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

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

> Mannitol improves patient lung function, preventing one in four exacerbations. For people with CF this means one less two-week stay in hospital per-year and it will help people with CF, their carers and friends and family, to get on with their lives. It also offers a potential saving to the NHS as every two-week hospitalisation costs approximately £3,000 per patient.
>
> Mannitol is quick and easy to use. Reducing the burden of treatment and care is vital for people with Cystic Fibrosis. As the treatment is delivered through a disposable inhaler it is convenient and hygienic to use, with limited cleaning needed.
>
> Mannitol will also help to increase adherence. Because of the huge burden of treatment many people with CF struggle to fulfil their daily medication and physio. Dry powder formulation offers convenience and simplicity. Adhering to the right dose and frequency will ensure maximum efficacy of the treatment.
>
> The treatment would be able to benefit a large number of adults with CF as it is effective regardless of mutation, type of infection present or extent of lung disease.

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

A petition of 428 signatures, asking that the relevant committee of NICE approves inhaled mannitol as a therapy for cystic fibrosis was received.

Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	[CF Trust] Mannitol is quick and easy to use. Reducing the burden of treatment and care is vital for people with Cystic Fibrosis. As the treatment is delivered through a disposable inhaler it is convenient and hygienic to use, with limited cleaning needed. [Personal context] The "burden of treatment" in my case occupies around between 5 and 7 hours daily; incorporating in excess of an hour of nebulised therapy (DNase (od), nebulised antibiotics (bd), hypertonic saline (bd), nebulised salbutamol (td)), and 4 or more hours (depending on my condition at the time) of physiotherapy. I regard myself as fortunate in that although my treatment does occupy a huge amount of my day - so long as I adhere to my treatment regime I remain sufficiently well enough that I am able to lead as normal a life as possible "outside of CF". I urge NICE to review their decision not to recommend Mannitol for CF and permit clinicians to prescribe Mannitol to those patient that may benefit (whether through improved lung function or reduced treatment time and quality of life) from it.
Section 4 (Consideration of the evidence)	•[CF Trust] Mannitol is quick and easy to use. Reducing the burden of treatment and care is vital for people with Cystic Fibrosis. As the treatment is delivered through a disposable inhaler it is convenient and hygienic to use, with limited cleaning needed. [Personal context] The "burden of treatment" extends beyond merely occupying time; it is also defined by need to be aware of proximity to home, or more accurately nebuliser, in order to administer nebulised medications. The requirement to always plan to have nebuliser access at the right times is a restriction that can cause as much inconvenience as any treatment itself. I nebulise hypertonic saline at lunchtime and in the evening; being able to use inhaled Mannitol at these times instead without the need to be at home to use nebuliser would give me a freedom that would be extremely welcome (e.g. use in quiet area of workplace, or at brother's house without needing to carry nebuliser, etc...). Given stated benefits of Mannitol, and the convenience and freedom that not being "tied to" a nebuliser for treatment would bring to myself and others with CF, I urge NICE to revise their decision not to recommend Mannitol for CF.

Role	
Location	England
Conflict	no
Notes	I have of course read the guidance document carefully, as well as the supporting documents (as far as a lay person is able) and if I had to single out one point which I think the committee has not fully appreciated (if you will forgive my saying so) it is the huge advantage which an inhaled therapy like mannitol has

	over one which has to be nebulised like hypertonic saline. Young people with CF already spend a great deal of their time simply trying to stay well. To add an unnecessary nebulised treatment, when an inhaled one is now available, is to completely ignore the enormous burden they already carry in their attempts to lead anything like a normal life. I have spent time in hospital with young adults with CF, and know something of the difficult lives they lead, which is why I felt strongly enough to start the petition. [NB, this petition included 428 signatures]

Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	• Mannitol improves patient lung function, preventing one in four exacerbations. For people with CF this means one less two-week stay in hospital per-year and it will help people with CF, their carers and friends and family, to get on with their lives. It also offers a potential saving to the NHS as every two-week hospitalisation costs approximately £3,000 per patient. • Mannitol is quick and easy to use. Reducing the burden of treatment and care is vital for people with Cystic Fibrosis. As the treatment is delivered through a disposable inhaler it is convenient and hygienic to use, with limited cleaning needed. • Mannitol will also help to increase adherence. Because of the huge burden of treatment many people with CF struggle to fulfil their daily medication and physio. Dry powder formulation offers convenience and simplicity. Adhering to the right dose and frequency will ensure maximum efficacy of the treatment. • The treatment would be able to benefit a large number of adults with CF as it is effective regardless of mutation, type of infection present or extent of lung disease. • There are other add on treatments for cf that have side effects and on introduction the benefits may have not been conclusive but ultimately have contributed to better health, life expectancy and quality of life. Those who have the burden of cystic fibrosis should be given the opportunity to benefit from Mannitol to ease their burden.

Role	NHS Professional
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	4.8. The Committee concluded that the FEV1 response outcomes were clinically relevant, but was not convinced that clinicians and patients would adhere to the stopping criteria assumed within the manufacturer?s submission - stopping rules are typically a medicines management team (MMT) function in terms of monitoring within PCOs and a MMT adheres strictly to NICE recommendations with formulary inclusion restricted to NICE parameters and medication stopped for patients falling

	outside these parameters. The availability of Eclipse Live (software for GP computer systems) now means that patient adherence to these parameters can now be monitored remotely. Patients FEV1 levels falling outside NICE parameters generates a message to both GP and MMT (and patient if required). 4.31. The availability of such remote monitoring software facilitates switching between medication when patient response to the first medication is either lacking or deteriorating.
Section 5 (Implementation)	MMT monitors spend resulting from NICE guidance. Any spend over expectation is immediately brought to the attention of the prescriber. Prescribers would be reminded of NICE parameters and an action plan drawn up to correct

Role	Public
Location	England
Conflict	no
Notes	Having a freind with Cystic fibrosis and knowing the difficulties in proforming all medicinal treatments, anything that reduces the amount of time to recieve medicine is welcomed and beneficial. Also anything that prevents hospital time is of economic benefit to the NHS. I know how difficult it is for my friend to preform all necessary treatments and on occasions something has to give.

Role	Carer
Other role	mother of patient
Location	England
Section 1 (Appraisal Committee's preliminary recommendations)	if it is improving lung function in cystic fibrosis patients, then why are they being denied the treatment. They should get all the treatment they need.
Section 2 (The technology)	may seem expensive looking at the figures, put inexpensive when it benefits many.

Role	other
Other role	Spouse
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Mannitol improves the lives of people with CF by reducing the amount of time required to adhere to treatments. In addition, it does not need to be refrigerated, which means that it does not go off and have to be thrown out like so many drugs when they arent kept at exactly the right temperature. Reducing this waste saves the NHS money and also ensures that patients take medication that is effective, thus improving patient outcomes. It would also mean that patients would be able to travel, as many are burdened by having to refrigerate their medications ?Mannitol improves patient lung function, preventing one in four exacerbations. For people with CF this means one less two-

	week stay in hospital per-year and it will help people with CF, their carers and friends and family, to get on with their lives. It also offers a potential saving to the NHS as every two-week hospitalisation costs approximately £3,000 per patient ?Reducing the burden of treatment and care is vital for people with Cystic Fibrosis ?The treatment would be able to benefit a large number of adults with CF as it is effective regardless of mutation, type of infection present or extent of lung disease
Section 2 (The technology)	If costs vary in different settings, then surely the NHS as a large-scale purchaser should be able to acquire a negotiated procurement discount.
Section 4 (Consideration of the evidence)	You cannot underestimate the difference that 10 minutes twice a day makes. Some patients spend 5-7 hours per day on treatments/medication/exercise. To be able to reduce this burden would make so much of a difference to a patients quality of life. Any medication that can provide good outcomes and reduce the burden of treatment for a patient should be properly considered, not just for the clinical benefits (which Mannitol would provide), but also for the impact that it can provide for a patients well-being.

Role	Carer
Location	England
Conflict	no
Notes	My daughter has cystic fibrosis and if this medicine can help her and save the NHS money why is it even going to consultation. This is a conundrum and I can not understand the reasoning behind this train of thought. To withold what I have been assured is an effective treatment for the lungs, can save the NHS money on reduced hospital addmissions, cut down on the amount of time people with CF spend on an already heavy daily regime of treatment. Furthermore it would reduce the time spent away from families, work, college further education and so on. It does stand to reason that with the research being carried out on gene therapy, that people who have CF would stay healthier longer in order to benefit from this other medication once trials were over which Mannitol would give. In addition It is therefore my opinion that even going to consultation is appears short sighted of those who make very important decisions.
Comments on individual sections of the ACD:	

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	CF patients often have a poor quality of life. Mannitol improves airway clearance (& thereby lung function), reduces exacerbations & is quick & convenient. It can be used anywhere in less than 2 mins, whereas hypertonic saline must be nebulised & takes much longer. Also, h/saline tastes horrible but mannitol is pleasant. Anything which helps CF patients to fit

	treatment into their daily lives will increase compliance. Patients will need fewer antibiotics and fewer admissions to hospital, to the benefit of themselves, reduced cost to the NHS, &less risk of resistant strains of bacteria gaining ground. CF is a burdensome condition and many sufferers still die young. This therapy, with its potential to improve quality of life and reduce morbidity and early mortality, should be approved without delay.
Section 2 (The technology)	Increased cough is beneficial in CF, where it results in airway clearance as it does with mannitol
Section 4 (Consideration of the evidence)	I agree with the points made by the patient expert

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 2 (The technology)	This cost is small compared with the cost of deterioration of lung function and increased hospitalisation.
Section 3 (The manufacturer's submission)	?Mannitol is quick and easy to use which is enormously beneficial in encouraging adherance to the daily routine of keeping well. Reducing the burden of treatment and care is vital for people with Cystic Fibrosis. It is so time consuming to steralise the nebuliser for the hypertonic saline process...as a parent of several children this routine day in, day out, morning and night is exhausting for the family and our daughter. An alternative gives us hope that our lives could becme easier one day in maintaining some normality for our daughter.
Section 4 (Consideration of the evidence)	Please reconsider this evaluation and consider trialling it for patients. Every individual responds differently to the host of medication and treatments available and this could be an additional tool that makes a significant difference to our daughters life and our family.

Role	Public
Other role	Grandparent
Location	England
Conflict	no
Notes	Mannitol improves patient lung function, preventing one in four exacerbations. For people with CF this means one less two week stay in hospital per year and it will help people with CF, their carers and friends and family, to get on with their lives. It also offers a potential saving to the NHS as every two-week hospitalisation costs approximately £3000 per patient. Mannitol is quick and easy to use. Reducing the burden of treatment and care is vital for people with Cystic Fibrosis. As the treatment is delivered through a disposable inhaler it is convenient and hygienic to use, with limited cleaning needed. Mannitol will also help to increase the adherence . Because of the huge burden of treatment many people with CF struggle to fulfil their daily medication and physio. Dry powder formulation offers convenience and simplicity. Adhering to the right dose

	and frequency will ensure the maximum efficacy of the treatment The treatment would be able to benefit a large number of adults with CF as it is effective regardless of mutation, type of infection present or the extent of lung disease. My Grandson is 22 years of age and has Cystic Fibrosis. He has just completed his final year at University achieving a BA Hons in Animation. He like many others with CF have every day of their life to follow a routine which involves several hours fulfilling their medication and physio needs. In a normal day he needs to allow 2 hours for medication and physiotherapy. The creon and other medicines result in an intake of about 40 tablets per day During his time at University he has spent 2 weeks at a time 3/4 times each year in hospital for Intravenous Antibiotics, Physiotherapy and Physical exercises and as a result throughout his time at University this required his tutors to agree to grant him extended time to complete much of his work. He also works part time at weekends for Sainsbury, those earnings help towards his cost of living. Sainsbury have also been most supportive when he has needed time off for his stays in hospital. Last year he spent 4 weeks travelling around Europe. Apart from arranging insurance with some difficulty as only a few companies will cover CF sufferers for travel, he had to ensure he had sufficient medication and equipment such as a nebulizer to sustain him during his travels. It cannot be overstated how much CF interrupts their work, university or social life. Mannitol has the potential to improve life for him and others who have Cystic Fibrosis. I trust it will be approved.
Comments on individual sections of the ACD:	

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I have had experience of developing intolerances to drugs and the more choice that is available for doctors to prescribe means that an alternative treatment is avilable.
Section 2 (The technology)	The nebulising, cleaning and sterilising of equipment used in my treatment is time consuming, this inhailer may be useful to reduce overall time taken by daily procedures.
Section 4 (Consideration of the evidence)	As a patient with a very low lung funcion the proportional effect of any additional mucolitic may be significant.

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1	Mannitol improves patient lung function, preventing one in four

(Appraisal Committee's preliminary recommendations)	exacerbations. For people with CF this means one less two-week stay in hospital per-year and it will help people with CF, their carers and friends and family, to get on with their lives. It also offers a potential saving to the NHS as every two-week hospitalisation costs approximately £3,000 per patient. Mannitol is quick and easy to use. Reducing the burden of treatment and care is vital for people with Cystic Fibrosis. As the treatment is delivered through a disposable inhaler it is convenient and hygienic to use, with limited cleaning needed. Mannitol will also help to increase adherence. Because of the huge burden of treatment many people with CF struggle to fulfil their daily medication and physio. Dry powder formulation offers convenience and simplicity. Adhering to the right dose and frequency will ensure maximum efficacy

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	manitol improves patient lung function preventing one in four exacerbations. for people with CF this means one less two-week stay in hospital per year and it will help people with CF, their carers and friends and family to get on with their lives. it also offers a potential saving to the NHS as every two week hospitalisation costs approximately £3000 per patient. Mannitol is quick and easy to use. Reducing the burden of treatment and care is vital for people with CF. As the treatment is delivered through a disposable inhaler it is convenient and hygienic to use, with limited cleaning needed. mannitol will also help to increase aherence. because of the huge burden of treatment many people with CF struggle to fulfil their daily medication and physio. dry powder formulation offers conenience and simplicity. adhering to the right dose and frequency will ensure maximum efficacy of the treatment. the treatment would be able to benefit a large number of adults with CF as it is effective regardless of mutation, typeof infection present or extent of lung disease. I have a son and daughter with CF and the administration of medication has been problematic through out their lives.

