Psoriasis stakeholder workshop
Discussion group questions
27 July 2010

No.	Scope section	Question

1.	**4.1 Population**
	a) People with a diagnosis of psoriasis
	b) Consideration will be given to the specific needs, if any, of:
	- people with psoriatic arthritis (up to the point of referral)
	- children and young people and older people
		Points relating to the appropriateness of the population
		• Cross over between primary diagnosis of psoriasis/psoriatic arthritis - possible inclusion of psoriatic arthritis
		• Need to define age range (consider the changing retirement age and demographics, research base and product licensing in different ages)
		• Are infants included under children?
		
		• Special considerations
		  ○ Psoriasis in pregnancy or after pregnancy
		  ○ HIV psoriasis (management via sexual health services)
		  ○ Consider different subtypes of psoriasis (eg. guttate)
		  ○ Equalities issues relating to socioeconomic status/group, social and cultural differences, which may lead to a slightly different type of psoriasis requiring different management
		  ○ Importance of screening to lead to an earlier diagnosis of psoriatic arthritis with regular assessment for signs of psoriatic arthritis

2.	**Clinical Management**
	4.3.1 Key clinical issues
	a) Evaluation of disease severity and impact
	b) Diagnosis of psoriatic arthritis (up to the point of referral)
	e) Self-management
	f) Management of psychosocial impact of psoriasis
		Important points relating to key clinical issues
		• Terminology: Disease activity vs disease severity
		• Assessment tools
		  ○ PASI vs DLQI (neither is ideal)
		  ▪ people with devastating psoriasis can have low DLQI because they have learnt to cope
		  ▪ older patients have got used to their disease
		  ▪ patients may be “trained” to get better scores
		  ○ Gatekeepers for medications
		  ○ Primary vs secondary care evaluation of severity, usage of tools and medications available
		• Referral from primary to secondary care very important to patients (See ‘Eczema in children guideline’ Evidence Base to holistic care)
		• Screening for psoriatic arthritis
		• Assessment/screening for other co-morbidities e.g. cardiovascular disease
		• Psychological therapies (psychological feeds into economic)
		  ○ Serious consideration
		  ○ Separate out various therapies
		  ○ Restricted specialist psychologist services
		  ○ Liaison psychology important in secondary care
		• Social implications: note that this intervention may not be at the level of the individual
		• Separate psychological from social issues

3.	**Clinical management** **4.3.1 Key clinical issues** **Pharmacological interventions, for example:** **<u>Topical therapy</u>** - Self-administered by the patient: Emollients Corticosteroids Vitamin D analogs Retinoids Tar based products Non-licensed calcineurin inhibitors - Administered in specialist settings: Coal Tar (+/- phototherapy) Dithranol (+/- phototherapy) **<u>Systemic therapy</u>** - Licensed: Ciclosporin Methotrexate Acitretin - Unlicensed: Fumaric acid esters **<u>Biological therapy</u>** - Etanercept - Infliximab - Adalimumab - Ustekinumab } Cross ref. to TAs - ABT-874 (due for licensing and undergoing HTA at present)	**Pharmacological treatments** Emollients • Patient choice vs effectiveness? • Over the counter vs prescription (large amount) • Inequalities associated with socioeconomic status • Not thought to be very different – could leave out Dithranol • Used in daycare centres **and** at home • Is efficacy related to person applying? • Application in older people can be a problem (self applied or carer applied) Tar-based products • evidence poor but common practice Biologics • Etanercept assessment is set by NICE TA at 12 weeks but it doesn't work at this time • Inappropriate dosing • Step up vs step down therapy (prognostic implications) • Sequencing and timing of sequencing important (NB UVB impact on future biologic use) • Pharmaceutical company interests Antibiotics • Antistreptococcal treatment for guttate psoriasis (see Cochrane review) Combination therapies important to patients • Example vitamin D and steroid • Methotrexate and infliximab / methotrexate and ciclosporin • Ciclosporin and acitretin • Acitretin + TL01 or PUVA (phototherapy combined with drug) Exclude ○ Tazarotene – (topical retinoid - vitamin A analogue) HE issues • Monitoring, bloods (liver function – pro collagen 3 blood test vs liver biopsy) • Nursing and consultant time 3/12 involved Service delivery • Consultation behaviour • Diagnosis by GPs and then time gap before referral • Repeat prescriptions given without examination • Changes in funding of care over 2 years of guideline development • Discontinuation issues if need to attend for repeat script • DELPHI technique for consensus recommendation? Prioritisation • Systemic therapies and biologics should take precedence over topical therapies but some topical therapies should be included • Topical therapies ○ Emollients and vitamin D are the most used in primary care ○ Dithranol and coal tar were more expensive treatments so evidence of their efficacy would be useful • Systemic therapies ○ The group suggested that as many drugs as possible were included as drugs can lose efficacy over time ○ Other systemic therapies suggested: hydroxyurea, mycrophenolate mofetil and leflunomide ○ Methotrexate is <u>not</u> licensed for use with children ○ Steroids: there are problems around the use of steroids for people with psoriatic arthritis as withdrawal from this drug can cause flares in psoriasis (worse with oral rather than intravenous) Steroids e.g. dovobet • Extensive incorrect usage in primary care • Inappropriately long term use • Expensive • Safety issues • Pharmaceutical company interests

