Name	[redacted]
Role	Public
Location	England
Comments	This is a debilitating, distressing and antisocial disease. Any medication is worth a try - lives can be transformed if remission or control is achieved.

Name	[redacted]
Role	Patient
Job title	Recruitment Consultant
Location	England
Comments	I welcome the introduction of vedolizumab as a pathway to treat ulcerative colitis sufferers. I personally have acute left sided UC, diagnosed 5 years ago. I have struggled to keep in remission during this time. I have tried asacol, and been on azathioprine for the last 18 months. These have not worked for me and as steroids are not seen as a long term treatment, and with the withdrawal of other biologics for maintenance therapy the only other real course of treatment for me would be surgery. I am a 35 women with a young family. The affects of this disease on my quality of life have been severe. I have been fortunate to have understanding employers and a very supportive network, but there are times when I struggle to function at all. This new drug presents a real opportunity for me to be able to continue in my career and make a positive contribution to the economy, as well as being able to be a proper parent to my children.

Name	[redacted]
Role	Patient
Location	England
Comments	I am very concerned with the proposal to make Vedolizumab unavailable to those who have not had a response to, or have lost response to treatment with a TNF-alpha inhibitor. I have severe ulcerative colitis (pan-colitis). I have recently come out of hospital, where I was treated with IV steroids and Infliximab. I have finished the three doses funded by the NHS. I have had some response but am not in complete remission. I have not been able to work since July. The only option now is for me to take Azathioprine, with all the risks and nasty side effects this entails. If this does not work, or the side effects/complications are too drastic, I will be looking at surgery. It is not clear whether I would be eligible for Vedolizumab - I was able to tolerate Infliximab and did not lose response; more than 3 doses were simply not funded. I would very much like to try Vedolizumab. I understand that it is expensive, but this would also be making savings in other areas - such as treating the side effects/complications associated with Azathioprine, or the cost of surgery. Not to mention I would be able to return to work, and pay tax once again. Together with

	Crohns and Colitis UK, I urge NICE to reconsider extending access to vedolizumab to include those - such as myself - most in need.

Name	[redacted]
Role	Patient
Location	England
Comments	I have had UC for 30 years and my son aged 26 has had UC for 5 years. My son is a promising academic at Cambridge University.His academic career has been interrupted on numerous occasions by UC flares and there have been times when it was feared that his career would break down completely because of flares at crucial times eg during exams and periods in hospital. Above all what has been lacking is a drug which can give long term remission. My son has tried Infliximab both in the UK and in France where Infliximab is freely available to UC patients and regarded as a best option. Infliximab was of short term but not long term benefit to my son.He remains steroid dependent and unable to achieve long term remission. To deny the class of UC patients which includes my son ie those who have tried but not gained long term benefit from other mabs the opportunity to try Vedolizumab is both unfair and a poor clinical decision. No patient will wish to continue on a serious drug if it is ineffective. No patient should be forced toward surgery if a promising drug has not been tried no matter what drugs he has tried before. [redacted]

Name	[redacted]
Role	Patient
Job title	Builder
Location	England
Comments	I am a patient with ulcerative colitis which has not responded to conventional treatments. I am due to start on infliximab tomorrow and am concerned if this does not work or is unsuitable I will have no other options and no hope for the future. As a father of 3 children I really need more than just surgery that has too many drawbacks for me. I want the chance to live an independent life and be able to earn a living, pay the mortgage, be able to support my family and see my children grow up. I hope this more targeted drug can give myself and others a chance to live a more normal life with fewer side

	effects. Thank you. I am self employed and am at risk of losing my business and family home due to the effects of my illness. Please make this drug available to people who desperately need a viable alternative to the other medication available. This illness is very debilitating and we feel that we are running out of options. Our children need their father back in their life again. Please give us some real hope. (Partner of ulcerative colitis sufferer).

Name	[redacted]
Role	NHS Professional
Location	England
Comments	I am 23 years old and I was diagnosed with ulcerative colitis back in 2012 during my 3rd year at university studying dentistry. I had learnt about this condition during my dental studies and never dreamed that I would soon be suffering from it. When I was first diagnosed back in May 2012, I was admitted to hospital for 1 week. I was given medication and prednisolone to taper down on. I did this and had my first relapse in November 2012 where I again had to be admitted to hospital due to having extreme abdominal pain, going to the bathroom over 10x a day and passing blood. I was still working out how to manage this disease and was determined not to let this interfere with my 4th year of dentistry as I was currently in the middle of exams. I was discharged on oral steroids which was to be followed up with the view to starting azathioprine. As soon as I started taking azathioprine I started suffering from extreme abdominal pain at night which I had never experienced to this extent. I was later told to stop taking this and the pain disappeared. I was then given 6-Mercaotopurine but had the same response to the azathioprine which I therefore had to stop. I was offered the AMGEN trial or surgery but at this stage in the middle of my exams and having just gone through the traumatic experience of taking the oral immunosuppressants I declined. I later started infliximab. At the time I started infliximab I was already feeling better and back to normal due to having been tapering on steroids. I felt normal after having my infusions and a month later once I had come off the steroids again, I had another relapse. I then went back on prednisolone and was stable again. I now felt it was time to take control of my health and although only empirical evidence available decided to change my diet. I have since cut out all dairy, grains and try to have a low sugar diet. For the whole of my 5th year at university I stayed on a low dose of 5mg oral prednisolone and stuck to my new lifestyle change. I did not have to be admitted to hospital and if I felt a relapse was starting, I would act fast by using steroid and mesalazine enemas to take control which worked. I have never felt happier and in control of my disease. Knowing I could feel so well again with diet and medication, I could not even think

	about surgery. I was doing very well and in consultation with my consultant decided to come off steroids with a view to starting the amgen trial. Unfortunately, the trial was no longer accepting patients and I was very angry with myself for missing out on this opportunity earlier. Having come off steroids, I later relapsed and on the 27th June had to be admitted to hospital again due to having severe headaches along with UC symptoms. The severity of the headaches prevented me from controlling my UC symptoms which I would normally do with the use of suppositories and usual medication. Once discharged, I again started tapering the oral steroids but have stayed at a maintenance dose of 10mg steroids. I feel well and know I cannot stay on oral steroids for the rest of my life. I canâ€™t comprehend having surgery which is irreversible unless life-threatening. I feel so well even though steroid dependant but I know if I come off them I will eventually relapse and I will be back in the viscous cycle. Evidence has shown vedoluzimab to be efficacious in those who have failed anti-TNF-Î± treatment and could be a last treatment option prior to surgical intervention. Knowing that there a drug which has had success even in those who have had TNF therapy which has failed, at 23 years old I am not prepared to go through such drastic life changing surgery until I have tried every option available. I am managing my condition to my best ability through medication and diet and I will remain strong and positive in the hope that I will be able to receive vedoluzimab one day. I am so grateful for being given the opportunity to express my views to NICE and this could change my life completely no longer living in fear of when I will next relapse.