Role	Carer
Location	Wales
Conflict	no

Role	other
Other role	trustee cystic fibrosis trust
Location	England
Conflict	no

Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The basic recommendation is mistaken
Section 2 (The technology)	Dry powder is much less onerous to adhere too than existing medication
Section 3 (The manufacturer’s submission)	for cystic fibrosis patients any treatment that can improve lung function is much to be welcomed
Section 4 (Consideration of the evidence)	doubtless very well considered.However convenience of use adherence to the requirement of the treatment have not been given sufficient weight
Section 7 (Proposed date of review of guidance)	Cf patients,esp those in transition to adult cannot wait as long as this if the negative view relating to this drug approval persists

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 2 (The technology)	Any form of quick acting device to inhale drugs must be welcomed. The ineb is particularly effective and easy to use and it sounds as though Mannitol is is even simpler.
Section 3 (The manufacturer’s submission)	It is clear from the above that mannitol has proved effective with improved lung function results. As a cf patient, keeping our lungs as clear as possible is arguably the most important part of our ongoing treatment and anythting that may help this is absolutely vital. It also seems as though Mannitol is easy to administer which sounds like excellent news. Medical advances have proved significant in recent years with the introduction of the ineb and any further quick form of effective treatment must be welcomed.
Section 4 (Consideration of the evidence)	It is clear that there are many differing views on this and clearly cost is a factor. As i was not part of the trial it is difficult to make specific comment on he effectivenes of the drug, albeit in all new cf medication, it is soon apparent what works and what doesnt. Therefore, i conclude that any new drugs must be of benefit, as they are bound to improve the lives of some with cf, if not all.
Section 7 (Proposed date of review of guidance)	This does seem to me to be an awfully long time to review the guidance. Again, i am not an expert on these things and am not really able to offer a qualified comment, other than to say that if this drug is going to benefit cf patients then the sooner the better for any subsequent review.

Role	other
Other role	Parent of 2 adult CF sufferers
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	In considering cost effectiveness insufficient account has been taken on whole life costing. Accepted costs of treatment

	against non treatment has been taken into account but potential costs of future hospitalisation, unproductive work time and its effect on the economy as a whole and greater reliance on benfits in the future appear to have been excluded. the future long term care needs both by individuals and the state will be less cost effective than approving the drug.

Role	NHS Professional
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	I believe that this is a step change as there is an unmet need in CF and new medications and I believe that this presents an additional therapy for patients who have limited treatment options. Exacerbations are serious events and should not be underestimated and they do have an impact upon trusts and patients. FEV1 maintanance is the goal for CF patients, so any improvement is very positive. Exacerbations dont occur that often, therefore FEV1 is the regular way in which airway clearance interventions are measured. I believe that Bronchl can replace existing nebulised therapies, e.g. patients who dont like nebulisation. Finally, I believe that professionals in the CF field have a record of controlling costs relating to patient treatment

Role	Carer
Other role	Mother
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	My 8 year has CF, Manitol would mean less time off school, improve life quality.

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Mannitol improves patient lung function, preventing one in four exacerbations. For people with CF this means one less two-week stay in hospital per-year and it will help people with CF, their carers and friends and family, to get on with their lives. It

	also offers a potential saving to the NHS as every 2-week hospitalisation costs approximately £3k per patient. My daughter has had 4 hospital stays in the last year, she has been off sick from school for 8 weeks requiring home tuition. Mannitol is quick and easy to use. Reducing the burden of treatment and care is vital for people with CF. As the treatment is delivered through a disposable inhaler it is convenient and hygienic to use, with limited cleaning needed. Mannitol will also help to increase adherence. Because of the huge burden of treatment many people with CF struggle to fulfil their daily medication and physio. Dry powder formulation offers convenience and simplicity. Adhering to the right dose and frequency will ensure maximum efficacy of the treatment. The treatment would be able to benefit a large number of adults with CF as it is effective regardless of mutation, type of infection present or extent of lung disease.
Section 3 (The manufacturer’s submission)	all the drugs prescribed to people with CF have side effects which they live with daily. This data shows that the drug would be of huge benefit to people with CF. Their lives are dictated to by the disease, often being unable to organise anything in advance due to their health. Anything that makes their lives easier & reduces the numbers and doses of other medications can only be of benefit.
Section 4 (Consideration of the evidence)	Again it shows that the product could reduce the time and effort spent on the daily routine for CF sufferers and their carers, so should be made available if suitable for the patient.

Role	Public
Location	Scotland
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	With Mannitol on prescription adults with CF will benefit plus it will be cost effective.

Role	other
Other role	CF sufferers grandmother
Location	England
Conflict	no
Notes	Let the patient and clinician decide if the use of Manitol would help please dont rob the sufferers of the opportunity...a concerned Nana

Role	Carer
Location	England
Conflict	no
Notes	My 14 year old daughter has cystic fibrosis.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary	My 14 yr old daughter has CF and this may be important for her future health.

recommendations)	

Role	Carer
Location	England
Conflict	no
Notes	Living with CF isnt great at the best of times and, at the worst of times its hell. Things can and do change very quickly for people living with CF. Often the most effective treatment will be based on doctor, patient and carer knowledge of the disease, the patient, the situation and the available medicines. To limit options by denying a treatment that could make a big difference to the quality of life of a CF sufferer is unjust. The heartbreak and helplessness you feel when your 18 year old daughter or your 16 year old son is begging you to help them breathe is beyond words. There are only around 10,000 sufferers in the UK who, through absolutely no fault of their own, have this dreadful life-limiting disease. Please help keep the options open. Thank you.

Role	Carer
Other role	Parent
Location	England
Conflict	no
Notes	Refusal to recommend this drug removes one of the options for treatment of our 9 month old Son as he grows up. We as parents of course want him to have every chance of receiving every help he can to extend the quality of his life. Not recommending this drug is the first time we have come across such a decision that has personally affected us and our family. The work done by scientists and drug companies gives us hope for the future and that drugs can be prevented from being provided on cost grounds takes away some of our hope. As a family we ask you to reconsider this decision, and re-affirm our hope that medicine can one day find a cure, and that cure can be approved on medical grounds, not financial ones. In the absence of a cure, please approve this medication. Thank you!

Role	Carer
Other role	Housewife
Location	England
Conflict	no
Notes	Our son [redacted] has CF
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	As this treatment is effective then it must be available to improve best outcomes.
Section 2 (The technology)	All treatments that are effective should be available if the best

	outcome to overall health is readily available
Section 3 (The manufacturer's submission)	If this treatment is proven to be effective as it clearly is, then it should be available to obtain the best outcomes for each individual patient
Section 4 (Consideration of the evidence)	Cost is clearly a consideration, however the patients that rely on this treatment to obtain and manitin a quality of life should be able to do so without worrying about this factor.
Section 5 (Implementation)	Ask the patients what they want and deliver the care expected, incuding the use of innovative drugs if proven to be effective
Section 6 (Related NICE guidance)	None
Section 7 (Proposed date of review of guidance)	Why so long? The evidence is clear the technology works so why wait?

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	As the mother of a 3o year old CF patient I should like to stress the supreme importance of adherence in the treatment of this condition. Any form of medication that makes life easier for patients striving to hold down a job and have a reasonable quality of life should be available to them. Nebulised hypertonic saline is neither effective nor tolerated by all CF patients and is a time consuming addition to their daily routine. The prevention of costly exacerbations and hospital admissions, such as my son is currently experiencing, must surely be a priority not only for the patient, but also for the NHS. In the interest of the increasing number of young CF adults, I would ask the Appraisal Committee to reconsider its decision and to recommend that Mannitol be available for prescription where it is deemed appropriate by clinicians.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The drug clearly shows benefits to patients if clinicians are prescribing it to their patients. This being the case the potential medical, emotional and social benefits far out way financial savings by refusing to issue the drug.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I am a healthy cystic fibrosis patient, and I want to stay this way.

Role	Carer
Other role	Father
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	As the father of a CF sufferer I do not feel that sufficient weight was given to the impact on the life of the whole family in the treatment benefits. I am supportive of the CF Trusts position. The treatment would be able to benefit a large number of adults with CF.

Role	Patient
Location	England
Conflict	no
Notes	As a sufferer or Cystic Fibrosis I like many others welcome any drug that may improve my health, please please please consider what it being asked. Yes it may not help everyone, but if it even helps one patient then surely it is worth it.
Comments on individual sections of the ACD:	

Role	NHS Professional
Other role	Clinical Senior Lecturer, Dept.of Primary care and Public Health, Imperial College, London
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 2 (The technology)	This product would present and additional therapy for patients who have limited options after Dornase alfa. there has been little or no innovation in this area for many years. there is unmet need in CF.
Section 3 (The manufacturer's submission)	exacerbations in CF have a significant impact on healthcare services and patients quality of life. the reduction shown in the submission is meaningful. Also an improvement in FEV1 of 100ml in already treated patients is meaningful as an aim of CF treatment is to maintain FEV1
Section 4 (Consideration of the evidence)	4.8 having been involved with shared care agreements for Dornase Alfa, I would challenge the view regarding stopping treatment. all protocols should have exit criteria written into them and patients must be informed at the outset. Cood clinical governance would also determine stopping ineffective treatment. Patients must be reviewed regularly to ensure that they adhere to treatment. CF patients are heavily treated and evidence fro other therapeutic areas would suggest that adherence is sub-optimal. the new developments in the NHS mandate that ineffective treatment be stopped to eliminate waste. 4.31 there have been few advances in CF in recent years, this product may or may not be a significant advance, but I wonder whether patients would choose a hand held inhaler or a

	nebuliser. there is evidence that improved adherence to therapy is one of the most effective theapeutic options(refs can be supplied). this product should help improve complinace and therefore clinical outcome. .
Section 5 (Implementation)	from my own experience with dornase alfa, prescribing protocols in CF are generally well adhered to. the introduction of this product would have a small budgetary impact on prescribing costs, but there may be savings in the cost of exacerbations. the guidance must identify those patients to be treated.

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	I am an aunt of a 10 year old with cystic fibrosis, who has to endure 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 Trust believes that Mannitol should be available on prescription because of the benefits it brings to someone with CF. People with CF and their clinicians should have the opportunity to assess whether Mannitol is right for them. I support this viewpoint and believe that by recommending inhaled Mannitol for prescription, people with Cystic Fibrosis will have a greater choice and can make their own choice about what treatment works best for each individual.

Role	other
Other role	Parent of CF adult
Location	England
Conflict	no
Notes	I support the CF Trust in their view that Mannitol should be licensed for patient use. My son will soon be 26 and he has worked hard to care for himself and minimise the effects of his condition. This treatment would appear to be something very benefical for improving his level of health and well being.

Role	Public
Other role	Grand-parent of a CF sufferer
Location	England
Conflict	no
Notes	I am not medically qualified, and have limited understanding of some of the abbreviations and data referred to in your findings, however I have had regular contact with, and have studied data from, the CF Trust over the past few years and have developed a great deal of faith in their expertise and the way they apply it. I am therefore supporting their request to comment on your findings in the certainty that they would not have requested my

	help had they any doubts over the prospect of this medication being of benefit to CF sufferers. It is my firm belief that cost-effectiveness should not be a bar to introduction of new medication: it should be used as one of the indicators of success (or otherwise) of a treatment after initial introduction to ensure that value for money over time in the field is achieved.
Comments on individual sections of the ACD:	
Section 2 (The technology)	Surely, anything that increases the hydration level and therefore the speed at which fluid is secreted/moved on is potentially beneficial. If there is any doubt as to the veracity of the manufacturers data, this should be highlighted, or considered during a conditional implementation (i.e. limited open introduction) period

Role	other
Other role	Father of son with CF
Location	England
Conflict	no
Notes	"After considered thought, it seems short term cost has made your decision not to license Mannitol. The CF trust has asked people like myself to comment on your decision and have prepared a 4 bullet point comment that sums up the benefits for Mannitol. I personally believe your rejection for using Mannitol will be because of in house political, cost or some other issue that is not conducive to helping actual CF patients that could benefit from Mannitol!!!!!! If Mannitol were to be licensed I would recommend that each patient be properly looked at before being prescribed as it seems that a certain percentage of patients would be ruled out straight away, but for a large percentage of CF sufferers Mannitol would benefit them and significantly improve their lifesyle and life expectancy."
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I believe it should be considered as an option to ease the life style & life expectancy of a large percentage of CF sufferers
Section 2 (The technology)	If used on only patients that would receive the benefits and it would then reduce time in hospital and other associated costs, then there is both a saving of lives and a long term saving to the NHS of money
Section 4 (Consideration of the evidence)	CF is a long term illness and as such you should also take a long term look at all treatments that will add life expectancy to many CF sufferers and you should not just look at the short term cost benefits to the NHS, but also the long term cost benefits to both the NHS and every tax payer !!!!!
Section 5 (Implementation)	I do believe Mannitol is not for every CF sufferer but you cannot take a blanket NO decision for this drug, you should say yes to its use but only for patients that will benefit its use.
Section 6 (Related NICE guidance)	There is a huge amount of guidance available to those people prepared to look for it!!!
Section 7 (Proposed date of review	Stop delaying and do something positive. We pay your wages!!!! By 2015 you only put back 3 more years where many

of guidance)	CF sufferers could start to benefit and much more data could be collated for your review then?

