National Institute for Health and Clinical Excellence

Psoriasis Quality Standard Consultation Comments Table

| ID | SH ID | Stakeholder | Statement No | Comments Please insert each new comment in a new row. | Responses |
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| 001 | 001 | Lancashire Care NHS Foundation Trust | General | Because there is no QOF attached to dermatology we have a concern the CVD risk factors are likely to get missed | Thank you. Going forward, QOF indicators will be based on NICE guidance and quality standards. Therefore, following publication of the psoriasis quality standard, further work will be done by NICE to determine whether any suitable QOF indicators can be developed. |
| 002 | 001 | Lancashire Care NHS Foundation Trust | General | We agree with the standards generally, the number, wording etc | Thank you. |
| 003 | 003 | NHS Commissioning Board | General | Most patients with psoriasis do not seek medical advice, but when they do around 60% require specialist assessment. It is not clear whether the standard will seek to ensure that everyone with the condition will be offered an assessment of disease severity, an assessment of the impact of the disease on physical, psychological and social wellbeing and an annual assessment for psoriatic arthritis. It would be helpful to specify the cohort involved (eg. those recorded on the GP database as having the condition) | Thank you. Unless specifically stated otherwise, the statements refer to all people with psoriasis, which we would anticipate are recorded as such on GP databases. |
| 004 | 004 | Primary Care Dermatology Society | General | We at the PCDS are very disappointed that Dermatology does not have a specific Domain presence since it is a major cause of morbidity of all types, occupying up to a part of a quarter of all GP consultations. It has an acute and chronic component to the presentation and management in both primary and secondary care. No statements regarding how we think Psoriasis should be managed and measured will have significant effect without financial incentives such as inclusion in Quality Outcomes Framework (QOF.) Placing yet more requirements for assessments and demonstrations of adherence to complex standards may have a reverse effect of passing on the responsibility by increased referrals to a specialist service. We note the use of "specialists or specialist services" in the document but do not see a definition of what this may comprise. In particular we are concerned that accreditation and re-accreditation of all consultant and GPs with a Special Interest (GPwSI) services is key to an effective and integrated service. | Thank you. Going forward, QOF indicators will be based on NICE guidance and quality standards. Therefore, following publication of the psoriasis quality standard, further work will be done by NICE to determine whether any suitable QOF indicators can be developed. Please see the definition section of statement 3 in the final quality standard, where specialist assessment has now been defined. |
| 005 | 004 | Primary Care Dermatology Society | General | There are areas where the use of interpreters is being severely restricted by local authorities and GPs cannot be required to provide what is not available. Translations of questionnaires are not available in all likely | Thank you. Good communication is an essential element of high quality care and information should be available in an accessible format to those who do not speak English, |

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| 006 | 004 | Primary Care Dermatology Society | General | languages. We feel the availability of specialist services may prejudice the ability of GPs to adhere to referral standards. There needs to be a caveat of "where available" for individual GPs but not for Commissioners. | through access to an interpreter if necessary. Thank you. While 100% compliance may not be possible in all areas immediately, the quality standards aim to encourage quality improvement through the commissioning of high quality services by setting 'aspirational but achievable' goals. NICE has produced a support document to help commissioners and others consider the commissioning implications and potential resource impact of this quality standard, available from www.nice.org.uk. |
| 007 | 005 | Dermal Laboratories | General | "Adults with severe psoriasis are offered a cardiovascular risk assessment at initial presentation and at least every 5 years." This quality statement could contribute to Domain 1 of the NHS Outcomes Framework – Preventing people from dying prematurely, in addition to Domains 2 and 4. Evidence statements to support not only increased risk of developing cardiovascular risk factors but also increased risk of dying from these risk factors in people with psoriasis can be found within the NICE full psoriasis guideline. "[Cardiovascular] risk is greater among those with more severe psoriasis" "The studies investigating risk factors for cardiovascular diseases suggest that people with psoriasis are at increased risk of developing cardiovascular risk factors (i.e., diabetes, hypertension, hyperlipidaemia and obesity) and death from cardiovascular risk factors compared to people without psoriasis" Within the BAD and Multi-Stakeholder developed document, Outcomes for Skin Disease, a proposed outcome within Domain 1 is a "Reduction of death due to co-morbidities of skin disease". The aim of which is to reduce cardiovascular mortality in people with chronic moderate to severe inflammatory skin disease. http://www.bad.org.uk/Portals/_bad/outcomes%20for%20skin%20Disease%20Jan%202011.pdf | Thank you. The outcomes, overarching indicators and improvement areas referenced from the frameworks are those which we believe the quality standard could contribute towards achieving. Whilst we acknowledge that studies reviewed in the NICE guideline suggest that people with psoriasis may be at greater risk of death from cardiovascular risk factors, we are unable to propose that achieving the quality standard will directly impact upon those indicators; for example the quality standard does not contain actions or interventions that would directly impact upon mortality. We acknowledge that there are many other areas that care will impact upon, and we are currently in the process of assuring our methods of linking quality standards to the outcomes framework with NHS England's domain directors. |
| 008 | 006 | British Association of Dermatologists | General | The quality standards contain dermatologists-endorsed comments and suggestions including 'a person-centered and integrated approach to provision of care' and acknowledgement that commissioners should take standards of care into consideration when designing services is particularly helpful. Further clarification of 'integrated' to include multidisciplinary teams including access to allied specialists such as nurses, rheumatologists, psychologists, phototherapists, GPs, etc. in addition to a dermatologist when indicated would enable the development of services to address the wider needs of patients with psoriasis. However, these | Thank you. The quality standard states that psoriasis services should be coordinated across all relevant agencies encompassing the care pathway. This would include between primary and secondary care as well as amongst all healthcare professionals involved in the care. We would anticipate that, together with the underpinning guideline, the quality standard can serve to raise awareness of the disease and its wider impact on patients. |

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| | | | | quality standards need to include equitable access to NICE-approved treatments which is where resources should be focused. | Equitable access to NICE-approved treatments is considered to be covered by the NHS Constitution, which mandates compliance with NICE technology appraisals (and is therefore 'another lever in the system' to address this issue). |
| 009 | 800 | Psoriasis Association | General | The Psoriasis Association largely welcomes the Draft Quality Standard on Psoriasis. It is much needed and relevant due to the multi-faceted nature of the disease, and range of care required to treat appropriately across a lifetime. | Thank you. |
| 010 | 008 | Psoriasis Association | General | The Psoriasis Association welcomes the acknowledgement for need to assess and manage psoriasis, however the Draft Quality Standard appears to concentrate more on assessment. | Thank you. The Quality Standards Advisory Committee considered that assessment was a key issue for quality improvement in the care of people with psoriasis, and that if the quality of assessment was improved, better management would follow. |
| 011 | 008 | Psoriasis Association | General | Whilst we notice the Quality Standard covers "psoriasis", and there is passing mention of acute guttate psoriasis, nail psoriasis, and the rarer generalised pustular psoriasis and erythroderma, there is no mention of palmoplantar pustulosis; a distressing, painful and difficult to treat condition that can impact on ability to work. | Thank you. Unless specifically stated otherwise, the statements refer to all people with psoriasis. NICE clinical guideline 153, which underpins the quality standard, covers the specific treatment of different types of psoriasis in more detail. |
| 012 | 008 | Psoriasis Association | General | We welcome the statement "A person-centred and integrated approach to provision of services" – however feel that the integration should be more explicit in definition. For example, is the integrated approach between primary and secondary care? Or is it an integrated approach amongst the healthcare professionals a person with psoriasis should have access to, such as GP, Dermatologist, Psychologist, Rheumatologist etc? | Thank you. The quality standard states that psoriasis services should be coordinated across all relevant agencies encompassing the care pathway. This would include between primary and secondary care as well as amongst all healthcare professionals involved in the care. |
| 013 | 010 | Psoriasis and Psoriatic Arthritis Alliance | General | This submission is based on comments made by people with psoriasis who are in contact with PAPAA. In that context some comments may fall outside the remit of the standard, but we felt it would be useful to include them since our understanding is that the quality standard is also for patients to use as a measure of service provision. PAPAA welcomes the progress being made for people with psoriasis and psoriatic arthritis and the development of objective standards of care, which can be measured. There is a need for psoriasis (and psoriatic arthritis) to be recognised as a significant disease, which may have a large impact on an individual's quality of life. | Thank you. NICE quality standards will be of interest to patients, carers and the public, as well as health and social care workers, provider organisations and commissioners, and we welcome feedback from all stakeholders. We would anticipate that, together with the underpinning guideline, the quality standard can serve to raise awareness of the disease and its wider impact on patients. |
| 014 | 010 | Psoriasis and Psoriatic Arthritis Alliance | General | Introduction: Although this section mentions the impact on the patient, employment and income, there is no reference to the potential impact on family life and/or relationships. There is a mention of 'highly visible' sites and associated stigma, but this does not give a complete picture. The side-effects associated with some treatments, for example the shedding of skin, can put a significant strain on the patient and on those around | Thank you. This is an introductory section designed to give a brief overview of the disease, its prevalence and management. Unless specifically stated otherwise, the statements refer to all people with psoriasis. NICE clinical guideline 153, which underpins the quality standard, covers the issues around specific disease location in |

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| | | | No | Please insert each new comment in a new row. him/her. In some cases this results in poor adherence to treatment and worse outcomes, with further strain on family and working relationships. The magnitude of the psychosocial load imposed by psoriasis in this way is too often under-estimated. The location of psoriasis in any individual case can also be a source of embarrassment, which may make the patient less likely to seek expert advice or to talk to family and friends. For example, statistics from our charity website www.papaa.org show that searches on genital psoriasis are easily the most common. It is therefore not unreasonable to assume that this problem is highly prevalent, under-diagnosed and therefore under-treated. Hence, a standard which includes careful attention to the location of disease as well as the diagnosis might be worth considering. Domain 2 of the NHS outcomes framework - "Enhancing Quality of Life for People with Long-Term Conditions" - certainly appears to fit these issues. | more detail. |
| 015 | 010 | Psoriasis and Psoriatic Arthritis Alliance | General | Section 2: This section does appear to be rather general, which may be intentional. However, there doesn't appear to be any direction as to who will be assuming responsibility of long-term care. From a patient perspective it isn't clear what to expect, since there could be differences in local care provision, depending on what commissioners decide. In circumstances where psoriasis treatment is given a low priority, it will be difficult for any individual to know whether the care they are offered is sub-optimal or simply the norm. It would be helpful if the standard included a clear statement of what a minimal standard of treatment would look like. | Thank you. This is an introductory section which is included within each quality standard. It is the individual quality statements which illustrate what high quality care should look like and so do not address minimal standards of care. |
| 016 | 011 | Pfizer Ltd | General | Pfizer would like to thank NICE for the opportunity to respond to the draft quality standard for psoriasis and we very much support its development. This is an important document to help ensure that any potential inappropriate variance in managing patients with psoriasis is mitigated. In order for the quality standard to realise the aspirations it will be essential that providers plan and have the capacity and resource to deliver the quality measures. Additionally, it is important that the quality standard is future proofed, such that it is aligned to the health technology appraisal process to minimise the need for updating. | Thank you. NICE has produced a support document to help commissioners and others consider the commissioning implications and potential resource impact of this quality standard, available from www.nice.org.uk . NICE quality standards will be reviewed every 5 years. |
| 017 | 013 | LEO | General | As highlighted in the initial engagement exercise, LEO still believe that "People with psoriasis should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professional" is a key area for quality improvement. We believe quality statement 5 in the Chronic heart failure quality standard (NICE QS9) to be similar and therefore suggest similar wording for a psoriasis statement. | Thank you. Patient choice and shared decision-making are important themes for all NHS care. The NICE quality standard on 'patient experience in adult NHS services', which is cross-cutting and referenced in this quality standard, covers this area in more detail. |

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| | | | | Evidence suggests that when patients' needs and preferences are taken into account, adherence to their care pathway is improved. This not only improves patient outcomes but potentially reduces unnecessary visits to health care professionals and reduces the volume of wasted or unused medicines. | |
| 018 | 014 | University of Manchester (impact) | General | The Identification and Management of Psoriasis Associated ComorbidiTy (IMPACT) study is a research collaboration between the University of Manchester, Salford Royal NHS Foundation Trust, 3 Primary Care Trusts across the North West of England and the Psoriasis Association. It is funded by the National Institute of Health Research (NIHR). The IMPACT study aims to develop care and training packages to improve self care and access to targeted high quality services for people with psoriasis. For further information please visit www.impactpsoriasis.org.uk The quality standards (QS) are a welcome addition to the clinical guideline and NICE is to be commended for producing this standard setting document. | Thank you. |
| 019 | 014 | University of Manchester (impact) | General | It is particularly helpful to see the QS mapping onto the NHS Outcomes Framework so clearly. We feel it could have also included the 'No Health Without Mental Health' strategy. | Thank you. We are currently in the process of assuring our methods of linking quality standards to the outcomes framework with NHS England's domain directors. |
| 020 | 014 | University of Manchester (impact) | General | We welcome the emphasis on competency based training for healthcare professionals. It is not sufficient to assume health professionals have the knowledge or skills to implement these standards without training. A recent qualitative study (Nelson et al., 2013 submitted [1]) found that general practitioners varied in their confidence to assess and manage psoriasis as a long-term condition, and often felt they had limited understanding of the condition and its impact upon patients. | Thank you. |
| 021 | 014 | University of Manchester (impact) | General | Section 4: We feel that the wording of the first paragraph is ambiguous and suggests the QS as markers of high quality care are actually optional and could easily be ignored. Furthermore, while they are 'intended to improve structures, processes and outcomes of care in areas identified as requiring quality of improvement', they will fall short of achieving this in the area of psychological care for people with psoriasis, a well documented area of very poor quality service provision. We would ask the team to revisit this important area of patient care and word the QS in line with the needs of patients in this specific area. 1. P A Nelson, Z Barker, CEM Griffiths, L Cordingley, C A Chew-Graham 'On the surface': a qualitative study of GPs' and patients' perspectives on psoriasis' Submitted for review to British Journal of General Practice March 2013 | Thank you. Quality standards are not mandatory and it is important that they are considered alongside the guidelines on which they are based. The Quality Standards Advisory Committee anticipated that improved assessment of the impact of psoriasis on physical, psychological and social wellbeing would improve access to specialist psychological support for those people who may benefit from it (please see statement 2 in the final quality standard). |

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| | | | | Zigmond, A.S. & Snaith, R.P. (1983). "The hospital anxiety and depression scale". Acta Psychiatrica Scandinavica 67 (6): 361–370 Finlay, A. Y., & Khan, K. G. (1994). Dermatology Life Quality Index: a simple practical measure for routine clinical use. Clinical and Experimental Dermatology, 19(3), 210-216 Nelson, P. A., Chew-Graham, C. A., Griffiths, C. E. M., Cordingley, L., & on behalf of the IMPACT Team. (2013). Recognition of need in health care consultations: a qualitative study of people with psoriasis. British Journal of Dermatology, 168(2), 354-361. Beresford, A. (2002). Psoriasis Association Members Questionnaire: Report prepared by independent market researcher. Northampton, UK: Psoriasis Association. Shaw, C., Abrams, K., & Marteau, T. M. (1999). Psychological impact of predicting individuals' risks of illness: a systematic review. Social Science & Medicine, 49(12), 1571-1598 | |
| 022 | 016 | Novartis Pharmaceuticals | General | The 6 Quality Statements in the Quality Standard appear to relatively general and do not provide guidance on referral times, diagnosis rates and time progressing through the treatment pathway. | Thank you. NICE Quality Standards define priority areas for quality improvement and illustrate what high quality care should look like. They do not provide a comprehensive service specification or prescribe local service delivery arrangements. |
| 023 | 018 | AbbVie Ltd | General | AbbVie welcomes the Quality Standard on Psoriasis and its focus on driving consistent, high quality care for patients. A Quality Standard is particularly relevant for psoriasis due to the multi-faceted nature of the disease and the range of care that may be appropriate for its treatment. Evidence has demonstrated the significant impact that psoriasis can have on a person's emotional and physical wellbeing. The multi-faceted nature of psoriasis means the effects go beyond visual signs and symptoms. It can impact on emotional and physical wellbeing and in some people it is associated with depression, anxiety and suicidal thoughts, particularly in those affected with more severe psoriasis. Sandard's recognition of the need for an integrated approach to psoriasis treatment, but also | Thank you. Outcome measures are stated where the Quality Standards Advisory Committee felt these were appropriate, measurable and specifically attributable to the action in the statement. Each statement is followed by a rationale section which provides a brief explanation for why the statement is important, with some reference to the outcomes that the action referred to in the statement has a potential causal link to. The statements aim to be concise, precise and measurable. The quality standard is based upon, and derived from NICE Clinical guideline 153, and is underpinned by its recommendations. NICE quality standards do not replace |

