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skin 'n' bones connection

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papaa

Dear Reader

Welcome to the latest edition of Skin 'n' Bones Connection.

Within this issue we look at the work performed by the National Institute for Health and Care Excellence (NICE) and the National Institute for Health Research (NIHR) pages 3 and 9. NICE primarily provides guidance, based on evidence, while the NIHR is for funding and looking at getting that evidence.

Once good evidence has been collected, and used to inform guidance, the next stage is to implement it for the care of people who use the NHS. This can only be achieved by educating those who deliver the care. On pages 10-11, we report on our efforts to support professionals and what they are required to do to keep up-to-date with new developments. This latter point is demonstrated on page 12, where a recent survey from the US suggests that older doctors do not always keep up and/or learn as much as their younger counterparts, which could have a detrimental affect.

The state of the health of people in the UK and the pressure on the NHS to cope is continually reported in the media. Lack of staff and money appear to be part of the issue, although potential use of digital applications may help resolve some of the pressures. A study reported on page 13 suggests that although problems exist with digital applications, they are not insurmountable. Although, given the report on page 15 about stress and losing a smartphone being considered as a stressful event, one wonders whether the digital revolution within the health service may have unintended consequences, not only on the staff but also on the patients they serve.

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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The National Institute for Health and Care Excellence (NICE) is often seen as the enemy of patients, with headlines about rationing of drugs and a postcode lottery for treatments. So is that what NICE does? The following is what NICE does and encompasses more than just what you see in headlines:

- Aims to improve outcomes for people using the NHS and other public health and social care services
- produces evidence-based guidance and advice for health, public health and social care practitioners
- develops quality standards and performance metrics for those providing and commissioning health, public health and social care services
- provides a range of information services for commissioners, practitioners and managers across the spectrum of health and social care
- offers evidence-based guidance and advice.

Since 1999, NICE has provided the NHS, and those who rely on it for their care, with an increasing range of advice on effective, good value healthcare, and has gained a reputation for rigour, independence and objectivity. In April 2013 NICE gained new responsibilities for providing guidance for those working in social care, which is defined as the provision of social work, personal care, protection or social support services to children or adults in need or at risk, or adults with needs arising from illness, disability, old age or poverty.

Within those activities NICE produces clinical guidelines, which recommend how healthcare professionals should care for people with specific conditions. They can cover any aspect of a condition and may include recommendations about providing information and advice, prevention, diagnosis, treatment and longer-term management.

In February this year NICE published Spondyloarthritis in over 16s: diagnosis and management (NG65). The remit for the guideline from the Department of Health was 'to produce a guideline on the diagnosis and management of seronegative arthropathies'. The group of conditions that are included within this term are psoriatic arthritis, ankylosing spondylitis, reactive arthritis, enteropathic arthritis, and undifferentiated spondyloarthritis.

The process for producing a guideline can take 2-3 years. To provide suitable breadth of opinion an expert committee is brought together, which includes patient representation. The guideline recommendations are based on evidence, which is then graded. Randomised Controlled Trial (RCT) studies in which people are allocated at random (by chance alone) to receive one of several clinical interventions, are seen as the best source of evidence, but unfortunately many are of poor quality, or lack the right type or number of participants, to provide good evidence to support recommendations. Consensus and expert opinions are often used to provide the evidence of a collective view in order to provide a robust set of recommendations where evidence is poor or lacks scientific significance.

Guideline NG65 mainly focused on axial and peripheral spondyloarthritis. For axial this essentially covers ankylosing spondylitis and for peripheral mainly psoriatic arthritis.

The recommendation covered the following areas:

- recognition and referral in non-specialist care settings
- diagnosing spondyloarthritis in specialist care settings
- information and support
- pharmacological management of spondyloarthritis
- non-pharmacological management of spondyloarthritis
- surgery for spondyloarthritis
- managing flares
- long-term complications
- organisation of care.

Guidelines will also refer to or incorporate other NICE guidance, including technical appraisals such as those for biologic agents and other clinical guidelines, in this case for helping with a diagnosis of psoriatic arthritis. The recognition of psoriasis is identified as follows:

If a person with suspected spondyloarthritis has signs or symptoms of undiagnosed psoriasis, follow the recommendations in the NICE guideline on psoriasis: Psoriasis: assessment and management clinical guideline [CG153].

The aim of linking to other guidance is to raise suspicion of a condition and provide the appropriate referral for diagnosis and care.

Within the guideline are recommendations for research, where evidence for existing practices are weak or do not exist. The research recommendations included in NG65 were:

- referral criteria for people with suspected axial spondyloarthritis
- long-term complications of spondyloarthritis
- educational intervention to improve healthcare professionals' awareness of spondyloarthritis
- pharmacological management of peripheral spondyloarthritis
- biological therapies for peripheral spondyloarthritis.

Finally, once published, the next stage is to put the guideline into practice. However, putting recommendations into practice can take time. How long may vary from guideline to guideline, and depends on how much change in practice or services is needed. Implementing change is most effective when aligned with local priorities.

Changes recommended for clinical practice that can be done quickly such as changes in prescribing practice, should be shared quickly. This is because healthcare professionals should use guidelines to guide their work and are required to do so by professional regulating bodies such as the General Medical and Nursing and Midwifery Councils.

Unfortunately, this work is often overlooked, but people with psoriatic arthritis can play a key role. Look at the guidelines and alert your healthcare provider about them. Being informed and understanding the process of diagnosis and referral will allow you to be more active in your care and know why certain procedures are done.

Guidelines are not just for healthcare professionals, they are also there to give clarity and confidence to patients, so you can feel that the care you receive is of the highest quality and based on robust scientific evidence. So is NICE the patients' enemy? Well based on its record, perhaps not all is as reported in the headlines.

Glossary

Technical appraisal recommendations are based on a review of clinical and economic evidence.

- Clinical evidence shows how well the medicine or treatment works.
- Economic evidence shows how well the medicine or treatment works in relation to how much it costs the NHS - does it represent value for money?

The axial skeleton includes the bones that form the skull, laryngeal skeleton, vertebral column, and thoracic cage.

Peripheral joints are joints other than the spine. Examples of these joints are the shoulder, elbow, wrist, hip, knee, ankle and foot.

Guidance:

- Spondyloarthritis in over 16s: diagnosis and management (NG65).
  www.nice.org.uk/guidance/ng65
- Psoriasis: assessment and management clinical guideline [CG153]
  www.nice.org.uk/guidance/cg153

Authored by David Chandler with source information from www.nice.org.uk accessed 31 May 2017

It is well recognised that being overweight is a risk factor for the development of psoriasis and psoriatic arthritis, if you are predisposed to developing the conditions. There is also evidence to show that being overweight reduces the therapeutic benefit of many of the medications used in treating psoriasis. If you are overweight and are predisposed, you are more likely to have psoriasis and the medications used in treatment, could be less effective.

The question is, which comes first? Does being overweight lead to psoriasis or does having psoriasis make someone more prone to putting on weight? Interestingly there is evidence pointing both ways.

For example, in the Nurse's Health Study, researchers followed 67,300 women over a period of 12 years, among whom a total of 809 self-reported as having developed psoriasis. Results showed that women who gained weight were at a substantially higher risk of developing psoriasis – the more weight gained, the greater the risk. Women in the overweight category were 21% more likely to develop psoriasis, but those classified as obese were more than twice as likely to develop the disease.

Other studies have shown that not only the risk but the severity of psoriasis is associated with weight gain and a recent report also confirmed a strong association between body weight and psoriatic arthritis.

