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skin 'n' bones connection

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Dear Reader

In this issue you will see that inflammation is highlighted in articles on pages 7 and 10-12.

So why is inflammation such an important topic? For psoriasis and psoriatic arthritis, inflammation is the key driver of symptoms.

Inflammation is a normal and important process that allows your body to heal, usually as a response to an illness, injury or something that doesn't belong in your body (like germs or toxic chemicals).

Understanding the triggers that lead to inflammation is important, and will lead to better control of what is happening within the bodies of people with psoriatic disease.

But until that has been achieved, we still need to manage the condition and navigate the available services.

On pages 8, 13 and 14, we look at the NHS's planning to provide better access to current services.

Managing editor

PAPAA's position on pharmaceutical funding

PAPAA does not receive funds (either directly or in kind) from the pharmaceutical industry or commercial sector. All activities are funded via donations, subscriptions, charitable grants, legacies or other income generation. We believe that this allows us to act in an open, non-biased way and free from any perceived influence or agendas that may arise. We do not link our activities to commercial marketing or public relations campaigns and will only link our name or logo to an activity if we believe it is beneficial to our constituent group.

Disclaimer

The contents of the journal are aimed at providing information that may be of interest to people with psoriasis and/or psoriatic arthritis or those who have a specialist interest, whether in a personal or professional capacity. Some articles which will be included are of general interest and may or may not relate directly to either psoriasis or psoriatic arthritis. This material may include aspects related to health, services or products that are available.

We believe that at the time of printing all information is correct and cannot be held responsible for any inaccuracies that may occur, nor do we endorse any products that may appear in this journal.

All opinions are of the contributors and not necessarily those of the Psoriasis and Psoriatic Arthritis Alliance.

Always consult your own doctor or medical healthcare provider.

PAPAA is an independently funded UK patient-centred charity that supports both patients and professionals by providing material that can be trusted (evidence based), which has been approved and contains no bias or agendas

Main activities revolve around the themes of Care, Cause and Cure, where we provide extensive information, provide education and support research via a small grants scheme. Collaborative work is also part of the charity's activities, we are open to approaches to work together as a partner organisation or as a supportive promotor, to raise awareness of areas of activity, which are beneficial to people affected by psoriasis, psoriatic arthritis and associated co-morbid conditions, including other auto-immune mediated diseases.

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Healthcare system

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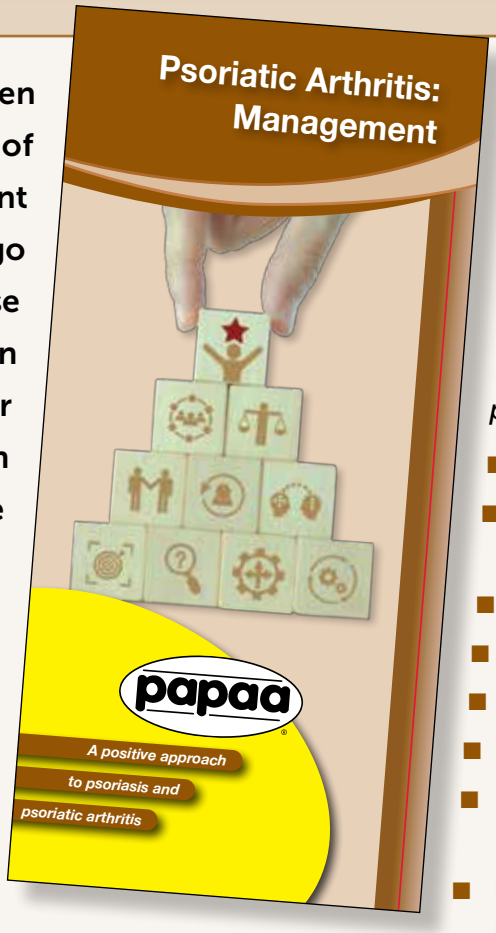
Psoriatic Arthritis: Management

Significant strides have been taken in the management of psoriatic arthritis over recent years. It was not so long ago that the only options for those affected by the condition were very limited. For someone being diagnosed in the 21st century, the future is much more optimistic, with a greater likelihood of finding an appropriate way of managing the symptoms.



To provide a useful understanding of how the management of psoriatic arthritis is now delivered, PAPAA has produced a new leaflet called *Psoriatic Arthritis: Management*.

The leaflet has been written to help people understand more about how the condition is currently managed. The material takes the reader through the period following diagnosis with a list of those individuals they are likely to encounter when beginning treatment.

The sections include:

- who is involved
- ongoing monitoring
- what treatments may be offered
- options
- shared decisions
- treatment planning
- assessment
- best practice
- treatment considerations
- reviews *and*
- follow-ups.

This medically reviewed information is part of a wide range of printed material PAPAA produces, and is also available as a digital download from the PAPAA website.

The following is the full list of printed material available:

- About Us
- Childhood Psoriasis: An Introduction
- Clinical Trials: An Overview
- Emollients and Psoriasis
- Genital Psoriasis
- Nail Psoriasis
- Occupational Therapy and Psoriatic Arthritis
- Physiotherapy and Exercise: Psoriatic Arthritis
- Psoriasis and Phototherapy
- Psoriasis and Sensitive Areas
- Psoriasis and the Heart
- Psoriasis and the Sun
- Psoriatic Arthritis: An Introduction
- Psoriatic Arthritis: Management
- Psoriatic fatigue: Why do I feel so tired?
- Psoriatic Lifestyle and Nutrition
- Psychological aspects of psoriasis
- Pustular Psoriasis
- Scalp Psoriasis
- The Psoriatic Foot
- Treatments for Psoriasis
- Treatments for Psoriatic Arthritis
- What is Psoriasis?
- What is Psoriatic Arthritis?