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| | | | NO | believes that it should include explicit reference to the relevant specialisms. Furthermore, AbbVie considers that the quality statements included in the draft need to more specific and objective in healthcare outcome measures to ensure that high quality care is being achieved and that the standard of care is accurately measurable. AbbVie understands that many of the Quality Statements are further detailed in the "definitions" section but considers there is a need to include some of this definition into the individual statement to avoid subjectivity. Where appropriate, a recommendation of specific outcome measure relating to each quality statement has been made below. In addition, AbbVie considers that there should be more reference made to the recently published NICE Clinical Guideline 153 within the Quality Statements to set a benchmark of aspects of quality care in the management of psoriasis. AbbVie welcomes the reference in section 2 to a "person-centred and integrated approach to provision of services" and believes that details of what such an integrated approach should include ought to be explicit within the quality standard and reflected throughout. Due to the multifaceted nature of psoriasis, it is essential that psoriasis patients have access to a full range of services including a specialist dermatologist, rheumatologist, dietitian, cardiologist and psychologist when required. The Quality Standard should therefore include explicit reference to all of these specialisms. | existing guidance, and the guideline is referenced as the key development source for the quality standard. The quality standard states that psoriasis services should be coordinated across all relevant agencies encompassing the care pathway. This would include between primary and secondary care as well as amongst all healthcare professionals involved in the care. NICE Quality Standards define priority areas for quality improvement and illustrate what high quality care should look like. They do not provide a comprehensive service specification or prescribe local service delivery arrangements. |
| 024 | 020 | See Psoriasis Look Deeper | General | The See Psoriasis Look Deeper Collaboration welcomes the Quality Standard on Psoriasis and its focus on driving consistent, high quality care for patients. See Psoriasis Look Deeper is a collaboration formed in 2012 to address the link between psoriasis and mental health. The Collaboration consists of The Psoriasis Association; Mental Health Foundation; Dr Sandy McBride, Consultant Dermatologist at Royal Free Hampstead NHS Trust; and Dr Christine Bundy, Senior Lecturer in Behavioural Medicine at the University of Manchester. The Collaboration is funded by AbbVie Ltd. More information and a copy of the See Psoriasis Look Deeper report can be found here. The Quality Standard is a welcome addition to the clinical guideline and NICE is to be commended for producing this standard setting document. It is particularly helpful to see the Quality Standard mapping onto the NHS Outcomes Framework so clearly. We feel it could have also included the No Health Without Mental Health strategy. The Quality Standard contains many welcomed comments and suggestions including 'a person-centered and integrated approach to | Thank you. We are currently in the process of assuring our methods of linking quality standards to the outcomes framework with NHS England's domain directors. The quality standard states that psoriasis services should be coordinated across all relevant agencies encompassing the care pathway. This would include between primary and secondary care as well as amongst all healthcare professionals involved in the care. We would anticipate that, together with the underpinning guideline, the quality standard can serve to raise awareness of the disease and its wider impact on patients. |

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| | | | | provision of care', and acknowledgement that commissioners should take standards of care into consideration when designing services is particularly helpful. We suggest that details of what such an integrated approach ought to consist of be explicit within the quality standard: to include multi-disciplinary teams including access to allied specialists such as nurses, rheumatologists, psychologists, phototherapists, GPs, dietician, cardiologist etc. in addition to a dermatologist. This would enable the development of services to address the wider needs of patients with psoriasis. We welcome the emphasis on competency based training for healthcare professionals. It is not sufficient to assume health professionals have the knowledge or skills to implement these standards without training. | |
| 025 | 020 | See Psoriasis Look Deeper | General | Section 4: We feel that the wording of the first paragraph is ambiguous and suggests the Quality Standard as a marker of high quality care is actually optional and could easily be ignored. Furthermore, while it is 'intended to improve structures, processes and outcomes of care in areas identified as requiring quality of improvement', it will fall short of achieving this in the area of psychological care for people with psoriasis, a well documented area of very poor quality service provision. We would ask the team to revisit this important area of patient care and word the Quality Standard in line with the needs of patients in this specific area. | Thank you. Quality standards are not mandatory and it is important that they are considered alongside the guidelines on which they are based. The Quality Standards Advisory Committee anticipated that improved assessment of the impact of psoriasis on physical, psychological and social wellbeing would improve access to specialist psychological support for those people who may benefit from it (please see statement 2 in the final quality standard). |
| 026 | 021 | Royal College of Physicians | General | The quality standards contain dermatologists-endorsed comments and suggestions including 'a person-centered and integrated approach to provision of care' and acknowledgement that commissioners should take standards of care into consideration when designing services is particularly helpful. Further clarification of 'integrated' to include multidisciplinary teams including access to allied specialists such as nurses, rheumatologists, psychologists, phototherapists, GPs, etc. in addition to a dermatologist when indicated would enable the development of services to address the wider needs of patients with psoriasis. However, these quality standards need to include equitable access to NICE-approved treatments which is where resources should be focused. | Thank you. The quality standard states that psoriasis services should be coordinated across all relevant agencies encompassing the care pathway. This would include between primary and secondary care as well as amongst all healthcare professionals involved in the care. We would anticipate that, together with the underpinning guideline, the quality standard can serve to raise awareness of the disease and its wider impact on patients. Equitable access to NICE-approved treatments is considered to be covered by the NHS Constitution, which mandates compliance with NICE technology appraisals (and is therefore 'another lever in the system' to address this issue). |
| 027 | 009 | Lilly UK | Question 1 | Other established patient reported outcomes in Psoriasis that could be included to measure the quality of life include: Psoriasis Scalp Severity Index to measure impact on the scalp and Nail Psoriasis Severity Index to assess the impact on nails. | Thank you. Outcome measures are stated where the Quality Standards Advisory Committee felt these were appropriate, measurable and specifically attributable to the action in the statement, and as each statement applies to all people with psoriasis, specific outcomes relating to scalp and nails have not been explicitly stated. |

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| | | | | | However, it is assumed that they will form part of disease severity assessment for people in whom these areas are affected by psoriasis. |
| 028 | 011 | Pfizer Ltd | Question 1 | We believe that it is important that within the primary care setting patients assessment for their psoriasis should be assessed at a minimum with both the Physicians Global Assessment and Patients Global Assessment. The assessment should be routinely carried out. As per NICE clinical guideline 152, patients should be referred to a specialist in the case of: • There is diagnostic uncertainty or • Any type of psoriasis is severe or extensive, for example more than 10% of the body surface is affected or • Any type of psoriasis cannot be controlled with topical therapy or • Acute guttate psoriasis requires phototherapy (see recommendation 1.4.1.1) or • Nail disease has a major functional or cosmetic impact or • Any type of psoriasis is having a major impact on a person's physical, psychological or social wellbeing. Within the secondary setting, Psoriasis Area and Severity Index (PASI) and Dermatology Life Quality Index, should be used routinely to assess the effectiveness of treatment and disease severity. OS2: There are a number of assessment tools we believe should be considered when assessing the physical, psychological and social wellbeing impact of the disease. These should be described and include Dermatology Life Quality Index (DLQI) or Children's Dermatology Life Quality Index (CDLQI) for young people in the specialist setting or non specialist setting where practical, Hospital Anxiety and Depression Scale (HADS) in non specialist setting. Assessments should be routinely completed. QS3: Outcome is the number of patients referred to specialist care as per NICE clinical guideline 152. QS4: Offer adults with severe psoriasis any type of validated cardiovascular risk assessment at presentation. Offer further assessment of cardiovascular risk every 5 years, or more frequently, if indicated following assessment, as Psoriasis patients are at increased risk of cardiovascular disease. Outcome would be number of patients who have received an appropriate | Thank you. Please see statement 1 in the final quality standard which references use of the Physician's Global Assessment and Patient's Global Assessment tools. Statement 2 includes reference to the Dermatology Life Quality Index and Children's Dermatology Life Quality Index, as per the underpinning NICE Clinical Guideline 153. Statement 3 in the final quality standard addresses the indications for referral for assessment by a specialist, and will measure the proportion of people referred. Please see statement 4 in the final quality standard, which will measure the proportion of people with severe psoriasis receiving a cardiovascular risk assessment. Statement 5 will measure the proportion of people receiving annual assessment for psoriatic arthritis, as per the underpinning guideline recommendation, and statement 6 will measure the number of people on systemic therapy being monitored appropriately. |

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| 029 | 014 | University of Manchester (impact) | Question 1 | Please insert each new comment in a new row. cardiovascular risk assessment QS5: People with PsO should be offered at least an annual assessment for psoriatic arthritis (PsA) using a diagnostic tool such as Psoriasis Epidemiological Screening Tool (PEST) [note children with PsO should also be screened for PsA]. This assessment should take place regardless of severity of PsO. We question whether a six monthly as opposed to a yearly screening would be more appropriate as one of the major issues with PsA is the length of time a patient presenting with PsA is referred and subsequently diagnosed by a rheumatologist Outcomes would be the number of PsO patients assessed for PsA and the number of patients referred through to a rheumatologist when presenting with PsA. QS6: Patients using systemic treatment should be monitored against national guidance and guidelines and local guidelines in order to maximise the potential beneficial effects of systemic treatments. National registers should also be considered to help monitor use of systemic treatments. Other outcomes for this draft quality measure should include: Number of patients who qualify for systemic treatment (systemic and biologic therapy) Number of patients receiving the appropriate systemic treatment. Number of patients receiving biologic therapy Specifying the important healthcare outcomes for each individual QS are essential to ensuring they are implemented. While dermatologists may be mainly focused on disease activity, patients will be focussed on the impact of the disease on their functioning in life in general. The use of patient reported outcomes must be integrated with clinician reported outcomes. Distress is an important and often overlooked health outcome but needs to form part of the dermatology specialist's assessment and management strategy. Only validated measures should be used to assess and direct care. The Hospital Anxiety and Depression Scale (HADS - Zigmond & Snaith 1983 [2]) is a well validated, easy to use screening measure of dist | Thank you. Please see statement 2 in the final quality standard, which addresses assessment of the impact of the disease on physical, psychological and social wellbeing, and references assessment tools which may support this, as per the underpinning guideline recommendations. |
| | | | | to form part of the dermatology specialist's assessment and management strategy. Only validated measures should be used to assess and direct care. The Hospital Anxiety and Depression Scale (HADS - Zigmond & Snaith 1983 [2]) is a well validated, easy to use screening measure of | |

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| 020 | 020 | Can Dagrigain Look Dagray | Ougation 1 | a distress scale in the DLQI. | Thank you Diagon and statement 2 in the final quality |
| 030 | 020 | See Psoriasis Look Deeper | Question 1 | Specifying the important healthcare outcomes for each individual quality statement is essential to ensure they are implemented. While dermatologists may be mainly focused on disease activity, patients will be focussed on the impact of the disease on their functioning in life in general. The use of patient reported outcomes must be integrated with clinician reported outcomes. Distress is an important and often overlooked health outcome but needs to form part of the dermatology specialist's assessment and management strategy. Only validated measures should be used to assess and direct care. The Hospital Anxiety and Depression Scale (HADS - Zigmond & Snaith 1983) is a well validated, easy to use screening measure of distress and is well used in psoriasis research, it could be recommended for clinical use also. The DLQI is a broad measure of the impact of psoriasis on wider functioning and, in the absence of a more comprehensive measure could be recommended, especially if used in conjunction with the HADS to supplement the lack of a distress scale in the DLQI. Specific measures for the draft quality statements would be: 1. PASI (secondary care) % surface area and assessment of inflammation (primary care). 2. DLQI and HADS (primary and secondary care), 3. DLQI >5, or >5% surface area affected or a special site affected (face, hands/feet, or genitals). 4. Annual PEST questionnaire. | Thank you. Please see statement 2 in the final quality standard, which addresses assessment of the impact of the disease on physical, psychological and social wellbeing, and references assessment tools which may support this, as per the underpinning guideline recommendations. Statements 1 and 4 also reference the relevant assessment tools. |
| 031 | 003 | NHS Commissioning Board | Question 2 | The standards will ensure that patients with psoriasis are assessed at each stage of the care pathway across a range of measures and this is welcome. However there is no mention in the standard of linking this assessment to treatments that patients can expect to receive. Patients should be able to expect that following assessment, management will be in accordance with the relevant guideline (NICE clinical guideline 153). Previous studies have demonstrated an inequity of access to specialist treatments for people with psoriasis. The NICE guidance seeks to address this and the quality standard needs to demonstrate that the implementation of the guideline has reduced this inequality. | Thank you. The Quality Standards Advisory Committee considered that assessment was a key issue for quality improvement in the care of people with psoriasis, and that if the quality of assessment was improved, better management would follow (in line with the underpinning guideline recommendations). Equitable access to NICE-approved treatments is considered to be covered by the NHS Constitution, which mandates compliance with NICE technology appraisals (and is therefore 'another lever in the system' to address this issue). |
| 032 | 003 | NHS Commissioning Board | Question 2 | Continuing with the theme of the need for assessment to lead to improved quality of care, assessment of psychological morbidity needs to be linked to treatments offered and improvement in psychological wellbeing. | Thank you. The Quality Standards Advisory Committee anticipated that improved assessment of the impact of psoriasis on physical, psychological and social wellbeing would improve access to specialist psychological support for those people who may benefit from it (please see statement 2 in the final quality standard). |
| 033 | 005 | Dermal Laboratories | Question 2 | General comment about areas of care not covered in the draft quality | Thank you. Equitable access to NICE-approved |

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| | ID | | No | standard. In the NICE Psoriasis Clinical Guideline (CG153) all key priorities for implementation have been covered by quality statements in the Quality Standard with the exception of Topical therapy and Phototherapy. "Topical therapy: general recommendations Offer practical support and advice about the use and application of topical treatments. Advice should be provided by healthcare professionals who are trained and competent in the use of topical therapies. Support people to adhere to treatment in line with Medicines adherence (NICE clinical guideline 76)." "Phototherapy (broad- or narrow-band ultraviolet B light) Offer narrowband ultraviolet B (UVB) phototherapy to people with plaque or guttate-pattern psoriasis that cannot be controlled with topical treatments alone. Treatment with narrowband UVB phototherapy can be given 3 or 2 times a week depending on patient preference. Tell people receiving narrowband UVB that a response may be achieved more quickly with treatment 3 times a week." We believe that two separate quality statements should be included in the Psoriasis Quality Standard. 1. Topical therapy – Treatment, education & support For most people psoriasis is managed in primary care with topical therapy prescribed as first line treatment. For optimum use of topical treatments patients should be provided with support and advice/education about the treatments and the disease itself by suitably trained healthcare professionals. Support for inclusion of a quality statement for effective topical therapy can be sourced from the NICE psoriasis clinical guideline. "One of the principles of care in the NICE guidance is to offer people with any type of psoriasis (and their families or carers), support and information tailored to suit their individual needs and circumstances, in a range of different formats so they can confidently understand • Their diagnosis and treatment options • Relevant lifestyle risk factors • When and how to treat their condition • How to use prescribed treatments safely and e | treatments is considered to be covered by the NHS Constitution, which mandates compliance with NICE technology appraisals (and is therefore 'another lever in the system' to address this issue). Providing information for patients to support their treatment is an important theme for all NHS care. The NICE quality standard on 'patient experience in adult NHS services', which is cross-cutting and referenced in this quality standard, covers this area in more detail. Medicines adherence may also be covered by a cross-cutting medicines optimisation quality standard topic that has been referred to NICE. NICE Quality Standards define priority areas for quality improvement and illustrate what high quality care should look like. The quality standard is based upon, and derived from NICE Clinical guideline 153, and is underpinned by its recommendations. NICE quality standards do not replace existing guidance, and it remains important that other evidence-based guideline recommendations continue to be implemented. |

