Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA001

I am a 67 year old male and have had Ulcerative Colitis since I was 21. For the last 46 years the disease has controlled my life (and the lives of family members) - absolutely! It has affected both my work life and social life.

The impact on my working, social and family life has been considerable

Impact of UC on my life - UC had an adverse bearing on how I performed my job and my confidence levels on a daily basis. My career as a marketing manager was severely impacted. During meetings I needed to leave the room several times an hour to relieve myself. Colleagues were aware I was unwell but I was too embarrassed to tell them why.

When travelling for work, I had to plan journeys using motorways. This enabled me use WC's at motorway service stations en-route. On occasions, I was also forced to stop by the roadside so I could relieve myself on the hard shoulder, crouching between open front and rear doors. Probably illegal - definitely embarrassing.

I have had to abandon meetings through feeling unwell so I could return home (sometimes over 100 miles away) to meet with my consultant for emergency treatment.

When experiencing a flare up I need to remain housebound to stay near toilet facilities. When able to leave the house I need to find where public toilets are located in case I get the urgent need to go. At times I have forgone holidays abroad because of toilets restrictions on airplanes.

The Progression of My UC Flare ups were less common in the early years and were controlled by Asacol, prednisolone and Predsol enemas. All the while I was taking using codeine phosphate and Loperamide to control the frequency of my bowel movements which during a flare up are around 8 to 20 times daily, sometimes more.

Prednisolone caused mood swings and I put on several stone in weight. My mood swings had a severe impact on my family life and marriage.

As my disease progressed, my life became one continuous flare up with all the attendant pain, discomfort and embarrassment. My consultant continued to prescribe steroids (prednisolone and predsol enemas) but in the end they were having no effect.

Eventually, I was forced to retire at the age of 56 when the affects of the disease grew so bad my working life became impossible. As steroids were not having any affect my consultant prescribed cyclosporin, which proved ineffective. My consultant then prescribed azathioprine but this caused unbearably severe headaches and nausea.

If you have not experienced it, UC is a painful miserable life limiting disease. With all the pain, tiredness and limitations on my life I became very depressed and I began to consider the futility of carrying on.

My consultant said the next step would be surgery. I have resolutely tried to avoid surgery due to the additional negative impact it would have on my family/social life. So a last resort my consultant prescribed infliximab.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA001 (cont'd..)

Infliximab worked liked a miracle - After just ONE infusion my Colitis symptoms almost disappeared and my life almost normalised. After the second infusion my Colitis was under control. I lead an almost normal life. I could leave the house without having to plan potential toilet stops and was free of the pain that had impacted my life for the last 40 years. Nor was I experiencing the loss of blood, tiredness and anaemia that had been a feature of my life for so long. **In addition, subsequent colonoscopy examinations revealed that my bowel showed no active sign of the disease.**

After a couple of years on infliximab, my consultant asked me to change to Humira. I believe the change was due to cost savings. So around two years ago I was prescribed Humira which has proved very effective in keeping the worst of my UC symptoms at bay. I still lead an almost normal life.

I am still resisting surgery because I have been informed that my ability to recover from surgery is reduced because of my age.

I have not suffered any apparent side affects using infliximab or humira. I am aware that my immune system is reduced and take great care to stay away from people with obvious illnesses, e.g. cold symptoms or cold sores, etc. I have noticed though that I take longer to recover from any common illnesses that I get.

I am also aware that I am more prone to other more serious illnesses and cancers. But I rely on my consultant to monitor and screen me for potential side effects.

MY PLEA TO NICE UC and Crohns are always mentioned in the same breath. They have similar symptoms and causal factors. . I cannot see the logic and fairness of funding Crohns and not UC.

My UC symptoms would return if NICE were to withdraw funding for my Humira. Conventional treatments are no longer working for me and surgery in not an option. Please continue funding for Biologics for UC.

This submission focuses on the impact of the Personal Independent Payment (PIP) assessment on people with Inflammatory Bowel Disease (IBD).

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA002

I was first diagnosed with pancolitis in November 2011 aged 28. I was treated with IV steroids in hospital and mesalazine. This worked for about 9 months after I was discharged. In January 2013 I had to start on oral steroids again due to a flare up and every time I came off the steroids between January and November that year my UC would flare up again. In November my consultant said he was not happy to prescribe me any more steroids. I was also unable to take aziothiaprine as I also had pancreatitis at the time of diagnosis and aziothiaprine is not compatible with this. So, my consultant wanted me to start methotrexate and infliximab as my next best option. I started methotrexate in November 2013 and have been trying to secure funding for infliximab ever since. I have been refused funding by the CCG but am now waiting to hear the decision from the individual funding team for me as a special case.

Currently the methotrexate is working ok for me but it is incompatible with pregnancy. I was married in April 2014 and my husband and I would like to start a family. We cannot do this while I continue to take methotrexate. I feel that the decisions (based on the current NICE guidelines) are preventing me from having the opportunity to have a family of my own. If the NICE recommendations are upheld after this consultation, there would not be any benefit to me. Surgery is a very serious consideration for me and not a decision I would take lightly, particularly as I haven't had a family yet. There is no alternative for me at the moment than to stop taking methotrexate and hope my colitis will not relapse in the 6 months I need to clear the drug from my system in order to try to get pregnant.

The NICE view that using biologics for patients like myself is not cost-effective seems very harsh to me and feels like it prejudices those who have not already had children. Surgery options will permanently affect people's quality of life and should always be a last resort. If there are drug treatments that can delay or prevent this outcome then I believe people should be offered the opportunity to try biologics if they could work for them and they cannot take other options. I would imagine the costs of fertility treatment for those who cannot use biologics would be extremely high so wonder if NICE have compared the cost of allowing short-term use of biologics for people such as me, i.e. 9-12 months coverage, to get pregnant, versus the cost of a surgical plus fertility treatment option. If they have not then maybe they should be encouraged to do so otherwise there is a risk that their proposals discriminate against women of child-bearing age.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA003

Having being diagnosed with UC 3 years ago I was given all the normal medication which for 2 years held my condition at bay. At the end of last year I had a massive flare up which resulted in medication no matter what doses I had would not control the flare up. I was left not being able to work as to the frequent need for the toilet anything up to 20 times a day. This left me losing lots of weight, feeling permanently tired , fatigued and depressed. After many appointments at the hospital and many tests It was agreed that I could have infusions of infliximab. I had the first of 3 on the 12th June within 48 hrs the improvements were remarkable, I then had another 2wks later then 4wks after that.

Since then I have returned to a normal life almost as good as before I was taken ill over 3yrs ago. It may be expensive but if the results are as good as most sufferers of UC report this must in the long term be very cost effective to the NHS.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA004

I was put on infliximab in August 2013 after being taken into hospital as an emergency very ill. I had 17 BM the first day admitted. Cortisone did not work for me after 5 days. It was then I was put forward for infliximab. It was administered at 7 pm over 2 hours. By
5 am the BM had almost ceased. I could not believe it was happening to me but it did.
The relief was fantastic.

I have suffered with UC for about 45 years the doctors in the olden days said it's just one of those things and did not take much notice of me. Never had any treatment over about 30 years.
My mother suffered with it and eventually had an iliostomy for 26 years, this was what was facing me if infliximab did not work. I know how my mother suffered with it I did not want to go down that route. I looked after her the later part of her life and changed her bag for her on many occasions so I knew what I would be facing.

Little did I think I could be facing the same situation near the end of my life If infliximab was taken away from me I am sure I would not cope with an iliostomy .

I have never felt better in my life . I am so grateful to being on infliximab. Please use this email to show NICE my views and thank them for me to able to put on it.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA005

In 2012 I had severe UC it had become steroid resistant and I couldn't tolerate 6MP azathioprine I was put on 6 weekly infusions of Infliximab as a last hope solution! Within days my 20+ toilet visits per day were down into single figures Within 6 weeks I was normal I had a colonoscopy 3 months later and my colon looked normal! I was in remission I have stayed this way ever since I have received 7-8 weekly infusions now for 22 months and only had I minor flare up in March this year which was the direct result of trying to make me go 9 weeks between infusions If I have an infusion every 7 weeks I don't have UC Infliximab has given me my life back Its been my wonder drug

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA006

As a patient who has UC and has been treated with Infliximab, all be it privately through health insurance, I'm very concerned that this treatment will not be made available to all suffers who do not respond to conventional medicines as myself. My experience of Infliximab is indeed that it is a wonder drug, one that prevented surgery and effectively brought a normal life back to me.

I was diagnosed with UC finally after 2 years of visits to my GP where very little was done, I managed to persuade my GP to refer me to a consultant, Mr Przemioslo in August 2012 where the disease was confirmed, after treatment with Asacol, Salofalk, Prednisolone and Azathioprine failed to control the condition over the next 12 months the decision was made for me to begin a course of 3 Infliximab infusions over a 6 week period.

There was an improvement a short while after the first infusion, with the condition finally under control by the end of the 6 weeks, and has been in remission since then simply controlled with Asacol and Azathioprine once daily.

It is not difficult to relay the difference that Infliximab made to my life, I could return to work on a normal basis, which as it happened was working on Bristol's new super hospital, rather than pretty much confined to home working, it meant that normal bowel function was returned at a healthy frequency, not the 20 times a day just 6 weeks previous. Infliximab allowed me to have a normal life, enjoy days out and simply not worry anymore, obviously my mental state was so much better as well as my physical state.

To take this opportunity away from sufferers of this cruel condition is not acceptable and NICE must acknowledge the amazing benefits this drug can bring to UC patients. To differentiate between UC and Crohn's patients is also not correct, however why is this not obvious to NICE? Sometimes I wonder if those making decisions for NICE actually know what the acronym means, it is certainly not clinically excellent to deny UC suffers a life changing therapy, one that may prevent major surgery, one that can allow an ongoing normal life to be maintained afterwards by simply taking some very inexpensive medicines.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA007

I am speaking as a concerned mother of a sufferer of UC. My daughter was diagnosed with UC following a prolonged bout of bloody diarrhoea and 2 visits to A&E and a stay in hospital.
It was only thanks to very understanding teachers and the Gastro staff at Queens Hospital, Romford, that my daughter Aimee, was able to complete her A levels and obtain a place at her chosen University. It is only through her ongoing drug regimen that her health remains fairly stable and that regimen is Pentasa, Azathioprine and Humira. Without the Humira added to her regime, she would neither be able to continue her studies, nor lead a fairly normal life and a very valuable life experience would not be open to her. She is now 19 and has, hopefully, a long and active life ahead of her. To consider denying her that because of a money saving exercise is unacceptable to us. There are many sufferers in similar positions I am sure and I believe that those with the ability to help have the responsibility to help. They ALL deserve more from their health service, not less.

IBD is a nasty set of conditions, under-publicised, under-researched and totally undeserving of this kind of cruel and senseless treatment. You cannot let this happen. You must not let this happen.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA008

I currently take Humira (adalumimab) and have done for over 2 years, without this I would have already had to have surgery. Instead I still have all my insides and am able to lead a normal life.

My experience of living and dealing with UC is a slow degeneration in the function of the colon which has impacted every area of my life. I have had to systematically work my way through all conventional treatments with varying degrees of success, but none which have successfully got my UC into remission.

I have suffered severe side effects to the medications prescribed and have often had to take multiple medications at the same time - some to treat the UC and others to treat the side effects of the other drugs. As a result, I have suffered eczema and psoriasis, extreme hair loss, depression and low mood, weight gain due to fluid retention and 'puff' (made worse by having to take steroids for a number of years), extended periods of proctitis, severe anaemia, insomnia, chronic and debilitating fatigue, at times chronic constipation and at others lengthy extreme bouts of explosive diarrhoea.

Since I received my diagnosis in 2007 and I have been on several kinds of mesalazine (currently mezovant), azathioprine (I reacted badly to it), mercaptopurine, methotrexate, regular extended courses of prednisolone. When none of this worked effectively my anaemia become so bad I was hospitalised and had to have a blood transfusion of 2 units of blood along with fluids and steroids.

After this I was tried on Infliximab and had one transfusion which seemed to have an almost immediate positive effect, all symptoms settled right down and I seemed to be going into remission for the first time since diagnosis - but then within 6 weeks my liver stopped working properly and I was hospitalised again with jaundice and suspected liver failure (it didn't fail but was definitely struggling for a few weeks). I was hospitalised twice more (roughly every 6 months over a 2 year period) as we struggled to get my UC controlled, regular colonoscopies and sygmoidoscopies showed ongoing large areas of low-to-medium inflammation no matter what we tried.

When I was last admitted my consultant discussed remaining options, I am almost out of drug options and surgery was given as a very serious alternative if things did not improve. I chose to meet with one of the surgeons and a nurse practitioner in aftercare so that understood fully the implications and what would lie ahead. I agreed to try the last option available to me, which was the Humira injection - I figured I had nothing to lose and if it didn't work for me then at least I knew I'd exhausted every possible alternative.

The positive effect of the Humira was a slow burner, rather than being a radical overnight change it took several months to see that slowly things were settling down - my blood counts became more normal, I no longer needed iron supplements, my fatigue levels became more manageable and my last colonoscopy was completely normal. I have also managed to reduce my tablet load to 2 mezovant per day with one injection per fortnight, I stopped taking steroids 13 months ago too.

I have done a lot of work on improving my health and fitness levels, I have lost over 1.5 stone in weight and now exercise daily. I am careful with my diet, but can eat more or less normally without any problems.

Individual submission forwarded via Crohn's and Colitis UK

NICEMTA008 (cont'd..)

I really feel that I have been given my life back with Humira - without it I would have been subjected to surgery by now and would either be living with am ileostomy or may possibly have had more surgery to reconnect my colon or what was left of it. This is incredibly invasive with an extended recovery period each time, which would have a massive impact on my life and my relationship with my partner and family.

I do not currently have children as my health previously was always so poor I doubted my ability to fall pregnant or be able to maintain a pregnancy, never mind get through a birth and be able to look after a newborn while trying to get my UC under control again. Surgery would have a major negative impact on whatever fertility levels I have left after years of toxic medications. Now that my health has improved and stabilised, I am hoping to be able to start a family in the near future, a position I don't think I would be in if I had been denied the opportunity to try Humira.

I understand that this may not be a long term fix for all patients, but it has made a massive difference to my health and enabled me to get stronger and fitter for whatever lies ahead - if my future involves surgery after all then I am a stronger, fitter person now and better able to cope with the recovery than I would have been a couple of years ago before I started on Humira.

I would like to see a faster route for patients to treatments such as infliximab and humira, as the current conventional treatments are hit-and-miss at best and quite often have side effects worse than the symptoms already being experienced. I know I personally spent years feeling like I was being fobbed off each time there was a medication change, frequently being put on the highest dosage allowed only for it not to work effectively for me and then have to go onto the next thing - each time having to endure this for a minimum 6 months each time so that the drug could build up in my system before its effectiveness could be properly measured. The drugs currently used for conventional treatment have extreme side effects and in some cases are used for cancer treatment and chemotherapy, so they are in a very different league entirely to popping a couple of paracetomol.

