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Multiple Technology Appraisal (MTA)

Infliximab, adalimumab and golimumab for treating moderately to severely active ulcerative colitis after the failure of conventional therapy (including a review of TA140 and TA262) [ID695]

Thank you for agreeing to give us your views on the technology and the way it should be used in the NHS.

Patients and patient advocates can provide a unique perspective on the technology, which is not typically available from the published literature.

To help you give your views, we have provided a template. The questions are there as prompts to guide you. You do not have to answer every question. Please do not exceed the 8-page limit.

About you

Your name: Mark Byrne

Name of your organisation: N/A

Are you (tick all that apply):

- a patient with the condition for which NICE is considering this technology? ✓
- a carer of a patient with the condition for which NICE is considering this technology?
- an employee of a patient organisation that represents patients with the condition for which NICE is considering the technology? If so, give your position in the organisation where appropriate (e.g. policy officer, trustee, member, etc)
- other? (please specify)

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What do patients and/or carers consider to be the advantages and disadvantages of the technology for the condition?

1. **Advantages**

(a) Please list the specific aspect(s) of the condition that you expect the technology to help with. For each aspect you list please describe, if possible, what difference you expect the technology to make.

Having been diagnosed with Ulcerative Colitis in 2003, at the age of 15, Prednisolone was primarily used, to limited and inconsistent effect, to treat my condition up until starting Infliximab treatment in 2010, and to date, continue to have infusions for every eight weeks. Since starting Infliximab, my Colitis has been in a state of remission.

(b) Please list any short-term and/or long-term benefits that patients expect to gain from using the technology. These might include the effect of the technology on:

- the course and/or outcome of the condition
- physical symptoms
- pain
- level of disability
- mental health
- quality of life (lifestyle, work, social functioning etc.)
- other quality of life issues not listed above
- other people (for example family, friends, employers)
- other issues not listed above.

Infliximab treatment had an immediate impact on my quality of life, as I could class myself as being in remission for the first time since my initial diagnosis. I have been able to live a normal day in life, without pain, without concerns about rushing to the toilet, without feeling constantly tired, something which I had not being able to experience previously.

My physical symptoms have improved dramatically since starting Infliximab treatment. I did not know it was possible for a person to be so pleased about having regular bowel movements! Prior problems with fatigue and irregular sleeping patterns have also been significantly reduced.

The contrast in pain before and after starting Infliximab treatment is vast. Whereas moderate to severe stomach pain was commonplace before starting Infliximab, occasional bouts of IBS are now my only concern, with stomach pain being a rarity, but this is easily treatable with Mebeverine tablets.

The long-term benefits of the treatment have been monumental. Whereas previously, I would go from being well to unwell on a regular basis, While on Infliximab, I have been in a state where my health has been consistent for a prolonged period.

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The frustrations that came with my state of health being so inconsistent had a severe impact on my mental health. In addition to my Ulcerative Colitis symptoms having a negative effect on my physical appearance, the short-term and long-term effects of taking Prednisolone also had a detrimental impact on my confidence and self-esteem. Being in a state of remission since starting Infliximab has allowed me to rebuild my mental wellbeing by being able to go to University, find a job and attend social events in the evening, something which I would not have even contemplated doing previously.

What do patients and/or carers consider to be the advantages and disadvantages of the technology for the condition? (continued)

2. **Disadvantages**
Please list any problems with or concerns you have about the technology. Disadvantages might include:

- aspects of the condition that the technology cannot help with or might make worse.
- difficulties in taking or using the technology
- side effects (please describe which side effects patients might be willing to accept or tolerate and which would be difficult to accept or tolerate)
- impact on others (for example family, friends, employers)
- financial impact on the patient and/or their family (for example cost of travel needed to access the technology, or the cost of paying a carer).

I have no major concerns regarding Inxflimab, and to date, have not encountered any major side-effects while having the treatment. The cost of travel and having to attend the hospital for treatment is nothing for the benefit it has on my health.

3. Are there differences in opinion between patients about the usefulness or otherwise of this technology? If so, please describe them.

I am somewhat aware that some patients respond better to Infliximab than others, but have no knowledge regarding differing opinions on the treatment.

4. Are there any groups of patients who might benefit **more** from the technology than others? Are there any groups of patients who might benefit **less** from the technology than others?

I feel it would be of particular benefit to those who have tried the more traditional treatments (e.g. Prednisolone, Azathioprine), but are in need of alternative therapies to help try and improve their state of health and mental wellbeing.