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| | | | No | Please insert each new comment in a new row. information and advice about their condition and the services available at each stage of the care pathway." 2. Phototherapy It is important to ensure that access to phototherapy is available for those patients requiring this treatment as per the NICE psoriasis pathway and should be included as a quality statement within the psoriasis quality standard. | |
| 034 | 011 | Pfizer Ltd | Question 2 | We suggest that as for the proposed QS#4, patients with severe psoriasis should also be assessed for diabetes, as this is a common co morbidity of psoriasis. Similarly, a patient's BMI should be taken. | Thank you. Statement 4 refers to assessment of cardiovascular risk in line with the underpinning guideline recommendation; it may be appropriate to undertake other assessments according to clinical judgement. |
| 035 | 014 | University of Manchester (impact) | Question 2 | Assessment <u>and management</u> of lifestyle behaviours associated with psoriasis, including smoking, alcohol use, being overweight and lack of exercise is missing from these standards. Given the volume of evidence showing these factors are related both to psoriasis (consistent evidence indicating people with psoriasis significantly more likely to engage in unhealthy behaviours) and to cardiovascular disease, this is an oversight. Furthermore, this is an opportunity to reinforce the necessary lifestyle change required to better self-manage long-term conditions which psoriasis is. | Thank you. The Quality Standards Advisory Committee considered that assessment of cardiovascular risk was a key issue for quality improvement in the care of people with psoriasis, and that improved assessment would result in better management, as well as serving to raise awareness of the increased cardiovascular risk, together with the underpinning guideline. |
| 036 | 017 | Royal College of Nursing | Question 2 | Access to a specialist nurse regards topical treatments/management in primary care would help in reducing the burden on GPs and referral into secondary care. Better adherence to topical management and managing expectations of what can be achieved with the treatments available. | Thank you. The Quality Standards Advisory Committee prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. Providing information for patients to support their treatment is an important theme for all NHS care. The NICE quality standard on 'patient experience in adult NHS services', which is cross-cutting and referenced in this quality standard, covers this area in more detail. Medicines adherence may also be covered by a cross-cutting medicines optimisation quality standard topic that has been referred to NICE. |
| 037 | 018 | AbbVie Ltd | Question 2 | The following are additional Quality Statements which AbbVie considers are important in achieving quality standards of care in psoriasis AbbVie considers it a priority that all psoriasis patients who meet the NICE recommendation criteria for biological therapy in accordance with NICE TA's 103, 134, 146 and 180 are offered biological treatment in a timely manner if it is considered clinically appropriate. In addition, AbbVie considers that patients who are primary or secondary | Thank you. Equitable access to NICE-approved treatments is considered to be covered by the NHS Constitution, which mandates compliance with NICE technology appraisals (and is therefore 'another lever in the system' to address this issue). NICE quality standards do not replace existing guidance, and it remains important that other evidence-based guideline recommendations continue to be implemented. |

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| | | | | non-responders to an initial biological agent or who are contraindicated to one should be offered a second biological drug in line with recommendations made in the NICE CG 153. As part of the Guideline development, an economic evaluation found the use of a second biological agent in eligible patients to be a cost-effective use of NHS resources with an ICER of £10,755 per QALY versus Best Supportive Care. AbbVie suggests the following Quality Statement should be added: "All adult psoriasis patients fulfilling the NICE criteria for biological therapy in accordance with NICE TA's 103, 134, 146 and 180 are offered therapy if it is considered clinically appropriate" AbbVie suggests the following measures should be used to assess adherence to these recommendations: Numerator: Number of eligible adult psoriasis patients being treated with a biological drug their condition in accordance with NICE TA's 103, 134, 146 and 180 Denominator: Number of adult psoriasis patients eligible for a biological drug in accordance with NICE TA's 103, 134, 146 and 180 | |
| 038 | 018 | AbbVie Ltd | Question 2 | Abbvie considers that it is important to refer patients with suspected psoriatic arthritis at the earliest possible time to a rheumatologist for assessment and appropriate treatment. This recommendation is made in NICE CG 153 in the "top ten key priorities for implementation" and AbbVie considers this to be important in improving health outcomes in patients with psoriatic disease. PsA is a chronic, inflammatory arthritis that occurs in psoriasis patients and usually involves pain and inflammation of affected joints. ⁶ It is estimated that more than half of all PsA patients exhibit progressive, erosive arthritis that often is associated with functional impairment. ⁷ ⁸ ⁹ The Psoriasis Association state that in most cases (70%) psoriasis precedes psoriatic arthritis ¹⁰ and that undiagnosed PsA may be prevalent because many asymptomatic psoriasis patients show radiological evidence of joint damage . ¹¹ | Thank you. The Quality Standards Advisory Committee considered that assessment for psoriatic arthritis was a key issue for quality improvement in the care of people with psoriasis, and that improved assessment would result in better management/earlier referral. The quality standard does not replace NICE clinical guideline 153, and it remains important that these recommendations continue to be implemented. |

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| 039 | 018 | AbbVie Ltd | Question 2 | NICE TA199 ¹² , page 7 section 2.5 states: 'Aggressive treatment of early stage progressive psoriatic arthritis can help to improve prognosis.' AbbVie considers that early, effective treatment of PsA patients with NICE recommended drugs in accordance with NICE TA199, may prevent functional disability and radiographic progression associated with the condition. AbbVie suggests adding the following Quality Statement: "As soon as psoriatic arthritis is suspected, refer the person to a rheumatologist for assessment and advice about planning their care." AbbVie suggests the following measures should be used to assess adherence to these recommendations: Numerator: Number of adult patients in whom PsA is suspected who are referred to a rheumatologist for assessment and advice about planning their care Denominator: Number of adult patients in whom PsA is suspected As well as being physically debilitating, psoriasis can have a deep | Thank you. Please see statement 2 in the final quality |
| | 010 | AND THE LIGHT | Quosiion 2 | psychological impact. ¹³ AbbVie considers that a validated tool should be used to assess the effect that a patient's psoriasis may be having on their psychological well-being. This recommendation is consistent with recommendations made in NICE CG 153. Psoriasis has long been recognised to be associated with adverse effects on mental health. A recent publication has analysed this systematically using the UK general practice database, ¹⁴ and examining the records of 146,042 patients with mild psoriasis, 3956 patients with severe psoriasis and 766,950 control patients. The authors found that 31.8% of patients with severe psoriasis had a diagnosis of clinical depression, and that patients with severe psoriasis are 72% more likely than risk matched control patients to suffer from clinical depression, and 51% more likely to suffer from suicidality. Results from a randomised controlled trial suggest that appropriate intervention with biologics in patients with moderate to severe psoriasis reduces symptoms of depression as well as improving health-related quality of life. ¹⁵ The authors concluded: "Although screening for depression symptoms is not commonplace in | standard, which references the use of relevant tools to support assessment. The definitions section has now been extended to include reference to the need to consider depression when assessing the impact of the disease on the patient. |

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| | | | No | Please insert each new comment in a new row. dermatology practice, appropriate management of psoriasis should include depression screening, with reduction of depression symptoms a treatment goal." AbbVie suggests adding the following Quality Statement: "Formally assess, with a validated instrument, whether people with any type of psoriasis are depressed when assessing disease severity and impact, and when escalating therapy." AbbVie suggests that one such practical tool which can be used in specialist and non-specialist settings to assess the effect of psoriasis on a patients psychological well-being is the Hospital Anxiety Depression Scale (HADS) which is both simple and quick to complete. AbbVie suggests the following measures should be used to assess adherence to these recommendations: Numerator: Number of patients who are identified as being significantly affected by depression using the HADS and who are referred or treated appropriately Denominator: Number of psoriasis patients who are identified as being significantly affected by depression using the HADS | |
| 040 | 018 | AbbVie Ltd | Question 2 | AbbVie believe the assessment of an individual's ability to work is a significant omission. Domain 2 of the NHS Outcomes Framework has employment for patients with long-term conditions as an indicators and this omission is incongruent with this NHS Outcomes Framework indicator. Wu et al. (2009) ¹⁶ studied the effect of psoriasis on work productivity. In a retrospective analysis of 40,730 patients, 1127 with psoriasis were matched with a cohort of non-psoriasis patients. Results showed that psoriasis patients were more likely to have missed work for health-related reasons (p < 0.05), had significantly more health-related work productivity impairment (p < 0.001), more overall work impairment (p < 0.001), and more impairment in activity other than work (p < 0.001) than non-psoriasis patients. The authors concluded that the results of this large-scale national survey suggest that psoriasis has a significant negative impact on overall work productivity. | Thank you. The Quality Standards Advisory Committee considered statement 2 to contribute towards improving the quality of life for people with psoriasis in general terms, although does not explicitly address employment-related issues (and therefore a link is not made between the quality standard and the NHS Outcomes Framework indicator for employment of patients with long term conditions). |
| 041 | 020 | See Psoriasis Look Deeper | Question 2 | Assessment and management of lifestyle behaviours associated with psoriasis, including smoking, alcohol use, being overweight and lack of exercise is missing from these standards. Given the volume of evidence showing these factors are related both to psoriasis and to cardiovascular disease, this is an oversight. Furthermore, this is an opportunity to reinforce the necessary lifestyle change required to better self-manage | Thank you. The Quality Standards Advisory Committee considered that assessment of cardiovascular risk was a key issue for quality improvement in the care of people with psoriasis, and that improved assessment would result in better management, as well as serving to raise awareness of the increased cardiovascular risk, together |

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| | | | | long-term conditions which psoriasis is. | with the underpinning guideline. |
| 042 | 003 | NHS Commissioning Board | Question 3 | Standards 1 to 4 and 6 are the most important standards. Standard 5, whilst helpful, risks the redirection of scarce resources into an area where return may be limited in terms of improved health outcomes. | Thank you. Please see statement 5 in the final quality standard, which has been revised in terms of the denominator population to ensure that annual assessment for psoriatic arthritis is done appropriately as part of holistic assessments of people with psoriasis having treatment and already in contact with healthcare professionals. |
| 043 | 004 | Primary Care Dermatology Society | Question 3 | Informed assessment of disease severity and the availability of treatment options are key to the whole quality standards. | Thank you. Please see statements 1 and 3 in the final quality standard. |
| 044 | 011 | Pfizer Ltd | Question 3 | The most important QSs are #1, #3 and #5 QSs #1 and #3 are important as these facilitate patients to the appropriate treatment of their condition based on severity and response to initial treatments. Currently too many patients are suffering with their condition, which could be better controlled if they were referred to specialist. QS#5 is important as there are a large number of patients suffering with PsA and are not being referred to a rheumatologist and thus missing out of essential treatment of their the condition. This would potentially reduce severe disability and suffering in these patients with severe disease as there is evidence to show that biologic therapies do halt the progression of radiographic joint damage. | Thank you. Please see statements 1, 3 and 5 in the final quality standard. |
| 045 | 014 | University of Manchester (impact) | Question 3 | There is overlap between these standards, however, referral to specialist services is the most important one and is the one most likely to result in the others being address by people knowing the need to adopt the broader standards. Specifically: 1. severity is likely to be assessed using more standardised and reliable methods in specialist settings; 2. comorbidities including psoriatic arthritis is more likely to be identified and managed earlier in specialised settings, this is crucial to prevent future health problems for example irreversible joint destruction; 3. psychological assessment is more likely to occur in specialist settings, all of the research on psychological aspects of psoriasis has come out of secondary care settings; 4. regular follow-up monitoring and referral for other specialist services is also more likely to happen in secondary /tertiary care setting where there is greater concentration of specialist activity. We know from the Psoriasis Association survey that a high proportion of patients are dissatisfied with their experiences in primary care especially. This has been followed up in qualitative research (Nelson et al 2013) [4]. If patient experience is important to improve the psychological aspects of | Thank you. Please see statement 3 in the final quality standard. NICE quality standards are not prescriptive about the settings in which assessments or interventions should take place to allow for flexibility in local service configurations. It is anticipated that the quality standard will facilitate quality improvements in the care of people with psoriasis in both primary and secondary care. |

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| | | | | psoriasis (beliefs about illness, beliefs about treatment and distress, coping behaviours) have to be addressed in a systematic and evidence based way. | |
| 046 | 017 | Royal College of Nursing | Question 3 | The most important questions are 2 and 3 in the quality standards as only the patient knows what psychological effect their disease has on them and this standard should mean clinicians take this more seriously. Many patients are refused referral into specialist care as their disease is not "severe" enough. This standard should help to make access to specialist care equitable. | Thank you. Please see statements 2 and 3 in the final quality standard. |
| 047 | 018 | AbbVie Ltd | Question 3 | AbbVie considers that all of the Quality Statements within this draft Quality Standard are appropriate and welcome the suggestions which have been made. However AbbVie would like to stress the particular importance of Quality Statements 1, 2, 6, 7 and 8 in improving the standards of care in the management of psoriasis. | Thank you. Please see the statements in the final quality standard. |
| 048 | 020 | See Psoriasis Look Deeper | Question 3 | There is a degree of overlap between the quality statements. However, referral to specialist services is the most important to secure, as it guarantees that patients are referred to those experts that understand all elements of the broader quality statements. Specifically: 1. severity is likely to be assessed using more standardised and reliable methods in specialist settings; 2. co-morbidities including psoriatic arthritis is more likely to be identified and managed earlier in specialised settings, this is crucial to prevent future health problems for example irreversible joint destruction; 3. psychological assessment is more likely to occur in specialist settings, all of the research on psychological aspects of psoriasis has come out of secondary care settings; 4. regular follow-up monitoring and referral for other specialist services is also more likely to happen in secondary /tertiary care setting where there is greater concentration of specialist activity. We know from the Psoriasis Association survey that a high proportion of patients are dissatisfied with their experiences in primary care especially. If patient experience is important to improve then psychological aspects of psoriasis (beliefs about illness, beliefs about treatment and distress, coping behaviours) have to be addressed in a systematic and evidence based way. | Thank you. Please see statement 3 in the final quality standard. NICE quality standards are not prescriptive about the settings in which assessments or interventions should take place to allow for flexibility in local service configurations. It is anticipated that the quality standard will facilitate quality improvements in the care of people with psoriasis in both primary and secondary care. |
| 049 | 011 | Pfizer Ltd | Question 4 | Pfizer agrees with all the draft quality measures, they are all appropriate. | Thank you. |
| 050 | 018 | AbbVie Ltd | Question 4 | AbbVie welcomes the draft Quality Statements and considers all of the Statements included in the draft to have an impact on promoting quality care in psoriasis. AbbVie have suggested additional Quality Statements for consideration above in order to address areas which may not have been covered by the draft statements. | Thank you. |

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| 051 | 002 | British Medical Association | Statement 1 | We feel that the suggestion (via the clinical guideline cited as a reference) of using the physicians static global assessment (PSGA) is unhelpful in a general practice setting. The PSGA requires a longer assessment than can be carried out in a 10 minute consultation and it is unclear how familiar GPs will be with the gradations used by the PSGA. | Thank you. The Quality Standards Advisory Committee agreed that use of the Physician's Static Global Assessment may not be appropriate in all circumstances. Please see statement 1 in the final quality standard where the definition section has been extended to include reference to a clinical assessment, as well as to the available tools. |
| 052 | 003 | NHS Commissioning Board | Statement 1 | Assessment of disease severity: Whilst the physician and patient global assessment tools may be of value in primary care, all patients who are being assessed in specialist departments for second line treatments should have an objective measurement of their disease severity. It is suggested that this is by measurement of the PASI score. This can then be used to assess response to second line treatments as a validated outcome measure. The standard should reflect the need to use this assessment tool. | Thank you. The Quality Standards Advisory Committee acknowledged that in secondary care a PASI score would be used to initiate and direct future treatment. However, it was considered that the focus of this statement was about general assessment in order to determine what action to take, rather than specific treatment decisions. |
| 053 | 004 | Primary Care Dermatology Society | Statement 1 | If we suggest a yearly review then a yearly estimate of severity would be appropriate. It could be required by the specialist provider to accept a referral e.g. in local protocols. | Thank you. The Quality Standards Advisory Committee discussed how best to improve the measurability of the statement and considered that an arbitrary fixed review period may be difficult to set due to the unpredictable nature of the disease. Please see statement 1 in the final quality standard which focuses on the key points of diagnosis and when assessing response to treatment. |
| 054 | 006 | British Association of Dermatologists | Statement 1 | The assessment of disease severity is essential to assess baseline severity, response to treatment and identify patients particularly at risk of co-morbidities, or who would benefit from escalation of therapies. Within secondary care, it should be standard to measure PASI at baseline and at 3 and 6 months and 3 to 6 monthly thereafter. The baseline measurements would act as a useful audit tool for appropriateness of referral. In primary care, an estimate of percentage (%) surface area affected, together with the degree of inflammation (mild/moderate/severe) should be the minimum expected assessment performed at baseline, and to assess efficacy of treatment. It should be noted that sites such has face, scalp, hands/feet and genitals may have considerable functional and psychological impact life despite affecting a relatively low % area, or PASI, and therefore need special consideration which is recognised by NICE. | Thank you. The Quality Standards Advisory Committee discussed how best to improve the measurability of the statement and considered that an arbitrary fixed review period may be difficult to set due to the unpredictable nature of the disease. Please see statement 1 in the final quality standard which focuses on the key points of diagnosis and when assessing response to treatment. |
| 055 | 800 | Psoriasis Association | Statement 1 | Whilst the Psoriasis Association welcomes assessment of disease severity at first presentation, before referral for specialist advice, at each referral point in the treatment pathway and to evaluate the efficacy of interventions it is disappointing that the Physician's Global Assessment, and the Patient's Global Assessment are the only measures explicitly | Thank you. The Quality Standards Advisory Committee acknowledged that in secondary care a PASI score would be used to initiate and direct future treatment. However, it was considered that the focus of this statement was about general assessment in order to |