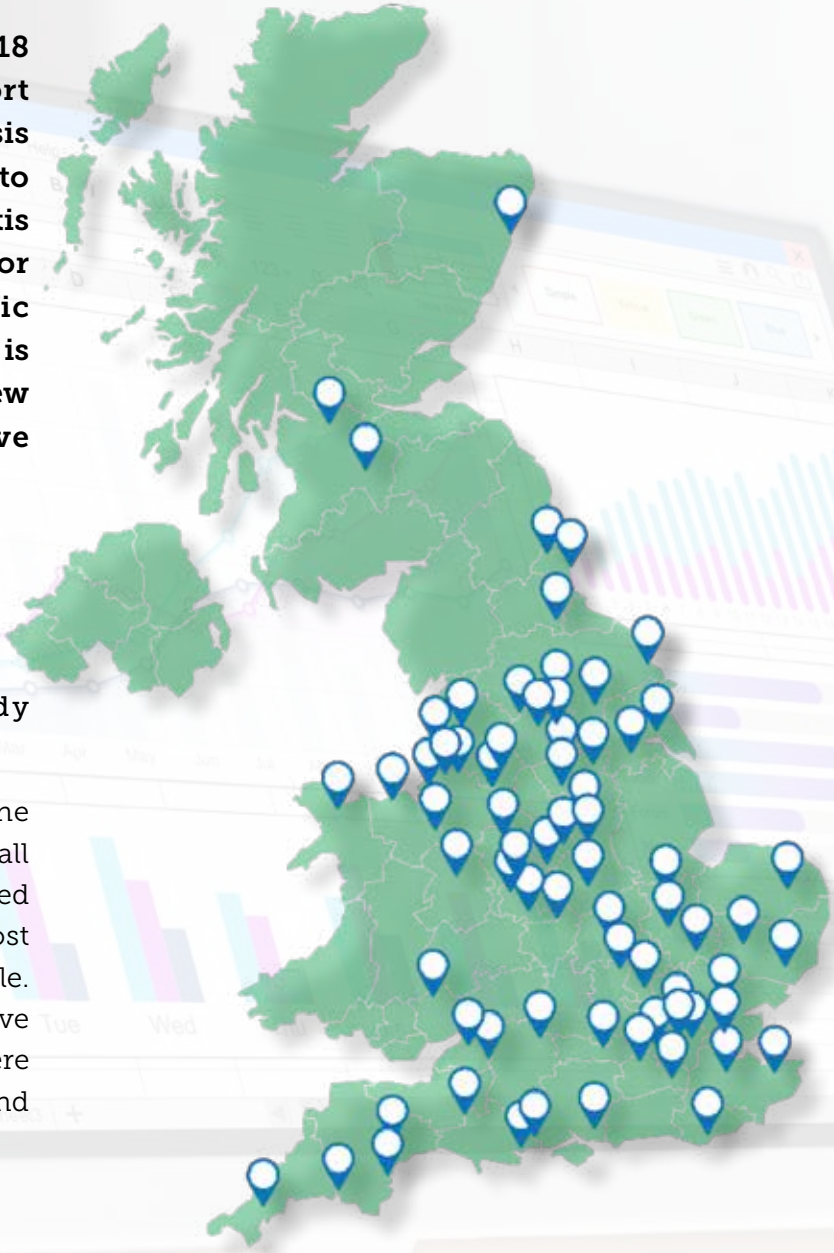
Single copies can be ordered for free or you may see them at your local hospital, pharmacy, or GP surgery, as PAPAA provides bulk copies to healthcare professionals for distribution.

The BSR-PsA register was set up in 2018 and is a long-term observational cohort study of patients with a clinical diagnosis of psoriatic arthritis. The main aims are to investigate the impact of psoriatic arthritis on patients' quality of life and to monitor the effectiveness and safety of biologic and conventional treatments. The study is recruiting patients who have started a new biologic therapy and patients who have never used one of these treatments.

There are two main forms of data collection:

1. clinical data collected from a patient's medical notes; and
2. questionnaires completed by study participants.

Some patients also donate blood and urine samples for storage in a PsA biobank. Like all studies, there are certain criteria patients need to meet to be able to take part, although most patients with a diagnosis of PsA will be eligible. Your local rheumatology team also needs to have enrolled as a recruiting centre. Currently, there are 78 hospital sites enrolled across the UK and they are still looking for new sites to join!

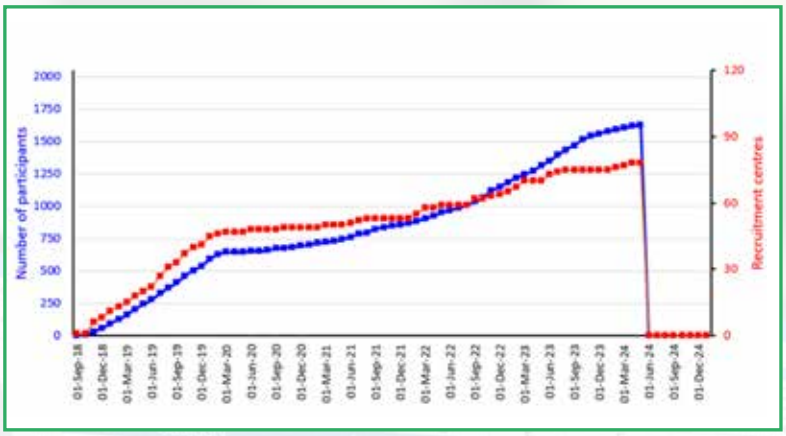


BSR-PsA Recruiting Sites

2018-2024 and beyond

Whilst the register was initially set up to collect long-term data over five years, the funder has recently agreed to extend the study until autumn 2027, with data collection culminating in 2026. This means the register can continue to collect long-term follow-up data and employ an analyst to explore the findings from the 1600+ participants enrolled to date.

This is particularly welcome news given the detrimental impact of the pandemic on participant recruitment; most recruiting centres (understandably) had to stop all non-Covid activities during this time. Since then, they have been busy re-opening study sites and recruitment has now returned to pre-pandemic levels – see the table opposite for participant



numbers and recruitment centres. Their current aim is to enrol ~2000 patients as this would greatly enhance the statistical power of the study.

Data analysis

Now back on track, one of their main priorities is to use the data from the register to try to answer various research questions. In the autumn of 2019, which feels like a very long time ago now, there was a consultation day with various key stakeholders – patient partners, academics, and clinicians – to discuss how the data could be used and to identify key research priorities (in the expectation there would be a robust dataset available from 2020 onward).

Fast forward to 2024 and some of those research questions are still unanswered (e.g. which biologic therapy should be prescribed to which patients and in what sequence), but some questions have received attention and may be less relevant now. Thus, there is a plan to organise a second consultation day to revisit the research priorities which were initially identified and ensure they are addressing questions currently important to clinical and patient communities.

Whilst the main data analysis is yet to be undertaken, they are lucky to have had several fantastic PhD students use the register as part of their doctoral studies: Stephanie Lembke, Dr Michelle Muller, and Mr Ross Macdonald. Lembke, for example, has been exploring predictors of treatment response to biologics and presented her initial analysis last year at the GRAPPA symposium in Dublin (see https://bit.ly/3V6or0m for more information). The findings from this doctoral work should provide valuable insights to help manage PsA and highlight another strength of the register in that several researchers can use the dataset to explore different questions at the same time.

The team is extremely grateful to all the participants who are taking part and to all the hospital sites who contribute time and effort to help with recruitment and clinical data collection. In the long term, the register should help to answer important research questions of interest to anyone impacted by psoriatic arthritis, and the wider rheumatology community.

BSR-PsA Team

Study website: abdn.ac.uk/bsr-psa

Source:
Dr Karen Forrest Keenan
BSR-PsA Study Co-ordinator
Epidemiology Group
University of Aberdeen

Stress and psoriasis

Young adults who find it harder to cope with stress are more likely to develop psoriasis later in life. Low stress-resilience when enlisting for military service involves a 31% higher risk of developing psoriasis compared to high stress-resilience. This has been shown by a large register-based study at the University of Gothenburg.

The study is based on data from more than 1.6 million Swedish men who enlisted for military service between 1968 and 2005.

As part of the enlistment process, all the men underwent psychological assessment in accordance with the same strict template. Based on this assessment, the researchers divided the data on men's stress resilience into three levels. A fifth (20.4%) of those who enlisted were placed in the lowest group, and a further fifth (21.5%) were placed in the highest group. More than half were therefore placed in the intermediate group. Data relating to the men was then cross-checked with other registers. The National Patient Register was used to obtain the diagnosis codes for psoriasis and the joint disease psoriatic arthritis.

