BANNAR statement of understanding of current clinical practice for biologic and biosimilar use in JIA in the UK
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At least half of children and young people with juvenile idiopathic arthritis (JIA) will have active disease into adult life. In adult services the childhood-onset nature of inflammatory joint disease may not be recognised and adults with JIA are often reclassified as having seronegative rheumatoid arthritis. Consequently the burden of JIA in adult rheumatology populations is under-recognised.

This under-recognition has led to a commissioning, licensing and research gap with respect to the range and use of biologic medicines available to adults with JIA. NICE guidance for biologics in JIA was updated in 2015 enabling rational and evidence-based use of etanercept, adalimumab, intravenous tocilizumab and intravenous abatacept in JIA. This guidance recognised a life-course approach to JIA and has no upper age limit, thereby allowing treatment with all four of these agents in adults with JIA.

Adults with JIA are frequently excluded from clinical trials of novel and exciting biologic and biosimilar medications. The burgeoning field of biologic medicines and the development of biosimilars (both outwith current NICE guidance) has led to some challenges for clinicians managing adults with JIA. These challenges have been discussed by the Barbara Ansell National Network for Rheumatology (BANNAR), a multidisciplinary group of professionals from medical, nursing and allied health backgrounds working in adolescent and young adult (AYA, aged 10-24) rheumatology across the UK.

The following points summarise current concerns:

1. Mode of administration
Current NICE guidance recommends intravenous tocilizumab (8mg/kg 2-4 weekly) and intravenous abatacept (10mg/kg, maximum1000mg 4 weekly) for people with JIA. This reflects current UK paediatric licencing. However, both medicines are widely used in rheumatoid arthritis as weekly, self-administered subcutaneous injections. Regular IV treatment is a significant barrier to treatment compliance in young adults endeavouring to maintain challenging educational and vocational commitments.

With this in mind, BANNAR professionals have confirmed that in real-world clinical practice adults with JIA are prescribed subcutaneous preparations of both tocilizumab and abatacept. Since these subcutaneous preparations are not technically NICE approved, there have been some funding challenges to these prescribing patterns.

BANNAR have agreed to evaluate the number of patients to whom this applies but wish to emphasise a general professional agreement that this is a patient-centred and appropriate use of available medicines.

2. Biosimilars

Biosimilar preparations of etanercept (benepali and erelzi) are both licensed for use in children, young people and adults. BANNAR professionals confirm the widespread adoption and switching of adults with JIA to biosimilar medicines to realise the significant associated cost savings.

3. Treatment of refractory JIA

Adults with JIA may have severe, refractory, long-standing JIA and are in a position analogous to adults with refractory presentations of other inflammatory arthritides. Because of the under-recognition of adult JIA and relative rarity compared for example to RA, there is an absence of evidence about optimal treatment strategies. Clinicians have to make difficult treatment decisions by extrapolating treatment strategies for refractory JIA from other refractory arthritides.

BANNAR professionals have discussed this difficult situation and demonstrated they work in close collaboration with paediatric and adult colleagues in a case-by-case approach. It is inevitable and appropriate that clinicians will request funding for newer agents or agents not yet licensed in JIA – at the time of writing these include subcutaneous tocilizumab, suncutaneous abatacept, intravenous infliximab, golimumab, certolizumab, rituximab, tofacitinib and baricitinib.

As a professional group, we recognise this as reasonable and furthermore wish to emphasise the importance of acknowledging the diagnosis of adult JIA; simply relabelling these patients with seronegative rheumatoid arthritis to gain access to medicines is not in the best interests of our patients. We wish to highlight the persistence of JIA into adult life, thereby highlighting the persistent gap in evidence and importance of future research into the treatment of refractory JIA.

4. JIA in pregnancy

The BSR recently provided an evidence based approach to biologic (and other medicine) use in pregnancy. A number of the biologic medications advocated as best practice during pregnancy are not NICE approved for adults with JIA (eg certolizumab).

BANNAR professionals have agreed that it is unreasonable to deny safe biologic treatment to women who are pregnant or wanting to get pregnant and wish to advocate managing pregnant women with JIA according to the BSR guidance.

In summary we urge government, commissioners, clinicians and researchers to consider JIA as a life-long disease, commission medicines within disease specific rather than age-banded frameworks and to continue to work towards improving the evidence-base for the full range of available treatments for JIA.

References:

Abatacept, adalimumab, etanercept and tocilizumab for treating juvenile idiopathic arthritis
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