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| | | | No | Please insert each new comment in a new row. mentioned. Whilst the PGA is useful in mild psoriasis as a benchmark to measure treatment success / failure, the Psoriasis Area and Severity Index (PASI) provides a more thorough measure of severity, useful particularly when referring on to secondary care services, and whilst being treated in secondary care, this would ensure consistency with the NICE Guideline on Psoriasis, and the Technology Appraisals 146, 103, 134 and 180. We note also that the suggested assessments for disease severity are physical severity measures, and feel that psychological assessments are equally as important – level of physical disease severity is not linked to level of distress for example. Assessment for levels of distress, anxiety and depression should also be used, such as the Hospital Anxiety and Depression Scale and the Patient Health Questionnaire 9, by suitably trained staff. When assessing psoriasis, it is important to note that high impact sites may affect a relatively low percentage area, but have considerable life impact, and so a low PGA or PASI may not always be indicative of mild psoriasis. | determine what action to take, rather than specific treatment decisions. Please see statement 2 in the final quality standard which addresses the assessment of the impact of the disease on physical, psychological and social wellbeing. |
| 056 | 009 | Lilly UK | Statement 1 | We would recommend that there should be an ongoing assessment with frequency linked to the severity of the disease, with a minimum of annual assessment for all PS patients. We believe that annual assessments and assessment at change in severity will help physicians and patients monitor if current treatment regimens are proving the necessary level of care. | Thank you. The Quality Standards Advisory Committee discussed how best to improve the measurability of the statement and considered that an arbitrary fixed review period may be difficult to set due to the unpredictable nature of the disease. Please see statement 1 in the final quality standard which focuses on the key points of diagnosis and when assessing response to treatment. |
| 057 | 010 | Psoriasis and Psoriatic Arthritis Alliance | Statement 1 | People with psoriasis have an assessment of disease severity. This is important but location/site and impact need to be considered within the delivery of this standard. There is also a concern that the clearance goal may not be the patient goal. Some patients may be happy not to achieve complete clearance if the treatment impact is low, so whilst applying a cream once a day may not result in an optimal outcome, it may have less impact on daily living than the alternatives. Equally, the escalation of treatment and potential side-effects of trying to achieve a guideline standard, whilst providing benefit, may not fit with the patient's wishes. Hence the aim here should be for an outcome which is commensurate with the patient's wishes and objectives. | Thank you. The Quality Standards Advisory Committee agreed that the skin clearance goal may not always be the patient goal. Please see the revised rationale section of statement 1 in the final quality standard. |
| 058 | 012 | Janssen | Statement 1 | We suggest the Physician's Global Assessment and Patient's Global Assessment (PGA) tools be used in the primary care, and PASI in the secondary/specialist care. Rationale: According to CG153 Psoriasis (page 8), people with a PASI score of more than 10 should be offered systemic non-biological therapy. | Thank you. The Quality Standards Advisory Committee acknowledged that in secondary care a PASI score would be used to initiate and direct future treatment. However, it was considered that the focus of this statement was about general assessment in order to |

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| | | | | PASI measurement is also necessary for initiation of systemic biological therapy, and for subsequent monitoring. Therefore, it makes sense that PASI is used in the secondary/specialist care when assessing disease severity. | determine what action to take, rather than specific treatment decisions. |
| 059 | 014 | University of Manchester (impact) | Statement 1 | It is disappointing that the Psoriasis Area Severity Index (PASI) is not specified. While the Physician/Patient Global Assessment (PGA) is sometimes used in clinical practice, the PASI, provides a better opportunity to measure severity in a more precise way and refer to specialist services. In addition, because of the established role of the PASI in determining and escalating treatments, this appears to be the most appropriate severity assessment tool to recommend. | Thank you. The Quality Standards Advisory Committee acknowledged that in secondary care a PASI score would be used to initiate and direct future treatment. However, it was considered that the focus of this statement was about general assessment in order to determine what action to take, rather than specific treatment decisions. |
| 060 | 015 | MSD Ltd | Statement 1 | Quality Statement 1 states that "the Physician's Global Assessment and Patient's Global Assessment tools can be used to assess disease severity". MSD kindly suggests that in addition to these tools, the Psoriasis Area and Severity Index (PASI) and the Nail Psoriasis Severity Index (NAPSI) should be recommended, in order to ensure that this Quality Standard more accurately reflects the current published guidance on psoriasis, e.g. NICE Technology Appraisal 134 and NICE Clinical Guideline 153 | Thank you. The Quality Standards Advisory Committee acknowledged that in secondary care a PASI score would be used to initiate and direct future treatment. However, it was considered that the focus of this statement was about general assessment in order to determine what action to take, rather than specific treatment decisions. |
| 061 | 016 | Novartis Pharmaceuticals | Statement 1 | The guidance is lacking specifics in terms of frequency/timing, which is important as the severity and impact can both change over time. We assume this quality statement covers specialist and non-specialist care? The full version of the NICE Clinical Guidelines suggests: In any healthcare setting this includes a static Physician's Global Assessment (classified as clear, nearly clear, mild, moderate, severe or very severe) and the patient equivalent, the static Patient's Global Assessment, and measurement of body surface area affected (BSA). In specialist care severity assessments include the above, <u>plus</u> the Psoriasis Area and Severity Index (PASI) and the nail equivalent NAPSI where required. Whilst there is no recommendation for frequency within the NICE Clinical Guidelines, the European S3 guideline recommends 8-weekly during maintenance treatments for psoriasis. The SIGN guideline recommends 4-6 weekly for topical therapies when they are initiated but makes no frequency recommendations for systemics. Real-life experience is that 3-6 monthly severity assessment is more common in secondary care, but this is not always as detailed as a PASI/DLQI. Expert clinical opinion suggests that this should be occurring more frequently. | Thank you. The Quality Standards Advisory Committee discussed how best to improve the measurability of the statement and considered that an arbitrary fixed review period may be difficult to set due to the unpredictable nature of the disease. Please see statement 1 in the final quality standard which focuses on the key points of diagnosis and when assessing response to treatment. |
| 062 | 016 | Novartis Pharmaceuticals | Statement 1 | Focus is on Patient's / Physician's Global Assessment – what about using PASI to align with clinical trial measures? What about regular assessment via a trained PASI Nurse? | Thank you. The Quality Standards Advisory Committee acknowledged that in secondary care a PASI score would be used to initiate and direct future treatment. However, it was considered that the focus of this |

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| | | | | | statement was about general assessment in order to determine what action to take, rather than specific treatment decisions. |
| 063 | 018 | AbbVie Ltd | Statement | AbbVie welcomes the recommendation to assess disease severity in all psoriasis patients. However, AbbVie feels very strongly that the use of Psoriasis Area and Severity Index (PASI) assessment should be recommended as the appropriate tool for assessment for adult patients in specialist settings to allow timely access to NICE recommended biologic therapies in accordance with NICE Technology Appraisals (TA) 103, 134, 146 and 180. In a recent survey conducted by The Psoriasis Association, it was reported that, although patient's awareness of the PASI measurement has nearly trebled to 59% since 2011, only 32% of psoriasis patients in the UK had their disease severity assessed by a doctor using the PASI. NICE TA's 146, 103 and 180 relating to adalimumab, etanercept and ustekinumab respectively, recommend the use of these therapies in eligible patients with severe psoriasis, defined as patients with a PASI score of greater than or equal to 10 (and DLQI of greater than 10). NICE TA 134 relating to the use of infliximab in psoriasis recommends the therapy in eligible patients with very severe psoriasis as defined by patients with a PASI score of greater than or equal to 20 (with a DLQI of greater than 18). In this way access to biological therapy is defined by a patient's PASI score and no reference is made in the TA's to patients meeting the NICE eligibility criteria with equivalent Patient Global Assessment or Physician Global Assessment scores. If a patient is not assessed using PASI, it is not possible to determine in clinical practice whether or not they are eligible for a biologic based on their disease severity. This raises a number of important issues. Eligible patients may not be offered biologic therapies in accordance with NICE TA's 103, 134, 146 and 180 due to the failure to measure PASI scores, which will result in under-treatment with biological therapies. Furthermore, if regular PASI measurements are not taken at follow-up monitoring visits, it is not possible to objectively measure response to treatmen | Thank you. The Quality Standards Advisory Committee acknowledged that in secondary care a PASI score would be used to initiate and direct future treatment. However, it was considered that the focus of this statement was about general assessment in order to determine what action to take, rather than specific treatment decisions. NICE quality standards do not replace existing guidance and it remains important that other evidence-based guideline recommendations, such as those within the NICE technology appraisals, continue to be implemented. The Quality Standards Advisory Committee discussed how best to improve the measurability of the statement and considered that an arbitrary fixed review period may be difficult to set due to the unpredictable nature of the disease. Please see statement 1 in the final quality standard which focuses on the key points of diagnosis and when assessing response to treatment. |

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| | | | | severity in non-specialist settings may not be practical for all patients, AbbVie strongly urges NICE to recommend the PASI as the recommended assessment tool in specialist settings to enable patients to access NICE recommended therapies in a timely manner. This recommendation is in accordance with previously issued NICE guidance. From a United Kingdom long-term prospective observational study to monitor the safety of biologics; The British Association of Dermatologists Biologics Interventions Register (BADBIR), a sub-analysis of patients initiated on adalimumab was undertaken. It was observed that psoriasis patients were initiated on adalimumab treatment with a mean disease severity higher than that recommended by NICE. It was observed that at initiation the mean (SD) score for PASI was 16 (8), and for DLQI was 15 (9). ¹⁸ It was observed that the mean PASI, mean DLQI are considerably higher than the eligibility criteria for biologics (10 for both PASI and DLQI) and that the mean duration of psoriasis symptoms was 23 years at time of initiation of adalimumab. It is hypothesised that this may be due to a lack of regular standardised disease assessment. It is unknown how long these patients had symptoms before being referred to secondary care. In a non-specialist setting, AbbVie considers the Patient Global Assessment, Physician Global Assessment and Body Surface Area (BSA) to be appropriate and practical in assessing disease severity in accordance with recommendations made in NICE CG 153. In terms of timing of assessment of disease severity, AbbVie considers that all psoriasis patients referred to secondary care should have their disease severity assessed using PASI at the first visit following referral from a non-specialist setting and at all subsequent monitoring visits, at a frequency consistent with NICE guidance, to assess efficacy of therapy and disease progression. AbbVie suggests: "People with psoriasis have an assessment of disease severity, in the case of adults in a specialist setting and at each s | |
| 064 | 019 | British Dermatological Nursing Group | Statement 1 | With regard to the statement that the majority of patients with psoriasis are treated in primary care. Who will be responsible for the training and education of the healthcare professionals? So they are able to assess disease severity and assessment of the impact on physical, psychological and social wellbeing of our patients using the tools we have i.e. PASI and DLQI scoring | Thank you. The introductory section of the quality standard notes that the standard should be read in the context of national and local guidelines on training and competencies. Please see statement 2 in the final quality standard which addresses the patient perspective through the |

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| | | | | There is a lot of evidence that patient perception of disease severity often differs from physician assessment. Both perspectives of disease severity are important for different reasons. Patient perception of severity is a particularly important marker of psychological well-being as it has generally been shown to be highly correlated with a variety of measures of distress or quality of life functioning. However, physician assessment of severity tends to not correlate well with psychosocial wellbeing. Therefore, in the definitions of measurement within this statement I would recommend that the standards suggest seeking patient rated in addition to using physician rated severity. Patient rated severity can be gained using simple likert scales of subjective rating of severity. | assessment of the impact of the disease on physical, psychological and social wellbeing, and specifically notes that its impact on wellbeing cannot be predicted from the severity of the disease. |
| 065 | 020 | See Psoriasis Look Deeper | Statement 1 | It is disappointing that the Psoriasis Area Severity Index (PASI) is not specified. While the PGA is sometimes used in clinical practice, it is more commonly used as a research tool. The PASI provides an opportunity to measure severity in a more precise way. In addition, because of the established role of the PASI in determining and escalating treatments, this appears to be the most appropriate severity assessment tool to recommend. We would recommend the routine use of PASI scores in secondary care at baseline and then 3 monthly thereafter, depending upon treatment regimes. In primary care we would recommend an estimation of surface area together with an assessment of degree of inflammation, again at baseline and to assess efficacy of treatments. It should be noted that sites such has face, scalp, hands/feet and genitals may have considerable life impact despite affecting a relatively low % area and therefore need special consideration. | Thank you. The Quality Standards Advisory Committee acknowledged that in secondary care a PASI score would be used to initiate and direct future treatment. However, it was considered that the focus of this statement was about general assessment in order to determine what action to take, rather than specific treatment decisions. |
| 066 | 021 | Royal College of Physicians | Statement 1 | The assessment of disease severity is essential to assess baseline severity, response to treatment and identify patients particularly at risk of co-morbidities, or who would benefit from escalation of therapies. Within secondary care, it should be standard to measure PASI at baseline and at 3 and 6 months and 3 to 6 monthly thereafter. The baseline measurements would act as a useful audit tool for appropriateness of referral. In primary care, an estimate of percentage (%) surface area affected, together with the degree of inflammation (mild/moderate/severe) should be the minimum expected assessment performed at baseline, and to assess efficacy of treatment. It should be noted that sites such has face, scalp, hands/feet and genitals may have considerable functional and psychological impact life despite affecting a relatively low % area, or PASI, and therefore need special consideration which is recognised by NICE. | Thank you. The Quality Standards Advisory Committee discussed how best to improve the measurability of the statement and considered that an arbitrary fixed review period may be difficult to set due to the unpredictable nature of the disease. Please see statement 1 in the final quality standard which focuses on the key points of diagnosis and when assessing response to treatment. |
| 067 | 004 | Primary Care Dermatology | Statement | At presentation and at yearly medicines review for QoL and simple | Thank you. The Quality Standards Advisory Committee |
| | | Society | 1 - | arthritis question would seem most appropriate. ? by pharmacist | discussed how best to improve the measurability of the |

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| | | | Question 5 | /nurse/GP. | statement and considered that an arbitrary fixed review period may be difficult to set due to the unpredictable nature of the disease. Please see statement 1 in the final quality standard which focuses on the key points of diagnosis and when assessing response to treatment. |
| 068 | 011 | Pfizer Ltd | Statement 1 - Question 5 | QS1: We believe that people with psoriasis should be routinely assessed for disease severity. We suggest every 3-6 months dependent on disease severity and current treatments being administered in primary and secondary care. | Thank you. The Quality Standards Advisory Committee discussed how best to improve the measurability of the statement and considered that an arbitrary fixed review period may be difficult to set due to the unpredictable nature of the disease. Please see statement 1 in the final quality standard which focuses on the key points of diagnosis and when assessing response to treatment, to ensure that severity is assessed on an on-going basis. |
| 069 | 012 | Janssen | Statement 1 – Question 5 | We suggest disease severity and quality of life be assessed at each consultation regarding psoriasis. Rationale: Systematic and on-going assessment of disease severity and quality of life is necessary to monitor effectiveness of treatments offered to people with psoriasis. | Thank you. The Quality Standards Advisory Committee discussed how best to improve the measurability of the statement and considered that an arbitrary fixed review period may be difficult to set due to the unpredictable nature of the disease. Please see statement 1 in the final quality standard which focuses on the key points of diagnosis and when assessing response to treatment, to ensure that severity is assessed on an on-going basis. |
| 070 | 013 | LEO | Statement 1 – Question 5 | Annual reviews (as per NICE & SIGN clinical guideline recommendations) would be reasonable unless an individual patient needed more frequent assessment. | Thank you. The Quality Standards Advisory Committee discussed how best to improve the measurability of the statement and considered that an arbitrary fixed review period may be difficult to set due to the unpredictable nature of the disease. Please see statement 1 in the final quality standard which focuses on the key points of diagnosis and when assessing response to treatment, to ensure that severity is assessed on an on-going basis. |
| 071 | 018 | AbbVie Ltd | Statement 1 – Question5 | AbbVie welcomes the recognition that assessment of both disease severity and the effect of the disease on physical, psychological and social wellbeing will positively impact standards of care in psoriasis. However, AbbVie considers that there is a need to add the suggested timing and frequency of these assessments to the Quality Statements in order to aid measurability. As highlighted, AbbVie suggests the PASI to be recommended as the assessment for all patients in specialist settings on their first visit following referral from a non-specialist setting. Thereafter, AbbVie suggests that a PASI assessment is carried out at each subsequent monitoring visit, at a frequency consistent with NICE guidance, to assess a patients response to treatment over time. | Thank you. The Quality Standards Advisory Committee discussed how best to improve the measurability of the statement and considered that an arbitrary fixed review period may be difficult to set due to the unpredictable nature of the disease. Please see statement 1 in the final quality standard which focuses on the key points of diagnosis and when assessing response to treatment, to ensure that severity is assessed on an on-going basis. The Quality Standards Advisory Committee acknowledged that in secondary care a PASI score would be used to initiate and direct future treatment. However, it was considered that the focus of this |

