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skin 'n' bones connection

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Correspondence Address:
PAPAA
3 Horseshoe Business Park, Lye Lane, Bricket Wood,
St Albans, Herts. AL2 3TA
E-mail: info@papaa.org
Web: www.papaa.org
Tel: 01923 672837 Fax: 01923 682606

Production team:
Julie Chandler
Managing Editor

Artwork and Design
Macpro Design and Print Ltd., St Albans

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Registered office: Acre House
11–15 William Road, London NW1 3ER

papaa

Dear Reader

Have you ever wondered why there are so many regulations and why we are bombarded with warnings?

Perhaps it is because the world has become a more dangerous place, we have become risk-adverse or it's just the evolution of a more careful and caring society.

It may even be that media demand for more news has prompted both relevant and irrelevant warnings, which could mean that really important safety messages get lost in the mountain of information.

Risk and benefit, particularly in health, are very relevant. Preventing access because of a few reported risks could deny more people a useful and much needed benefit, so issuing informative warnings is probably a sensible approach. On pages 3 and 4 this is highlighted in relation to the use of emollients and the few incidents of fire-related deaths.

Further risks relate to misleading information, found in the report on pages 5 and 6 about YouTube videos.

It is also important that risk and any subsequent warnings are based on robust evidence and good quality research which is conducted appropriately. On pages 8 and 9, the newly created biologics register for psoriatic arthritis is a good example of how long-term safety studies can provide reassuring and useful data that aids outcomes.

Finally, providing suitable education and being treated by a suitably qualified professional are the best ways to feel reassured that all those risks, benefits and warnings have been weighed up and applied appropriately; read page 14 to see what is required to meet those standards.

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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Watch your step sign on the tile floor. By Wor Sang Jun

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Emollient precautions

People who use emollient creams to treat dry and itchy skin conditions are being warned that residue can build up on fabrics, such as clothing or bedding, and cause them to catch fire more easily.

The Medicines and Healthcare products Regulatory Agency (MHRA) is recommending that labelling and product information for these emollient products should include a warning about the fire hazard, with clear advice not to smoke or go near naked flames and information about the risk of severe burn injury or death when clothing, bedding and dressings with emollients dried on them are accidentally ignited.

Dr June Raine

The likelihood of fabric that has been in contact with emollient products catching fire through an individual smoking or being near a naked flame is low, but if this does occur it could cause severe burns which may result in death. We want users to be aware that fabrics which have come into contact with an emollient can be highly flammable, even after washing. The risk is greater when emollients are applied in large quantities or to large areas of the body.

Following an extensive review of the available evidence, the Commission on Human Medicines (CHM) recommends that:

- outer packaging and product containers should include a warning about the fire hazard and advice not to smoke, accompanied by short explanatory text and a picture warning in the most prominent field of view
- where available, the patient information leaflet or instructions for use and the summary of product characteristics (SmPC) should be updated to include warnings about the risk and how best to minimise it.

The text will clearly warn users not to smoke or go near naked flames due to the risk of severe burns, that as fabric (such as clothing, bedding and dressings) which has been in repeated contact with these products burn more easily and can be a serious fire hazard. Washing clothing and bedding may reduce product build-up but not totally remove it.

Medicines & Healthcare products Regulatory Agency

The MHRA and industry are working together to apply the CHM recommendations and develop suitable ways to make sure the warning is appropriately prominent. Additionally, they are setting up a specific stakeholder group to manage education and awareness of this issue.

It was previously thought the risk occurred with emollients which contain more than 50% paraffins. However, evidence now points to a risk with emollients which contain lower levels of paraffin and with paraffin-free emollients. This advice therefore applies to all emollients, whether they contain paraffin or not.

It is important that people prescribing, dispensing or using any emollient, or caring for someone who uses an emollient, are aware of the potential fire risks and take appropriate action to reduce them.

June Raine, director of MHRA's vigilance and risk management of medicines division, said:

"We don't want to unduly worry people into not using these products which offer relief for what can be chronic skin conditions, but it is equally important people are aware of the risks and take steps to mitigate them.

Our new evidence-based recommendations are intended to empower proper use of these tried and trusted treatments and we are working with industry to support delivery of prompt packaging and labelling warnings and advice.

If you use emollients and have any questions or concerns, we'd recommend speaking 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 this product, or more generally with any medical

Emollient precautions

device, to our Yellow Card Scheme. https://yellowcard.mhra.gov.uk "

Watch manager Chris Bell, from West Yorkshire Fire and Rescue Service and National Fire Chiefs Council's lead for emollient creams, said:

"We welcome this recommendation. There have now been in excess of 50 deaths in the UK where the build-up of emollients on bedding, dressings or clothing may have contributed to the speed and intensity of the fire. Many of these fires were caused by people who smoked and were unaware of the fire risks associated with emollient build-up on fabrics.

We have been trying to raise awareness about this issue with the public and health and care professionals. Ensuring that these products carry warnings will certainly help us as we continue to work with pharmacists, the NHS and care sector to prevent any future deaths."

John Smith, chief executive of PAGB, the consumer healthcare association, said:

"Emollient products are an important and effective treatment for chronic and often severe dry skin conditions, such as eczema and psoriasis. People should continue to use these products, but it is vital they understand the fire risk associated with a build-up of residue on fabric and take steps to mitigate that risk.

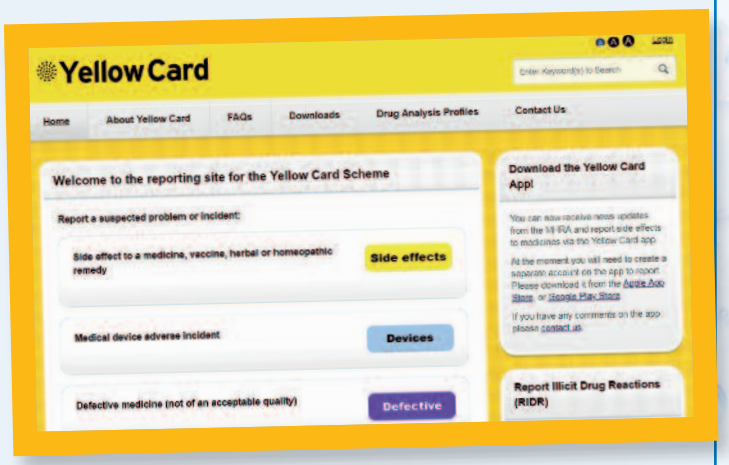
Safety is of paramount importance to the consumer healthcare industry and PAGB member companies are committed to adding a clear warning statement to the packaging of emollient products. We have been working with MHRA during its review of the evidence to ensure the warning is implemented consistently across industry and to support efforts to raise awareness of this issue."