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	My daughters experience of CF is that the physical exertion required to clear airways is the primary problem associated with fatigue and clearence. The more difficult it is to clear airways the more opportunity bacteria has to establish itself. Medication such as Mannitol that assists in this process would enhance the quality of life experienced by my daughter. It would enable patients not to reach the final stages of CF sooner than necessary thereby enhancing quality life and promoting improved independence through not being as ill and needing to rely on inpatient drug treatment. Considering the average cost per day of hospital beds and the cost of medication regimes when admitted, Mannitol would offer a considerable saving to health authorities.

Role	other
Other role	Parent of adult CF patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Mannitol helps clear sticky lung secretions in CF patients, typically preventing a quarter of occasions on which lung function is so compromised as to require a two-week stay in hospital costing the NHS approximately £3000 each time. As important, this reduces disruption to the lives of CF patients that interferes with education, damages employment opportunities and increases the burden of treatment and care on carers and families. Reduced employment opportunities lead to greater pressure on government funded services and benefits as do the pressures on carers and families. Mannitol offers savings here as well. Mannitol?s dry powder formulation offers convenience and simplicity. Treatment is delivered through a disposable inhaler making it convenient with limited cleaning needed. The ease of use helps adherence to daily medication which with physio is a huge burden on CF patients. Using the right dose and frequency ensures maximum efficacy. The treatment would be able to benefit a large number of adults with CF as it is effective regardless of mutation, type of infection present or extent of lung disease.

Role	other
Other role	Patients family
Location	England
Conflict	no
Notes	Patients deserve every chance to minimise disruptive hospital stays.
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	Section 4.4 refers to the liklihood of patients continuin g with this treatment compared to use of a nebulizer. This is an important point as no benefit is gained when a treatment is not used due to difficulties in administration.

Role	other
Other role	friend of patient
Location	England
Conflict	no
Notes	Short of finding a cure for CF, sufferers should be given every assistance to ease their symptoms.

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Your recommendation is ill informed. It is on the basis of minor technical complaints about some small oversights in the manufacturers submission. This is a silly reason to reject such a simple and powerful treatment. It is clear to me that the treatment will save the money (in terms of hospital admissions) and improve quality of life for patients. Mannitol prevents one in four exacerbations. This means one less two-week stay in hospital per year for each CF patient. It will help people with CF, their carers and friends and family, to get on with their lives. It also offers a massive saving to the NHS as every two-week hospitalisation costs ~£3,000 per patient. For people with CF, all the daily medication and physio is a tremendous burden. Mannitol is convenient, simple and easy to use. You have a duty to assess the application properly and seriously and not to reject it on the basis of a few minor technical complaints. Regards, [redacted] (Father of baby with CF and University Lecturer, University of Cambridge)

Role	NHS Professional
Other role	carer
Location	England
Conflict	no
Notes	I am a doctor and also have a son with CF.
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	The impact of less hospital time due to mannitol is significant, as hospital represents a real threat to CF patients deterioration in health as they are very susceptible to resistant microorganisms in hospital environments.
Section 7 (Proposed date of review of guidance)	The time for review should be brought forward as there are so few positive treatments for CF currently available and the impact reassessed when a further positive study is carried out.

Role	Carer
Location	England
Conflict	no
Notes	My Partner has the horrible condition and i believe that all available medications possible should be made available to the patient and their support teams. Not trying a new drug leads to one answer. No Cure.

Role	Carer
Location	England
Conflict	no

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I think Mannitol should be recommended by NICE.

Role	other
Other role	PARENT OF CF CHILD
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 2 (The technology)	DRS ASSESS EACH PATIENT INDIVIDUALLY AND WOULD CEASE TREATENT IF ADVERSE REACTIONS HAPPENED. CLINICIANS SHOULD DECIDE ON THE TREATMENT OF PATIENTS AND NOT NICE

Role	Carer

Location	England
Conflict	no
Notes	I am a parent of a Cystic Fibrosis sufferer.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Because of the huge burden of treatment many people with CF struggle to fulfil their daily medication and physio and have to choose which medication they will take that day, often missing medication especially nebulised medication.

Role	Carer
Other role	Parent
Location	England
Conflict	no
Notes	Whilst my daughter is only 8 and this is aimed at adults she will hopefully benefit from its availability when she is old enough.

Role	other
Other role	partner of a patient
Location	England
Conflict	no
Notes	as a partner i see the effects of cystic fibrosis daily and if this drug will benefit i would be very grateful.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	One of my friends has CF and I feel that a variety of treatments should be available to her.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	To save money, you have to spend money. People are spending time in hospital, costing the NHS. Prevention is better than cure! Not to mention the moral issues of denying somebody something that could help them...if the NHS were to stop allowing people to have boob jobs and labiaplasty, maybe they could afford to save lives?

Role	Carer
Location	England
Conflict	no

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	By refusing to recommend Mannitol, NICE effectively euthanases thousands of CF patients.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Because of the huge burden of treatment many people with CF struggle to full fill their daily medication and physio.
Section 2 (The technology)	Mannitol is quick and easy to use. Reducing the burden of treatment and care is vital for people with Cystic Fibrosis. As the treatment is delivered through a disposable inhaler it is convenient and hygienic to use, with limited cleaning needed. Mannitol will also help to increase adherence. Because of the huge burden of treatment many people with CF struggle to full fill their daily medication and physio. Dry powder formulation offers convenience and simplicity. Adhering to the right dose and frequency will ensure maximum efficacy of the treatment. The treatment would be able to benefit a large number of adults with CF as it is effective regardless of mutation, type of infection present or extent of lung disease.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	As a CF patient I greatly appreciate every treatment option, particularly those that improve lung function, as not all treatments are effective or practical for every person, and many drugs become ineffective after a while because of resistance. I would urge NICE to recommend Mannitol to enhance the wellbeing of people with CF. Mannitol improves patient lung function, preventing one in four exacerbations. The treatment is effective regardless of mutation, type of infection present or extent of lung disease.

Role	Carer

Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 2 (The technology)	Mannitol is quick and easy to use. Reducing the burden of treatment and care is vital for people with Cystic Fibrosis. As the treatment is delivered through a disposable inhaler it is convenient and hygienic to use, with limited cleaning needed.
Section 3 (The manufacturer's submission)	Mannitol will also help to increase adherence. Because of the huge burden of treatment many people with CF struggle to fulfil their daily medication and physio. Dry powder formulation offers convenience and simplicity. Adhering to the right dose and frequency will ensure maximum efficacy of the treatment.
Section 4 (Consideration of the evidence)	The treatment would be able to benefit a large number of adults with CF as it is effective regardless of mutation, type of infection present or extent of lung disease.

Role	NHS Professional
Location	Scotland
Conflict	no
Comments on individual sections of the ACD:	
Section 2 (The technology)	The dry powder formulation is highly suitable to CF patients, and I think represets good value for money.

Role	Patient
Location	England
Conflict	no
Notes	While i have not yet had the chance to trial this treatment, Im open to anything that will potentially improve my breathing ability while reducing the incidence of further illness or hospitalisation. If this is not given as an option then I feel it will be detrimental to the well being of myself and many other patients with CF, which will ultimately cost the NHS more money in alternative treatments when lung function deteriorates.

Role	Patient
Location	Other
Conflict	no
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	I have cystic fibrosis. I do 5 nebulisers a day which in total including washing and preparing takes approximately 1 hour a day. Trying to fit this in around a busy life style is difficult. Taking all my nebulisers and treatments with me when I go travelling and on holiday is extremely challenging. In total including my physio and nebulisers I spend on average 2-3 hours per day doing treatments for my CF. Can you imagine having to go through that every day? I believe all patient with CF should be able to choose which treatments are best for them. For me personally mannitol would reduce the amount of time each day I have to spend doing nebulisers. I strongly

	believe mannitol should be made available for people with CF.

Role	Carer
Other role	Father
Location	England
Conflict	no
Notes	I am interested in anything that can improve my sons quality of life particually the daily grind (as he sees it)of treatment.
Comments on individual sections of the ACD:	
Section 2 (The technology)	I would like to have more detailed discussions around adverse reactions with my sons consultant.

Role	other
Other role	grandmother of patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 5 (Implementation)	I think the drug should be available on prescription because of the benefits it brings to someone with CF. People with CF and their clinicians should have the opportunity to assess whether mannitol is right for them, but if NICE do not recommend it, they wont get that opportunity.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Mannitol should be available for prescription due to the fact it reduces the burden of care and improves quality of life in CF patients

Role	Public
Location	England
Conflict	no
Notes	The treatment should be available for prescription due to the fact it reduces the burden of care for CF sufferers and it improves their quality of life.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The treatment should be available for prescription due to the fact it reduces the burden of care for CF sufferers and it improves their quality of life.

Role	Carer
Other role	parent of a beautiful 11 year old CF sufferer
Location	England
Conflict	no
Comments on individual sections of the ACD:	

Section 1 (Appraisal Committee's preliminary recommendations)	Any product that reduces a dependence on hospital and the drain on that resource should be pursued.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Mannitol is proven to be effective in preventing exacerbations in adults with CF, incredibly improving their quality of life and reducing the burden of care. I think that mannitol should be approved for use by patients where appropriate.

Role	Patient
Location	England
Conflict	no
Notes	The treatment would be able to benefit a large number of adults with CF as it is effective regardless of mutation, type of infection present or extent of lung disease.

Role	other
Other role	mother carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Mannitol should be offered to adults with cf. It is very effective, my daughter was on the trials and benefited from the medication straight away. She has always had difficulty clearing airways but as soon as she used mannitol it moved mucas on her chest and this has made a big differance in her life as to the physio she has to do. This treatment cuts down a lot! of time in physio and has redused chest infections. Which must means saving the nhs a lot of money in hospital admissions. It is very difficult to stress how much this medication has changed her life. My daghter is still on manitol because she was on the trial and it made such a differance. It will be very short sighted if this is not passeed so adults can bennifit from this treatment. This is quiet a straight forward drug to take and quick when you have to consider all the other medication peaple with cf has to take and how time consuming it al can be. My daughter was very lucky to have been given the actual drug in the trial and she said straight away on the first dose she was on the real drug as she could feel the movement of mucas in her chest immediatly! If she had to stop i think it would be a big step backward
Section 2 (The technology)	My daughter had small reaction at first, which was a cough but after a few doses this disappered.

Role	other
Other role	grandparent

Location	England
Conflict	no

Role	Patient
Location	England
Conflict	no
Notes	As a CF patient, I spend an average of three and a half hours a day on assorted treatments for my condition, of which an average of two and half hours is physiotherapy. My mucus is relatively thick ? and I produce relatively high quantities ? making it an absolute necessity for me to stick to this regime if I am to maximise my time out of hospital. But it is a tough, exhausting regime that reduces my quality of life and I?m desperately looking for further help in my battle. I feel that both my overall health ? and quality of life ? would be improved if there were further medications, such as Mannitol, as it?s proven to reduce the treatment burden by both enhancing airways clearance and ? and thus reducing physio time but also improve lung function, as the trials have indicated (my trend is downward, so even a small bump up in lung function would be significant). Hypertonic saline is a treatment available, yes, but it had two drawbacks for me: 1. It wasn?t easily tolerated and despite bronchodilators, it continued to cause bronchoconstriction, leaving me breathless. This is the case for many with CF. 2. It required a separate nebulising set of equipment, rather then an inhaler, which took about 10 minutes to dispense the hypo-saline, followed by twice daily cleaning and drying of this nebulier, representing an increase of up to 40 minutes a day. This is an unfair extra burden, which reduces treatment adherence: I couldn?t cope with the extra time required each day and, more problematic, the tightness it caused. Mannitol, appears to be better tolerated by the lungs, and as it comes in a disposable inhaler, vastly reducing treatment time (quick inhalation, no cleaning and sterilising required) by over an order of magnitude, thus would ensure much better treatment observance. It?s also been shown to reduce exacerbations, of which I have one every 7 months: potentially saving me time and the NHS money. Please do consider the benefit a new drug like Mannitol will have for me ? and others. Many thanks [redacted] [redacted]
Comments on individual sections of the ACD:	
Section 1	As a CF patient, I spend an average of 3-4 hours a day on

(Appraisal Committee's preliminary recommendations)	treatments for my condition, of which an average of 2 and half hours is physiotherapy. My mucus is relatively thick and in high quantities, making it a necessity to stick to this regime to maximise time out of hospital. But it is an exhausting regime that reduces my quality of life and I?m desperately looking for further help in my battle. I feel that my overall health ? and quality of life ? would be improved if there were further medications, such as Mannitol, as it?s proven to reduce the treatment burden by enhancing airways clearance ? and thus reducing physio time and improving lung function, as the trials have indicted. Hypertonic saline had two drawbacks for me: 1. It wasn?t easily tolerated causing bronchoconstriction and eventually I ceased treatment. 2. It required a separate nebulising set of equipment, rather then an inhaler, representing an increase of up to 40 minutes a day for nebulising and cleaning. This extra burden reduced treatment adherence. Mannitol has also been shown to reduce exacerbations, of which I have one every 7 months: potentially saving me time and the NHS money. Please reconsider.

Role	Carer
Other role	Father
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Our son [redacted] was on the trial drug Mannitol, When it came to the end of the trial we asked if we could stay on it as his blows had improved. While we were waiting for a desision around 5 weeks, his blows had dropped about 5 percent! When he was put back on his blows went back up! So there no doubt in my mind that Mannitol really works.

Role	other
Other role	Parent
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	The CF Society have proved over the 30 years we have had dealings with them to be well informed , resonsible and accurate about best treatment, they would not argue with your conclusions without being convinced of the drugs benefits and cost effectiveness. Please listen to the stakeholders!