If Humira was no longer available on the NHS, I would not be able to continue taking this treatment and would have to again suffer the slow decline of my UC. This would lead to surgery which would mean I would be reliant on my partner and family for an extended period as I would not be able work, I would also be unable to pay my mortgage or bills and would be reliant on benefits while recuperating. It is unlikely I would be able to fulfil my dream of having a family of my own.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA009

I am age 33, and I was diagnosed with colitis aged 20. I now have an amazing career, a loving fiancé, a really nice kind family and I also have my health. However, at age 20, little did I know of the roller coaster of events that would follow, and I am glad of that!

I was diagnosed with colitis whilst completing a year placement as part of my degree, where I was working away from home. The first symptom was complete overwhelming tiredness. Then I noticed blood on the toilet roll. I went to see the doctor twice where I was accused of having had anal s*x! He said he would refer me to a surgeon, but the referral never came through in 6 months despite me going back to see him. Clearly not a clued up doctor about such a serious illness.

I then went back to my university town doctor in Lancaster, and they were a lot more clued up. They sent me straight to see a gastro consultant in Lancaster hospital, and on the spot I was told I had proctitis. Things quickly got worse in that year though and I ended up on steroids as I was bleeding quite heavily. I needed an extension to complete my dissertation whilst at university - I was very lucky as university obliged, and I still came out with a first class degree and I then landed my dream job at KPMG. However, after not having worked there for too long, I unfortunately ended up in hospital back up in Lancaster as the doctor in London thought it would be nicer for me to be nearer to home. He always told me I was such a pale girl and always looked so unwell and that he was very concerned if I would not admit myself into hospital.

Whilst in hospital, the steroid experience was awful for me. I had hallucinations in hospital and then there was extreme mood swings from a complete lack of sleep. I probably slept about only 10 hours in over a month. I was shaking and then laughing uncontrollably and then crying at nothing. What a really horrible experience and I don't know why it affected me so badly, the doctors seemed to shrug it off as steroid mania! I also lost my memory, to the point, I never have felt it has come back completely. Again I was lucky, as KPMG treated my very well and I went back to work on a phased return. However, due to my medication which was azathioprine, asacol and steroids again at the time, my head was literally falling onto the table with tiredness. I decided to relocate to Manchester office back home so I could be with my family and be well looked after.

I struggled on for about 6 more years and was bleeding heavily each day and was completely exhausted but was managed as an out-patient of Blackburn hospital, perhaps inappropriately at this time. I studied in nutritional therapy, paid for acupuncture, homeopathy, all sorts of probiotics from America, and had all kinds of other therapies desperate to get better, spending a large part of my wage on this, well into several thousands of pounds. However, after a trip to Mexico and contracting Salmonella, then I was severely ill. I ended up in intensive care and was told by then my colon was affected the whole way round. I was too poorly to even have a colonoscopy as the doctors feared my colon would rupture. I had a sigmoid scope and was not allowed sedation as I was so poorly, and surgery was on the cards, but I was lucky I just escaped. My mum, dad and I had to literally beg the surgeon not to do it, we said I wasn't married, and too young to have this happen. I was very unwell though at this point at 7 stone, 12 pounds, and I had formed a large abscess that needed to be drained and peritonitis to go with it from what the doctor described as a small rupture.

Thereafter, I still wasn't well, I also came down with C Diff, and the days in work and the embarrassment of having to permanently sneak about and run to the toilet, mid-way through meetings was extremely embarrassing. I also remember numerous accidents in the car, literally

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA009 (cont'd..)

walking into work etc. Despite all this, I still worked full time in a pressured job, and had moved to Deloitte. I didn't want the illness to stop my career.

However, I then became ill again, going to the toilet once more over 30 times per day, and this time, having just bought my first apartment, I ended up in hospital in Manchester. I had a bath the morning before I went to A&E, knowing what would likely happen, but hoping that because things were so severe perhaps it was C Diff again, and could they just check that out, as I didn't feel I could have more time off work in hospital again? I said to who became my new consultant at the time, I cannot stay in hospital; I am working on an important job. He told me I had to stay in because if not my colon would rupture and I would be in surgery, and I was potentially only hours away from that.

I stayed in hospital for 2 weeks and again went through my 3rd horrific steroid experience with all the emotions and memory loss that went with it once again. I also got terrible depression once I got out of hospital and didn't care for my job or much else. Totally off character for me, and certainly a side effect of the drugs needed to get me better. The positive however, was that the consultant told me they couldn't be sure if I had Crohn's or colitis, but that they had a drug that would likely cure me of my illness, infliximab. I cried my eyes out in hospital, reflecting on the last 10 years and how ill I had been and wondering why the other hospitals hadn't helped me to get better.

I am now 2.5 years on from that experience. I have met my wonderful fiancé, who would now put up with me even if I did have to have the dreaded operation. However, had he met me prior to that, maybe it sounds superficial, but he probably would have not been with me. We have a wonderful new home, 2 kittens, and as you will guess, I also have my health. I couldn't be more grateful to the wonderful consultants at Manchester Royal Infirmary who have literally changed my life. I spent the last 18 months on secondment to Barclays, where I was able to sit through 3 or 4 hour meetings without going to the toilet. I would not have been able to do this before infliximab and it would have been one of the most embarrassing parts of my career ever had that not been the case, as I was working closely with one case director every day that would have spotted this happening, and I wouldn't have been able to hide it at this point. There is no blood now and I am so grateful for this. I am still extremely tired, but I can cope with that, I mean I have everything else at least for now. I do sometimes fear my illness coming back, but I know that whilst on infliximab this appears unlikely given I have been well for so long. This also means I contribute a significant amount in taxes, as I earn more than £80k so hopefully I am at least doing my bit for the NHS in this manner, and who knows maybe I will move on to more that will mean I can continue to contribute even more. I don't think this would have been at all possible had I had surgery, and I also don't think I would have met the man I am marrying too. Decisions as immense as considering to remove infliximab from those who really need it should be considered with this context and thought. How from the above can you possibly even believe it might not work?

I know a friend who had surgery who suffers with her confidence terribly. She is my year at school and was born the day after me. She is single and is still very unwell with pouchitis and also overwhelming tiredness. Perhaps I got lucky by the nature of the consultant and the drug he gave to me but I do believe this serves as a stark contrast.

Please, do not take this drug away from me, or from those that need it most.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA010

I was diagnosed with UC at the age of 60, which had a huge impact on my life. I was treated with Mesalazine from the onset which eventually controlled the disease, but not before I experienced the stress and inconvenience of urgently visiting the toilet between 9 - 13 times before midday, watching everything I consumed for anything that might trigger, or cause the condition to worsen. This resulted in huge weight loss, weakness and fatigue, not to mention complete loss in control of my life. I was given anti depressants as I was off work and unable to return until a suitable hours/post was found 14 months later!

I do not have firsthand experience of the drugs in question, but I cannot emphasise enough the devastation that this disease causes and my heart goes out to those who are diagnosed at a far younger age. People do not choose to take these medications, but without them they lead difficult lives and make exceptionally hard choices on a daily basis. The effect on other family members, loss of job/earnings and the general taboo from other sources cannot be under estimated, nor the impact it has on individuals.

NICE should ask themselves how they would feel if a drug that allowed near normal lifestyle, such as work, leisure, taking a holiday, or a day's outing was removed.

Please support those effected and allow them to lead as normal a life as possible; they are usually determined to work and do not want to be supported by the British tax payer.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA011

I had 3 loading doses of infliximab back in early 2014 to control a severe flare up of UC and to prevent further surgery. I had a subtotal colectomy and ileostomy formation last year. It worked brilliantly and I was amazed at my quality of life! For the first time in ages, I felt 'normal'. Then the funding ran out. Unfortunately, I received no further funding despite my consultants and IBD team's best efforts. I've been keen to avoid further surgery as it carries the risk of infertility amount other things. Finally, 3 or 4 months after my last dose, I was in one of my worst flare ups and stayed in hospital for 12 days. I was having reactions to azathioprine and 6MP and we'd tried everything else. Doctors somehow managed to secure a further 3 doses but there was no point. Being off it so long gave my body the chance to start fighting it and it's no longer so effective. I was absolutely gutted. I'm now scheduled to have surgery to remove my rectal stump in less than 2 weeks and it's awful knowing that it could have been avoided. Of course, I'd like to have children one day, but I'm not sure I'll be able to accept it if things go wrong, especially knowing that all this could have been avoided. My surgeon also wasn't keen to operate at first. I'm bleeding so much - up to 4 or 5 times a day. I'm exhausted and can't leave the house for days. I'm having severe anxiety issues and I think that it could have been so much easier had I been allocated more funding rather than being to feel so worthless.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA012

I am a male UC patient, diagnosed 10 years ago when I was 50 years old. At that time I was living and working in the USA and for the first 4/5 years the occasional flare-up was treated successfully with prednisone. In 2010 the prednisone stopped being fully successful and the condition worsened to the point that I was admitted to the MAYO clinic in Jacksonville Florida for treatment. I had been taking Asacol regularly and the treatment was changed to Azathioprine, unfortunately I was immediately ill and the Azathioprine stopped. My work entailed a great deal of international travel and any form of transfusion products would be difficult.

Fortunately Humira had just been approved as a medication for Ulcerative Colitis by the major US insurance companies and I started the treatment with great success, no side effects and very easy to travel with the medicine in a cold bag.

In 2012 I returned to the UK and was unable to continue with the Humira and immediately became ill. I have had 2 colonoscopies on the NHS, a five day stay in hospital and am still experiencing flare-ups which never really get cured.

I am an extremely active 60 year old and am not ready for surgery, It would be good if Humira was made available for UC in the UK.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA013

I have suffered with ulcerative colitis for five years and my father had had the condition for over twenty years. My Father's UC never responded to conventional therapies resulting in him having to undergo an ileostomy 15 years ago. With the benefit of hindsight he feels that this decision was made to quickly and without proper consultation and understanding. As a result of this surgery my father had to take on a less demanding job eventually resulting in early retirement through poor health due to an infection. His surgery also resulted in marriage difficulties.

My condition in comparison has been controlled using medication. It has taken a period of approximately 2-3 years to get my UC properly under control. The medication that I use enables me to maintain a career as a professional engineer including foreign travel and contribute to society and pay my National Insurance contributions. I persevered with azathioprine but eventually had to stop it because of sickness. I was lucky again after many months of perseverance a concoction of drugs held my condition at bay. This was almost my last chance at treatment but it kept me positive when my consultant said there was infliximab, adalimumab and golimumab. Clearly the National Health only use these drugs as a very last resort and sparingly. In my experience they are a better alternative to surgery especially with regard to quality of life.
After witnessing the negative effect of surgery on my father's life I would avoid surgery at all cost in favour of any medication.

I also have a work colleague whose partner works as a professional for a leading pharmaceutical company who uses infliximab. She lives a great life and is the life and soul of every social function thanks to infliximab. She suffers no negative side effects.

I think it is morally wrong to compare surgery to drug treatment purely on commercial levels; everybody should have the basic right of the best available quality of life. Even after surgery my Father has suffered from numerous infections and has had problems with his bags. This has resulted in him no longer travelling abroad and is reluctant to visit all but the closest family members.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA014

Following years of misdiagnosis from our GP and getting progressively worse my husband was in and out of hospital all year for treatment to get this condition under see control.

He was on a number of different drugs and nothing was working. He was so ill and as his wife and with our small child life was extremely difficult and upsetting. It wasn't until he was finally given (and not given lightly) infliximab that his quality of life improved by getting it under control. Sadly his condition was already so bad after being left for so long he had to have the surgery a year later. However it was a respite miracle for our little family after he had this drug. He wasn't able to take it again as second time around he had a bad reaction to it. However it completely eased his pain and suffering for a good amount of time. This is more valuable than anything and it saddens me to think others may not get its help.

I know it's expensive but if the people making the decision to withdraw it could really see and understand the relief and control it gives for the sufferer and their families they wouldn't withdraw it.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA015

I was diagnosed with this condition in April 2009 and with the exception for two periods of remission I have been continually unwell since then and my life has become almost unbearable. I have 3 children aged 6, 4 and 2 and my family live 240 miles away in North Yorkshire which means that the help they are able to afford me is very limited.

My day to day life involves driving my eldest child to school as I can't walk the ½ mile there as I wouldn't make it without needing the toilet. I then I have to drive a further ¼ mile to my 2nd child's pre-school, again for the fear that I would need the toilet as I have less than 10 seconds from needing to go before I do actually open my bowels. At least if I'm in the car I can drive straight home if the worst does happen. I then stay at home with my 2 year old before I have to pick up my pre-schooler. While my youngest sleeps after lunch I put on the TV for my middle child so I can try and have a nap on the sofa as I am so badly anaemic I can't stay awake. The school pick up follows and then I drive straight home again.

I can't take my children to the park, for a walk or play date or any of the other simple things that I used to take for granted. I do nearly all my grocery shopping on line and I cannot visit any shop that doesn't have a car park and a toilet on-site. This makes buying things such as a birthday card or school shoes nearly impossible unless I buy them from the local supermarket. It goes without saying that I do not have any kind of social life myself as it is simply not possible for me to go out when I may need to open my bowels with no warning. My relationship with my husband is also under a lot of pressure for obvious reasons.

I am 35 years old and feel like an old woman. Instead of being in the prime of my life, my world has become so small due to this horrific disease and therefore so have the lives of my children. The constant tiredness and the mood swings caused by all the steroids I take have made me a pretty poor mum. Recently my 2 year old son had to have an operation and I was too ill to stay with him in hospital overnight. It broke my heart. I want to get a job, enjoy my children and just start living again.

I have tried Mezevant XL, Pentasa, Steroid enemas, Non-steroid enemas, suppositories, Methotrexate, Azothioprin, Prednisolone

After receiving Humira during my recent admission to UCLH my life changed dramatically and thankfully the timing couldn't have been better as I have been able to lead a normal life during the school holidays. When I say 'normal life', I do actually mean normal in terms of park trips, picnics and going out for a coffee rather than anything out of the ordinary but it has been amazing. I feel like a huge weight has been lifted off my shoulders and it feels fantastic. When I am unwell the constant anaemia make everyday life feel like wading through treacle, the pain can be crippling. The very real concern of faecal incontinence gives me physical symptoms of stress as well as affecting me emotionally and mentally. The isolation I have felt has been over-whelming.

While I am still well currently, I have noticed some small changes which in the past have been the start of a flare up. I count every single day that I lead a normal life as a blessing and a bonus and I am asking you from the bottom of my heart to re-consider your decision to decline further funding. I do understand that Humira hasn't been approved by NICE for my condition and know that you have every right to turn me down. I also fully understand that there has to be a cost / benefit ratio but considering the amazing response I have had to the initial doses and the cost involved in a hospital admission (I have been admitted to hospital at least 7 times) I believe my case may be exceptional.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA016

I have had Ulcerative Colitis for the past eleven years and have been treated for my condition in many ways including drugs, infusions, enemas and injections. I have had quite a few serious flare ups over the years.