4.	**Clinical Management** **4.3.1 Key clinical issues** **Non-pharmacological interventions, for example:** **<u>Phototherapy</u>** - Broadband UVB - Psoralen + UVA (PUVA) - Narrowband TL01	**Is the list of non-pharmacological managements appropriate? If you could remove one, what would it be?** Key issues • Large treatment variation • TL01 should be number one priority – first line then PUVA (PUVA should be in the pharmacological section as it involves taking psoralen, a photo sensitizer (unlicensed), with the UVA (the P stands for psoralen) • Time implication and HE issue • Step up and step down approach important • Psychosocial impact o Suicidal ideation o Evidence base available Service provision • Multidisciplinary team approach – lacking in dermatology • Local access to therapies • Need endorsement for nurse therapists to use phototherapy • Patient travelling costs • Home UV lamps unregulated • Mobile phototherapy units provided by the NHS mainly in Scotland Add in • Guidance on what is acceptable for safe use of UV light – risks of skin cancer • Combination therapies • Psychological interventions and effect on outcomes may be important – e.g., peer support and phone and email messages and reinforcers o CBT especially • Role of multidisciplinary teams in management (dermatology, rheumatology, psychology, nutrition, social work, etc) • Self management: o Very important o Considered to be overarching principle, not specific to any one thing o Information provision about how to use the prescribed drugs and OTC drugs ➢ Own strong topic medication and know when to use it ➢ Steroids how long and how much ➢ Rebound flare ➢ Scalp psoriasis – problematic, treatment for scalp psoriasis often prescribed by the GP, patient uses it – then ensuing problem for secondary care as need to taper down due to flare issues ➢ Topical application and site e.g. products not for use on face Exclude • Broadband (UVB rarely used)

5.	**Clinical Management**
	4.3.2 Clinical issues that will not be covered
	a) Management of psoriatic arthritis
	b) Complementary and alternative treatments
		Is the list of clinical issues not covered appropriate?
		Group 1:
		• Consider skin psoriasis and psoriatic arthritis as a composite and hence include psoriatic disease as a composite
		• Complementary therapies: split opinion as to whether to include or not in the scope
		  ○ Many people do turn to complementaries
		  ○ Limitation - 'complementary needs to have evidence about validity'
		  ○ SIGN guidance does look at this
		  ○ Few head-to-head comparisons in literature of any psoriasis therapies (including standard therapies)
		  ○ Especially in children parents will try complementary therapies (perceived safer)
		• Diet – no evidence but patients often ask GP if there is anything diet wise
		
		Group 2: Complementary therapies are used. Also people often ask GP about diet but group felt no evidence in this area. Overall, balancing the included and excluded sections of the scope, group 2 agreed with the listed exclusions (that is they agreed with excluding complementary and alternative treatments / diet / PA).
		