Role	other
Other role	grand parent
Location	England
Conflict	no
Section 2 (The technology)	This is a simple method compared with some and the cost will come down. The quality of life for the patients should be

	paramount, not the initial cost.
Section 3 (The manufacturer's submission)	any improvement in quality of life is cost effective. Money should never be an issue for a drug that has been shown to be effective. It will save the NHS money in the long term
Section 4 (Consideration of the evidence)	The CF trust is the expert body on the treatment of CF, not NICE. If the CF trust recommends it their views should be paramount. I cannot understand why people who do not know the punishing drug regimens these people have to undergo every day of their lives, should pass judgement on something that could prove beneficial and save on hospital visits

Role	other
Other role	Friend of sufferer of cystic fibrosis
Location	England
Conflict	no
Notes	CF people need every opportunity to live a full and active life. That means being able to benefit from any new treatment in order for him to continue to extend his life opportunity. Living with this disease means he is fully aware of his potential limited life expectancy therefore any risks in any treatment are measured against this life limiting illness and therefore I beleive that it is vital that you acknowlege the issues in the benftits of Manitol for the following reasons: [arguments provided by CF Trust] Mannitol will also help to increase adherence.

Role	Patient
Location	Wales
Conflict	no
Notes	this is exciting help for those millions of people with breathing difficulties. It has been shown to improve lung function and reduce infections therefore exacerbations. So the NHS can save a lot of money through less antibiotics and steroids etc, less medical treatments and fewer hospital stays. It is more convenient to use than nebulisers and will help people work and have beneficial effect on the economy. It should be made available to CF patients and others with breathing difficulties. Another important general benefit will also be reduced antibiotic resistance as fewer are used.
Comments on individual sections of the ACD:	
Section 3 (The manufacturer's submission)	this is exciting help for those millions of people with breathing difficulties. It has been shown to improve lung function and reduce infections therefore exacerbations. So the NHS can save a lot of money through less antibiotics and steroids etc, less medical treatments and fewer hospital stays. It is more convenient to use than nebulisers and will help people work and have beneficial effect on the economy. It should be made available to CF patients and others with breathing difficulties. Another important general benefit will also be reduced antibiotic resistance as fewer are used.

Role	Carer
Other role	
Location	England
Conflict	no
Notes	Dear Sir/Madam I am writing as my son has CF and needs to have every opportunity to live a full and active life. That means being able to benefit from any new treatment in order for him to continue to extend his life opportunity. Living with this disease means he is fully aware of his potential limited life expectancy therefore any risks in any treatment are measured against this life limiting illness and therefore I beleive that it is vital that you acknowlege the issues in the benftits of Manitol for the following reasons: Mannitol improves patient lung function, preventing one in four exacerbations. For people with CF this means one less two-week stay in hospital per-year and it will help people with CF, their carers and friends and family, to get on with their lives. It also offers a potential saving to the NHS as every two-week hospitalisation costs approximately £3,000 per patient. ? Mannitol is quick and easy to use. Reducing the burden of treatment and care is vital for people with Cystic Fibrosis. As the treatment is delivered through a disposable inhaler it is convenient and hygienic to use, with limited cleaning needed. ? Mannitol will also help to increase adherence. Because of the huge burden of treatment many people with CF struggle to fulfil their daily medication and physio. Dry powder formulation offers convenience and simplicity. Adhering to the right dose and frequency will ensure maximum efficancy of the treatment. ? The treatment would be able to benefit a large number of adults with CF as it is effective regardless of mutation, type of infection present or extent of lung disease. The need for a clear understanding of the benefits are essential if savings are to be achieved on a very streached Health Service, hence the use of this drug is unquestionable. Yours sincerely, [redacted]

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 2 (The technology)	Any new safe drug therapy that will help keep CF Sufferers out of hospital is a good thing. Hospitalisation is expensive for the NHS and exhausting both physically and mentally for the patient.
Section 3 (The manufacturer's submission)	Any new safe drug that maintains good lung function is vitally important to CF Sufferers

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	People with cf should have the choice to see if it will help them or not
Section 2 (The technology)	This seems very expensive but as a parent of a child with cf I would pay any price help her in life as every day is a struggle for her as well as us
Section 3 (The manufacturer's submission)	Let every one have there chance dont play god

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 CF sufferer I understand how life changing this condition is. The demands of living with CF are enormous. Hours are spent each day keeping the sufferer in good health with a wide variety of medication and physio. Good developments in terms of treatment seem to be fairly rare and so when something comes along which has shown positive results I believe we should do all we can to get it to sufferers. We know that it improves lung function and reduces exacerbations. We also know that it can be used by all adult sufferers and that it is quick and easy to use. This is so important bearing in mind the terrific burden that sufferers already carry with them on a daily basis. AS a result I implore you to recommend its use for UK sufferers.

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 2 (The technology)	I am not medically trained but care for our daughter who has cf.I feel stongly that for those individuals suited to benefit from taking Mannitol, anything which can lessen the collosal impact that cf has on the lives of young people suffering from cf must morally be given to help improve the quality of their lives and that of their families. Time is of the essence for those affected by cf and if Mannitol can give people more time with their loved ones at home rather than in hospital this must surely be of bennefit to all involved be it on a personal or medical level.Financial savings to health authoities, freeing up vital bed space and medical equipment due to less freequent hospital addmissions.A great financial burden would be lessened on the cf persons familys and family, social and work situations would be less dissrupted :thus aiding a better quality of life.

Role	other
Other role	mother of Son with CF
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	Although Mannitol is described as an add on it will still be of enormous benefit to those who have difficulty with adherence and will ultimately keep them healthier and therefore out of hospital and so ease the burden of hospitalization on the NHS. It would be a major boost to all CF sufferers and it means a positive step in the way their care is delivered.

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 5 (Implementation)	It is imperative this drug is made available to increase/improve the available preventative treatments for the young adults suffering from Cystic Fibrosis. My son is fast approaching 30 and has recently been admitted for intravenous treatment as his lung function had dropped by nearly 20%. At present he is holding down a full time job and any time saving advantages of this inhaler would benefit him greatly. He also has CF related diabetes thus adding to his regime of treatments. This young man adheres to everything to keep himself well and NICE should be supporting his drive!!!!
Section 7 (Proposed date of review of guidance)	It would be greatly appreciated by all the CF family if this could be approved urgently!

Role	Carer
Location	England
Conflict	no
Notes	We have two daughters with Cystic Fibrosis. One of them is 28, the other 15. They both have to spend long periods of time in hospital because of lung infections. If this helps to reduce this time then this will save money in the long run as well as improving their prognosis. A stay in hospital is expensive, as well as meaning a bed is not available for someone else who may need it. CF patients need isolation due to the high risk of cross-contamination, making a stay in hospital more expensive than normal. If this treatment helps to reduce the risk of illness then it will reduce the likelihood of a heart / lung transplant being necessary as well. This means that it should save a considerable amount of money in the long term."

Role	Carer

Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 3 (The manufacturer's submission)	Mannitol offers a potential saving to the NHS as every two-week hospitalisation costs approximately £3,000 per patient. Moving treatments out of the expensive hospital setting and back into the relatively more cost effective community/home environment setting should be an option that is always available.

Role	other
Other role	Parent of adult CF sufferer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The report of the patient expert (4.4) and the identification, from a patient viewpoint, of a "step change in treatment" are of great significance and seem to have been dismissed because of lack of data relating to improvements in quality of life. I would ask that the quality of life issues be reconsidered. Without rehearsing the comments in 4.4 I must emphasise that for a CF patient - in particular one who is working - the saving on daily treatment time, (and associated risk reduction of skimping on treatment), would be of immense benefit. The Committees considerations have correctly identified the unusual aspects of the diversity of treatment required for CF - a continuous intensity of treatment which can only be fully appreciated by a patient. In this context, Mannitol would provide a genuine "step change" and I would ask the Committee to re-examine its view.
Section 4 (Consideration of the evidence)	The report of the patient expert (4.4) and the identification, from a patient viewpoint, of a "step change in treatment" are of great significance and seem to have been dismissed because of lack of data relating to improvements in quality of life. I would ask that the quality of life issues be reconsidered. Without rehearsing the comments in 4.4 I must emphasise that for a CF patient - in particular one who is working - the saving on daily treatment time, and associated risk reduction of skimping on treatment, would be of immense benefit. The Committees considerations have correctly identified the unusual aspects of the diversity of treatment required for CF - a continuous intensity of treatment which can only be fully appreciated by a patient. In this context, Mannitol would provide a genuine "step change" and I would ask the Committee to re-examine its view.

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary	Mannitol is quick and easy to use. Reducing the burden of treatment and care is vital for people with Cystic Fibrosis. As the treatment is delivered through a disposable inhaler it is

recommendations)	convenient and hygienic to use, with limited cleaning needed. Mannitol will also help to increase adherence. Because of the huge burden of treatment many people with CF struggle to fulfil their daily medication and physio. Dry powder formulation offers convenience and simplicity. Adhering to the right dose and frequency will ensure maximum efficacy of the treatment. The treatment would be able to benefit a large number of adults with CF as it is effective regardless of mutation, type of infection present or extent of lung disease.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	My daily treatment regime takes several hours. Any treatment that reduces this should be made available.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Many new antibiotics are now coming as inhalers, instead of nebulisers. To have this option for a mucolytic would greatly improve my quality of life. The time it takes to sterilise, dry and prepare nebulisers not to mention batteries running out bits breaking, is what leads to my compliance issues. You say it is an add on treatment but so are all CF drugs. Consultants rarely swap one for another and leave it for the patients judgement. The patient often decides for themselves which one works better for them. Also I have been prescribed dnase twice a day, this is impossible to fit in with work. I could do dnase in the morning and mannitol in the afternoon which may really help me. If you want us to be productive members of society drugs administered like this are the way fw.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	?Mannitol is quick and easy to use. Reducing the burden of treatment and care is vital for people with Cystic Fibrosis. As the treatment is delivered through a disposable inhaler it is convenient and hygienic to use, with limited cleaning needed. ?Mannitol will also help to increase adherence. Because of the huge burden of treatment many people with CF struggle to fulfil

	their daily medication and physio. Dry powder formulation offers convenience and simplicity. Adhering to the right dose and frequency will ensure maximum efficacy of the treatment. ?The treatment would be able to benefit a large number of adults with CF as it is effective regardless of mutation, type of infection present or extent of lung disease.

Role	NHS Professional
Location	England
Conflict	no
Notes	I have previously attended an advisory board for the manufacturers of this product, and I was a clinical expert at teh NICE appraisal meeting.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It is disappointing that the preliminary recommendation from NICE is that mannitol is not recommended as an add-on therapy. Clinical trials and discussions with patients who have used mannitol have shown the significant improvement that patients feel when they use mannitol. Daily airway clearance in CF can be extremely challenging and energy-consuming and any product or technology that enhances and improves airway clearance is a real benefit to patients. Although the studies did not specifically look at sputum clearance or ease of learance this is a real positive benefit for patients clinically. In addition, the convenience of a dry powder product over the usual nebulised therapies cannot be underestimated to patients when they have a high treatment burdern to contend with every day. Very few therapies enhance mucociliary and airway clearance and the development of mannitol is a welcomed therapeutic agent that not only delivers enhanced clearance benefits in teh short-term, but also long term benefits such as improvement in lung function.
Section 2 (The technology)	The devlopemnt of dry-powder inhaled technologies is a significant step forward in teh medical management of CF. Individuals with CF have a very high daily treatment burden and are often on several nebulised medications. Each of these nebulisers takes at least 10 minutes to nebulise, in addition to the time required for cleaning and dryong the nebuliser component parts after each use (due to infection control reasons). Patients are genuinely excited by the development of dry powders for their inhaled therapies due to the convenience, ease of delivery and significant reduction in time required to take the medication. Adherence to nebulised medications is often variable because of teh time required, equipment component parts and teh cleaning/drying required. The use of dry powders such as mannitol mean that the dose can be taken in a few minutes and with practice I think this would be approximately 2 minutes. Although one of the most common adverse reactions is reported to be cough, from a physiotherapy perspective, if the patient is taught and advised on the optimal inhalation technique to take mannitol, including cough control,

	then irritable cough can be significantly reduced.
Section 3 (The manufacturer's submission)	The improvements seen in FEV1 and reduced exacerbations from teh manufacturers trials do have a significant benefit and impact on patients with CF. There are currently very limited treatment options available for enhancing mucociliary and airway clearance and mannitol is a therapy that offers an additional treatment option for many patients, in particular those who are not responsive to rhDNase or those who cannot tolerate hypertonic saline. Both rhDNase and hypertonic are nebulised therapies requiring greater treatment times, availability and cleaning of equipment, and rhDNase needs to be refrigerated while a high proportion of patients dislike the strong salty taste of hypertonic saline which invariably impacts on tehir adherence to these medications. From a cost effectiveness perspective, in clinical practice if patients are not finding a particualr treatment beneficial then that treatment is stopped because otherwise is adds to the already high treatment burden. FEV1 is routinely used in clinical practice to monitor patients improvement/decline/health status. Although QoL improvements were not siginificant in the trials, patients are very positive re dry powders and want more.
Section 4 (Consideration of the evidence)	The improvements in FEV1 and exacerbations with mannitol are an important step change in CF. There are limited treatment options in CF to improve these two outcomes and teh vast majority are nebulised therapies (e.g. inhaled antibiotics, rhDNase, hypertonic saline) which are all very time consuming. Not all patients are able to take rhDNase or hypertonic saline and mannitol is therefore a significant treatment option for this cohort. It directly assists in mucociliary and airway clearance which is required daily in CF. Any reduction in FEV1 has a significant impact on patients and how they feel, what they can achieve each day, and ultimately mortality. A 24% reduction in exacerbations is significant in clinical practice as it enhances the health status of patients and reduces healthcare infective exacrebation costs (clinic visits, antibiotics, hospital admissions etc). Patients and clinicans alike aim to maintain FEV1 and mannitol can assist this. The development of dry powders should not be underestimated as a significant innovation in CF care when daily treatment burden is so high at present. CF crae not does easily fit into economic model analysis as it is a multi-faceted diseas

Role	other
Other role	Grandparent of CF Sufferer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Mannitol improves patient lung function so any plan to limit its availablity will have the effect of limiting lung function and reducing the quality of life.
Section 2 (The technology)	· Mannitol would benefit a large number of adults with CF as it is effective regardless of microbiological status or extent of lung disease.

