The Royal College of Nursing Rheumatology Forum - submission to NICE on the reappraisal of anti-Tumour Necrosis Factor alpha blockers adalimumab, etanercept and infliximab in the treatment of Rheumatoid Arthritis.

The Royal College of Nursing Rheumatology Forum (RCNRF) represents members of the RCN who have an interest in rheumatology. There are approximately 1,400 members of this Forum representing a wide range of nursing roles including nurse consultants, ward and community nurses. The daily clinical experience of caring for individuals receiving these therapies together with the evidence based research, form the basis of this response.

Nurses and practitioners are an integral part of the team providing support to those being assessed, treated and monitored with anti-TNF therapies. Responsibilities include screening patients and ensuring they are adequately informed about the risks and benefits of treatment, training and administering therapies and monitoring patients regularly including data that informs long term outcomes and adherence to guidelines. Nurses and practitioners also provide telephone helpline services and easy access to prompt advice and support for patients.

Pain, fatigue, depression and disability have a significant consequence on those with Rheumatoid Arthritis and their quality of life and ultimately use of healthcare resources. Treatments that address these symptoms are imperative if we are to reduce the downward spiral of progressive disability and other co-morbidities such as cardiovascular disease. The ability of individuals to participate more fully in their own care and activities of daily living has the potential to enable some patients to return to work or at the very least be more independent and in some cases potentially release carers to return to work.

In the last four years, clinical experience of anti-TNFa therapies has enabled patients and healthcare professionals to recognise the importance of these treatments. In addition to the already recognised and demonstrated criteria to measure benefits of treatment smaller qualitative studies (accepting limitations in transferability and possibly robustness) have highlighted the fact
that we need further research to gain a wider global understanding of the measures we should use to capture the patients’ experience of reductions in symptoms, in addition to the already clearly demonstrated benefits based upon the current criteria for evaluating anti-TNFa therapies \(^1\), \(^2\) One such measure is that of fatigue.

Anecdotal experience highlights some omissions from the current guidelines that should be considered. These include the fact that patients receiving treatment with anti-TNFa therapies often have an improvement in symptoms (pain being one of the most significant) that potentially can enable them to reduce their non-steroidal anti-inflammatory, analgesics and possibly reduce oral steroids. These reductions have a benefit in reduced prescribing costs and risks related to these therapies. Due to the current restrictions in the criteria, patients are often reluctant to attempt any reduction in their medications in case it should adversely affect their disease activity score (DAS) and threaten their eligibility to continue treatment.

In addition, early evidence appears to show significant radiological benefits to those treated with anti-TNFa therapies. However, currently patients are anxious about reducing these in case their disease activity scores deteriorate so that they slip just below the current response criteria. It is hoped that as part of the overall review, NICE will consider less stringent disease activity criteria used by our European partners and still demonstrate the value of treatment.

Nurses and allied healthcare professionals have directed their efforts since the first NICE guidance to ensuring patients are empowered and effectively managed according to the current guidance. This has had an impact on services but one that is achievable if services can begin to look at a long term strategy of delivering these therapies to eligible patients. Practitioners have also had to undertake additional work to ensure that detailed data has been collected for the BSR BR. It is hoped that the NICE review will have access to this data.

The RCN Rheumatology Forum developed a guidance document for practitioners to support good practice and adherence to BSR/NICE guidance (RCN, 2003). This has supported practitioners in identifying key factors to consider in relation to eligibility criteria and aided transparency in the patient's pathway of care. \(^3\)