About Yellow Card

The Yellow Card Scheme is vital in helping the MHRA monitor the safety of all healthcare products in the UK to ensure they are acceptably safe for patients and those that use them.

Reports can be made for all medicines, including vaccines, blood factors and immunoglobulins, herbal medicines and homeopathic remedies, and all medical devices available on the UK market.

From the 20th of May 2016, the MHRA is also collecting reports of safety concerns associated with e-cigarette products through the Yellow Card Scheme.



The scheme collects information on suspected problems or incidents involving:

- side effects (also known as adverse drug reactions or ADRs)
- medical device adverse incidents
- defective medicines (those that are not of an acceptable quality)
- counterfeit or fake medicines or medical devices
- safety concerns for e-cigarettes or their refill containers (e-liquids).

It is important for people to report problems experienced with medicines or medical devices as these are used to identify issues which might not have been previously known about. The MHRA will review the product if necessary, and take action to minimise risk and maximise benefit to patients. The MHRA is also able to investigate counterfeit or fake medicines or devices and if necessary take action to protect public health.

Source:
MHRA News centre

In the last few decades, the internet has become an unimaginably vast and detailed source of information on every conceivable health problem. For example, if I simply enter the word "psoriasis" in Google, it gives 92,600,000 results in 0.47 seconds. Moreover, evidence suggests that around 80% of internet users access health information online, especially those with chronic illnesses who may rely heavily on internet-based sources.

In parallel with this, the rise of social media has become increasingly important in the context of healthcare. Perhaps the best example is that of YouTube, an open-access video-sharing platform which hosts a huge number of videos offering medical information and advice. YouTube has around five billion visits, with an estimated one billion hours watched every day. At one level, of course, this must be a good thing. If people are better informed, they are more able to make educated decisions about their health and medical treatment. Conversely, inaccurate or misleading information can cause unnecessary worry and distress, especially for those who are already anxious about their health. In this interesting study – the first of its kind - the authors set out to evaluate the quality of the information provided in YouTube videos on psoriasis.

The authors point out that psoriasis is a hot topic in social media with psoriasis foundations and associations being among the most popular dermatology-related organisations on Facebook, Twitter and LinkedIn. In addition, previous publications have shown that YouTube is heavily accessed as a source of information on psoriasis. However, because most of these videos are privately posted, rather than originating from trustworthy institutions, there is a concern about the scientific quality of the information provided. Hence the objectives of this study were:

- to identify and upload the 100 most viewed psoriasis-related videos from YouTube
- to evaluate the quality of YouTube videos as a source of information on psoriasis
- to correlate viewers' ratings with expert quality assessments
- to point out strategies whereby the quality of video clips and medical content uploaded to YouTube could be improved.

Method

The investigators carried out a search on YouTube on 27th July, 2017. From this they identified the top 100 videos offering information related to psoriasis, which achieved a total of 73 million views. Interestingly, the video clip in 100th place achieved only 40,000 views, which suggests that videos ranked below the first 100 would have a negligible impact on study outcomes.

After collecting information regarding source, topic, duration etc, the quality of the video clips was then evaluated by a team of experienced dermatologists, using two validated assessment instruments: (1) The Global Quality Scale and (2) the DISCERN tool. They also classified the videos as useful, misleading or dangerous.

The main findings

1. Most video clips contained anecdotal personal experiences, with complementary and alternative psoriasis treatments, topical treatments, and nutrition and diets being the most frequently addressed topics.

2. While advertisements accounted for 26% (26/100) of the videos, evidence-based health information amounted to only 20% (20/100).

3. Overall, 32% (32/100) of the videos were classified as useful, 52% (52/100) as misleading, and 11% (11/100) as potentially dangerous.

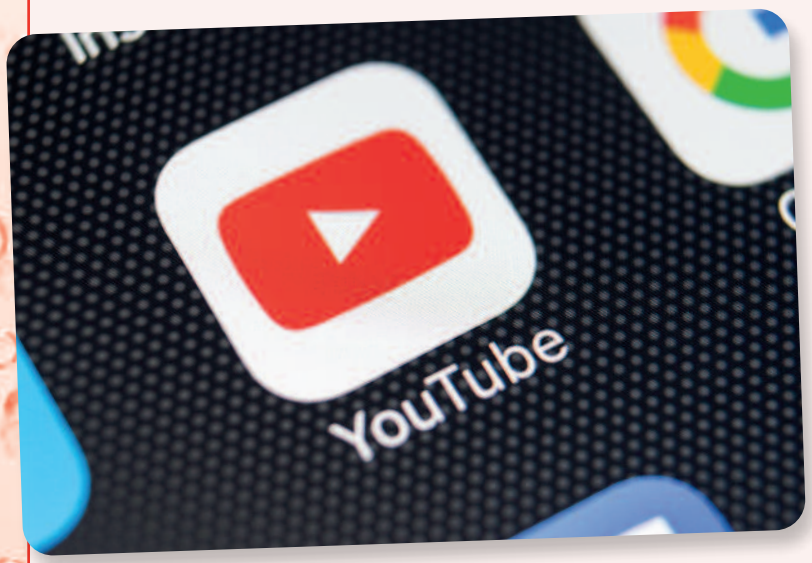
4. Almost two-thirds (63%) of the videos spread misleading information and recommendations.

5. According to the results of the GQS and DISCERN tools, only 11% and 12% of the videos, respectively, were of good or excellent quality with unbiased, evidence-based information.

6. Viewers rated poor-quality videos better than higher-quality videos.

Discussion

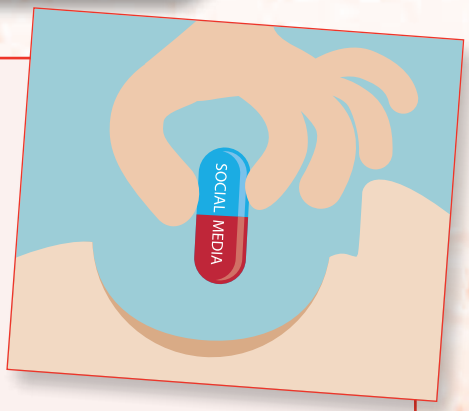
Psoriasis patients are avid users of social media, including YouTube, as a source of information on their disease. For this reason, that fact that nearly two-thirds of the psoriasis-related videos analysed in this study disseminate misleading or even dangerous content is clearly worrying. Subjective, anecdotal and unscientific content is clearly over-represented.



