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# FIGHTING BACK AGAINST PSORIASIS

### A Report by the PSO What? Taskforce

The PSO What? Taskforce is a multidisciplinary group representing people living with psoriasis, psoriasis advocacy and professional groups, and healthcare professionals



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The PSO What? initiative is a partnership programme led by the Patients Association and LEO Pharma, in collaboration with the expert PSO What? Taskforce. LEO Pharma has provided core funding, editorial input and undertaken survey-based research to support the development of the PSO What? Report. Job Code: UK/IE/MAT-07179 | Date of Preparation: April 2017

The fear of being rejected as a result of my psoriasis has stopped me from pursuing a relationship. I would prefer to remain single and keep my psoriasis a secret than take the risk of being judged based on my skin."

Nicola, age 49, living with psoriasis since age 7

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## A MESSAGE FROM THE CHIEF EXECUTIVE OF THE PATIENTS ASSOCIATION, KATHERINE MURPHY

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Today in the UK and Ireland, nearly **2 million** people are living with psoriasis,<sup>1,2</sup> a common, serious, lifelong, incurable condition that develops when the immune system attacks and destroys healthy cells in the body (known as an autoimmune disease). Psoriasis often places a severe burden on individuals and their families and costs the UK economy over **£1.07 billion** in lost productivity alone.<sup>3</sup> It also represents a significant burden to the health service, with nearly a quarter of the population seeking a GP consultation on skin matters in England and Wales; 5% on psoriasis alone.<sup>4,5</sup> This workload is not balanced by adequate dermatology education for GPs and there is a chronic shortage of dermatologists.<sup>4</sup> This report highlights the necessity to take action now to address the significant unmet need that continues to weigh heavily on the UK and Irish economies and health services, and above all the individuals living with psoriasis and its physical and emotional impact, for many years - sometimes lifelong.

The most obvious physical effects of psoriasis are the painful, itchy, scaly patches or 'plaques' seen on the skin. However, as with any autoimmune disease, people with psoriasis also run the risk of developing potentially lifelimiting physical and psychological associated conditions, known as comorbidities.

From the perspective of patient wellbeing, the most important considerations are:

- Around one in three people with severe psoriasis develops the painful symptoms of psoriatic arthritis;<sup>6,7</sup>
- Younger people with severe psoriasis have three times the risk of a heart attack compared to people of their own age without psoriasis;<sup>8</sup>
- And one in ten people with the condition have contemplated suicide.<sup>9</sup>

Living with a physical, chronic autoimmune disease like psoriasis is challenging enough in its own right. Yet, as this report shows all too clearly, there is still a lack of understanding, including among some healthcare professionals, of the significant impact of psoriasis and the distress it causes. Worse still, as a survey commissioned for this PSO What? report reveals, people with psoriasis continue to live with anxiety, embarrassment, loss of confidence and social exclusion.<sup>10</sup>

Over 20 years ago, a survey found that **71%** of people living with severe psoriasis would be prepared to pay **£1000** or more, and **38%** would pay **£10,000**, for a cure for their condition.<sup>11</sup> This was at a time when the average disposable income for UK households was £21,125.<sup>12</sup> Can you imagine the price that they would be willing to pay today?



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## PSO Why Now and What Needs to Change?

In recognition that much needs to change, only as recently as 2014 did the World Health Organisation (WHO) recognise psoriasis as an area of focus and global concern.<sup>7</sup> WHO reports on the public health impact of the condition, the inadequacies in the provision of care and societal stigma experienced by those affected.<sup>7</sup> This is a big step forward globally for psoriasis; what about here, closer to home? As with any long-term condition, people with psoriasis can be – and are – affected for many years or even for life: they ultimately deserve more from our care systems. Right now, our UK and Irish health economies are under overwhelming pressure from a range of longterm health conditions.<sup>13,14</sup> Despite the negative affect psoriasis can have on those affected, it receives little attention and deserves to be viewed in the same way as other long-term conditions. The ongoing individual efforts of the Taskforce and wider psoriasis community to uncover and address unmet needs in psoriasis are much-needed, but together we can do much more.

Now people with psoriasis have decided that it is time to take control and fight back with the facts about the condition. They have joined with psoriasis advocacy and professional groups, and healthcare professionals to form the PSO What? Taskforce, in partnership with The Patients Association and LEO Pharma.

#### Its objectives are to:

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1 Challenge the misconception and stigma that psoriasis is 'just a skin condition', by creating better understanding that it is a chronic autoimmune condition that significantly impacts the lives of those affected and so deserves to be a higher healthcare priority.

2 Support people living with psoriasis and healthcare professionals in working together to agree individual psoriasis management goals. Help patients work towards these goals by optimising treatments and providing holistic care that will address the management of the physical and emotional effects of the condition.

3 Drive the implementation of a regular psoriasis review, at least annually, and more frequently if required, and regular screening for comorbidities.

#### **PSO What? Can You Do?**

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Despite the physical, psychological and emotional consequences that can affect many people, the Taskforce has an ambition to help facilitate positive, realistic and long-standing changes in the management and perception of psoriasis.

The PSO What? Taskforce is now calling on everyone in the UK and Ireland to take the PSO What? Challenge and make a pledge to give confidence to people living with psoriasis and to help improve their health and quality of life. This PSO What? report suggests possible actions you, as someone touched by psoriasis, could take, for example, if you are living with psoriasis, a healthcare professional managing patients with the condition, a healthcare commissioner, policy maker or a member of the general public. In addition, our aim is that you will be inspired to offer your own pledges based on your experience of psoriasis to make a difference in whatever way you can.

As an organisation dedicated to supporting change to promote empowerment, equal access and the best possible experience of care and outcomes for all patients, I ask you to put yourselves in the shoes of a person living with psoriasis. How would you feel?

The Patients Association is proud to support the PSO What? initiative and on behalf of the Taskforce members I would like to thank those people living with psoriasis who have shared their personal stories and spoken out on behalf of others. ( )

So join The Patients Association now and take up the PSO What? Challenge. We can drive change, together.

Yours sincerely,

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Katherine Murphy Chief Executive The Patients Association

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Psoriasis impacts almost every aspect of my life, but I am determined that it should not define me or change the person that I am. Sometimes, other's views or inaction are the greatest challenge."

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Aimee, age 24, living with psoriasis since age 3

# **EXECUTIVE SUMMARY**

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#### **PSO WHAT? IS THE IMPACT OF PSORIASIS?**

Psoriasis is a lifelong, painful, disabling, autoimmune disease that affects nearly **2 million** people, or around **2-3%** of the population of the UK and Ireland collectively.<sup>1,2</sup> Its most visible effects are on the skin: about 80% of people have chronic plaque psoriasis, in which thickened, scaly plaques appear on the surface of the skin, causing scaling, itching, stinging, burning and bleeding.<sup>7,15</sup> The exact cause remains unclear, but like other autoimmune diseases, psoriasis develops when the immune system becomes overactive.<sup>16</sup>

Psoriasis can be diagnosed at any age, although people are most often first diagnosed in one of two peaks: in their late teens and early twenties, and during their fifties.<sup>7</sup> Many people with psoriasis require lifelong care, education and access to holistic resources to give them the confidence to take full control of their condition.

