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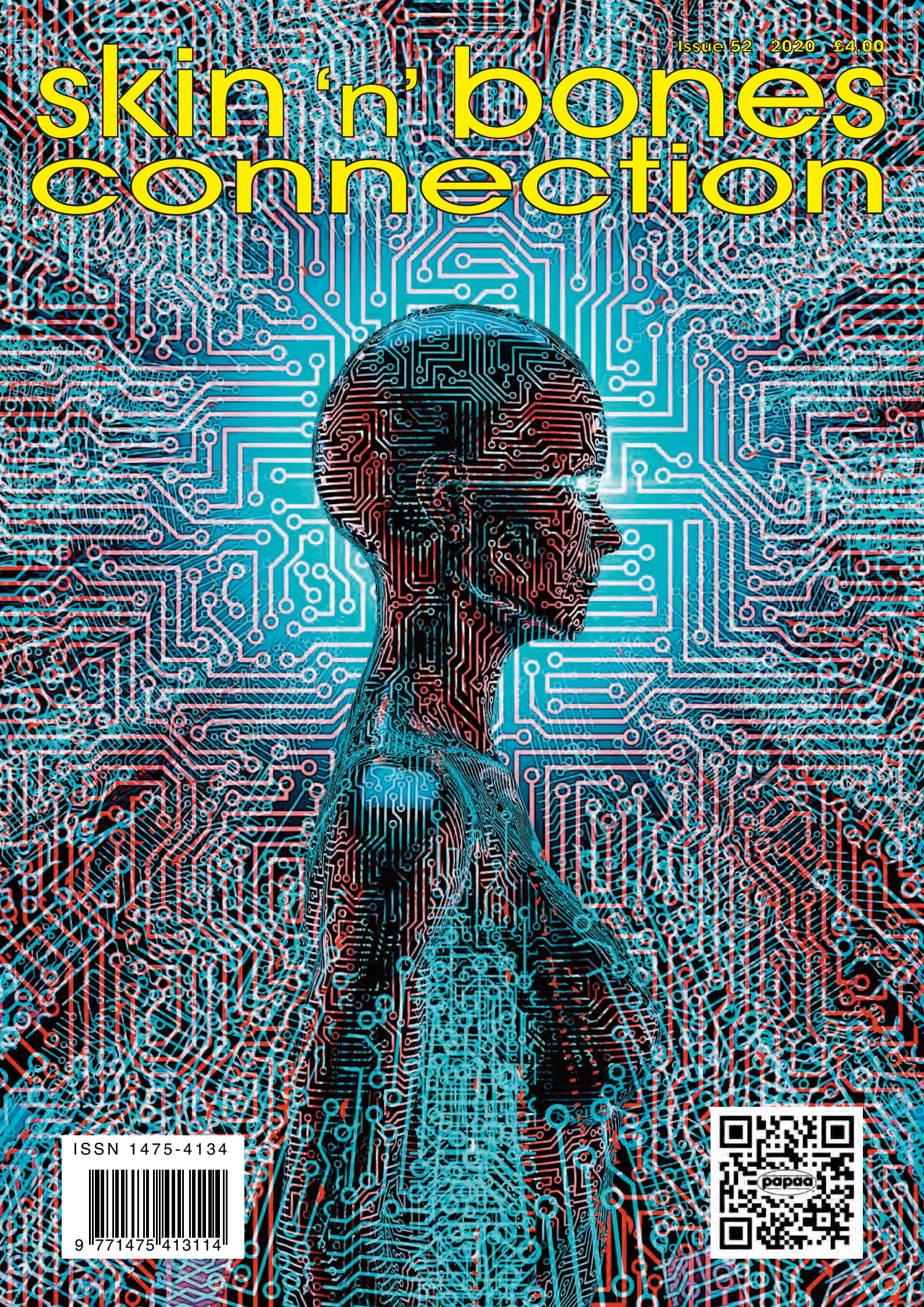
skin 'n' bones connection



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Dear Reader

Welcome to issue 52 of Skin 'n' Bones Connection. In this edition we cover a number of topics that are relevant not only to the current health situation, but also to the future world in which we will all need to live.

Understanding what is important to people with psoriatic arthritis is reported on page 3 as part of the desire to influence the research agenda using the James Lind Alliance Priority Setting Partnership.

The need for clinical research data and real-life experiences is going to be even more important to managing conditions. On pages 4-7 we explore the development of artificial intelligence and machine reading in healthcare, which is being demonstrated in the current work being carried out by the British Association of Dermatologists' COVID-19 skin rash study app.

In an article on pages 10-11, the environmental and climatic factors in psoriasis are discussed; this also links to work around the internal environment of our bodies, where research on the gut-skin axis is beginning to provide a better understanding of how that might influence the development of new treatments for psoriasis.

It is certainly an exciting, if challenging, time, but the picture is beginning to become more complete in the understanding of psoriasis and psoriatic arthritis.

Managing editor

The Psoriasis and Psoriatic Arthritis Alliance (PAPAA) is the new single identity of the Psoriatic Arthropathy Alliance and Psoriasis Support Trust. The organisation is independently funded and aims to be a definitive source of information and educational material for people with psoriasis and psoriatic arthritis in the UK. To be a support to both patients and professionals by providing material that can be trusted (evidence based), which has been approved and contains no bias or agendas. We will be looking to provide positive advice that enables people to be involved as they move through their healthcare journey in an informed way, which is appropriate for their needs and any changing circumstances.

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Artificial intelligence By GrandeDucl

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In 2019, a Psoriatic Arthritis Priority Setting Partnership (PSP) began, with the aim of identifying unmet needs in psoriatic arthritis. The project is funded by The British Psoriatic Arthritis Consortium (BritPACT) and led by Dr Laura Coates from the University of Oxford. The project follows methods set out by the James Lind Alliance which have been used for many different conditions since 2004.

In 2020, the first step was taken: to ask everyone affected by psoriatic arthritis - individuals who live with the condition, their families and friends and the clinicians who treat them - what they perceive to be the unmet needs in psoriatic arthritis, via a large online survey. The survey asked people to submit key research questions that they want to see addressed.

The first-stage survey closed in September and the steering group collated similar submitted questions into groups and summarised the wording. Part of the process was for the steering committee to check and ensure that the questions had not already been satisfactorily addressed by research studies. Any questions found to have already been answered by existing research studies will be collected to share with healthcare professionals and research organisations, so that they can think about how to better communicate this information to healthcare professionals and the public.

Once the questions have been developed, a second (shortlisting) survey will be performed, again with all people affected by psoriatic arthritis invited to take part, and respondents will be asked to pick up to ten questions that matter to them most.

After the results of this second survey are available, people with psoriatic arthritis, their families, and healthcare professionals will be invited to a final workshop to discuss and rank the most popular questions from the survey, producing a final 'Top Ten' list. This list of priorities will help to inform researchers and research funders working in the area of psoriatic arthritis so that, in future, work is done in areas that are deemed most important.

