimethate nebuliser twice a day. Although each session lasts for around half an hour, it should be taken into consideration that I have to also take other nebulised medication & that the preparations of the solution as well as the cleaning and sterilising of the apparatus take up valuable time. I would love to spend this time every day with with my friends and family, studying, or dancing, which I very much love, rather than being reminded that I have a life-threatening condition. Being able to administer this drug as a dry powder for inhalation

	would mean that I could take this medication on-the-go. I could travel; go on holiday; camp even! I could spend a day somewhere & not have to miss valuable (and expensive) degree study sessions. I wouldn?t have to leave special occasions early to race home & do my treatments before I need to sleep. The fact of the matter is that it would improve the quality of life that I have. It's stressful to have to plan every day down to the minute. Sometimes I just need to breathe easy.
Date	11/12/2012 10:08:00 PM

Name	[redacted]
Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	If you do not recommend colistimethate sodium dry powder, you will restrict those patients who are unable to use tobramycin because it has caused side effects in the past to a altenative nebulised colistine which takes a considerable amount of time to mix up and adminsiter, and is difficult to store and requires additional equipement to mix up and administer, which is costly and inconvenient.
Date	11/12/2012 9:45:00 PM

Name	[redacted]
Role	other
Other role	Parent
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Our Son has CF. I believe it would be MORALLY wrong to deny our son and any CF sufferers any treatment which may give him and others a better quality of life.PLEASE make this available.
Date	11/12/2012 7:44:00 PM

Name	[redacted]
Role	Public
Other role	Friend
Location	England
Conflict	no
Notes	I have a friend suffering from cystic fibrosis and she needs all the help she can get. Â She believes this would help her enormously as this drug would save her about 20-30 mins each morning with a noisy machine and mask on her face? and would cut it down to just an inhaler!! Which she feels is very exciting!
Comments on individual sections of the ACD:	
Date	11/13/2012 10:17:00 AM

Name	[redacted]
Role	Carer
Location	Wales
Conflict	no
Notes	I should add to this that my 5 year old daughter suffers from CF. She currently spends up to 2 hours a day receiving treatment, including up to 3 nebulised medication . Anything that could reduce this burden and help her and children like her spend more time being normal children should be encouraged.
Comments on individual sections of the ACD:	
Date	11/12/2012 4:43:00 PM

Name	[redacted]
Role	NHS Professional
Location	Wales
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Antibiotic resistance is much commoner with tobramycin than colistin. A dry powder form of colistin would be of benefit to the tobramycin resistant Â patient who's poorly compliant with nebulised medication
Section 2 (Clinical need and practice)	AS patients are surviving longer antibiotic resistance will become more of a problem and need to swap inhaled anti-pseudomonal antibiotics will become common. A dry powder alternative for our least resistant antibiotic (i.e. colistin) should be available at similar price to nebulised form
Section 3 (The technologies)	having to take 1 capsule of colistin dry powder compared with 4 capsules of tobramycin dry powder would improve compliance particularly in our adolescent / teenage patients
Date	11/12/2012 6:15:00 PM

Name	[redacted]
Role	Carer
Other role	Hard working middle class
Location	England
Conflict	no
Notes	Simple : This is for children dying! If my tax can go to India any other countries for stupid reasons and Illegal immigrants can have free HIV/AIDS treatment, then please advise what's NICE's argument is over these drugs?
Comments on individual sections of the ACD:	
Date	11/12/2012 5:30:00 PM

Name	[redacted]
Role	Carer
Location	England
Conflict	no

Notes	I have two children with cf who this would benefit
Comments on individual sections of the ACD:	
Date	11/12/2012 5:11:00 PM

Name	[redacted]
Role	Carer
Location	England
Conflict	no
Notes	As a parent of a person with Cystic Fibrosis who has had chronic lung infection with Pseudomonas I obviously think that any treatment that could help my daughter live longer without the need for a lung transplant has to be worthwhile. Â People with Cystic Fibrosis do not choose their lifestyle (as maybe alcoholics or drug users) - their life is affected from the moment they are born and if any medicine can give them an improved quality of life then they should have access to it. Please listen to the families living with Cystic Fibrosis and help them help themselves to a longer life.
Comments on individual sections of the ACD:	
Date	11/12/2012 7:58:00 PM