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| | | | | AbbVie considers that the DLQI questionnaire should form routine part of specialist and non-specialist consultation as detailed above. In the case of non-specialist settings, AbbVie recommends that the DLQI be administered following a diagnosis of psoriasis in primary care and then again following assessment of response to 1st line topical therapies after 4-6 weeks of treatment in-line with SIGN Guidelines for the management of psoriasis. AbbVie further recommends that the DLQI should be recommended as the assessment for all patients in specialist settings on their first visit following referral from a non-specialist setting. Thereafter, AbbVie suggests that a DLQI assessment is carried out at each subsequent monitoring visit in specialist settings, at a frequency consistent with NICE guidance, to assess a patients response to treatment over time. | statement was about general assessment in order to determine what action to take, rather than specific treatment decisions. Please see statement 2 in the final quality standard for reference to the DLQI. |
| 072 | 002 | British Medical Association | Statement 2 | We agree that it is important to assess the impact of psoriasis on the social and psychological wellbeing of a patient. However, rather than using a questionnaire which cannot practically be completed during an initial consultation, we would prefer GPs to make this assessment on the basis of their well-developed consultation skills. Relying on the questionnaire will mean the patient completing the questionnaire after the consultation and then having a follow-up consultation to review their condition. We are also unconvinced of the benefits of questionnaires of this type in general practice, a setting which otherwise relies on the communication and relationship between the patient and doctor. | Thank you. The Quality Standards Advisory Committee agreed that use of the Dermatology Life Quality Index may not be appropriate in all circumstances. Please see statement 2 in the final quality standard where the definition section has been extended to include reference to a clinical assessment, as well as to the available tools. |
| 073 | 003 | NHS Commissioning Board | Statement 2 | Whilst the DLQI is an excellent tool to assess impact of psoriasis on quality of life, psychological impact is better assessed using the widely used Patient Health Questionnaire 9 (PHQ9) assessment tool. PHQ9 is widely used in primary care and is simple to administer, it is suggested that this tool is used in addition to the DLQI. The Hospital Anxiety and Depression score (HAD) could also be used. | Thank you. The quality standard reference to the DLQI is consistent with the underpinning evidence-based recommendations from the NICE Clinical Guideline on which the standard is based. |
| 074 | 004 | Primary Care Dermatology Society | Statement 2 | As for 1 DLQI is appropriate. | Thank you. |
| 075 | 006 | British Association of Dermatologists | Statement 2 | We would recommend the title as "Quality of life and Psychological impact". Quality of life does not necessarily equate to psychological distress. Consideration of psychological and social wellbeing as well as physical severity is to be commended. DLQI assessment should be obligatory and carried out in conjunction with an assessment of disease severity, both in primary and secondary care, to get a full understanding of the impact of disease. Since DLQI does not measure psychological distress and patients with psoriasis experience high rates of anxiety and depression, a baseline and then an annual measurement of distress | Thank you. Please see statement 2 in the final quality standard where the statement title has been amended to 'assessing impact of disease', in order to better cover all the issues concerned. |

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| | | | | using a validated measure such as the Hospital Anxiety and Distress Scale is recommended. If these factors are assessed there needs to be adequate service provision to manage patients with psoriasis and psychological disease. A multi-disciplinary or integrated service is important as this is very under-resourced and a poorly recognised aspect of care. | |
| 076 | 008 | Psoriasis Association | Statement 2 | The Psoriasis Association welcomes the statement and definition that the impact of disease on physical, psychological and social wellbeing should be assessed at first presentation, before referral for specialist advice, at each referral point in the treatment pathway and to evaluate the efficacy of interventions, and feel assessment at all of these stages is vital. However, there must also be access to the necessary services and healthcare professionals for treatment and management should the assessment indicate further help is required. Whilst we welcome the use of the Dermatology Life Quality Index, this only assesses a patient over the most recent week, feelings of distress at (another) flare-up would not be captured by the DLQI and therefore suggest the HADS could also be used. Therefore we suggest the statement should read "People with psoriasis have assessment of the impact of the disease on physical, psychological and social wellbeing, and access to relevant mental health services should they be required." | Thank you. The quality standard reference to the DLQI is consistent with the underpinning recommendations from the NICE Clinical Guideline on which the standard is based. The Quality Standards Advisory Committee anticipated that improved assessment of the impact of psoriasis on physical, psychological and social wellbeing would improve access to specialist psychological support for those people who may benefit from it. |
| 077 | 009 | Lilly UK | Statement 2 | We know that Psoriasis plaques can have particularly significant physiological and social impact on younger adults. Thus, we suggest that this patient segment is highlighted for special attention in this quality statement. We also recommend that the impact of the disease on physical, psychological and social wellbeing should be assessed annually (same frequency as psoriatic arthritis assessment). | Thank you. The quality statements apply to all people with psoriasis, and as such the quality standard is expected to have a positive impact on younger adults. The Quality Standards Advisory Committee discussed how best to improve the measurability of the statement and considered that an arbitrary fixed review period may be difficult to set due to the unpredictable nature of the disease. Please see statement 2 in the final quality standard which focuses on the key points of diagnosis and when assessing response to treatment. |
| 078 | 010 | Psoriasis and Psoriatic Arthritis Alliance | Statement 2 | Quality of life. This is an important issue and needs to be considered along with severity as indicated in the rationale. Nevertheless, it should not be assumed that everyone with psoriasis has a poor quality of life. From comments we receive, many people feel that it's the public perception of psoriasis that has a greater impact. What we do not want to create is a situation where the negative stereotypes associated with psoriasis are compounded by applying a compulsory mental health pathway to every patient, with all the unforeseen consequences of inappropriate referral. We have to consider the wider impact on | Thank you. Please see statement 2 in the final quality standard where the statement title has been amended to 'assessing impact of disease', in order to better cover the issues concerned. The Quality Standards Advisory Committee agreed that assessing need for further support at diagnosis was important. |

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| | | | | education, employment and future relationships. Some individuals take a long time to come to terms with their disease and their needs may vary at different stages in the adjustment process. Our experience is that in early stages of disease, patients often do not get the reassurance they need that there is long-term support available. A good outcome would be one in which there is a consideration of the <i>individual</i> impact of psoriasis and that help is available. So perhaps some measure of help offered and the actual take-up would be useful. | |
| 079 | 014 | University of Manchester (impact) | Statement 2 | We respectfully remind the QS development group that there is no simple relationship between disease severity and level of distress. There is evidence that people with psoriasis have higher levels of suicidality and alexithymia (difficulty expressing distress and identifying strong emotions) than other comparable groups and they may need additional monitoring of mood and support to self-manage. For this reason, assessment of the severity of distress should occur at first referral, six monthly and if triggered by an event (flare; patient report; treatment change). This assessment should be carried out by suitably trained specialist staff. | Thank you. Please see statement 2 in the final quality standard which specifically notes that the impact of psoriasis on wellbeing cannot be predicted from the severity of the disease. The Quality Standards Advisory Committee discussed how best to improve the measurability of the statement and considered that an arbitrary fixed review period may be difficult to set due to the unpredictable nature of the disease. Please see statement 2 in the final quality standard which focuses on the key points of diagnosis and when assessing response to treatment, to ensure that impact is assessed on an on-going basis. |
| 080 | 014 | University of Manchester (impact) | Statement 2 | Despite the weight of evidence showing high levels of distress in this patient group the QS focus almost entirely on managing the physical aspects of psoriasis only. We concur with the recommendation that the DLQI is the most appropriate validated condition-specific quality of life measure to use and would provide the vehicle for discussion of wider impact. Quality of life (QOL) (plus other recommended measures) should be administered and interpreted by suitably trained individuals. | Thank you. The Quality Standards Advisory Committee considered that statement 2 in the final quality standard addresses the impact of the disease on psychological wellbeing. |
| 081 | 014 | University of Manchester (impact) | Statement 2 | The statement that the DLQI can be used to assess the impact of the disease on physical, psychological and social well-being is not the case. The DLQI is a broad brush measure of <i>quality of life</i> , and while quality of life can be affected by distress, distress is more specific. There are suitable measures of distress (HADS for example) that could be used relatively easily in the clinical setting. Furthermore, QOL is also driven by cognitions, yet there is no recommended measure of cognitions, and without a detailed assessment of beliefs and emotions it is difficult to design an intervention that will improve QOL. | Thank you. The quality standard reference to the DLQI is consistent with the underpinning recommendations from the NICE Clinical Guideline on which the standard is based. |
| 082 | 014 | University of Manchester (impact) | Statement 2 | The draft QS raises expectations that if something is important enough to be measured, it will be managed, however, the QS does not mention what to do about the impact of psoriasis on quality of life. In our opinion this is a major oversight and a missed opportunity to improve standards of care. People with psoriasis are dissatisfied with the standards of care | Thank you. The Quality Standards Advisory Committee considered that assessment was a key issue for quality improvement in the care of people with psoriasis, and that if the quality of assessment was improved, better management would follow. |

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| | | | No | they receive (Psoriasis Association Patient Survey data Beresford 2002 [5]) and this adds to already elevated levels of distress, which it is likely has direct and indirect impact on disease activity. Service provision should reflect need but does not; rather there is vast unmet need in dermatology services. We believe not to address this in the QS supports the status quo and will compound distress. Shaw et al., (1999) [6] demonstrated that to raise awareness but not provide management strategies in other Long Term Conditions increased distress. | NICE quality standards do not replace existing guidance, and it remains important that other evidence-based guideline recommendations continue to be implemented. NICE Quality Standards define priority areas for quality improvement and illustrate what high quality care should look like. They do not provide a comprehensive service specification or prescribe local service delivery arrangements. |
| 083 | 016 | Novartis Pharmaceuticals | Statement 2 | Work & Productivity assessments are lacking, and therefore the impact of disease itself, and or correlation to long-term psychological sequelae are not captured. Suggest baseline and quarterly DLQI, EQ-5D, WPAI-SHP, FDLQI. | Thank you. It is anticipated that an assessment of the impact of the disease on a person's wellbeing might include reference to employment issues; the quality standard does not provide an exhaustive list of all issues that might be covered with each individual patient. |
| 084 | 017 | Royal College of Nursing | Statement 2 | In primary care the DLQI could be easily used to help with the assessment of this quality statement. For example a score between 5 and 10 suggests an impact on their well being. Over 10 is a significant impact used to assess for 2 nd /3 rd line treatment. The DLQI is a useful tool that could be used more widely and after each treatment period to assess reduction or increase in impact. | Thank you. Please see statement 2 in the final quality standard which focuses on the key points of diagnosis and when assessing response to treatment. |
| 085 | 018 | AbbVie Ltd | Statement 2 | The government has recognised in a recent framework of care that enhancing QoL for people with long-term conditions is of great importance when considering patient management. ¹⁹ AbbVie strongly urges that the impact of psoriasis on physical, psychological and social wellbeing should be formally assessed using a validated instrument in both specialist and non-specialist settings. AbbVie considers there would be value in introducing DLQI questionnaires to patients diagnosed with psoriasis in a primary care setting in England. This suggestion is based on SIGN guidelines for the management of psoriasis. ²⁰ It is hoped that this will facilitate referral of patients in whom quality of life is significantly affected by their psoriasis despite topical therapy. These patients can then be further assessed by a specialist using the PASI and clinical judgement to optimise treatment. Harlow et al. (2000) examined the feasibility of using the DLQI in primary care amongst patients with a variety of skin conditions including psoriasis. The authors concluded: "the DLQI was easy to use in general practice. It was acceptable to the patients, who found it quick and easy to complete. Scoring was also | Thank you. The definitions section in this quality statement references the available tools that can be used to support the assessment of disease impact, in line with the recommendations from the underpinning NICE guideline. It is worth noting that the development of tools to support assessment of disease severity and impact in both non-specialist and specialist settings was a research recommendation made the guideline developers. Please see statement 2 in the final quality standard which focuses on assessing disease impact at the key points of diagnosis and when assessing response to treatment. |

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| | | | No | Please insert each new comment in a new row. quick and simple" AbbVie considers that implementation of this recommendation would not be resource intensive and will identify patients who need further clinical investigation using PASI in secondary care sooner than is currently being done. AbbVie suggests that the Quality Standard recommends that patients complete the DLQI questionnaire following an initial diagnosis of psoriasis in primary care and then again following assessment of response to 1st line topical therapies after 4-6 weeks of treatment. It is suggested a referral be made to specialist care if the patient has not responded to topical therapy after this period and they have a DLQI of >5, consistent with SIGN guidelines for psoriasis. AbbVie suggests changing the draft Quality Statement to reflect these recommendations: "People with psoriasis have an assessment of the impact of the disease on physical, psychological and social wellbeing using the DLQI or Children's DLQI in non-specialist and specialist settings. In specialist settings, this assessment should be on first visit following referral and at each subsequent monitoring visit" | |
| 086 | 020 | See Psoriasis Look Deeper | Statement 2 | We respectfully remind the Quality Standard development group that there is no simple relationship between disease severity and level of distress. There is evidence that people with psoriasis have higher levels of suicidality and of alexithymia (difficulty expressing distress and identifying strong emotions) than other comparable groups and they may need additional monitoring of mood and support to self-manage. For this reason, assessment of the severity of distress eg using the HADS should occur at first referral, six monthly and if triggered by an event (flare; patient report; treatment change). This assessment should be carried out by suitably trained specialist staff. | Thank you. Please see statement 2 in the final quality standard which specifically notes that the impact of psoriasis on wellbeing cannot be predicted from the severity of the disease. The Quality Standards Advisory Committee discussed how best to improve the measurability of the statement and considered that an arbitrary fixed review period may be difficult to set due to the unpredictable nature of the disease. Please see statement 2 in the final quality standard which focuses on the key points of diagnosis and when assessing response to treatment, to ensure that impact is assessed on an on-going basis. |
| 087 | 020 | See Psoriasis Look Deeper | Statement 2 | Would it be possible to change the title of this section to 'Quality of life and Psychological Impact'? | Thank you. Please see statement 2 in the final quality standard where the statement title has been amended to 'assessing impact of disease', in order to better cover all the issues concerned. |
| 088 | 020 | See Psoriasis Look Deeper | Statement 2 | The Collaboration welcomes the recognition in the Quality Standard that "It is important to measure the impact of the condition on physical, psychological and social wellbeing". However, it is crucial that such an assessment uses validated measures in order to avoid a purely subjective assessment for psychological and social wellbeing. We therefore suggest that the Quality Standard reads, "It is important to | Thank you. The definitions section in this quality statement references the available tools that can be used to support the assessment of disease impact, in line with the recommendations from the underpinning NICE guideline, but the Quality Standards Advisory Committee did not consider it appropriate to recommend use of the |