On the other hand, there are studies showing that people with psoriasis don't exercise or eat as well as they might and also drink alcohol to excess; all factors which could help explain why some people gain weight after a diagnosis of psoriasis. To make matters worse, many people with psoriasis become depressed and many of the commonly prescribed anti-depressants can be associated with weight gain.

The best explanation is that the relationship between psoriasis and overweight is bi-directional - obesity predisposes to psoriasis and psoriasis increases the risk for weight gain. Many studies have shown the association to be strong and consistent – but why?

What is the link between psoriasis and obesity?

Psoriasis is a chronic autoimmune disease that inflames areas of skin, causing discomfort, itching and raised skin lesions. This underlying inflammation is caused by special molecules called cytokines. It turns out that fat cells also produce inflammatory molecules – called adipokines – which produce a similar inflammatory response to that found in psoriasis. Importantly, several of these cytokines are common to both obesity and psoriasis.

So, it seems that as your weight increases, the degree of inflammation also increases, thereby either making existing psoriasis worse or triggering new disease. This explains why some studies show the severity of psoriasis to be closely related to the degree of overweight or obesity.

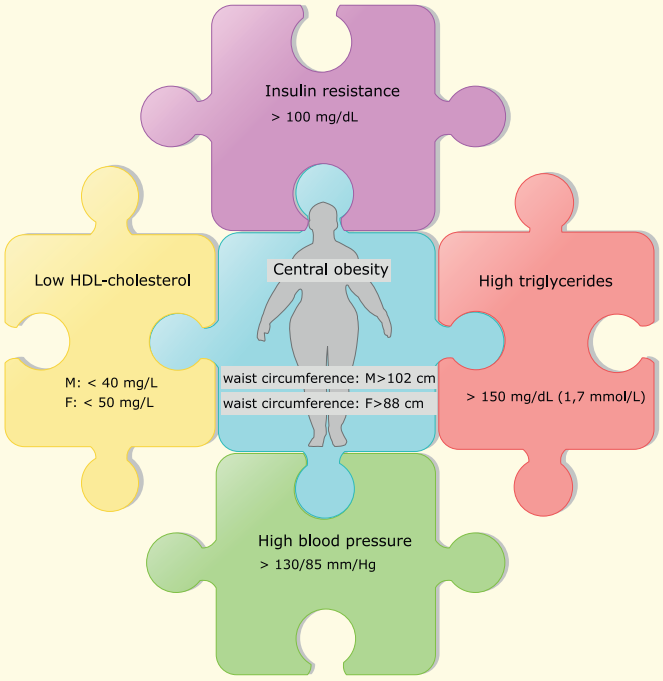
It is also important to note that if you are overweight, you are significantly less likely to achieve the full benefit of many of the systemic and biologic drugs used to treat the disease.

Inflammation and metabolic syndrome

The problem is that low-grade inflammation, of the sort we find in obesity and psoriasis, can lead directly to a condition called metabolic syndrome.

Metabolic syndrome is the medical term used to describe a clustering of risk factors, including a large waist measurement, raised blood fats, high blood pressure (hypertension), an increased tendency to develop blood clots and insulin resistance.

Several studies have shown a strong association between psoriasis and metabolic syndrome. A large study involving more than 45,000 subjects in the UK



Overweight and psoriasis

(4,065 of whom had psoriasis) found metabolic syndrome in 32%, 36% and 40% of those with mild, moderate and severe disease respectively.

But why does this matter?

It matters because the presence of metabolic syndrome in psoriasis and obesity greatly increases the risk of heart disease, diabetes, stroke and some types of cancer. In addition, inflammation of the liver, known as non-alcoholic fatty liver disease (NAFLD), may also occur.

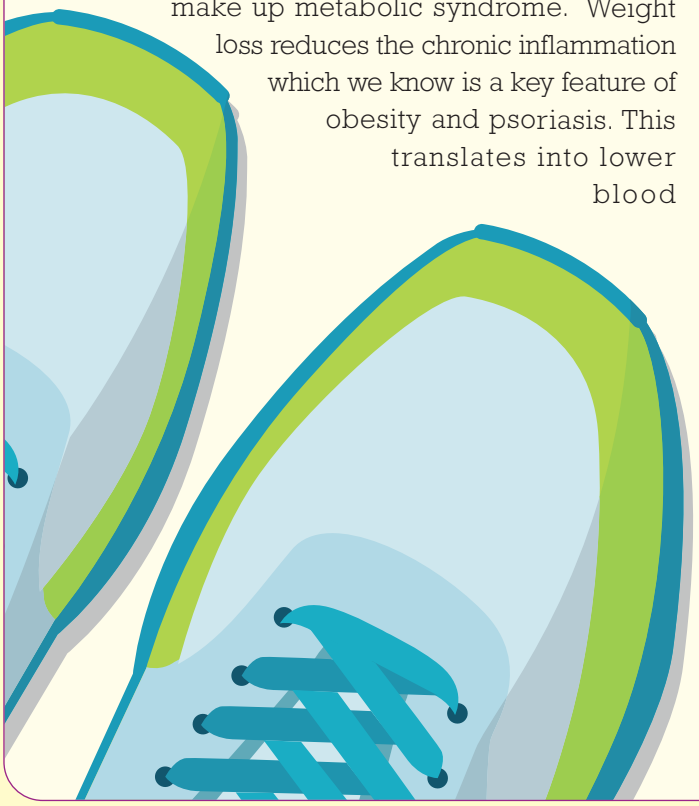
So, to summarise, both psoriasis and obesity are inflammatory conditions which increase the risk of metabolic syndrome and thereby the risk of a variety of health problems, including heart disease, type 2 diabetes, liver disease and some forms of cancer.

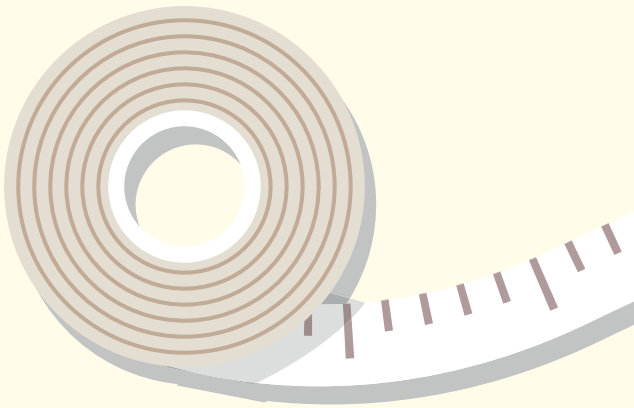
Does losing weight make a difference?

If being overweight makes psoriasis worse, or triggers the disease in the first place, what impact does losing weight have? More specifically, does losing weight reduce the risk of developing metabolic syndrome and the associated health problems such as heart disease, diabetes, cancer and liver disease?

Weight loss and metabolic syndrome

There is ample evidence to show that losing weight has a dramatic impact on all the various factors which make up metabolic syndrome. Weight loss reduces the chronic inflammation which we know is a key feature of obesity and psoriasis. This translates into lower blood pressure, improvements in insulin and glucose metabolism, reduced blood fats and reversal of liver inflammation. These metabolic improvements dramatically reduce the risk of heart disease, diabetes and cancer.