Around 36,000 of the men developed psoriasis or psoriatic arthritis later in life. Low stress-resilience in men involves a 31% higher risk of developing psoriasis compared to high stress-resilience.

More severe cases of psoriasis and psoriatic arthritis were also found to be particularly clearly linked to stress. For in-patient diagnoses, low stress-resilience meant a 79% higher risk of psoriasis and a 53% higher risk of psoriatic arthritis compared to high stress-resilience.

Psychological sensitivity

This is the first study to date supporting the hypothesis that sensitivity to stress is a risk factor for psoriasis. As psoriasis is a chronic inflammatory systemic disease, the link to stress could be due to an increased inflammatory response in the body.

"We have shown that lower stress resilience in adolescence is a potential risk factor for psoriasis, at least for men," says the study's lead author, Marta Laskowski, a doctoral student in dermatology at the University of Gothenburg and a resident physician at Sahlgrenska University Hospital. *"Our results suggest that those with psoriasis have a hereditary psychological sensitivity. It is therefore important that healthcare professionals also pay attention to the mental wellbeing of patients with psoriasis."*

Marta Laskowski, Sahlgrenska Academy at the University of Gothenburg. Photo by Elin Lindström.

When estimating the increased risk, the researchers adjusted for other risk factors such as BMI and socioeconomic factors. However, the study could only be adjusted indirectly for smoking, which is a well-known risk factor for psoriasis. The researchers note that one weakness of the study is that stress resilience was only tested on one occasion, at the time of enlistment when the men were 18 years old.

"Stress resilience can vary throughout life," adds Marta. *"However, we have not had the opportunity to investigate these changes."*

The results of the study have been published in the Journal of the European Academy of Dermatology and Venereology.

To see PAPAA's information and resources about the psychological aspects of psoriasis, visit: www.papaa.org/psy

Source:
EurekAlert news release May 2024

A new study finds that a certain biological pathway, a set of linked reactions in the body, drives the inflammation seen in psoriasis.

The work could lead to improved therapies for all inflammatory skin diseases, including atopic and allergic dermatitis and a type of boil called hidradenitis suppurativa, say the study authors. Inflammation is the body's natural response to irritation and infection, but when out of control, it can lead to the reddish, flaky, itchy lesions that come with these skin conditions.

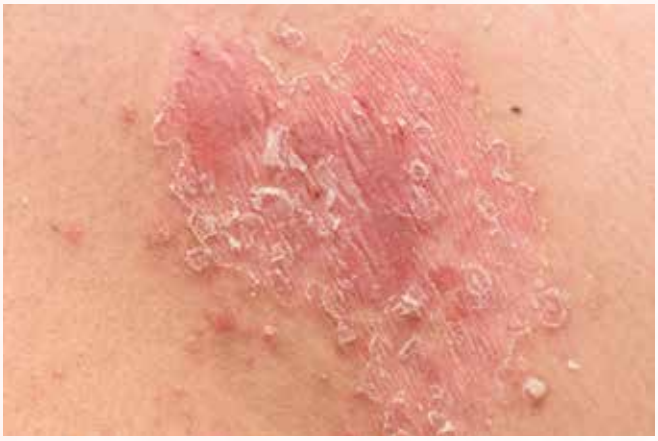
Led by researchers at NYU Langone Health*, the new study found that the interleukin-17 (IL-17) pathway, whose activity is blocked by existing anti-inflammatory drugs, activates a protein called hypoxia-inducible factor 1-alpha (HIF-1-alpha) in psoriasis. Researchers say that IL-17 has long been known to be active in inflammation, but the role of HIF-1-alpha has until now been unclear.

The research team also found that HIF-1-alpha lets inflamed skin cells more actively break down sugar for energy, supporting their metabolism and leading to the production of a waste product called lactate. When consumed by inflammatory T cells, lactate triggered the production of IL-17, fuelling even more inflammation.

Publishing in the journal *Immunity* online in May, the findings show that in human skin tissue samples from people with psoriasis, measures of gene activity around IL-17 and HIF-1-alpha were similar, suggesting that these factors are interconnected. Experiments in mice treated to develop psoriasis found that subsequent treatment with an experimental drug that blocks the action of HIF-1-alpha, called BAY-87-2243, resolved inflammatory skin lesions.

Further, skin samples from 10 patients successfully treated with anti-inflammatory drug etanercept showed diminished activity for both IL-17 and HIF-1-alpha, suggesting to researchers that when IL-17 is blocked, so is HIF-1-alpha.

"Our study results broadly show that activation of HIF-1-alpha is at the crux of metabolic dysfunction observed in psoriasis and that its action is triggered by IL-17, another key inflammatory-signalling molecule," said corresponding study author Shruti Naik, PhD, associate professor at NYU Grossman School of Medicine in the Departments of Pathology and Medicine, and the Ronald O. Perelman Department of Dermatology.



Further experiments were performed on skin samples from five patients with psoriasis whose healthy and inflamed skin was separately treated with either BAY-87-2243 or an existing combination of topical drugs (calcipotriene and betamethasone dipropionate). Researchers then compared differences in inflammatory gene activity as a measure of impact and found that the HIF-1-alpha inhibitor had a greater effect than existing topical drugs. Specifically, skin samples that responded to HIF-1-alpha therapy had 2,698 genes that were expressed differently, while standard-of-care–treated samples had 147 differently expressed genes.

"Our findings suggest that blocking either HIF-1-alpha's action or its glycolytic metabolic support mechanisms could be effective therapies for curbing the inflammation," added Naik, who is also the associate director for NYU Langone's Judith and Stewart Colton Centre for Autoimmunity.

Naik points out that while many available therapies for psoriasis, including steroids and immunosuppressive drugs, reduce inflammation and symptoms, they do not cure the disease. She said further experiments are needed to refine which experimental drug works best, concerning HIA-1-alpha inhibition, before clinical trials could start.

About:

*NYU Langone Health is an American academic medical centre that states it is devoted to excellence in patient care, education, and research.

Source:
NYU Langone Health
News release May 2024

Topical steroids

Topical steroid products are safe and highly effective treatments for the management of a wide range of inflammatory skin diseases but have important risks, especially with prolonged use at high potency. In psoriasis, the use of large quantities of topical steroids is associated with a risk of more severe disease, such as generalised pustular psoriasis.

In the coming months, as a result of regulatory action, topical steroid products will be labelled with information on their potency to simplify advice for patients. The introduction of new labelling and a reminder of the possibility of severe side effects, including topical steroid withdrawal reactions (TSW), follows work undertaken by the Medicines and Healthcare products Regulatory Agency (MHRA).

Since its last review of this issue in 2021, the MHRA has continued to receive reports and concerns from patients regarding TSW. The MHRA has carefully reviewed information received since the last review of this risk, and sought advice from the Commission on Human Medicines, with clinical experts in dermatology and representatives from dermatology charities included in these discussions.

Adverse reactions have been reported following long-term (generally 6 months or more) use of moderate or stronger potency topical steroids, particularly when used for eczema treatment – these reactions are often referred to as TSW.

Cases of skin reactions have been reported by long-term users of topical steroids when stopping treatment, including intense redness, stinging, and burning of the skin that can spread beyond the initial treatment area. The exact frequency cannot be determined but the reactions are estimated to be rare.

