# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## Patient/carer organisation submission (STA)

## Secukinumab for treating moderate to severe plaque psoriasis (ID718)

Thank you for agreeing to give us your views on this treatment that is being appraised by NICE and how it could be used in the NHS. Patients, carers and patient organisations can provide a unique perspective on conditions and their treatment that is not typically available from other sources. We are interested in hearing about:

- the experience of having the condition or caring for someone with the condition
- the experience of receiving NHS care for the condition
- the experience of having specific treatments for the condition
- the outcomes of treatment that are important to patients or carers (which might differ from those measured in clinical studies, and including health-related quality of life)
- the acceptability of different treatments and how they are given
- expectations about the risks and benefits of the treatment.

To help you give your views, we have provided a questionnaire. You do not have to answer every question — the questions are there as prompts to guide you. The length of your response should not normally exceed 10 pages.

## *1. About you and your organisation*

**Your name:** [redacted]

**Name of your organisation:** Psoriasis and Psoriatic Arthritis Alliance (PAPAA)

**Your position in the organisation:** [redacted]

**Brief description of the organisation:**

We are asking for your collective view as an organisation and will be asking patient experts for their individual input separately. If you have the condition, or care for someone with the condition, you may wish to complete a patient expert questionnaire to give your individual views as well.

(For example: who funds the organisation? How many members does the organisation have?)

PAPAA is a principal source of advice, support and information on psoriasis and psoriatic arthritis in the United Kingdom. PAPAA provides support to people with psoriasis and psoriatic arthritis, their families and carers. We also support healthcare professionals and assist the wider community to understand the needs of people affected by both conditions. The organisation maintains a register of people with/or interested in both conditions. The register currently has >13,000 people, and is free to join. The organisation has a strict funding policy and does not accept funding from pharmaceutical companies either directly, in kind or via third party agencies.

## *2. Living with the condition*

**What is it like to live with the condition or what do carers experience when caring for someone with the condition?**

Living with psoriasis for most people can be a trivial irritation and confined to small areas. For these individuals the use of intermittent topical applications or exposure to sunlight will be enough to maintain low levels of obvious psoriasis. However, some with such minimal disease will find it very difficult to cope with and the impact of the condition and where it is located on the exposed areas such as the hand or face may not equate to the severity of psoriasis when measured using tools such as the Psoriaisis Area Severity Index (PASI). Often the disease progresses and this minimal disease

becomes more widespread, but many still cope and contain the disease with modest use of topical applications. As the condition is life-long and often starts in teenage years the relentless remission/relapse cycle can be very difficult to cope with and during a flare can take a huge amount of dedicated self-treatment for a number of weeks or months. For many this can be too much and lead to untreated psoriasis. Even at this point, many people will quietly get on and hide the condition, avoid circumstances or events where they may be embarrassed by their skin or feel low and isolated. This can impact on family and friends as many people will also be aware that those around them might also be targeted for abuse or disgust by association with someone with scaly sore skin, this particularly impacts on parents of young children and can lead to avoidance of events such as swimming or outdoor activities. Choice of clothing is also effected and many will wear clothes which hide arms and legs and in colours and material which disguises the falling flakes of skin. There comes a point either soon after diagnosis or after many years of the condition being in this mild to moderate state, when the condition can become more severe or becomes impossible to self-treat, at this point escalation to more aggressive therapies are required. Although this may be what is needed, many feel apprehensive about such treatments. UV light or DMARDs such as methotrexate can be very worrying with adverse event risks being the main reason for reluctance to use these. Also, given the potential age of some of these individuals, concerns about fertility and conception and potential issues around skin cancer (light therapy) also play high on their minds. A common issue raised around the use of methotrexate for younger men is the avoidance of alcohol whilst on treatment. These issues may appear to be unimportant in the scheme of disease management, but can be a key influencer for people when making a decision to start a treatment that may have to be taken for many years. Psoriasis is a lonely disease and when flaring will impact everyday and every aspect of an individuals life. Once clear, the inevitable return is a worry, the impact on relationships and intimacy can cause tension, with low self-esteem, low mood and depression being commonly reported. This wide impact of quality of life and psychological impact should not be underestimated and is not only associated with the most severe forms of the disease.

## *3. Current practice in treating the condition*

**Which treatment outcomes are important to patients or carers? (That is, what would patients or carers like treatment to achieve?) Which of these are most important? If possible, please explain why.**

People with psoriasis would like to see an outcome, which leads to complete clearance and long-term remission in the shortest period. Adverse events also need to be minimal or at least not worse than the effects of psoriasis.

**What is your organisation's experience of currently available NHS care and of specific treatments for the condition? How acceptable are these treatments and which are preferred and why?**

Topical therapies for mild psoriasis can work but require dedication and consistent use on a daily basis for 4-6 weeks to see initial benefit. Light therapy also requires dedication with regular visits to a specialist centre for a number of days per week and for a number of weeks per year. This can be difficult for people who work although the sessions are short, the overall time can be considerable when taking into account the travel to and from hospital. Disease modifying drugs and newer biologic agents either oral or injection provide more convenient options, but have side effect profiles which many worry about.

## *4. What do patients or carers consider to be the advantages of the treatment being appraised?*

Benefits of a treatment might include its effect on:

- the course and/or outcome of the condition
- physical symptoms
- pain
- level of disability
- mental health
- quality of life (such as lifestyle and work)
- other people (for example, family, friends and employers)
- ease of use (for example, tablets rather than injection)
- where the treatment has to be used (for example, at home rather than in hospital)
- any other issues not listed above

**Please list the benefits that patients or carers expect to gain from using**

**the treatment being appraised.**

A key important issue for the treatment being appraised would be immediate and quick reduction of symptoms, with long-term reduction of symptoms, clearance and remission.