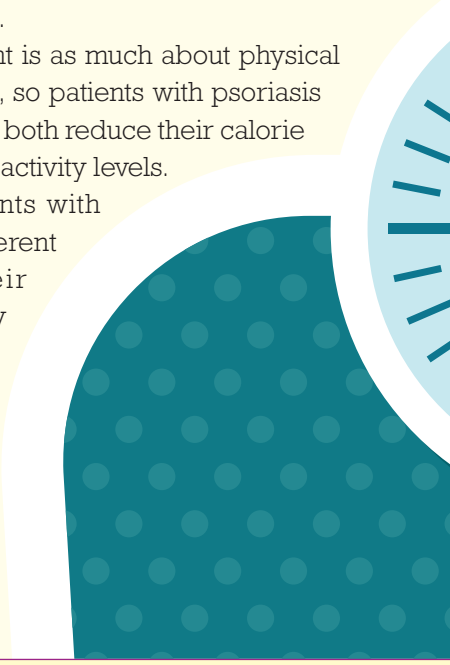


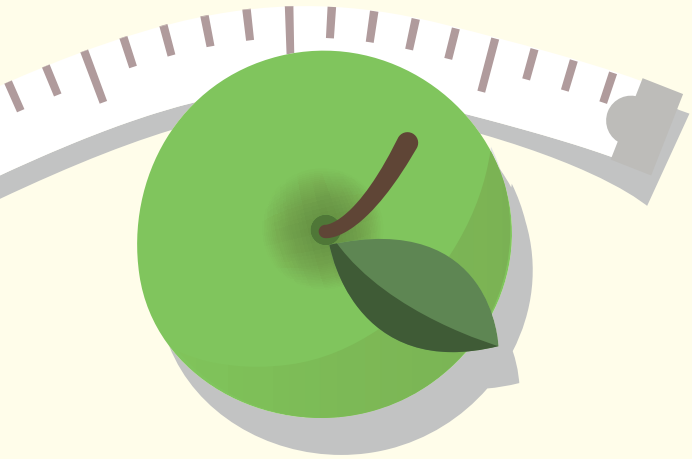
Weight loss and psoriasis

What about the impact of weight loss on psoriasis and psoriatic arthritis? Several studies have shown that in overweight individuals with psoriasis, losing weight reduces the severity of the disease. In a well designed study, a total of 60 overweight individuals with psoriasis were divided into two groups, one receiving a low-calorie diet and the other being allowed to eat normally. At 16 weeks, the dieting group had lost 15.4kg more than the control group and has also experienced a significantly greater reduction in disease severity. Interestingly, the same researchers followed both groups in this study for a further 48-week period. They found that the diet group maintained both their weight loss and the marked improvement in the severity of their psoriasis.

Of course, losing weight is as much about physical activity as it is about diet, so patients with psoriasis should be encouraged to both reduce their calorie intake and increase their activity levels. In addition, many patients with psoriasis are taking different medications for their disease. So, a key question is whether diet and exercise can improve psoriasis beyond any benefit that medication alone would benefit.

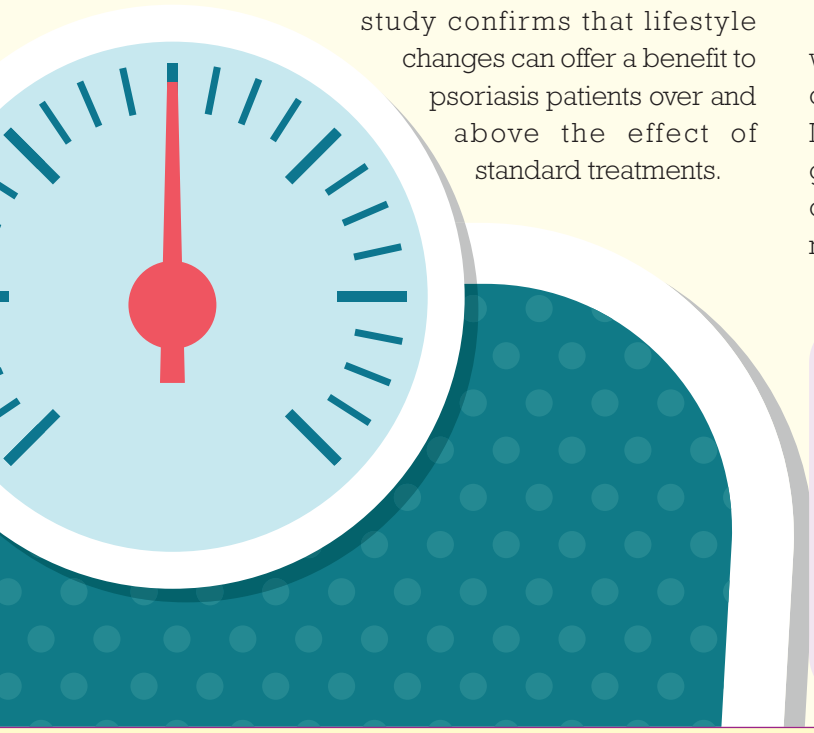
To answer this, researchers divided





303 study participants with moderate to severe plaque psoriasis into two groups. The dietary intervention group ate three low-calorie meals a day and exercised three times a week, while the control group simply attended one informational session on weight loss and psoriasis at the start of the study. Every study participant had previously tried a systemic treatment, but failed to achieve clearance after four weeks. They maintained this therapy for the duration of the 20-week trial.

Patients on the diet experienced a significant improvement in their psoriasis, measured by changes in their Psoriasis Area and Severity Index (PASI) score. Their median PASI score was reduced by 48%. In comparison, the median PASI score of the control group was reduced by just 25.5%. This study confirms that lifestyle changes can offer a benefit to psoriasis patients over and above the effect of standard treatments.



Studies have also shown dramatic improvements in psoriasis among obese patients undergoing weight loss surgery, especially gastric bypass. In some cases, surgery may result in complete remission of the disease. Interestingly, reports suggest that improvement of psoriasis is initiated immediately following surgery – well before any weight loss could have occurred.

Weight loss and psoriatic arthritis

Weight loss and treatment may also work together to improve disease symptoms in overweight people with psoriatic arthritis. A study published in June in Annals of the Rheumatic Diseases found that patients who took a certain kind of biologic medication (TNF- blockers) while losing weight improved more than patients who just took the medication.

A total of 138 overweight individuals with psoriatic arthritis were divided into two groups: half (69) were given a low-calorie diet (1500 calories a day) and the other a normal diet. Patients were evaluated once a month, with a final assessment at the end of the six-month study. Researchers employed many different methods of measuring disease improvement, such as the number of swollen or tender joints, the degree of pain the patient experienced and the severity of skin symptoms. These measurements were combined to determine which patients achieved Minimal Disease Activity (MDA), which was defined as a successful treatment outcome.

Researchers found that almost 45% of the patients who lost 5-10% of their body weight – and almost 60% of the patients who lost more than 10% – achieved MDA. Interestingly, some individuals in the non-diet group also lost weight and they too benefited in terms of achieving MDA. This suggests that it is weight loss, not the specific diet, that matters.

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Medical and scientific adviser, PAPAA

Blue-Light treatment for psoriasis

The Philips BlueControl is claimed by the manufacturers to be the world's first blue light therapy home treatment for mild to moderate plaque psoriasis.

The device uses LEDs (light-emitting diodes) set to a specific wavelength which is believed to stimulate natural processes in the skin. Of course light therapies (UVA, UVB and PUVA) have been used to treat psoriasis for many years, but blue light is claimed to be less damaging to the skin and avoids the potential risks associated with long-term UV light treatments. The manufacturers cite two publications as evidence of safety and efficacy - both of which report positive outcomes[1,2]. The underlying mechanisms of blue light are interesting.