These flare ups make me feel quite ill needing the toilet many times a day and leaving me tired and weak. This does have a negative effect on my family and my ability to work.
I was first treated using anti inflammatory drugs and later steroids. The steroids do help to clear the flare up but inevitably I become steroid dependant and when the dose is reduced the flare up returns. It has taken up to two years to get off the steroids without a flare up.

In the first instance I was treated privately on my medical insurance but latterly I have been treated on the NHS. I have only praise for the treatment I have received.

I have been prescribed azathioprine but reacted against this drug. I also tried infliximab infusions but I developed antibodies and had to stop this treatment.

Steroids have been prescribed in my latest flare and I have been able to reduce the dose to almost nothing with the help of Humera injections every two weeks.
I am not happy about the effect of long term use of steroids on my body and am pleased to be on a low dose.

Obviously I would prefer to take medication to deal with my Ulcerative Colitis but am concerned that if I am unable to continue with my injections I may face surgery in the future which I want to avoid.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA017

Since I was diagnosed with UC in 2008, I have found that I am completely intolerant to mesalazine (suffering every side effect possible) and have struggled to contain my UC with azathioprine and topical steroids. The latest treatment I tried was alicaforsen and this had no effect whatsoever. Withdrawing drugs like Infliximab takes me one step closer to surgery which I dread so please do not take away such opportunities when there are success stories out there to show that it can work.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA018

My fiancé suffers from severe UC. It began in her early 20's and had plagued her for a decade before she was offered Infliximab. This was a decade that was nothing less than a nightmare.

My fiancé is an intelligent girl. She worked hard at school and later at university, achieving a first class degree and masters. This achievement is all the more impressive considering that she would be running to the toilet some 20-30 times a day, without warning, to pass blood.

This was pretty much the theme for my fiancé's 20's, a time that should have been spent enjoying life. It was a very difficult period in her life and her general health was atrocious, with her ending up in intensive care twice and spending weeks in hospital.

Please try and understand how hard life would be if at any time and without warning, on a regular day, you could find yourself seconds away from involuntarily passing blood from your back passage. You could be anywhere, at work, out shopping, on a plane, anywhere! This was my fiancé's life for a decade, not a nice thing to happen to a young girl, a very nice young at that.

One day my fiancé was laying in a hospital bed, completely fed up, surrounded by doctors who were drawing pictures of her colon on a whiteboard and telling her she was going to surgery to have it removed, and would have to carry a bag with her for the rest of her life. Her parents begged the doctors for an alternative and it was decided that the one last option that remained would be given a chance but if it failed surgery would go ahead. This last option was Infliximab.

Infliximab worked. For the first time in just over ten years my fiancé's symptoms ceased. She could go out without fear, she could do the most basic things in life that other people take for granted. She was cured. There were a lot of tears, all of joy and not only from my fiancé, but from her whole family and friends. Everyone breathed a massive sigh of relief and said a prayer of thanks for this miracle.

My fiancé is a good person, she has a heart of gold and deserves this chance of a better life. There is no price you can put on the happiness she had found in Infliximab, each visit to receive her infusion is its own miracle.

I know the country has a deficit. I know cuts are required and we all need to make small sacrifices, but please, please let's keep the sacrifices that we all make small, let's not take the second chance at life away from people like my fiancé.

I am begging you. You can email me, I will come to your home and get down on my knees and kiss your feet. Please, for the love of everything sacred in this world, please don't take Infliximab away from my fiancé. She didn't deserve to have UC, she didn't deserve the years of ill health and the embarrassment that would often come with it. Please don't send her back there. Please!

I have no idea who you are or what your circumstances are, and I am very grateful that you have read this email, but if you could just do one last thing for me. Imagine that my fiancé is your daughter, that she is your little girl. It's a cruel and desperate request but please just imagine that she was your own blood and ask yourself then if Infliximab is worth the cost.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA019

I was diagnosed with Ulcerative Colitis (UC) in 1997 and later diagnosed with Primary Sclerosing Cholangitis(PSC) in 2010.

In order to manage my UC, I have been prescribed a number of medications over the years. From that age of 7-18, I had been prescribed Sulphasalazine and numerous courses of both oral and rectal steroids in an attempt to manage symptoms and to prevent subsequent flares.
I was teased at school, mainly name calling, which I guess was my first experience of "but you don't look sick" and I relied heavily on my parents throughout school years, often reluctant to socialise with my peers due to a fear of not knowing where my nearest toilet would be, coupled with a fear of not making it to the toilet in time. After contracting noravirus in January 2008, my UC flared to the point where I was unable to walk the 15-20minutes it took for me to get to school due to crippling stomach pains and excessive diarrhoea.

After a course of steroids was unable to control my symptoms, I was commenced on Mercaptopurine in August 2008 and I appeared to respond well, although in April 2008 I started to experience flu like symptoms and in May 2009 I was admitted to hospital with neutropenia sepsis, due to the mercaptopurine.

At this point I was prescribed mezevant XL 2.8g with a course of steroids and I started to respond well and managed to reduce my steroids by 5mg on a weekly basis until the course was finished. I required an increase of my mezevant XL due to personal stress causing a flare of my UC and I also required another course of steroids at this time. Over the years I have become dependent upon steroids, whether it be prednisolone or budoneside. Since 2008, I have only managed a period of 6months being steroid free, but even then, I still suffered the side effects (moon face, mood swings, acne), which left me with low self esteem and low confidence.

In December 2013, I suffered another flare and was commenced on steroids once more. In April 2014, I required a course of rectal steroids to better manage my inflammation, but by May/June 2014, I was still losing a lot of blood and experiencing chronic diarrhoea and at this point Infliximab was discussed as a possible course of treatment.

Since December 2013, I have been in regular contact with my IBD nurse and in July 2014, she requested hospital admission, where I was given an IV course of steroids, however this started to affect my mental health and after discussion with my consultant, this was stopped an oral steroids commenced again.

I was granted approval for Infliximab on August 1st 2014 and had my infusion on August 7th. It wasn't until I received my second dose on August 21st that I started to notice an improvement, I was no longer experiencing blood or mucus with my bowel movements and I noticed that I started to have more energy, for a period of time, I couldn't stand for more than 5minutes without being in excruciating pain.

I do notice that for 3-5 days before I'm due an infusion, my symptoms reoccur, however once I have my infusion, these quickly settle and I find I'm not as fearful to socialise with my peers. Family, friends and colleagues have commented on how well I look compared to before my admission, and I believe Infliximab has been responsible for this marked improvement.
I'm aware that surgery is in my future, but given the low self esteem and low confidence I have experienced over the 17yrs, I'm psychologically prepared for it and I find Infliximab is less invasive and allows me to get on with my life as fully as possible.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA020

My daughter was diagnosed with moderate ulcerative colitis more than two years ago, and had symptoms for at least two years prior to the diagnosis being made. As the disease developed, she was given various medications to help manage her condition. Until May this year (2014) the medication she was taking did not really work. With constant flare ups of her disease and effective control through azathiaprine, asacol and steroids not working, my daughter at the age of 15 - just before her GCSE exams - was offered infliximab as her ulcerative colitis had become steroid dependent. The centre where my daughter is receiving treatment did not enter into this course of action without assessing the chances of success, and having carried out their analysis, it was deemed that my daughter was a good candidate for having infliximab which would continue to be effective after a year of use.

Since having regular infusions of infliximab the impact on my daughter's day to day living has been a revalation. Not only does she now look more normal as she doesn't have the side effects from the steroids, she has stabilised her weight and has been able to attend school regularly. Prior to her infliximab infusions she had extended periods of time away from school which isolated her from her peer group and had a very negative impact on her self esteem and her ability to maximize her potential in her school work. My daughter was a very sporty child before diagnosis, however, since her diagnosis her engagement in sporting activity has been hugely reduced - that is until now and since she has been on infliximab. My daughter is now able to participate in sport like any other child at her school, and this has had a very positive effect on her. Now my daughter comes home from school tired because she has been active, not because she is exhausted from just having her disease.

There are also other benefits of having infliximab, which includes the potential healing properties of this biologic medication. It is clear to me that the possibility of healing is worth the price regardless of the cost at present. I am aware that infliximab (Remicade) is soon to come out of patent, and as this is the case the cost will become significantly cheaper as biosimilars will be made available. At present the cost is high, but this will change. NICE could decide to allow this drug to be prescribed on the NHS, or they could settle for a cost over quality of life decision and push my daughter towards a life away from school, away from work, needing unplanned hospital admissions, the potential for huge cost to the NHS and potentially other government departments for decades to come.

Without infliximab there will be a direct impact on the quality of life for my daughter and for me as a parent. I have also had to take extended time off work to care for my daughter, but since she has been on the infliximab the only time I needed to take off are when she has a pre-planned hospital appointment. Discussions have been had between my daughter, consultant and me as a parent about the possibility of surgery. Due to the nature of my daughter's particular ulcerative colitis, any surgery would involve complete removal of her rectum and would result in her lifelong need for an ostomy bag. Surgery is NOT the answer for everyone, and presently as the use of infliximab has been so effective, my daughter and family were devastated by the news that infliximab may be withdrawn for her to use.

I sincerely hope that you reverse your decision and continue to allow this life changing drug to be made available to patients through the NHS when it is appropriate to have it prescribed.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA021

I was diagnosed in December 2009 with UC and became poorly very quickly. I was put on Balsalaside with no luck then several courses of steroids which was a terrible experience, I gained do much weight was agitated all the time and had no peace of mind. Following this the next step was to go on azathioprine which was tried for several months with still no ease from my symptoms.

During this time my quality of life changed dramatically. I found it difficult to hold down my full time job and by the time the weekend came I was so exhausted from the visits to the loo, to working and at times having accidents that I could not leave the house and at times I couldn't even manage to get out of bed. I would go as far to say that I absolutely no life at all. This condition had a huge impact on my family too, I couldn't go on holiday or days out with them and they were so worried.

My consultant then decided to put me on infliximab and this had been life changing for me. I have my life back and I can't tell you how happy that has made me and my family. Infliximab got me well enough that I could start and eat healthy and exercise to the point where I have lost 9 stone I'm fitter and healthier I have ever been and my UC is in remission and I will be stopping infliximab soon. I had been facing surgery at the beginning of the year and now I no longer need this.

This drug in UC is life changing, life saving and a life line to patients like me.

Please do not take this option away from suffers.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA022

I would like you to consider my reason for asking for Infliximab to continue to be funded by the NHS for the treatment of Ulcerative Colitis.

I was offered Infliximab in March 2010 after suffering for 18 years with active Ulcerative Colitis (with frequent hospital stays during this period) and with steroid treatment eventually failing to keep the condition under control. Surgery was looking to be a very real option (but not my preferred option).

My life has changed dramatically since being on Infliximab. I now lead a normal life, much like anyone else – I am able to work, plan holidays, participate in family life (I have been able to attend both my children's graduations) something prior to Infliximab would have been very unlikely. I don't even think about my UC now – what a fantastic result.

My family and friends tell me all the time how well I look, and I agree, I do. I haven't felt this well in years. I am eternally grateful that I was offered Infliximab and I truly hope that in the future all my fellow sufferers have the same opportunity.

Prior to March 2010 I was on and off of steroids for 18 years with the resulting side-effects – loss of bone density, weight gain, mood-swings, hair loss. I have also been on Azathioprine, Alendronic Acid, Calcichew, foam enemas. I currently take Salazapyrin which I have been on since diagnosis.

I often read (and hear) the expression "living with UC". I would like to stress that this is not an accurate statement. I would prefer to say that "I existed with UC". When I was first diagnosed in 1992 my children were 4 and 2 years old. When I look back I cannot even begin to imagine how I coped with family life. During flare-ups it was very difficult to even leave the house to take the children to nursery school. I knew where every public WC was located and quite often had to stop 3-4 times on the 10 minute journey to use the toilet (and many times without success) and having to return home to change. My children certainly did not see the best of me during their growing up years. I missed many a school play or sports day. UC did affect my whole family – not just me.

I would like to continue on Infliximab treatment as I am living and enjoying my life. I do not want to go back to where I was in 1992.

Thank you for taking the time to read a brief insight into my story prior to 2010. I have given you a very short edited version of events – if I had gone into much more detail it would have turned into a book!

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA023

I suffer from the debilitating condition ulcerative colitis. I am being treated with azathioprine (3 tablets daily), asacol (12 tablets daily), predfoam (2 enemas daily), omeprazole (2 tablets daily), ferrous sulphate (1 tablet daily), adcal (2 tablets daily). I also take Macrogel laxatives, eat very healthily, have acupuncture and pay attention to my physical fitness.

Try as I might, thus far, I have not been able to stop my rectum ulcerating. I have worked hard at getting my colon under control (it was previously fully ulcerated), with some result. I have had one colonoscopy this year and am due for another one shortly to ascertain if the increase in azathioprine tablets has been useful to stopping the ulceration in the colon.

If the azathioprine does not halt the ulceration of the rectum, my next step will be Humira. To read that this next step may potentially be denied me is very stressful and not conducive to the management of my condition. Presumably, if Humira is not an option the NHS wishes to offer those suffering from ulcerative colitis, then one must assume they are promoting the use of surgery and colostomy bags and the attendant issues associated with these. This seems to be short-sighted.

One wonders how much pain and suffering an individual has to experience before being allowed to have Humira. Those with serious ulcerative colitis can tell you that without drug therapy, they would not be able to function. Leaving the house is taken with trepidation. The constant loss of blood causes serious iron deficiency which is very hard to cope with. Administering foam enema to an already ulcerated area, or indeed, having an examination, is not for the faint-hearted, believe me.

I would request that you submit my views to NICE

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA024

I am a 36 year old Palliative Care Nurse. I have three children age 4, 6 and 7. I have worked hard all my life, working many additional unpaid hours in the NHS, and I would feel very let down if NICE make the decision to take this drug away from me and advise that for people in my situation this drug cannot be a cost effective option. My life would not be worth living if I had continued with the severity of my symptoms before infliximab was prescribed. This disease uncontrolled without infliximab impacts all aspects of my life. Physically the symptoms of UC are well documented so I don't feel in need to describe them they are horrific. Socially before I had infliximab I was isolated, couldn't leave the house, at times was too unwell to care for my children and an enormous strain was put on my marriage. Financially I couldn't work, this disease has cost me thousands of pounds in loss of earnings, childcare, loss of holidays, hospital parking (£10-15 a time often weekly), petrol to travel an hour to and from hospital etc. Mentally this disease and treatment has also been very hard to manage and the fatigue and pain was unbearable. I could not have managed life as it was without infliximab. It's had enabled me to live a normal life again.

This is my medical history with UC.