What is equally concerning is the observation that poor-quality video clips consistently receive more positive quality ratings than higher quality videos. In other words, viewers have a limited capacity to distinguish between scientifically based evidence, as opposed to the anecdotal and purely subjective. The authors speculate as to why this might be the case.

At least one factor is that most individuals searching the internet for medical information, exhibit "confirmation bias" – i.e. they are more likely to believe what they read or see when the information presented matches what they already believe or know. Another factor may be that "personal" accounts of illness may feel more rooted in actual experience than the rather sterile accounts provided by more scientifically credible sources.

The investigators also speculate on what might be done to improve the quality of information disseminated through YouTube. Clearly, closer cooperation between social media, dermatology associations and psoriasis self-help organisations would facilitate the availability of medically accurate information about psoriasis. Ideally, websites and video clips with medical content would be subject to standardised quality control or minimum standards through government regulations. As the authors point out, however, given the sheer amount of information being posted online every day, this is simply not feasible.



Conclusion

This was a well-executed and in-depth study that exposed worrying features about the quality of psoriasis-related YouTube video clips. Almost two-thirds of the videos evaluated were judged to be either misleading or potentially dangerous. Subjective and anecdotal content was clearly disproportionately over represented and poor-quality videos were given consistently higher ratings by viewers than the better-quality videos. There is an urgent need for professional dermatological organisations to engage with social media platforms, especially YouTube, to improve the quality of online psoriasis-related information.

Dr David Ashton MD PhD

Scientific references

- Mueller SM, Jungo P, Cajacob L, et al. The Absence of Evidence is Evidence of Non-Sense: Cross-Sectional Study on the Quality of Psoriasis-Related Videos on YouTube and Their Reception by Health Seekers. J Med Internet Res 2019;21(1): e11935.
- Lenczowski E, Dahiya M. Psoriasis and the digital landscape: YouTube as an information source for patients and medical professionals. J Clin Aesthet Dermatol 2018;11(3):36-38.
- Qi J, Trang T, Doong J, Kang S, Chien AL. Misinformation is prevalent in psoriasis-related YouTube videos. Dermatol Online J 2016;22(11):1.

In the current economic climate it is more difficult than ever for researchers to secure the necessary financial support. As a charity, PAPAA, wishes to support research into all aspects of psoriasis and psoriatic arthritis whenever possible, though of necessity the amounts we are able to commit are relatively small.

We are registered with the National Institute of Health Research (NIHR) as a partner organisation, which allows us to be added to the UK Clinical Research Network portfolio when we support any research that qualifies.

We will consider funding applications for small, relatively low-cost (<£10k) research projects in the following areas:

- short-term observational studies
- psoriasis in children
- systematic reviews
- funding of feasibility and pilot studies
- small epidemiological surveys.

The trustees of the charity will consider other areas of research, provided there is likely to be a tangible benefit for patients affected by psoriasis and/or psoriatic arthritis.

Funding strategy

To learn more about our funding strategy, go to the following page on guidance for applicants.

www.papaa.org / research-grants / guidance-applicants-seeking-funding

Other support:

In addition to funding, PAPAA can provide support for research in a variety of other ways.

We can:

- help publicise the research or trial
- promote participation & help with recruitment
- provide lay patient and public involvement (PPI)
- publicise the results online and in print
- provide NIHR partner organisation status.

The current projects we are funding include:

Dr Andrew Thompson - University of Sheffield

Study title: Mindfulness Parenting Study; Understanding psychological wellbeing in childhood skin conditions.

Dr Rod Tucker – Robert Gordon University Aberdeen

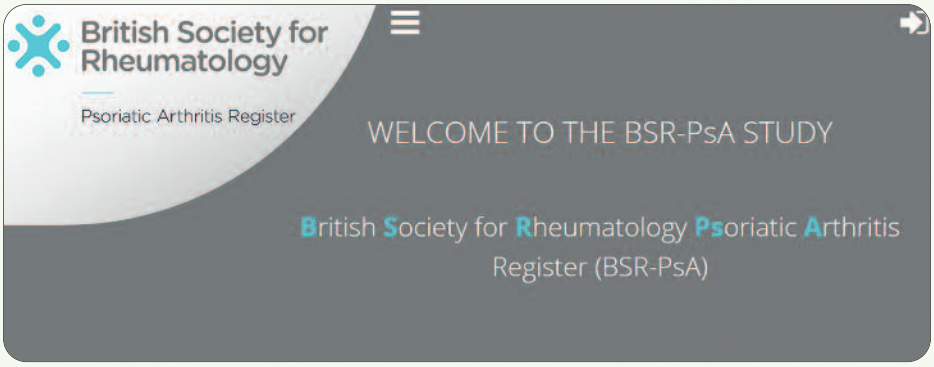
Study title: Can screening undertaken in the community pharmacy help identify patients who have psoriatic arthritis?

Dr Ashley Elliot – Queen's University Belfast

Study title: An observational study evaluating ultrasound-confirmed enthesitis as a prognostic marker for response to biologic therapy in psoriatic arthritis.

Launch of new study

A large UK-wide study examining the impact of targeted drugs on psoriatic arthritis was officially launched at the end of 2018.



The British Society for Rheumatology Psoriatic Arthritis Register (BRS-PsA) aims to recruit 1500 patients from 80 hospital centres across the UK and the study will be led by a team based at the University of Aberdeen.

Around 120,000 people in the UK have psoriatic arthritis which, in addition to the common skin disease psoriasis, causes inflamed, stiff and painful joints. In severe cases joints can become permanently deformed or damaged, which may require surgery.

Dr Gareth Jones

There are now a number of exciting and potent drugs available that target the specific defective pathways in the immune system which lead to the condition. This study will carefully examine the longer-term effects and impact of these therapies in patients in the UK.

The five-year study will compare the progress of people with the condition receiving these targeted drugs and those who receive other treatments as part of their standard NHS care.

Because the therapies alter the function of parts of the immune system, they could expose patients to a higher risk of unwanted side effects such as infections. The British Society for Rheumatology Psoriatic Arthritis Register will help to show whether or not this is the case. It will also address issues highlighted by patients as priority research areas, such as the use of these drugs in pregnancy and understanding their impact on pain, fatigue and ability to work.

Dr Gareth Jones, reader of epidemiology at the University of Aberdeen, said:

"The combination of arthritis and psoriasis can greatly reduce an individual's quality of life, and can affect all aspects of their life, including their mental health and their work.