In plaque psoriasis (the most common type), cells called keratinocytes proliferate (grow) much faster than usual and have no time to develop properly. This is what causes inflammation and the familiar scaly plaques on the skin. A recent study from a group in the Netherlands showed that blue light works by reducing the rate of proliferation of keratinocytes[3]. In other words, it helps the skin to regenerate at a normal speed – thus reducing redness and inflammation.

Another study compared the cost-effectiveness of blue-light therapy with a two-compound formulation (TCF) called Dovobet [calcipotriol + betamethasone]) in mild to moderate psoriasis. Subjects were randomised to receive either 12 weeks of blue-light therapy or the TCF. At the end of the treatment period there was no significant difference in PASI reduction between the two treatments (71 vs 72%), though the blue-light treatment was significantly less costly[4].

Whilst more research is needed, blue-light treatment appears to be a safe and effective treatment for mild moderate plaque psoriasis.

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New psoriasis drugs

The National Institute for Health and Care Excellence (NICE) has recommended ixekizumab as an option for treating plaque psoriasis in adults.

Ixekizumab is a biologic medicine for the systemic treatment of psoriasis. It is a humanised monoclonal antibody designed to selectively bind to and inhibit interleukin 17A (IL-17A), a pro-inflammatory cytokine, to offering another option for treating psoriasis in the clinical treatment pathway.

The Scottish Medicines Consortium (SMC) has also accepted ixekizumab for restricted use within NHS Scotland for moderate to severe plaque psoriasis in adults who are candidates for systemic therapy.

Under the acceptance, the treatment will be restricted to patients who have failed to respond to standard systemic therapies (including ciclosporin, methotrexate and phototherapy), are intolerant to, or have a contraindication to these treatments.

In trials, ixekizumab was superior to placebo and to a tumour necrosis factor (TNF) antagonist for improving symptoms of adults with moderate to severe plaque psoriasis.

This SMC advice takes account of the benefits of a Patient Access Scheme (PAS) that improves the cost-effectiveness of ixekizumab. This advice is contingent upon the continuing availability of the PAS in NHS Scotland or a list price that is equivalent or lower.

The recommended dose of ixekizumab is 160mg by subcutaneous (SC) injection (two 80mg injections) at Week 0, followed by 80mg (one injection) at Weeks 2, 4, 6, 8, 10, and 12, then maintenance dosing of 80mg (one injection) every four weeks.

To learn more, visit the NICE and SMC websites:
www.nice.org.uk/guidance/ta442
www.scottishmedicines.org.uk

Clinical trials are an essential part of medical research. They help to develop better treatments, which improve healthcare for adults and children. This can lead to real breakthroughs that save lives and improve quality of life.

The National Institute for Health Research's (NIHR) campaign, called I Am Research, gives patients, the public and health and social care research professionals a chance to shout about how fantastic research is. The aim is to raise awareness of the benefits of research and the positive impact it has on people's lives.

Every year, more than half a million people help the NHS improve healthcare and develop life-saving treatments by taking part in health research. This research drives new and better treatments and though there's not always a research study to suit everyone, there are other ways to be involved or stay in touch.

By taking part in a clinical trial, you may feel that you are taking an active role in your healthcare. This may benefit you. On some clinical trials your condition may be monitored more regularly than with standard care.

Taking part in a trial is just one way you can get involved, but there are other ways you can also contribute.

You could:

- **help select research that is important and relevant**
- **help researchers design their projects**
- **help develop understandable information sheets for people taking part in research**
- **join a research management or advisory group**
- **train to carry out some research**
- **help interpret the results of research**
- **help make sure the research is reported in understandable ways**
- **help make sure good research is heard about**
- **help to decide which research should be funded.**

To find out how to help, you can visit the UK Clinical Trials Gateway (UKCTG): www.ukctg.nihr.ac.uk

I AM RESEARCH

Be part of the solution

The UKCTG is there to help you make informed choices about clinical trials. It offers useful guidance on how trials work and helps connect you to researchers running trials you might be interested in.

Remember, it's also OK to ask your doctor, nurse or healthcare professional about research opportunities available to you.

OK TO ask about clinical research

About the NIHR

The National Institute for Health Research (NIHR): improving the health and wealth of the nation through research. Established by the Department of Health, the NIHR:

- funds high-quality research to improve health
- trains and supports health researchers
- provides world-class research facilities
- works with the life sciences industry and charities to benefit all
- involves patients and the public at every step.

For further information, visit the NIHR website: www.nihr.ac.uk

We need your help

As part of The Information Standard scheme we have developed a patient user group to review all written material. We are grateful to those members of PAPAA who have already agreed to carry out this role.

If you would like to get involved in reviewing our material then please get in touch.

For more information about the role and specification contact: Caroline Marven on 01923 672837 or email cjm@papaa.org

Raising awareness takes many forms and a way in which PAPAA does this is to provide support and awareness of the needs of people with psoriasis and psoriatic arthritis amongst healthcare professionals. We achieve this by having awareness stands at events and conferences that healthcare professionals are likely to attend. In particular, we try to raise awareness with primary care healthcare professionals, as we believe this is an area where awareness is in great need.

In May, we attended for the fourth year the Primary Care and Public Health conference at the National Exhibition Centre (NEC) in Birmingham, which is an extremely popular event. Those attending the event included nurses, GPs, healthcare assistants, podiatrists, midwives, dieticians, chiropodists, physiotherapists, school nurses and health visitors. These front-line healthcare professionals attend such events to increase their knowledge and to support their continuing medical education (CME).

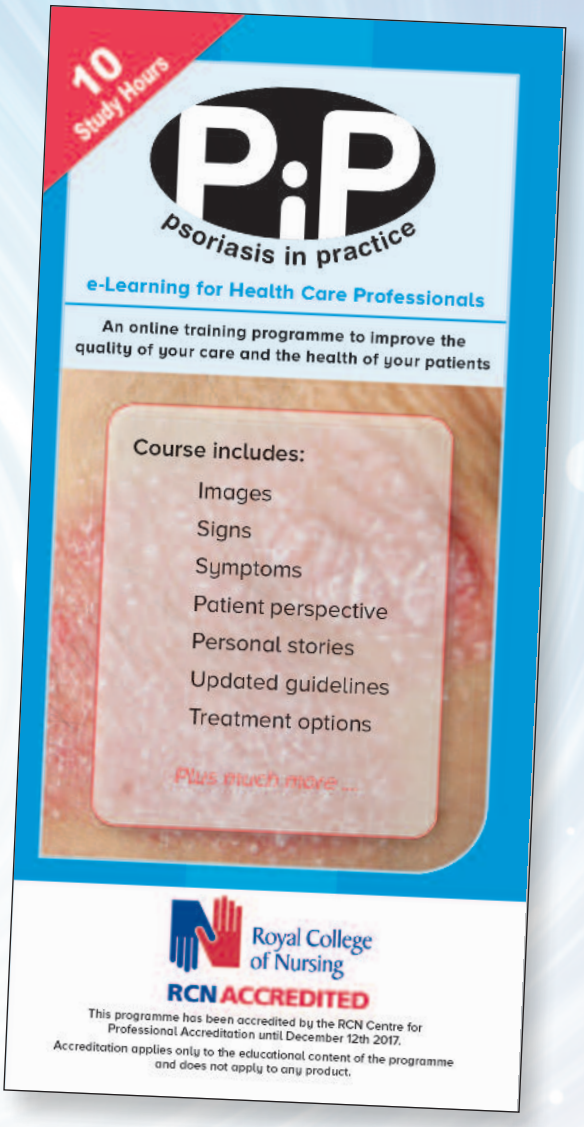
CME or continuing professional development (CPD) are requirements that professionals need to complete in order to continue to be registered to practice. Each governing body sets it own rules and will have differing levels that need to be adhered to. For example, the Nursing and Midwifery Council (NMC) requires those on its register to revalidate every three years, with a mixture of different types of learning and reflective activities, to include 35 hours of CPD, 20 hours of participatory learning, which has to be relevant to their scope of practice.