More information can be found at:
https://www.britpact.org/news-events/priority-setting-partnership-survey/

Brit-PACT
British Psoriatic Arthritis ConsorTium

James Lind Alliance
Priority Setting Partnerships

About BritPACT

The British Psoriatic Arthritis Consortium (BritPACT) is a UK collaboration established in 2014 aiming to bring together individuals in the UK with an interest in psoriatic arthritis. Membership includes a variety of healthcare professionals with a clinical and/or research interest in psoriatic arthritis, alongside patients with the condition who engage with policy, research and educational initiatives.

About the James Lind Alliance

The James Lind Alliance (JLA) is a non-profit-making initiative established in 2004. It brings patients, carers and clinicians together in Priority Setting Partnerships (PSPs), the aim of which is to identify and prioritise uncertainties, or 'unanswered questions', about the effects of treatments and interventions in different health conditions, topics or settings.

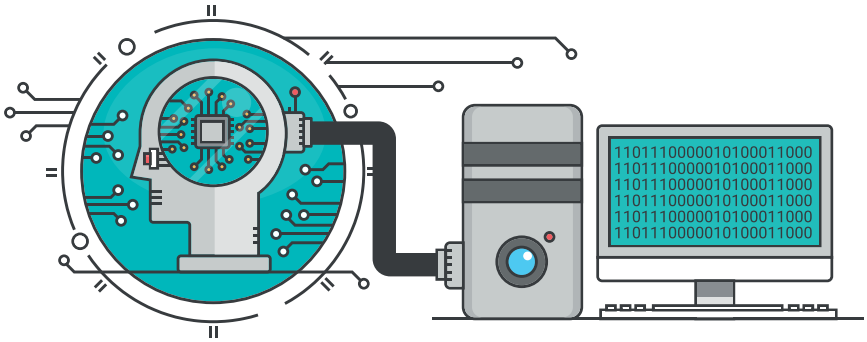
The JLA believes that addressing uncertainties about the effects of treatments or interventions should become accepted as a much more routine part of clinical practice, and patients, carers and clinicians should work together to agree which of those uncertainties matter most and thus deserve priority attention.

The JLA is funded by the National Institute for Health Research (NIHR) and is coordinated through the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC). To find out more about current and past PSPs, please visit www.jla.nihr.ac.uk.

Artificial intelligence, or AI, is becoming increasingly part of our lives. It may feel like something new, but it has been in development since 1955, when John McCarthy, an American computer scientist pioneer and inventor often given the title *father of artificial intelligence*, played a seminal role in the field and development of intelligent machines. The first artificial intelligence conference was the 1956 Dartmouth Conference held at Dartmouth College, New Hampshire, in America. At the time, McCarthy said it could take "five to 500 years" to make a breakthrough. McCarthy's Lisp computer language, created in 1958, became the standard AI programming language and is still used in many applications, such as credit card security, smart phones and voice recognition.

Machine learning (ML), which is another term used as a sub-set of AI, uses large amounts of data of past events to help predict future outcomes. The algorithms produced from data gathering are essentially a list, set of rules and steps that lead to an outcome. In the area of health, it could be a diagnosis, a pathway or a course of treatment.

In real life, when you develop a set of symptoms, and see your doctor, they will use their knowledge and experience to assess how those symptoms match a particular condition. In ML, the AI process will use previous diagnoses of other people to match your symptoms and come to a diagnosis. In both instances the presentation will be matched against a list, whether learnt through years of study and experience of seeing patients, or imputed data based on previous real-life cases.



AI in health

It is interesting to see that, in research published in 2019 by Moorfields Eye Hospital, DeepMind Health and UCL, the AI system recommended the correct referral decision for more than 50 eye diseases, with 94% accuracy, matching world-leading eye experts.

Other areas are beginning to explore the area of AI, with funding being made available via the NHS Artificial Intelligence in Health and Care Awards. The Artificial Intelligence Award is run by the Accelerated Access Collaborative (AAC) in partnership with NHSX and the National Institute for Health Research (NIHR). It will make £140 million available over three years to accelerate the testing and evaluation of the most promising AI technologies which meet the strategic aims set out in the NHS Long Term Plan.

A recent award to researchers and clinicians at the University of Dundee and NHS Tayside sees the collaboration receiving £150,000. The team hope to develop technology capable of diagnosing skin cancer. Project leader Professor Stephen McKenna, of the university's Computing department, said,

"Success in this area will be gradual, starting with goals such as clinical decision support for the most common benign lesions. Skin disease naturally lends itself to automated image analysis. Lesions can be photographed easily and then analysed with the help of deep learning technology."

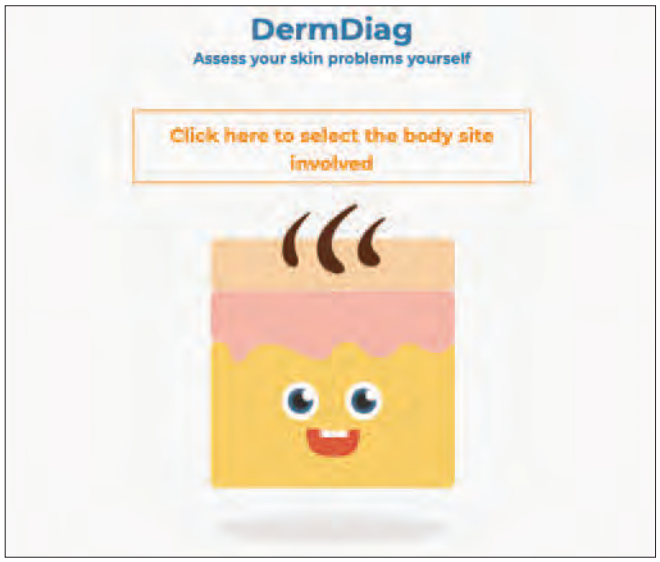
Secretary of State for Health and Social Care Matt Hancock said "The 'Deep learning for effective triaging of skin disease in the NHS' project will see researchers develop an AI system to accurately distinguish between benign lesions and cancers."

Emerging evidence in psoriatic arthritis was presented as an abstract at the American Academy of Rheumatology by rheumatologist Philip Mease and colleagues, titled *'Machine learning identifies an association between pre-existing radiographic damage and long-term clinical outcomes with secukinumab therapy in patients with psoriatic arthritis'.* The authors said, "A strong and significant association was demonstrated between disease activity and baseline radiographic damage at the individual joint level, whereas the analysis at patient level showed a weaker association. High radiographic damage at baseline was associated with a lower rate of achieving remission."

Diagnosing skin disease with algorithms

In a project funded by PAPAA, DermNet New Zealand has developed The DermDiag tool, which has been designed to help people understand their skin condition. This online tool does not offer medical advice, but provides a series of questions which leads towards a potential match to the symptoms entered within the programme.

The DermDiag tool is based on the bestselling book for doctors, *Differential Diagnosis in Dermatology* by Dr Richard Ashton. You can access the tool on the symptom checker page, found under 'LEARN' at **www.papaa.org**.



What's the future?

It is certainly an exciting time. Wearable technology that can record real-time health data, which can be uploaded to a database, offers the prospect of not only monitoring and helping to manage health, but also to help develop machine learning and artificial intelligence algorithms to aid diagnosis and predict outcomes.