In January this year I was diagnosed with severe ulcerative colitis. This became severe as I had been going to the GP for three years with symptoms but it took that long to get diagnosis and treatment. I have been very unwell. This year I have been in and out of hospital and could have died as a result of errors and poor care that I received in the NHS. Finally after becoming very unwell as an inpatient the Clinical Director took over my care for which I am so grateful. Things started to improve for me. I have had every drug for ulcerative colitis and suffered the side effects that come with them with little improvement in my disease. I spent 9 months so unwell at times that I couldn't even care for my children and was too weak to walk across the room. My hair has fallen out in clumps due to this illness and the medications I have been on. Socially it is isolating and I have not been able to go out with friends, go on holiday or have a good quality of life. I have been in agony with pains in my joints from the disease also causing inflammatory arthritis. In August after all other treatment failed my consultant started me on IV Infliximab. It has been life changing. The bleeding and abdominal pain stopped that day. Each day I have gone from strength to strength. I am able to care for my children again. I returned back to work last week as a Palliative Care Nurse and I am hoping that I will be well enough to go on my Christmas nights out! Without this drug I don't know where I would be as there is no way I could have carried on living life with the severity of my symptoms.

Please consider what I have taken time to write. I understand as I am a nurse, my husband is a consultant and my dad is a GP that the NHS is very strained financially. However for the few people that receive this drug when all other treatment has failed it can be life changing and life saving.

For the very small group of patients that require this drug in comparison to treatments for other diseases it can make a massive difference to peoples' lives. None of us asked for this disease, it is a humiliating, degrading, depressing disease to live with. Every day can be a battle as when the disease is active all aspects of life are affected; physically, socially and mentally. It is already a very frightening situation to be in as there is no cure or medication after Infliximimab if it stops working. There is a desperate need for more research, awareness and funding needed for this disease, not cost cutting for people who are genuinely suffering through no fault of their own. If funding for this medication is taken away then my disease will become severe again. I will be housebound, in agony and unable to work or care for my children again. This cannot and should

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA024 (cont'd..)

not happen, it has been a life saving drug for me and could be for other people in my situation. I am aware that is all my individual experience of infliximab and when evaluating cost effectiveness this is not the gold standard randomised control trail that would make a cost effective decision. But this is the problem with UC as there is many unknown areas of the disease care must remain individualised. The Clinician must be able to provide individualised care in managing UC to make their treatment successful and cost effective. There are drug tests available to predict which patients respond to which drugs. Surely developing this technology to predict which patients with UC will respond to Infliximab would be a more cost effective solution than advising it not to be used at all for UC. I am also aware of the argument that I could have radical surgery. Yes I could but that does not come without major risks, complications and long term costs for the individual and the NHS. It would also cure the gut symptoms but not the inflammatory arthritis and other symptoms that come with this disease. If there is a medication that can achieve and maintain remission for all their symptoms of the disease that makes it a cost effective treatment for that individual.

As a nurse I am aware of the cost of infliximab and have given it to many patients. I am therefore aware of the side effects and the limited response many people have from it, but this is not everyone. UC effects everyone very differently and care needs to be very individualised for it to be cost effective. I understand why there needs to be limitations on its use but it is still an essential IV drug that clinicians need to be able to make the decision for the individual patient whether to prescribe it or not.

Medications and treatment are not limited on the NHS for people who have influenced the development of their disease through lifestyle choices such as smoking, drinking and being overweight. I have no choice other than to receive treatment on the NHS as private healthcare will not insure me with this disease and as a nurse I could not afford to pay for my Infliximab. The cause of UC is unknown and multifactorial with various theories. Until a cure or treatment is developed further this is a cost effective drug to use in order to provide individualised care to patients. Please understand this and keep it as a drug that clinicians can still access for patients like myself as it has made every aspect of my life worth living again with obtaining and maintaining remission of my disease.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA025

At the age of 36, in 2003 I started having symptoms of rectal bleeding but no diagnosis was given at this point and nothing significant was thought of it by the GP or Gastroenterologist. By 2006 it was progressing and my GP put it down to haemorrhoids and tried to treat me for this. As they did not help I continued to consult him using the practises emergency system which he felt was not appropriate. I think he got fed up with me and referred me to a surgeon for banding thinking this would sort me out. The surgeon disagreed with the GP and gave the diagnosis of UC following a colonoscopy. I was devastated as I knew this was incurable and meant a lifetime of tablets, a restrictive diet and a restricted lifestyle.

I started with Mesalazine tablets and foam enemas. The tablet were fine but the foam enemas were very difficult and painful to use. I persevered as I was assured that using it everyday for 4 weeks will help. This was fine for a while, until I had my first most severe flare up which left me going to the loo almost every 10-15 minutes in debilitating pain and passing blood. When I described the pain to my wife she said that sounds like being in labour but with no desirable end in sight!

Thankfully my consultant was able to see me within a couple of days, and on having a brief look inside, said I have never seen you this bad before and immediately put me on prednisalone. Within just a few days I felt so much better and thought that this was the answer to my UC. So every time I had a flare up I was put on steroids, but a month after stopping I would flare up again and again. Soon the steroids lost their efficacy as I became steroid resistant and I was advised to start on Azathioprine. Knowing this would reduce my immune system I was reluctant as I work as an Optometrist and I am constantly exposed to many different members of the public who may have colds and flu etc. every day. But this was the next form of management open to me.

The azathioprine was very effective at the optimum dose for my weight but very quickly I began to suffer from Neutropenia and Leucocytopenia. Reducing the dose did not help me recover from this and a very low dose of the tablets failed to give relief. I was put on to 6-Mercaptopurine as this was a purer form of the drug, but I still suffered the same side effects.

After a whole year of being incredibly ill with severe pain and bleeding, funding for infliximab was pursued. I have been on this for a year now and my blood count have returned within the normal range and I no longer suffer from the debilitating pain and the loss of copious amounts of blood.

Up until I started the infliximab, for the period of 7 years using initial drug therapies, I was always having to hold back on social and physical activities, as an urgent need for a bathroom would have to be considered. I was having to restrict my diet as I found many foods would irritate my symptoms and cause a flare up. As a father of primary school aged children I was not able to set the examples they need to follow for a healthy active lifestyle. They very often missed out on the normal growing up fun things in life I could not do because I was physically unable to, like simply playing in the park or going to the cinema because I was in bed and having to run to the bathroom several time every hour. Holidays abroad or even in the UK was something very difficult to plan or even go on.

Physically, I had lost a lot of weight very quickly during flare ups. When on steroids however, my weight would increase rapidly but I would also get quite short tempered and aggressive and often took it out on my loved ones which I regretted later. I would feel helpless to control these side effects. When on the alternative Azathoprine and 6-MP, thankfully I did not get these side effects, but as mentioned above I would suffer a great loss of white blood cells and the time spent trying to juggle a therapeutic dose versus flaring was very draining and eventually unsuccessful. I was

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA025 (cont'd..)

always lacking in energy and found it very difficult to live a full days worth of activity, whether it was going to work or spending quality time with the family, after work or on weekends, with my young children who want their parent's time and attention. Emotionally it has been a roller coaster with severe times of depression, anger, lethargy, frustration and not feeling in control of myself, not being the father and husband I should be. Quite often my wife would have to work extra to make up for my time off sick. The kids were the ones that would lose out. This is all quite soul destroying.

As I have always been self employed and run my own Opticians, having time off sick is always unpaid. My staff have been understanding but being unable to develop my business not only impacts my earnings, but those I employ as well.

Stress I believe plays a part of every ones well being. I believe it does with UC also. Alternative therapies is always something I try look for in an effort to reduce my dependence on prescription drugs whatever the format. I have tried Yoga, Reiki, Acupuncture, Chinese Herbal Medicines, Various exclusion diets, Various supplements from Omega 3, Vitamin D, protein powders, Glutamines, Pro-biotics, colostrum..... Unfortunately there has not been any single or combination of alternative therapies that have eliminated the need for medication. I continue with the Omega 3s, Vitamin D and Pro-biotics as guided by my Gastroenterologist. I also continue with Yoga. But unfortunately they alone do not give sufficient relief from the symptoms of UC.

For the year I have been on Infliximab, I have not had any side effects, symptoms are greatly reduced, I have had an increase in energy levels, I can now eat a normal healthy diet with some variety to maintain a good balance, I am able to see out a full days activity without having to go to bed early before the kids, I am now able to give my time to others that are important in my life (ie my family). I can now give much better attention to my business and staff and have been able to develop my business and at the same time develop my staffs' own ambitions and career levels within my Opticians practise.

Another alternative to this treatment is surgery which I have heard some people have when drug therapy does not work.

Surgery would be a route I would NOT be willing to go down. Infliximab is working for me at present and there are still other drugs that can be tried well before surgery should be an option. My view on surgery is that it is a last case senario and if my actual life was dependant on it. If there was a drug that delays the need for surgery, I feel this should be offered as surgery is absolute and at present there is no method of "transplantation" surgery.

I hope this small breakdown of my experience is helpful. UC is on my mind almost every minute of the day. Infliximab has helped me to stop it being something that controls my life.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA026

I am writing on behalf of my 17 year old son (who I am hoping will also make his own personal submission).

David first became ill aged 12 in the summer of 2008 with persistent gastric symptoms: severe diarrhoea and abdominal pain which continued on and off for a number of months. Six months later, he was diagnosed with colitis and started taking Mesalazine based drugs to control the condition.

He had his first severe flare up in December 2010 which required hospitalisation for 3 weeks and treatment with steroidal drugs. He was placed on Azathioprine to try to control the incidence and severity of the flare ups as well as continuing with the Mesalazine. Exactly one year later, however, in December 2011, he had his second even more severe flare up which resulted in a period of hospitalisation of nearly four weeks. It was at this point that he first received Infliximab as an in-patient, an intensive course of four intravenous infusions and from this point on he has continued to receive Infliximab infusions every 8 weeks as a maintenance course.

Before Infliximab, he was at the mercy of frequent mild flare ups and annual severe flare ups of his UC. He was frequently in pain with very unpredictable bowel movements. On the physical side, he lost large amounts of weight and frequently missed schooling at a very critical stage in his life leading up to his GCSEs. There is no doubt that his academic performance at GCSE suffered as a result of the missed schooling and the perpetual fatigue. As a teenager struggling to cope with the physical effects of what was for him an extremely painful and debilitating illness, there were also manifold emotional and psychological impacts and at one point we employed the services of a psychologist to try to cope with the impacts of living with pain as a teenager trying to lead a normal life.

Since he has been receiving regular Infliximab infusions, it is no exaggeration to say that David's health has completely revolutionised, both physically and mentally. He has not had a flare up since his recovery from the last severe flare up in the winter of 2011/12. As a result, he has not taken steroids since and no longer suffers from the physical impact of these drugs. His weight has stabilised at a healthy level for someone of his size and age, and as the months (and years) progress, he can start to feel a little confident and optimistic that if he gets minor UC symptoms, which he does from time to time, things will not degenerate into a severe flare up requiring extended hospitalisation and treatment. This has had a major and positive impact on his confidence and psychological state and social interactions, meaning he believes that he can now lead a normal life as a teenager, which he could not do before. His schooling has also improved, and as David heads towards his A levels this coming summer, there is every reason to believe that he will be able to go to university, which was certainly not something that could have been considered prior to receiving infliximab Infusions. David has no known side effects from infliximab.

If David were no longer able to receive Infliximab at this stage of his life, we would be very concerned for his future health prognosis if history is regarded as the best predictor of the future. Infliximab allows my son to lead a normal, robust and healthy life for a teenager, and this is also the views held by his medical professionals at UCLH where he is treated.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA027

As a sufferer of ulcerative colitis who is treated with Infliximab, I am responding to your recommendation to withdraw Infliximab, Adalimumab and Golimumab for ulcerative colitis sufferers.

My Experience

Looking back, I believe that I have suffered from ulcerative colitis all of my adult life, but I was only diagnosed in my late thirties/early forties. I was a teacher, determined to do the very best for pupils in my care and consequently determined to be in work, even on days when I wasn't well. I managed to get by, taking Asacol and using Predsol Retention Enemas or Prednisolone Rectal Foam when necessary. During the last two years of my teaching career, the colitis flare ups were increasing in frequency and intensity. I was having to rush to the toilet several times a day, constantly worried that I may have to leave a class unattended, or suddenly leave a meeting with a parent, pupil or member of staff in my office (I was a deputy head), unable to explain the reason. I constantly fought the symptoms in order to maintain a professional, calm, authoritative appearance. At one stage, I was prescribed Prednisolone, but they did not seem to have any impact on my condition. I did, however, suffer side effects, (including a bloated face which made me feel awkward at work), my heart was racing making it impossible to sleep and I felt constantly tense and anxious.

I retired after 38 years of teaching at the age of 59. Unfortunately, my symptoms became even more severe. I started to lose a considerable amount of blood. I could barely eat and was terrified to leave the house in case I needed to rush to the toilet. I was having to constantly get up during the night and sometimes would have to return to the toilet as soon as I got back into bed. Following a colonoscopy, (I had had several before), the consultant prescribed a high dose of Prednisolone. Over the next few days, my condition deteriorated further and I was admitted to hospital for just under a week. It seems that my system was so badly inflamed that the steroids had not been able to have an impact. The high doses of intravaenous steroids I received in hospital gradually brought the condition under control. I had lost nearly a stone in weight (I only weighed just over 8 stones to begin with) and I had lost all my muscle tone throughout my whole body with the use of steroids. When I returned home, I could only walk up the stairs 1 step at a time with my husband's help and I was terrified of having a bath in case I couldn't get out. When I looked in the mirror, I did not recognise my body.

I started the long journey back to some kind of normal existence. I was on a high dose of Prednisolone with the same side effects as previously, but this time they did keep the colitis under control. The consultant advised that steroids could not be a long term treatment, and that I needed to gradually reduce the dose in order to start taking Azathioprine. Unfortunately, after a few weeks and an increase of dosage on Azathioprine, my condition started to deteriorate and I also started to have double vision. I was taken off Azathioprine and put back on Prednisolone whilst other medication was considered and tests were undertaken.

Just over two years ago, I started my Infliximab treatment. I cannot tell you the difference this has made to my, and consequently to my husband's, lives. Yes, I still have days when I am tired and need to rest and stay at home, but overall I can now lead a relatively normal life which is what I had been hoping for when I retired. I can go for some walks, ride my horse, meet friends and for the first time in years, we have just had a week's holiday abroad. I have recently volunteered to become a school governor and have expressed an interest in joining the patient reference group at my local medical centre. None of this would have been possible without the Infliximab treatments.

Individual submission forwarded via Crohn's and Colitis UK

NICEMTA027 (cont'd..)

I cannot contemplate what would happen if Infliximab were to be withheld from people with my condition. I understand considers surgery to be an alternative option. Who would want to undergo intrusive surgery with the associated risks and live with a colostomy bag when there are treatments which can prevent this? It appears that the decision to recommend this change is based on cost effectiveness. I also understand that patients receiving the treatments in question are often able to stop taking them after a few years. Surgery is a very unpalatable option. Surely, it is not a cheap option either. It certainly cannot be guaranteed as a "one off" with many people needing further surgery with all the aspects of after care and follow up.