These drugs have proven to be hugely beneficial in treating rheumatoid arthritis so there is great interest in being able to study their benefits in psoriatic arthritis. Studies like this are absolutely essential to get 'real world' data on the effects and effectiveness of these new drugs in comparison to traditional treatments.

We will follow up with patients regularly to check on their progress. A long-term approach to this study is required to make sure we are getting a full picture of what happens over a long period of time and to be able to document the benefits and any unwanted side effects"

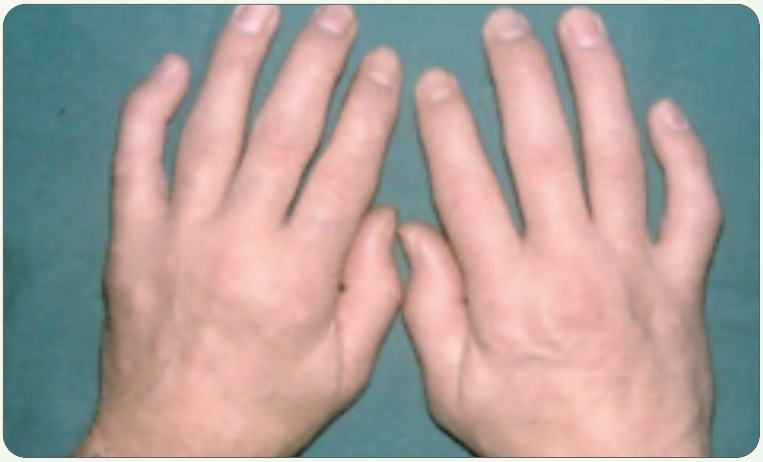
Ali Rivett, chief executive, British Society for Rheumatology, said:

"Everyone personally affected by or with professional interests in psoriatic arthritis in the UK needs to be aware of this new patient register. The British Society for Rheumatology is an

enthusiastic partner in this work led by the team at the University of Aberdeen, and we hope to engage and enthuse health professionals, patients and researchers to ensure that as many hospital rheumatology units as possible join the study."

About the University of Aberdeen:

The University of Aberdeen was named Scottish University of the Year 2019 by The Times and The Sunday Times Good University Guide, and shortlisted for UK University of the Year in the same guide. Established in 1495, the University of Aberdeen is the third oldest in Scotland fifth oldest in the UK and has a community of students and staff covering more than 120 nationalities.



About the British Society for Rheumatology:

The British Society for Rheumatology exists to promote excellence in the treatment of people with arthritis and musculoskeletal conditions and to support those delivering it. It is the leading UK specialist medical society for rheumatology and musculoskeletal care professionals, representing the whole multidisciplinary team: consultant rheumatologists, trainees, specialised nurses, physiotherapists, occupational therapists, psychologists and GPs with special interest in rheumatology. The society aims to improve standards of care in rheumatology and secure a high priority for rheumatology services.

British Society for Rheumatology Biologics Registers:

The British Society for Rheumatology runs four biologics and biosimilars registers. Three are for adult patients receiving treatments for rheumatoid arthritis, ankylosing spondylitis and psoriatic arthritis, and the fourth is for young patients with juvenile idiopathic arthritis. The data collected from these registers generates vital evidence on patient safety in the long term as well as the efficacy of treatment.

For more information visit:
www.rheumatology.org.uk/practice-quality/registers/psoriatic-arthritis

Aquatic physiotherapy

Anna Carter and Dr. Carol McCrum

Exercising in warm water has long been used as a way of gently moving painful joints, rehabilitating after injury or flares of arthritis and helping to keep fit. Recent NICE guidance has advised that health professionals should consider offering hydrotherapy (also more recently known as aquatic physiotherapy, AqPT) as an adjunct to other dry-land forms of exercise. Exercising in a warm pool can be a helpful way for people to get moving and keep fit with less pain.

How do the properties of water help problems from psoriatic arthritis?

Water is special because it provides buoyancy which reduces the load on weight-bearing joints such as the back, hips, knees, ankles and feet. This means that activities that can be very difficult on dry-land such as walking, squatting and even jogging can be much easier in the water. The buoyancy can also assist movement so can be very helpful for exercising painful, stiff shoulders and elbows as well as the lower limb joints. The pool is a safe environment to be able to practise balance exercises because of the support the water provides. This can help develop confidence with starting or returning to exercising.

Julie (a patient with psoriatic arthritis) used hydrotherapy when first diagnosed and now to keep her fitness and mobility:

"It is such a fabulous feeling to be able to move so freely in the lovely warm water, with minimal pain or stiffness, I can even jog my way round the pool! The benefits of moving freely continue for a while afterwards as well so it's a win win!"

The water can also be used as a resistance to movement for strengthening muscles. The unique quality of water is that the quicker you move the more force it applies. Slow movements will only create a gentle resistance which means water exercises can be adapted for a person's individual ability.

Exercises can be undertaken in any pool, however the temperature of hydrotherapy pools is typically around 35 degrees celsius. The warm water creates an environment which is comfortable even when exercising slowly. People are able to enjoy exercising for longer as they do not get as cold as they might in a cooler pool. The warmth can be soothing for stiff, painful joints and can stimulate blood flow. The temperature and the sensation of being in water can produce a relaxation effect.

Another property of water is hydrostatic pressure. This pressure increases with depth caused by the weight of the water pressing down from above. This can be of great benefit to decrease swelling and can be used to increase demands on the heart and lungs for fitness training.

Along with the benefits of exercise on mental health and well-being, immersion in water also suppresses the sympathetic nervous system which can have a positive effect on mental well-being.

What to expect in a pool session?

Typically you would be assessed by a physiotherapist and agree a treatment plan. This should include:

- poolside assistance if required
- goals of your rehabilitation
- appropriate exercises and progressions.

Therapy may be provided on an individual basis or in a group setting.

Time in the water and number of sessions may vary depending on ability and nature of the problem.

You should take: a swimming costume, a towel and medication that you may need when exercising, such as an inhaler, GTN spray or glucose tablets if diabetic.

Floatation aids and other equipment may be used

Sometimes people may feel some aching and tiredness when first starting which normally improves as your fitness improves.

You will be encouraged to drink plenty of water after your sessions to stay hydrated.

You may be encouraged to explore local pool facilities so you can continue your programme independently to help manage your condition in the longer term. Some hydrotherapy pools offer access in fee-paying groups and private hire.

Common concerns for people with psoriasis and some solutions that can help

"I can't swim!"

You do not need to be able to swim to participate in hydrotherapy

"I'm scared of water"

Pools often have shallow and deeper areas and handrails so you do not ever have to be out of your depth. Your therapist will help build your confidence in the water.

