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Re: Consultation on the appraisal of Psoriatic Arthritis - etanercept, infliximab and adalimumab (review)

Thank you for the opportunity to comment on the ACD for the above appraisal.

As these technologies are expensive we welcome the committee's decision to continue to recommend these treatments as being cost effective for use in people affected by psoriatic arthritis.

With regard to the specific questions, we believe that:

The summaries of clinical and cost effectiveness reasonable interpretations of the evidence

The provisional recommendations are sound and a suitable basis for guidance to the NHS

We don't believe that there are any aspects of the recommendations that need particular consideration to avoid unlawful discrimination against any group of people on the grounds of gender, race, disability, age, sexual orientation, religion or belief?

Although, I have some concerns with section 6 for further research. it says:

"...6 proposed recommendations for further research.

6.1 The Committee was aware of the importance of collecting further data within registries including patients receiving biologic treatments for psoriatic arthritis to enable the collection of information on long-term outcomes including adverse events..."

Which although laudable, doesn't mean very much, if such data isn't collected in a methodical manner. Therefore, it occurs to me that there is some inequity for people who only have psoriatic arthritis when prescribed biologics. No data appears to be gathered in a registry for outcomes and adverse events as is the case for psoriasis, rheumatoid arthritis and the soon to be started ankylosing spondylitis registry.

The Charity for people with psoriasis and psoriatic arthritis

*PAPAA the new single identity of the
Psoriasis Support Trust and the Psoriatic Arthropathy Alliance
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Would the committee consider inserting such an assertion into this guidance along the following lines?

...The Committee was aware of the importance of collecting further data within registries including patients receiving biologic treatments for psoriatic arthritis to enable the collection of information on long-term outcomes including adverse events. In future a dedicated psoriatic arthritis data set or registry should be setup similar to those for psoriasis and rheumatoid arthritis as set up by the British Association of Dermatologist (BADBIR) and the British Society for Rheumatology (BSRBR)...

It would appear logical to me that it might be possible for those data to be collected via these existing registries, if appropriate outcomes were recorded, but I accept that NICE wouldn't be in a position to formally insist, as this would need to be appropriately discussed with the registry owners. Therefore, by mandating the need to collect data an appropriate solution might emerge, which collects data that is beneficial to current and future patients, when deciding on the risk benefits associated with biological therapies.

Thank you for considering this suggestion.

Yours sincerely

[Redacted signature]