If using more than one topical steroid on different body areas, ensure you are using the correct strength for the area of the body concerned. In the future, the strength will be displayed on the packaging of your medicine. Seek medical advice before using a topical steroid on a new body area as some areas may require a different topical steroid

Always apply topical steroids as instructed and read the patient information leaflet provided with your medicine. If you have any questions about your medicines or are concerned about side effects, ask your prescriber or pharmacist, and report suspected side effects to the Yellow Card scheme.

Topical steroids are available in different potencies:

- mildly potent (for example, hydrocortisone)
- moderately potent (for example, clobetasone)
- potent (for example, betamethasone)
- very potent (for example, clobetasol).

The lowest potency topical steroid for effective treatment should be used and this may mean using different potency products for different body areas.

Over the coming year, topical steroids will be labelled with their potencies to aid in the correct selection and to simplify the advice to patients requiring multiple steroid products of differing potencies. These will be labelled 'mild steroid', 'moderate steroid', 'strong steroid', and 'very strong steroid'.

There are more than 11 million prescriptions issued for topical steroids each year. From the data available, TSW reactions are estimated to be rare; however, the reaction frequency cannot be confirmed due to uncertainties regarding the under-reporting of adverse reactions and the number of patients receiving repeat prescriptions. The number of reports of adverse reactions received must be put into context for the millions of people who have benefitted from topical steroid treatment without experiencing any problems.

Healthcare professionals, patients, and caregivers are asked to submit reports using the Yellow Card scheme electronically at: https://yellowcard.mhra.gov.uk

On the site, you can report to the Medicines and Healthcare Products Regulatory Agency any suspected side effects to medicines, vaccines, e-cigarettes, medical device incidents, and defective or falsified (fake) products.

To make a report, visit the YellowCard website: https://yellowcard.mhra.gov.uk/

Source: MHRA alert
Published 29 May 2024

Yellow Card | Making medicines and medical devices safer

Proposals set out in a joint NHS England and NICE consultation outline a new route for MedTech developers to access NHS funding to fast-track clinically and cost-effective products for use by the healthcare system.

The plans will ensure the growing number of game-changing products recommended by NICE can be introduced to the NHS on a large scale to improve patient outcomes.

The proposals in the consultation document have been developed by NHS England and NICE with input from the Department of Health and Social Care and other partners, including the Office for Life Science (OLS) and the Medicines and Healthcare products Regulatory Agency (MHRA).

Along with improving outcomes for patients, the proposals in the consultation will provide greater certainty for MedTech innovators and suppliers, with a commitment to automatic funding to support routine commissioning for those technologies that meet the required criteria.

Feedback on the proposals is being sought from patients, clinicians, academics, and industry, and can be submitted via the consultation webpage.

The consultation will run for 12 weeks, closing at midnight on Thursday 15 August.

Dr Vin Diwakar, interim medical director for transformation at NHS England, said: *"Medical technology plays a vital role in the nation's health and these proposals outline how we can fully maximise its use for the benefit of patients.*

"We are eager to hear from patients, industry, clinicians, and the public to help us develop and shape the MedTech pathway to ensure it can provide the greatest clinical and cost-effective benefit, so please come forward with your views."

Mark Chapman, director of the Health Technologies Programme at NICE, said: *"The speed of change and the sheer number of new products being brought to market within the MedTech world has determined the need for a clear pathway to ensure that the most promising new and or transformative technologies recommended by NICE can be adopted at scale by the NHS within a timely manner.*

"This new pathway aims to ensure that patients in every area of the country can benefit from the best products, devices, digital technologies, or diagnostic innovation. It will bring clarity to MedTech developers, giving them a clear route to accessing NHS funding, in the same way the pharmaceutical industry currently benefits from."

The proposals will strengthen the NHS Long Term Plan's commitment to accelerate the uptake of selected innovative medical devices, diagnostics, and digital products.

This public engagement is open until midnight on Thursday 15 August 2024. Consultation website: https://www.engage.england.nhs.uk/specialised-commissioning/building-an-integrated-rules-based-medtech-pathway/

Source:
NHS England
May 2024

Feeling fatigued?

In the UK, 10-20% of the population report being tired for a month or longer, with 1.5% feeling a need to see their GP. The symptoms often include difficulty sleeping; muscle or joint pain; headaches; painful lymph nodes; sore throat; cognitive dysfunction; symptoms made worse by physical or mental exertion; flu-like symptoms; dizziness; nausea; or palpitations.

Is it normal to feel fatigued with psoriatic disease?

It is normal to feel tired after exertion, insufficient sleep, or at the end of the day; this tiredness is usually relieved by rest or sleep. With fatigue, the symptoms often go beyond normal tiredness and can include decreased or lack of energy with accompanying physical or mental exhaustion. These symptoms usually persist even after a good night's sleep.

What causes fatigue?

As described above, inflammation appears to be part of the process of feeling fatigued, but researchers do not know exactly what the link is, or how increased levels of inflammatory substances in the body influence fatigue.

Myths and misconceptions

There are many myths and misconceptions about fatigue. People are sometimes wrongly viewed as being "lazy" by their work colleagues and sometimes by their family members.

The reason that the person affected by fatigue is unable to carry out basic everyday tasks is the inflammatory process taking place in their body. People often think that caffeine will help wake them up. As caffeine is a stimulant, the effects are short-lived; people often feel more tired once the initial effect wears off. Caffeine is typically found in coffee, tea, cola, and energy drinks. Caffeine is also a diuretic, causing dehydration, which will also have a negative effect. In some instances, people may resort to the use of alcohol, under the misapprehension that it will relieve the symptoms. However, alcohol is likely to make people drowsier and depressed and can affect sleep, which will also contribute to fatigue.

What can I do?

If you feel tired all the time, tell your healthcare provider, as it is important to rule out any other causes of fatigue. Sometimes you may need to have your medication changed or take tests so that what is happening can be fully understood.

With or without medical intervention, several lifestyle changes may help you feel generally less exhausted.

Dietary advice

- Eat a diet providing at least five servings of fresh fruit or vegetables a day
- Reduce the animal fats in your diet and avoid fatty foods as much as possible
- Eat fresh, home-made foods rather than prepackaged convenience foods
- Increase your intake of B-group vitamins, needed for the production of energy in the body. These are found in brown rice, whole

grain bread and cereals, oatmeal and oat flakes, pulses, green leafy vegetables, oily fish and poultry

- Aim to eat more oily fish, virgin olive oil or rapeseed oil, nuts and seeds
- If you are unable to increase your intake of fish, consider taking an omega-3 fish oil supplement
- Cut back on saturated spreads and vegetable oils and products that contain them, such as shop-bought biscuits and cakes
- Consider taking a vitamin and mineral supplement supplying around 100% of the recommended daily amount for as many nutrients as possible.

