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

Name	[redacted]
Role	NHS Professional
Other role	
Location	England
Conflict	no
Notes	I Have treated over 20 patients with Rifaximim for disabling encephalopathy. This has had a major positive effect with patients returning to independent existence no longer needing frequent hospitalisations or longterm care institutions. In many this has been bridge to recovery from significant alcohol related liver disease or transplantation. Never have I witnessed a drug with ability to improve my chronic liver patients lives and reduce the burden on struggling hospitals. I am aware there is not enough robust data BUT hepatologist after hepatologist will tell you effective it has been in reducing hospitalisations and improving quality of life. It would be virtually impossible to get robust data - as improvements are hard to quantify
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	pleased dont need to withdraw treatment
Section 2 (The technology)	no comment
Section 3 (The manufacturer's submission)	submission valid
Section 4 (Consideration of the evidence)	almost impossible to get anything except experiential evidence - hepatology could give report of survey
Section 5 (Implementation)	no comment
Section 6 (Proposed recommendations for further research)	no comment
Section 7 (Related NICE guidance)	new evidence can be complied by hepatologist before this date on clinical effectiveness in routine practise so far accumulated
Section 8 (Proposed date of review of guidance)	no comment
Date	7/16/2013 6:22:00 PM

Name	[redacted]
Role	Private Sector Professional
Other role	British liver nurses forum comittee member
Location	England
Conflict	no
Notes	
Comments on individual sections of the ACD:	

Section 1 (Appraisal Committee's preliminary recommendations)	Whilst the ERG has not recommended Rifaximin is the cost were to be more realistic would NICE reconsider recommending Rifaximin for patients with encephalopathy and low MELD scores especially as this subgroup would not be candidates for liver transplantation.
Date	7/9/2013 10:01:00 PM

Name	[redacted]
Role	NHS Professional
Other role	
Location	England
Conflict	yes
Notes	I am a [redacted] and [redacted] I have consulted with Norgine on rifaxamin with recgard to its potential as a long trem prevetative stratgy against infection in cirrhosis, and recently been at a consultation board for hepatic encephalopathy. Â The key issue is that encephalopathy when it worsens requires hospital admission in over 90% of cases in my experience.The hospital admissiom usually is over 3 days as precipitating causes are sought and treated.This can happen repeatedly even when the patient is on lactulose.Rifaximin has been shown to reduce hospitalisation rates for recurrent encephalopathy.It greatly improves quality of life for the patient and carers.I do not see in the documentation consideration of this.I am not convinced the hospital readmission rates have been factored in properly.Personal experience with the drug as 400mg bd to which we have had access to has shown dramatic results in patients on liver transplant waiting lists who are very prone to acute encephalopathy superimposed on chronic encephalopathy.It is a very useful drug which has helped patients failing lactulose and enemas (given by community nurses,GPs etc ...another cost not factored in) and has further potential in chronic liver disease.Studies with the 400mg formulation have shown reduction in infections (spontaneous bacterial peritonitis) and increased survival over a five year pperiod.The drug needs urgent reconsideration as some patients will lose out without it.Encephalopathy has a mortality rate ,and if the patient is waiting for a transplant , the premature death related to encephalopathy is a clinical failure... rifaximin will lessen this possibility.
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	Do not agree as costs associated with readmission encephalopathy include not only hospital costs but ambulance rides call out to GPs and loss of work time for carers
Section 2 (The technology)	fine
Section 3 (The manufacturer's submission)	neomycin is ototoxic and is avoided if at all possible.To my knowledge not licensed for hepatic encephalopathy.This is not a useful clinical comparison
Section 5 (Implementation)	true costs of recurrent encephalopathy not addressed
Section 6	faulty

(Proposed recommendations for further research)	
Section 7 (Related NICE guidance)	immediate
Section 8 (Proposed date of review of guidance)	no expert who has dealt with patients with this condition need gastroenterologist or hepatologist on panel
Date	7/4/2013 3:42:00 PM

Name	[redacted]
Role	NHS Professional
Other role	
Location	Wales
Conflict	no
Notes	I have given a talk on encephalopathy sponsored by Norgine
Comments on individual sections of the ACD:	
Section 1 (Appraisal Committee's preliminary recommendations)	I use rifaximin as a second / third line agent to prevent encephalopathy, and have absolutely no doubt it is effective, and keeps patients out of hospital. As long as it is not misused (i.e. given to everyone from the outset) it is a really important tool in managment, very well tolerated.
Date	7/4/2013 1:04:00 PM