For a GP the requirement is different; whereas a nurse needs a specific number of study hours, a GP's activities have to be appropriate to their specific practice, and will be different for each doctor. The doctor assesses their own needs and addresses them appropriately to reflect how they fulfil their professional duty to keep their knowledge and skills up to date throughout their working lives. This approach makes revalidation less of a 'tick box' approach and a more meaningful activity, where learning, expanding and gaining knowledge is a more appropriate revalidation method.

Ultimately, for all healthcare professionals, clinical practice is seen as a process of learning and increasing knowledge and reinforcing what patients want from a healthcare service in the 21st century.

As a patient-centred charity, we acknowledge these differing needs and therefore have developed ways to support healthcare professionals that not only supports their CPD needs but also provides support to people with psoriasis and psoriatic arthritis. Attending such events provides us with the opportunity to raise awareness amongst this group, provide support to their patients and understand how

we can help professionals develop their knowledge. They also help us, as at a previous event and following feedback, we produced The Psoriatic Foot leaflet, as this was identified as an area of unmet need by those who attended.



At the NEC meeting, we promoted our Psoriasis in Practice course, which is an online distance learning programme providing 10 Royal College of Nursing study hours. The course covers all the topics which might arise in primary care and provides up-to-date data on treatments and when to refer. The course, which has been available for 4 years, has proven to be very popular.

We also promoted our information distribution service, where we provide our patient leaflets and awareness material in bulk for display and distribution via clinics. This is also a very popular service and if you see our material in your local clinic, it will be because a healthcare provider has made the effort to get the information from us to display.

Glossary:

Primary care is healthcare provided in the community for people making an initial approach to a medical practitioner or clinic for advice or treatment. It is usually delivered by a General Practitioner (GP) or a group of healthcare professionals.

Secondary care services are usually based in a hospital or clinic as opposed to being in the community and patients are usually referred to secondary care by a primary care provider such as a GP.

Older doctors linked to higher death rates

Patients in US hospitals treated by older doctors have higher mortality than patients cared for by younger doctors, except those doctors treating high volumes of patients, finds a study recently published in the British Medical Journal (BMJ).

If the results are causal, they suggest that for every 77 patients treated by doctors aged 60 or older, one fewer patient would die within 30 days of admission if those patients were cared for by physicians aged under 40.

However, the researchers stress that their findings should be regarded as exploratory.

Clinical skills and knowledge accumulated by more experienced doctors can lead to improved quality of care. It is possible, however, that doctors' skills may become outdated as scientific knowledge, technology, and clinical guidelines evolve.

Whether quality of care differs between younger and older doctors remains largely unknown, so a team led by Yusuke Tsugawa at Harvard T H Chan School of Public Health in Boston set out to investigate whether outcomes of patients who were admitted to hospital differ between those treated by younger and older doctors.

They analysed 30-day mortality, readmissions and costs of care for a random sample of 736,537 elderly Medicare patients (aged 65 or older) managed by 18,854 hospital doctors (average age 41) at US acute care hospitals from 2011 to 2014.

Patients were assigned a doctor based on scheduled work shifts and patients' characteristics were similar across doctor ages.

After adjusting for patient, doctor and hospital characteristics that could have affected the results, patients' 30-day mortality rates were 10.8% for doctors aged under 40, 11.1% for doctors aged 40-49, 11.3% for doctors aged 50-59, and 12.1% for doctors aged 60 or older.

Among physicians with a high volume of patients, however, there was no association between doctor age and patient mortality, suggesting that high volumes could be "protective" of clinical skills, say the authors.

Readmissions did not vary with doctor age, while costs of care were slightly higher among older doctors. And similar patterns were observed after further analyses to test the strength of the results.

The researchers say this is an observational study, so no firm conclusions can be drawn about cause and effect, and state that some limitations could have introduced bias.

Nevertheless, they conclude that "within the same hospital, patients treated by older doctors had higher mortality than patients cared for by younger doctors, except those doctors treating high volumes of patients."

In a linked editorial, researchers at the University of Pennsylvania ask what the options are for ensuring, that quality and safety of care is optimised for patients.

They point out that patient outcomes research "is providing much needed evidence to inform clinical practice, educational innovation, organisational redesign, and healthcare policy."

The challenge, they say, "is to integrate findings across multiple studies within an overarching framework of health system responsibility, as recommended by the Institute of Medicine, which holds promise of safe care and good patient outcomes despite diversity of performance by individuals."

Editor's comment: This is a report from North America and given the differences in healthcare delivery and need for continuing medical education (CME) in the UK, this study may not be reflective of UK patient experience. If you do have comments or have experienced such instances as outlined in the this study, please let us know.

Reference:

Research: Physician age and outcomes in elderly patients in hospital in the US: observational study http://www.bmj.com/content/357/bmj.j1797

Source:
BMJ press office

A new study led by the University of Glasgow reports on key barriers and facilitators to implementing a digital health* programme – and provides recommendations to move the field forward.

The study, published in the Journal of Medical Internet Research, suggests that while there are many challenges, these are not "insurmountable". The authors write that the current UK healthcare system, as well as the wider population and market, are not entirely ready for a wide-scale digital health programme or digital health platforms.

Alongside revealing barriers and facilitators, the authors of the study also reveal their ten key recommendations to aid and accelerate uptake in the digital health field.

Digital health programmes include apps, personal health records, telehealth and wearable activity trackers.

The researchers found that while there is receptiveness to digital health, key barriers remain at every level: market and policy level, organisational level and within the general professional and public population, but intensive engagement, clinical endorsement and upskilling efforts can prove beneficial.

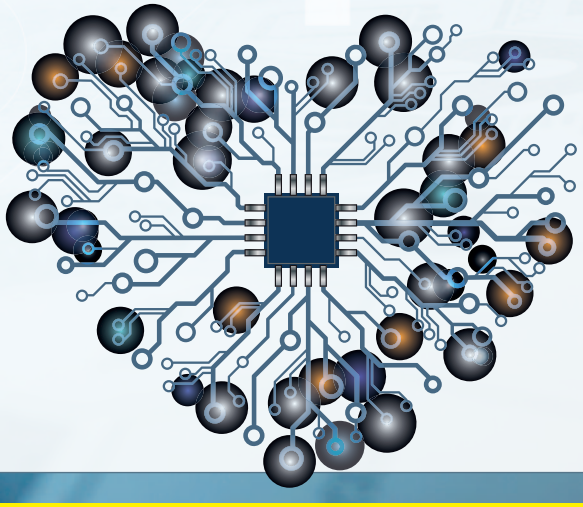
Factors hindering implementation included a lack of IT infrastructure (including universal broadband); uncertainty around information governance; and trust in the security of digital health platforms.

The commercial market was perceived as difficult to navigate, with concerns over accountability and liability voiced from within the commercial sector.

The authors' recommendations include further commitment and investment in digital healthcare at a national and local level, and support for those who are not digitally fluent. The researchers also suggest training the next generation of health professionals to make them more digitally able and upgrading the technical capabilities of the health service.

The study lead, Professor Frances Mair, professor of primary care research from the College of Medical, Veterinary and Life Sciences, said:

"Given the current self-care agenda, the drive towards more personalised medicine and person-centred digital health solutions, this study is timely and has the opportunity to make an important contribution to understanding the implementation of digital health innovations."