### PSO WHAT? ARE THE COMORBIDITIES OF PSORIASIS?

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Up to **35% of people** suffer not only the severely negative effects of psoriasis on their skin, but also the pain, joint damage and disability that results from psoriatic arthritis.<sup>7</sup> People with psoriasis are also at risk of developing other serious comorbidities (the presence of one or more additional diseases), including cardiovascular disease, inflammatory bowel disease, liver disease, vision problems and some cancers.<sup>7,17-22</sup>

The effects of psoriasis on the skin cause people with the condition to suffer embarrassment, loss of confidence, depression and anxiety; all of which are compounded by myths and misconceptions that lead to stigma, discrimination and social exclusion. The psychological comorbidities of severe psoriasis are at least as significant as those seen in people with other serious diseases and may lead some people to contemplate suicide.<sup>9,23</sup> Consequently, there is a clear need for a holistic approach to the treatment and support of the person as a whole, including the management of their psoriasis and all the associated comorbidities.

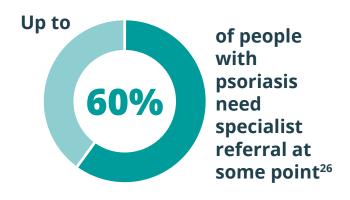
#### **PSO WHAT? IS THE REALITY OF PSORIASIS CARE?**

Effective management of psoriasis depends on a holistic approach to treatment and care to support the needs and preferences of each person and which does

not simply focus on the state of their skin. Given the right access to appropriate treatments and information, most people with psoriasis can be managed effectively in primary care by their GPs, nurses and pharmacists. However, with only a third of people with psoriasis actively seeking such support from their GP, many are living in silence unnecessarily.<sup>24</sup>

Across the UK and Ireland, guidance for healthcare professionals and healthcare commissioners on the frequency and nature of reviews varies widely, leading to potential confusion and inconsistent implementation. For example, guidance from the National Institute for Health and Care Excellence (NICE) recommend that some people with psoriasis should be offered regular reviews to assess the severity and impact of their psoriasis, response to treatment, and to address physical and psychological comorbidities.<sup>25,26</sup> However, this is not what happens in practice.

A survey commissioned for this report shows that some people with psoriasis receive effective care from their GPs, but the experience varies.<sup>10</sup> However, many others are not offered their guideline-recommended regular review(s) or the education, support and information that they need to effectively manage their condition. Nearly a third of them stated they do not visit their GP at least once a year to review their psoriasis.<sup>10</sup> Additional research conducted amongst psoriasis patients shows half of them collected their prescriptions repeatedly without having a review with their GP; 50% continued this 'repeat cycle' for over four years.<sup>27</sup>



In England and Wales, although nearly a quarter of the population seek advice from their GP about a skin condition,<sup>4</sup> people with psoriasis and GPs admit lacking in confidence, knowledge and understanding to share care and manage the condition effectively.<sup>28</sup> Psoriasis is the reason for up to **5%** of all GP dermatology consultations.<sup>4</sup>

In addition, it accounts for up to **11%** of dermatology specialist workload, which compares to up to 50% for skin lesions and 10-12% for cases of eczema.<sup>4</sup> Up to **60%** of people with psoriasis need specialist referral at some point in their lives,<sup>26</sup> but face significant barriers when accessing services because of rising referral rates for skin conditions and not enough numbers of consultant dermatologists compared to other specialties.<sup>4</sup>

In Ireland, around **70%** of people have to pay a GP consultation fee of between  $\in$ 35 (£29) to  $\in$ 55 (£46).<sup>29</sup> However, research shows that more than one in four of that population, when suffering with a health problem during a 12 month period, will not see their GP because of cost.<sup>29</sup> Here it is even more vital that patients can access secondary care services given the financial barriers in the primary setting.

#### DERMATOLOGY TRAINING AND EDUCATION – THE STATUS QUO

An independent report by the King's Fund, commissioned by the British Association of Dermatologists, draws attention to the inadequate management of skincare at both education and training, patient care, and policy levels.<sup>4</sup> The authors state that dermatology represents an important part of the services provided by the NHS: each year, GPs have approximately **13 million** consultations for skin conditions, with 716,830 referrals to secondary care.<sup>4</sup> However, this area of medicine remains poorly understood, and, in comparison to other conditions, receives little attention with commissioning and service provision woefully inadequate.

In the UK, the 40,000 GPs managing this workload have received little dermatology training and education but there are only 650 consultants to advise them, and provide more specialist care.<sup>4</sup> However, GPs will only be equipped to manage psoriasis if they begin their careers in general practice with the knowledge needed to assess, manage and treat their patients. Yet, the provision of dermatology training has historically been poor with no compulsory requirement within undergraduate or postgraduate curricula.<sup>4,30</sup> In some cases, training is less than 5 days,<sup>30</sup> despite a minimum of 2 weeks recommended within the 2006 dermatology curricula, distributed to all medical schools.<sup>30</sup> In Ireland the situation is worse still, with many undergraduates receiving as little as 6 hours' dermatology education (if any) throughout their entire training.<sup>31</sup>

Consultant dermatologist staffing in Ireland is 50% below international best practice and at secondary care level, dermatology has the fourth-longest waiting list with 34,805 patients, and an average waiting time for routine assessment of 12-18 months.<sup>31</sup> Given this lack of investment and resource, nursing and GP training (undergraduate and postgraduate) must be sufficient so that doctors have a basic knowledge of dermatology for common and important diagnoses. Basic nurse and pharmacist training must include dermatology and those specialising in dermatology should have easy

managing this workload **have received little dermatology training** and education but there are only **650 consultants** to advise them, and provide more specialist care.<sup>4</sup>

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#### In some cases, **dermatology training** is less than 5 days,<sup>30</sup> despite a



minimum of 2 weeks recommended within the 2006 dermatology curricula, distributed to all medical schools.<sup>30</sup>

In Ireland the situation is poorer with many undergraduates **receiving as** 

training.31



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little as 6 hours dermatology education (if any) throughout their entire access to post-qualification training. This can widen the pool of clinicians with some dermatology expertise and facilitate earlier diagnosis and treatment.