Section 3 (The manufacturer's submission)	To be honest, I did not understand it.
Section 4 (Consideration of the evidence)	For people with CF, Mannitol results in one fewer two-week stay in hospital per-year, helping them, their carers, friends and family to get on with their lives. It also offers a potential saving to the NHS as every two-week hospitalisation costs approximately £3,000 per patient.
Section 5 (Implementation)	My grandchildren have some years to go before they are adults but the idea of heading towards some "cliff edge" as they grow older is worrying. NICE should undertake to recommend the use of Mannitol by adults with CF.

Role	Carer
Other role	Teacher
Location	England
Conflict	no
Notes	I am the parent of two young adults, both of whom do struggle with the demands of maintaining their daily regime of medication and therapies. Any new medication which has the potential to reduce exacerbation and hospital in-patient admissions would make such a difference to all of our lives as a family. Both of my youngsters suffer from both depression, anxiety and anger at times due to their condition my daughter in particular is receiving counselling and takes anti-depressants. It affects myself and my husband and my two other children as well - their condition dominates all of our lives. Both of my unwell youngsters are at university, trying hard to complete their studies and make their way in the world. University is a challenge for most serious and intelligent students and their passage through the system is made so much more difficult due to their condition. The chances of their medication being taken religiously will be dramatically increased with access to a drug such as mannitol, reducing their burden and because new and effective medication for their condition always inspires them, and the rest of the family, to believe they can carry on with their lives and that progress in treatment is being made for them: there is some hope. I do realise that the NHS has many demands on its services and resources but as this is a chronic disorder, medication that can slow down the process of its progression and maintain health will ultimately be so much more cost effective. Preventative care is crucial for them as once they become ill, hospital admission and aftercare(which demands expensive treatment, time off work/studies for carers as well as sufferers and causes incredible anxiety)can take weeks or even months and leave the individual permanently damaged. This eventuality will make them more vulnerable, physically and mentally, to further expensive (money and in terms of human suffering) treatments.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Neither of my youngsters currently receive mannitol but it is fair to give them the opportunity to try it.

Section 2 (The technology)	Many patients may benefit from mannitol rather than have exacerbations.
Section 3 (The manufacturer's submission)	In consideration of whether mannitol was suitable for a patient, the individual patients circumstances/response to treatment are key.

Role	Pharmaceutical Industry
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	My Mum has been taking mannitol for 2 years. Firstly in a clinical trial and now via named patient use. I am so grateful that my mum is still able to receive mannitol in this way, as her health has been turned around by this amazing drug. I believe strongly that patients should be allowed to have access to mannitol on the NHS. My Mum always says what a huge difference it has made to her life - her chest feels much clearer and she is much more active & healthy. In addition the convenience of the inhaled mannitol as opposed to nebulised hypertonic saline should not be overlooked. Anything to make CF more manageable for the people who have this condition should be considered favourably and offered to these patients. Mannitol has been shown to significantly improve lung function because of its efficacy in lung clearance. Mum has certainly benefitted in this way. Surely with a better lung function, patients would need fewer admissions to hospital, fewer antibiotics etc. which would in turn cost the NHS less? I feel very strongly that CF patients (and my Mum) should be given the opportunity to lead substantially better and longer lives by having access to this treatment on the NHS.

Role	other
Other role	Relative of CF sufferer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Mannitol is important as a means of reducing the amount of time CF sufferers spend taking their daily medication. The various regimes impose a huge burden on young sufferers, and if young adults are to move towards responsibility for their own drug regimes a readily usable drug such as Mannitol, without an additional burden of equipment preparation and cleaning, is highly important.

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary	All Patients should have access to Mannitol if required.

recommendations)	
Section 2 (The technology)	This is not expensive compared to the cost of a cf patient in hospital.
Section 3 (The manufacturer's submission)	Following the care regime for a Cystic Fibrosis person is a grulling 24hr 7 day a week task, anything that helps should be available.
Section 4 (Consideration of the evidence)	In the long run any treatment that saves time, is easier to use, and helps will save money and lives.
Section 7 (Proposed date of review of guidance)	Please review earlier.

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Mannitol improves lung function in some people with cystic fibrosis and should therefore be available at the discretion of specialist clinicians. It prevents one in four exacerbations saving the NHS an annual two week patient in stay of £3000 per patient
Section 2 (The technology)	cystic fibrosis carries a huge and intrusive burden of care which limits ability to take part in normal activities of daily living. this medication is easy to use, decreases the burden of care and is efficient in delivery
Section 5 (Implementation)	people with cystic fibrosis struggle to maintain the huge burden of medication and physio they are obliged to maintain. this impacts heavily upon their function and their ability to take part in normal activities of daily living and carry out full time working. the delivery of mannitol is by contrast both convenient and simple to administer allowing maximum compliance with and effectiveness of this treatment. As a parent of a young adult with cystic fibrosis I would respectively ask the committee to take this reduction in treatment burden into account. There are not enough words available to emphasise the intrusive nature this dreadful condition causes and the impact it makes upon these young lives. The approval of mannitol would allow my daughter and many others to take a more productive active role in society unchained of the treatment burden they carry. Please, please consider this medication in terms of increased quality of life and not just on its cost.

Role	Patient
Other role	Clinical Care Patient Adviser
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Physicians should be able to have the choice to give to their patients the best treatments for their needs and demands of CF. This limits the physician ablility to treat his patient and the patients adherence and best treatment not being given.

Section 2 (The technology)	All exisitng treatments for CF have adverse affects but these depend from patient to patient and again if you limit the physicians ability to prescribe the patient does not receive the best care available. The associated benefits of a hand held device would contribute to adherence for the patient having a knock on effect ie patients will continue to stay well for a longer period of time and thus save money in another area.
Section 3 (The manufacturer's submission)	As I have already mentioned I feel that the patient and their needs should be the dictator. And what should be best prescribed for them.

Role	Carer
Other role	Teacher
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Mannitol should be available to adults with cystic fibrosis
Section 2 (The technology)	Mannitol is a cost effective and easy to manage drug treatment.
Section 3 (The manufacturer's submission)	The trials have been thoroughly proved and the drug is safe to administer.
Section 4 (Consideration of the evidence)	Given all the evidence on the benefit for mannitol, it should be made available to adults with Cystic Fibrosis to help improve the quality of their lives.
Section 5 (Implementation)	Mannitol is easy to implement for patients with Cystic Fibrosis.
Section 6 (Related NICE guidance)	There is no related guildance for this technology.
Section 7 (Proposed date of review of guidance)	The proposed date should be earlier than 2015.

Role	NHS Professional
Other role	Carer
Location	Wales
Conflict	no
Notes	I am both a hospital pharmacist and a Mother of a child with CF.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I feel it is very sad that NICE have not recommended the use of mannitol for CF patients. Although the results of the trial do not show marked improvements of lung function, exacerbations were reduced. CF is a progressive condition and any reduction in pulmonary exacerbations may reduce lung damage over the long term. Trials cannot show this, but long term data may well. Surely watching and waiting would provide very valuable information. Small changes over many years could produce great improvements.
Section 2 (The technology)	The introduction of a medication that reduces the viscosity of CF airway secretions available as an inhaler is a huge advancement for CF patients. Nebulised therapy is time

	consuming and in the case of hypertonic saline unplesant. It should be considered that in the future with further information, a patient with CF could use such an inhaler whilst at school or work, in conjunction with regular nebulised hypertonic saline. To not approve this medication will limit future developments and reduce patient choice.
Section 4 (Consideration of the evidence)	When considering the evidence, which I agree does not show amazing results, it must be considered the improvement in quality of life for patients. CF is a time consuming and difficult condition to manage, ANYTHING that makes life easier for CF patients is valuable.

Role	NHS Professional
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Mannitol would be an incredibly useful addition to CF care, we have patients that have failed tolerance of hypertonic saline and DNase and another substance, with a totally different method of inhalation may be their only option.
Section 4 (Consideration of the evidence)	Patients who are intolerant to hypertonic saline and DNase may be able to take mannitol as an alternative. Also, in the light of antibiotic inhalers, the ability to offer an inhaler based mucolytic would be incredibly valuable as we try to maintain compliance with therapy for these young adults while allowing them to live and travel as unrestricted as possible.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It should be recommended as add on for those who need it, and should be able to continue for as long as needed.
Section 2 (The technology)	The dose is quick and easy so therefore would be appealing to use for those of us suffering with the illness. Though there are some side effects, (some perhaps seen as severe) many of these are side effects of CF itself, such as haemoptysis, headaches, fatigue and so forth. The positives outweigh the negatives by far. The prices are not overly excessive compared to other significant treatments.
Section 3 (The manufacturer's submission)	Significant differences and can therefore be life changing for a vast amount of people. Therefore should be readily available.
Section 5 (Implementation)	n/a
Section 7 (Proposed date of review of guidance)	make is a lot earlier, perhaps 2013/2014?

Role	Carer

Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I would ask the committee to reconsider as I do not think that you have adequately considered the positive impact on the quality of life for sufferers of CF of both an increase in lung function (FEV1), and also of taking a treatment which is neither burdensome nor unpleasant. My daughter is only nine but already her lung function is declining and I see her beginning to be limited by her declining lung function. She is a talented swimmer and runner but is already being limited by lung function and she looks bewildered and disappointed as she can no longer keep up with children who she could easily beat a year ago. As the treatment pathway of people with CF is complex, variable and patient specific Manitol should be cosidered as an option rather than an add-on as this would seem to increase the impact of treatment and also the cost effectiveness where used. CF is a disease of young people and sufferers die prematuraly after a long decline (I expect quality of life to be extremely poor for a third of my daughters life) therefore quality of life impact should be given great weight in considering new treatments.
Section 2 (The technology)	As a parent and carer of a child with CF (who, hopefully will grow into an adult), I would welcome any treatment which does not involve another nebuliser. The adverse reactions do not look worrying as the increased cough may indicate that the lungs are being cleared and treatment could surely be stopped if the patient judged that their particular set of adverse reactions outweighed the benefits.
Section 3 (The manufacturer's submission)	Would it not be more sensible and efficient to raise these concerns about the statistics and modelling prior to the trials taking place? Either these concerns about post-hoc stratification and non inclusion of children resulting in small sub-group size etc render the results meaningless or they dont. I cannot find anything in your text to suggest that the cost effectiveness modelling includes quality of life (v. additional years), as I can find nothing on the borderline between good and poor quality of life. This is extremely important in the case of CF as prior to death people with CF experience a number of years of extremely poor quality of life due to their lung function falling and the cumulative impact of bacterial infections. Any decrease in the rate of decline in lung function as an adult should be given great weight in your model. Although as I understand it the trial showed a positive impact on FEV1 but not on exacerbations I cant relate this to my own experience whereby my daughter cannot clear her lungs as her sputum must be so very thick and sticky resulting in frequent new colds and courses of antibiotics
Section 4 (Consideration of the evidence)	I do not believe that the impact on quality of life - both through improved FEV1 and reduced burden treatment (which would be the case as it should be approved as an option for treatment rather than an add-on)- has been adequately considered. The lack of long-term data surely cannot be criticised in a trial as this can only be gained through approving the drug and

	subsequently monitoring impact (which is done by the CF trust databank on treatments and outcomes). I do not think this recommendation has adequeately considered the complexity of the care pathway for CF and the patient specific nature of treatment. There are may CF sufferers who do not respond dramatically to DNASE and so anything which offers a treatment to them should ne approved as an alternative.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 3 (The manufacturer's submission)	At the end of the day it is not just the direct cost of medecine that is important, but the significant affect the length of treatment has on the chances of someone with CF succeeding at Uni or getting a full time job.
Section 4 (Consideration of the evidence)	NOthing else should matter other than whether evidence shows that this drug works, and works better than another drug available at the time that targets the same thing.

Role	Carer
Location	England
Conflict	no
Notes	My 2 year old daughter has CF
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	My daughter was diagnoised with CF through the heel prick test at 3 weeks old. Here care has been amazing through the NHS, however revisions in drugs that have been supported by the CF Trust, the leading charity and researcher in this area is a true concern. CF effects life expectancy and we need to provide this care to ensure my daughtr lives longer. Key points about the new treatment Mannitol improves patient lung function, preventing one in four exacerbations. For people with CF this means one less two-week stay in hospital per-year, helping them, their carers, friends and family to get on with their lives. It also offers a potential saving to the NHS as every two-week hospitalisation costs approximately £3,000 per patient. Mannitol is quick and easy to use. Reducing the burden of treatment and care is vital for people with Cystic Fibrosis. As it is delivered through a disposable inhaler the treatment is convenient and hygienic to use, with limited cleaning needed. Mannitol will also help to increase adherence. Because of the huge burden of treatment many people with CF struggle to fulfil their daily medication and physio. Dry powder formulation offers convenience

Role	Public

Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It cannot be right that this treatment is not recommended for adults as an add-on therapy. From a pure quality of life point of view, this has been proven to improve lung function. It can reduce the number of hospital stays required, which only patients that have to do this regularly can fully appreciate.It can reduce the time spent on the numerous amounts of individual treatments, ensuring that ALL treatments are able to be accomodated within a semplance of a normal life. Economically the case for it is also sound as every hospital stay avoided saves money (approx £3000.00) therefore supporting the economical use of this treatment, and freeing up the beds for more critical use. It is difficult to see why it is recommended for one group of patients and not another as it is effective in all patients irrespective of condition, and therefore restriction of its use is discriminatory.
Section 3 (The manufacturer's submission)	See above. the cost case is proven on the basis that it reduces the need for hospital stays negating the cost to the NHS. To exclude a small number of patients on a cost basis is discriminatory.