Name	[redacted]
Role	Carer
Other role	Parent of cf child
Location	England
Conflict	no
Notes	I have a daughter with cf. do you...?? Please think again as if you had a loved one with cf you might reconsider this awful decision... You can contact me anytime to discuss
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	We need this drug
Section 2 (Clinical need and practice)	We need this drug
Section 3 (The technologies)	We need this drug
Section 4 (Evidence and interpretation)	We need this drug
Section 5 (Implementation)	We need this drug
Section 6 (Proposed recommendations for further research)	We need this drug
Section 7 (Related NICE guidance)	We need this drug
Date	11/12/2012 10:10:00 PM

Name	[redacted]
Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 2 (Clinical need and practice)	my daughter is chronically infected with P aeruginosa and as a result suffers the acute exacerbations associated with it. Against enormous odd she is a university student living away from home and working hard on her studies. She cannot manage home based IV treatment in a shared student accommodation. Hospital admission for IV treatment is a huge cost to the NHS and could be avoided with a home treatment which limited the huge burden associated with nebulised antibiotics. Colobreathe would free this burden and enable my child to manage her studies and in future become a hardworking tax paying employee contributing back to society. Please please help my daughter and other young people with this dreadful disease to have improved quality of life by agreeing to the provision of this drug asap.
Date	11/12/2012 8:29:00 PM

Name	[redacted]
Role	NHS Professional
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The failure to support colistin DPI is wrong for patients with CF. Â In clinic they are desparate for options that reduce their treatment burden, allowing them to lead more normal lives (college, work etc). Â Their decisions are often between one or the other, and DPI colistin gives them this option, greatly improving their Quality of Life.
Section 2 (Clinical need and practice)	The current research is recognising that the CF airway microbiology is about much more than Pseudomonas. Â Please see Stressman et al Thorax 2012, and Daniels et al Journal of Cystic Fibrosis (in press).
Section 4 (Evidence and interpretation)	Colistin DPI has been compared and shown to be efective against the clinical Gold standard of wet Tobramycin. Â Whether or not it is effective against wet colistin is irrelevant, as this has never been defined as the gold standard but has been pragmatically accepted by clinicians.
Date	11/5/2012 3:37:00 PM

Name	[redacted]
Role	Patient
Location	England
Conflict	no
Notes	I have had cf all my life and been through so much. Anything that could help my illness would be a great help as there is no cure. If this inhalers helps our illness in anyway then please

	don't stand in the way of it being released to us
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Just because something is not recommended doesn't mean that it won't do nothing. Every cystic is different,therefore without giving it to people how are you meant to know
Section 2 (Clinical need and practice)	For cystic fibrosis patients, going in hospital for antibiotics is normal, some orals just don't do enough. But then sometimes neither do antibiotics. Cf patients can come resistant to many antibiotics, therefore if the option of these inhalers was there, it could combine with other medicine to fight the p.aeruginosa.
Section 3 (The technologies)	If these inhalers help cystic fibrosis in anyway, prices should not matter as your helping save people's lives in which there is not a cure.
Section 4 (Evidence and interpretation)	I don't think with the evidence given that these inhalers would not be beneficial
Section 5 (Implementation)	I think these inhalers should definitely be made available for cystic fibrosis sufferers and on prescription
Section 6 (Proposed recommendations for further research)	People with cystic fibrosis like myself would tell how vital this is ,so the quicker you make a decision ,the better
Section 7 (Related NICE guidance)	I think making it available as soon as possible is a must
Date	11/12/2012 5:28:00 PM

Name	[redacted]
Role	NHS Professional
Location	England
Conflict	yes
Notes	I am a microbiologist (now retired) who was funded by Forest Laboratories, UK to screen isolates of Pseudomonas aeruginosa from cystic fibrosis patients involved in the trial of colistimethate sodium (COLO/DPI/02/06)for resistance to colistin and tobramycin.
Comments on individual sections of the ACD:	
Section 4 (Evidence and interpretation)	The finding of the EAGER trial that 20% of P. aeruginosa had an MIC of 8 mg or Â greater should be directly contrasted with the 1.1% rate of resistance for colistimethate; tobramycin is thus likely to be ineffective for a significant number of patient isolates.
Date	11/7/2012 11:06:00 AM