It is therefore essential to address the current lack of training and formal assessment of practical dermatology skills that exist in the current medical school curricula.<sup>32</sup>

The PSO What? Taskforce believes that the continuing variations in standards of psoriasis care are unacceptable and contravene the responsibility of healthcare commissioners to eliminate unlawful discrimination, advance equality of opportunity and reduce health inequalities.<sup>26</sup>

In Ireland similar variations in standards of care exist due to inequality of access and lack of publicly funded consultant dermatologist posts.<sup>29,31</sup>

#### THE PSO WHAT? TASKFORCE AND CHARTER

The PSO What? Taskforce is a multidisciplinary group representing people living with psoriasis, psoriasis advocacy and professional groups, and healthcare professionals. It was convened to address concerns about quality of care that impact people living with psoriasis by formulating solutions to tackle the problems.

The PSO What? Charter has been issued as a result and includes calls to action that everyone touched by psoriasis can take to help improve the physical and emotional wellbeing of those living with the condition.

#### The Charter sets out the following aims:

1 Challenge the misconception and stigma that psoriasis is 'just a skin disease', by creating better understanding that it is a chronic autoimmune condition that significantly impacts the lives of those affected and so deserves to be a higher healthcare priority.

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- 2 Support people living with psoriasis and healthcare professionals in working together to agree individual psoriasis management goals. Help patients work towards these goals by optimising treatments and providing holistic care that will address the management of the physical and emotional effects of the condition.
- **I** Drive the implementation of regular psoriasis reviews, at least annually, and more frequently if required, and regular screening for comorbidities.

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"The increased demand for dermatology is not being matched by the number of trainees entering the specialty, with around 180 unfilled Consultant Dermatologist positions, out of a total of 830 positions. That means one in five Consultant posts are empty.

The workforce problem is exacerbated by the under-provision of dermatology training amongst GPs. Only 20% of GP vocational training schemes contain any dermatological component. Training, when it is provided, is on average limited to a mere six days during the whole of their time as undergraduate students and in postgraduate GP training. Newly appointed GPs therefore have little experience of dermatological problems. It is a serious concern that there appears to be an 'inverse training law' in operation in dermatology, whereby in the area which is most routinely seen by GPs, the amount of training is the least.

Psoriasis can affect people very differently, but patients can live full and happy lives. It is important that medical professionals who are treating psoriasis are adequately trained and offer a full service (including the exploration of how each patient's condition is affecting both their mental and physical health, and the regular review of the effectiveness of treatments) if they are to contribute towards their patients' successful management of their conditions."

#### The British Association of Dermatologists

#### PURPOSE OF THE PSO WHAT? TASKFORCE

Against a continued background of social stigma, inadequate care and not least, the physical and emotional consequences of living with psoriasis, the PSO What? Taskforce is challenging this status quo. They question why, despite the clear unmet needs and the WHO recognising psoriasis as an area of focus in 2014 and the advent of new treatment options, has nothing significant changed on a practical level in the UK and Ireland in the past

decade? We must now act collectively to change and improve the perception of psoriasis and how it is managed so we can ultimately enhance the lives of those living with this life-long condition.

Recognising that all parties need to collaborate, we are primarily targeting people living with psoriasis, the clinicians who treat them, as well as society and the employers - who often unintentionally judge them.



The general lack of understanding about psoriasis is shocking. It is often viewed as 'just' a skin condition, with the mental and physical elements being ignored. The visual representation of psoriasis can be so damaging for those living with it, not only painful and uncomfortable but also with public perception. Many are misinformed on what psoriasis is and therefore jump to conclusions from appearance that it is contagious, disgusting and unsightly. On one occasion I was stopped and questioned about my skin by a desk clerk before boarding a flight. He claimed it was a "health and safety" issue and it was clear the airline staff thought I was contagious.

This sort of treatment is humiliating and only goes further to stigmatise people with skin conditions. Having reports and further research will help put psoriasis on the Health Agenda and enable those living with it to live well with it."

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Holly Dillon, age 27, living with psoriasis since age 14

### **PSO WHAT? NEEDS TO CHANGE?**

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#### **Reduce Stigma**

We must fight stigma with the facts to give people with psoriasis the **confidence** 



to speak openly to their healthcare professionals and others about how their

**condition** impacts their daily lives and to seek the support that they need.

#### Promote Understanding and Recognition

Psoriasis must be recognised as a serious, lifelong autoimmune condition with a severe impact on quality of life and health. Each person with psoriasis must have **access to an assessment**,



meaningful information, holistic support and the treatment that they need to control their condition as they wish.

#### Increase Awareness and Improve Proactive Management of Comorbidities (Related Health Conditions)

People with psoriasis and their healthcare professionals must be

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made aware of the risk of other serious, potentially life-threatening comorbidities

to ensure access to advice and effective of their condition to redu

management of their condition to reduce these risks.

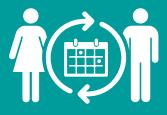
#### Understand the Psychological Impact



We must recognise the severe impact of **psychological comorbidities or related health conditions** and

ensure that people with psoriasis are offered support to maintain their mental health.

#### **Improve Standards of Care**



### Everyone with psoriasis must be offered at least an annual

**review,** or more frequently if required, so that they receive personalised, effective treatment, meaningful information and care plans.

#### Offer Holistic Care and Management

Everyone with psoriasis must be **offered** holistic support, including



information about upto-date treatments that they have been prescribed as well as psychological support ۲

and social care services, to equip them with the confidence, knowledge and resources to take control of and better manage their condition and emotional wellbeing.

For simple actions we can all take to change the lives of those living with psoriasis, turn to page 29 of this report.

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Some nights my psoriasis is so itchy that it keeps me awake as I am constantly scratching, which causes my skin to bleed. The next day I am so tired that I often find it hard to function!"

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Jacqueline, age 42, living with psoriasis since age 8

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## **PSO WHAT? IS THE IMPACT OF PSORIASIS?**

Psoriasis is a lifelong, serious, disabling autoimmune condition that currently has no cure. Its negative impacts on the physical and psychological health and quality of life of people with psoriasis often continue to be compounded by a lack of public understanding, stigmatisation and exclusion.

Psoriasis affects around 2-3% of the population, or nearly **2 million** people, in the UK and Ireland.<sup>1,2</sup> About **80%** of these individuals have chronic plaque psoriasis, which means that they will likely have to live with the condition for many decades.<sup>15</sup> It is characterised by thickened, red, scaly patches or 'plaques', which are formed from the build-up of skin cells on the surface of the skin and which cause itching, pain, stinging, burning, and bleeding. Plaques most commonly occur on the elbows, lower back, navel and knees, but can appear on any part of the body, including the nails, scalp, genitals and skin folds.<sup>7</sup>



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It is important to support people at all stages of their journey

with psoriasis. As it is a chronic condition, someone diagnosed as a teenager could have to live with the challenges of the condition for 50-60+ years."