Behavioural changes

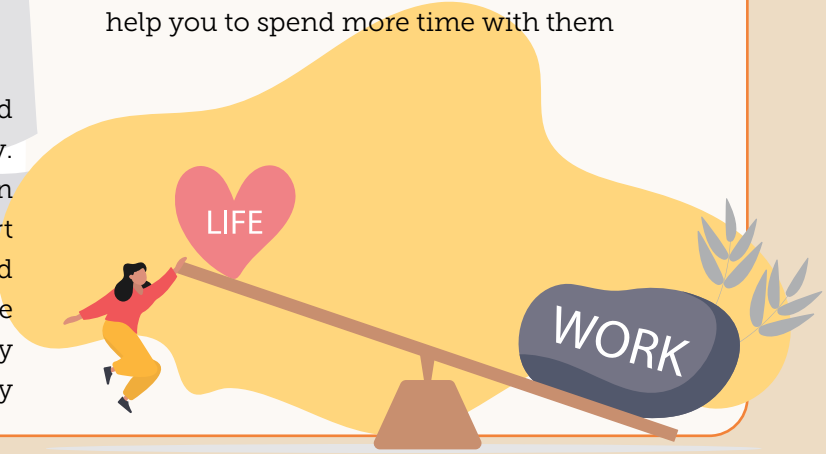
- Avoid things that interfere with sleep, such as caffeine, nicotine, excessive alcohol, and eating rich, heavy food late at night
- Avoid excess stress
- Aim to lose excess weight
- Put yourself first
- Take some time to rest during the day
- Keep a balance between the demands on you and your energy
- Learn to say no, if possible
- Tell people when you are tired
- Avoid using unnecessary energy.

Physical activity

Some people find it difficult to get motivated and take part in some form of physical activity. As everyone has different activity levels, pain thresholds, and body weight, you should start by finding activities that keep you mobile and strengthen your muscles, but which do not cause you any pain. Try to think of a physical activity that you enjoy that you can easily fit into your daily routine. If you enjoy walking, try to go for a walk a few times a week and increase the walking time by a minute or so per session. After a few weeks, you will have learned how far you can comfortably manage without experiencing pain. Other activities you may find beneficial are cycling, gentle gym exercises, or more complementary therapies such as yoga or pilates. See our leaflet ***Physiotherapy and Exercise: Psoriatic Arthritis*** for more detail.

Balancing energy

- Try to keep back some energy for something you like to do; it will give you satisfaction and a morale boost
- Use pain relief regularly and as directed, as constant pain will make you fatigued
- Take regular, gentle exercise
- Take a rest before the children arrive home from school or if you are having visitors, as this will help you to spend more time with them



- Spread chores out over a few days rather than trying to complete them on the same day
- Stop any activity before you are too tired. Rest and then start again
- Plan your activities so that you can take time out to rest before and after
- Find time to relax by learning mindfulness or other similar relaxation techniques
- If you have been concentrating on a particular activity, you may find it helpful to follow it with some physical activity, change of scene, and rest
- Sit down and use labour-saving devices when you can, as these will preserve your energy
- Be kind and gentle to yourself.

Keeping a diary

People find it difficult to understand why they feel fatigued; often there appears to be no obvious cause. You may find it useful to record the days and times you feel fatigued and for how long it lasts. Log the actions from the previous few days that might influence your energy levels, such as work, sleep, events, occasions, and even your food and drink. This may help you to understand the patterns and adjust your lifestyle and activities to reduce the incidence of fatigue. You will then be able to plan your life more effectively. It may also be useful to share this information with your healthcare provider, as they may be able to help you understand the causes.

If you are employed, it may be helpful to talk to your human resources department or your line manager, as they may be able to adjust your working environment. Under the Equality Act 2010 (Amendment) Regulations 2012, employers must make reasonable adjustments to make sure that workers with disabilities, such as physical or mental health conditions, are not substantially disadvantaged when doing their jobs. This applies to all workers, including trainees, apprentices, contract workers, and business partners.

Conclusion

Although it is well recognised in many published scientific studies that fatigue is a very common symptom in both psoriasis and psoriatic arthritis, it can be difficult to express exactly how it affects you. Most people with psoriasis and psoriatic arthritis who experience fatigue will find that it leaves them debilitated and affects their ability to function or carry out daily tasks, including work and studies. Even though there may be little interest from healthcare professionals in these symptoms, you should persist and continue to report them as it is an indicator of what is going on in your body. Following some of the advice listed in this article may not completely solve the fatigue that you experience, but it will go a long way towards helping you cope, manage, and deal with the symptoms that occur.

PAPAA produces a leaflet called:
Psoriatic fatigue: Why do I feel so tired?
Available from the PAPAA Shop:
www.papaa.org/shop

Following a successful trial last year involving more than a million users, NHS England has added a new service to its app, which allows people to see when their prescriptions have been issued and view their prescribed medication.

Those waiting for elective hospital treatment will also now be able to see the average waiting time for their procedure at their local trust, and users without a nominated pharmacy will be able to use a barcode in the app to collect their prescription from any pharmacy instead of needing a paper version.

Anyone who has a nominated pharmacy can continue to collect medication without a paper prescription or barcode, as details are sent to their pharmacy electronically.

The new features are being added as the NHS runs a campaign to encourage more people to use the app in their everyday lives and help free up time on the front line.

People can already use the NHS App to request repeat prescriptions digitally and the number of repeat prescriptions ordered through the app has grown by 45% over the past year, with an average of 3.1 million now requested every month.

Each repeat prescription ordered electronically saves GP practices three minutes, with those ordered using the app expected to save the equivalent of 1.85 million hours in 2024.

For users, it can save an average of 18 minutes with each online order, making it more convenient and freeing up frontline staff to do other important duties.

Vin Diwakar, national director for transformation at NHS England, said: *"The NHS App is transforming the way people manage their healthcare, freeing up valuable time for healthcare professionals.*

"Giving all patients in England direct access to prescription information through the app means they'll know when their prescription is issued and avoid delays in collection.

"The new feature will also mean people who haven't set a nominated pharmacy will be able to present the barcode in the app to a pharmacy of their choice without needing a paper version.

"The prescription service is the latest in a number of services we're adding to the NHS App to provide better care for patients. I'd encourage anyone who hasn't used the NHS App for a while, or who has never downloaded it, to tap the app and see what it has to offer."

Joe Harrison, national director of digital channels at NHS England, added: *"The NHS App is helping to support our frontline staff, freeing up time to treat more patients and enabling patients to get more involved in their care.*

"Millions of people are already using the app to order repeat prescriptions, and they'll now also be able to view and manage their prescriptions using the new service in the app."

The NHS App has gained 33.6 million registered users – equivalent to around three-quarters of the adult population – since its launch five years ago.

The campaign is spreading the message that whether sorting a repeat prescription, checking your GP record, or accessing a wealth of information and connected services, you simply need to 'tap the app'.

The campaign coincides with improvements within the app to make it easier to find services by providing a simplified and more intuitive experience.

More details on how to register with the NHS App are available at www.nhs.uk/nhs-app.

Source:
NHS: January 2024

Pharmacy First

The NHS launched a new campaign to raise awareness of the additional conditions that can now be treated by high street pharmacies, without needing to see a GP. The NHS in England has worked with pharmacies to promote the new support available for patients as part of its Help Us, Help You campaign, to raise awareness of the services, now available across the country.

What you need to know

People can now get treatment for seven common conditions directly from their local pharmacy, without the need for a GP appointment or prescription.

