NICE National Institute for Health and Care Excellence

Professional organisation submission

Chlormethine gel for treating mycosis fungoides-type cutaneous T-cell lymphoma ID1589

Thank you for agreeing to give us your organisation's views on this technology and its possible use in the NHS.

You can provide a unique perspective on the technology in the context of current clinical practice that is not typically available from the published literature.

To help you give your views, please use this questionnaire. You do not have to answer every question – they are prompts to guide you. The text boxes will expand as you type.

Information on completing this submission

- Please do not embed documents (such as a PDF) in a submission because this may lead to the information being mislaid or make the submission unreadable
- We are committed to meeting the requirements of copyright legislation. If you intend to include **journal articles** in your submission you must have copyright clearance for these articles. We can accept journal articles in NICE Docs.
- Your response should not be longer than 13 pages.

About you	
1. Your name	**Julia Scarisbrick**
2. Name of organisation	**British Association of Dermatologists**

3. Job title or position	**Consultant Dermatologist and Lead Cutaneous Lymphoma Service Birmingham**
4. Are you (please tick all that apply):	☒ an employee or representative of a healthcare professional organisation that represents clinicians? ☒ a specialist in the treatment of people with this condition? ☒ a specialist in the clinical evidence base for this condition or technology? ☐ other (please specify):
5a. Brief description of the organisation (including who funds it).	**Professional body for UK dermatologists.**
4b. Has the organisation received any funding from the manufacturer(s) of the technology and/or comparator products in the last 12 months? [Relevant manufacturers are listed in the appraisal matrix.] If so, please state the name of manufacturer, amount, and	**No**

purpose of funding.	
5c. Do you have any direct or indirect links with, or funding from, the tobacco industry?	**No**
The aim of treatment for this condition	
6. What is the main aim of treatment? (For example, to stop progression, to improve mobility, to cure the condition, or prevent progression or disability.)	The population to treat would be all patients with CTCL with symptomatic or troublesome patch/plaque lesions of MF.
7. What do you consider a clinically significant treatment response? (For example, a reduction in tumour size by x cm, or a reduction in disease activity by a certain amount.)	
8. In your view, is there an	There is a huge unmet need for patients with patch / plaque lesions of MF which cause pain, itch, functional

unmet need for patients and healthcare professionals in this condition?	disability and disfigurement. There are few treatment options and after failure of topical steroids patients have either to come to hospital for courses of light treatment (phototherapy) which are limited in number as they cause other skin cancers with more frequent use or radiotherapy with significant local and long term side effects. A topical preparation which is effective and safe is needed. Patients with CTCL have painful, itchy and often unsightly skin lesions and as a result suffer a reduced HRQoL [ref 1,2]. This is compounded by living with an incurable cancer with a lack of effective treatments. Most treatments result in only partial responses of short duration (<1 year) so patients consequently have active lesions throughout [ref 3]. Those with earlier stages often exhaust the small repertoire of anti-CTCL treatments and have to be managed with supportive therapy alone. 1. Molloy K, Jonak C, Woei-A-Ji S, Guenova E, Busschots A, Bervoets A, Hauben E, Knobler R; Stefanie Porkert; ard Cowan, Evangelina Papadavid, Marie Beylot-Barry, Peng C, Howles A, Yoo J, Evison F, Scarisbrick J. Characteristics associated with significantly worse quality of life in mycosis fungoides/Sézary syndrome from the Prospective Cutaneous Lymphoma International Prognostic Index (PROCLIPI) study. Br J Dermatol epub 2019 2. Constanze Jonak, Stefanie Porkert, Simone Oerlemans, Evangelia Papadavid, Kevin Molloy, Eva Lehner-Baumgartner, Antonio Cozzio, Fabio Efficace, Julia Scarisbrick. Health-related quality of life in cutaneous lymphomas: past, present and prospective. Acta Derm 2019;99(7):640-646 3. Gilson D, Whittaker S, Child F, Scarisbrick J, Illidge T, Parry E, Rezvani K, Dearden C, Morris S. British Association of Dermatologists and UK Cutaneous Lymphoma Group Guidelines for the Management of Primary Cutaneous Lymphomas. *Br J Dermatol.* 2019 Mar;180(3):496-526
What is the expected place of the technology in current practice?	
9. How is the condition currently treated in the NHS?	
• Are any clinical	

guidelines used in the treatment of the condition, and if so, which?	
• Is the pathway of care well defined? Does it vary or are there differences of opinion between professionals across the NHS? (Please state if your experience is from outside England.)	
• What impact would the technology have on the current pathway of care?	
10. Will the technology be used (or is it already used) in the same way as current care in NHS clinical practice?	
• How does healthcare resource use differ between the technology and current care?	

• In what clinical setting should the technology be used? (For example, primary or secondary care, specialist clinics.)	
• What investment is needed to introduce the technology? (For example, for facilities, equipment, or training.)	
11. Do you expect the technology to provide clinically meaningful benefits compared with current care?	
• Do you expect the technology to increase length of life more than current care?	
• Do you expect the technology to increase health-related quality of life more than current care?	

12. Are there any groups of people for whom the technology would be more or less effective (or appropriate) than the general population?	
The use of the technology	
13. Will the technology be easier or more difficult to use for patients or healthcare professionals than current care? Are there any practical implications for its use (for example, any concomitant treatments needed, additional clinical requirements, factors affecting patient acceptability or ease of use or additional tests or monitoring needed.)	

14. Will any rules (informal or formal) be used to start or stop treatment with the technology? Do these include any additional testing?	
15. Do you consider that the use of the technology will result in any substantial health-related benefits that are unlikely to be included in the quality-adjusted life year (QALY) calculation?	
16. Do you consider the technology to be innovative in its potential to make a significant and substantial impact on health-related benefits and how might it improve the way that current	

need is met?	
• Is the technology a 'step-change' in the management of the condition?	
• Does the use of the technology address any particular unmet need of the patient population?	
17. How do any side effects or adverse effects of the technology affect the management of the condition and the patient's quality of life?	
Sources of evidence	
18. Do the clinical trials on the technology reflect current UK clinical practice?	
• If not, how could the results be extrapolated to	

the UK setting?	
• What, in your view, are the most important outcomes, and were they measured in the trials?	Yes, add pruritus score, the assessment should be of clinical benefit this may include various clinical responses from stable disease 0-50% improvement plus better HRQL, to partial responses >50% or occasional CR 100% better
• If surrogate outcome measures were used, do they adequately predict long-term clinical outcomes?	
• Are there any adverse effects that were not apparent in clinical trials but have come to light subsequently?	
19. Are you aware of any relevant evidence that might not be found by a systematic review of the trial evidence?	
20. Are you aware of any new evidence for the comparator treatment(s) since the	The best comparators would be phototherapy, bexarotene of sc interferon alpha – but all have a completely different side effect profile and application / dosing/ monitoring

publication of NICE technology appraisal guidance [TA577]?	
21. How do data on real-world experience compare with the trial data?	
Equality	
22a. Are there any potential equality issues that should be taken into account when considering this treatment?	
22b. Consider whether these issues are different from issues with current care and why.	
Key messages	

23. In up to 5 bullet points, please summarise the key messages of your submission.

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Thank you for your time.

Please log in to your NICE Docs account to upload your completed submission.

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