I urge you to reconsider your recommendation.

Individual submission forwarded via Crohn's and Colitis UK

NICEMTA028

I have a sixteen year old son who was diagnosed with ulcerative colitis one year ago.

He had been experiencing severe diarrhoea for several months and following a flexible sigmoidoscopy and biopsies it was confirmed that he had ulcerative colitis and was commenced on pentasa 1g twice a day. His condition showed no signs of improvement with the pentasa and so he was started on pentasa enemas and eventually oral steroids.

His condition continued to deteriorate and he was now experiencing joint pains, anaemia, severe diarrhoea and severe weight loss. He was also being incontinent of faeces not only at home but also several times at school and was finding this extremely embarrassing and hard to deal with. Eventually he was so weak he had not even enough energy to get from the bed to the bathroom and had lost half a stone inside one week. This was extremely stressful and frightening for not only my son but the whole family, and we were very concerned about him. He was then admitted to hospital for a week of intravenous steroids and was also commenced on azathioprine 40mg and discharged home also on pentasa 1.5g and oral steroids.
His colitis settled for about six weeks while on the steroids and he started to put on weight again so his azathioprine was increased to 50mg a day.

As soon as he finished the course of steroids his symptoms flared up again. He was trying to study for his GSCE exams at this point and he was finding it extremely difficult being up during the night with diarrhoea and also having several episodes at school during the day as this was leaving him very tired and with no energy. After discussions with the consultant he decided to start the steroids again to get my son through this difficult period with as little added stress as possible. Once again his symptoms settled for about six weeks during the steroid therapy. It was still very stressful for him trying to sit his GSCE's, but also having the added fear of the possibility of needing to run out to the toilet during these important exams.

A few weeks after the steroids finished the symptoms started again. My son was having severe diarrhoea and passing a lot of blood in the toilet, which frightened him. We contacted his consultant and he increased his dose of azathioprine to 75mg and restarted the pentasa enemas. My son was unable to retain the enemas in his bowel so we had to try supposorties. My son found this very embarrassing at sixteen having to get supposorties inserted into his back passage. He was now up

at the toilet about ten times overnight and the same during the day leaving him very lethargic all the time. This is how he spent his summer holidays off school, having no confidence in going out anywhere due to his urgency of needing a toilet
constantly. I was going into work every day totally exhausted as I had had no sleep due to my son being up with diarrhoea every hour during the night, at times I don't know how we all kept functioning. It was extremely hard as a mother to reassure my son when he was sitting in the bathroom in the middle of the night crying that he was fed up couldn't take any more of this.

Once he was out playing golf with his dad and was incontinent and I had to bring a complete change of clothes. How do you think that made a sixteen year old boy feel! We have a family tent and normally go camping over the summer months, but we were unable to do so as my son could not have coped with having to go a distance to the toilets at a campsite. So he had a pretty miserable summer.

Individual submission forwarded via Crohn's and Colitis UK

NICEMTA028 (cont'd..)

As we live in a converted bungalow my son normally sleeps upstairs but the bathroom is downstairs, so to facilitate my son when he has been unwell his dad has slept upstairs to let our son be near the bathroom at night. So for about eight months out of the last year my husband and I have slept in separate beds, which added more stress to the whole situation.

After seeing the consultant my son went for an urgent endoscopy and was admitted directly to the ward following this for another week of intravenous flagyl and steroids. Thankfully the consultant said during this admission that my son couldn't go on like this anymore and that he was going to apply for funding for infliximab as the only other option at this stage for my son would have been surgery. We were not keen on surgery for our son at such a young age, so we were willing to try any other options available regardless of the side effects.
He had his first dose of infliximab during this hospital admission and started to notice a difference immediately when he went home, as he wasn't running to the toilet as many times as previously. Two weeks later he attended the IDB nurse for his second infliximab treatment and following this he was beginning to get a full night's sleep again, without being up at the toilet every hour. This meant he was able to move back upstairs to his own bedroom again. He was able to go back to school again without the fear and embarrassment of having to rush out of class to the toilet or even being incontinent with not making it in time.

Thankfully he has now been able to socialise again as a normal teenager should be, and able to stay for after school activities. He is now looking forward to a youth weekend away this Saturday, and feels he has got a life again.

He is going for his third dose of infliximab tomorrow and the only side effects he has had is nausea and headaches for a few days following the treatment, which is a small price to pay considering what he's been through over the past year.
Although my son had little side effects with conventional drug treatments, they just didn't do anything to help his ulcerative colitis and he was becoming steroid dependant which I didn't want at sixteen years of age.

I would like to think that if he had a relapse again that he would be able to be offered another course of infliximab, as we could not cope with going through all that again.

Infliximab studies have shown to bring on remission, promote healing and reduce the need for surgery in people in ulcerative colitis who were not responding to conventional therapy - so why change things.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA029

Our Son who is 15 years old has been injecting this every other week for the last 4 months. He is currently enjoying a symptom free existence and not experiencing a flare up.

He was first diagnosed with IBD when he was just 7 years old and has been on many, many different drugs which include several long term doses of steroids. These have at times affected him psychologically as well as affecting his joints severely for which, despite his real love of sport, he has had to be under a physiotherapist. He saw this same physio this week and he was extremely pleased with his improvement and asked if he was currently under control of his IBD too - when he replied yes, he said that they often go hand in hand.

We are so pleased with the positive results of Himura for our son and feel it would be devastating if he now, along with countless other patients, had to be stopped from his only drug option left before major surgery.

The argument over whether surgery or continuous use of Humira and similar drugs is cost effective does not take into account in any way the extreme psychological issues surrounding surgery of this nature. We do not want our **child** to undergo such surgery, with the known psychological issues that can occur, unless it was absolutely necessary from a medical view point and certainly **not** because there was not the funding available.

A child, who has yet to go into the next stage of life involving relationships etc should not be forced into this surgery at any cost and at the same time cannot be left with the embarrassing, extremely painful symptoms of this illness without these drugs being available to give them back a much needed improvement in their quality of life. Please seriously, reconsider this possible action and allow Humira and similar drugs to still be prescribed for UC patients!

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA030

I am a suffer of UC and have been for about 4 years. For the last year I have been on the treatment Infliximab and I can't praise it enough. It has been fantastic for me, made a huge difference to my life and I would struggle without it.

Before I had the treatment, I would be going to the toilet at least 4 or 5 times a day, always urgently i.e. having to run to get there in time. There were regular occurrences where I did make it and had to go through the trauma of pooing my self, then cleaning up and changing my clothes, all while trying to lead a normal life with a young family.
I would always being thinking where is the nearest toilet and can I get there in time, if I get the sudden urge to go to the toilet. I struggled to go out with my young family on my own in case I had to rush off. It was a rather unpleasant life to lead.
I have also suffered from flare ups and have off work for significant periods of time.

I was trying to manage my condition through pentasa and azathioprine, but they had a minimal effect on my condition. When I suffered the flare ups, I had to take steroids to get my condition under control. While they were effective in working, they had negative side effects on other aspects of my life, poor kidneys and bad steroid ache (from which I have suffered scaring). I believe my health would suffer badly if I had to continually use steroids to control my condition. The other option is surgery, which only something I would do if all other medication didn't work. It would take 2/3 operations, then I would require a stoma bag for the rest of my life, plus I would be off work for a long period of time. Surgery is not an option I would like to take when I know infliximab has such a positive effect on my condition.

Since I've been on the treatment Infliximab, my condition has changed dramatically! No more running to the toilet, no more watery/runny stools, no more pooing myself and no more thoughts about where is the nearest toilet! What a difference that has made, I can take my children to the cinema on my own or to the park. I can't praise this drug enough for the difference it has made in my life, please do not remove Infliximab as a treatment from the NHS, it works and changes mine and other peoples lives. I could understand removing it, if there were only minimal positive effects but as it makes such a positive impact, I would hope it is continued to be offered and funded by the NHS.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA031

I was diagnosed with Ulcerative Colitis in 2009, during that time I have suffered with flare ups of the disease with intermittent periods of remission. My experience of living with UC has been very difficult with symptoms including diarrhoea, extreme urgency when needing the toilet, passing blood in stool, stomach cramps, chronic tiredness, nausea and generally feeling unwell. I have also suffered with Anaemia due to ongoing blood loss which made me feel incredibly tired and unwell.

Living with Ulcerative Colitis has been very difficult and as a result would often make me feel isolated. I felt unable to go out into public places for fear of having an accident as I had no warning or control over my bowel movements. Also the fear of leaving home came from a lack of decent public toilet facilities and feeling uncomfortable going to the toilet in a public place. I found it difficult to maintain a social life, in particular going on holiday and travelling on public transport was impossible for the reasons given above.

Ulcerative Colitis has had an impact on my work life as I often wouldn't feel well enough to attend work, which in turn has affected my attendance record. Having discussed this with my line manager I was able to explain about the condition and appreciates the reasons for needing time off work. Luckily my work place has good toilet facilities and I am able to go whenever I need to, however part of my job includes going out of the work places which I was unable to do whilst having a flare up.

I was initially diagnosed with Proctitis in 2009 however the disease has got progressively worse with the flare ups and symptoms getting harder to control. I was subsequently diagnosed with Distal Colitis and Total Colitis as recent colonoscopies have shown extensive ulceration and inflammation affecting most of the bowel.

I was initially prescribed topical aminosalicylates which included anti-inflammatory and steroid foam enemas however these became ineffective and difficult to use as the lower part of my bowel was quite inflamed and I was unable to retain the fluid in my bowel. My next option was to try oral aminosalicylates including Sulfasalazine, Mesalazine, and Balsalazide. This type of medication seemed to control my symptoms initially but often didn't last long and I continued to suffer with repeated flare ups of UC.

Over the years as the disease has become increasingly difficult to bring under control and maintain periods of remission. I was prescribed oral corticosteroids (Prednisolone), which was effective and managed my symptoms well. I suffered many side effects however from this type of medication including weight gain, rounding of the face, sleep disturbance, anxiety and shaking hands, headache, nausea etc. I have had subsequent steroid treatment as symptoms began to return after a few months of remission. As steroid treatment was becoming ineffective my next alternative was to try Immunosuppressant's including Azathioprine and Mercaptopurine. Unfortunately I was unable to unable to tolerate this medication as it began to adversely affect my Liver Function.

After years of failed responses to a variety of medications I was considered for Infliximab Infusions. Initially I was quite worried about starting the treatment but the IBD nurse was very reassuring and provided me with lots of information about the medication and procedure. I have had three infusions so far and now attend clinic every eight weeks with the results looking promising. I have the infusion at my local hospital which approximately lasts 4-5 hours in total (for the first three infusions and less time thereafter). Whilst having the infusion I am monitored and made to feel at ease by the nurses.

Individual submission forwarded via Crohn's and Colitis UK

NICEMTA031 (cont'd..)

During the infusion I usually feel quite well however I do tend to develop a headache and I generally feel somewhat tired after the treatment, this often doesn't last long and in comparison to the side effects of other medication (in particular steroids) this is not very significant.

I have had a positive response to Infliximab and I feel the time taken to attend clinic for the infusion is well worth it. My line manager understands that I need time off work to attend clinic and appreciates that in the long run it will be beneficial as I hopefully maintain longer periods of remission.

In my experience Infliximab became effective within weeks of starting treatment and to date I have been relatively symptom free for approximately four months. For the first time in a long time I am able to go about my daily life without worry of having an accident. Generally I feel in good health and don't tire as easily as I used to, this has improved both my work and social life.

I appreciate that I have only had three infusions so far have a long way to go with my treatment but only time will tell if it is successful. In the short time that I have been on Infliximab it has had a big impact on my life. I feel it has given me my freedom back, I am able to go out and do simple things which I took for granted before.

With regards to surgery I think this is a big step to take and where possible I believe that other treatments should be tried in the first instance. Where drug treatments have continually failed to treat UC and where there is poor quality of life should surgery be explored. I believe surgery is essential for some in order to maintain a better quality of life where other treatments have failed. Ulcerative Colitis affects people in different ways and so is difficult to compare experiences, where one person may need surgery this may not be the right option another person.

I personally haven't had surgery and this would be a major decision to make. Having bowel surgery presents its own risks in terms of the procedure itself, recovery periods and adapting to a new way of life.

Before considering surgery I would prefer to explore other alternatives, only where there was no hope of success with other treatments or where symptoms where severely affecting quality of life would I consider this. Where drug treatment could possibly delay but not potentially avoid surgery I still believe that this would be beneficial to try. This may help in getting well enough in preparation for surgery and give time to help to come to terms with adapting to a new way of life.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA032

I have suffered with Ulcerative Colitis for 10 years. I am a 50 year old professional female. My symptoms gradually worsened over the years and I have tried every pill available from sulfasalazine to azathioprine to steroids, eventually becoming steroid resistant.

At this time, I was virtually housebound and needing the toilet up to 30 times a day and obviously unable to work. Fortunately, I was able to claim some sick pay from my employers at that time. It is fair to say that I had virtually no quality go life. It was impossible to leave the house for fear of having an accident.

It is hard for people to understand that as well as having an illness which makes you feel so poorly, the symptoms are something which make life unbearable and unable to do ANYTHING. Normal things like shopping, going to the hairdressers, dental appointments (which you may have to cancel and which then presents its own problems) are all put on hold. It puts a great burden on family and friends as you have to rely on others for so many things. It was at this time I was offered the chance to try Infliximab and what a change it has made to my life - I cannot tell you. It began to work almost immediately and has TRANSFORMED my life beyond belief. I have had NO time off sick from work in the last 5 years and have suffered no side effects whatsoever.

I now live what I consider to be a normal life, something which I never believed possible 5 years ago. I can work full-time, have not needed to claim any benefits and therefore am not a burden on society. If Infliximab was withdrawn, I am 100 per cent sure that my symptoms would return and I would be back to "square one". I would, therefore, respectfully request that you carefully consider your decision regarding the withdrawal of Infliximab for moderate to severe Ulcerative Colitis.
Thank you.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA033

I have had Proctitis since the 1990s. I went through all the usual simpler potential remedies (aminosalicylates etc) until I was put on prednisolone in 2001(tablets, foam suppositories) which gave me periods of relief. But I got no permanent relief until I heard of mercaptopurine and asked to be put on it. The result was I had no flare ups from April 2009 to January 2014 and was able to resume normal life. How restrictive of ordinary living my moderate and sometimes severe Ulcerative Colitis(Proctitis) had become was then absolutely clear.

Since January this year I have had four flare ups and it would seem I can no longer rely on sustained remission or lead a reasonably normal life.

Why a distinction should be made between Crohn's Disease and Ulcerative Colitis is beyond me.