		Group 3: Overall, felt complementary therapies should be included, no conclusion regarding what should be excluded.
		
		Group 4: Overall felt that not to include the management of psoriatic arthritis was a missed opportunity.
		The group agreed that there was no need to include complementary or alternative treatments.

6.	**4.3 Clinical management** **GENERAL**	**Is the approach for this scope appropriate?** Yes about right

7.	**4.3 Clinical management GENERAL**	**What are the top two issues i.e. what will most improve patient and carer outcomes?**
		• Primary care management
		  ○ Diagnostic competency
		  ○ Identification of co-morbidities
		  ○ Prescriber education
		• Secondary care (or tertiary)
		  ○ Appropriate referral e.g. early referral (younger patients), standardised referrals based on disease severity scores
		  ○ Access e.g. one year open appointment, telephone care
		• Patient education/self-management
		  ○ Psychosocial aspects of living with the disease
		  ○ Support groups
		• Holistic approach / MDT approach / stepped care approach (matrix)
		• Steroids
		• Knowing when to step up care, how long to try something before moving to next treatment
		• Discharging patients and calling back for later follow-up vs discharging and then granting them rapid-access for some specified length of follow-up

8.	**4.3 Clinical Management GENERAL**	**Are there areas of poor/unsafe practice that require address?**
		
		Predominantly safety issues
		• Potent topical steroids (dovobet particularly)
		  ○ Appropriate amounts
		  ○ Cross refer to medicines adherence guideline
		• Methotrexate
		  ○ 2.5 / 10mg safety issue (dermatologists vs rheumatologists)
		  ○ Shared care of drug administration
		• Patient information
		  ○ Dangers of methotrexate
		  ○ Danger of phototherapy i.e. not using tanning salons
		• Unregulated repeat-prescriptions
		• Long term monitoring of the use of systemic therapies and biologics
		• Phototherapy records and ensuring implementation by trained personnel
		• Inadequate training in primary care on dermatological issues

9.	**4.5 Economic aspects**	**Which new practices will have the most marked/biggest health implications for patients?**
		
		• Biologics
		• Appropriate management of comorbidities
		• Sequencing
		  ○ Combination treatments and phototherapy vs upstream biologics
		  ○ Monitoring / time taken issues
		• Psychological interventions

10.	**4.5 Economic aspects**	**Which new practices will have the most marked/biggest cost implications for the NHS?**
		
		• Appropriate treatment
		  ○ Sequencing of biologics vs systemic therapy
		  ○ Timing of therapies, including topical treatments
		  ○ Notable issues in children
		  ○ Psychological interventions
		• Service provision implications
		• Screening for co-morbidities

11.	**4.5 Economic aspects**	**Are there any new practices that might save money compared to existing practice?**
		
		• Generic biologics – but need to demonstrate bioequivalence
		• Appropriate
		  ○ Screening
		  ○ Assessment
		  ○ Prescribing
		  ○ Methotrexate may save money as it is less expensive than other systemic therapies and biologics
		• Patient education on the proper use of topical treatments by specialist nurses has proved effective

12.	**4.5 Economic aspects**	**If you had to rank the clinical issues in order of importance what would be your top 3?** Group 3: • TL-O1 unit availability • Biologics • GP prescriptions Group 4: • Evaluation of disease severity • Early screening and diagnosis of psoriatic arthritis • Pharmacological interventions