Links:

https://www.papaa.org/learn-about-psoriasis-and-psoriatic-arthritis/symptom-checker/

Sources:

John McCarthy obituary, The Independent, November 2011

BBC Bitesize, November 2020

Dartmouth College https://home.dartmouth.edu (accessed November 2020)

Moorfields Eye Hospital media release, 2019

University of Dundee media release, September 2020

American Academy of Rheumatology meetings abstracts (accessed November 2020)

The COVID Symptom Study

In September, ZOE and the British Association of Dermatologists launched a website dedicated to images of COVID-19 related skin rashes: www.covidskinsigns.com. The website includes more than 400 images of the different types of related rashes. The most common are a hive-type rash (urticaria), 'prickly heat' or chickenpox-type rash (papular or vesicular rash) and COVID fingers and toes rash (chilblain-like).

The images were collected via the COVID Symptom Study app, which was launched by British health science company ZOE in March, to help scientists at King's College London gather information from members of the public about the symptoms of COVID-19. It has since been downloaded by more than four million people in the UK.

Early reports of rashes in hospitalised COVID-19 patients emerged from different parts of the world by late spring. As a result, rash as a symptom was added to the app to investigate further. This allowed the team who created the app to gather data about skin symptoms. App users were also invited to anonymously submit images of their rash to the COVID Symptom Study website. A total of 3,195 images were uploaded.

A team of senior UK dermatologists reviewed all the images, classifying and curating them according to the different clinical types. More than 400 images were selected and can be seen at www.covidskinsigns.com, which has been funded and created by the British Association of Dermatologists.

The research generated by the app uncovered that 9% of swab-positive COVID-19 app users reported either a body rash or a rash on fingers or toes, suggesting that rashes are a key symptom. Rashes were twice as common in children as in adults. A new skin rash was a slightly better predictor of having a positive swab test than a fever or cough. According to the data, rashes may appear before, during or after the presence of other COVID symptoms and sometimes many weeks later. Importantly, rashes were the only sign of infection for 21% with a rash and a positive nasal swab.

This new website is accessible to everyone, to help doctors and the general public worldwide to identify whether an unusual rash may be a sign of COVID-19. The gallery will be updated as the research and understanding of related skin signs progresses.

Dr Tanya Bleiker, president of the British Association of Dermatologists, comments:

"The association between certain rashes and COVID-19 has become increasingly clear, and being able to recognise these is crucial for reducing the spread of the disease. We're delighted to announce the launch of the COVID-19 skin signs image gallery, with the COVID Symptom Study team. The extensive library will be an invaluable resource for both healthcare professionals and members of the public in helping to identify rashes which may indicate COVID-19 infection, particularly in those who are otherwise asymptomatic."

Veronique Bataille, consultant dermatologist, who led the COVID skin research, comments:

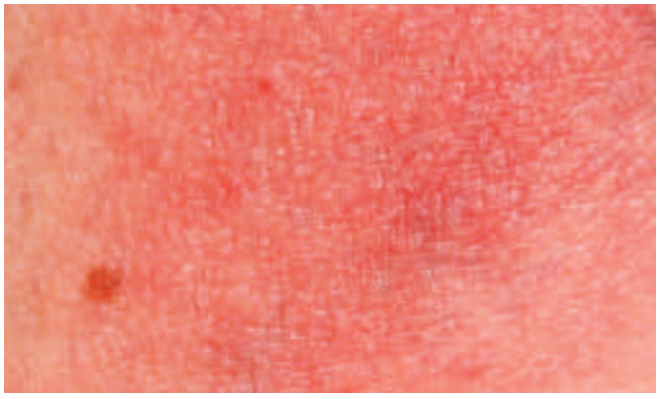
"We have created this COVID-19 rash gallery so that clinicians and any interested parties can have access to it and help them identify potential COVID-19 rashes. Our research shows that rashes can be more predictive of COVID-19 than fever and cough, particularly in children. We found that one in six children gets a rash without any other classical symptoms. For most, COVID-19 rashes last for a few weeks and eventually disappear. In some cases, prescribed medication may be needed if the rash is very itchy."

Tim Spector, professor of genetic epidemiology at King's College London, lead of the COVID Symptom app, comments:

"Thanks to our millions of app users we were quickly able to confirm the link between skin rashes and COVID-19 but also the timing of the rashes, their associations with other COVID-19 symptoms, as well as the different types of rashes across different age groups. We are extremely grateful to all app users who provided pictures via the app as without them none of this would have been possible. We have asked the government to add a new skin rash to the official NHS list of signs and symptoms of COVID-19 as it will reduce infections and save lives."

Dr Justine Kluk, consultant dermatologist, involved in the research and curating of images for the website, comments:

"A group of different skin rashes are now recognised as possible indicators of COVID-19 infection and may be the first or only symptom of the disease in some sufferers. Early reporting of these rashes by members of the public and increased awareness and recognition of them by frontline health workers could help us detect more cases and avoid further spread. This new atlas of COVID rashes, the first of its kind, is an important step forward in helping to raise awareness."



About the COVID Symptom Study app

The COVID Symptom Study app is a not-for-profit initiative launched at the end of March 2020 to support vital COVID-19 research. It was launched by health science company ZOE with scientific analysis provided by King's College London. With 4 million contributors globally, it is the world's largest ongoing study of COVID-19 and is led by ZOE's co-founder and King's College London.

About ZOE

ZOE is a health science company using data-driven research to tackle the world's health issues. By using artificial intelligence combined with digital technologies like mobile phones, ZOE enables large-scale scientific studies to tackle issues like COVID-19, inflammation and the impact of nutrition on health.

Located in London and Boston, ZOE was founded by machine learning leader Jonathan Wolf and entrepreneur George Hadjigeorgiou, along with Professor Tim Spector of King's College London.

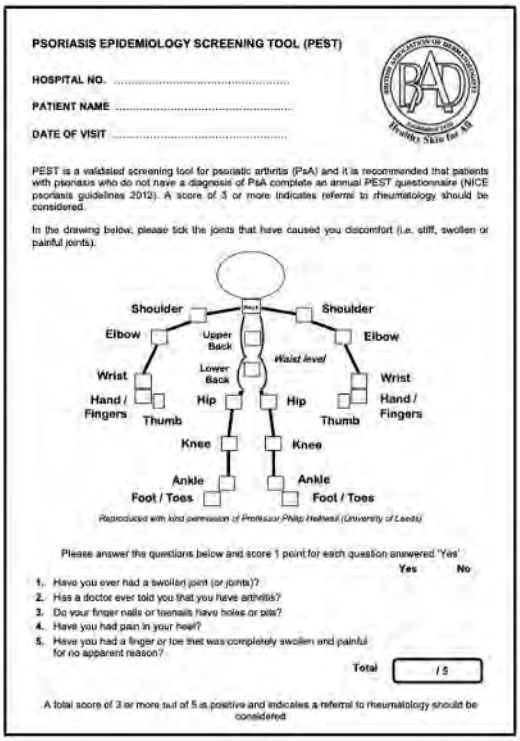
Website:
www.covidskinsigns.com

Source:
British Association of Dermatologists

Psoriatic arthritis screening

In a recent study funded by the Psoriasis and Psoriatic Arthritis Alliance, research pharmacist Dr Rod Tucker examined whether the new breed of clinical pharmacists working within general practices could be used to help identify patients with psoriatic arthritis (PsA).

