

Elaine Steven – Patient and Chairman of Board of Trustees of the National Association for Colitis & Crohn`s Disease (Voluntary position)

Technology Appraisals Committee for Drugs for Crohn's disease - Infliximab and Adalimumab

Patient Expert Personal Statement

I have been a sufferer of Crohn`s Disease for 18 years. For the first 8 years or more I was at times exceptionally unwell and found it difficult to control my condition with the existing treatments available at that time. I also developed, during the initial stages of my condition, a rectal vaginal fistula which has never been closed. My drug regime has included mesalazine, steroids and azathioprine, which I was on for 6 years. From those first years of relenting illness I have a particularly scarred and narrowed piece of bowel which caused an obstruction last September and occasioned an emergency admittance to hospital. Fortunately no surgery was required at that time but this remains as a possibility for the future. I continue to use mesalazine as a maintenance drug.

From my own experience, I believe that my condition may have warranted using one or other of these therapies had there been that choice of therapies available at the time. I would have seriously considered using either Infliximab or Adalimumab. I would, naturally, expect to have been guided by my physician on which would be, personally, my best option and make an informed choice. The desperation I felt in being so ill for such a long time, with the effect that had on my work and social life, leads me to believe that, should I find myself in the same position again, I would welcome a greater choice of treatments. It is this choice, assuming that proper explanation about potential side effects is given by an experienced clinician, that I feel offers patients today a great advantage.

For a patient who finds themselves desperate to feel better, to live without pain and the feeling of being constantly unwell, with the depression and weariness that all of that entails, combined with the effect on work, social and family life, the potential benefits of these technologies are immense. To feel well, enjoy an increased quality of life, maybe be able to return to work or education or be able to attend a family or social event without fear of embarrassment is something that cannot be quantified but to the individual concerned, has the potential to transform their life.

Speaking personally, the potential for any long term serious side effects would concern me and I would hope that these therapies would not be offered to me unless my clinician felt that this would offer me the best outcome in terms of my health and wellbeing. I would also hope that any side effects or risks would be fully explained allowing me to make an informed choice about whether to use these technologies or not. Knowing what it feels like to be exceptionally unwell with a condition like CD, with all the pain, diarrhoea, sickness and accompanying indignities makes me believe that short term side effects would probably be tolerated fairly well. There may be a financial implication for some if travelling to receive the therapy is necessary, although very sick patients may already be travelling to clinics, or their relatives to visit inpatients. These technologies may offer some hope of that situation being relieved.

The NACC has carried out a survey on patient/ carer views of the condition/ existing treatments that is relevant to the appraisal of this technology.

If this technology was made available on the NHS there would be an extended choice of medical treatment to either avoid or delay surgery which would be of benefit to patients.

If the technology was not made available to patients on the NHS it would restrict the number of options and remove the hope of a return to `normal life` to patients, and their families, experiencing such a debilitating and disabling condition.