Role	Carer
Location	England
Conflict	no
Notes	Mother of 4 . 1Wcf 3wocf cf son yrs
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	People using manitol should be given the opportunity to continue if it showing to be helping their condition. Stopping suddenly cod be detrimental to the heal th of the user.
Section 2 (The technology)	This may be a large sum of money but it is still much cheaper than repeated regular antibiotics in hospital. My son has spent 7 Weeks on Ive th is year alone. Around 15 Weeks last year and is steadily becoming more frequent.
Section 4 (Consideration of the evidence)	I feel th at if a life can be made more manageable through the use of mannitol then people should be given the choice wether they wish to continue with it or not. My son currently uses nebulosus colostin.dnase. Hypertonic saline. And amicacin. If even 1 or 2 of these were replaced by one some inhaler pi t would make his life that little but more variable and mine too as it is a constant battle with physio and mend.

Role	other
Other role	Relative of Adult patient
Location	Scotland
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Mannitol improves patient lung function, preventing one in four exacerbations. For people with CF this means one less two-week stay in hospital per-year, helping them, their carers,

	friends and family to get on with their lives.
Section 2 (The technology)	Mannitol is quick and easy to use. Reducing the burden of treatment and care is vital for people with Cystic Fibrosis. As it is delivered through a disposable inhaler the treatment is convenient and hygienic to use, with limited cleaning needed.
Section 3 (The manufacturer's submission)	Mannitol will also help to increase adherence. Because of the huge burden of treatment many people with CF struggle to fulfil their daily medication and physio. Dry powder formulation offers convenience and simplicity. Adhering to the right dose and frequency will ensure maximum efficacy of the treatment.
Section 5 (Implementation)	The treatment would benefit a large number of adults with CF as it is effective regardless of microbiological status or extent of lung disease.

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I am father to a 7 year old son with cystic fibrosis, he was diagnosed at age 3. He had numerous hospitalisations for intravenous antibiotic treatments before he was started on twice daily hypertonic saline nebulisation , he had previously been on once daily rhDNAse. Since starting on the hypertonic saline 2 years ago he has not required any hospital admissions and his lung function has been good. However hypoertonic saline is too strong for him to use in his fast e-flow nebuliser and he has to use a slower compressor type nebuliser. Bothe treatments take 80 minutes to complete , so for this to be replaced by a treatment that only takes 6 minutes would be life changing for him as even at the age of 7 he spends 2-21/2 hours every day doing nebulised treatments and physiotherapy

Role	other
Other role	Brother of CF sufferer
Location	England
Conflict	no
Notes	- Mannitol improves patient lung function, preventing one in four exacerbations. For people with CF this means one less two-week stay in hospital per-year, helping them, their carers, friends and family to get on with their lives. It also offers a potenti

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The option for each patient to conmtinue each drug is beneficial to each individual on different scales. If a patient feels it still works for them as an adult, then why not. Patients feel and experiences benefits and side effects of each drug.

Section 2 (The technology)	This sounds similar to other drugs but with ease of administration. Adverse reactiopns would be based on individual.

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I am very upset to hear that NICE is not minded to allow Mannitol to be prescribed on the NHS. It is proven to improve lung function, and to prevent one in four exacerbations. If you have CF, this means one less two-week stay in hospital per year. Not to mention the expense to the NHS of those hospital stays, which is approximately £3,000 per person. My daughter is currently 9 years old and has Cystic Fibrosis. Already, the burden of treatment that she is on means that we spend hours every day on her treatments. ANYTHING that is quick and easy to use is to be massively welcomed. She is not currently on Mannitol (she is still a child) but I dread the problems we will have in the future, when she is a young adult, about making her stick to her treatments and not rebellilng against her extremely arduous regime of medication, exercise, physiotherapy, nebulisers, countless pills and so on. Mannitol is proven to encourage adherence to the treatment regime, precisely because it is so easy to use, and this is very very important. It is also proven that Mannitol helps people with CF REGARDLESS of what bugs they are growing in their lungs and how severe their lung damage.
Section 2 (The technology)	The ease of use of Mannitol is so important, as it helps people to stick to their very very heavy treatment burden. There is no washing up the nebuliser in its own washing up bowl with its own toothbrush no sterilisng the nebuliser components after each dose and leaving them to air dry on kitchen roll .... you just thorw it away once it has been used. SOOOO much easier! Anything that reduces the amount of time you have to treat your CF, in order that you can try and actually live your life, must be a good thing.
Section 3 (The manufacturer's submission)	I am only a parent, and not a health scientist, able to comment on this level of detail.
Section 5 (Implementation)	I am unable to comment on this as am just a parent of a child with CF. I know that people with CF cost a lot of money, but advances in treatments have made such a difference to life expectancy over recent years that we cannot refuse people treatments like Mannitol which will really have a huge impact on their quality and quantity of life. Whgen Ella was born almost tean years ago, life expectancy for her was median 31. It is now thought to be a median of 41. That is amazing progress, and gives me so much hope that my daughter will stand a

	chance for a happy, healthy and productive life. And not just die in her late 20s like all the other young women I have met with CF. Please please please do think very hard about what a difference this medicine is making to people with CF, and dont take away the chance for my daughter to receive it when she is older.

Role	Carer
Other role	Mother
Location	Wales
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Please reconsider this recommendation. My daughter spends 2 hours per day using then cleaning nebulisers. She has a degree and wants to use it in the workplace - this is prohibitive. This drug could mean that she spends a month a year less in hospital. You probably have no idea what that would mean to use personallly but in financial terms a saving of £12,000
Section 2 (The technology)	Surely we should always strive for best possible standards of treatment - this would surely lead to a cure eventually
Section 3 (The manufacturer's submission)	This could save my daughters life - improving lung function while she is waiting for a double lung transplant.
Section 4 (Consideration of the evidence)	Surely if these drugs are available they must be provided. What kind of society deprives a person of a life saving therapy on the grounds that the MODEL isnt correct ??? CF patients get very little in theway of community support and many are carrying out treatments at home which would normally be the responsability of a team of nurses whithin a hospital setting. 6 weeks of home IVs saves the NHS £18,000 in terms of bed costs.
Section 7 (Proposed date of review of guidance)	Please review this now.

Role	other
Other role	Parent, [redacted] (Son) lives in Northampton
Location	England
Conflict	no
Notes	When you live with a child with Cf you always want what you consider the best for them. My view is that when Cf research over the years comes to fruition. Its only Wright regardless of cost that patients are the immediate benefactors. There suffering sometimes goes unheard because there are no physical signs and empathy towards anyone who suffers this terrible disease tends to go unnoticed. Despite the fact that internally there life is deteriorating.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	When you live with a child with Cf you always want what you consider the best for them. My view is that when Cf research over the years comes to fruition. Its only Wright regardless of cost that patients are the immediate benefactors. There suffering sometimes goes unheard because there are no physical signs and empathy towards anyone who suffers this

	terrible disease tends to go unnoticed. Despite the fact that internally there life is deteriorating.
Section 2 (The technology)	The continued exploration and research regarding Mannitol can only be a good thing, as reactions to new complex drugs can have there own side effects that need to be monitored and assessed. However it appears that any reaction to Mannitol may vary, as each suffer has different signs, symptoms to others in reflection of dosage etc.
Section 3 (The manufacturer's submission)	When you live with a child with Cf you always want what you consider the best for them. My view is that when Cf research over the years comes to fruition. Its only Wright regardless of cost that patients are the immediate benefactors. There suffering sometimes goes unheard because there are no physical signs and empathy towards anyone who suffers this terrible disease tends to go unnoticed. Despite the fact that internally there life is deteriorating. Though everything possible to help people who suffer with Cf should not be regarded as an after thought? More should be done to help rather than hinder the development process for suffers. Likewise the continued exploration and research regarding Mannitol can only be a good thing, as reactions to new complex drugs can have there own side effects that need to be monitored and assessed. However it appears that any reaction to Mannitol may vary, as each suffer has different signs, symptoms to others in reflection of dosage etc.
Section 4 (Consideration of the evidence)	When you live with a child with Cf you always want what you consider the best for them. My view is that when Cf research over the years comes to fruition. Its only Wright regardless of cost that patients are the immediate benefactors. There suffering sometimes goes unheard because there are no physical signs and empathy towards anyone who suffers this terrible disease tends to go unnoticed. Despite the fact that internally there life is deteriorating. Though everything possible to help people who suffer with Cf should not be regarded as an after thought? More should be done to help rather than hinder the development process for suffers. Likewise the continued exploration and research regarding Mannitol can only be a good thing, as reactions to new complex drugs can have there own side effects that need to be monitored and assessed. However it appears that any reaction to Mannitol may vary, as each suffer has different signs, symptoms to others in reflection of dosage etc.
Section 5 (Implementation)	Though everything possible to help people who suffer with Cf should not be regarded as an after thought? More should be done to help rather than hinder the development process for suffers.
Section 6 (Related NICE guidance)	Though everything possible to help people who suffer with Cf should not be regarded as an after thought? More should be

	done to help rather than hinder the development process for suffers.

Role	Patient
Location	England
Conflict	no
Notes	In addition to the above points, from a patients perspective this would transform my life by reducing the onerous daily treatment that I will have to carry out for the rest of life. I currently take approx 30 tablets a day, spend 1 hour doing physiotherapy, 1 hour on nebulised therapy and try to include regular exercise as well as ensuring every meal will provide me with enough calories to survive every day. Mannitol would be more convenient and easy to use, therefore increasing the amount of usage. In addition to my daily routine, hospital visits take place several times per year which increase the chances of picking up serious infections, require time off work and reduce my quality of life, physically and psychologically. If Mannitol could reduce the likelihood of having to attend hospital even once in my life, then this is a positive outcome for myself and thousands of other Cystic Fibrosis suffereers like myself. Thank you.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Mannitol should be able to be used by clinicians as an alternative treatment, if considered appropriate.
Section 2 (The technology)	Cost of treatment is far less than a stay in hospital, of which the frequency of these visits can be reduced by the use of Mannitol. The first dose of Mannitol should be supervised in order to ensure no adverse reactions take place, as is the protocol with other treatments.

Role	Patient
Location	Wales
Conflict	no
Notes	Currently prescribed mannitol
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Mannitol is working very well for me - alongside dnase and physiotherapy, with no noted side effects.
Section 2 (The technology)	No noted side effects personally - very quick and efficient to use. Great alternative to hypertonic saline, which I did not tolerate well.
Section 3 (The manufacturer's submission)	My lung function is stable, if not improved since being on mannitol. My treatment time has decreased and my quality of life has increased. I have been on mannitol since the trial.
Section 4	I am currently receiving the mannitol treatment and have been

(Consideration of the evidence)	since I took part in the trial. I have not noticed any of the side effects mentioned and my lung function is very stable, if not improved since being on mannitol. This medication means that I do not have to nebulise hypertonic saline, which causes nausea, bronchospasm and general distaste. It is easy to take in a bag and dispose of, is not noisy and is very discrete in comparison to a large, noisy and time consuming nebulister. I am prescribed Dnase also - and I beleive they work in harmony with physiotherapy to keep my chest as clear as possible and as well as I am. I do realise that not all medications suit everyone - but I do think it is important to have a wide range of treatments available to tailor the treatment to the individual.

Role	other
Other role	Parent of adult CF patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	My son has problems completing all the CF treatments he ought to do each day, and often doesnt do physio, or take his inhaler with him if he is away from his home anything that makes him more likely to carry out treatment is an excellent benefit for his health.
Section 2 (The technology)	Dry powder is much easier to use than anything requiring mixing.

Role	other
Other role	Parent of CV sufferer
Location	England
Conflict	no
Section 2 (The technology)	?Mannitol is quick and easy to use. Reducing the burden of treatment and care is vital for people with Cystic Fibrosis. As it is delivered through a disposable inhaler the treatment is convenient and hygienic to use, with limited cleaning needed. ?Mannitol will also help to increase adherence. Because of the huge burden of treatment many people with CF struggle to fulfil their daily medication and physio. Dry powder formulation offers convenience and simplicity. Adhering to the right dose and frequency will ensure maximum efficacy of the treatment. ?The treatment would benefit a large number of adults with CF as it is effective regardless of microbiological status or extent of lung disease.
Section 3 (The manufacturer's submission)	As a father of an adult daughter who suffers from CF, I would support, and would expect Government to support, any treatment which assists the sufferer in living with this terminal disease.
Section 4 (Consideration of the evidence)	?Mannitol improves patient lung function, preventing one in four exacerbations. For people with CF this means one less two-week stay in hospital per-year, helping them, their carers, friends and family to get on with their lives. It also offers a potential saving to the NHS as every two-week hospitalisation

	costs approximately £3,000 per patient
Section 5 (Implementation)	Use of Mannitol should be implemented immediately for CF sufferers of any age if recommended by the applicable CF consultant.
Section 6 (Related NICE guidance)	No comment
Section 7 (Proposed date of review of guidance)	Why wait 3 and a half years. If there is to be a review, make it every 2 years (or sooner).

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I feel very strongly that CF suffers shoul dindeed have the chance/choice to use Mannitol at a very early stage in their life (16+). Anything that will prolong this horrible disease is worth a try.
Section 2 (The technology)	I think that if this drug is proven to work and help CF suffers, then the pain and complications far outway the symptoms of the disease. When the doctor meets with the patient and explains all of these reactions the patient can then decide if they want to go ahead. But the choice should at least be given to every CF patient. I think from a patients point of view the price is irrelevant over their life-span.

Role	Carer
Location	England
Conflict	no
Notes	My daughter, [redacted], is 12 and has Cystic Fibrosis. The results of this trial gives hope to all parents that have endured the pressures and strains that CF brings and if a decision is made that the mannitol treatment is not used, it does make you question what is the point for research to continue and maybe the government can decide to kill any person as soon as they are diagnosed with an illness that could potentially cost the tax payers any money. problem solved!!