The chronic and progressive nature of PsA highlights the need for regularly screening of patients with psoriasis to help identify potential sufferers so that they can be promptly referred to a rheumatologist for further assessment. According to NICE, PsA affects up to 30% of those with psoriasis and its psoriasis guideline recommends that healthcare professionals "offer an annual assessment for psoriatic arthritis to people with any type of psoriasis" and that "as soon as psoriatic arthritis is suspected, refer the person to a rheumatologist for assessment and advice about planning their care".



PSORIASIS EPIDEMIOLOGY SCREENING TOOL (PEST)

HOSPITAL NO. .....

PATIENT NAME .....

DATE OF VISIT .....

PEST is a validated screening tool for psoriatic arthritis (PsA) and it is recommended that patients with psoriasis who do not have a diagnosis of PsA complete an annual PEST questionnaire (NICE psoriasis guidelines 2012). A score of 3 or more indicates referral to rheumatology should be considered.

In the drawing below, please tick the joints that have caused you discomfort (i.e. stiff, swollen or painful joints).

Shoulder, Shoulder, Elbow, Upper Back, Elbow, Waist level, Wrist, Lower Back, Wrist, Hand / Fingers, Hip, Hip, Hand / Fingers, Thumb, Thumb, Knee, Knee, Ankle, Ankle, Foot / Toes, Foot / Toes

Reproduced with kind permission of Professor Philip Helliwell (University of Leeds)

Please answer the questions below and score 1 point for each question answered 'Yes'

	Yes	No
1. Have you ever had a swollen joint (or joints)?		
2. Has a doctor ever told you that you have arthritis?		
3. Do your finger nails or toenails have holes or pits?		
4. Have you had pain in your heel?		
5. Have you had a finger or toe that was completely swollen and painful for no apparent reason?		
Total	/ 5	

A total score of 3 or more out of 5 is positive and indicates a referral to rheumatology should be considered

In primary care, the Psoriasis Epidemiological Screening tool (PEST) represents a means of identifying those who may have PsA. The tool asks patients five simple yes/no questions about swollen joints and heel pain. Where at least three of these questions are answered in the affirmative, patients should be referred to a rheumatologist.

However, a recognised limitation of PEST is the inability to identify patients with axial (i.e. spinal) PsA. Consequently, an additional inflammatory back pain tool (IBP) can be used in conjunction with PEST for those with inflammatory back pain (which can be due to axial PsA).

Although performing a screening programme would appear straightforward, a major barrier in primary care is that joint pain is extremely common. For example, in one study in over 15,000 individuals, 54% reported multiple-site joint pain. Consequently, if a patient with psoriasis complains of joint stiffness and pain, unless their GP is aware of PsA, it is more likely that he/she will provide symptomatic relief with a prescription for painkillers rather than trying to establish the underlying cause.

A further concern in primary care is that a screening programme might lead to additional GP appointments and since many GPs already feel under pressure, they are unlikely to be supportive of such an initiative.

The study

One potential solution to avoiding the potential increased GP workload from screening would be to make use of the increasing number of practice-based clinical pharmacists working in general practice to support GPs. Their role is predominately medicine management, which involves reviewing current medicines.

Although it would be easy enough for the pharmacists to undertake a screening programme, what about patient referral? This is usually done via GPs, who would normally want to see and examine the patient to confirm the suspicion of PsA. This would obviously increase their workload. A solution was for the practice pharmacist to agree a referral template letter with the GP.

After all, according to the NICE guideline, once PsA was suspected, as would be the case from a screening programme, then referral to a rheumatologist is warranted. It therefore doesn't really matter whether the patient was seen by the GP because the index of suspicion for PsA would already be raised.

For the study, a total of five GP practices agreed to participate in the research and in each case,

I contacted the lead GP to discuss the project to ensure their support as well as speaking with the clinical pharmacist and the practice manager.

Each practice performed a search of its patient database using criteria kindly developed by one of the practice's IT staff. Identified patients were sent an information leaflet describing the nature of the study and a consent form (required for NHS ethics approval) together with a copy of the PEST and IBP tools, which they were asked to complete and return to the practice.

The predefined referral criteria were a PEST and IBP after discussion with the specialist rheumatologist who sat on the NICE psoriasis guideline group. The clinical pharmacist reviewed the returned forms and arranged for any relevant blood tests (as dictated by local referral policies) to be done, prior to referral. The local rheumatology departments were also contacted to inform them about the study – primarily to inform them of a potential surge in referrals!

The results

In total, 276 eligible patients were identified, with a response received from 184 (66%). Interestingly, the mean sample PEST score was 2.12 and the IBP score was 1.61, which were substantially lower than the referral criteria. In fact, only 18 patients met the predefined referral criteria (i.e. PEST and IBP) and, of these patients, a total of nine were currently prescribed analgesics for "joint pain".

Unfortunately, and despite several requests, only 13 patients attended their rheumatology appointment, from which only a single patient was diagnosed with PsA. Other diagnoses included osteoarthritis but, in some cases, while PsA was ruled out, no specific diagnosis was given on the letter sent to the practice.

Conclusion

In a sample of 184 primary care psoriasis patients, only 18 met the criteria for referral to a rheumatologist with only one being subsequently diagnosed with PsA. Nevertheless, since five patients did not attend their outpatient appointments, additional cases may have been missed.

An important recommendation from the study was that clinical pharmacists should perhaps refocus their efforts away from general screening and concentrate more on performing annual medicine reviews in those with psoriasis. In addition, they could provide educational support, alerting patients to the main symptoms of PsA and undertaking screening among those displaying symptoms to ensure a more targeted approach so that referrals become more appropriate.

Study lead
Dr Rod Tucker

Factors in psoriasis

Psoriasis is a chronic disease which has clear geographic variations, with prevalence rates higher in those countries more distant from the equator. This suggests that climatic factors such as sun exposure and humidity may be relevant, though these and similar factors have not been much studied in specific populations.

In a 2013 study from Naples, researchers used a specific questionnaire to investigate the effect of weather and both indoor and outdoor environmental factors on the clinical course of psoriasis. The setting was a psoriasis outpatient department in a university medical centre and a total of 300 consecutive patients were enrolled into the study.

Questions in the survey were detailed and quite specific, covering outdoor environmental factors such as exposure to sunny, rainy, windy, muggy, hot and cold climates. Additional questions covered indoor climatic factors, such as seasonal exposure to domestic heating and ventilation systems.

The investigators divided the study participants into two groups:

- 121 patients with psoriasis only (Ps), and
- 179 patients with psoriasis and psoriatic arthritis (PsA).

For both groups, the researchers evaluated the impact of the various environmental factors on skin and (in the PsA group) arthritis.

Outdoor environmental factors

This study showed that skin manifestations in both groups improved dramatically in the summer months and were significantly worse during winter – an observation clearly related to the beneficial effects of UV light on the skin.

Conversely, arthropathy in PsA patients showed little variation between winter and summer, with the majority (67% and 68.2%) reporting their arthritis as stable throughout the summer and winter. Nevertheless, a significant proportion (24%) of PsA patients reported an improvement in arthritis during the summer.

Regarding reported wind exposure, there was a worsening of skin symptoms in a minority in both groups, but no reported effect on arthritis.