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| | | | INO | measure the impact of the condition on physical, psychological and social wellbeing <i>using validated measures</i> " One example of such a validated measure is the HADS test, explained earlier. | tools in all circumstances. |
| 089 | 020 | See Psoriasis Look Deeper | Statement 2 | Despite the weight of evidence showing high levels of distress in this patient group the Quality Standard focuses almost entirely on managing the physical aspects of psoriasis only. We concur with the recommendation that the DLQI is the most appropriate validated condition-specific quality of life measure to use and would provide the vehicle for discussion of wider impact. Quality of life (QOL) (plus other recommended measures) should be administered and interpreted by suitably trained individuals. | Thank you. The Quality Standards Advisory Committee considered that statement 2 in the final quality standard addresses the impact of the disease on psychological wellbeing. |
| 090 | 020 | See Psoriasis Look Deeper | Statement 2 | The statement that the DLQI can be used to assess the impact of the disease on physical, psychological and social well-being is not the case. The DLQI is a broad brush measure of <i>quality of life</i> , and while quality of life can be affected by distress, distress is more specific. There are suitable measures of distress (HADS for example) that could be used relatively easily in the clinical setting. Furthermore, QOL is also driven by cognitions, yet there is no recommended measure of cognitions, and without a detailed assessment of beliefs and emotions it is difficult to design an intervention that will improve QOL. | Thank you. The quality standard reference to the DLQI is consistent with the underpinning recommendations from the NICE Clinical Guideline on which the standard is based. |
| 091 | 020 | See Psoriasis Look Deeper | Statement 2 | The draft Quality Standard raises expectations that if something is important enough to be measured, it will be managed. However, the Quality Standard does not mention what to do about the impact of psoriasis on quality of life. In our opinion this is a major oversight and a missed opportunity to improve standards of care. People with psoriasis are dissatisfied with the standards of care they receive (PA Patient Survey data) and this adds to already elevated levels of distress, which it is likely has direct and indirect impact on disease activity. Service provision should reflect need but does not. Rather, there is massive unmet need in dermatology services. We believe not to address this in the Quality Standard supports the status quo and will compound distress. Marteau and French (2008) demonstrate that to raise awareness but not provide management strategies in other long-term conditions increases distress. | Thank you. The Quality Standards Advisory Committee considered that assessment was a key issue for quality improvement in the care of people with psoriasis, and that if the quality of assessment was improved, better management would follow. NICE quality standards do not replace existing guidance, and it remains important that other evidence-based guideline recommendations continue to be implemented. NICE Quality Standards define priority areas for quality improvement and illustrate what high quality care should look like. They do not provide a comprehensive service specification or prescribe local service delivery arrangements. |
| 092 | 021 | Royal College of Physicians | Statement 2 | We would recommend the title as "Quality of life and Psychological impact". Quality of life does not necessarily equate to psychological distress. Consideration of psychological and social wellbeing as well as physical severity is to be commended. DLQI assessment should be obligatory and carried out in conjunction with an assessment of disease severity, both in primary and secondary care, to get a full understanding | Thank you. Please see statement 2 in the final quality standard where the statement title has been amended to 'assessing impact of disease', in order to better cover all the issues concerned. |

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| | | | | of the impact of disease. Since DLQI does not measure psychological distress and patients with psoriasis experience high rates of anxiety and depression, a baseline and then an annual measurement of distress using a validated measure such as the Hospital Anxiety and Distress Scale is recommended. If these factors are assessed there needs to be adequate service provision to manage patients with psoriasis and psychological disease. A multi-disciplinary or integrated service is important as this is very under-resourced and a poorly recognised aspect of care. | |
| 093 | 004 | Primary Care Dermatology Society | Statement 2 – Question 5 | At presentation and at yearly medicines review for QoL and simple arthritis question would seem most appropriate. ? by pharmacist /nurse/GP. | Thank you. The Quality Standards Advisory Committee discussed how best to improve the measurability of the statement and considered that an arbitrary fixed review period may be difficult to set due to the unpredictable nature of the disease. Please see statement 2 in the final quality standard which focuses on the key points of diagnosis and when assessing response to treatment. |
| 094 | 011 | Pfizer Ltd | Statement 2 – Question 5 | QS2: We believe that people with psoriasis should be routinely assessed to determine how their physical, psychological and social wellbeing is being affected by having psoriasis. Quality of life assessments may be part of the continued monitoring of response for treatments like biologics and therefore may be taken a more regular time intervals in some patients. | Thank you. The Quality Standards Advisory Committee discussed how best to improve the measurability. Please see statement 2 in the final quality standard which focuses on the key points of diagnosis and when assessing response to treatment, to ensure that impact is assessed on an on-going basis. |
| 095 | 012 | Janssen | Statement 2 – Question 5 | We suggest disease severity and quality of life be assessed at each consultation regarding psoriasis. Rationale: Systematic and on-going assessment of disease severity and quality of life is necessary to monitor effectiveness of treatments offered to people with psoriasis. | Thank you. The Quality Standards Advisory Committee discussed how best to improve the measurability. Please see statement 2 in the final quality standard which focuses on the key points of diagnosis and when assessing response to treatment, to ensure that impact is assessed on an on-going basis. |
| 096 | 013 | LEO | Statement 2 – Question 5 | Annual reviews (as per NICE & SIGN clinical guideline recommendations) would be reasonable unless an individual patient needed more frequent assessment. | The Quality Standards Advisory Committee discussed how best to improve the measurability of the statement and considered that an arbitrary fixed review period may be difficult to set due to the unpredictable nature of the disease. Please see statement 2 in the final quality standard which focuses on the key points of diagnosis and when assessing response to treatment. |
| 097 | 018 | AbbVie Ltd | Statement 2 – Question 5 | AbbVie welcomes the recognition that assessment of both disease severity and the effect of the disease on physical, psychological and social wellbeing will positively impact standards of care in psoriasis. However, AbbVie considers that there is a need to add the suggested timing and frequency of these assessments to the Quality Statements in order to aid measurability. | Thank you. The Quality Standards Advisory Committee discussed how best to improve the measurability of the statement and considered that an arbitrary fixed review period may be difficult to set due to the unpredictable nature of the disease. Please see statement 2 in the final quality standard which focuses on the key points of |

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| | | | No | Please insert each new comment in a new row. As highlighted, AbbVie suggests the PASI to be recommended as the | diagnosis and when assessing response to treatment, to |
| | | | | assessment for all patients in specialist settings on their first visit | ensure that impact is assessed on an on-going basis. |
| | | | | following referral from a non-specialist setting. Thereafter, AbbVie | The definitions section in this quality statement |
| | | | | suggests that a PASI assessment is carried out at each subsequent | references the available tools that can be used to support |
| | | | | monitoring visit, at a frequency consistent with NICE guidance, to assess | the assessment of disease impact, in line with the |
| | | | | a patients response to treatment over time. AbbVie considers that the DLQI questionnaire should form routine part of | recommendations from the underpinning NICE guideline. |
| | | | | specialist and non-specialist consultation as detailed above. In the case | |
| | | | | of non-specialist settings, AbbVie recommends that the DLQI be | |
| | | | | administered following a diagnosis of psoriasis in primary care and then | |
| | | | | again following assessment of response to 1st line topical therapies after | |
| | | | | 4-6 weeks of treatment in-line with SIGN Guidelines for the management of psoriasis. AbbVie further recommends that the DLQI should be | |
| | | | | recommended as the assessment for all patients in specialist settings on | |
| | | | | their first visit following referral from a non-specialist setting. Thereafter, | |
| | | | | AbbVie suggests that a DLQI assessment is carried out at each | |
| | | | | subsequent monitoring visit in specialist settings, at a frequency | |
| | | | | consistent with NICE guidance, to assess a patients response to treatment over time. | |
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| 098 | 002 | British Medical Association | Statement 3 | We would prefer it if 'indicated' was replaced with 'suggested' in the first sentence of the definition. | Thank you. The wording in the definition section links back to the statement wording. |
| 099 | 003 | NHS Commissioning Board | Statement 3 | This statement recognises that referral and re-referral may be needed for relapsing disease but does not include a measure of whether patients with the condition have timely re-access to appropriate specialist services when their condition flares. Whilst this need is described in the guideline, it requires reinforcement in the quality standard. This could be measured by patient questionnaires to those receiving repeated specialist treatments. | Thank you. The Quality Standards Advisory Committee considered this statement to address access to specialist services for relapsing disease. |
| 100 | 004 | Primary Care Dermatology Society | Statement 3 | We are unsure why nails for referral should be mentioned whilst severe scalp psoriasis and palmar-plantar pustulosis are not both of which are significant aspects of the disease for most. Patient wishes including non interference are paramount. | Thank you. The definitions are derived from the underpinning guideline recommendations, and the statement applies to people with all types of psoriasis. All statements are underpinned by patient choice and involvement in the decision-making process. |
| 101 | 006 | British Association of Dermatologists | Statement 3 | There needs to be an audit of where, when and why there are delays in patients receiving NICE approved treatments. Many patients have never been fully examined by their GP and some remain for years with severe disease and poor quality of life when they are compliant with NICE-approved therapies. The barriers to equitable care need to be known and acted upon. Many patients are reluctant to be discharged from secondary care as they fear they will not be re-referred when necessary. Referral criteria to secondary care should not only be based on physical severity, but also quality of life impact, e.g. DLQI>6 or HADS >8 as in SIGN guidance. This is alluded to in the comment "any type of psoriasis that is having a major impact on a person's physical, psychological or social wellbeing", however, an exact measure would be helpful. Psoriasis tends to wax and wane – provision for quick access to a dermatology specialist without having to go back to the GP should be catered for within the commissioning of psoriasis services. | Thank you. It is anticipated that statement 3 will contribute to quality improvement in this area. The definitions are derived from the underpinning guideline recommendations, and the Quality Standards Advisory Committee did not consider it necessary to define precise scores that would indicate referral to specialist services. |
| 102 | 007 | Royal College of Paediatrics | Statement | We were pleased to see that the standard recommends that all children | Thank you. |

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| | | and Child Health | 3 3 | Please insert each new comment in a new row. diagnosed with psoriasis should be referred at presentation to a specialist as we feel that this is most important recommendation for children with this chronic condition. | |
| 103 | 008 | Psoriasis Association | Statement 3 | Unfortunately not all Dermatology Departments are able to treat the psychological impact of psoriasis, and so for some, with less severe physical signs of psoriasis, help may not be available. We would prefer the statement to read "People with psoriasis who have been assessed in a non-specialist setting are referred to a dermatology, rheumatology or mental health specialist if indicated." Re-referral to specialist care when needed is vital, and this needs to be prompt. Re-access to services must be appropriate and timely. Whilst the Psoriasis Association agrees with the definitions of when people are referred to a specialist, the Guideline on Management of Psoriasis also listed high impact sites – we would like this to be consistent, and request this is added to the list. | Thank you. The Quality Standards Advisory Committee anticipated that improving referral into specialist services would facilitate improved access to the support needed. The definitions are consistent with the underpinning NICE guideline recommendation, and 'any type of psoriasis is having a major impact on a person's physical, psychological or social wellbeing' is considered to include high impact sites. |
| 104 | 009 | Lilly UK | Statement 3 | We believe that referrals to specialist are the most important quality statement particularly because of the expertise needed to appropriately assess and assign treatment for moderate-severe PS. We would also suggest that this statement is closely associated to quality statement 2, to ensure that the referral is having a positive impact on the patient's quality of life. | Thank you. |
| 105 | 010 | Psoriasis and Psoriatic Arthritis Alliance | Statement 3 | Referral to specialist services. This is linked very much to statements 1 and 2 with re-access also being important. Speedy referral when appropriate and the avoidance of unnecessary delays in treatment when disease becomes refractory would be extremely useful to patients. An outcome measuring time-to-treatment would be very helpful here. Psoriasis can spread quite rapidly and delays in treatment may eventually require more aggressive therapy or even hospital admission, which may have been avoided with earlier intervention. | Thank you. It is anticipated that this statement will contribute towards quality improvement in this area. |
| 106 | 014 | University of Manchester (impact) | Statement 3 | Please read in conjunction with the general comments about referral above in General Question 3. We agree with the general tenet of the statement but are disappointed that it refers to a dermatology specialist only. This implies the full range of specialist expertise is available in the dermatology service but we know this is not the case for psychological expertise (BAD Psychodermatology report 2013). Could this be rephrased to read 'People with psoriasis who have been assessed in a non-specialist setting are referred to <i>the appropriate</i> specialists if indicated'? | Thank you. The Quality Standards Advisory Committee anticipated that improving referral into specialist services would facilitate improved access to the support needed. |
| 107 | 016 | Novartis Pharmaceuticals | Statement 3 | Lack of clinical measures of disease progression and associated comorbidities are likely to hamper referral to secondary care. In an ideal world, PASI assessment (PEST for PsA), DLQI, PsAQOL and WPAI-SHP would be used to drive referral. We are aware of instances of patients | Thank you. The Quality Standards Advisory Committee anticipated that statements 1, 2 and 3 in particular, would improve referral to specialist care when needed. |

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| | | | | with moderate Pso and erosive PsA languishing in Primary Care as there are no strict measures of disease and psychological burden applied / used to drive referral. The NICE Clinical Guidelines may be overly complex for referrals whereas the Scottish recommendations are relatively straightforward (SIGN 121): If a patient has DLQI>5 after 2 nd topical therapy in primary care then patient is referred to secondary care. We suggest a more streamlined referral process. | |
| 108 | 018 | AbbVie Ltd | Statement 3 | AbbVie believes that it is crucial that patients with psychological needs have access to all appropriate services and not just dermatology specialists if required. Services need to be adequately integrated so that patients can be referred to trained healthcare professionals for all comorbidities, including psychological support. In addition, in order to standardize practice in the UK, AbbVie also suggests making reference to NICE guidance on the management of psoriasis: "People with psoriasis who have been assessed in a non-specialist setting are referred to a dermatology specialist if indicated according to NICE guidance and have access to other appropriate specialities including psychology services if required." | Thank you. The Quality Standards Advisory Committee anticipated that improving referral into specialist services would facilitate improved access to the support needed. Please see the definition section of statement 3 in the final quality standard, which defines the criteria for referral to a specialist, as per the underpinning NICE guidance. |
| 109 | 020 | See Psoriasis Look Deeper | Statement 3 | Please read in conjunction with the general comments about referral above in General Question 3. We agree with the general tenet of the statement but are disappointed that it refers to a dermatology specialist only. This implies the full range of specialist expertise are available in the dermatology service but we know this is unlikely to be the case for psychological expertise (BAD Psychodermatology report 2013). Could this be re-phrased to read 'People with psoriasis who have been assessed in a non-specialist setting are referred to <i>the appropriate</i> specialists if indicated'? Services need to be adequately integrated so that patients can be referred to trained healthcare professionals for all comorbidities, including psychological support. Ideally these specialists would form part of a broad multi-disciplinary team to enable multi-disciplinary discussion and decision-making. | Thank you. The Quality Standards Advisory Committee anticipated that improving referral into specialist services would facilitate improved access to the support needed. |
| 110 | 020 | See Psoriasis Look Deeper | Statement 3 | Many people with severe psoriasis only receive effective treatment decades after the start of their condition and are unaware that effective treatment is available. GPs are also often unaware both of the life impact of psoriasis and of available treatments which hinders referral to appropriate specialists. Many patients are reluctant to be discharged from secondary care as they fear they will not be re-referred when necessary. Referral criteria for referral to an appropriate specialist should not only be based on physical severity, but also quality of life impact and distress. | Thank you. The Quality Standards Advisory Committee anticipated that statements 1, 2 and 3 in particular, would improve referral to specialist care when needed. The definitions are derived from the underpinning guideline recommendations, and the Quality Standards Advisory Committee did not consider it necessary to define precise scores that would indicate referral to specialist services. |

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| | | | | E.g. DLQI>6 or HADS >8 as in SIGN guidance. This is alluded to in the comment 'any type of psoriasis that is having a major impact on a person's physical, psychological or social wellbeing' however an exact measure, using a validated scale, would be helpful. Psoriasis, tends to flare and then remit – provision for quick access to a dermatology specialist for flares of psoriasis should be catered for when commissioning psoriasis services. An audit of how many patients with severe psoriasis within primary and secondary care not receiving optimal treatment should be performed. | The British Association of Dermatologists are conducting an audit of patients in specialist services and the treatment currently offered. |
| 111 | 021 | Royal College of Physicians | Statement 3 | There needs to be an audit of where, when and why there are delays in patients receiving NICE approved treatments. Many patients have never been fully examined by their GP and some remain for years with severe disease and poor quality of life when they are compliant with NICE-approved therapies. The barriers to equitable care need to be known and acted upon. Many patients are reluctant to be discharged from secondary care as they fear they will not be re-referred when necessary. Referral criteria to secondary care should not only be based on physical severity, but also quality of life impact, e.g. DLQI>6 or HADS >8 as in SIGN guidance. This is alluded to in the comment "any type of psoriasis that is having a major impact on a person's physical, psychological or social wellbeing", however, an exact measure would be helpful. Psoriasis tends to wax and wane – provision for quick access to a dermatology specialist without having to go back to the GP should be catered for within the commissioning of psoriasis services. | Thank you. It is anticipated that statement 3 will contribute to quality improvement in this area. The definitions are derived from the underpinning guideline recommendations, and the Quality Standards Advisory Committee did not consider it necessary to define precise scores that would indicate referral to specialist services. The British Association of Dermatologists are conducting an audit of patients in specialist services and the treatment currently offered. |
| 112 | 002 | British Medical Association | Statement 4 | Whilst we recognise the importance of testing patients with severe cases of psoriasis for cardiovascular disease, these patients will be automatically referred to an outpatients clinic and it would make more sense for these tests to be carried out there. This would mean that patients did not need to attend both their dermatology clinic and then their GP for separate testing. The quality statement should also clarify what tool should be used for those over 75, who cannot use QRisk. | Thank you. Implementation may depend on local service configuration; the quality standard describes priority areas of care for quality improvement but allows flexibility at local level to determine how exactly such services are commissioned and delivered. It is anticipated that a clinical assessment of cardiovascular risk factors may be necessary for over 75s given the lack of validated risk assessment tools for this age group. |
| 113 | 004 | Primary Care Dermatology Society | Statement 4 | Cardiovascular risk is important in all patients and currently available for the older patients in the general population. This extends it to an earlier age. We support the principle. The evidence that mild psoriasis carries significant increased risk is not proven as yet so phototherapy for guttate psoriasis in the teens? requires a single assessment at the time. Q4. Adding severe psoriasis to the criteria for QOF CVS risk factors would be a small and easy step. | Thank you. We note that the complex interaction between psoriasis and cardiovascular risk is yet to be fully understood, but that studies are underway to investigate the link, with a view to informing any potential future action in relation to this issue. |
| 114 | 006 | British Association of Dermatologists | Statement 4 | Psoriasis is not just associated with cardiovascular disease but multiple co-morbidities – NAFLD and NASH in particular are very common in this | Thank you. The Quality Standards Advisory Committee considered that assessment of cardiovascular risk was a |