Consequently I think NICE should make infliximab, adalimumab and golimumab available on the NHS to treat moderate to severe Ulcerative Colitis where all other remedies have failed.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA034

Since my wife has been treated with Infliximab, her health has been transformed. She no longer suffers flare-ups and has been able to enjoy a normal life, carrying out everyday tasks with confidence and without the continual fear of falling ill. This in turn has meant that our married life has returned to normal and removed the strain and anxiety that I had also been experiencing. Before being treated with Infliximab, my wife was so ill that I felt I needed to be close at hand at all times, as I was fearful for her health and well being. Since the Infliximab treatment, I have been able to return to work confident that my wife no longer requires constant support. Therefore, there is no doubt in my mind that the Infliximab has been, and continues to be, an effective treatment for my wife, and I am extremely concerned about the NICE recommendation.

I understand that where the Infliximab treatment has been successful, as it currently is with my wife, patients can come off the treatment when the time is right. It is to be hoped that, irrespective of the NICE recommendation, where this is the case patients can be allowed to continue receiving the treatment until it is no longer needed.

I would implore NICE to reconsider, and reverse their recommendation.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA035

I am a sufferer of UC and was most disappointed when I read about the proposal around Infliximab.

Having only being diagnosed with UC in 2012 I began taking Asacol to try and manage my condition. This medication along with other medication were unsuccessful and my condition declined rapidly. At my worse I was making half hour trips to my bathroom and was confined to my home. I was fortunate to have a supportive family and employer during this difficult time but despite this every day was a challenge and unsurprisingly took its toll on my body. I was admitted to hospital in Jan 2013 to go on steroid drip every 4 hours and a concoction of other medicines which resulted in taking over 20 tablets orally in 1 day in addition to the steroid infusions and blood transfusion. Following 3 weeks of this treatment there were no signs of my condition improving and surgery seemed inevitable.

Surgery was such a significant concern to me. Only half of my bowel was inflamed however the only option was to remove the whole bowel. I was tired and my body was drained. I didn't want any more pain, I didn't want to take all these tablets, I didn't want my steroid face any longer however I didn't feel ready to give up my battle. After meeting with my consultant I asked whether we could try anything else and he mentioned Infliximab. The improvements were instant which gave me some hope. I was allowed home and despite not being able to walk properly due to muscle wastage I was determined to beat this flare up and keep my bowel.

I continued the Infliximab infusion for 12 months on a by-monthly basis and haven't looked back. I am stronger and my condition is significantly improved to the point that I am only on 1 azathioprine a day now. I find it frustrating that somebody can put a price on health as to me a healthy body is priceless. Evaluating the cost of surgery vs treatment is short-sighted. Infliximab was a one off cost for me and I am now in remission. I am sure that there is several ongoing cost implications around Surgery beyond the operation not to mention the emotional impact it has on individuals. I will end my experience with this question…..

…..Is it ethically right to deny people of treatment that has a proven track record.....?

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA036

My Story

My Colitis story begins in November 1999 when, at the age of 43 I took the brave decision to stop smoking. It was a real uphill battle for me with many slips. I chewed Nicorette for two and half years, becoming firmly addicted. In the spring of 2002 I decided to stop the Nicorette and replaced it with ordinary sugar free chewing gum. That summer, while on a holiday, I had a week of bloody diarrhoea, day and night, which I couldn't stop even with Imodium. When I returned home I went to see my GP who began to arrange tests and I was signed off sick, for the first time, from my job as a Clinical Manager of a team of Community Psychiatric Nurses.

For the next three years I had various investigations under the bowel surgeon team, including barium enemas, colonoscopies and biopsies. Every time an investigation was arranged, the delay was such that by the time I was seen my symptoms had spontaneously gone into remission. So by the time investigations were carried out I was symptom free and no diagnosis was possible. However, in 2005 a diagnosis of Proctitis was made.

Eventually I became so unwell in January 2006 that Ulcerative Colitis (UC) was diagnosed by a Gastroenterologist (GI) and the road of trying out different drugs to try to control my symptoms was begun. After trying ten other therapies first, ***all of which have either produced adverse side effects or have been ineffective***, I am now receiving regular infliximab infusions every eight weeks and have been for the last three years. ***This has been the only treatment that has allowed me to have something like a normal life and kept my symptoms mostly in remission.***

The effect this disease has had on me personally is devastating, particularly in my relationship with my husband. He became my carer, a situation I would never have wanted. This disease changes the way people relate to each other. Our physical relationship has been badly affected and we no longer sleep in the same bed. When I was disturbing him all night long, running to the toilet, when he had to go to work the next day, I began sleeping in another room. Now we are used to sleeping separately. My children now see me as ill, not the strong independent woman I used to be. I socialise much less as alcohol and certain foods disagree with me, my fatigue won't let me stay up late (though this is far better on infliximab) and I often do not feel I have the energy to entertain, or to just be good company. I cannot do aerobic exercise as attempting this has caused a flare-up on three occasions. I cannot eat many vegetables or fibre and therefore keeping my weight to a healthy level is extremely difficult.

However, I would be in a far, far worse position without my regular infliximab infusions. Probably the combination of not having any more work stress and the infliximab mean that I now have a relatively normal life. A few days before my eight-weekly infusions I suffer with diarrhoea and other unpleasant symptoms but I now organise my life around this. Once when I had to delay the infusion by a week the symptoms really began to re-emerge and the diarrhoea and abdominal pains rapidly became very unpleasant and disabling.

To argue as NICE has done, that infliximab is not effective as a treatment for people with moderate to severe ulcerative colitis and that surgery is a cost-effective option wholly ignores the reality that for many UC patients and their families to live with the devastating reality of an incurable, chronic condition, regular biologic infusions are their only choice***. The care pathway should be a simple one, with the biologics being a last resort maintenance treatment when all other treatments have failed. Only if these fail should surgery be the final option.*** Rather than alleging that the

Individual submission forwarded via Crohn's and Colitis UK

NICEMTA036 (cont'd..)

biologics are not 'value for money' for the NHS for UC, why is NICE not putting pressure on the manufacturers to reduce the price to something sensible or pursuing alternative biologics as infliximab, adalimumab and golimumab lose their patents? Why has NICE been unable to find prices for the new biologics? Surely this would make a huge difference to judgements regarding value for money if the new biologics are significantly less expensive?

I would be shattered to lose my infliximab infusions. I cannot bear the thought of returning to that level of illness and pain again. It would be intolerable to face a future under the NICE guidelines, where I would limp from one flare-up to the next, spending much of the time between my three permitted infusions in a poor state of health and with a significant level of disability. Having lived for twelve years with this condition I know, without a shadow of a doubt that this is not a life. Not being able to leave the house for fear of an 'accident'; being so sick and unhealthy and feeling so bad; being bedridden; the chronic pain; the intense fatigue. If I were to go onto 'emergency treatments' of Infliximab of three at a time, I am sure I would be unwell in between these courses as I already suffer a few days before my infusion is due. It is obviously only just holding me in remission. Surgery isn't necessarily more cost effective if it has a negative effect on the patient. It is a procedure I would fight against every inch of the way. The impact on my body image and confidence would be devastating, not to mention the amount of self-care required with a colostomy bag and the restrictions on what you can and can't eat. The risk of complications involved in this procedure is also very real. I know several people who have had colostomies and suffered from terrible complications, not to mention the impact on their personal lives, self-image and self-esteem. I could not bear the thought of having a collectomy and I think I might well become significantly depressed if forced to undergo this procedure***. The effect infliximab has had on my life is hard to put into words and it sounds trite to say that it has given me my life back, but it has.*** Too late to save my career, but I do have a life now.

I feel so utterly let down by the NHS I have worked for and have paid into all my working life. Having lost me my job due to them not being willing to make adjustments for my disability, the NHS now appears to be being told by NICE not to use Infliximab to treat moderate to severe UC. If this is so, then I face losing the only treatment that has allowed me to live a relatively normal life over the last three years.

As I have tried ten other treatments which have at best failed and at worst left me with permanent side effects, surely the fact that I have been given a drug that works for me is 'evidence' enough that this is an effective treatment? This is also true for other people, so what more evidence is needed? How many people does this actually apply to; how many people are 'held in remission' by treatment with biologics? Is it many thousands or hundreds? Surgery should only be considered an option if it is a life or death situation or if all treatments, including the biologics, have failed.

My husband has also now retired, partly because of my UC. We have always promised ourselves we will move to our favourite county when we both retired. However moving house may now mean that I cannot obtain Infliximab in a new county, so our life is on hold while NICE makes this decision. The stress of not knowing whether I will be able or allowed to continue with the only treatment that has worked for me in 12 years and given me back a relatively normal life, is affecting my health again. It is also affecting our quality of life.
I believe that withholding this treatment on the grounds of cost effectiveness is morally indefensible.

Individual submission forwarded via Crohn's and Colitis UK

NICEMTA036 (cont'd..)

Treatment History
2002 -2005: Investigations into what was causing bloody diarrhoea, extreme abdominal pain and urgency.
2005: February 2005 diagnosis of Proctitis. Mesalazine commenced. Side effects: persistent itching, dry scaly skin rashes (which have never fully resolved) and severe headaches. I was advised to stop the treatment, which I did.
2006: 2002 to 2006 naturally occurring remissions got shorter and shorter. January 2006 I became extremely unwell, was bedridden and running to the toilet 22 times day and night. I was losing a lot of blood and was very weak, losing a pound a day in weight. My Hb went down to 8. I was also in intense pain for most of the time and couldn't lie on my left side at all.

At that point my GP was so concerned he wanted to admit me to the DGH. However I did not want to go into hospital as I was very worried about contracting an infection as I was bleeding so heavily. I therefore remained at home being cared for by my husband who was also working full time. My GP was advised by the bowel surgeons to refer me to a GI. My GP told me I might have to wait as I was a new referral but having had sight of my blood test results, the Gastroenterology department rang me that evening with the offer of an initial out-patient appointment the following day. The GI diagnosed Ulcerative Colitis and commenced me on prednisolone and I gradually began to have reduced symptoms. This course of treatment lasted many weeks during which I gained four stone, experienced marked and unpleasant psychological symptoms and became Cushingoid. Consequently budesamide was then tried on a number of occasions but this only had a mild effect. Following this treatment I was then commenced on azothiaprine. Although it helped my UC, after a few weeks I was unable to move due to severe joint pain and stiffness. I felt about ninety and had yet another protracted period of sickness absence from work. My level of fatigue again at this time meant I could do very little and spent most of the day in bed asleep (when symptoms permitted sleep). In December 2006 Predfoam enemas were tried without success but when used in conjunction with loperamide they afforded me a brief respite.

2007 – 2008: In early 2007 another relapse signed off sick again and recommenced on azothiaprine. The same side effects ensued. December 2007 – I was commenced on 6mercaptopurine. In January 2008 I had another flare up and this time I did not respond to prednisolone. I also had to stop taking 6mercaptopurine due to joint pain. loperamide and budesamide were now the only things that helped to control the diarrhoea but the incontinence, abdominal pain and urgency continued. In February 2008 I commenced arsenic suppositories twice. I responded at first, but two weeks after stopping both courses I again relapsed.
By this time I was suffering from continual urgency and incontinence. I was unable to move very far from a toilet and my manager (at the time) agreed for me to work from home most of the time to help me reduce my sickness record. This worked for a while although my self confidence suffered enormously with the incontinence issue. I had many 'accidents' during meetings and travelling to and from work and had to carry two spare changes of clothing with me at all times.
2009: In May 2009 I had to take antibiotics due to an infected insect bite and this caused another full blown flare-up. At that time my consultant agreed to try nicotine therapy. As my UC had begun when I stopped nicotine, we thought it might work. I tried nicotine patches and gum but they only exacerbated the diarrhoea. So in July 2009 I recommenced 6mercaptopurine at the minimum dose, which I still take today. Though it helped, it failed to put me into remission. By this time I was so depressed I could not return to work and was commenced on Lofepramine by my GP. My quality of life was low and my self confidence and self respect nonexistent. I thought I would never lead a normal life as I was still only 53 and living like an elderly woman. The fatigue, which has always been a huge feature of this condition, was terrible.

Individual submission forwarded via Crohn's and Colitis UK

NICEMTA036 (cont'd..)

2010: By May 2010 I began to pick up a bit emotionally and I thought that if lost the weight I had gained on the many courses of prednisolone I might feel better. With the approval of my GI and GP I commenced the Cambridge diet. I lasted three weeks, losing some 20 pounds but unfortunately the colitis flared up again. My GI said it was as an unanticipated result of the Cambridge Diet.
2011: By February 2011 I consulted about the constant incontinence because I really didn't feel I could go on living my life like this. A colonoscopy was arranged and a polyp indentified. A registrar tried to remove it without success and I went back a few weeks later for my GI to remove it. It turned to be a pseudo polyp, a result of over-healing in my colon. That was on 14th

July 2011 and I was once again off sick. My GI also identified in the colonoscopy that I was in another flare up.
Infliximab: My GI pointed out that I had not had a proper remission for years and suggested, as a final resort (having exhausted all other avenues of treatment) that we try infliximab. By this time I had tried ten different treatments and my GI felt that cyclosporine would be inappropriate due to my reaction to azothiaprine and the higher doses of 6mercaptopurine. I had the first infusion of infliximab in October 2011. At this time my main symptoms were again diarrhoea, urgency, incontinence, bleeding, extreme abdominal pain and persistent fatigue. Unsurprisingly I was also quite depressed. Infliximab slowly began to work for me although I was rather up and down to begin with and needed Colifoam enemas as well to stop the bleeding. ***At no time during this initial treatment phase or at any point since, have I experienced any adverse side-effects of having infliximab.***

I have, incidentally, also seen a gradual but enormous improvement in my asthma and gingivitis symptoms since commencing infliximab.

In early 2012 I began negotiations to return to work. My new manager refused to allow me to work from home or have concessions due to my level of disability. Despite Union intervention I could see no way of returning to a job where I would have to travel over 15 miles just to reach the office, before even starting work. My Union advised that I had a strong case against my employer under the Disability Discrimination Act, but I felt unable (and could not financially afford) to face a protracted legal battle in my fragile (though improving) state of health. I therefore took redundancy and early retirement, leaving me much more financially unsound than I ever thought I would be. I now live off a small NHS pension and will not receive a state pension for another 8 years. I cannot therefore afford to pay for infliximab myself.

However continuing with my eight-weekly infusions has produced a gradual but cumulative improvement in my health and symptoms. In November 2013 (two years after commencing infliximab infusions) my calprotectin levels, at last, returned to within normal limits. I have continued to improve and feel that, at last, a relatively normal life is within reach, only to find that NICE are proposing to consign me back to a life of disability and pain.

Drugs taken for UC over 12 years

1. Mesalazine
2. Prednisolone
3. Azothiaprine
4. Predfoam enemas
5. 6mercaptopurine

Individual submission forwarded via Crohn's and Colitis UK

NICEMTA036 (cont'd..)