Heat appeared to have a negative effect on skin symptoms in both groups, but only in a minority (22.3% in Ps and 14% in PsA respectively). Perhaps surprisingly, heat had no effect on arthritis. On the other hand, cold appeared to have a significant negative effect on skin manifestation of psoriasis in both groups and there was a striking worsening of arthritic symptoms in the PsA group.

Exposure to muggy and rainy climates seems to have had no impact on either group in terms of skin or arthritic symptoms.

Indoor environmental factors

Regarding the indoor environment, patients in both groups reported no relationship at all between symptoms and the use of air conditioners, heaters, radiators or open fireplaces. This finding seems at odds with anecdotal reports which suggest that air conditioning can make psoriasis worse because it tends to dry out the surface layers of the skin.

The key findings from the study are summarised in the table below:

This is a small study carried out in an outpatient setting and based on a questionnaire. It therefore has significant limitations.

Factor	Patient g
	P Skin
Winter	1.7 % vs [59.8%]
Summer	71.5% vs [12.8%]
Wind	0% vs [29%]
Cold	2.8% vs [38.5%]
Heat	14.5% vs [14.0%]
Key: Symptoms improved %	Symptoms worse [%]

Firstly, the information collected is qualitative, which means that the results are entirely dependent upon the accuracy of the responses. In addition, questions relating to disease severity are difficult to interpret and patients with arthritis may have a different perception of their skin condition compared with those with psoriasis alone. There are also problems with definitions of terms such as "muggy" and "humid" which may mean different things to different people.

Nevertheless, this is a helpful attempt to raise the question about the impact of climate and environmental factors on patients with psoriasis. This is especially relevant given that the global climate

appears to be changing at an unprecedented rate.

The observation that increased UV exposure during the summer months had a major beneficial effect on skin symptoms among patients with and without arthritis, is well recognised and has been the basis for various therapeutic interventions for many years. Sunlight during summer months tends to improve skin lesions by slowing the rate of skin growth and shedding which are typical of psoriasis.

Another important factor is the generally higher humidity during the warmer, summer months. This tends to increase skin moisture, making psoriatic patches less prone to cracking. Conversely, lower levels of humidity in winter months increases skin permeability, induces thickening of the epidermis and stimulates production of inflammatory mediators, making skin lesions worse. For these reasons (and as might be predicted), skin symptoms were much worse in winter in both Ps and PsA groups – almost identically so (59.5 and 59.8% respectively).

groups and symptoms

PsA	Ps
Arthritis	Skin
0% vs [31.8%]	1.6% vs [59.5%]
24% vs [8.9%	69.4% vs [13.2%]
0% vs [0%]	0% vs [19.8%]
1.7% vs [43.6%]	4.9% vs [22.3%]
7.8% vs [0%]	6.6% vs [22.3%]

There is little scientific evidence regarding the effects of sunlight on psoriatic arthritis, so it is interesting that while most (67%) patients with arthritis remained stable during the summer period, almost a quarter (24%) of study subjects reported improvement.

Regarding exposure to wind, cold and heat, skin lesions in most patients in both groups generally remained stable. However, both wind and cold had a greater negative effect on skin in the PsA group than Ps only.

For patients with psoriatic arthritis, cold has a relatively large negative effect on symptoms, while neither wind nor heat made any difference.

Key points

- Skin manifestations of psoriasis invariably improve during summer months (due to UV light and increased humidity) and predictably worsen during the winter.
- Psoriatic arthritis shows little seasonal variation, remaining relatively stable throughout the year, though a minority may experience an improvement in summer months.
- Wind and cold may have a negative impact on skin lesions in a significant minority of both groups, but greater in those with psoriatic arthritis.
- Cold appeared to have a significant negative impact on arthritis.

Finally, these results suggest that climatic factors and seasonal variations should be taken into account when planning treatment for patients with psoriasis and psoriatic arthritis. While further research is needed, these preliminary observations represent an important basis for more advanced study.

Dr David Ashton MD PhD

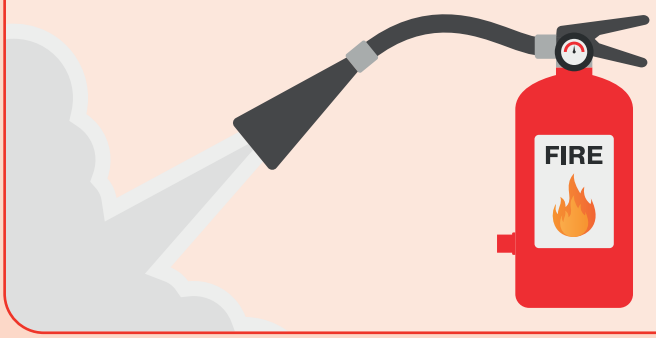
Safety campaign

Some skin creams, when dried on to fabric, can create a highly flammable combination that can cause serious injury and death. This has been highlighted again by regulators, following research showing that the risk arises even if the creams do not contain paraffin.

The Medicines and Healthcare products Regulatory Agency (MHRA) has partnered with the National Fire Chiefs Council (NFCC), fire and rescue services and health charities, including PAPAA, in a new campaign to raise awareness of the fire risk and the precautions that need to be taken by users of skin creams. A video and support material has been produced to support the campaign. The video can be viewed at www.papaa.tv.

Emollient skin creams are used by thousands of people every day to manage dry, itchy or scaly skin conditions such as eczema, psoriasis and ichthyosis. They are easily transferred from skin to clothing and bedding. When fabric with dried-on cream comes into contact with a naked flame, the resulting fire burns quickly and intensely and can result in serious injury or death.

The risk increases with every application of the cream as it transfers, dries and builds up on the fabric. Some cream remains even when the items are washed, so it's important to minimise the risk in additional ways, such as removing long-sleeved or loose clothing before cooking or using a safety lighter.



These creams are vital in helping to manage dry skin conditions. The creams alone are not flammable, nor are they flammable when on the body. Healthcare professionals should continue to recommend them for chronic dry skin conditions and those using them should continue as directed while remaining alert to the risk of fire when cream dries on to fabric.

MHRA first took regulatory action on the issue in 2008 and since 2018 has recommended that labelling and product information for emollient products should include a warning about the fire hazard, with clear advice not to smoke or go near naked flames.

Since 2010, more than 50 deaths and serious injuries have been linked to the use of emollient skin creams. A review has shown that those most at risk tend to be over 60, smokers and have reduced mobility. The MHRA recommends anyone in this high-risk group, or their carers, should arrange a fire service assessment of their personal surroundings. They must exercise caution when close to naked flames or potential ignition sources (for example, lighting a cigarette).

Sarah Branch, director of MHRA's vigilance and risk management of medicines division, said:

"We want to ensure that those who are at greatest risk, and their carers, understand the fire risk associated with the build-up of residue on clothing and bedding and take action to minimise the risk. Anyone who uses emollients and has any questions

or concerns should speak to a healthcare professional, such as your pharmacist or GP. Patient safety is our highest priority. We strongly encourage anyone to report any issues with such products, or more generally with any medical device, to our Yellow Card Scheme."