"I am worried about my skin"

Most people do not have any problems with the pool water affecting their psoriasis. Rash vests or t-shirts can be worn if feeling self-conscious. Vaseline can be used as a skin barrier and does not affect the pool chemicals. Showering well and applying cream after sessions is important.

"Can you go in a pool with a stoma bag or catheter?"

Yes! Most stoma / catheter bags can be submerged in water but it is a good idea to check with the manufacturer. It is important to have an empty bag before your pool session. You can purchase specialist swimwear which can cover your bag.

"I don't like getting cold!"

Hydrotherapy pools are typically 35 degrees so you should not feel cold in the pool. If you are in a cooler pool then rash vests or T-shirts can be worn. Warm towels or dressing gown can be left poolside to use after getting out.

"I'm embarrassed about my body"

People of all shapes and sizes attend hydrotherapy sessions. They are all there with the same aim to help their condition. Some pools offer single-sex sessions. Cover-up swimsuits can be purchased or additional clothing can be worn.

"My eyes get sore with chlorine"

Goggles can be worn to protect your eyes. You do not have to put your head underwater.

"Can I do hydrotherapy during a flare?"

Hydrotherapy can be helpful to gently maintain mobility during a flare and may help to ease the pain.

"I'm worried I can't get in and out of the pool"

Most hydrotherapy pools have both steps, handrails and hoist access if required. Assistance can be provided as needed.

How can I access aquatic physiotherapy?

A number of NHS Trusts across the UK provide access to a hydrotherapy pool. Referral to the hydrotherapy service can be arranged through your GP, local physiotherapy and rheumatology services.

There may also be private hydrotherapy facilities local to you which can be accessed.

Medical screening will be undertaken to ensure it is safe for you to undertake hydrotherapy. It is important that your physiotherapist is aware of any other medical problems you may have so they can be taken into account.

Helpful links and resources

Aquatic Therapy Association of Chartered Physiotherapists (ATACP)
https://atacp.csp.org.uk/
Chartered Society of Physiotherapy (CSP)
www.csp.org.uk

Specialist swimwear
https://supplierdirectory.disabledliving.co.uk

Authors: Dr Carol McCrum, consultant physiotherapist Physiotherapy Dept., East Sussex Healthcare NHS Trust.

Anna Carter, clinical lead MSK aquatic physiotherapy, East Sussex Healthcare NHS Trust.

Heather's challenge

It's 30 years since my dad passed away, a young man just 46 (I was 18), so I decided to run in his memory and raise funds for PAPAA.

He suffered from psoriasis and psoriatic arthritis, mainly in silence. Sometimes he spent weeks at a time smothered in hideous cream, wrapped in bandages in hospital.

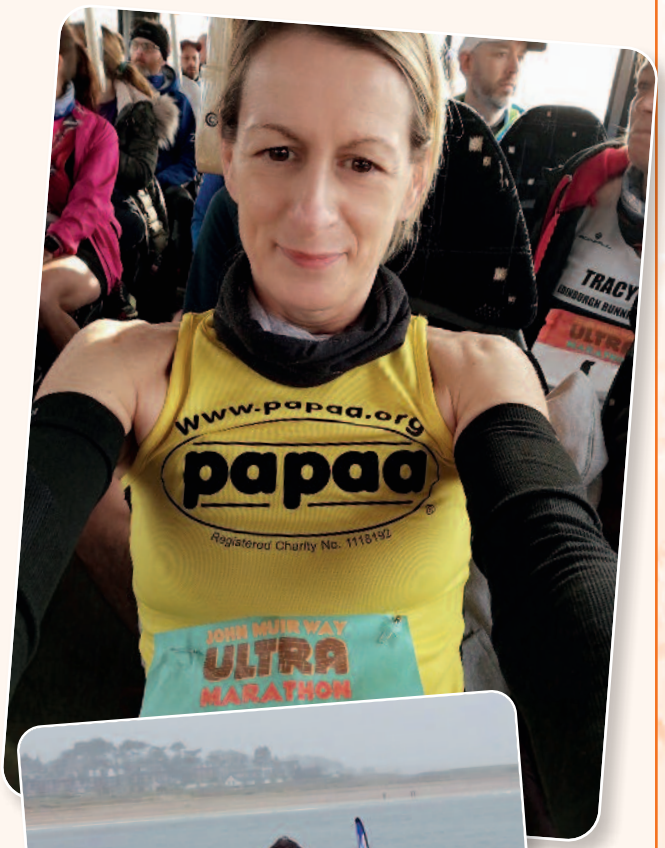
On the 30th March 2019, I ran a 30-mile ultra along part of the John Muir Way. It was a very dreich (dreary) day but a fantastic scenic route, which I completed in 4hrs 38mins, taking 2 minutes off last year's time.

Then on the 28th April 2019, I ran the Stirling Marathon. Again a great route, just a bad day for me. I started with a sore head, feeling sick which went from bad to worse ... I then got a stitch, stomach cramps and just for good measure choked on a fly. So delighted I managed to finish in 4hrs 1min. It just shows you can be well prepared, then on the day it just doesn't fall your way.

I am very thankful to all who sponsored me and the support given on the two runs, which turned out to be a lot more emotional that I had been prepared for. So I am absolutely delighted to have raised £2,105 for PAPAA.

I have since completed a half marathon in 1hr 40, a 15mile trail run in 2hrs (1st female over 40), and a hilly 10k 41mins 14sec. (2nd female over 40), and racked up 1,345km so far this year.

I spend a lot of my training time on Arthur Seat in Edinburgh. In July 2019, I have a 12 mile run from the Pentlands Allermuir Hill @493m high down towards Musselburgh beach, and lastly (well, for now, ha ha!), to mark the calender for the Mhor marathon in August 2019 ... Then maybe a rest!!!



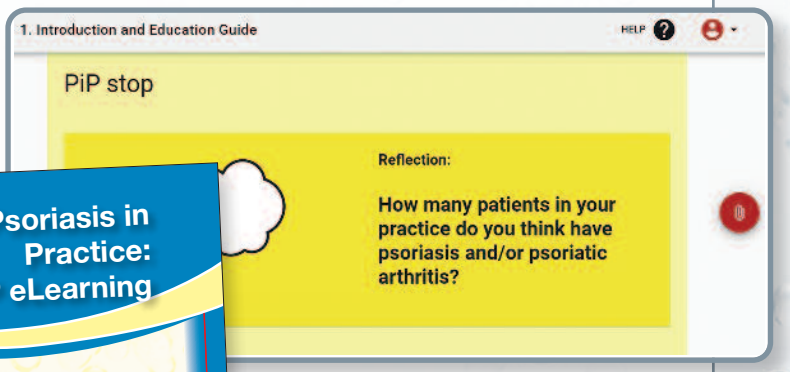
Thank you Heather, congratulations and well done for your fantastic efforts and the funds you have raised to support the work of PAPAA, it is really appreciated.