Julie Van Onselen, Dermatology Education Specialist and Independent Nurse, Dermatology Education Partnership Ltd, Oxford The precise cause of psoriasis remains unclear, but like other autoimmune diseases it occurs when the immune system attacks and destroys healthy cells. It is thought that immune system T-cells (which normally attack foreign substances like bacteria or viruses that could harm the body) become overactive, speeding up normal cell replacement and leading to build-up of plaques on the surface of the skin.<sup>16</sup> Psoriasis can be diagnosed at any age, although people are most often first diagnosed in one of two peaks: either in their late teens and early twenties, or in their fifties.<sup>7</sup> Other family members may be affected,<sup>16</sup> and first and subsequent episodes or flare-ups can be triggered by injury to the skin, infection, sunburn, medications and stress.<sup>7</sup>



Psoriasis has had a huge impact on my career. Following my

first flare-up when psoriasis erupted over 90% of my body I had to take six months off work and then when my condition didn't respond to treatment I ended up on sick-leave for most of 2012. Even today my life still revolves around hospital appointments and this is very challenging to juggle around work commitments."

Stu, age 42, living with psoriasis since age 38

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#### LIVING WITH PSORIASIS: THE REALITY

#### **Quality of Life**

The reality of life with psoriasis is highlighted in a survey commissioned for this report.<sup>10</sup> The UK and Ireland survey involved nearly 500 healthcare professionals (GPs, nurses and pharmacists) and over 160 people living with mild, moderate and severe psoriasis. From those people surveyed, 93% reported that their psoriasis affected their quality of life. Virtually all (99%) of healthcare professionals surveyed agreed that psoriasis impacts their patients' quality of life,<sup>10</sup> but the PSO What? Taskforce challenges whether they proactively ask their patients how they feel and if their psoriasis is causing them distress. The survey suggests that some healthcare professionals may actually underestimate the level of impact of psoriasis on quality of life: **39%** of healthcare professionals thought that psoriasis affected their patients' confidence and selfesteem, compared with over half (54%) of people with psoriasis, who ranked the impact on their confidence and self-esteem as the most negative effect on their quality of life.10



Day-to-day life with psoriasis, especially during a flare-up, is a real

challenge, and the constant need to apply creams that leave greasy marks on my clothes still makes me feel very self-conscious. The psychological effects of this condition can be as debilitating as the physical symptoms, however in all the years that I have had psoriasis I can't remember the last time my GP asked me how I was feeling or coping."

#### John, age 45, living with psoriasis since age 23

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### of people surveyed reported that their psoriasis negatively affected their quality of life

Also underestimated by healthcare professionals is the negative impact of psoriasis on their patients' sleep.<sup>33</sup> In the survey, **53%** of people with psoriasis reported one to four nights of disturbed sleep each week and **10%** reported five to seven nights. However, just a third of the healthcare professionals surveyed routinely ask if sleep loss is a problem for their patients.<sup>10</sup>

#### **Employment and Education**

The impact of life with psoriasis on employment and education can result in a significant economic burden for individuals and society. Of people with psoriasis in employment, 43% believe that their condition limits their income and/or future earnings, with individuals taking up to 26 sick days each year and nearly a fifth claiming to have quit their job or been dismissed as a result of their psoriasis.<sup>3</sup> Psoriasis currently costs the UK economy an estimated £1.07 billion each year in lost productivity alone, and it is calculated that a 10% reduction in sickness absence for people living with the condition would result in a £50 million boost to the economy.<sup>3</sup>

> sick days each year as a result of psoriasis

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#### Myths and Misconceptions

As highlighted earlier, the World Health Organization (WHO) recognises psoriasis as a serious noncommunicable disease,<sup>7</sup> but myths and misconceptions continue to compound the burdens of people living with the condition. It is a myth that psoriasis is contagious, but stigma, discrimination and social exclusion are widespread.<sup>7</sup> It is similarly a misconception that psoriasis does not affect quality of life and emotional wellbeing if plaques are limited in extent or are hidden under clothes.<sup>34</sup>

The impact of psoriasis goes far beyond the apparent severity of symptoms, and the WHO states that there is an urgent need for early intervention and evidence-based treatment to avoid long-term suffering, disease progression (comorbidities) and continuing adverse effects on quality of life.<sup>7</sup> The PSO What? Taskforce supports this call.



when a hairdresser once asked if my scalp

psoriasis was contagious and made a point of putting on protective gloves before cutting my hair. It was humiliating."

Lesley, age 45, living with psoriasis since age 18



ever going out in public wearing shorts or a skirt

that would expose the psoriasis plaques on my legs. I am so worried about the hurtful things people might say about my skin that it is easier to hide it away and avoid having to have the conversation."

Nicola, age 49, living with psoriasis since age 7

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When I look in the mirror, I no longer recognise my reflection – it's as if psoriasis has turned me into a monster." Stu, age 42, living with psoriasis since age 38

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# **PSO WHAT? ARE THE COMORBIDITIES OF PSORIASIS?**

Although its most obvious impact is on the skin, psoriasis is not simply a skin condition. Like other serious, autoimmune diseases, psoriasis is associated with physical and psychological health problems or comorbidities (related conditions) that may shorten the lives of people with living with the condition.

It has become increasingly clear that health services must adapt if they are to meet the challenges posed by the complex healthcare needs of an ageing population, the rising toll of lifelong disease and the expectations of their citizens for high standards of healthcare. Looking at the UK, in 2002 the Wanless Report estimated that without addressing these challenges, the NHS would need to spend an extra £30 billion by 2023 - or half of the NHS's expenditure at 2002 prices – in order to meet these needs.<sup>35</sup> These and other sobering forecasts have led to an ever greater focus on financial investment in disease prevention and early intervention. It remains a key focus of health systems across the UK and Ireland to address health inequalities and reduce the burden of comorbidities associated with long-term conditions, which weigh heavily on individuals, health services and society as a whole.14,36

The Five Year Forward View in England, Together for Health in Wales, Transforming Your Care in Northern Ireland, A Fairer Healthier Scotland, and the Framework for Improving Quality in Ireland all recognise that effective prevention of, and early intervention in, longterm conditions will only be achieved through a patientcentred partnership between individuals, healthcare professionals and health services.<sup>37-41</sup>

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Simon Stevens, NHS England Chief Executive, set out his vision for a patient-centred NHS at the launch of the Five Year Forward View: "The NHS must change to meet the needs of a population that lives longer, for the millions of people with long-term conditions, and for all patients who want person centred care. It means breaking down the boundaries between family doctors and hospitals, between physical and mental health and between health and social care. The Five-Year Forward View sets out new models of care built around the needs of patients rather than historical or professional divides."<sup>42</sup>

Yet it is clear to the PSO What? Taskforce that this focus is not being reflected in psoriasis care because of the opportunities that are being missed to prevent and diagnose early the comorbidities that shorten the lives of people with psoriasis.



Psoriasis is life ruining, and it can also be life shortening

because of the time bomb of comorbidities."