Rick Hylton, NFCC's Home Safety Committee Lead said:

"We now know that all emollients, combined with factors such as smoking or mobility issues, pose potential fire risks and this applies to both paraffin and paraffin-free products. Washing fabrics does not fully remove this risk. This doesn't mean people shouldn't use these products but we urge people to follow the updated fire safety advice. If you use these products and smoke, don't do so when wearing clothes or bandages that may have dried on emollients. Don't smoke in bed as bedding may have residue on it and be careful around other heat sources such as gas, halogen or open fires and when cooking."

About the partners

Medicines and Healthcare products Regulatory Agency is responsible for regulating all medicines and medical devices in the UK by ensuring they work and are acceptably safe. All of its work is underpinned by robust and fact-based judgements to ensure that the benefits justify any risks.

MHRA is a centre of the Medicines and Healthcare products Regulatory Agency, which also includes the National Institute for Biological Standards and Control (NIBSC) and the Clinical Practice Research Datalink (CPRD). MHRA is an executive agency of the Department of Health and Social Care.

The research referred to came from the Forensic and Investigative Science Research Group, Anglia Ruskin University, De Montfort University and West Yorkshire Fire and Rescue Service.

NFCC is the professional voice of the fire and rescue service, representing all fire services to coordinate national work for local benefit and driving improvement. It leads on national fire service campaigns to ensure the best outcomes for those communities served by its members.

Source:
MHRA

Arthritis and work

The European League Against Rheumatism (EULAR) has called upon the European Union to work with member states to create a comprehensive strategy to tackle rheumatic and musculoskeletal diseases (RMDs). The COVID-19 pandemic has compounded the risks facing this vulnerable group and, with Europe facing the growing challenges of an ageing population and workforce, it is vital that the EU addresses the hidden costs of workplace exclusion for people suffering one of the more than two hundred diseases under the RMD umbrella.

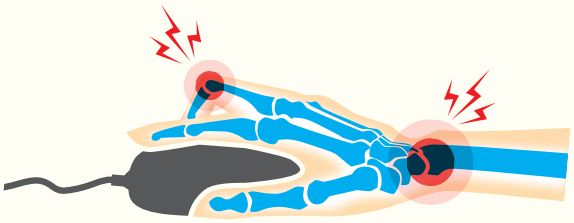
It is estimated that more than 100 million European citizens, many young and of working age, currently suffer with RMDs. They are the main occupational disease type, accounting for around 60% of all health problems in the workplace, and are the biggest cause of sick leave and premature retirement due to work disability in Europe.

The pandemic has compounded the challenges faced by this vulnerable group in different ways. Some have greater vulnerability to COVID-19 due to being treated with immunosuppressants and steroids or have a common co-morbidity, such as cardiovascular disease, that signify higher risk. RMD sufferers have also been affected by reduced access to medication, or the reprioritisation of healthcare facilities away from people with chronic conditions. Job access and security is also a highly significant concern as RMD sufferers may face potential workplace absenteeism during a global downturn.

Speaking during the EULAR Brussels Forum, a high-level online panel discussion on the "Employment risks and impacts for Europeans with RMDs during the COVID Recession", Professor Iain McInnes, EULAR president, said:

"For many people living with RMDs, job insecurity and unemployment are a daily reality that much of the rest of society only experiences in times of crisis. The pandemic has created new workplace barriers for Europeans with RMDs, but it has also highlighted the opportunities flexible working patterns and digital workplace and healthcare solutions can offer this community."

The exclusion of RMD patients from the workplace costs Europe an estimated €163bn annually. The short-term impact of the COVID-19 pandemic, with the longer-term trend of an ageing European population, are expected to dramatically increase this impact without urgent action.



Roberta Metsola, MEP, chair of the European Parliament Interest Group on RMDs, added:

"To support the economic recovery, and ensure that Europe can cope with an ageing population and workforce in the future, the EU must act decisively to develop a comprehensive approach to tackling the hidden human and economic cost of excluding people with RMDs from the workplace. One element of the EU strategy on RMDs must be to ensure that the post-2020 EU disability strategy better responds to the employment needs of people with RMDs, and sets member states clear targets and timelines to ensure adequate resources are available."

Europe needs policies and programmes that create an open, positive and supportive culture between patients, colleagues, and employers; including strong protection against workplace discrimination. It also needs to create ergonomic workplaces to increase comfort and reduce risk of accidents and flares, as well as to promote flexible work schedules and tele-working. The EU should also guide and support the member states as they develop strategies to deliver more effective RMD-related health promotion, prevention, treatment and rehabilitation.

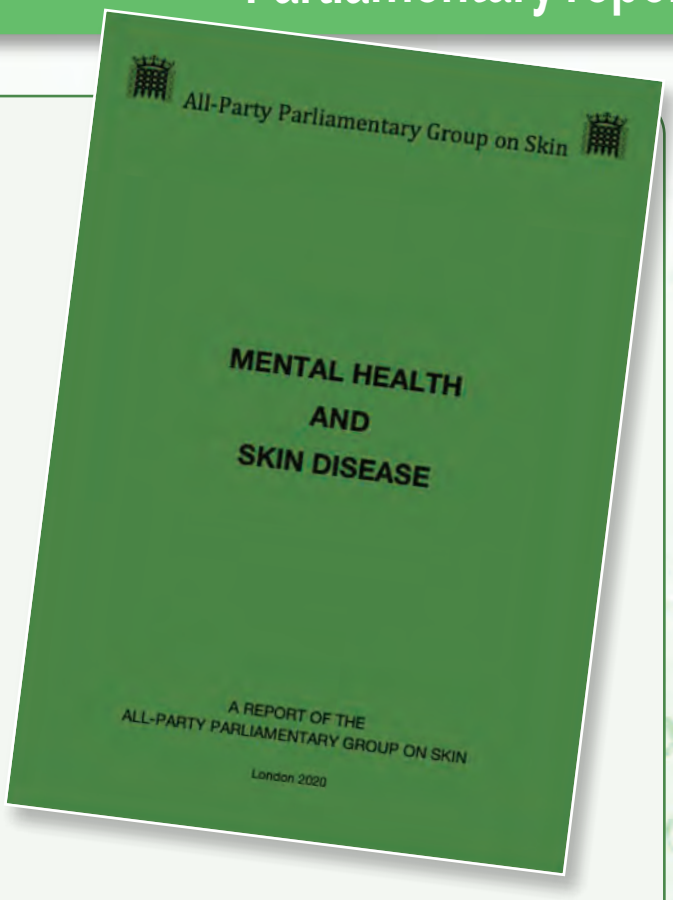
About EULAR

EULAR is a non-profit scientific organisation based in Zurich, Switzerland, representing scientific societies, societies of other health professionals, professional associations and organisations for people with rheumatic and musculoskeletal diseases (RMDs).

The aim of EULAR is to reduce the burden of RMDs on the individual and society and to improve the treatment, prevention and rehabilitation of RMDs.

Further information: www.eular.org

Source:
The European League Against Rheumatism (EULAR) October 2020



New mental health funding promised to Clinical Commissioning Groups (CCGs) must urgently be used to invest in and improve mental health services that are dedicated to dermatology patients, according to a report published today by the All-Party Parliamentary Group on Skin (APPGS).