The Pharmacy First scheme was launched by the government and NHS England in January 2024 to give patients quick and accessible care and ease pressure on GP services.

But what does it cover and who will benefit?

Here's everything you need to know.

What is Pharmacy First?

Pharmacy First will enable community pharmacists to supply prescription-only medicines, including antibiotics and antivirals where clinically appropriate, to treat seven common health conditions without the need to visit a GP.

What are the seven common conditions?

- Sinusitis
- Sore throat
- Earache
- Infected insect bite
- Impetigo (a bacterial skin infection)
- Shingles
- Uncomplicated urinary tract infections in women.

How can I access treatment from my pharmacy?

You can get treatment for these conditions by walking into the pharmacy or contacting them virtually. GP receptionists, NHS 111, and providers of emergency care will also be able to direct patients to pharmacies that offer the service if contacted.

What will happen when I arrive at the pharmacy?

The pharmacist will be able to speak to you privately in a separate consultation room. They may perform an examination or ask to access your medical records. The pharmacist will be able to recommend the best course of action on an individual patient basis, including issuing prescriptions for antibiotics or antivirals where necessary.

How will this reduce NHS waiting times?

By reducing the number of patients with common conditions, needing blood pressure checks or oral contraception visiting a GP, Pharmacy First aims to free up 10 million GP appointments a year by next winter. This will allow GPs more time to see patients with more complex conditions.

Four in five people in England can reach a community pharmacy within a 20-minute

walk and there are twice as many pharmacies in the most deprived communities, making access to care quicker and more convenient.

How do I know if my local pharmacy is offering the service?

More than 10,000 pharmacies have already signed up to Pharmacy First – that's more than 95% of all those in England.

Will I have to pay for my medication?

Usual prescription charges will apply for the seven common conditions. Patients who were already exempt from prescription charges will still be exempt.

What if I still want to see my GP?

Patients can still choose to visit a GP if they wish to. Pharmacy First offers alternative access for these seven conditions and we encourage people to make the most of this service and to consult the highly trained professionals in their local pharmacy.

What else has been expanded in pharmaceutical services?

Women have been able to get their contraceptive pill from their local pharmacy, with up to 25% of all women on oral contraception being able to benefit from this new service.

Pharmacists are also increasing the number of life-saving blood pressure checks given to at-risk patients over the next year, with a commitment to deliver 2.5 million a year by spring 2025 – up from 900,000 carried out last year. It is estimated this could prevent more than 1,350 heart attacks and strokes in the first year.

Where does Pharmacy First apply?

This new service is run by NHS England and therefore will be available across England.

Will Pharmacy First have an impact on anti-microbial resistance?

Anti-microbial resistance occurs when the body's microbes no longer respond to medicines due to over-usage, making infections harder to treat.

This scheme is not expected to result in larger volumes of antibiotics being prescribed, and patients will still undergo a consultation with a pharmacist before any medicine is dispensed.

Medicine supply must be clinically appropriate and only after a shared discussion between the patient and pharmacist on the risks and benefits of taking the medicine, and of any alternative self-care options.

For more information, visit

www.nhs.uk

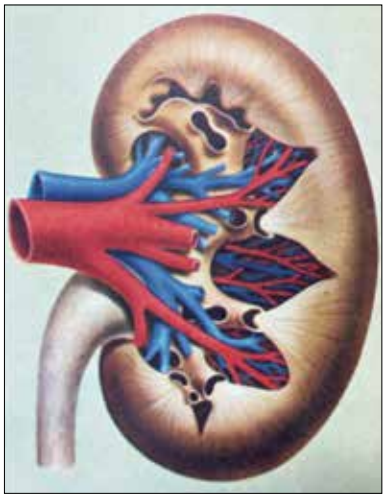
and search for pharmacy first

Source:

NHS England: February 2024

Kidney stones

Kidney stones (urolithiasis) are common, with around 1 in 10 people getting them, usually between the age of 30 and 60. They can be very painful and if left untreated lead to infections and the kidneys not functioning correctly.



According to a recent study published in *The Journal of Dermatology*, people with psoriasis are more prone to getting kidney stones than the general population. The study was relatively small; it included 67 people with psoriasis compared to 65 people never diagnosed with psoriasis. Stones were found in 13 people with psoriasis, versus only five within the control group. The conclusion from the researchers was that this is significant enough to consider that people with psoriasis were at greater risk, particularly those with more severe disease.

Of course, this was a small study and further investigation needs to be undertaken, but as with other studies, the picture of what is now called psoriatic disease is broader and more complicated than the skin manifestation suggests.

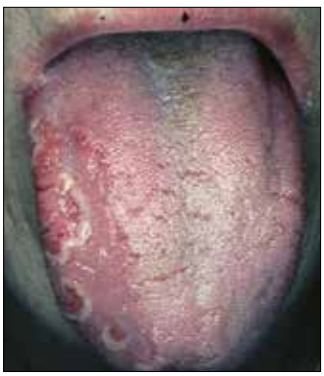
Source reference:

Relationship between psoriasis and urolithiasis. I Oğuz ID, Oğuz U, Usta M, Kulaklı S, Tosun A, Demirelli E, Burak Akşan, Emecen Ö, Yüzüak E. First published: 12 December 2023 https://doi.org/10.1111/1346-8138.17058

For tips on how to manage kidney stones, visit the NHS website:
https://www.nhs.uk/conditions/kidney-stones/

The tongue and psoriasis

Our tongues are sensitive muscular organs. Covering the tongue are layers of papillae and taste buds that encase our mouths with a delicate balance of flora and mucus, working to keep the environment of the tongue, mouth, and gums moist and bacteria-free, fighting infections. When our mouths get a viral or bacterial infection, it is these papillae that start fighting off the infection.



People often wonder whether a condition called geographic tongue is psoriasis. In theory, any part of the body – including the mouth – could be affected by psoriasis. It is rare, although it is more likely to occur in people with existing psoriasis. A study published by the Brazilian Society of Dermatology in 2016 reported:

"The difficulty, however, in accepting the diagnosis of geographic tongue as oral psoriasis is the fact that not all patients with geographic tongue present psoriasis. Some authors believe that the prevalence of geographic tongue would be much greater if psoriatic patients underwent thorough oral examination."

Other studies, the authors suggest, "...show that geographic tongue is the oral manifestation more commonly associated with psoriatic disease. These studies are based on observation of its fundamental lesions..."