The study, which was conducted in collaboration with researchers from the University of Strathclyde and Newcastle University, evaluated the £37m digital health programme Delivering Assisted Living Lifestyles at Scale (dallas) between 2012 and 2015.

The dallas programme aimed to develop and implement a range of digital health products to enable self-care and preventative care. To understand the barriers and hurdles faced during the programme, the researchers interviewed people involved and examined a vast quantity of documentary evidence over the course of the three-year project.

Researchers took care to include representatives from all the types of organisations involved, including private, public and voluntary, along with persons from all levels of the project from management to those delivering it to patients. There were also focus groups held with digital health users, including patients and health professionals, to gain their insight.

Dr Marilyn Lennon, first author, from the University of Strathclyde's Department of Computer & Information Sciences, and co-lead of the study, said: "Digital health is a huge market with the potential to make a massive impact on society, but making it a part of routine care delivery has been much slower than expected.

"This is not due to any lack of technical innovation, but to uncertainty over the role of technology in delivering care. There's also uncertainty about managing and using health data - many people go online to do banking or to use social media but seem wary about doing the same for health. Sharing this data with doctors or friends and family for example could avoid GP visits or prolonged stays in hospital.

"Our research responds to calls for exploration of current barriers to the wide-scale adoption of digital health, and offers recommendations that could help to realise its full potential."

The dallas programme was funded by Innovate UK, the National Institute for Health Research, the Scottish government, Scottish Enterprise and Highlands and Islands Enterprise.

The paper, Readiness for Delivering Digital Health at Scale: Lessons From a Longitudinal Qualitative Evaluation of a National Digital Health Innovation programme in the United Kingdom, is published in the Journal of Medical Internet Research.

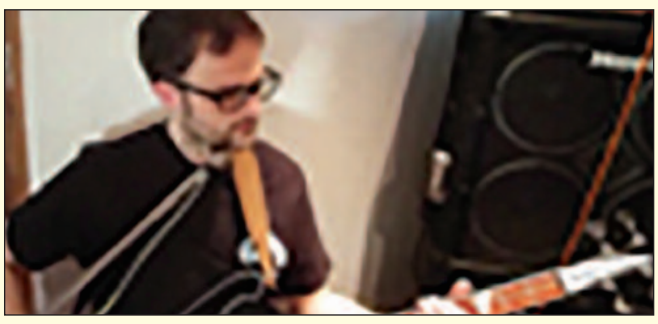
*Digital health is the convergence of digital and genomic technologies with health, healthcare, living and society to enhance the efficiency of healthcare delivery and make medicines more personalised and precise.

The study was funded by Innovate UK (UK's innovation agency): www.gov.uk/government/organisations/innovate-uk

Remap is a unique national charity that brings together two sets of people: volunteers who are skilled at making things, and people with a disability who could be helped by a piece of specialist equipment. The result each year is over 3,500 pieces of custom-made equipment which help transform the lives of disabled people and their carers.

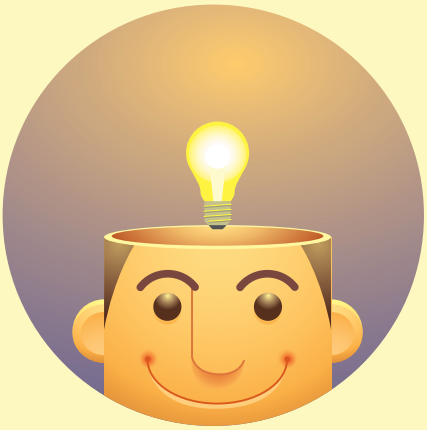
Summer is a five-year-old girl who wanted more independence at school when getting her dinner; she wanted to take her own meal to the table but as she uses a walking frame this was difficult. Remap devised a way to attach a melamine tray to her walking frame using clips. You'll notice the tray is decorated with a picture of her favourite pet – a cat!

Thankfully, disabled people can usually buy equipment to help overcome some common problems, but often a 'made to measure' solution is required. This is where Remap's army of ingenious inventors comes in. They design and make equipment and gadgets for young or old alike and these are then provided free of charge. The aim is always to help people achieve independence and quality of life, filling the gap where no suitable equipment is available commercially.



Bass guitarist Ben wanted to use effects pedals with his guitar, but his multiple sclerosis prevents him using the foot switches. Remap has devised a clever system to enable Ben to operate the pedals with a 'sip and puff' switch. Simply blowing a puff of air into the straw turns on the effects for that distorted bass sound he sometimes wants.

Not only do inventions like this give much needed independence to the people Remap helps, they also provide carers with respite and an opportunity to focus on other things.



Do you know someone that could be helped by Remap?
For more details visit the website www.remap.org.uk or contact the central office on 01732 760209.
We would be delighted to help you!

Source:
David Martin
Network Development Manager, Remap

New research has highlighted the potential gender gap in stress, with women reporting higher stress from life events such as death of a loved one, illness, losing their smartphone and Brexit.

The study, based on YouGov research commissioned by The Physiological Society, asked more than 2000 people to rate how stressful they found key life events – and for every event, women were more stressed than men. The biggest difference was in the stress caused by the threat of terrorism and the smallest for the arrival of the first child.

The study builds on the famous stress work of Holmes and Rahe in 1967 to determine how different life events affect people.

Key findings from the study included:

Geographic variations: The most stressed area was Scotland, while the least stressed was the South East of England. The East of England was notably upset by delays in their commutes, while Londoners were most sanguine about going on holiday.

The results for some events point towards stress levels increasing with age, most strongly for long-term problems such as illness or imprisonment. Exceptions to this trend were the loss of a smartphone, which fits with the added difficulties this would cause to highly-connected younger generations, and the arrival of a first child. This was rated highest by those aged 25-34, who are likely to be the group experiencing this most recently.

Brexit had the greatest variety of responses given, with the 18-24 age group most likely to be stressed by it. Those living in London and Scotland are also more stressed by Brexit than those from Wales and much of the rest of England. Most markedly, those respondents educated to higher degree level reported considerably greater stress from Brexit than people with only GCSEs or A-Levels.

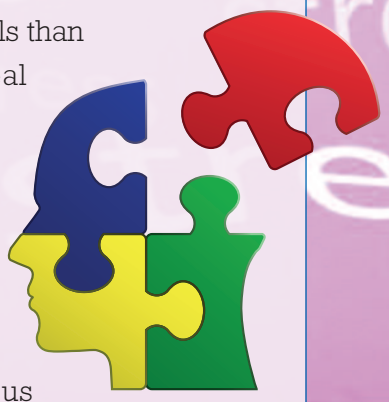
The Physiological Society is using the study to raise awareness of the effect of stress on the body's function. During stress, the body prepares for action by releasing hormones into the blood stream, which affects the heart as well as digestive and immune systems. Frequent and prolonged stress can cause long-term physiological problems in the body. With women more likely to report feeling stressed than men, this could have a very real impact on their health.

This is part of The Physiological Society's year-long theme Making Sense of Stress, which includes public lectures and seminars.

Commenting on the study, Dr Lucy Donaldson, chair of the physiological society's policy committee, said:

''The modern world brings with it stresses we would not have imagined 50 years ago, such as social media and smartphones.

''It was striking that for every single event in this study, from money problems to Brexit, women reported greater stress levels than men. This could have a real impact on women's health.



''While many people are aware of the effect of stress on mental wellbeing, it is also important to consider the impact on the body's systems. Your brain, nervous and hormonal systems react to

stress and it affects your heart, immune system and gastrointestinal system. When stress is prolonged, these effects on the whole body can result in illnesses such as ulcers or increased risk of heart attack.''