The call is prompted by survey data revealing that 98% of skin disease patients feel their condition affects their emotional and psychological wellbeing, and 5% have suicidal thoughts, yet only 18% have received some form of psychological support. Over half of the patients surveyed for the report did not realise specialised support was available for people with skin conditions, in the form of psychodermatology.

The APPGS raises concerns that access to specialist mental health support for people with skin disease is limited throughout the UK, despite a growing need for such services. This is particularly worrying since the COVID-19 pandemic has exacerbated mental health distress in a skin community that was known already to experience significant appearance-related distress.

Evidence was collected in March and April 2020 from over 500 UK patients with a range of skin conditions, a hundred clinicians, and 16 organisations operating in the field of dermatology. Of the 16 skin organisations contributing to the report, all said that they felt NHS service provision in this area is either 'poor' (80%) or 'very poor' (20%).

The aim of the report was to gain insight into the state of mental health services available to patients with skin conditions in the UK and the psychological impact of these conditions.

Mandatory psychodermatology training, an increase in dermatology training numbers, and comprehensive dedicated psychodermatology services in each region of the UK were all identified as key recommendations for improving services. In addition, the report found that there is a need for all dermatology units to have named, dedicated staff either to manage patients with skin and mental health disease or refer patients to a nearby regional service. The density of dermatology units able to offer these services needs to reflect the UK population and needs to include all devolved nations, as currently there are no services in Wales and few in Scotland and Northern Ireland.

Another major issue identified by the report is the lack of paediatric psychodermatology clinics – currently there is only one in the UK. All too often, children are not offered support services, which has a profound impact on their long-term mental health, life course and wellbeing into adulthood. Therefore, a key recommendation of the report is that, at a minimum, there should be access to regional paediatric psychodermatology clinics.

Psychological burdens are extremely common in people with skin conditions. The impact can be debilitating and seen across all aspects of patients' lives. The APPGS survey of people with skin conditions found:

- 93% of people with skin disease reported a negative impact on their self-esteem
- 87% of people with skin disease reported a negative impact on their social life or leisure and sporting activity
- 83% of people with skin disease reported a negative impact on their sleep

Parliamentary report

- 73% of people with skin disease reported a negative impact on intimate relationships
- 69% of people with skin disease reported a negative impact on their work or education
- 5% of people with skin disease reported having suicidal thoughts
- 100% of the 27 children who responded to the survey indicated that their skin condition affected their psychological wellbeing and 85% felt they had low self-esteem
- of the children with low self-esteem, 85% reported this being particularly in relation to engaging with peers at school.

Sir Edward Leigh MP, Chair of the All-Party Parliamentary Group on Skin and Member of Parliament for Gainsborough, said:

''This timely report comes out during a period of unprecedented psychological distress for many people living with a skin condition. The COVID-19 pandemic has exacerbated anxiety and stress amongst those already known to experience significant appearance-related distress.

''I know from direct experience the impact skin conditions can have on your mental health. I have rosacea, which is an incurable condition causing red and visible blood vessels on the skin. On almost a daily basis I am mocked on social media for the noticeable visible difference caused by my rosacea. It is clear, from the powerful and moving testimony we received from skin patients, that many others experience similar episodes of discrimination, rejection and negative reactions. This can be alienating and deeply distressing.

''People living with a skin condition deserve the right to be provided with excellent and appropriate psychological support to manage their condition. However, I was alarmed by the lack of psychological support that is available to people with a skin condition. Therefore, the NHS must urgently invest in, and expand, specialist mental health support for people with a skin condition.

''The APPG on Skin will be discussing the findings and recommendations from our report with government and key policy-makers within the NHS to ensure that vital improvements are made to services.''

Dr Tony Bewley, consultant dermatologist and chair of the All-Parliamentary Group on Skin's Expert Committee, said:

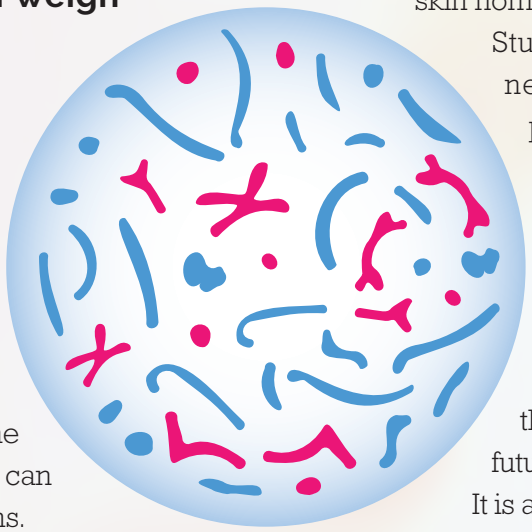
''Skin conditions are extremely common, and it has been shown time and again that they often have a significant impact on peoples' mental health. Despite this, the availability of specialised mental health services for people with skin conditions remains poor, and in some regions non-existent.

''As this vital report illustrates, children and young people, who can be particularly vulnerable to mental health issues and bullying related to their skin health and appearance, have been particularly let down in this area. As it stands there is only one paediatric psychodermatology clinic in the UK, which is clearly inadequate.

''Evidence is increasingly showing that providing comprehensive dedicated services for patients with skin and mental health disease is both cost and clinically efficient. We are keen to urge commissioners to recognise the evidence highlighted in this report which shows that investment in specialised mental health services for people with skin conditions is cost-effective compared to the alternatives.''

The full report can be read here: www.appgs.co.uk/mental-health-and-skin-disease-report-2020/

Did you know that more than half of your body is not human? The human cells make up less than half of the body's total cell count, while the rest are microbes. There are an estimated 39 trillion bacteria to about 30 trillion human cells. A collection of all microbes, such as bacteria, fungi, viruses, and their genes, that naturally live on our bodies and inside us, is called a microbiome. The gut microbiome alone can weigh up to 2kg.



Why is this relevant to psoriasis?

Researchers are now looking at the relationship between the gut microbiome and psoriasis; recent advances in immunology have enabled the development of therapies that can dramatically reduce symptoms.

In an article published in *The International Journal of Molecular Science*, it has been reported that there have been some advances in the understanding of the microbes in the gut and their implications for the treatment of psoriasis, including the potential for treatments based on the gut microbiome.

Researchers have suggested that psoriasis studies have been wide-ranging because there is still so much about the disease that is misunderstood. One of the unsolved mysteries in psoriasis has been why systemic inflammation has its most prominent symptoms on the skin and joints. It is suggested tissue resident cells play an important role.

One area of emerging research with potentially broad implications for psoriasis is the gut microbiome. One possible pathway to better understanding psoriasis is dysbiosis in gut microbiota (an imbalance between the types of organism present in a person's natural microflora, especially that of the gut) of people with psoriasis, though is not clear if the imbalance has a pathogenic role or is simply a result of systemic inflammation.

The gut and the skin are organs with crucial immune and neuro-endocrine roles and are uniquely related in purpose and function. The intimate relationship between these organs is referred to as the skin-gut axis and numerous studies have linked gastrointestinal (GI) health to skin homeostasis.

Studies suggest that a number of new therapeutic approaches to psoriasis could be coming; accumulating evidence in the gut-skin axis would favour a nutritional approach or signal inhibition to change microbiome composition, which could increase therapeutic options available for future psoriasis treatments.