Dr Anthony Bewley, Consultant Dermatologist

#### **PHYSICAL COMORBIDITIES**

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Note: Risks shown are compared with those in people of the same age who do not have psoriasis

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As well as living with the disabling and often disfiguring effects of psoriasis on the skin, up to one in three or **35%** of people with the severe form of the condition develop psoriatic arthritis.<sup>67</sup> This inflammatory form of arthritis can impair the function of any joint in the body, but typically attacks the hands, feet, knees, neck, spine and elbows. The resulting pain, stiffness and swelling can limit everyday activities and severely affect quality of life.<sup>7</sup>

People with psoriasis are nearly 3 times more likely than those without psoriasis to have Crohn's disease, a form of inflammatory bowel disease and another lifelong autoimmune disease.<sup>21,45</sup> In Crohn's disease, inflammation to the lining of the intestines leads to scarring, severe pain and damage to the bowel and it is associated with an increased risk of colorectal cancer.

A UK study found that people with severe psoriasis are nearly twice as likely as people without psoriasis to develop metabolic syndrome.<sup>19</sup> This combination of risk factors includes obesity, high cholesterol, high blood pressure and insulin resistance, and it is linked to the development of type 2 diabetes and cardiovascular disease.

The cardiovascular risk is increased for young people; one study concluded that a **30-year old with severe psoriasis has 3 times the risk of a heart attack as someone of the same age without psoriasis**.<sup>8</sup> Inflammatory or psoriatic arthritis is a common comorbidity and is a recognised risk factor for cardiovascular disease: the risk of people experiencing a major cardiovascular event, such as heart attack or stroke, was found to be 36% higher in people with inflammatory arthritis, when compared with those who did not have these conditions.<sup>44</sup> When I was first diagnosed with psoriasis I had no idea of the other serious health conditions that are linked to it, such as psoriatic arthritis which I was later diagnosed with. It's only through doing my own research and speaking to other people with psoriasis and experts at get-togethers like the PSO What? Taskforce meeting, that I have become aware of the risks, and I am now actively discussing all these conditions with my healthcare professionals."

Kathy, living with psoriasis and psoriatic arthritis since age the age of 13



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of people with psoriasis develop psoriatic arthritis<sup>6,7</sup> - (



The risk of serious, life-limiting comorbidities amongst

psoriasis patients, especially those with a familial history, is high. I urge all healthcare professionals to regularly screen their psoriasis patients for symptoms of these associated conditions and to actively discuss the risk factors with them. Earlier diagnosis results in more effective treatment outcomes, limiting the long-term burden on healthcare services and ultimately improving the patient's quality of life."

Dr Helen Young, Senior Lecturer and Consultant Dermatologist Atherosclerosis and inflammation, both recognised risk factors for heart attack and stroke, are also more common in people with psoriasis than in people without the condition.<sup>8</sup> People with psoriasis additionally have a significantly higher risk of developing atrial fibrillation (AF), an abnormality of the heart rhythm that is known to increase the likelihood of stroke and heart failure.<sup>17</sup> A nationwide Danish study concluded that the risk of AF and subsequent stroke is nearly tripled in younger people (aged less than 50) with severe psoriasis.<sup>17</sup>

Non-alcoholic fatty liver disease (NAFLD) occurs in 17-60% of people with psoriasis, especially if they also have psoriatic arthritis. As the term suggests, NAFLD is a build-up of fat in the liver that is not associated with alcohol intake. It generally does not get worse or cause symptoms. However, people with psoriasis are more likely to develop more serious forms of NAFLD, such as non-alcoholic steatohepatitis, when the liver becomes inflamed, and cirrhosis, which causes permanent scarring of the liver and ultimately liver failure.<sup>20</sup>

Psoriasis is also associated with a higher risk of nonmelanoma skin cancers, especially if a person with the condition has received ultraviolet light and high doses of immunosuppressive drugs to manage their psoriasis.<sup>20</sup> In addition, there is a **small increase in the risk of some other cancers**, including non-Hodgkin's lymphoma, liver cancer, and cancer of the respiratory and urinary tracts.<sup>43</sup>

**People with psoriasis can report eye problems**, especially if they also have psoriatic arthritis. The most serious of these ocular comorbidities is an inflammatory disease of the eye called uveitis, which may occur in 7-20% of people with psoriasis. It is more likely to occur in older people with psoriasis and, if left untreated, may lead to permanent damage and loss of vision.<sup>18</sup>



Risk of stroke is nearly tripled in younger people with severe psoriasis<sup>17</sup>

#### **Psychological Comorbidities**

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A life with psoriasis may come with significant, farreaching and too-often underestimated costs to psychological health. The **psychological comorbidities of psoriasis are at least as severe as those seen in people with other serious diseases such as heart disease, diabetes, kidney failure, cancer and liver diseases.**<sup>23</sup> Compared with people with other skin disorders, people with psoriasis are more likely to suffer from psychological problems that may in themselves trigger or worsen psoriasis symptoms.<sup>46</sup> Over half of people with psoriasis makes them feel self-conscious (73%), embarrassed (69%) and anxious (59%).<sup>10</sup>

People with psoriasis may take up coping strategies such as smoking, which could impair both their mental and physical health and add to the already significant psychological and emotional burden of the condition.<sup>47,48</sup> Studies have shown that not only is smoking an independent risk factor for the development of psoriasis, but that people with established psoriasis continue to smoke more than those without psoriasis.<sup>48</sup> Regardless of the location and extent of psoriatic plaques, anxiety and depression are common. In a large study, over **60% of people with psoriasis had symptoms of depression**.<sup>49</sup>

Psoriasis is a visible condition and it can have a disfiguring effect. It can change someone's appearance in many different ways. Western societies, as well as other societies, attach a great deal of importance to the complexion, and beauty is typically defined as an even skin tone that is free from blemishes.<sup>50</sup> A finding that is common across most skin conditions, including psoriasis, is that the degree of psychological distress as a result of looking different is not correlated to the severity of the condition. It is the person's subjective experience and perceived severity that predicts the level of distress, rather than objective clinical severity.<sup>51</sup> Often clinical assessments conducted by medical professionals (dermatologists and GPs) do not have a psychosocial component.

**People with psoriasis are more likely than people with other skin conditions to contemplate suicide**,<sup>52</sup> and in a study of 127 people with psoriasis, 9.7% reported a wish to be dead and 5.5% reported actively

thinking of suicide.<sup>9</sup> It is estimated that more than 10,400 diagnoses of depression, 7,100 of anxiety, and 350 of suicidal thoughts and behaviour are attributable to psoriasis each year in the UK .<sup>53</sup>



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Psoriasis is a horrible condition to live with on a daily

basis, and it's embarrassing having to explain to friends and colleagues why I am constantly scratching and why my skin is bleeding. I have suffered from depression in the past as a result of my condition, however I no longer let it control my life!" Jacqueline, age 42, living with psoriasis since

age 8



In my opinion, the psychosocial impact of psoriasis is

vastly overlooked. Data show us that there is a strong link between psoriasis, depression, anxiety and even suicide. It is essential that we take a holistic approach to treating psoriasis by addressing the psychological as well as physical symptoms."