13.	**4.4 Main outcomes** **a) Health related Quality of Life (QoL)** <u>Scales for health related QoL:</u> - Dermatology Life Quality Index (DLQI). The range is between 0 and 30. If DLQI > 10, psoriasis has a significant effect on the patient quality of life. - SF-36 - EQ-5D <u>Scales of objective disease severity</u> - PASI score (Psoriasis Area and Severity Index). The scores give a range of 0 to 72. PASI > 10 considered severe psoriasis and correlates with a significant impact on QoL - Physicians global evaluation, for example, clear/nearly clear/mild/moderate/severe **b) Length of hospital stay** **c) Time to recurrence** **d) Maintenance of remission** **e) Toxicity of treatment** **f) Concordance or compliance with treatment** **g) Withdrawal rates** **h) Relapse rate** **i) Cosmetic acceptability** **j) Tolerability**	**Please prioritise the specified list of outcomes** General • Existing scales inadequate • Literature search for new scales (some of them validated) for example: o SKINdex (but in Italy) o SPASI o Psoriasis life stress inventory (PLSI) o Salford psoriasis index (SPI) o Self administered PASI (SAPASI) (patient satisfaction) o PASI 75 • Consider management of psoriasis in difficult areas of the body Include • DLQI and childhood DLQI widely used in published evidence so have to include or else will not be able to demonstrate if treatments improve QOL NB. Determines funding • Literature supports PASI/childhood PASI • Important to include patient and parent global evaluation/assessment. (SAPASI, PASI75) • Physician's global evaluation (common, major end point) • QoL scales that are psoriasis specific **-** Possibly two missing – psoriasis disability index (PDI)? • Priority should be on patient-specific measures o Cosmetic acceptability of the topical treatment o Reducing itch is important in tolerability (treatment may make it worse) o Redness o Inflammation • Toxicity • Concordance/adherence (mixed opinion on terminology) Exclude • Length of hospital stay (patients not generally admitted, except tertiary centres) • Delete 4.4 f 'concordance' replace with adherence • Recurrence and remission as a measure assume that the disease is fully cleared (but this doesn't happen often) • Withdrawal rate • Relapse rate (varies by age) Note: confusion about difference between time to recurrence and relapse rate and maintenance of remission

14.	**GDG Constituency**
	• Dermatologist special nurse
	• Nurse from primary care
	• Dermatologist (x2, one to cover paediatric)
	• GP x2 (one non-specialist, one with special interest in dermatology)
	• Pharmacist
	• Patient/carer member (x2)
	• Rheumatologist (co-optee)
	• Psychologist (co-optee)
	• Dermatologist with a speciality in phototherapy or Medical physicist (phototherapy expert) (co-optee)
	• Occupational health professional (co-optee)
		Do we have the right expertise on the group?
		
		Include
		• 2 x dermatologists
		  ○ Adult
		  ○ One specialist in psoriasis and one generalist
		• Paediatric
		• Physicist (phototherapy expert) definitely needed (engineer knows about equipment, maintenance, monitoring of machines if recommendations are going to be made for wider use of phototherapy)
		• 2 x Specialist nurses in dermatology
		  ○ Phototherapy knowledge
		  ○ Paediatric knowledge
		• 2 x patient/carer
		  ○ Recent
		  ○ Longer-term diagnosis
		  ○ Child/parent carer
		• Pharmacist representing
		  ○ Hospital
		  ○ Community
		• Social care sector worker
		• 2 x GP
		  ○ General
		  ○ GP with special interest in dermatology
		
		Co-optees (MDT important aspect)
		• Cardiologist
		• Endocrinologist
		• Psychologist
		• Paediatric rheumatologist
		• Rheumatologist
		• Occupational health
		
		Remove
		• “Dermatologist with a speciality in phototherapy”
		  ○ Specialist nurses know most about this

15.	**Equality**	**Does the scope promote equality of opportunities (about for example: ethnicity, disability, age, gender, sexual orientation, socio-economic status and religion)?** • It's fine / nil known • Access in rural areas to phototherapy may be difficult • Management of long-term condition among working poor (may not be able to afford medicines, may not be able to take time off work for some treatments, etc) • Psoriasis in black people is not difficult to recognise. Better training and awareness of dermatologists would address this perceived problem