It is a complex area and needs further research and understanding of how the microbiome influences the skin and joint manifestations seen in psoriatic disease. It will be interesting to see how this exciting area of research develops in the future.

Source and reference:

Komine M. Recent advances in psoriasis research; the clue to mysterious relation to gut microbiome. International Journal of Molecular Sciences. 2020; 21(7):2582. doi: 10.3390/ijms21072582.

In a new study presented at the 2019 The American College of Rheumatology ACR/ARP annual meeting, researchers found that the age of psoriasis onset determines whether arthritis or psoriasis starts first in people with psoriatic arthritis. Additionally, they found that pustular psoriasis is associated with arthritis onset two years earlier than the intercept interval, and there is an increased delay for nail involvement, plaque psoriasis or family history of psoriasis from psoriasis to arthritis by approximately two years for each characteristic.

This study explored the relationships between the characteristics of skin psoriasis, arthritis and the timing of arthritis onset using PsART-International, which is a web-based registry of PsA patients under routine care in Turkey, Italy and Canada. PsART-International includes detailed disease history about the type and onset of skin and joint disease.

"The PsART-International cohort focuses on PsA patients in whom musculoskeletal symptoms start before skin lesions, which is approximately 5-10% of all PsA patients. We need more patients to determine related factors," says Umut Kalyoncu, MD, professor of internal medicine and rheumatology at Hacettepe University in Turkey and the study's lead author.

"PsA is a heterogeneous disease for clinical presentation and treatment response. If patients with arthritis first are really a different subgroup, it means that treatment response and prognosis could be different from others. Indeed, in our cohort, achieving minimal disease activity is statistically less frequent in patients with arthritis first."

The researchers extracted data on demographic characteristics, family history of psoriatic disease regardless of skin or arthritis, types of skin psoriasis, site of skin psoriasis onset and components of PsA ever observed. They tabulated patient characteristics in three groups: arthritis-first, psoriasis-first and synchronous, or onset of skin and joint disease within 12 months. The study's primary outcome was the absolute time elapsed in months after skin disease to arthritis, with negative values indicating arthritis onset before psoriasis.

They included 1,631 patients in the study, including 71 who had arthritis first, 309 with synchronous onset, and 1,251 who had psoriasis first. According to their findings, the age of psoriasis onset, not arthritis, determined if arthritis or psoriasis would appear first. Their analysis also shows a 65-month delay of arthritis onset after psoriasis when other independent variables are set to their baseline values.

"In the cluster analysis, we know that psoriasis has at least six different subtypes: starting age of disease, extensity of skin involvement, psoriasis skin type (pustular or plaque), nail and musculoskeletal involvement. Starting age of psoriasis is particularly important, because it depends on the genetic background," says Dr Kalyoncu. "Early-onset psoriasis is strongly associated with HLA-Cw6. However, late-onset psoriasis is not associated with it. In our study, arthritis-first is highly related with late-onset psoriasis. This means arthritis-first patients may be a different subgroup of PsA, and treatment response could be worse in these patients as well. If these results are confirmed in other, well-defined PsA cohorts, we may have determined a subgroup of this highly heterogeneous disease."

Conclusions

The age of psoriasis determines whether arthritis or psoriasis starts first in PsA patients. Pustular psoriasis is associated with a shorter time interval after psoriasis to arthritis, while nail involvement, plaque psoriasis and psoriatic family history are associated with a longer interval.

About the American College of Rheumatology

The American College of Rheumatology (ACR) is an international medical society representing over 8,500 rheumatologists and rheumatology health professionals with a mission to empower rheumatology professionals to excel in their specialty. In doing so, the ACR offers education, research, advocacy and practice management support to help its members continue their innovative work and provide quality patient care. Rheumatologists are experts in the diagnosis, management and treatment of more than 100 different types of arthritis and rheumatic diseases.

Source: ACR

The MHRA's Enforcement Group, working in collaboration with German law enforcement partners, has helped to dismantle a global criminal network involved in the illegal sale of medicines online.

The network stretched across Europe and as far afield as Singapore and Australia. On October 13, German authorities in Munich arrested two individuals suspected of being the leaders of this extensive criminal network.

In 2019, during the MHRA's earlier operation to dismantle the UK element of the network, investigators seized over half a million doses of unlicensed medicines and class C controlled drugs across the country, from residential and commercial premises in Bournemouth, London and Gateshead. These included treatments for cancer and HIV as well as antibiotics, erectile dysfunction pills and weight-loss medication.

Side effects from these illicit medicines can be serious and include vomiting and abnormal heartbeat. Medicines from sources outside the regulated supply chain may also contain dangerous ingredients that can have devastating consequences for the people who use them.

Significant financial assets, held in multiple bank accounts, were also seized in this operation, as suspected proceeds from these crimes.

The perpetrators used illegal websites to advertise and supply these medicines to people in the UK.

Two people have been charged so far in the UK and are awaiting trial, while the others remain under investigation.

The MHRA worked closely with Germany, Spain, the US and Europol to identify and dismantle this criminal network.

The agency is also reminding consumers that, when buying online, they should be wary of dodgy websites, suspicious URLs and remember that claims such as '100% safe, no side effects' or 'quick results' are often warning signs. Reduced prices and speedy deliveries can expose the unwary to fake medicines, identity theft and fraud.

Andy Morling, head of enforcement at MHRA, said:

"This is a great example of international collaboration resulting in the dismantling of criminal networks operating across international boundaries. I have no doubt that the action taken by our German colleagues and the contribution made by the UK and other international partners will have a significant positive impact in tackling the illegal sale and supply of medicines.

"I would encourage anyone with a medical condition to seek advice from a healthcare professional. If medicines are required, then only purchase them from an authorised seller."

About the MHRA

Medicines and Healthcare products Regulatory Agency is responsible for regulating all medicines and medical devices in the UK by ensuring they work and are acceptably safe. All of its work is underpinned by robust and fact-based judgements to ensure that the benefits justify any risks. MHRA is a centre of the Medicines and Healthcare products Regulatory Agency, which also includes the National Institute for Biological Standards and Control (NIBSC) and the Clinical Practice Research Datalink (CPRD). MHRA is an executive agency of the Department of Health and Social Care.

Source:
MHRA

Marketplace

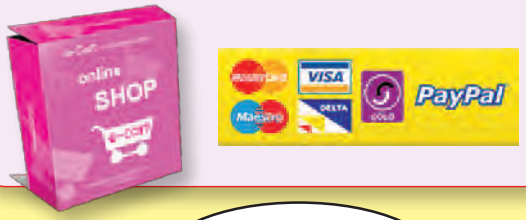
Promotional material

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?

Visit the PAPAA shop

www.psoriasis-shop.org

- Order free information
- Join and pay for your subscription
- Renew your subscription
- Make a donation
- Purchase from a selection of books
- Informative training programmes.



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.

Join the conversations

If you have a social media presence, then why not follow us and join the conversation to see what others have to say?

The following are the links to our pages:

Facebook:	**www.facebook.com/papaa.org**
Twitter:	**@PsoriasisInfo**
Pinterest:	**www.pinterest.co.uk/psoriasisuk**
Instagram:	**www.instagram.com/the_papaa_eye**
LinkedIn:	**www.linkedin.com/company/papaa/**