**Please explain any advantages that patients or carers think this treatment has over other NHS treatments in England.**

Some other treatments of similar class have a more frequent dosage regime. If this agent were to be used less often for maintenance after the initial doses that would be seen as being more convenient.

**If you know of any differences in opinion between patients or carers about the benefits of the treatment being appraised, please tell us about them.**

We have no information on this issue, as the treatment is not currently in general use.

## *5. What do patients and/or carers consider to be the disadvantages of the treatment being appraised?*

We do not have any information to answer this question.

Disadvantages of a treatment might include:

- aspects of the condition that the treatment cannot help with or might make worse
- difficulties in taking or using the treatment (for example, injection rather than tablets)
- side effects (for example, type or number of problems, how often, for how long, how severe. Please describe which side effects patients might be willing to accept or tolerate and which would be difficult to accept or tolerate)
- where the treatment has to be used (for example, in hospital rather than at home)
- impact on others (for example, family, friends and employers)
- financial impact on the patient and/or their family (for example, the cost of travel to hospital or paying a carer)
- any other issues not listed above

**Please list any concerns patients or carers have about current NHS treatments in England.**

The mess, smell and inconvenience of topical treatments is a major issue with patients, this in conjunction with an often lack of efficacy and unpredictability of who will benefit, concerns patients and carers. UV light therapy is often difficult to access or locally unavailable, carries risks of skin cancer, and is limited to a maximum lifetime exposure criteria. The side effect profiles of treatments such as methotrexate for younger people of child bearing age is a major concern, and can impact heavily on relationships and planning the future. There are still a large proportion of participants who do not achieve clearance or partial clearance with current therapies, this uncertainty of efficacy is a constant concern.

**Please list any concerns patients or carers have about the treatment being appraised.**

This drug is similar in action to others in the same class and patients are familiar with the need to self inject and how to store the drugs. As with other biologic agents, the long-term adverse event profile is unknown and patients will have concerns about these, therefore the need to be monitored through the BADBIR registry should be made mandatory. The availability and access to these therapies due to high cost is also a concern, many patients worry whether they will be available or restricted and therefore often feel that they are being denied a therapy that will be of benefit because of financial constraints, even if recommended by NICE.

**If you know of any differences in opinion between patients or carers about the disadvantages of the treatment being appraised, please tell us about them.**

We do not have any information on this question.

## *6. Patient population*

**Are there any groups of patients who might benefit more from the treatment than others? If so, please describe them and explain why.**

If there is any data to support added benefit to those with psoriatic arthritis, that could be seen as a benefit. If the drug is more effective for difficult to treat

types of psoriasis such as, scalp, nails, sensitive areas, guttate or palmoplantar, that could be seen as more beneficial.

**Are there any groups of patients who might benefit less from the treatment than others? If so, please describe them and explain why.**

Anyone who is likely to have a profile, which is more susceptible to the adverse events.

## *7. Research evidence on patient or carer views of the treatment*

**Is your organisation familiar with the published research literature for the treatment?**

☑ Yes ☐ No

**If you answered 'no', please skip the rest of section 7 and move on to section 8.**

**Please comment on whether patients' experience of using the treatment as part of their routine NHS care reflects the experiences of patients in the clinical trials.**

Not currently used in routine care but the drug in trial data appears to have similarities to other similar class agents.

**Do you think the clinical trials have captured outcomes that are important to patients? Are you aware of any limitations in how the treatment has been assessed in clinical trials?**

To a point, but given that clearance is highly rated by patients as an outcome low levels of complete clearance in the trial data may not meet patient expectations. With more drugs being trialled in psoriasis, there should be a higher emphasis on a target of clearance. An improvement of PASI 75, still leaves a patient with psoriasis, which although is a significant improvement is not clearance. Low levels of psoriasis still have an impact on people's quality of life.

**If the treatment being appraised is already available in the NHS, are there any side effects that were not apparent in the clinical trials but have emerged during routine NHS care?**

We do not have any information on this issue.

**Are you aware of any relevant research on patient or carer views of the condition or existing treatments (for example, qualitative studies, surveys and polls)?**

☐ Yes ☑ No

**If yes, please provide references to the relevant studies.**

## *8. Equality*

NICE is committed to promoting equality of opportunity, eliminating unlawful discrimination and fostering good relations between people with particular protected characteristics and others. Protected characteristics are: age; being or becoming a transsexual person; being married or in a civil partnership; being pregnant or having a child; disability; race including colour, nationality, ethnic or national origin; religion, belief or lack of religion/belief; sex; sexual orientation.

Please let us know if you think that recommendations from this appraisal could have an adverse impact on any particular groups of people, such as:

- excluding from full consideration any people protected by the equality legislation who fall within the patient population for which the treatment is/will be licensed;
- having 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 treatment;
- any adverse impact on people with a particular disability or disabilities.

**Please let us know if you think that there are any potential equality issues that should be considered in this appraisal.**

No

**Are there groups of patients who would have difficulties using the treatment or currently available treatments? Please tell us what evidence you think would help the Committee to identify and consider such impacts.**

No

## *9. Other issues*

**Do you consider the treatment to be innovative?**

☐ Yes ☑ No

**If yes, please explain what makes it significantly different from other treatments for the condition.**

**Are there any other issues that you would like the Appraisal Committee to consider?**

To consider the issue around sequencing of this therapy, by identifying which patients are more likely benefit. To give more weight and focus on the data which shows higher levels of clearance.

## *10. Key messages*

**In no more than 5 bullet points, please summarise the key messages of your submission.**

- Impact of psoriasis is not always linked to severity
- Clearance should be the goal
- Sequencing, who will benefit
- Difficult to treat disease is an unmet need
- Cost of drugs impacts on access