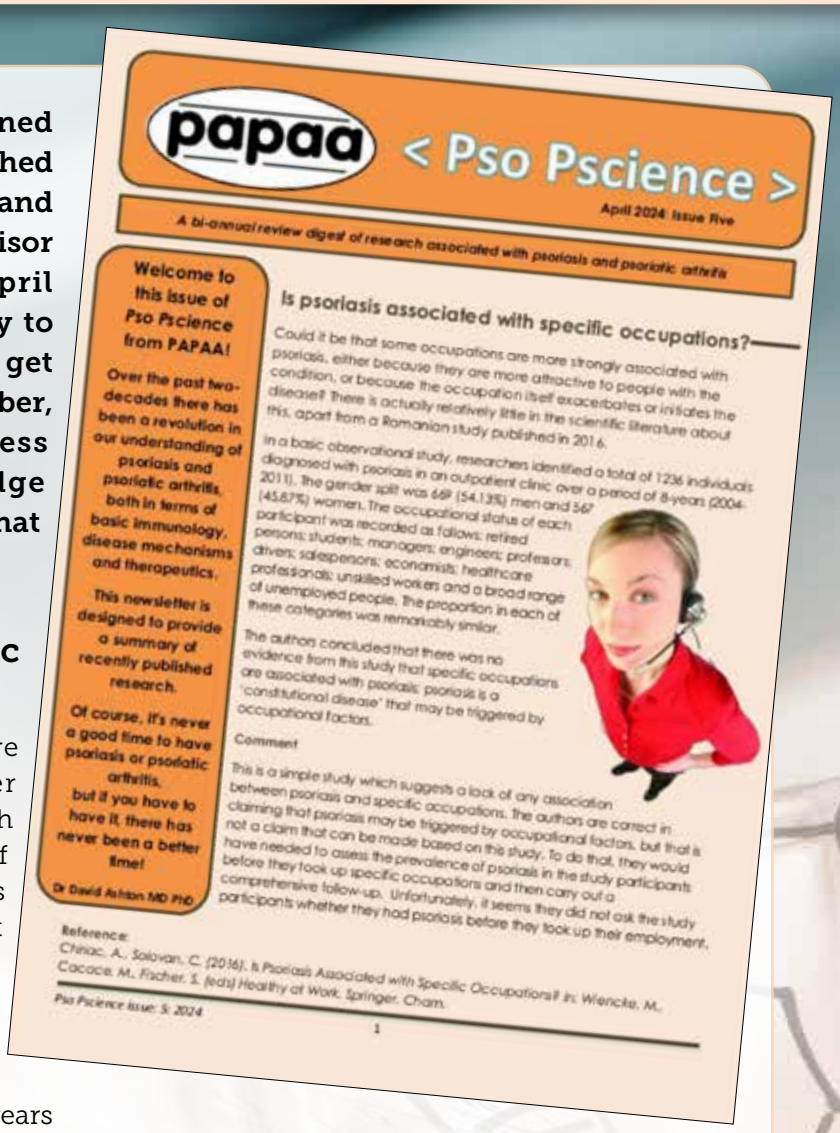
In conclusion, it is again another aspect of psoriatic disease that perhaps needs further consideration when looking at people who present with several symptoms. It also hints at the deeper, widespread nature of this inflammatory condition.

Reference:

Geographic tongue and psoriasis: clinical, histopathological, immunohistochemical and genetic correlation – a literature review: Picciani BLS, Domingos TA, Teixeira-Souza T, de Carla Batista dos Santos V, Fernando de Sousa Gonzaga H, Cardoso-Oliveira J, Gripp AC,3 Eliane Pedra Dias EP Carneiro S. An Bras Dermatol. 2016 Jul-Aug; 91(4): 410–421.

Learn more about geographic tongue in our knowledge bank:
https://www.papaa.org/knowledge-bank/further-reading/geographic-tongue/

This science-based newsletter is designed to provide a summary of recently published research. The material has been written and brought together by PAPAA medical advisor Dr David Ashton. It is available in April and October, as a free digital-only copy to download from the PAPAA website. To get access you will need to be a website member, which is also free and gives full access to material within PAPAA's Knowledge Bank. The following are the 4 articles that appeared in issue No. 5, April 2024.



papaa < Pso Pscience >

April 2024 Issue five

A bi-annual review digest of research associated with psoriasis and psoriatic arthritis

Welcome to this issue of Pso Pscience from PAPAA!

Over the past two-decades there has been a revolution in our understanding of psoriasis and psoriatic arthritis, both in terms of basic immunology, disease mechanisms and therapeutics.

This newsletter is designed to provide a summary of recently published research.

Of course, it's never a good time to have psoriasis or psoriatic arthritis, but if you have to have it, there has never been a better time!

Dr David Ashton MD PhD

Is psoriasis associated with specific occupations?

Could it be that some occupations are more strongly associated with psoriasis, either because they are more attractive to people with the condition, or because the occupation itself exacerbates or initiates the disease? There is actually relatively little in the scientific literature about this, apart from a Romanian study published in 2016.

In a basic observational study, researchers identified a total of 1236 individuals diagnosed with psoriasis in an outpatient clinic over a period of 8-years (2004-2011). The gender split was 669 (54.13%) men and 567 (45.87%) women. The occupational status of each participant was recorded as follows: retired persons; students; managers; engineers; professors; drivers; salespersons; economists; healthcare professionals; unskilled workers and a broad range of unemployed people. The proportion in each of these categories was remarkably similar.

The author concluded that there was no evidence from this study that specific occupations are associated with psoriasis; psoriasis is a 'constitutional disease' that may be triggered by occupational factors.

Comment

This is a simple study which suggests a lack of any association between psoriasis and specific occupations. The authors are correct in claiming that psoriasis may be triggered by occupational factors, but that is not a claim that can be made based on this study. To do that, they would have needed to assess the prevalence of psoriasis in the study participants before they took up specific occupations and then carry out a comprehensive follow-up. Unfortunately, it seems they did not ask the study participants whether they had psoriasis before they took up their employment.

Reference:

Chiriac, A., Solovan, C. (2016). Is Psoriasis Associated with Specific Occupations? In: Wiencke, M., Cacace, M., Fischer, S. (eds) Healthy at Work. Springer, Cham.

Pso Pscience Issue: 5: 2024

1

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New risk predictor for psoriatic arthritis

A new tool for predicting which patients with psoriasis will develop psoriatic arthritis (PsA) is showing promise, according to a summary of progress at the annual meeting of the 2023 Canadian Rheumatology Association. The predictive method, called PRESTO (Prediction of Psoriatic Arthritis Tool), is based on variables readily available in clinical practice. According to Dr Lihi Eder of the

University of Toronto, the tool allows the risk of PsA to be easily predicted over a 1-year or 5-year time frame, using a simple calculator.

There are seven factors used in the calculation:

1. Morning stiffness; 2. PASI (Psoriasis Area and Severity Index) score; 3. Nail lesions; 4. FACIT (Functional Assessment of Chronic Illness Therapy) Fatigue Scale; 5. Use of systemic non-biologics or phototherapy; 6. Pain level, and 7. Duration of psoriasis.

In studies to date, PRESTO has a predictive accuracy of 72% for the 1-year time window and 75% for the 5-year time window. (Note: a test with a predictive accuracy of 70% or above is considered acceptable). Further validation studies in larger populations are currently underway.

Comment

The ability to predict which patients with psoriasis will go on to develop PsA is a hugely important step in the management of psoriasis. Those at highest risk can be monitored more closely and treatment implemented at a much earlier stage. More work needs to be done on the model.

Reference

Canadian Rheumatology Association Meeting, Quebec City, Quebec, Canada, February 8-11, 2023

The Journal of Rheumatology June 2023, jrheum.2023-0216.