**Dr Anthony Bewley, Consultant Dermatologist** 

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A simple walk to the shops is often beyond me because of intense fatigue and severe joint pain caused by my psoriatic arthritis."

Mark, age 31, living with psoriasis and psoriatic arthritis since age 18

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# **PSO WHAT? IS THE REALITY OF PSORIASIS CARE?**

Effective management of psoriasis depends on careful and holistic assessment at diagnosis to individualise treatment, when assessing treatment response and to identify and manage comorbidities (related conditions). However, many people with psoriasis are still not receiving their guideline-recommended regular review and the holistic help and support that they need.

The aims of psoriasis treatment are to address skin inflammation and maintain skin hydration to achieve the control of symptoms desired by each person with the condition. Most people with mild to moderate psoriasis can be effectively managed by their GP,<sup>26</sup> but many continue to suffer in silence, and around two thirds do not actively seek treatment for their condition.<sup>24</sup>

Guidelines and Quality Standards from the National Institute for Health and Care Excellence (NICE) recommend doctors discuss risk factors for cardiovascular comorbidities with people who have any type of psoriasis (and their families or carers where appropriate), and where appropriate offer preventative advice and healthy lifestyle information.<sup>25,26</sup> They also state that that people having treatment are offered an annual assessment for psoriatic arthritis.<sup>25,26</sup>



The fear of being rejected as a result of my psoriasis

has stopped me from pursuing a relationship. I would prefer to remain single and keep my psoriasis a secret than take the risk of being judged based on my skin."

Nicola, age 49, living with psoriasis since age 7



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Most people with mild to moderate psoriasis can be effectively managed by their GP,<sup>26</sup> but many continue

to suffer in silence, and around two thirds do not actively seek treatment for their condition.<sup>24</sup>

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### NICE GUIDELINES:25,26

According to NICE Clinical Guidance:

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Offer a review at least annually to adults with psoriasis who are using intermittent or short-term courses of a potent or very potent corticosteroid (either as monotherapy or in combined preparations) to assess for the presence of steroid atrophy and other adverse effects.



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Offer a review at least annually to children and young people with psoriasis who are using corticosteroids of any potency (either as monotherapy or in combined preparations) to assess for the presence of steroid atrophy (skin damage resulting from the prolonged use of steroids) and other adverse effects.



**Offer annual assessment for psoriatic arthritis to people with any type of psoriasis.** Assessment is especially important within the first 10 years of onset

of psoriasis. Annual assessment for the condition (which may form part of a holistic review of response to treatment and disease severity and impact) could help to identify people with psoriatic arthritis earlier, so that treatment can be planned accordingly and before joint damage occurs.

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The Taskforce feels however that assessment of the severity and impact of psoriasis, including physical and psychological comorbidities, is critical to improving outcomes in psoriasis. During the important period of the first 10 years following diagnosis, regular psoriasis reviews, at least annually, can provide a key opportunity for people with the condition to proactively discuss how they feel; manage potential or existing comorbidities and also explore new treatment options and not solely focus on assessing for any adverse effects of treatments, as the NICE Guidelines currently highlight.<sup>26</sup> Regular consultations also help to cement a trusting relationship between a person with psoriasis and their healthcare professionals, helping to promote adherence to treatment and improve outcomes.54

A third of people with psoriasis have not had an annual review with their GP for 5 years.<sup>27</sup> Without regular reviews, at least annually, there is a potential risk that people with the condition can become locked in a cycle of repeat prescriptions on what may be an inappropriate treatment.<sup>24</sup> We know from research that as many as 50% of psoriasis patients are on a repeat prescription and that half of these individuals have received their repeated treatment for 4 or more years.<sup>27</sup>

The management of psoriasis should encompass the assessment and treatment of the individual's skin and psychosocial and physical comorbidities, as well as education on the condition and its treatments. NICE guidance stresses that good communication between people with psoriasis and their healthcare professionals is essential if individuals are to make informed decisions about their care and treatment.<sup>26</sup> This can only be achieved through a patient-centred partnership, in which the professional asks the patient about how they are feeling and their goals for treatment, and both agree on a plan of how to reach these goals.

Although nearly a quarter of the population seek advice from their GP about a skin condition,<sup>4</sup> people with psoriasis perceive GPs to be lacking in confidence in assessing and managing their condition, and both groups feel that they lack adequate knowledge and understanding,<sup>28</sup> including the psychosocial needs of patients.<sup>5</sup> While psoriasis is the reason for 5% of all GP dermatology consultations, it accounts for 11% of dermatology specialist workload.<sup>4</sup> However, people with psoriasis may face significant barriers when they need to be referred because of rising referral rates for skin conditions in general and not enough consultant dermatologists. For example, based on recommended



As healthcare professionals, we must remember that each person experiences psoriasis in their own unique way. So we

will only manage the condition effectively if we engage our patients in a conversation to find out their personal psoriasis needs and goals."

Julie Van Onselen, Dermatology Education Specialist and Independent Nurse, Dermatology **Education Partnership Ltd, Oxford** 

A third of people with psoriasis have not had an annual review with their GP for **5 years**.<sup>27</sup>

numbers of dermatologists from the Royal College of Physicians, no region in England has enough dermatology consultants, with the lowest number on the South East coast, in the North East and in the East Midlands. This contrasts with rising numbers of consultants in other specialties, such as gynaecology and rheumatology.<sup>4</sup>

#### Access to Care

Psychosocial needs of psoriasis patients often go unrecognised.<sup>5</sup> Healthcare professionals are not properly trained to conduct psychological assessments, or they lack the confidence or understanding of various tools to facilitate this.<sup>55</sup> When a psychosocial assessment is part of a dermatology consultation and it is established that intervention is needed, often there is no adequate referral pathway, there are long waiting lists or there is not enough trust that patients' needs will be met.<sup>55,56</sup>

Throughout the NHS more generally it is becoming increasingly difficult for patients to access appointments, with some GP practices moving towards a triage system that sees receptionists screening patients and only referring those for a telephone or in-person consultation that they deem to have serious enough symptoms. With such a significant proportion of GP consultations relating to skin conditions, these are very relevant challenges. Similar issues exist in accessing cancer care with **42%** of patients finding it difficult to get an appointment with a particular GP, or at a convenient time (42%), whilst **40%** of patients disliking talking about their symptoms with the surgery receptionist.<sup>57</sup>

NICE emphasises that people with any type of psoriasis should be offered support, education and information tailored to their individual needs.<sup>26</sup> There is, however, a clear divergence between the experience of people with psoriasis and that of healthcare professionals. Four in five (81%) of healthcare professionals surveyed said that they provide additional information to educate their patients on how to effectively use their prescribed treatments.<sup>10</sup> In contrast, less than half (45%) of people with psoriasis reported feeling well-supported by their doctor in managing their condition.<sup>10</sup>

A list of psoriasis resources for both patients and healthcare professionals can be found on page 34 of this report



### 42% of patients find it difficult to get an appointment with a particular GP<sup>57</sup>



I often struggle to book a GP appointment, even when I have a

bad flare-up, as the receptionists do not consider psoriasis a serious condition and do not understand the impact it has on my wider health and wellbeing, as a result I tend to give up."