Comparing the technology with alternative available treatments or technologies

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NICE is interested in your views on how the technology compares with with existing treatments for this condition in the UK.

(i) Please list any current standard practice (alternatives if any) used in the UK.

Prednisolone was primarily used to treat my condition in the preceding years before starting Infliximab. Azathioprine, and an alternative steroid with less side-effects associated to it than Prednisolone, were also used during this time.

(ii) If you think that the new technology has any **advantages** for patients over other current standard practice, please describe them. Advantages might include:

- improvement in the condition overall
- improvement in certain aspects of the condition
- ease of use (for example tablets rather than injection)
- where the technology has to be used (for example at home rather than in hospital)
- side effects (please describe nature and number of problems, frequency, duration, severity etc.)

The maximum dose of Prednisolone would relieve my symptoms to an extent in the short-term, however, my symptoms would often return upon reducing the dose, which created a frustrating cycle of upping and then lowering my Prednisolone intake. The side-effects to taking Prednisolone also caused additional problems. The short-term side-effects, notably rounded face and severe acne, significantly lowered my self-esteem during my teen years. Taking prednisolone over a number of years has also weakened my bones and joints.

Azathioprine also helped alleviate my symptoms to a degree, but again, treatment with this therapy was inconsistent, due to the effect it would have on my white blood count. Having regular blood tests was also a requirement while taking this tablet.

The improvement in my physical symptoms, mental wellbeing and condition overall, while having Infliximab treatment, has been far greater than at any point when alternative therapies were being used. I have also encountered minimal side-effects when compared to the alternative therapies.

(iii) If you think that the new technology has any **disadvantages** for patients compared with current standard practice, please describe them. Disadvantages might include:

- worsening of the condition overall
- worsening of specific aspects of the condition
- difficulty in use (for example injection rather than tablets)
- where the technology has to be used (for example in hospital rather than at home)
- side effects (for example nature or number of problems, how often, for how long, how severe).

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While one day in my life is focused around travelling to and from hospital for treatment, and the time spent having said treatment, this is offset by the reduced tablet intake and the severe side-effects associated with the alternative therapies previously stated.

Equality and Diversity

NICE is committed to promoting equality of opportunity, eliminating unlawful discrimination and fostering good relations between people with particular protected characteristics and others. Please let us know if you think that this appraisal:

- Could exclude from full consideration any people protected by the equality legislation who fall within the patient population for which [the treatment(s)] is/are/will be licensed;
- Could lead to recommendations that have a different impact on people protected by the equality legislation than on the wider population, e.g. by making it more difficult in practice for a specific group to access the technology;
- Could lead to recommendations that have any adverse impact on people with a particular disability or disabilities

Please tell us what evidence should be obtained to enable the Committee to identify and consider such impacts

N/A

Research evidence on patient or carer views of the technology

If you are familiar with the evidence base for the technology, please comment on whether patients' experience of using the technology as part of their routine NHS care reflects that observed under clinical trial conditions.

N/A

Are there any adverse effects that were not apparent in the clinical trials but have come to light since, during routine NHS care?

N/A

Are you aware of any research carried out on patient or carer views of the condition or existing treatments that is relevant to an appraisal of this technology? If yes, please provide references to the relevant studies.

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N/A

Availability of this technology to patients in the NHS

What key differences, if any, would it make to patients and/or carers if this technology was made available on the NHS?

Having alternative treatments presented to you helps in making you feel more positive about the future, knowing that there are options available should you become unwell for whatever reason. Going through the routine of using the same therapy repeatedly, knowing that the impact it will have is limited, was one of the more frustrating aspects in my experience.

What implications would it have for patients and/or carers if the technology was **not** made available to patients on the NHS?

From a personal perspective, it would have a detrimental impact on my quality of life if the therapy was no longer made available. For the first time since being diagnosed, I have been able to live something that resembles a normal routine, and the thought of that being taken away is unimaginable. The severe pain that came with my condition being at its most active is not something that I wish to relive at any time soon.

Are there groups of patients that have difficulties using the technology?

I am not aware of any patients that have difficulty using the therapy.

Other Issues

Please include here any other issues you would like the Appraisal Committee to consider when appraising this technology.

I have tried my upmost to put my experience of living with Ulcerative Colitis, and the positive impact Infliximab had on my condition and my quality of life, into words, within this short statement. Infliximab helped in changing my life to something that resembled normal, and attending this meeting to discuss my positive experience with the treatment is the least I could do. It is my hope that more people will become as fortunate as I have with Infliximab, and it has a similar impact on their health and wellbeing as it did me.