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| | | | | sub-group of patients and there are significant consequences for treatment toxicity and disease outcomes. Obesity, diabetes, arthritis, hypertension, anxiety and depression are also associated with psoriasis. It is important to screen for these conditions and also have pathways in place to manage them, as many of the risk factors such as obesity, smoking and alcohol consumption can be modified. As well as screening, services should include the ability to address and manage these lifestyle issues within the broader multi-disciplinary team, which may span primary and secondary care. | key issue for quality improvement in the care of people with psoriasis, and that if the quality of assessment was improved, better management and appropriate intervention for those modifiable risk factors would follow. |
| 115 | 008 | Psoriasis Association | Statement 4 | Whilst the Psoriasis Association welcomes the statement that "Adults with severe psoriasis are offered a cardiovascular risk assessment at initial presentation and at least once every 5 years", we are concerned that there is no mention of management, and query whose responsibility it is to carry out the assessment and management? | Thank you. The Quality Standards Advisory Committee considered that assessment of cardiovascular risk was a key issue for quality improvement in the care of people with psoriasis, and that if the quality of assessment was improved, better management and appropriate intervention for those modifiable risk factors would follow (in accordance with the recommendations in the underpinning NICE Guideline). Implementation may depend on local service configuration; the quality standard describes priority areas of care for quality improvement but allows flexibility at local level to determine how exactly such services are commissioned and delivered. |
| 116 | 009 | Lilly UK | Statement 4 | Given the underlying risk, we recommend that Psoriasis patients should have their cardiovascular risk assessed annually rather than every 5 years. | Thank you. The statement is derived from the underpinning evidence-based NICE guideline recommendation for assessment once every 5 years. |
| 117 | 010 | Psoriasis and Psoriatic Arthritis Alliance | Statement 4 | Assessing cardiovascular risk. The emphasis here needs to be on severe disease, otherwise there is a risk of unnecessary anxiety among those with more moderate disease. The aim should be to identify higher risk patients in whom age and associated risk-factors (eg hypertension, dyslipidaemia) are key factors. | Thank you. The statement refers to people with severe psoriasis only. |
| 118 | 014 | University of Manchester (impact) | Statement 4 | Please read in conjunction with General Question 2 above. The standard reads as though providing people with an assessment of risk is sufficient to prompt people to modify those risk factors that can be affected, it is not. Furthermore, cardio-vascular risk assessment communication alone with no associated management strategy may increase distress. People will adopt behaviour changes if they are advised how to using an evidence-based approach, not otherwise. Can this QS be changed to include assessed <i>and managed</i> appropriately? | Thank you. The Quality Standards Advisory Committee considered that assessment of cardiovascular risk was a key issue for quality improvement in the care of people with psoriasis, and that if the quality of assessment was improved, better management and appropriate intervention for those modifiable risk factors would follow (in accordance with the recommendations in the underpinning NICE Guideline). NICE quality standards do not replace existing guidance, and it remains important that other evidence-based guideline recommendations continue to be implemented, such as those relating to the |

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| 119 | 015 | MSD Ltd | Statement 4 | Quality Statement 4 defines severe psoriasis as "psoriasis which requires treatment with phototherapy or systemic agents or requires hospital admissions". MSD recommends using a definition of severe psoriasis which is consistent with the current published guidance on psoriasis, e.g. NICE Clinical Guideline 153 where the definition of severe psoriasis includes PASI and Dermatology Life Quality Index (DLQI) scores | management of cardiovascular risk factors. Thank you. The definition of severe used for this statement is derived from the studies behind the guideline recommendation, as this is where the evidence for increased cardiovascular risk is, rather than the definition of severe that is used for treatment. |
| 120 | 018 | AbbVie Ltd | Statement 4 | AbbVie considers that "severe" psoriasis may be misleading when used in this context. The definition of severe disease on page 12 of the draft states: "Severe psoriasis can be defined as psoriasis which requires treatment with phototherapy or systemic agents or requires hospital admission." However, AbbVie considers that patients with psoriasis who require systemic therapies are not limited to those patients with a PASI score of 10 or greater and a DLQI of greater than 10 and therefore there is a disconnect between the wording in the Quality Statement and the definition provided of "severe". AbbVie considers the current wording may mislead the audience in only offering a CV risk assessment to a more severe cohort of psoriasis patients than intended. AbbVie suggests expanding the wording in the Quality Statement to prevent misinterpretation: "Adults with psoriasis which requires treatment with phototherapy or systemic agents or requires hospital admission are offered a cardiovascular risk assessment at initial presentation and at least once every 5 years." | Thank you. The definition of severe used for this statement is derived from the studies behind the guideline recommendation, as this is where the evidence for increased cardiovascular risk is, rather than the definition of severe that is used for treatment. The definition will be presented alongside the statement so it is expected that audiences will refer to it when reading the statement. |
| 121 | 019 | British Dermatological Nursing Group | Statement 4 | With regard to the cardiovascular risk assessments to be performed every 5 years who takes up that responsibility | Thank you. Implementation may depend on local service configuration; the quality standard describes priority areas of care for quality improvement but allows flexibility at local level to determine how exactly such services are commissioned and delivered. |
| 122 | 020 | See Psoriasis Look Deeper | Statement 4 | Please read in conjunction with General Question 2 above. The standard reads as though providing people with an assessment of risk is sufficient to prompt people to modify those risk factors that can be affected, it is not. Furthermore, cardio-vascular risk assessment communication alone with no associated management strategy may increase distress. People are more likely to adopt behaviour changes if they are advised how to do so using an evidence-based approach, not otherwise. Can this Quality Statement be changed to include assessed and managed appropriately? Psoriasis is associated with multiple co-morbidities – cardiovascular disease, obesity, diabetes, arthritis, hypertension, anxiety and | Thank you. The Quality Standards Advisory Committee considered that assessment of cardiovascular risk was a key issue for quality improvement in the care of people with psoriasis, and that if the quality of assessment was improved, better management and appropriate intervention for those modifiable risk factors would follow (in accordance with the recommendations in the underpinning NICE Guideline). NICE quality standards do not replace existing guidance, and it remains important that other evidence-based guideline recommendations |

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| | | | No | Please insert each new comment in a new row. depression. It is important to screen for these conditions and also have pathways in place to manage them. People with psoriasis have high rates of modifiable risk factors such as obesity, smoking and alcohol consumption. Addressing these modifiable risk factors (such as reduction in alcohol and weight) may improve psoriasis and reduce the need for potentially toxic drug therapy. Service provision should include the ability to address and manage these lifestyle issues within the broader multidisciplinary team, which may span primary and secondary care. | continue to be implemented, such as those relating to the management of cardiovascular risk factors. The Quality Standards Advisory Committee considered that assessment of cardiovascular risk was a key issue for quality improvement in the care of people with psoriasis, and that if the quality of assessment was improved, better management and appropriate intervention for those modifiable risk factors would follow. |
| 123 | 021 | Royal College of Physicians | Statement 4 | Psoriasis is not just associated with cardiovascular disease but multiple co-morbidities – NAFLD and NASH in particular are very common in this sub-group of patients and there are significant consequences for treatment toxicity and disease outcomes. Obesity, diabetes, arthritis, hypertension, anxiety and depression are also associated with psoriasis. It is important to screen for these conditions and also have pathways in place to manage them, as many of the risk factors such as obesity, smoking and alcohol consumption can be modified. As well as screening, services should include the ability to address and manage these lifestyle issues within the broader multi-disciplinary team, which may span primary and secondary care. | Thank you. The Quality Standards Advisory Committee considered that assessment of cardiovascular risk was a key issue for quality improvement in the care of people with psoriasis, and that if the quality of assessment was improved, better management and appropriate intervention for those modifiable risk factors would follow. |
| 124 | 002 | British Medical Association | Statement 5 | Whilst we recognise that it is important that people with psoriasis are tested for psoriatic arthritis, we would argue that testing annually is excessive: many patients with psoriasis will not consult their GP about their psoriasis each year. However, we feel that PEST is an effective tool for opportunistic screening within general practice. | Thank you. Please see revised statement 5 in the final quality standard, which takes account of this point. The population is described as those receiving treatment, which acts as a proxy measure for those people with psoriasis already in regular contact with healthcare professionals, where the assessment for psoriatic arthritis can be done as part of a wider review. |
| 125 | 003 | NHS Commissioning Board | Statement 5 | Annual review of all patients with psoriasis (1.9% of the population, potentially around 1 million people) for psoriatic arthritis risks redirecting scarce NHS resources away from patient care. | Thank you. Please see revised statement 5 in the final quality standard, which takes account of this point. The population is described as those receiving treatment, which acts as a proxy measure for those people with psoriasis already in regular contact with healthcare professionals, where the assessment for psoriatic arthritis can be done as part of a wider review and without risking redirection of resources away from patient care. |
| 126 | 004 | Primary Care Dermatology Society | Statement 5 | This statement will increase dramatically referrals to rheumatology to "cover" the risk of complaints. A further questionnaire may be considered excessive for the myriad of aches and pains of life and the PEST has significant limitations. | Thank you. Please see revised statement 5 in the final quality standard, which takes account of this point. The population is described as those receiving treatment, which acts as a proxy measure for those people with psoriasis already in regular contact with healthcare professionals, where the assessment for psoriatic arthritis can be done as part of a wider review. |

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| 127 | 006 | British Association of Dermatologists | Statement 5 | The importance of screening for psoriatic arthritis is now well accepted. It is also important that patients are not only screened for the presence of psoriatic arthritis, but receive early referral to an appropriate specialist for treatment, again preferably within the same multi-disciplinary team. Yearly screening is an ideal but this should not divert resources away from treatment of severe skin disease. | Thank you. Please see revised statement 5 in the final quality standard. The population is described as those receiving treatment, which acts as a proxy measure for those people with psoriasis already in regular contact with healthcare professionals, where the assessment for psoriatic arthritis can be done as part of a wider review. The Quality Standards Advisory Committee considered that assessment for psoriatic arthritis was a key issue for quality improvement in the care of people with psoriasis, and that if the quality of assessment was improved, earlier referral when necessary would follow. |
| 128 | 007 | Royal College of Paediatrics and Child Health | Statement 5 | For children, we think the quality statement should be "all children are assessed annually for joint disease and information is shared at diagnosis advising parents/young person that joint problems are associated with psoriasis". There is greater responsibility to ensure that a child has the assessment than for an adult and so we think the standard should be that the annual assessment of joints takes place. Chronic inflammatory arthritis in a child with psoriasis is technically not called psoriatic arthritis, but called the psoriatic subtype of JIA. Our impression is that it is even more common in children (than in adults) for psoriatic JIA to have lengthy delays from onset of symptoms to diagnosis/treatment. Studies into the patient journey show that some of the longest waits for all subtypes of JIA are for patients with the psoriatic subtype. A UK study in 2007 showed a range of wait times from onset of symptoms to seeing a paediatric rheumatologist of 24 – 260 weeks, with a median wait of 53 weeks: see ref 1. It is a recurring theme that families and health professionals do not recognise that children can develop arthritis, so we think it important that the sharing of this information is part of the quality statement. There is clear evidence of improved outcome from early diagnosis and treatment in JIA: see refs 2-6. The annual joint assessment for children will be predominantly by GPs, dermatologists and paediatricians. Whilst there is no validated tool specifically for this assessment in children with psoriasis, the Paediatric Gait Arms Legs Spins (pGALS) system would be a very suitable learning tool for an effective assessment, incorporating history and examination. This was developed by Prof Helen Foster with Arthritis Research UK, ref 7. If there are concerns identified at the annual assessment or in between, then a child under 16 years of age should be referred to a Paediatric Rheumatology service. UK BSPAR/ARMA standards of care aim for all children with symptoms suggestive of arthritis to be assess | Thank you. The quality statement covers all people with psoriasis, including children. Information provision about a person's condition is an important theme for all NHS care. The NICE quality standard on patient experience, which contains principles relevant to children and parents and is referenced in this quality standard, covers this area in more detail. |

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| | | | | weeks of onset of symptoms, with the referral made within 6 weeks of onset of symptoms. Ref 8 1 - Arthritis Rheum. 2007 Aug 15;57(6):921-7. Delay in access to appropriate care for children presenting with musculoskeletal symptoms and ultimately diagnosed with juvenile idiopathic arthritis. Foster HE, Eltringham MS, Kay LJ, Friswell M, Abinun M, Myers A. 2 - Foster HE, Marshall N, Myers A, Dunkley P, Griffiths ID. Outcome in adults with juvenile idiopathic arthritis: a quality of life study. Arthritis Rheum 2003;48:767–75. 3 - Packham JC, Hall MA. Long-term follow-up of 246 adults with juvenile idiopathic arthritis: social function, relationships and sexual activity. Rheumatology (Oxford) 2002;41:1440–3. 4 - Packham JC, Hall MA. Long-term follow-up of 246 adults with juvenile idiopathic arthritis: education and employment. Rheumatology (Oxford) 2002;41:1436–9. 5 - Packham JC, Hall MA. Long-term follow-up of 246 adults with juvenile idiopathic arthritis: functional outcome. Rheumatology (Oxford) 2002;41:1428–35. 6 - Ruperto N, Ravelli A, Levinson JE, Shear ES, Murray K, Link Tague B, et al. Long-term health outcomes and quality of life in American and Italian inception cohorts of patients with juvenile rheumatoid arthritis. II. Early predictors of outcome. J Rheumatol 1997;24:952–8. 7 - Arthritis Rheum. 2006 Oct 15;55(5):709-16. Musculoskeletal screening examination (pGALS) for school-age children based on the adult GALS screen. Foster HE, Kay LJ, Friswell M, Coady D, Myers A. 8 - Davies K, Cleary G, Foster H, Hutchinson E, Baildam E. BSPAR Standards of care for juvenile idiopathic arthritis: executive summary. Rheumatology 2010;49:1406-8. | |
| 129 | 007 | Royal College of Paediatrics and Child Health | Statement 5 | Alongside other NICE guidance relevant to psoriasis, the NICE technology appraisal No 35 for etanercept for treatment of juvenile idiopathic arthritis (JIA) should be referenced as psoriatic arthritis presenting before 16 th birthday is classified as the psoriatic subtype of JIA | Thank you. The Quality Standards Advisory Committee considered this statement to focus on the assessment for psoriatic arthritis rather than the treatment of it. |
| 130 | 008 | Psoriasis Association | Statement 5 | Only assessment is mentioned. The Psoriasis Association would welcome this statement to echo the NICE Psoriasis Guideline and state "People with psoriasis are offered an annual assessment for psoriatic arthritis and referred to a rheumatologist if suspected." | Thank you. The Quality Standards Advisory Committee considered that assessment for psoriatic arthritis was a key issue for quality improvement in the care of people with psoriasis, and that if the quality of assessment was improved, earlier referral when necessary would follow. It remains important that other evidence-based guideline recommendations continue to be implemented. |
| 131 | 009 | Lilly UK | Statement 5 | We are pleased patients will be offered an annual assessment for Psoriatic Arthritis (PsA). | Thank you. Implementation may depend on local service configuration; the quality standard describes priority |

