Name	[redacted] – Liver for Life
Role	other
Other role	[redacted]
Location	England
Conflict	no
Notes	Liver4Life have applied to be a consultee on this process
Comments on individual sections of the ACD:	
Section 4 (Consideration of the evidence)	The Appraisal Committee has stated that it is interested in receiving comments on the following: Has all of the relevant evidence been taken into account? In the opinion of Liver4Life they have not. Patient experiences are about more than the effects of lactulose, and the effect that an episode of HE can have on a family can be devastating. My own Father had episodes of HE in 2007/8 which brought my whole family to a standstill. I had to take time off from work to look after him as my mother 'couldn't cope' with his unpredictable nature. This involved expensive journeys from Bournemouth to Coventry two or three times a week. I have also included statements from two other patients below who have experienced HE first hand. December 2013 [redacted]. As a result of my condition I also have been diagnosed with oesophageal varices, enlarged spleen, osteoporosis, IBS, liver cirrhosis and most recently have been showing symptoms of Hepatic Encephalopathy. I was prescribed Rifaximin just under a year ago now when I began experiencing changes in my general wellbeing. My main initial complaint was the uncontrollable feeling of being 'on edge' and tiredness as I wasn't able to sleep at night and therefore found myself extremely fatigued and sleepy during the day. Â This slowly progressed and my ability to concentrate on simple day to day things became increasingly difficult as I would forget things and be confused with basic communication and tasks, which would make me so frustrated as it was not like me to be 'intellectually' that way. Â It was a scary time as it felt as though my normal mental ability and retention was diminishing and I would get moody because of the frustration as to the reasons why this was happening. Â Ultimately, these symptoms gradually began to have a knock on effect on my life. Â My immune system was weakened by the exhaustion and I was contracting infections/viruses more frequently, which are more consuming when you are suffering from liver disease as well. Â This situation resulted in increased

levels of antibiotics, time off work and decreased physical capability to function as a mother/homemaker & wife (especially when my partner isn't at home a lot due to work commitments and my family live 250 miles away). Â My performance in my career also drastically altered. Â I was turning up late as I'd not had a night's sleep and was leaving early as the day utterly wiped me out, which caused my weekly contracted hours to be down. Â Mistakes were being made and my general common sense approach had deteriorated. My usual attention to detail, my ability to provide solid business advice as well as to soak up new information were all suffering and it soon started to have an effect on my self-confidence and enthusiasm. Sadly and guiltily, during this time my child also endured as I was either not remembering her schedules or unable (as was ill or asleep) to cater for her as much as usual, which to me is a completely unacceptable state to be as a mother and something needed to be done about it. Â

Finally, I notified my consultant about my experiences and after about 1-2 months of taking Rifaximin I noticed a significant change in my physical and mental state. It was like fragments of my typical self were steadily regaining and the overall irritability of the past few months were dispersing into the distant past. Gradually at last I was getting back my normal body clock and managing to get a full quota of sleep at the right time of the clock. My feeling of everything making sense had returned, my motivation increased and my home/work life balance soon got back on track as did the correct mother/daughter duties and relationship.

I personally hope to have Rifaximin readily available for me on a indefinite term as I'm certain I wouldn't be at the place where I am now without it and could not even think nor tolerate being back as it was beforehand.

November 2013

I am 56 years old. In 2008 I was admitted as an emergency patient losing massive quantities of blood due to oesophageal varices. After this I do not remember anything for several days. I believe I had a TIPPS operation. After this everyone who visited me said I spoke complete gibberish.

After about a week, I began to return to my usual self and was able to do crossword puzzles. I drove to the supermarket for essential provisions.

The next day I began to realize things were not as good as I thought they should be. I could not operate the washing machine or the oven. As things got worse, I was unable to dress or feed myself. My elderly and disabled husband could only watch with rising panic.

A GP visited, diagnosed encephalopathy and prescribed

	antibiotics. These worked after a while. The trouble was that these attacks would come on unpredictably and quickly. One day I was going to have lunch with my mother and in the course of an hour I lost the plot completely, drove to the wrong village and was found collapsed in a car park by some kind people who called an ambulance. Anyone in his right mind would have used a mobile to get help but I was not in my right mind and, to make matters worse, all these episodes are accompanied by a slurring of the voice leading to the assumption of drunkenness. I think I was hospitalized three times before I met [redacted], who prescribed Rifaximin. To me this has been a life changer - I can make appointments and be sure to be able to keep them. I can drive my car without fear for the safety of others. Now my husband is dead and I live alone. I have no-one to tell me that I am behaving oddly or that my voice is slurred. Personally I do not realize when I have gone mad and because of that would not think of calling my GP. Rifaximin is my insurance against madness. Are the summaries of clinical and cost effectiveness reasonable interpretations of the evidence? No. From my own personal experience, and the experience of our case studies, secondary costs and implications do not appear to have been taken into account in this appraisal. I appreciate that they may be difficult to quantify but they need to be accounted for somehow. Our feedback is that Rifaxamin makes a difference to a lot of people. Are the provisional recommendations sound and a suitable basis for guidance to the NHS? No. Again, based on the above testaments, not approving Rifaxamin for use in the whole of the NHS would subject the lives of many people (with HE and caring for people with HE) to suffer the effects of HE needlessly. This technology can significantly improve the lives of many people, both affected by HE and caring for patients.
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