6. Arsenic suppositories
7. Loperamide
8. Nicotine patches and gum
9. Budesamide
10. Colifoam enemas
11. Infliximab

During this time I have also intermittently been prescribed Adcal3 and HRT due to the effects of steroid use and ferrous sulphate, on many occasions, due to anaemia and mebeverine and codeine for pain.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA037

I was first diagnosed with UC mid 2009, when a short use of topical Asacol resolved the problem for a few months.

However when the next flare up happened, the topical drugs did not work so I used oral Asacol but things got worse and I spent all of my time either in the bathroom or bed with a very worried husband. The drugs appear to have exacerbated the UC. I was hospitalised for a fortnight before eventually Cyclosporin brought the UC under control, unfortunately I could't continue with it because of high blood pressure.

Corticosteroids brought the next flare up under control, a further flare up was treated with Mercaptopurin, but this caused pancreatitis.

Around two and a half years after initial diagnosis I started treatment with Infliximab, which improved my quality of life and gave my husband his life back, as I felt able to leave the house with a degree of confidence. Unfortunately I had an allergic reaction during the 6th infusion.

Since then I have been using Corticosteroids to try to control flare ups, but these have side effects e.g. sleeplessness, weight gain, easy bruising etc. and whilst stopping the bleeding and reducing the frequency of bowel movements they do not necessarily completely stop the urgency, which arguably is the worst symptom of UC.

I am hoping to try Adalimumab shortly as I would like to recapture the feeling of life before UC.

I have been offered surgery a number of times, but I view this as risky, irreversible and subsequent problems such as blockages and ruptures require further surgical interventions. Also although many people find living with an ostomy bag a better alternative to UC, others have a number of problems with them.

Finally I feel surgery removes the possibilities for the illness burning itself out or trying new treatments as they arise.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA038

I was first treated with Infliximab in May 2010 after all other options had been explored & failed. I was in hospital unable to even drink a sip of water, I was facing emergency surgery with a surgeon on standby ready to act when I was given my infliximab on Friday morning this was followed by four units of blood as I had lost so much & my blood count was so low, after my treatment I couldn't even move. On the Monday lunchtime so only 3 days later my Consultant came to see me & was so pleased with how well I was he said I could go home tomorrow as long as my latest bloods & x rays for inflamation were ok, which they were. I was back at work a week later.

I had no further problems at all & was as good as new from that day & was officially in remission when I was once again fully reviewed after regular checks until Christmas & I needed no further infliximab. I stayed in remission until January this year so 3 full years without needing further treatment & 3 and a half with no problems at all.

Once again after two weeks in hospital & all else failing & getting worse by the hour I was given Infliximab on the Thursday afternoon, I went home on the Saturday lunchtime so 48 hours later & back at work only a few days later.

Infliximab has changed & saved my life & gave me my life back, how can it be morally or ethically right to withhold/deny me something that helps/makes me better almost instantly or to say this will not be funded for me any further & I have to have life changing surgery instead.

The thought of surgery is not only terryfying for me but also life changing. I could not afford to be off work either financially or professionally & my position would not enable this to be possible for either myself or my company.

How can the hospitalisation, treatment & aftercare not to even mention the medical supplies I (& ever other patient who required life changing surgery) would need for the rest of our lives possibly be more cost effective than any of the drugs you look at removing.

How can life changing surgery not be my (or any other persons) decision to make, by changing the guidelines for the worse as you propose you are taking that choice & decision away from me by denying me the option of treatment that would make me better.

From a personal point of view I have worked & paid my taxes & national insurance all my life since leaving school so I believe I have the right to the treatment I want & choose & you should not be allowed to make that decision for me/take it away from me.

I started my e-petition a few months ago hoping to help & make a difference with a change to you guidelines for the better in this review, to help others who aren't as lucky as me to have the support & care of the best IBD Specialist Nurse & Consultant in the world looking after them, rather than a change for the better you are looking at changing it for the worst possible outcome. So far I have well over 2000 signatures from fellow sufferers of this Chronic Illness who like me want a change for the better & my original purpose of my e-petition not the ones you are proposing

Please I am begging on behalf of myself & every other fellow sufferer do not let this happen & change mine & many thousands of others lives for the worse.

I don't want anyone else to be put in my situation or face the same fight/ life changing decisions I have.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA039

I was first diagnosed with Indeterminate Ulcerative Colitis back in 2001. I can still vividly remember that diagnosis and the emotions it brought. I cried at learning that I had a chronic illness that has no cure and would likely increase the chances of me being diagnosed with bowel cancer later in life.

Over the years I have tried a variety of treatments including the usual that suffers of the disease are given. I've tried numerous tablets, suppositories and enemas and steroids and at times meant I also had to have treatment for side effects such as depression.

The nature of the disease means that here are lots of unknowns. Treatments that work for some, don't work for others and treatments that appear to work, may, for some reason, suddenly stop working.

In summer 2013 I experienced a flare up which did not respond to steroid-based treatment. After an extremely traumatic colonoscopy my specialist presented me with two options — either have surgery to remove a section of my colon or try Humira. The surgery obviously has implications - have the surgery and you effectively are cured and no longer have to take medication and there is no longer an increased cancer risk but you will have to have a colostomy bag. To me that is something that at the time I wasn't prepared for so decided to take the Humira option.

I was explained the side effects of Humira, which were numerous and some cases serious, but I was prepared to take that risk. I see surgery as a final option After being accepted to take Humira and having initial training I started to administer the medication.

In a relatively short period of time noticed a significant improvement in my condition and had no side effects at all. I have been taking Humira for over a year and since taking it I have not experienced a flare up and everything is 'normal'.

I appreciate the costs involved with providing the treatment (it's not cheap) but personally I'm not prepared for the drastic surgery of having a part of my colon removed and am grateful for Humira and how it allows me to live a normal life. I am concerned that if Humira is not provided on the NHS then my condition may worsen resulting in a greater possibility of surgery.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA040

I was diagnosed with ulcerative Colitis in August 2013, I was put on asacol and prednisolone to help my symptoms. Unfortunately I was losing lots of weight and in December 13 became very ill and had severe pains and was bleeding. My bowel movements were around 18 per day and I wasn't sleeping due to regular toilet visits and pains. I was admitted into hospital a week before Christmas as my colon was severely inflamed and I was malnourished due to not being able to retain any nutrients and food. I was told by my consultant that if things didn't improve on iv steroids that I would be having my Colon out. I was extremely upset as I had only just been diagnosed and felt I wanted to at least try the other medications available to me. After many X-rays and continued IV steroids, I gradually got a little better and didn't need to have surgery. I am a mother to two young daughters and it was a tough week being away from them in hospital but I was lucky to go home on Christmas Eve to spend time recovering.

I was then put on Azathiaprine but unfortunately this made me quite ill and my liver couldn't tolerate it. I was still on high doses of prednisolone and my Consultant was keen to get this down as soon as possible, unfortunately as soon as I tapered down I flared up again. I was put on a very low dose of Azathiaprine again to see how my body would tolerate it but the same thing happened. My Consultant put me forward to have Infliximab as I have severe Pan-ulcerative colitis. I had my first infusion in June, as soon as I had that infusion I felt so much better. I have had 4 infusions so far and am able to sleep through the night, bowels are we open 2-3 times with a generally formed stool, no blood and no abdominal pain. I had a lovely Summer with my girls, Infliximab has given me my life back.

I think that if this infusion works well then why should it be taken away from people with this deliberating chronic illness. Please continue to give it to other people like me who desperately need it. Thank you for your time.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA041

I was diagnosed in September 2010 with ulcerative colitis, I was very ill at this time and I and my consultant believe that I have had this dreadful disease for a long time, undiagnosed.

Initially, I was started on predisonole for around about one year in total, and when my consultant tried to reduce my dose, I would have a bad flare again. I was hospitalised three times in 2011 and was on intravenous steroids. This, of course helped but then my symptoms returned within days of returning home. It was around this time that I started having dreadful joint pain and was admitted to hospital to investigate. I was treated with methotrexate which made me very sick so my medication changed to an injection form of the same drug and I still take this now. I am still troubled with joint pain and have a diagnosis of inflammatory arthritis. I also take liquid morphine.

I was then treated with a medication called aziathropine which made me violently sick so was taken off this also. After another stay in hospital I was asked about Infliximab. At this point I would have tried anything, I was in so much pain. Infliximab has been a life saver for me. I am now 59 years old and the thought of surgery are very frightening for me. This has Been discussed with me before but I do not wish to go down this drastic route. I feel that having a iliostomy would severely affect my mental health and thinking about this , I feel,that it would affect me socially too.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA042

I was officially diagnosed with Ulceractive Colitis (UC) in September 2012 and as my symptoms became very severe I was hospitalized for a week in May 2013. By this time I had lost 2 stone in weight, was unable to control my bowel movements, was not going out and was overall very unwell and tired. In hospital I was put on a course of steroids and the consultant started me on Infliximab.

I can say I had an immediate and good response to the Infliximab with no side effects. I have put a stone of weight back on and thanks to the Infliximab my symptoms are now under control and whilst I do have my off days the treatment has allowed me to carry on my life as normal. I am not restricted to home (ie my bowel movements are under control) and I am able to continue with my social life, work, holidays & days out with no worries of needing a toilet etc.

Inflixmab has brought me peace of mind and lessen the worry that the uncontrollable symptoms can bring. I have also found that as I come closer to the next appointment for my Infliximab treatment my health is just about hanging in there and the infusion brings strength back into my body.

Who knows what would have been my situation without the ongoing Infliximab treatment – would other treatments have worked? I feel I would have had more time off work (one month off in May 2013 & the odd day here & there) and would have been tied to the home due to needing to be near a bathroom and not venturing far due to the tiredness. This would have led to a loss of confidence in being able to do normal everyday things.

So far I have not required surgery and would hope that if it ever came to it surgery would be a last resort or had to be carried out due to twisted intestine etc.

To summarise, I feel that without the ongoing course of Infliximab my quality of life would be zero as I would have continued with all the main UC symptoms and not have been able to continue with my life as normal (bar the month off work).

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA043

I am a 20 year old student, and am about to begin a clinical trial for golimumab to treat my pancolitis. I have been 'steroid dependent', and azathioprine treatment is no longer effective for me.

I had to fight fairly hard to get a biologic drug. In other developed countries, particularly in North America, biologic drugs are the natural next step for treating UC when immunosuppressants fail. Many patients respond particularly to maintenance doses of infliximab. Speaking to acquaintances in other countries, they were shocked that I was instead being offered methotrexate, a chemotherapy drug which studies have shown has NO benefit for UC over placebo. The only reason they could think of was that methotrexate was dirt cheap compared to biologics, and it was extremely difficult for me to agree to start a medication which was so toxic, and that I knew probably wouldn't help. The right drugs existed, but were just out of my reach. I therefore jumped on the opportunity when I heard of a clinical trial for golimumab.

Many people have enjoyed a long and happy remission from their Ulcerative Colitis with the use of biologic drugs, and I seriously urge NICE to get up to speed with the rest of the world regarding UC treatments.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA044

Over the last three years I have been prescribed mesalazine, azathioprine and methotrexate. None of these has proved effective. I suffered severe side effects, including liver damage, with azathioprine.

High doses of steroids have proved more effective in the short term. But the side effects have been extremely unpleasant and, with a few weeks of finishing each course of steroids (Prednisolone), the ulcerative colitis symptoms have re-appeared and I have had to repeat the steroid treatment.

Some months ago the NHS consultant prescribed infliximab which is administered through a drip at my local hospital. This biologic is proving effective and offers the possibility of leading a normal life.

NICE needs to be aware that UC is a most debilitating chronic disease. If the use of infliximab postpones or prevents the need for surgery, then it is surely cost-effective. In my case, the extent of the UC would entail the removal of the entire bowel. So to take away my last hope of avoiding this dreadful prospect would be a bitter blow.

I urge NICE to reconsider their recommendation that patients should be deprived of this drug which offers the possibility of a much improved quality of life.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA045

I had been suffering a bad attack of ulcerative colitis since October 2013, getting progressively worse. I had failed to respond to the enemas prescribed by my gastro-enterologist and GP, both liquid and foam enemas, and eventually was in such a bad condition that I was admitted to hospital in January 2014. After a week of not responding to steroid treatments I was prepared for surgery, mentally and physically, but the specialist explained that they would try one last treatment before going ahead and that would be an infliximab infusion. The infusion made a big difference and I was able to avoid surgery which was an enormous relief. I then had a further two infusions as an out-patient and have continued to remain in remission since then.

I cannot begin to imagine what impact surgery would have had to my life and am extremely grateful that infliximab exists and I was able to continue without surgery. I believe that all surgery should be avoided if possible and, although I understand that treatments like infliximab are expensive, they must be preferable to surgery as surely surgery and its follow up attention and possible complications are more expensive in the long run.

I believe that the specialist medical teams should be in the position to have the choices for treatment and to make the decisions as they spend their lives with patients suffering from these diseases and together with the patients should make the decisions based on lifestyles, symptoms and consequences not just on budgets.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA046

I have had Ulcerative colitis since I was 19 (9 years). I was working full time when the symptoms began and after 6-7 months of going to my go with my symptoms and just being told it was IBS things finally come to a head when I was at work on a particularly bad day where I had lost a lot of blood and I was doing a facial treatment and the pains became so unbearable that I collapsed in the treatment and was taken to hospital and had biopsies taken and had a long stay in hospital when I then was diagnosed with Ulcerative colitis. Over the next 6 years I was tried on various medication pentasa, azathiprine, various sprays and enema and of course the awful steroids. I eventually had to leave my job because I was in hospital more than I was out and I was made to feel a problem at work so I left, I was living with my parents and I did not claim any benefits, I rarely left the house and when I did I had " accidents" so I began to lose my confidence leaving the house.

After three years on steroids unable to tolerate the other drugs I was then allowed to try a new drug which was so new they didn't know side effects etc but I was willing to give anything a try just so I can get this pain under control and stop being a burden and live a normal life. So I started Infliximab I was only allowed the initial therapy dose at that time but this allowed me to come off the steroids and I honestly felt like I had been cured! I began going outside again and eventually I decided to work for myself.

All was going well until around a year later and I relapsed with vengeance I was admitted again and was on if steroids and I was so deflated and desperate I had lived a "normal" life for nearly a year and now I found myself back to square one on steroids again. I was admitted again for around 4 weeks and my Consultant came around and said about trying the Infliximab again but that it is likely the same would happen again if we just had the therapy dose so I was going to have to come in for treatment every 8 weeks.

I have now been on Infliximab for coming up to 3 years with no relapses. I no longer panic about leaving the house, I no longer spend weeks on end in hospital. I no longer feel a burden on my family and I can actually work again. I feel like I actually have a quality of life again, I lost so many years of my young adult life because of my condition and when you are going through a relapse the pain never feels like it will pass and I have to admit one image that will always stay in my mind was just before I got admitted again and started on the Infliximab my mum had try to get me out of the house to just walk up the road and back, I didn't make it half way without having an accident and I ran home and was in the bathroom as my mum helped me get tidied up and I actually had hit rock bottom and I said to my mum then I just want to die, this is no life, constantly in pain or pooing and pouring with blood, too scared to leave the house, I had lost all my social life and confidence but this miracle drug I see was my life line.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA047

I totally support Infliximab being available as a maintenance medication for UC

I have had UC for over 5 years, with continued trouble and flares. Salofalk has not worked and 6MP has terrible side effects. In May I had an acute severe attack and hospitalised for a week. This qualified me for the 3 infusions. Ever since those infusions my UC has never been better allowing me to get on with my life/family/work.