Jacqueline, age 42, living with psoriasis since age 8

#### Access to Information

Education and information are critical for people with psoriasis to engage in effective shared decision making during their treatment reviews. Lack of education and understanding of how to use a treatment effectively were, however, cited as barriers to accessing the best treatment options for just over 40% of people with psoriasis.<sup>10</sup> Interestingly, 83% of healthcare professionals reported that patients not fully understanding how to use their treatment was the biggest barrier to the optimum management of their condition.<sup>10</sup> At the same time, nearly two thirds of people with psoriasis reported dissatisfaction with the quality of the information that they received.<sup>10</sup>



GPs and pharmacists play a critical role in supporting

their patients to get optimal outcomes from the management of their psoriasis. One of the most effective ways to do this is to direct patients to the wealth of information that already exists online regarding treatment options, lifestyle changes and support services available."

Dr Rod Tucker, Community Pharmacist with a special interest in dermatology



Ahead of attending a consultation, I would urge all patients

with psoriasis to prepare and think about what they want to say to their healthcare professional and what they want to achieve from the consultation. By being prepared, and really sharing how they feel and what they want, patients can ensure they get the best support and advice from their healthcare professional, as well as a treatment plan that is personalised to their needs and which will help them reach their psoriasis goals."

Dr Helen Young, Senior Lecturer and Consultant Dermatologist

I will never forget when a hairdresser once asked if my scalp psoriasis was contagious and made a point of putting on protective gloves before cutting my hair. It was humiliating."

Lesley, age 45, living with psoriasis since age 18

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# **PSO WHAT? CAN YOU DO?**

Psoriasis is a lifelong, serious autoimmune condition that for some people has the potential to devastate quality of life, health and wellbeing. Whilst the Taskforce recognises that some people can and are living positively with their psoriasis and are empowered to seek the help and support needed, the overall impact of psoriasis is still underestimated; people with psoriasis continue to suffer stigma, discrimination and social exclusion, and there remain unacceptable variations in their access to treatment, care and support.

The PSO What? Taskforce is calling on everyone in the UK and Ireland to take the PSO What? Challenge and make a pledge to help improve the health and quality of life of people living with psoriasis.

Below are some suggested actions you, as someone touched by psoriasis, could take. However, the Taskforce's aim is that you will be inspired to offer your own pledges based on your experience of psoriasis to make a difference in whatever way you can.

### **EXAMPLE PSO WHAT? ACTIONS**



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**As a person living with psoriasis,** I pledge to be open and frank about how my psoriasis makes me feel and to ask for support if I need it from healthcare professionals, friends, family and employers alike. For example, I will ask my doctor to review my psoriasis management, regularly, but at least once a year.



As a healthcare professional, I pledge to offer my patients a regular review of their psoriasis management, at least once a year, and to consider all aspects and possible comorbidities associated with this serious autoimmune condition to ensure they are being appropriately monitored and managed. For example, I will always ask my patient how their psoriasis makes them feel; how satisfied they are with their current treatment; discussing the latest treatment options available; and screening them where there is a risk of comorbidities.



**As a healthcare commissioner,** I pledge to take into account the quality of life benefits of holistic and joined-up care associated with this serious autoimmune condition when specifying local psoriasis services and treatments. For example, I will work to improve access for people with psoriasis to specialist healthcare professionals, including GPwSI (GP with a Special Interest), dermatologists, and psychologists.



**As a member of the general public,** I pledge to learn more about psoriasis and to act as an advocate to help break down the stigma associated with conditions that affect appearance. I will also support those I know living with the condition by giving them the opportunity to talk in an open and frank way about how it makes them feel and what impact it has on their health. For example, I will speak out when I hear others express less well-informed views about psoriasis, including that it may be contagious or 'just a skin condition'.



**As an employer,** I pledge to be proactive in the way I listen to my employees who have psoriasis, to adapt the working environment to their needs, provide them with any psychological support services if required, and to give them the flexibility to attend medical appointments. I will also work with them to ensure that their co-workers understand the condition and can act as advocates to help break down the stigma associated with psoriasis.



Regular reviews are critical if I am to partner with my psoriasis

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patients and provide them with the support and treatment that meets their changing and individual needs, and ensure they know how to get the best results."

Dr Angelika Razzaque, GPwSI Dermatology

# THE PSO WHAT? TASKFORCE

The PSO What? initiative is a partnership programme led by The Patients Association and LEO Pharma, in collaboration with the expert PSO What?Taskforce. LEO Pharma has provided core funding, editorial input and undertaken survey-based research to support the development of the **PSO What? Report.** 

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The PSO What? Taskforce is a multidisciplinary group representing people living with psoriasis, psoriasis advocacy and professional groups, and healthcare professionals. The pledge of each member of the Taskforce is to continue to have a voice and drive positive change for psoriasis and develop resources and programmes to facilitate this.

#### **The Patients Association**

#### People living with psoriasis



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Katherine Murphy, **Chief Executive** www.patientsassociation.org.uk





Gerry Driver

Aimee Senior\*



Kathy Driver



Mark Blackmore

Nicola Guy\*

Stu Lam

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Holly Dillon\*



Jacqueline McCallum



\*Supporter, but not present at the initial PSO What? Taskforce meeting, held May 2016





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#### **Psoriasis advocacy group** representatives



Ivon van Heugten, Changing Faces, www.changing faces.org.uk

David McMahon,\*

Irish Skin

Foundation,

www.irishskin

foundation.ie

Psoriasis Association,\*\* www.psoriasis-association.org.uk/

\*\* Consultant, but not present at the PSO What? Taskforce meeting, held May 2016

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#### Healthcare professionals



Ibrar Ahmed, Pharmacist and Commissioner, NHS Leeds South and East Clinical Commissioning

Group, Leeds, UK Dr Anthony



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Bewley, Consultant Dermatologist, Barts Health NHS, London, UK