Role	Carer
Location	England
Conflict	no

Role	other
Other role	parent of a patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	

Section 1 (Appraisal Committee's preliminary recommendations)	Dear Committee member Whilst I can see that an extensive trial has been conducted, and the relevant results presented, it is a shame to think of the consequences of removing Mannitol from the toolbox of solutions for the management of cf. [It would be fascinating to see the models outcome if the manufacturer was able to review its proposed costs of a daily treatment]. I can see that the committee has reservations over the way that the manufacturer has presented its findings, and the various regression techniques can be open to question, but if there was a way to allow a re-presentation of findings [with a lowered cost of treatment], then maybe the practitioners would have a wider array of tools to combat this most frustrating of conditions. The alternative is that the costs of this trial will be allocated to their next project as an overhead, Mannitol will be shelved and patients like my daughter are having to be ever more patient... Yours faithfully [redacted] [redacted]

Role	Carer
Other role	mother
Location	England
Conflict	no
Notes	As a parent with a 17 year old son and a 13 year old daughter both have cystic fibrosis and a another daughter who is 14 years old and all ok. having been given this mannitol meds would be so much nicer for an adult so they can carry on with there life as normal as possible. As nothing is worse for anyone having to go and stay in hospital at least of all cf patient knowing it is for 2 weeks or more in cf peoples case plus there life stops for those weeks why being in hospital meaning if they work they can not or going to college they cant or even uni. In my opion that isnt any life my son hospital is 50 miles away from where i live and that very hard to be able to go and see my son in hospital especially when you have other children and also has the same cf illness. Why should a cf adult have to stop there life for 2 weeks being in hospital costing thousands to the country when they could have mannitol at home so there life can carry on a lot more normal and costing our tax payers a lot more less money you have only got to ask the public and they would all say prescribe cf patients with mannitol so it would cost a lot less plus it will give cf adults to have a bit better normal life rather then them stuck in hospital only in a room for no real reason when they can be out of hospital living life to the best they can and us as a parents can be with them and help them more because of there short lifes this really isnt fair for parents and family and friends not being able to being a round them

	every day especially when the audlts hospitals is 50 miles away from there home. PLEASE PLEASE CHANGE THIS SO THEY CAN HAVE THE MANNITOL MEDS AT HOME NOW.

Role	Carer
Location	England
Conflict	no
Notes	My daughter has cf. She is 16 years old. We have worked hard her entire life at keeping her well. It is a disease you cannot afford to be complacent about at any time. She does her best to lead a normal life and wants to go to medical school to be a doctor. The most debilitating thing that leads to infection is the build up of mucus during and after a common cold. The mannatol drug would reduce this and therefore reduce infections. It would allow her to lead a more normal life without hospital admissions and the regular medication she must take. It would also increase her chances of survival. I understand it is expensive. But my daughter is so precious and we would be so grateful. Kind regards Sally Hutchings
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I would prefer patients like my daughter to have the choice and opportunity to take a medication which has been shown to reduce the symptoms of cf and assist her life expectancy
Section 2 (The technology)	The technology is simple and can be administered at home by the patient. The cost is small in comparison with a hospital admission which would cost around £2000. My daughter regularly is admitted to hospital
Section 3 (The manufacturer's submission)	The evidence of the improvement in fev is sustained in the majority of trial patients. This drug should be offered to all cf patients where fev reduction and mucus inducted chest infections are an issue
Section 4 (Consideration of the evidence)	The use of saline after DNase is unpleasant for the patient. So much so it is hard to convince a teenager to take it unless she is really unwell which lessens the preventative measures that can be experienced. My daughters life is badly affected by cf. The evidence suggests that mannatol would improve her quality of life
Section 5 (Implementation)	The cost of the drugs should be considered against the cost of hospital treatment

Role	Carer
Other role	Mother of two children with CF
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The clinical evidence shows that Manitor increases the lung function of those with CF. This increase in lung function will reduce the need to IV antibiotics to treat reductions in lung function. This will reduce the need for patients to be admitted to hospital for two weeks to be treated. This will greatly

	improve the care and life style of the patient and is surely a better standard of care than not having mannitol.
Section 2 (The technology)	The technology of mannitol if used by my child would possibly reduce the need for one nebulised drug that perform the function of reducing the viscosity of secretions and stimulating cough. Thus mannitol would reduce the burden of care a small amount. I cannot comment on the cost of hypertonic saline nebulised, but it takes at least 10 minutes to nebulise these, and this has to be done twice a day, a saving in time of at least 20 minutes.
Section 3 (The manufacturer's submission)	I am not convinved from the evidence that Mannitol would replace the use of hypertonic saline, and if not it would not reduce the burden of care, but would add to it. The addition of another treatment for the potential of such a small improvement in lung function is not significant enough for my child to consider using mannitol.
Section 4 (Consideration of the evidence)	My child has no problem with adherence to nebulising hypertonic saline, so the contribution of mannitol to treatment adherence is limited. However, the reduction of time in administerind the drug would have a positive contribution to life style over a long period of time. The reduction in equipment is also of no significance, as the nebuliser would still be needed for other treatments, so the addition of mannitol would have no impact on this.
Section 5 (Implementation)	the implementation of the guidance is adequate.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I have been taking mannitol now for in excess of 2 years and it has had a profound impact on my daily life and treatment times and lung function. After completion of the mannitol trial, my FEV1 increased by 13% which for me was amazing. By using it twice daily, it reduces the amount of time I need to spend on physio because it is so effective. I believe it helps reduce the number of chest infections I have.
Section 2 (The technology)	I have not suffered any adverse side effects since taking mannitol, it does make me cough and produce more sputum, which is the desired effect. If there is a reduction in infection that require antibiotics, the cost of the capsules and inhalers should be offset by this.
Section 3 (The manufacturer's submission)	As someone who took part in the mannitol trial. I have had outstanding results and a visible increase in my FEV1 reading (13%), I have not had any unwanted side effects and mannitol has significantly increased my quality of life. I have tried hypertonic saline in the past and not got on well with it. I believe that mannitol should be available on the NHS.
Section 4 (Consideration of the evidence)	AS a patient with cystic fibrosis, I can testify to the efficacy of mannitol, in terms of quality of life, I believe mine has improved, mannitol is easier to use in the inhaler than a nebuliser which makes it easier to adhere to, also there is less cleaning

	required. It is also easier for travel as it doesnt require taking a bulky nebuliser. To improve the health of cystic fibrosis patients, I believe mannitol should be available on the NHS as an alternative choice to hypertonic saline. As a user of mannitol, I certainly dont want to lose it and feel that other CF patients not involved in the trial should be given the option to use it

Role	other
Other role	Grandmother / fundraiser CF Trust
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	1.2 - to stop a treatment just because of an age reached seems quite inappropriate - the patient and clinician should be the ones who decide.
Section 2 (The technology)	The patient will know if there are any adverse reactions and would have stopped using it - regardless of age.
Section 3 (The manufacturer's submission)	The quality of treatment seems to be a very important point, and the fact that life expectancy was not altered is not a factor in CF - patients die because their lung function is non existant, and this will not change until there is a realistic cure regarding the lung function. If the treatment helps ease the life of the sufferer , then it as an important factor.
Section 4 (Consideration of the evidence)	It seems that short term cost has a lot to do with the report. There are statements regarding the way patients feel - , either "well", or "ill" and the fact that patients with CF do not feel well for most of their life, to consider making it more difficult for them is quite unnecessary, when there is a treatment which can be used , with the clinician and patients mutual consultation. The cost to the NHS if patients feel "unwell " & therefore need extra treatment, in hospital or by use of more expensive anti-biotics seems not only bad financial management, but also unfair treatment of the Patients with CF , whose lives are extremely painful at the end , when the lung function has deteriorated to such a point that even a transplant is not viable as they then are too unwell to cope with the operation.

Role	Public
Location	England
Conflict	no
Notes	"I do not understand why Mannitol is not being approved? two-week stay in hospital per-year, helping them, their carers, friends and family to get on with their lives. As it is delivered through a disposable inhaler the treatment is convenient and hygienic to use, with limited cleaning needed. The treatment would benefit a large number of adults with CF as it is effective regardless of microbiological status or extent of lung disease."
Comments on individual sections of the ACD:	

Section 1 (Appraisal Committee's preliminary recommendations)	Recommend Mannitol for CF in adults as an add-on therapy to best standard of care
Section 2 (The technology)	The cost is mitigated by the reduction in hospital admissions and illness rates.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Mannitol improves lung function and reduces hospital stays. it could surely increase life expectancy if this is the case. It is quick and easy to use and will therefore make managing treatment so much easier. Currently the treatment for CF is lengthy and arduous.
Section 2 (The technology)	The cost of treatment would be more than offset by the saving from fewer hospital stays, reduced necessity of intravenous drug treatment

Role	Carer
Other role	Physiotherapist
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	It should be recommended as it improves lung function and reduces exacerbations and therefore expensive hospital stays.
Section 2 (The technology)	If you are an adult it makes sense to take it - keeps the person with cf, and carers, in the workplace avoiding loss of earnings and will reduce the cost of drugs generally as it improves the health of the adult with cf.
Section 3 (The manufacturer's submission)	The medication clearly Improves lung function and adherence to treatment which improves the quality of life for the person with cf and their carers.

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	?Mannitol improves patient lung function, preventing one in four exacerbations. For people with CF this means one less two-week stay in hospital per-year, helping them, their carers, friends and family to get on with their lives. It also offers a potential saving to the NHS as every two-week hospitalisation costs approximately £3,000 per patient
Section 2 (The technology)	?Mannitol is quick and easy to use. Reducing the burden of treatment and care is vital for people with Cystic Fibrosis. As it is delivered through a disposable inhaler the treatment is convenient and hygienic to use, with limited cleaning needed
Section 3	?Mannitol will also help to increase adherence. Because of the

(The manufacturer’s submission)	huge burden of treatment many people with CF struggle to fulfil their daily medication and physio. Dry powder formulation offers convenience and simplicity. Adhering to the right dose and frequency will ensure maximum efficacy of the treatment.
Section 7 (Proposed date of review of guidance)	?The treatment would benefit a large number of adults with CF as it is effective regardless of microbiological status or extent of lung disease.

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Mannitol is quick and easy to use. Reducing the burden of treatment and care is vital for people with Cystic Fibrosis. It is also highly cost effective as it reduces the need for patients hospitalisation.
Section 2 (The technology)	Mannitol will help to increase adherence. Because of the huge burden of treatment many people with CF struggle to fulfil their daily medication and physio. Dry powder formulation offers convenience and simplicity. Adhering to the right dose and frequency will ensure maximum efficacy of the treatment.
Section 3 (The manufacturer’s submission)	The treatment would benefit a large number of adults with CF as it is effective regardless of microbiological status or extent of lung disease.
Section 4 (Consideration of the evidence)	Mannitol improves patient lung function, preventing one in four exacerbations

Role	Carer
Location	England
Conflict	no
Notes	mother to adult with cf
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	my daughter (age 18years)uses mannitol inhalations,for the last 3 years she responded well and her lung functions improved. given the choice of mannitol and the flutter (chest physiotherapy)she would do the mannitol as she feels this benefits her more.
Section 2 (The technology)	mannitol is easy to take and takes little time. feel the price is way too much.
Section 4 (Consideration of the evidence)	all i can go on is the evidence of how it has eased my daughters life.
Section 5 (Implementation)	worried that the mannitol will be stopped and daughters health will suffer.
Section 7 (Proposed date of review of guidance)	not soon enough

Role	Carer
Other role	Mother
Location	England

Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Of course cf patients should have access to mannitol. Life for cf adult is extremely difficult and mannitol improves their quality of everyday life immensely. It is easy to use and effective

Role	Carer
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The CF Trust are recommending all patients with CF should have Mannitol as is the Specialist treating my daughter
Section 2 (The technology)	As it is available and proved to be successful surely patients over 16 should not be discriminated against.
Section 3 (The manufacturer's submission)	There is a massive amount of Clinical data here. I have been a Carer for my 34 year old daughter and know that anything to make her life easier and healthier would be wonderful. She works and is a vibrant part of her community. Thanks to new drugs over these 34 years.
Section 4 (Consideration of the evidence)	Anything that would cut down the time to administer drugs has to be a good thing. And adherence will be much better, therefore leading to better quality of life and fewer admissions.

Role	Carer
Other role	Parent
Location	England
Conflict	no
Notes	My son has just turned 16 and we see that his treatments are becoming increasing important. I have researched mannitol and believe it would form an essential part of his treatment. As he becomes more independent it becomes more and more difficult for me to take control of his medication. Anything that would reduce the time spent in treatment and hospital would be a god send for us. At present, with medications, inhalations of steroids, saline inhalations, physiotherapy followed by antibiotic inhalations he spends more than 3 hours a day in treatment and cleaning his equipment - for someone trying to maintain an active and as normal a life as possible it is very difficult to ensure he does everything he is supposed to do in his daily routine. It is assumed that Mannitol can reduce hospital stays for CF patients by at least one visit per annum. The cost saving alone in this must be important as well as the impact this would have on his life - the number of trips, exams and events that he has had to miss due to hospital stays is a burden. Thank you for your time.

Role	Carer
Location	England

Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I have just returned from a 200 mile round trip to visit my 23 year old brother in hospital. Despite having 2 children and my own business I take this trip every day. The reason? Im not sure how much longer he will be with us. His lung function is 11% and he is going through the procedure of having going active on the list for a double lung transplant. If there is a drug that can 1/improve lung function,even meaning a 2 week less stay in hospital (saving NHS thousands)2/Reduce the burden of his gruelling medical regime(he spends hours a day having physio, nebulisers and tablets and 3/ most importantly benefit HIS severley damaged adult lungs then OF COURSE it should be given. Can the panel perhaps take a brand new balloon put in to there lips and breathe in and out through that for an hours? No, it is a terrible way to have to live 24 hrs a day not just an hour. If this medicine will ease a fraction of that then it should be recmmended.From birth our CF babies struggle, during childhood years miss out on school, trips and normal life. This may give them 2 extra weeks at home with their families, time they may never get back.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Why would this not be considered as an add-on therapy when nebulised hypertonic saline and DNase are? Typically different patients respond to different treatments, whilst it may be true that this will not benefit all this approach is a real barrier to those who may benefit from it. The guidance appears to suggest that adult patients are "beyond repair".
Section 3 (The manufacturer's submission)	The age related degredation is a very real factor in my experience. Both my condition and that of my now deceased sibling took on a more severe decline post 30 years of age. Whilst a treatment will not reverse any damage or even potentially stop exacerbations, has the manufacturer or committee considered this as a supporting medication alongside other treatments? I doubt that when DNase was developed it would have been considered alongside Hypertonic as a complimentary therapy?
Section 4 (Consideration of the evidence)	The manufacturers modelling excluding Hypertonic saline does appear to be a gross oversight, however it does need to be weighed up against the potential saving in patients who avoid hospitalisation and the associated cost of in-patient treatment through respiratory infections.