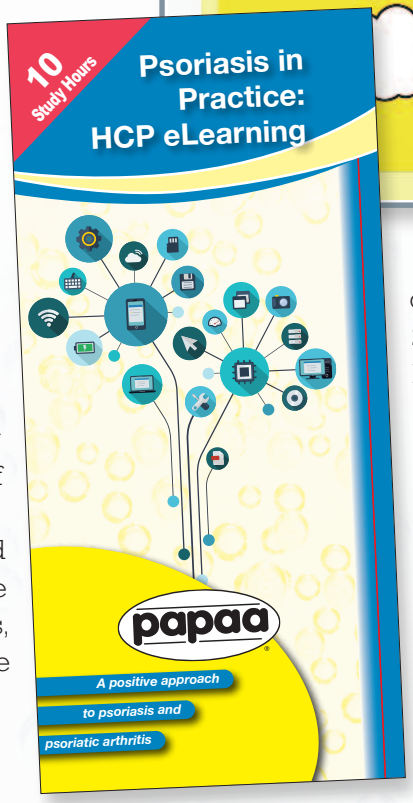
Source:
Heather Imrie

Get involved

If you would like to take up a challenge or support the work of PAPAA, visit our website for ideas:
www.papaa.org/get-involved/fundraising

PAPAA has concentrated on the patient perspective because it's the best way to find out the impact of psoriasis and psoriatic arthritis and their cost to patients' wellbeing. This course is designed to support professional training for the benefit of both patient and professional. The course is accredited by the Royal College of Nursing (RCN).





About the course

Psoriasis in Practice is a patient-centred education programme, using patient interviews and case studies, clearly illustrating the everyday impact of psoriatic disease on the individual.

The programme helps nurses and healthcare professionals understand the individual needs of people with psoriasis, including how to assess and safely manage treatment for psoriasis patients.

Holistic care

Psoriasis in Practice emphasises holistic care and informed choice, putting patients and their families at the centre, for all their needs concerning coping with and treating psoriasis.

Communication with psoriasis patients is emphasised and participants can learn with real-life patients (as patient films are included). The programme includes an emphasis on team working, how psoriasis care is addressed in primary and secondary care settings, including multi-disciplinary teamwork and referral to secondary care in the UK.

Develop skills

Psoriasis in Practice is intended for non-specialist care nurses and healthcare professionals, who want to expand their learning and understand more about psoriasis care; the programme is designed to provide nurses and healthcare professionals with the opportunity to develop themselves in learning about psoriasis care.

Access 24/7

The course can be accessed via any compatible device, computer, mobile and tablet. You can start on one device and continue on another 24/7, (it remembers how much you have completed), at your own pace, in your own time and at your own convenience. Learn in bite-sized chunks, whatever works well for your continuing learning needs.

- evidence-based content
- case studies and patient interviews
- aetiology and treatments for psoriasis and psoriatic arthritis
- nursing assessment and management
- evidence-based resources
- continuing professional development (CPD).

Course delivery

- the programme involves self-directed learning at your own pace
- you can enrol any week of the year and there is no requirement to attend, as delivery is online
- the course provides 10 study hours which can be accessed for six weeks from registration
- evidenced-based educational resources and self-assessments will help you reflect on your own professional practice.

Learning outcomes

On completion of the Psoriasis in Practice programme, you will:

- understand what psoriasis and psoriatic arthritis mean to the person and how their life may be compromised

- recognise that psoriasis and psoriatic arthritis are more than a skin and joint condition
- be able to advise people with psoriasis and psoriatic arthritis on managing their condition
- know when patients need more help and when to refer to specialist services.

Continuing professional development

On successful completion of the course a certificate will be issued by the RCN Centre for Professional Accreditation.

Course fees

The cost of the Psoriasis in Practice course is £50.

How to apply

The course is available to healthcare professionals (HCP) and allied health professionals (AHPs), which is not limited to, but includes those who have a professional qualification or are registered with an appropriate professional body such as the NMC or GMC etc.

The online application form can be found at www.papaa.org/pip; alternatively, contact us for a paper application form (see page two for contact details).

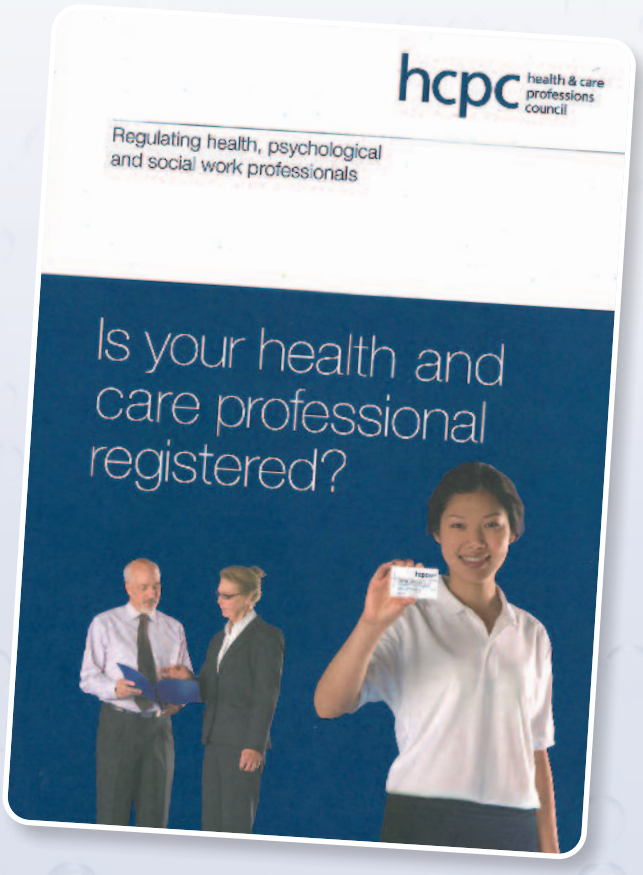
Checking the register

Did you know that there is a way of checking the competence of health and care professionals?

The Health & Care Professions Council (HCPC) regulates health and care professionals in the UK and was set up to protect the public. It only registers professionals who meet its standards for training, professional skills and behaviour. The council will take action against professionals who fall below its standards and also prosecute those who pretend to be registered.