Under-diagnosis of psoriasis in UK general practice

There is compelling evidence to suggest that even a modest delay in the diagnosis of psoriasis may have significant adverse consequences and sub-optimal long-term outcomes. In the case of psoriatic arthritis, even a delay of ≥6 months is associated with deterioration in patients' quality of life in comparison with shorter periods.[1]

In this important study from Manchester, researchers used two large electronic data sets from the UK Clinical Practice Research Datalink (CPRD) – Gold and Aurum.[2] The CPRD is one of the largest databases of longitudinal health records from primary care in the world. There were 17,320 people with psoriasis and 99,320 controls included from CPRD Gold, and 11,442 people with psoriasis and 65,840 controls extracted from CPRD Aurum.

The objective for the analysis of both data sets was to identify an 'index date' for the date on which psoriasis was diagnosed, and then to compare the history of those with psoriasis versus the controls in terms of the number of visits to the GP and the frequency of various diagnoses which might be confused with psoriasis. These included seborrhoeic dermatitis, various forms of eczema, and some skin infections, including tinea corporis, candida, and pityriasis rosea.

This is a large and complex study and so the analysis is also complex. However, the key points to note from both data sets are:

- patients eventually diagnosed with psoriasis were much more likely to visit their GP in the time leading up to that diagnosis than the controls;
- patients with psoriasis were more likely to have been given a diagnosis of conditions that may be confused with psoriasis – including pityriasis rosea, eczema, seborrheic dermatitis, and tinea corporis, than those in the comparator group; and
- individuals with psoriasis were almost eight times more likely to be diagnosed with pityriasis rosea and twice as likely to be diagnosed with seborrheic dermatitis and eczema, within the year before their index date.

Comment

This is the first study to retrospectively analyse data collected from medical records to investigate primary care (GP) consultations, leading up to a diagnosis of psoriasis. The findings suggest that psoriasis is significantly misdiagnosed in primary care, being frequently mistaken for a range of other common skin conditions, especially pityriasis rosea, and eczema. This raises serious questions as to the adequacy of GP training in dermatology and emphasises the need to improve the non-dermatologists' diagnostic skills. This could be achieved via specifically designed online training courses, along with increasing use of AI diagnostic tools.

References

1. Haroon M, Gallagher P, FitzGerald O. Diagnostic delay of more than 6 months contributes to poor radiographic and functional outcome in psoriatic arthritis. Ann Rheum Dis 74, 6, 1045–1050.
2. Abo-Tabik M, Parisi R, Morgan C, et al. Mapping opportunities for the earlier diagnosis of psoriasis in primary care settings in the UK: results from two matched case-control studies. British Journal of General Practice 2022; 72 (724): e834-e841

The last word on vitamin D in psoriasis?

Questions remain regarding the role of vitamin D in psoriasis, with conflicting results from different studies. In this very large and recently (published study investigators sought to assess the association between lower serum 25-hydroxyvitamin D – 25(OH)D – levels and psoriasis in a population-based study.[1] The secondary endpoint was to evaluate the possible effect modification of being overweight/obesity.

The database for this study was derived from the ongoing Tromsø Study, in which repeated health surveys are used to gather data on residents of Tromsø, Norway. The Tromsø Study included 19,520 individuals aged 40 to 79 years in the general population, 52.3% of whom were women. Overall, 1179 patients (6.0%) reported active psoriasis in the past 12 months, and 2088 patients (10.7%) reported lifetime psoriasis.

Patients with psoriasis tended to be older and had higher body mass index (BMI), hip and waist circumference, and total body fat, and led a sedentary lifestyle, compared to those without psoriasis. Additionally, those with psoriasis smoked more frequently, as well as used a solarium, omega-3 capsules, and oral vitamin D supplements more often.

Overall, there was no difference in blood levels of 25(OH)D in patients with or without psoriasis. The investigators did, however, find that low levels of 25(OH)D in combination with a BMI greater than 27.5 kg/m^2, increased the risk for active psoriasis.

Comment

This is a large, well-conducted study that showed no significant relationship between levels of vitamin D and psoriasis. Importantly, these findings are entirely consistent with the authors' previous study, which found that vitamin D supplementation conferred no significant benefit in psoriatic disease.[2] The observation of an association between body weight and psoriasis has been shown in numerous studies. Maybe these two studies will prove to be the last word on vitamin D and psoriasis – or maybe not.

References

1. Jenssen M, Furberg AS, Jorde R, Wilsgaard T, Danielsen K. The association between serum 25-hydroxyvitamin D levels and psoriasis in a large population-based cohort, a cross-sectional analysis of The Tromsø Study 2015-16. Br J Dermatol. Published online November 28, 2023.
2. Jenssen M, Furberg AS, Jorde R et al. Effect of Vitamin D Supplementation on Psoriasis Severity in Patients with Lower-Range Serum 25-Hydroxyvitamin D Levels: A Randomized Clinical Trial. JAMA Dermatol 2023; 159: 518-525.

Campaigning

- **Our vision:** To see psoriasis and psoriatic arthritis managed in a positive way, more effectively.
- **Our mission:** To put people with psoriasis and psoriatic arthritis at the centre of care, deserving of recognition and effective management.
- **Our values:** To act ethically, with integrity on behalf of our constituent group and represent them fairly.
- **Our strategy:** To educate and empower people affected by psoriasis and psoriatic arthritis and those who provide their support and medical care, in order to optimise available resources more effectively.

To supporting our aims, we have developed a campaign called: ~ Care ~ Cause ~ Cure:

- **Care** = Support and education – information, website, training programmes/events.
- **Cause** = Research – funding relevant aligned projects.
- **Cure** = Facilitating the conversation to meet peoples' needs.

Our achievements:

- Around three-quarters of a million pounds provided to support research and training initiatives in psoriatic disease.
- Created the most comprehensive psoriatic disease specific website in the UK, with thousands of free to access items and pages.
- Developed a huge range of printed leaflets on the core aspects of the condition, with hundreds of thousands distributed free.
- Trained multidisciplinary healthcare professionals via our CPD accredited Psoriasis in Practice (PIP) programme, with many subsidised to access the training at no cost.
- Provided anonymised access to peer support to those often desperate for someone to listen and hear their voice.
- More than 1,000 healthcare professionals provided with free patient support material regularly.
- Supported 3,500 UK pharmacies to provide free patient resource at the point of medicine delivery.
- Biannual journal called Skin 'n' Bones Connection regularly distributed since 1993 to patients and a wide range of healthcare providers.
- Engaged and represented patient views with UK regulators, including NICE, SMC, AWMSG and the MHRA, to provide input into new drug appraisals and regulatory affairs.
- Actively engaged across the most popular social media applications.
- Gathered real stories via our engagement group and PAPAA surveys with individual views and suggestions from lived experience of psoriatic disease.
- Regular updates provided via an eNewsletter to a large dedicated subscription list.

Promotional material

If you are thinking about supporting PAPAA or raising awareness on behalf of PAPAA about psoriasis and/or psoriatic arthritis, why not check out some of the merchandise we have available?

www.papaa.org/shop

We continue to further our ambition by:

- Raising the visibility and profile of psoriatic disease.
- Providing research funding and support.
- Improving and expanding professional training.
- Further developing information and support material.
- Reviewing and keeping the website accurate.
- Proactively engaging with relevant agencies.

We have so much more to do and your continued support is much appreciated. To see what others have done to support the campaign, go to:

www.justgiving.com/campaign/papaa

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