Role	NHS Professional
Location	England
Conflict	no
Notes	none
Comments on individual sections of the ACD:	

Section 1 (Appraisal Committee's preliminary recommendations)	the CCGs in Bradford and Airedale agree with this preliminary recomendation. Our view is that the evidence of benefit that has been published to date is not compelling, that this treatment does not represent a step change in care, and that the analysis of cost effectivness undertaken by NICE concludes that it is not a cost effective use of (exceptionally scarce) NHS resources.
Section 2 (The technology)	We are not convinced this represents a step change in NHS care available to this cohort.
Section 3 (The manufacturer's submission)	We agree with the ERG analysis and the conclusions reached by the committee, both on clicnial and cost effectivness. The key studies were small and underpowered. The comparator used was inappropriate, Hypertonic saline should have been used as a comparator. It was not We noted the ERG concerns about the design and conduct of the key studies, specifically wrt to the lack of blinding, lack of protocol and seeming change in the primary outcome measure.
Section 4 (Consideration of the evidence)	We are aware there are significant uncertainties as to the likely population that will be treated. However, we have seen estimates that the likely cost impact is £43k / 100k population. this is approximately £250k in Bradford and Airedale, money that will inevitably be found from disinvestment in other services. Given that the ERG and then the committee found the treatment not cost effective after taking into account all the uncertainties, this would mean a net social loss of healt. We would happily take advice from the manufacturer or the relevant patient groups as to which cohorts of patients we should not provide care for if NICE reverse this preliminary recomendation and recomends the treatment.

Role	Private Sector Professional
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	the therapy has been shown to improve lung function and reduce infections (and thereby drug treatment and hospital stays) is inhaled rather than nebulised (so much more convenient and less intrusive to fit into school, uni & working lives) is much pleasanter to taste AND its not even expensive - so it should be made available to CF patients as an alternative to hypertonic saline (which tastes bitter and in any event cannot be tolerated by everyone as it irritates the throat and airways). Also, any increased cough is an indication of more efficient airway clearance, and is more than outweighed by the benefits of mannitol the therapy has been shown to improve lung function and reduce infections (and thereby drug treatment and hospital stays) is inhaled rather than nebulised (so much more convenient and less intrusive to fit into school, uni & working lives) is much pleasanter to taste AND its not even expensive - so it should be made available to CF patients as an alternative to hypertonic saline (which tastes bitter and in any event cannot be tolerated by everyone as it irritates the throat and airways).

	Also, any increased cough is an indication of more efficient airway.
Section 4 (Consideration of the evidence)	A PROVEN TREATMENT MUST BE HAVE MORE BENEFIT THAN TREATING THE FOLLOW UP SYMPTOMS!

Role	Private Sector Professional
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Mannitol has been proven to help reduce chest infections and improve lung function. This in tern decreases the time patients spend in hospital and therefore reduces the cost to the NHS.Mannitol is used via an inhaler and therefore is more pleasent to the patient (no unpleasent taste). This is not a drug that that costs the earth and should be made available to all those in need of it to improve their quaity of life.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	this has been proven to improve lung function and reduce infections and so would minimise hospital costs as less need for this. It is also much quicker as its inhaled rather than nebulised so there isnt so much disruption on everyday life. Its also a pleasanter taste and inexpensive so please recommend mannitol.

Role	NHS Professional
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Mannitol should be recommended for the treatment of cystic fibrosis in adults. My personal experience is that it has changed the life of the sister of one of my friends. In practical terms its has been shown to improve lung functions and reduce infection. this in itself reduced drug therapy and hospital stays. It is also inhaled rather than nebulised to is so much more conveniently fitted in with every day life. It is a cheap effective alternative to hypertonic saline which cannot be tolerated by all CF patients.

Role	Public
Location	England
Conflict	no
Notes	No
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's	The therapy should be available to patients on the NHS. This

preliminary recommendations)	therapy is much more cost effective then hospitalising patients. As it is a nebuliser it offers patients a much easier and less burdomsom way of treating their condition. NICE should reverse their decision.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This treatment has been proven to work and isnt expensive. It should be issued to patients as it can be breathed in rather than nebulised so is far more conveient and less invasisve. It also has a much more pleasant a taste.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I have read that in studies of patients suffering from Cystic Fibrosis, Mannitol significantly helped to improve lung function and in using the therapy patients had reduced instances of infections. When such a therapy is found to work, surely it should be made available to patients if it improves their quality of life and alleviates some of the symptoms of this debilitating condition. When compared to the cost of lengthy hospital stays and antibiotics needed to treat infections, making Mannitol available on the NHS must be considered the ?smarter? option. I would therefore urge NICE to reconsider their recommendation.

Role	Private Sector Professional
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Although this therapy has not been recommended for the use in CF patients surely the fact that the therapy has been shown to improve lung function and reduce infections which in turn will reduce hospital stays and the amount of drugs needed to keep these patients well.
Section 2 (The technology)	This drug is inhaled rather than nebulised and is so much more convenient thus making it less intrusive to fit into school, uni & working lives and it is much pleasanter to taste. This drug is its not even expensive - so it should be made available to CF patients as an alternative to hypertonic saline (which i understand tastes very bitter, needs to be nebulised and in any event cannot be tolerated by everyone as it irritates the throat and airways).

	This in turn increased cough is an indication of more efficient airway clearance, and is more than outweighed by the benefits of mannitol.

Role	NHS Professional
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	the therapy has been shown to improve lung function and reduce infections (and thereby drug treatment and hospital stays) is inhaled rather than nebulised (so much more convenient and less intrusive to fit into school, uni & working lives) is much pleasanter to taste AND its not even expensive - so it should be made available to CF patients as an alternative to hypertonic saline (which tastes very bitter, needs to be nebulised and in any event cannot be tolerated by everyone as it irritates the throat and airways). Also, any increased cough is an indication of more efficient airway clearance, and is more than outweighed by the benefits of mannitol.

Role	NHS Professional
Other role	Anaesthetic Consultant
Location	England
Conflict	no
Notes	I am not involved in the care of patients receiving mannitol for cystic fibrosis but I do know some and have heard reports of others.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The use of mannitol as a mucolytic seems to be very effective in some CF patients better tolerated than hypertonic saline and it is not expensive. It should be a treatment option for all CF patients.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Mannitol is cheaper, more convenient (inhaled not nebulised), it has been shown to reduce infection (thus less drug treatment and hospital visits) and yes, increases cough but in CF sufferers this is a plus!!

Role	NHS Professional
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Knowing of someone who has seen significant improvements in their quality of life and health since beginning on the Mannitol trial, I urge NICE to reconsider their position regarding this

	treatment for CF. I understand that the side effects may be unpleasant for some users however the benefits of increased health and reduced intrusion of illness and treatments related to CF for those who are successfully using Mannitol cannot be underestimated. As NICE is recommending that those already on Mannitol treatment have the option to continue, surely it is right that others may have this option in the future.

Role	Private Sector Professional
Location	England
Conflict	no
Section 1 (Appraisal Committee's preliminary recommendations)	To Whom it may concern, It seems to be that Mannitol has been shown to improve lung function and reduce infections in CF patients in turn this reduces the need for hospital stay and, more importantly the use of other drugs such as antibiotics. This not only has the potential to make the use of Mannitol more cost-effective than the current alternatives, but also there is a moral stand to take by reducing the need for antibiotics to cure infections the production of drug resist strains of bacteria can be reduced. This obviously can affect the population wider than that of the CF population. As a side note exposure strong antibiotics such as gentamycin for the patients wellbeing also. It also seems that a drug which can be inhaled, rather than nebulised, would be beneficial to the patient as it is less disruptive to their lives in which they already suffer a great amount of disruption. To not recommend this drug as an alternative to hypertonic saline seems like an unfathomable decision Mannitol is cheap, cost-effective and has a greater benefit to the patient.

Role	Pharmaceutical Industry
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	This therapy reduces hospital admissions and drug treatment, it also fits in easier with patients every day life as it is inhaled not via nebuliser. It is cheaper and has a less bitter taste. I think all this is a plus both for patient care and resources as less admissions and less drug treatments are cetainly more cost effective.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's	I have been told that this therapy improves lung function and

preliminary recommendations)	reduces infections.

Role	Public
Location	Other
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The usual reason why NICE do not recommend things is cost, which can sometimes be understandable, however as cost is not an issue here and trials indicate great success with Mannitol it seem illogical of NICE not to recommend it. Obviously if it is not agreeable to the Patient then of course it would be stopped surely? Isnt that the Clinicians / Patients decision? But to not give CF sufferers the choice is just plain wrong when many on the trial of Mannitol have experienced great benefits.

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Mannitol should be authorised for use for all CF patients because 1 it improves lung function 2 it is inhaled rather than nebulised 3 it reduces exacerbations and therefore hospital admissions/IV ANTIBIOTICS and therefore cost to the NHS 4 CF is a very debilitating condition and anything which improves quality of life/life expectancy should be available. PLEASE RECONSIDER DECISION
Section 2 (The technology)	The cost will be met by savings in hosp aadmissions though infections

Role	other
Other role	Parent
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Inhaled mannitol can significantly improve lung function. It also reduces chest infections, and therefore the need for regular antibiotic treatment and hospital admissions. Because it is inhaled rather than nebulised, it is much easier and more convenient, so patients can get on with their lives. Mannitol is also much more pleasant to taste than the alternative of hypertonic saline, as it is slightly sweet whereas hypertonic saline is bitter and harsh to the throat. Any increased cough is a beneficial side effect, as it is an indication that the lungs are being more efficiently cleared, and is more than outweighed by the benefits of mannitol. Young CF sufferers have more than enough to deal with, without being denied the benefits of this new therapy.
Section 4	I agree with the patient experts views expressed in this section

(Consideration of the evidence)	

Role	Public
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Mannitol therapy has been shown to improve lung function, consequently greatly reducing the frequency of lung infections and therefore the number of hospital admissions. It is also much less intrusive in the patients life and is far more pleasant to take , both hugely important considerations in gaining the co-operation of young patients and their adherence to the regime, but also very important to older patients quality of life. True there can be side effects, but not all of the ones reported can definitely be linked to the use of Mannitol as CF itself causes many of them anyway. Use of Mannitol can be stopped if side effects persist. This is the first effective new treatment to be proposed for this horrible disease for many years and also the first hope for its sufferers and their carers, and as such I believe NICE should urgently and wholeheartedly recommend the availability of inhaled Mannitol as a valuable treatment for CF.
Section 4 (Consideration of the evidence)	Considering the evidence and all the agreed problems and limitations associated with hypertonic saline I believe NICE to have no alternative but to recommend use of Mannitol for those patients who are shown to benefit from it.

Role	Patient
Location	England
Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The use of Mannitol for CF patients would seem to have improved the quality of life for many taking this drug. It is quick, convenient and easily portable. Anything that can help CF sufferers to deal with the condition should, I believe, be very seriously considered as if it improves lung function and makes lung clearance easier then this would reduce the number of hospital admissions for I/V antibiotic therapy, saving far more than the cost of the Mannitol and would free up many hospital beds at the same time. As CF mainly affects the young, it would make their life easier and more convenient, especially for school patients. Mannitol does not require the use of a nebuliser either, thus reducing time which is a major consideration for CF patients as their self-treatment is very time consuming. Also, many patients find that nebulised hypertonic saline is unpleasant and I suspect that a number of patients do not use it as much as they should. It also requires the use of a portable nebuliser.

Role	Patient
Location	England

Conflict	no
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	The quality of life of CF patients can be greatly enhanced by inhaled mannitol. I know because it has transformed my life. CF is a burdensome condition, in terms of nebulised therapy, other drugs, & physiotherapy. Mannitol improves airway clearance, reduces exacerbations & is quick & convenient. The device can be used anywhere in less than 2 mins, whereas hypertonic saline has to be nebulised via a compressor & takes much longer. Not all patients can clinically tolerate h/saline (eg it makes my throat sore & irritates my airways), & the taste is disagreeable - especially to young people - compared with the pleasant taste of mannitol. Anything which helps CF patients to fit treatment into their daily lives will increase compliance & should be actively promoted. Also, mannitol has been shown to significantly improve lung function because of its efficacy in lung clearance. Therefore patients will need fewer antibiotics and fewer admissions to hospital, to the benefit of themselves and reduced cost to the NHS. CF is an onerous and life-limiting condition and many young people still die in their 20?s. This therapy, with its potential to improve their quality of life and reduce morbidity and early mortality, should be strongly recommended.
Section 2 (The technology)	2.1 The small, portable device is very convenient and each dose takes less than 2 minutes 2.2 Any initial tightening of airways is quickly reversible by 2 puffs salbutamol. The increased cough after physiotherapy is beneficial in order to expectorate the liquefied sputum. Obviously as this is a hyperosmolar agent, the aim of which is to improve clearance, some increased cough following the dose is inevitable. 2.3 The cost can be offset by reduction in prescription for antibiotics and hospital admission for IVs, and other clinical interventions eg visits to health professionals
Section 4 (Consideration of the evidence)	Throughout this section I am wholly in agreement with the views of the patient expert