The following are those who are regulated by HCPC.

- Arts therapists
- Biomedical scientists
- Chiropodists / podiatrists
- Clinical scientists
- Dietitians
- Hearing aid dispensers
- Occupational therapists
- Operating department practitioners
- Orthoptists
- Paramedics
- Physiotherapists
- Practitioner psychologists
- Prosthetists / orthotists
- Radiographers
- Social workers in England
- Speech and language therapists.



You can check the register online at **www.hcpc-uk.org/check-the-register** or telephone 0300 500 4472.

To check other healthcare professionals' registration with The Nursing and Midwifery Council (NMC) – **www.nmc.org.uk/registration/search-the-register/**

The General Medical Council (GMC) – **www.gmc-uk.org/registration-and-licensing/the-medical-register**

It continues to be a promising time for people affected by either psoriasis or psoriatic arthritis, with both the Scottish Medicine Consortium (SMC) and the National Institute for Health and Care Excellence (NICE) appraising and recommending treatments for use in the NHS.

PAPAA contributes in written form and by attending the meetings and provides expert patient input into these appraisals using data from our surveys and directly from those who contact us. This input is valued and helps to provide real-life experiences that shape the guidance the NHS use. If you have contributed to our surveys you will have helped inform those who make decisions about the treatment you may receive in the future.

The treatments under consideration were tildrakizumab, certolizumab pegol (National Institute for Health and Care Excellence) and tofacitinib (Scottish Medicine Consortium).

Tildrakizumab (brand name Ilumetri®) is for treating moderate to severe plaque psoriasis in adults after systemic therapy.

The treatment is designed to block interleukin-23, a cytokine that plays an important role in managing the immune system and autoimmune disease such as psoriasis. The treatment is self-administered as a subcutaneous injection. The following is the recommendation from the technology appraisal guidance (TA575):

''Tildrakizumab is recommended as an option for treating plaque psoriasis in adults, only if: the disease is severe, as defined by a total Psoriasis Area and Severity Index (PASI) of 10 or more and a Dermatology Life Quality Index (DLQI) of more than 10 and the disease has not responded to other systemic treatments, including ciclosporin, methotrexate and phototherapy, or these options are contraindicated or not tolerated and the company provides the drug according to the commercial arrangement.

1.2 Consider stopping tildrakizumab between 12 weeks and 28 weeks if there has not been at least a 50% reduction in the PASI score from when treatment started.

1.3 Stop tildrakizumab at 28 weeks if the psoriasis has not responded adequately. An adequate response is defined as:

- *a 75% reduction in the PASI score (PASI 75) from when treatment started, or*
- *a 50% reduction in the PASI score (PASI 50) and a 5-point reduction in DLQI from when treatment started.*

1.4 If patients and their clinicians consider tildrakizumab to be one of a range of suitable treatments, the least expensive should be chosen (taking into account administration costs, dosage, price per dose and commercial arrangements).''

Certolizumab pegol (brand name Cimzia®), for treating chronic plaque psoriasis, was also recommended by NICE. The treatment is an anti-TNF alpha blocker. It is known that TNF alpha is elevated in the skin in psoriasis, therefore the treatment reduces the symptoms and the mechanism of action. The treatment is self-administered as a subcutaneous injection.

The following is the recommendation from the technology appraisal guidance (TA574):

''Certolizumab pegol is recommended as an option for treating plaque psoriasis in adults, only if: the disease is severe, as defined by a total Psoriasis Area and Severity Index (PASI) of 10 or more and a Dermatology Life Quality Index (DLQI) of more than 10 and the disease has not responded to other systemic treatments, including ciclosporin, methotrexate and phototherapy, or these options are contraindicated or not tolerated and the lowest maintenance dosage of certolizumab pegol is used (200 mg every 2 weeks) after the loading dosage and the company provides the drug according to the commercial arrangement.

1.2 Stop certolizumab pegol at 16 weeks if the psoriasis has not responded adequately. An adequate response is defined as:

- *a 75% reduction in the PASI score (PASI 75) from when treatment started or*
- *a 50% reduction in the PASI score (PASI 50) and a 5 point reduction in DLQI from when treatment started.*

1.3 If patients and their clinicians consider certolizumab pegol to be one of a range of suitable treatments, the least expensive should be chosen (taking into account administration costs, dosage, price per dose and commercial arrangements).''

The Scottish Medicine Consortium accepted tofacitinib (brand name Xeljanz®) for restricted use within NHS Scotland. The treatment can be used in combination with methotrexate for the treatment of active psoriatic arthritis in adult patients who have had an inadequate response or who have been intolerant to a prior disease-modifying antirheumatic drug (DMARD) therapy.

The treatment is an oral tablet. Tofacitinib works by blocking the actions of a group of proteins (called janus kinases) which are involved in causing the inflammation in psoriatic arthritis. By blocking their actions, tofacitinib reduces the inflammation and other symptoms of psoriatic arthritis.

Warning from EMA

In May the European Medicine Agency (EMA) issued a safety warning for tofacitinib, and is advising healthcare professionals and patients not to exceed the recommended dose of tofacitinib when treating rheumatoid arthritis.

The advice follows early results from an ongoing study in patients with rheumatoid arthritis which showed an increased risk of blood clots in the lungs and death when the normal dose of 5 mg twice daily was doubled.

In the EU, 5 mg twice daily is the authorised dose for rheumatoid arthritis and psoriatic arthritis. The higher dose of 10 mg twice daily is approved for the initial treatment of patients with ulcerative colitis.

Read full press release at:
www.ema.europa.eu/en/news

The MHRA (Medicines and Healthcare products Regulatory Agency) has been working to prevent the further sale of Zudaifu cream and advises anyone who has bought it online to stop using it immediately.

Zudaifu cream is not a licensed medicine and has been marketed in the UK as a ''natural'' Chinese herbal remedy for the treatment of a range of skin conditions.

Analysis of the product found the presence of the steroid clobetasol propionate. This is the active ingredient in prescription-only medicines used for the treatment of conditions such as psoriasis and eczema.

Creams containing steroids should be used sparingly and as directed by the prescriber. They should not be used on children under one year of age.

Dr Chris Jones

This follows a warning earlier this year for a product called Yiganerjing Cream as a ''natural'' Chinese herbal medicine that contained the same steroid and antifungal ingredients.

Dr Chris Jones, manager of the Medicines Borderline Section at MHRA, said:

''We have again identified a potentially harmful cream described as a natural Chinese herbal medicine on the market.

Selling creams directly to the public that contain strong steroids is illegal and they are potentially dangerous if they are used without medical supervision.