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| | | | No | Please insert each new comment in a new row. To this end we would recommend that there is an expectation and/or formal platform for ongoing dialogue between the dermatologist and rheumatologist on the individual patient's care plan to allow a completely 'integrated / multidisciplinary' approach. | areas of care for quality improvement but allows flexibility at local level to determine how exactly such services are commissioned and delivered. |
| 132 | 010 | Psoriasis and Psoriatic Arthritis Alliance | Statement 5 | Psoriatic arthritis. This is extremely important issue as the level of knowledge among both patients and healthcare professionals is low. Many patients are completely unaware of psoriatic arthritis and the potential long-term problems associated with it. An annual assessment is clearly important, but patients need to be informed about the risk of arthritis when first diagnosed with psoriasis, whilst making it clear that not everyone with psoriasis with develop arthritis. | Thank you. Information provision about a person's condition is an important theme for all NHS care. The NICE quality standard on patient experience, which is cross-cutting and is referenced in this quality standard, covers this area in more detail. |
| 133 | 014 | University of Manchester (impact) | Statement 5 | As above, only assessment is recommended, that PSA is managed appropriately with expert input would seem to be the minimum requirement. Furthermore, given the severe impact that pain has on QOL and distress this too should be part of a recommendation to specialist services that are configured to manage the complexity of PSA and with the appropriately recognised psychological expertise. | Thank you. The Quality Standards Advisory Committee considered that assessment for psoriatic arthritis was a key issue for quality improvement in the care of people with psoriasis, and that if the quality of assessment was improved, earlier referral when necessary would follow. It remains important that other evidence-based guideline recommendations continue to be implemented. |
| 134 | 015 | MSD Ltd | Statement 5 | Quality Statement 5 states that "the Psoriasis Epidemiological Screening Tool (PEST) can be used to assess for psoriatic arthritis". MSD kindly suggests that the Psoriatic Arthritis Response Criteria (PsARC) should be recommended for use instead of PEST, in order to ensure that this Quality Standard more accurately reflects the current published guidance on psoriatic arthritis, e.g. NICE Technology Appraisal 199 and NICE Technology Appraisal 220 | Thank you. The reference to the PEST tool is derived from the underpinning recommendation from the NICE Clinical Guideline for Psoriasis, which published in 2012. |
| 135 | 018 | AbbVie Ltd | Statement 5 | AbbVie suggests standardizing the tool to assess psoriatic arthritis (PsA) by recommending the PEST for use and including wording to such effect within the Quality Statement itself. This would facilitate the measurability of care being received and preclude any subjectivity that may arise in the assessment of PsA. A report from the GRAPPA 2009 Annual meeting concluded: "Although several screening tools have been developed, the Psoriasis Epidemiology Screening Tool (PEST) has the advantage of simplicity and ease of use. This new instrument consists of 5 simple questions supported by the addition of a manikin for patient mark up. During development, the questionnaire has shown a sensitivity of 0.94 and a specificity of 0.78." AbbVie suggests adding to the current wording: | Thank you. The Quality Standards Advisory Committee considered that assessment for psoriatic arthritis was a key issue for quality improvement in the care of people with psoriasis, rather than which tool was used for the assessment. |

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| | | | | "People with psoriasis are offered an annual assessment for psoriatic arthritis, using the PEST in the case of adult patients" | |
| 136 | 020 | See Psoriasis Look Deeper | Statement 5 | As above, only assessment is recommended, that PSA is managed appropriately with expert input would seem to be the minimum requirement. Furthermore, given the severe impact that pain has on QOL and distress this too should be part of a recommendation to specialist services that are configured to manage the complexity of PSA and with the appropriately recognised psychological expertise within a multi-disciplinary team. | Thank you. The Quality Standards Advisory Committee considered that assessment for psoriatic arthritis was a key issue for quality improvement in the care of people with psoriasis, and that if the quality of assessment was improved, earlier referral when necessary would follow. It remains important that other evidence-based guideline recommendations continue to be implemented. |
| 137 | 021 | Royal College of Physicians | Statement 5 | The importance of screening for psoriatic arthritis is now well accepted. It is also important that patients are not only screened for the presence of psoriatic arthritis, but receive early referral to an appropriate specialist for treatment, again preferably within the same multi-disciplinary team. Yearly screening is an ideal but this should not divert resources away from treatment of severe skin disease. | Thank you. Please see revised statement 5 in the final quality standard. The population is described as those receiving treatment, which acts as a proxy measure for those people with psoriasis already in regular contact with healthcare professionals, where the assessment for psoriatic arthritis can be done as part of a wider review. The Quality Standards Advisory Committee considered that assessment for psoriatic arthritis was a key issue for quality improvement in the care of people with psoriasis, and that if the quality of assessment was improved, earlier referral when necessary would follow. |
| 138 | 002 | British Medical Association | Statement 6 | We would argue that monitoring biologicals is not part of the role of general practice. This should be specified, as otherwise we would be concerned that GPs (who do not have the skills or experience to do so) will be encouraged to monitor patients as part of inappropriate shared care arrangements. Shared care should only be allowed where the GP involved has suitable training and experience and is willing to undertake the care within the practice and subject to regular revision. | Thank you. Please see statement 6 in the final quality standard, where the definition section has been expanded to clarify that responsibility for use of systemic therapy should be in specialist consultant-led settings only but that certain aspects of supervision and monitoring may be delegated to other healthcare professionals and completed in non-specialist settings, and in such cases, the arrangements should be formalised. This is consistent with the underpinning recommendation in the NICE Guideline. |
| 139 | 004 | Primary Care Dermatology Society | Statement 6 | Agreed | Thank you. |
| 140 | 006 | British Association of Dermatologists | Statement 6 | This statement should include screening <u>and</u> monitoring, not just the latter. There should be equitable access for standard drugs such as methotrexate. Intrinsic to the provision of specialist services should be the safe screening and monitoring of patients on systemic medications in line with national guidelines (NICE, BAD, SIGN). Pathways including access | Thank you. The Quality Standards Advisory Committee anticipate that the quality statement will improve quality in this area. |

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| | | | | to drug monitoring nurses/clinics and shared care with GPs, again preferably within a broad multi-disciplinary team, should be part of the commissioning process. | |
| 141 | 008 | Psoriasis Association | Statement 6 | The Psoriasis Association agrees that certain aspects of supervision and monitoring may be delegated to other healthcare professionals and completed in non-specialist settings – these should be those in which it is most convenient to the patient to attend. We agree with, and welcome the point that "Patients should be fully informed of the risks and benefits of systemic therapies through detailed discussion, supported by the provision of written information." | Thank you. |
| 142 | 009 | Lilly UK | Statement 6 | The relegation of systemic therapy to specialist setting only (as described in the Consultation document) may be driven by the typically injectable delivery form and the monitoring requirements. We would suggest that some consideration be given for oral medications and the ability for those to be administered outside of a specialist setting, preferably in all cases, but at least in the case of refills. | Thank you. Please see statement 6 in the final quality standard, where the definition section has been expanded to clarify that responsibility for use of systemic therapy should be in specialist consultant-led settings only but that certain aspects of supervision and monitoring may be delegated to other healthcare professionals and completed in non-specialist settings, and in such cases, the arrangements should be formalised. |
| 143 | 010 | Psoriasis and Psoriatic Arthritis Alliance | Statement 6 | Systemic therapy. This statement appears to be vague and slightly confusing; as there are differing types of systemic treatment, it is unclear where the monitoring should take place. For biologics the NICE guidance indicates specialist setting and inclusion in a registry, but for DMARDs such as methotrexate, care is shared or undertaken by a GP. So a clear distinction would be useful within this statement. Therefore an outcome measure might be for stable patients with low adverse events and a reduction in routine hospital visits. From a patient perspective more local ownership of monitoring for controlled disease would be useful, thereby reducing the management burden for the patient. | Thank you. Please see revised statement 6 in the final quality standard, where the definition section has been expanded to clarify that responsibility for use of systemic therapy should be in specialist consultant-led settings only but that certain aspects of supervision and monitoring may be delegated to other healthcare professionals and completed in non-specialist settings, and in such cases, the arrangements should be formalised. As this is largely a structural measure the Quality Standards Advisory Committee did not consider the link with these outcomes to be strong enough to warrant inclusion of outcome measures, although it is envisaged that achievement of the statement would contribute towards these outcomes. |
| 144 | 012 | Janssen | Statement 6 | We suggest efficacy of systemic therapy be measured alongside with rates of adverse events. If a patient's PASI and DLQI scores are measured at each consultation with a specialist (as suggested above), efficacy of systemic therapy will be measured in a systematic and ongoing basis. Rationale: In order to follow CG153's 'key priorities for implementation' on systemic therapies, it is necessary that efficacy of systemic therapy is | Thank you. The Quality Standards Advisory Committee considered the statement to focus on monitoring arrangements for those people receiving systemic therapy rather than the efficacy of systemic therapy. The definition section states that locally agreed protocols should incorporate national accredited drug guidelines and policy, to promote consistency. |

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| | | | | measured systematically and on an on-going basis. | |
| 145 | 012 | Janssen | Statement 6 | We suggest the quality statement be rephrased as "People with psoriasis receiving systemic therapy are monitored in accordance with national drug guidelines." Rationale: We are aware that some local drug guidelines may be inconsistent with national ones, despite the efforts to reduce local variations (e.g. NICE good practice guide: Developing and updating local formularies (GPG1)). By stating "People with psoriasis receiving systemic therapy are monitored in accordance with national <u>and local</u> drug guidelines", the quality statement may result in an unintended consequence of undue local variations in quality of care. | |
| 146 | 015 | MSD Ltd | Statement 6 | In response to the statement "systemic therapy for psoriasis poses a risk of adverse events, for which careful monitoring is required", MSD would like to note that all therapies pose a risk of adverse events, not only systemic therapies. Therefore, MSD feels that highlighting the risk for systemic therapies specifically could unduly dissuade clinicians from their use. MSD kindly suggests rewording the statement to "systemic therapy for psoriasis requires careful monitoring" | Thank you. The rationale section provides a brief explanation for why the statement is important. We would assume that clinicians are aware of the risks posed by this treatment and would not be unduly influenced by the wording here. |
| 147 | 016 | Novartis Pharmaceuticals | Statement 6 | No mention of systemic and biologic therapy with respect to a managed care approach with Rheumatology for patients with Pso and PsA. We recommend encouraging a MDT approach, with co-management of patients with PsA with Rheumatology. | Thank you. Implementation may depend on local service configuration; the quality standard describes priority areas of care for quality improvement but allows flexibility at local level to determine how exactly such services are commissioned and delivered. |
| 148 | 017 | Royal College of Nursing | Statement 6 | PASI and DLQI should be used every 3 months to assess disease severity and outcome. 6 monthly audits of systemic monitoring should be completed. | Thank you. Implementation may depend on local service configuration; the quality standard describes priority areas of care for quality improvement but allows flexibility at local level to determine how exactly such services are commissioned and delivered. |
| 149 | 018 | AbbVie Ltd | Statement 6 | AbbVie welcomes this Quality Statement to address the variation in clinical practice observed in the management of psoriasis in the UK . The recently published NICE CG 153 has highlighted the cost implications to the NHS in treating sub-optimally managed psoriasis patients with reference to a large audit of clinical practice. However, AbbVie considers there is a need to add further clarity to this Quality Statement in order to standardize the variation of practices seen in the UK relating to the management of psoriasis patients. AbbVie suggests changing the wording to include reference to NICE guidance for the monitoring of systemic therapies: | Thank you. Please see the definition section of statement 6 in the final quality standard, which refers to NICE guidance and states that locally agreed protocols should incorporate national accredited drug guidelines and policy, to promote consistency. |

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| | | | | "People with psoriasis receiving systemic therapy are monitored in accordance with NICE guidance and local drug guidelines" | |
| 150 | 021 | Royal College of Physicians | Statement 6 | This statement should include screening and monitoring, not just the latter. There should be equitable access for standard drugs such as methotrexate. Intrinsic to the provision of specialist services should be the safe screening and monitoring of patients on systemic medications in line with national guidelines (NICE, BAD, SIGN). Pathways including access to drug monitoring nurses/clinics and shared care with GPs, again preferably within a broad multi-disciplinary team, should be part of the commissioning process. | Thank you. The Quality Standards Advisory Committee anticipate that the quality statement will improve quality in this area. |

These organisations were approached but did not respond:

AAH Pharmaceuticals

Alder Hey Children's NHS Foundation Trust

Alliance Pharmaceuticals

Allocate Software PLC

Amgen UK

Arthritis and Musculoskeletal Alliance

Association of Anaesthetists of Great Britain and Ireland

Autistic Rights Movement UK, The

Bard Limited

Barnsley Hospital NHS Foundation Trust

Bradford District Care Trust

British Association of Skin Camouflage

British Dietetic Association

British HIV Association

British Medical Journal

British National Formulary British Nuclear Cardiology Society British Psychological Society British Society for Dermatopathology British Society for Immunology Cambridge University Hospitals NHS Foundation Trust Camden Link Capsulation PPS Capsulation PPS Care Quality Commission (CQC) Celgene UK Ltd Central & North West London NHS Foundation Trust Central London Community Health Care NHS Trust Changing Faces Clarity Informatics Ltd Cochrane Skin Group Coeliac UK Croydon Health Services NHS Trust Department for Communities and Local Government Department of Health Department of Health, Social Services and Public Safety Northern Ireland DO NOT USE

Dorset Primary Care Trust East and North Hertfordshire NHS Trust Epsom & St Helier University Hospitals NHS Trust Faculty of Occupational Medicine Faculty of Sport and Exercise Medicine Five Boroughs Partnership NHS Trust Forest Laboratories UK Ltd Galderma General Hypnotherapy Register George Eliot Hospital NHS Trust GlaxoSmithKline Gloucestershire Hospitals NHS Foundation Trust Gloucestershire LINk Great Western Hospitals NHS Foundation Trust Guy's and St Thomas' NHS Foundation Trust H & R Healthcare Limited Hammersmith and Fulham Primary Care Trust Healing Honey International Ltd Health Protection Agency Health Quality Improvement Partnership Healthcare Improvement Scotland

Hermal

Hindu Council UK

Hockley Medical Practice

Hospira UK Limited

Humber NHS Foundation Trust

Independent Healthcare Advisory Services

Lambeth Community Health

Leeds Community Healthcare NHS Trust

Leeds Primary Care Trust (aka NHS Leeds)

Liverpool Community Health

Liverpool Primary Care Trust

Luton and Dunstable Hospital NHS Trust

Medac GmbH

Medicines and Healthcare products Regulatory Agency

Medway Community Centre

Milton Keynes Clinical Commissioning Group

Ministry of Defence

National Clinical Guideline Centre

National Collaborating Centre for Cancer

National Collaborating Centre for Mental Health

National Collaborating Centre for Women's and Children's Health

National Institute for Health Research Health Technology Assessment Programme

National Patient Safety Agency

National Public Health Service for Wales National Treatment Agency for Substance Misuse Neonatal & Paediatric Pharmacists Group NHS Bournemouth and Poole NHS Clinical Knowledge Summaries NHS Connecting for Health NHS County Durham and Darlington NHS Direct NHS Nottinghamshire County **NHS Plus** NHS Sheffield NHS Warwickshire Primary Care Trust NICE technical lead North and East London Commissioning Support Unit North Lancashire PCT Nottingham City Council PERIGON Healthcare Ltd Pharmametrics GmbH Psoriasis Help Organisation Public Health Wales NHS Trust RioMed Ltd. Roche Products

Royal Berkshire NHS Foundation Trust Royal College of Anaesthetists Royal College of General Practitioners Royal College of General Practitioners in Wales Royal College of Midwives Royal College of Obstetricians and Gynaecologists Royal College of Paediatrics and Child Health, Gastroenetrology, Hepatology and Nutrition Royal College of Pathologists Royal College of Psychiatrists Royal College of Radiologists Royal College of Surgeons of England Royal National Institute of Blind People Royal Pharmaceutical Society Royal Society of Medicine Sandoz Ltd Sanofi Scottish Intercollegiate Guidelines Network Sheffield Teaching Hospitals NHS Foundation Trust **SNDRi** Social Care Institute for Excellence

Social Exclusion Task Force

Society of Chiropodists & Podiatrists

Solvay South Asian Health Foundation South London & Maudsley NHS Trust South Tees Hospitals NHS Trust South West Yorkshire Partnership NHS Foundation Trust Southport and Ormskirk Hospital NHS Trust **Spectranetics Corporation** St Mary's Hospital Stiefel Laboratories Substance Misuse Management in General Practice Teva UK The Rotherham NHS Foundation Trust The Whittington Hospital NHS Trust **UK Clinical Pharmacy Association** University Hospital Birmingham NHS Foundation Trust University of Bristol Walsall Local Involvement Network Warwickshire County Council Welsh Government West Midlands Ambulance Service NHS Trust Western Cheshire Primary Care Trust

Solent NHS Trust

Western Health and Social Care Trust

Western Sussex Hospitals NHS Trust

Westminster Local Involvement Network

Wirral University Teaching Hospital NHS Foundation Trust

York Hospitals NHS Foundation Trust