About The Physiological Society

The organisation brings together more than 3,500 scientists from over 60 countries. Since its foundation in 1876, its members have made significant contributions to the knowledge of biological systems and the treatment of disease.

They promote physiology and support those working in the field by organising world-class scientific meetings, offering grants for research, collaboration and international travel, and by publishing the latest developments in our leading scientific journals, The Journal of Physiology, Experimental Physiology and Physiological Reports.

The society also runs events for the general public on how physiology relates to everyday life, and for students who may be considering physiology as a career.

Read the full report at www.physoc.org

Source:
The Physiological Society

PAPAA self-help

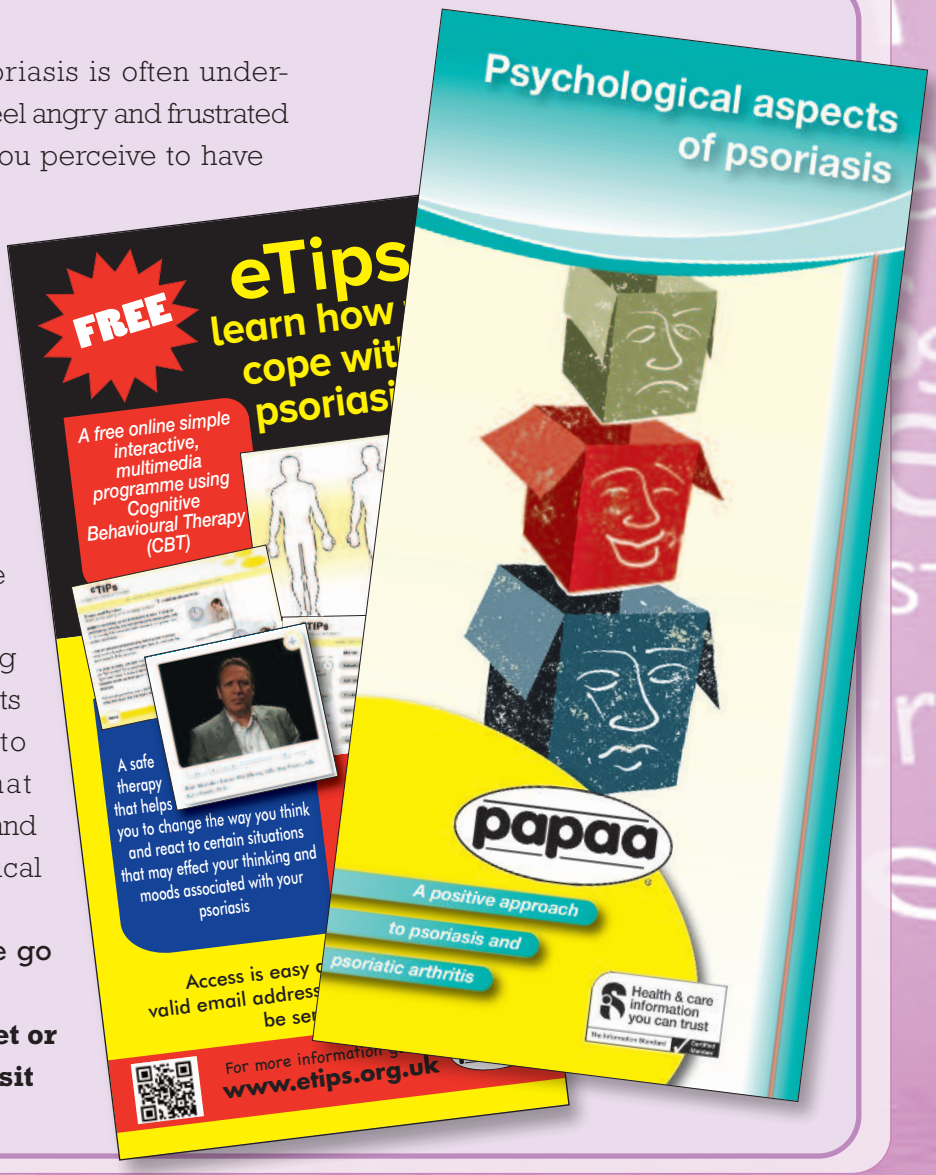
The psychological impact of psoriasis is often under-estimated; it is perfectly normal to feel angry and frustrated about having a condition which you perceive to have blighted your life. Understanding these feelings and learning how to manage negative thoughts can help.

PAPAA has a training programme called eTIPs (electronic Targeted Intervention for Psoriasis) which has been specifically designed to help individuals understand and change these negative thought patterns.

There is also an accompanying booklet called Psychological aspects of psoriasis. The booklet aims to describe the different ways that psoriasis may make you feel, think and behave. It also offers some practical advice to help you manage this.

To access the etips programme go to www.etips.org.uk

To get a FREE copy of the leaflet or to download a digital copy visit www.psoriasis-shop.org



Transport for London (TfL) announced earlier this year that a blue badge for those less able to stand on public transport will be introduced on a permanent basis in spring next year.

The 'Please offer me a seat' badge and accompanying card were trialled last year to help those who need a seat, but have difficulty getting one.

The six-week trial was in response to passenger feedback and TfL research, which found that those with hidden disabilities and conditions, or those undergoing treatments, can often find it difficult to get a seat when they need one.

Easier journeys

More than 1,200 people tested the new badges, which are similar to the popular Baby on Board badges.

During the trial, 72% of journeys were said to be easier as a result of the badge, in 86% of journeys participants reported feeling more confident when asking for a seat and 98% said they would recommend the badge and card to somebody who requires or would benefit from it.

When it is launched, TfL will become the first European transport provider to officially recognise invisible impairments and conditions in such a way.

Innovative trial

The mayor of London, Sadiq Khan, said: "I'm proud that Londoners embraced this innovative trial and that Londoners wearing the badges found travelling around our capital easier as a result.

"It's great news that next year we will be able to offer them to all those with hidden disabilities and conditions, and I'm really looking forward to the blue badges becoming as recognisable on public transport as our hugely successful Baby on Board ones."

Members of the public have been developing their own solutions to the problem, such as a 'cancer on board' badge. Its creator, James McNaught, took part in the TfL trial.

James McNaught said: "Getting a seat on transport when you need it can sometimes be really tricky, especially if the reason you need to sit down isn't obvious to others.

"When I was undergoing radiotherapy for throat cancer, it meant I couldn't talk to ask for a seat and the morphine I was taking made me appear drunk. It was a real struggle to get people to understand why I needed to sit down.

"I'm really pleased TfL completed this trial. A badge and card will help make a real difference to the lives of people undergoing drug treatment or with longer-term conditions or disabilities."

Constantly improve

Alan Benson, chair of Transport for All, said: "Transport for All are pleased to hear the Please offer me a seat trial was successful and TfL and the mayor will be launching it next year.

"While this will help many customers, there will be those who don't want to use a badge and card. We want to see those people supported too, and for everyone to get a seat who needs one."

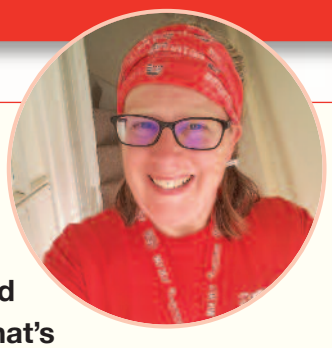
Mike Brown MVO, London's transport commissioner, said: "This trial has made a real difference to people with invisible impairments, conditions and injuries who find it difficult to get a seat when they need one.