Steroids must only be prescribed by healthcare professionals who follow strict criteria when prescribing them and can monitor patients using them. They can suppress the skin's response to infection and can also cause long-term thinning of the skin. If steroids are applied long term, particularly on children, they can lead to other medical problems.

Our advice to anyone who has bought it previously or is currently using Zudaifu cream – particularly on young children and babies – is to stop using it immediately. If you have any questions, please contact your healthcare professional.''

If you are unsure about the safety of a medicine claiming to be ''natural'' or ''herbal'' you should check for a Marketing Authorisation (MA) or Product Licence (PL) number or Traditional Herbal Registration (THR) number / the THR logo. This means the product has been assessed by MHRA for safety and has been manufactured correctly.

THR Certification Mark

For more information, visit www.nhs.uk or www.gov.uk

If you are aware of Zudaifu cream being sold, please report it to MHRA at **Borderline_medicine@mhra.gov.uk**

New safeguards

Online pharmacies in Great Britain will have to follow updated guidance to protect people getting medicines online.

The General Pharmaceutical Council (GPhC) has strengthened its guidance for pharmacy owners to help make sure that people can only obtain medicines from online pharmacies that are safe and clinically appropriate for them.

Online research by YouGov, commissioned by the GPhC, found that 25% of people say they are likely to use online pharmacies in the future, but 50% of those unlikely to do so have concerns about the safety of online pharmacies.

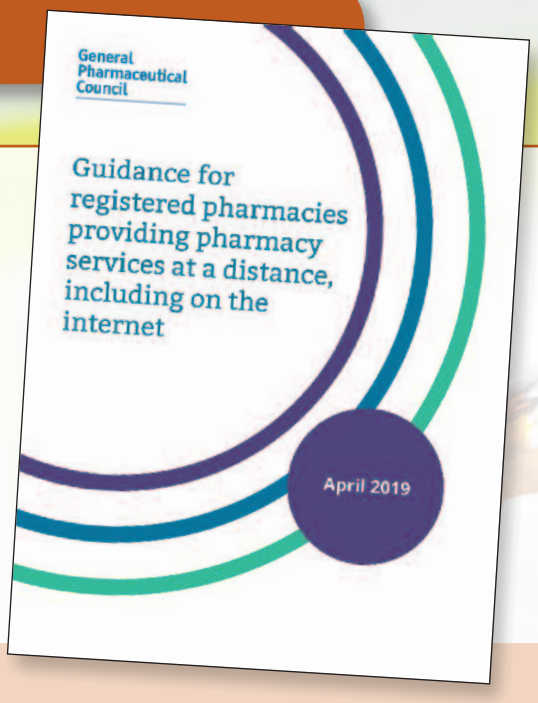
After considering feedback from the sector and patients and the public to proposals published last year, the GPhC has introduced further safeguards for patients and the public in several key areas.

Making sure medicines are clinically appropriate for patients – online pharmacies will have to make sure:

- there are robust processes in place to carry out identity checks on people obtaining medicines
- the pharmacy team can identify requests for medicines that are inappropriate, including by being able to identify multiple orders to the same address or orders using the same payment details
- the pharmacy websites do not allow a patient to choose a prescription-only medicine and its quantity before there has been an appropriate consultation with a prescriber.

Further safeguards for certain categories of prescription-only medicines – further safeguards will have to be in place before supplying the following categories of medicines to make sure that they are clinically appropriate:

- antimicrobials (antibiotics)
- medicines liable to abuse, overuse or misuse, or where there is a risk of addiction and ongoing monitoring is important. For example, opiates, sedatives, laxatives, pregabalin and gabapentin



- medicines that require ongoing monitoring or management. For example, those used to treat diabetes, asthma, epilepsy and mental health conditions
- non-surgical cosmetic medicinal products, such as Botox.

These safeguards include making sure the prescriber proactively shares all relevant information about the prescription with the patient's GP after seeking the patient's consent.

Transparency and patient choice – pharmacy owners will have to supply more details about where the service and health professionals involved in prescribing and supplying the medicine are based and how they are regulated, so people have enough information to make an informed decision about using the service and can raise concerns about the service if they need to.

Regulatory oversight – pharmacy owners working with prescribers or prescribing services operating outside the UK must take steps to successfully manage the additional risks that this may create, including assuring themselves that the prescriber is working within national prescribing guidelines for the UK.

These new safeguards received strong support overall from more than 800 individuals and organisations responding to a discussion paper published last year.

Duncan Rudkin, chief executive of the General Pharmaceutical Council said:

"We support pharmacy services being provided in innovative ways, including online, as long as the services are safe and effective for people. But providing pharmacy services online carries particular risks which need to be successfully managed."

People can be put at serious risk if they are able to obtain medicines that are not appropriate for them. We are now putting in place this updated guidance with further safeguards to protect people."

I would strongly urge patients and the public wanting to obtain medicines online to only use online pharmacies registered with us, to protect their health. These pharmacies have to meet our standards and follow this guidance, so they provide safe and effective services, and we will be inspecting pharmacies to make sure this is the case."

We are also continuing to work closely with other regulators involved in regulating online primary care services, governments and other stakeholders across Great Britain to improve the quality of care for patients online.

Separately, we are currently consulting on new guidance for pharmacist prescribers, including when prescribing remotely."

How to keep safe when using an online pharmacy

Make sure the online pharmacy is registered with the General Pharmaceutical Council. The online pharmacy should say this prominently on its homepage or 'About us' page and give its registration number. You might also see this logo, below which should click through to the register.

Registered Pharmacy 1000001

- Visit www.pharmacyregulation.org/registers/pharmacy to check the pharmacy is on the online register.
- Expect to be asked questions about your health and identity before being able to buy a medicine and answer them honestly. This will help the health professionals prescribing or supplying the medicine to make sure it is safe and appropriate for you.
- Avoid websites which offer to supply prescription-only medicines without a prescription; you could put your health at serious risk.

Source:

General Pharmaceutical Council media centre

www.pharmacyregulation.org

Marketplace

Promotional material

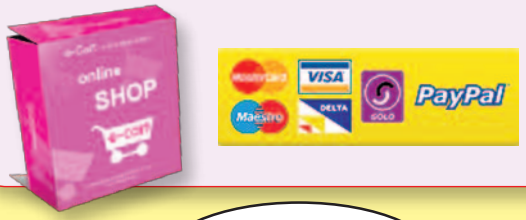
If you are thinking about supporting PAPAA or raising awareness on behalf of PAPAA about psoriasis and or psoriatic arthritis.

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/**