Julie Van Onselen, Dermatology Education Specialist and Independent

Nurse, Dermatology Education Partnership Ltd, Oxford, UK



Dr Helen Young, Senior Lecturer and Consultant Dermatologist, The University of Manchester

and Salford Royal Hospital, Manchester, UK



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Simon Oates, Mind & Skin, www.mindand skin.co.uk

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John Warne, Psoriasis Help Organisation, www.psoriasishelp.co.uk



Julie Peconi, Skin Care Cymru, www.skincare cymru.org



Jenny Hill,\* **Skin Conditions** Campaign Scotland, www.skinconditions campaignscotland.org

\*Supporter, but not present at the initial PSO What? Taskforce meeting, held May 2016

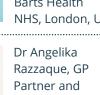
GPwSI in Dermatology, Queens Road Partnership, London, UK; Vice

Chair, Primary Care Dermatology Society

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Dr Rod Tucker, Community Pharmacist with a special interest in dermatology, Lloyds Pharmacy, Hornsea, UK





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PSO What? Taskforce Psoriasis Advocacy and Professional Organisations



Changing Faces works to help people who have a disfigurement find a way to live the life they want. It aims to help people conquer fears, take the first steps and ultimately take control, by being on a client's side and by their side as they define their own sense of identity, their purpose and realise their dreams. Changing Faces helps build people's confidence to live their life on their terms. And it challenges prejudice, respects differences and speaks to a world that needs to change.

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### Irish Skin Foundation

The Irish Skin Foundation (ISF) is a national charity dedicated to improving the quality of life of people with all kinds of skin diseases and conditions, to promoting skin health and the prevention of skin disease by providing support, information, engaging in advocacy and raising awareness. It operates a free helpline providing direct, accessible and specialist guidance about skin conditions. Throughout the year it runs events, including health promotion meetings and dermatology education for nurses and pharmacists.



Mind & Skin works to improve the daily quality of life for skin disease sufferers. It aims to provide "talking therapies" for service users and aspires to help dermatology patients by increasing their self-esteem, reducing stress and managing the physical and psychological aspect of their condition. The charity aspires to improved communications between the Government, all health related officials, and their patients.



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The Psoriasis Help Organisation website is dedicated to helping people suffering from psoriasis and is privately owned, run and administered by psoriasis sufferers for psoriasis sufferers. The primary aim for the site is to provide a discussion forum, a place where fellow psoriasis sufferers can exchange views and advice with how to live with and treat the condition.



Skin Care Cymru is a volunteer run patient support group, giving a voice to those with any skin condition in Wales. Working in partnership with other patient organisations, dermatology professionals, medical schools and others, it aims to advance the interests of skin condition sufferers and promote the provision of the best possible treatment and outcomes for them.



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Established in 2001, SCCS is a volunteer led, patient focused Scottish Charity that promotes the interests and shared aims of people in Scotland with Skin and Associated Rheumatic Conditions. SCCS operates as an umbrella group which campaigns, along with patient support groups and other stakeholders, to improve provision of care for all who live with skin conditions. The charity aims to include the views of every person living in Scotland who lives with, cares for, or cares about skin disease and shares the aim of improving access to the best possible treatment for all those affected.

#### Partners to the PSO What? Taskforce

### the patients association

The Patients Association's mission is 'Listening to Patients, Speaking up for Change'. This motto is the basis on which it builds all its campaigns. From the contacts it receives via its Helpline, The Patients Association captures thousands of accounts each year from patients, carers, family members and friends about people's experiences of the health and social care service. It uses this knowledge to campaign for real improvements across the UK. In addition, The Patients Association's Helpline provides valuable signposting and information for patients and supports them as they navigate through the healthcare services.

#### Follow us on Twitter: <u>https://twitter.com/PatientsAssoc</u>

Subscribe to our Facebook page: <u>www.facebook.com/</u> <u>thepatientsassociation</u>



LEO Pharma helps people achieve healthy skin. By offering care solutions and products to patients in more than 100 countries globally, LEO Pharma supports people in managing their skin conditions.

Founded in 1908 and owned by the LEO Foundation, the healthcare company has devoted decades of research and development to delivering products and solutions to people with skin conditions.

LEO Pharma is headquartered in Denmark and employs around 5,000 people worldwide.

For more information about LEO Pharma UK/IE, visit <u>www.leo-pharma.co.uk</u> or <u>www.leo-pharma.ie</u>

The UK/IE affiliate is headquartered in Hurley, Berkshire.

Like us on Facebook: https://www.facebook.com/ LEOPharmaUKIE

Follow us on Twitter: https://twitter.com/LEOPharmaUKIE

Subscribe to our YouTube channel: <u>www.youtube.com/channel/UC\_</u> <u>HWf4kPkN5Z3Po6\_KfN9xw</u>

#### Resources for People with Psoriasis and their Healthcare Professionals

#### Psoriasis/Dermatology Patient Groups

- Changing Faces, <u>www.changingfaces.org.uk</u>
- Irish Skin Foundation, <u>www.irishskinfoundation.ie</u>
- Mind & Skin, <u>www.mindandskin.co.uk</u>
- Psoriasis Help Organisation, <u>www.psoriasis-help.co.uk</u>
- Skin Care Cymru, <u>www.skincarecymru.org</u>
- Skin Conditions Campaign Scotland, <u>www.skinconditions</u> <u>campaignscotland.com</u>
- Psoriasis Association, <u>www.psoriasis-association.org.uk</u>

#### **NHS Resources**

 NHS Choices, <u>www.nhs.uk/</u> <u>Conditions/Psoriasis/Pages/</u> <u>Introduction.aspx</u>

#### LEO Pharma Support Services

# QualityCare™

 QualityCare<sup>™</sup> website - For more information about psoriasis visit: <u>https://psoriasis.qualitycarebyleo.</u> <u>co.uk</u>



 MyPso app - For practical advice to make small changes that can have a big impact on psoriasis, download the MyPso app at the Apple App Store or Google Play

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### Psoriasis resources for healthcare professionals

- British Association of
  Dermatologists, <u>www.bad.org.uk</u>
- British Dermatological Nursing Group, <u>www.bdng.org.uk</u>
- NICE Psoriasis Guidance, <u>www.nice.org.uk/guidance/</u> <u>conditions-and-diseases/skin-</u> <u>conditions/psoriasis</u>
- Primary Care Dermatology Society, <u>www.pcds.org.uk</u>

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| PSO What? Fighting Back Against Psoriasis





### A Report by the PSO What? Taskforce

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The PSO What? Taskforce is a multidisciplinary group representing people living with psoriasis, psoriasis advocacy and professional groups, and healthcare professionals





The PSO What? initiative is a partnership programme led by the Patients Association and LEO Pharma, in collaboration with the expert PSO What? Taskforce. LEO Pharma has provided core funding, editorial input and undertaken survey-based research to support the development of the PSO What? Report. Job Code: UK/IE/MAT-07179 | Date of Preparation: April 2017

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