"It is part of our commitment to constantly improve the network for all our customers and we will launch the badge and card permanently next spring, once a thorough review of the findings of the trial is complete."

'Please offer me a seat; packs can be sent to any address in the Greater London area, and South East England. You can order one by filling out the form at

tfl.gov.uk/transport-accessibility/please-offer-me-a-seat or by calling TfL Customer Services on 0343 222 1234.

Source:
Transport for London



If you had said to me that I would undertake the phenomenal challenge of walking 100km, I would have laughed so hard, and have thought you were crazy! But that's exactly what I did on a blistering hot bank holiday weekend: I joined a couple of thousand mad adventurers and walked the 62.3 miles from London to Brighton.

To say it was tough is a complete understatement, words cannot describe the experience, but the feelings of relief and jubilation when I saw the flags at Brighton racecourse was the most beautiful sight, and the most emotional and overwhelming feeling. Finishing totally exhausted both mentally and physically 25 hours 19 minutes and 59 seconds after starting – so incredible.

I'm just so honoured to have taken part in this challenge, and to walk for PAPAA. My beautiful mum Moira suffered for about 30 years with psoriasis that covered most of her body, and at times was incredibly painful, yet despite this she always remained cheerful and smiled through. To walk in her memory, raising money for PAPAA, although an emotional experience, has been one I have been proud to have been a part of.

The support and encouragement I've had has been so amazing and the messages en route kept me going even in the darkest times when I almost gave up.

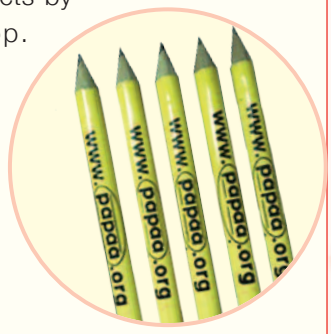
I'm not sure if I would take part in this challenge again, but who knows, once the feet have recovered, anything is possible!

Report by Clare Phillips about her London to Brighton challenge on 27 May 2017 to 28 May 2017.

Thank you, Clare, for your effort and support. The funds you have raised are much appreciated and you deserve to feel proud of your achievement.

Merchandise

If you want to show your support of PAPAA, we have lots of PAPAA psoriasis and psoriatic arthritis awareness related merchandise, which you can order from our shop. Below are some of the current items we have available: view the full range of merchandise and other products by visiting our psoriasis shop. **www.psoriasis-shop.org**



Do you have a computer or smartphone? Do you want to share your experiences?

Visit the PAPAA Facebook page and read what other people are talking about. You can access the PAPAA page by clicking the link from our website home page.

To-date, people have been discussing tiredness, diet and disability claims, amongst other topics.

We post interesting news items and links to fuller articles on our website: www.facebook.com/papaa.org

We also have a Twitter page linked to our Facebook page so if you prefer the micro-blogging site you can follow us by clicking the link, which is also located on our home page: www.twitter.com/PsoriasisInfo

Follow us on Facebook

In recent reports, the NHS has been criticised for not delivering the care and service people need and require. Lack of GP access, poor social care availability and even patients are being blamed for being too demanding.

We decided to see what people with psoriasis and psoriatic arthritis thought via a online survey.

We asked a simple question:

Tell us your experiences about the good the bad and the ugly and what you have encountered, or anything that you feel needs to be said about the UK health service.

"I see things from both sides of the fence as I work in the NHS and I am a patient. Yes, the waiting time for appointments is far too long, however there is also a serious abuse of the NHS because it is free to the end user. Don't get me wrong – I do not support privatisation but I do believe some people need to think, do they really need the appointment or an ambulance? If not, leave it for someone who really does."

"I think GPs are lazy; they do a clinic for about 2 hours in the morning, 2 hours pm and 1 hour evening, the rest of their time is spent either doing CCG [Clinical Commissioning Group] work or going on a golf course. My GP has a 4-week wait for an appointment. I have adrenal problems plus am very disabled with spinal damage following an accident, very asthmatic etc. To get their extra money for diabetics etc you have to have blood tests on your birthday or you will get nasty letters. When you call the surgery the first thing is a message saying if you feel you need urgent care go to A&E. This is causing A&E departments a lot of extra work, which the GP should be doing. After all, to make a mother wait 3-4 weeks because the child is unwell is not on."

"If I call for an appointment about my psoriasis this is not considered important so I have to wait. My consultant has just put me on Otezla pills due to not getting enough steroid creams, plus my last GP script had a note saying this was very expensive – Dovobet cream and gives me one tube. I am covered in psoriasis head to toe one tube doesn't last at all."

"My view is that GPs hold out far too long before referring to a dermatologist. I have steroid damage on my legs and arms which led me to an eating disorder. I thought fat people have stretch marks ... not realising that the steroids caused it. My GP prescribed salicylic acid for 9 years on a repeat prescription. He never told me about my condition and what caused it. I felt left to get on with it. I've been on a pathway of tablets that haven't worked and now due to start Cosentyx. The specialist I see now is fantastic but it's taken 30 years to get to this."

"I was a rheumatology specialist nurse for 15 years until I had to retire a year ago for health reasons. The care I was able to give as a specialist nurse had deteriorated due to management pressure, increased NICE guidance, lack of finances, patient numbers (treatments are more effective than previously and outpatient numbers increase all the time) and reduced autonomy. My job satisfaction had deteriorated and stress levels were unbearable, which affected my health."

"Better communication & integration of rheumatology & dermatology clinics. The disarray I have encountered recently is wasting everybody's time and is a poor use of resources. I came across a serious problem that dermatology had a longer flush-out period for biologics than rheumatology – totally bonkers! Trying to arrange appointments around work is difficult and stressful, especially as the dermatology unit has moved to another hospital and I have to allow over an hour to get there by bus. There has to be a more efficient way of treating PsA. I know some hospitals have combined clinics; this was tried in my area but it didn't work!"

If you have ANY thoughts or wish to respond to the questions or points raised, have your say online at **http://www.papaa.org/your-views or write to us at PAPAA via the contact details on page 2.**

Marketplace

New

Psoriatic, lifestyle and nutrition

For many people who develop psoriasis and psoriatic arthritis, a question they often ask is "Is the food I eat the cause of my condition and can I change my diet to improve things? As with many issues, it's not as simple as that, which is unfortunate, as it would be an easy solution.

It is true that modern lifestyles of eating and drinking in excess and our lack of exercise is contributing to many health problems people have in the 21st century. The increase in obesity, type II diabetes and high blood pressure are a consequence of the world we now inhabit. But for psoriasis and psoriatic arthritis the evidence is less clear.

The advice that the NHS wants the public to follow is to eat less and more healthily, move and exercise more; so take in fewer calories and burn off more. The benefits are well-documented, but having a chronic disease, which affects appearance, and movement makes some of these 'simple' pieces of advice virtually impossible.

To help people consider the benefits of how some small changes might lead to a general health gain, and possibly an improvement in the overall conditions, we have produced a booklet called Psoriatic Lifestyle and Nutrition. The information has been written by a leading expert in managing weight and lifestyle, with input from a registered dietician and reviewed by people affected by psoriasis and psoriatic arthritis.

The text provides some advice about developing ways to reduce weight and improve general health, which follows the national recommendation from the NHS.

It is clear that regardless of what other conditions we may have, keeping a healthy weight, eating a balanced diet and exercising more is of benefit and may improve not only general health but other conditions too. To order a FREE copy go to: **www.psoriasis-shop.org**

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

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.