Unfortunately, I am not allowed to continue with more infusions, so I stress each day waiting for the next attack/stint in hospital, whilst I continue to have poor experiences with other medications that don't work. This is terribly frustrating knowing that there is something at will make the world of difference to my life but am unable to receive it due to cost/red tape.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA048

I'm a 37 year old mother of two wonderful children and unfortunately I was diagnosed with IBD twenty years ago. I was using Asacol every day but lived with constant pain, discomfort and embarrassment. I managed to avoid any hospital stays however until last June when I was hospitalised as my bowel was close to perforating. I received IV steroids as the oral steroids I had been taking for my flare up had been ineffective. Even the IV steroids though were not bringing my inflammatory markers down and I was no closer to getting home to my seven month old daughter and eight year old son. Eventually after tying various treatments I was given my first dose of Infliximab. The results were great, I started to feel much better and my blood results backed this up and after nearly three weeks away from my family I was allowed home. I got two further doses of infliximab as an outpatient and all was rosy, for a while....

In May of this year, during another flare up, my knee became very swollen and I was unable to walk on it. Swollen joints are just another horrible side effect of my condition. My neck was also incredibly sore and I had to take time off work on the sick. I was unable to play with my children, drive a car or do the many things people take for granted on a daily basis. My consultant applied for a years funding for me to take infliximab again but the powers that be decided I could only have three doses. The morning after my first dose the changes were incredible. Again, I felt much better and the swelling in my joints had reduced considerably. I have now had two doses so unfortunately can only expect to be in remission until a few weeks after my last dose.

I fully support the idea that the NHS should fund infliximab and other similar drugs for those of us whose quality of life literally depends upon it. If those people making the decisions had to live with this terrible condition, we all know what the outcome would be!

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA049

I was diagnosed with U/C 6 years ago aged 38 on 31.3.08. I have 3 children then aged 4, 8 & 10. I worked part-time in central London two days a week. Life was hectic, but fun.

Diagnosis & the different drugs

On diagnosis I was prescribed asacol, after 1.5 months of being on the medication I had my 1st major flare. My consultant tried to settle this flare with 40mg of prednisolone. Unfortunately this did not work.

I was admitted to hospital for five days & given IV steroids & sent home on a course of oral prednisolone. My next medication to be prescribed alongside the asacol & prednisolone was azathriaprine. I could not tolerate this drug due to the side effects. My consultant then tried me on 6mp. This caused me such severe abdominal that I was unable to move, was screaming out in pain & crying. My consultant scanned all my vital organs to ensure no lasting damage had been caused, & luckily it had not. It was as this time that my consultant said he could no longer treat me as I could not take the conventional U/C medication. By this time my U/C was steroid dependent.

I was referred to St Marks Hospital, under Dr Hart. She began my treatment from the beginning & changed the asacol to pentasa & prednisolone, but the flare continued so I was once again admitted to hospital for further IV steroids. It was at this point that we discussed trying Tacrolemus. Funding was approved (thankfully) so along with the dreaded prednisolone. After a year of taking the Tacrolemus, on colonoscopy the u/c was in remission. Dr Hart & I agreed to stop the Tacrolemus as the side affects were horrible & it had done it's job. But unfortunately after a few months the flare began & so I was back on the awful prednisolone. I did not take the Tacrolemus again as the side effects affected my every-day life.

Dr Hart said it was time to explore all my options & speak to the surgeons. After meeting with the surgeon & stoma care nurse I was adamant that I did not want surgery. I have had surgery in the past (not on my bowel) & found the surgery & recovery very traumatic. I did not want to go through this again. So Dr Hart fought for funding for me for infliximab & was successful for the ridiculously small amount of three infusions allowed for u/c patients. This was my first glimmer of hope. After the first infusion I felt an improvement & this was reflected in my bloods. I HAD NO SIDE EFFECTS FOR THE TWO WEEKS IN-BETWEEN TREATMENTS I then began my second infusion & devastatingly went into anaphylactic shock. This was a really low point for me because I knew the drug worked for my u/c & between infusions I felt no side effects, but I could have it no more. I was distraught. The IBD nurse did mention to me that there was another drug I could try, but it would be almost impossible to get funding for, but they would try their best for me. This drug was called HUMIRA - my saviour, my wonder drug. Of course, nothing is easy. My funding request was turned down. During the appeal period I saw my MP who wrote a letter of support for funding, along with my consultant & IBD nurses to try to get funding for HUMIRA. I've lost track of time, but if I recall correctly my first funding request was turned down late July 2012. I finally heard that my funding for HUMIRA had been approved at the end of December in 2012 some 4 months later. I did not hear from the hospital about the funding approval, because they had not yet been informed, I heard from my MP's secretary who was so kind & efficient that she sent me a copy of the letter my MP had received from the PCT. My first reaction was relief & excitement, my second was anger & frustration because in the letter the PCT said they would be informing my hospital "early in the new year the funding had been approved"..... Did these people not know what living hell my family & I were going through living with U/C? The PCT thought it fine to wait another week/week & a half before informing the hospital. All this time I was still on the dreaded

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA049 (cont'd...)

prednisolone. I belong to a support group & it's so frustrating seeing other people on the group who do not live in my area who cannot get the drug, or do not have the support of an excellent consultant & IBD team or a high ranking MP to fight for them. I finally started my wonder drug HUMIRA in February 2013 SIX LONG, PAINFUL, EXHAUSING WASTED MONTHS OF MY LIFE AFTER WE FIRST APPLIED FOR FUNDING.

Now let me tell you how living with severe/moderate U/C has ruined my life & affected us all emotionally & financially.

During the majority of my time living with U/C & the ever changing drugs I had no quality of life. I was off sick from work for 8 months. I went onto half pay after six months & was not entitled to anymore paid sick days for many years to come.

I was unable to drive my children to or from school or make them their breakfast as this was the time, usually until about mid-day that I could not leave the toilet. There was no fun time with my 3 wonderful children or my husband &, I was always in bed, in pain or on the toilet. We did not cuddle or play, because if any of them touched my tummy it would be so sore.

My second born child, the 8 year old spent most of her time in the medical room at school getting cuddles & attention from the wonderful medical staff who understood that she was upset because 'mummy was unwell'. For years my youngest daughter would cry going into school because she didn't want to leave me.

I am so fortunate that I have a supporting family, my Dad or sister would do the school run for me. My mum or dad would cook & my husband & does all the cleaning, washing & ironing. We were entitled to no financial help from the government (apart from statutory sick pay) so if I did have a well period of time, there was no money to do anything fun or regularly go on holiday.

This period of illness really affected my confidence. My friends gave up coming around as I was so poorly, I would be curled up on the sofa under a blanket with a hot water bottle. They stopped asking me to go out with them because I always said no, they didn't underst& that I couldn't & that if they were going for a meal this would only make me ill.

When at work my quality of work really dropped. I continuously made mistakes because of the side effects from all the drugs, even when I was in remission whilst taking the Tacrolemus, my st&ard of work was terrible. This ruined my confidence & self esteem & I started to see a councillor at work. (My work did have an excellent support system, I was/am very fortunate with this employer & I know other employers would have found a way to 'let me go'.)

Another problem was the weight loss from the constant flare-ups & then the weight gain from the prednisolone. We had not spare money to buy clothes to fit my ever changing body shape. My 'moon face' from the constant use of prednisolone was depressing & because of my ill health my hair became really thin. Prednisolne also affected my mood. I was so angry & unhappy. They also kept me awake at night, so I took sleeping pills. This drug is not a good long term drug to manage a chronic illness such as u/c.

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That was then, but this is now. Life is fun & hectic. HUMIRA has given my family back their wife & mummy. I can laugh without pooing myself, I can tickle my children & they can tickle me back, we can go for long walks with our dog, to the theatre, for days out, whatever we want to do. I have even been working extra days at work & feel that I do a good job again! The only side effect I have from HUMIRA is tiredness once I have taken the drug, so I take it at night & go to sleep, no problem at all.

I know HUMIRA doesn't work for everyone with U/C, but please, at least give them a chance to see if it works for them, if that's what they want.

Thank you for taking the time to read this.

Drugs taken to try to reach & maintain remission:

Asacol
Pentasa
Pentasa Suppositires
Prednisolone (EVIL DRUG)
IV steroids (I can't remember what it was called) Azathriaprine 6MP Tacrolemus Infliximab
HUMIRA - Mission achieved!

P.S, I'm now 45, my children are 16 (nearly 17), 14 & 10. I've missed out on my eldest childhood. Please don't let this happen to other people.

P.P.S Please don't take HUMIRA away from me.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA050

I was diagnosed with Ulcerative Colitis in April 2012 after suffering with the symptoms for two years. After suffering constant bleeding and accidents on a daily basis I was sent for a colonoscopy where I was relieved to find out what had been causing all my problems. I immediately started my medication, Mezavant 2400mg, and quickly my symptoms eased and I was able to return to an almost normal life.

Unfortunately this did not last and in October 2013 I began to flare. I started using Pentasa Suppositories every night but to no avail. Within four weeks I had started a course of corticosteroids. Within two weeks of completing that course I began to flare again and after a further 10 days of corticosteroids I was admitted to hospital. I spent seven days in hospital where I received IV corticosteroids and I was also started on Azathioprine. My GI consultant has also increased my Mezavant to 4800mg.

Within two months of taking Azathioprine, along with corticosteroids, I began vomiting daily and had to be taken off Azathioprine. I was then prescribed mercaptopurine which unfortunately had the same effect and I was also taken off this.

After 7 months of steroids my intestines were looking a lot better but again after 10 weeks being steroid free, I appear to be flaring again. My GI Consultant has told me that he reluctant to give me any more steroids. I have been given the choice of taking Golimumab or having surgery. I do not wish to have surgery at this time as I cannot afford to take the time of work that I would need to recover (I am on a fixed term contract that I am hoping will be extended).
I would rather try to work through this illness with the help of medication and continue to work full time, than have to put myself and my family through the process of surgery. I understand that these drugs do not work for everyone but if it were to help prolong the possibility of surgery then I would rather try this to allow myself more time to prepare for life changing surgery.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA051

Following at least five years of repeated visits to my GP with agonising pain on the lower left side of my body I was finally diagnosed with moderate Ulcerative Colitis at the start of 2010 - having mentioned the symptoms at a check up for my Coeliac Disease where the consultant was more worried about the symptoms than my GP.

I spent the first six months of 2010 incapacitated with a severe relapse. I was treated with IV steroids in hospital and then spent the next four months on maximum dose oral steroids and aminosalycates (Asacol and later Balsalazide).

I spent this time on extended sick leave from work and barely able to move out of an armchair during the day due to the unbelievable fatigue. Thankfully my husband and sons were able to look after me during this time, although I became extremely depressed by my inability to even cook a basic meal or keep the house clean and tidy. I had quickly developed the classic characteristics of steroid treatment - exhausting insomnia (almost the worse side-effect) a round "moon" face (my spectacles made a deep groove down the side of my face) and a swollen upper body with a buffalo hump. When my symptoms finally improved so that I was actually able to leave the house with my husband I felt extremely self-conscious about my appearance and tried to avoid going out as I became convinced that people were staring at me.

It was only by chance that I was advised by a nurse to stop taking the aminosalycates on a trial basis and found that my symptoms improved. I was able to gradually reduce the oral steroids and was finally symptom free by the autumn.

Unfortunately the remission didn't continue and I experienced further relapses in 2011, 2012 and 2014. Each time the symptoms would become almost unbearable - extreme pain, fever and fatigue. Eventually I would have to admit defeat and agree to treatment by oral steroids (my only hospital admission in 2010 for iv steroids was so traumatic that I am determined not to repeat it - although it would probably achieve a faster remission).

Unfortunately I have now almost reached the end of the road in terms of medication - Aminosalycates make my symptoms worse, Azathroprine adversely affected my white cell count, although I can tolerate Mercaptopurine 6 it doesn't seem to have a huge effect on my symptoms, even steroids took some time to bring my last flare under control. I am devastated that the only option that now seems to be open to me is life-changing major surgery and I would be anaesthetised without even knowing whether the resultant and incontinent stoma was going to be a permanent part of my life or whether I would be able to choose to have a J pouch at a later stage.

I strongly urge NICE not to restrict the availability of biologics for the treatment of ulcerative colitis as this removes any choice about their treatment for patients (contrary to the NICE pathway for the care of adults with Ulcerative Colitis) and in the end we will be faced with surgery or nothing.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA052

I am writing to express my deep distress that NICE is proposing to withhold the use of Biologics for people with moderate to severe Ulcerative Colitis.

Though I do not use biologics at present and have been fortunate so far in managing my UC without. I would like to feel when the time came I would have a choice of medication or surgery. Surgery is not a panacea and carries with it great risks especially for someone of my age. I am 72 years old. Once the colon has been removed it can never be put back and this could be very significant for the majority of young people left with a stoma should a cure be found in the next twenty to forty years.
It is also discriminatory with options available to people with Crohn's not available to those with UC.

I trust that this decision will be reversed and Biologics will be available to clinicians to give their patients the best quality of life possible.

Individual submission forwarded via Crohn's and Colitis UK

Ref: NICEMTA053

I am 67 and was diagnosed with Crohn's 5 years ago. It is thought now, however, by my Consultants that I have Ulcerative Colitis.

I was initially treated with Prednisolone which helped until the amounts were being reduced and then my symptoms of abdominal pain,rectal bleeding(causing anaemia which had eventually to be treated with IV iron as I could not absorb oral iron),diarrhoea and urgency started again.
I was then commenced on Azathioprine initially 100mg daily, then increased up to 200mg.
My symptoms did not improve and 4years ago I had my first course of Infliximab.
However, having completed a year on it, I was advised to come off it as the side effects could be serious for a person over 60.

After a few months of not having the infusions, my symptoms returned despite taking Azathioprine and rectal suppositories and oral Pentasa.

Last year I was very depressed about my condition. I felt unable to leave the house as I needed to be near a toilet almost constantly and had to change sanitary pads every few hours. I could not see how I could go on but the thought of surgery frightened me a great deal. As a retired nurse I had cared for people with stomas so I knew what was involved.

My Consultant reluctantly agreed to restart the Infliximab. I have now had a year of 8 weekly infusions. My life has changed so much. I have no symptoms of UC at all. Normal bowel actions, no rectal bleeding. I have my life back thanks to Infliximab.

I am able to look after my young grandsons, do charity work in our village and have a social life. Please NICE do not stop the prescribing of this wonder drug.

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