

A report from The Economist Intelligence Unit

Encouraging policy action to address the psoriasis challenge

Commissioned by



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ABOUT THE REPORT

Encouraging policy action to address the psoriasis challenge is a report by The Economist Intelligence Unit (EIU), commissioned by Eli Lilly and Company. The report examines how health systems in Europe and Canada are responding to the World Health Organisation's support for worldwide action against psoriasis, an autoimmune disease. The findings of this report are based on research by The EIU and include insights from leading psoriasis experts in academia and the medical profession as well as patients and patient association leaders.

In August-October 2016 The EIU conducted interviews with numerous global psoriasis experts. The insights from these in-depth interviews appear throughout the report.

The EIU would like to thank the following interviewees (listed alphabetically) for sharing their insights and experience:

• Sophie Andersson, executive director, International Federation of Psoriasis Associations (IFPA), Sweden

• Kathryn Andrews-Clay, executive director, Canadian Skin Patient Alliance, Canadian Association of Psoriasis Patients

• Mélanie Aubin, communications director, France Psoriasis

• Jonathan Barker, professor of medical dermatology, St John's Institute of Dermatology, King's College London, UK

- Ina Campbell, co-chair, Patient Research Partner Group, Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA), Canada
- David Chandler, chief executive, Psoriasis and Psoriatic Arthritis Alliance, St Albans, UK
- Linda Davies, professor of health economics, University of Manchester, UK
- Paolo Gisondi, professor of dermatology, University Hospital of Verona, Italy

• Christopher Griffiths, foundation professor of dermatology, Faculty of Medical and Human Sciences, University of Manchester, UK; and president, International Psoriasis Council (IPC)

• Philip Helliwell, senior lecturer in rheumatology, Leeds Institute of Rheumatic and Musculoskeletal Medicine, University of Leeds, UK; and president, Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA), UK

- Christine Hewitt, psoriasis patient, UK
- Patricia Jimmy, board member and former vice president, Association France Psoriasis

• Richard Langley, professor of dermatology, Dalhousie University, Division of Clinical Dermatology and Cutaneaous Science, Halifax, Canada

• Nick Levell, president, British Association of Dermatologists, London, UK

- Ulrich Mrowietz, head of the Psoriasis Centre, University Medical Centre Schleswig-Holstein, Kiel, Germany
- Carla Renton, information and communications manager, Psoriasis Association, Northampton, UK
- Mariusz Sapijaszko, president, Canadian Dermatology Association
- Simmie Smith, president, Canadian Psoriasis Network
- David Trigos, vice president, Europso; and representative, Acción Psoriasis, Spain

The Economist Intelligence Unit bears sole responsibility for the content of this report. The findings and views expressed in the report do not necessarily reflect the views of the sponsor. Norma Beavers was the author of the report, and Edel McCormack was the editor.

EXECUTIVE SUMMARY

Psoriasis is an autoimmune skin disease which affects 1.5-5% of the population of most developed countries and an estimated 125m people worldwide. It manifests as a fluctuating inflammatory skin disease and affects to varying degrees the quality of life of those who suffer from it. Despite policy recommendations from the World Health Organisation (WHO),^{1,2} many governments have taken little or no action to improve the health of those living with psoriasis. Across Europe and Canada, work is under way by various parties to address the challenges posed by the disease, but those leading these efforts say that they would benefit from more government interest and support.

Together with negative physical and mental health strains, the economic impact of psoriasis is growing significantly. In a recent study of five European countries—France, Germany, Italy, Spain and the UK—the cost of psoriasis, regardless of the severity of the disease, was put at between US\$2,077 and US\$13,132 in purchasing power parity (PPP) terms per patient per year.³ The same study estimated that the direct and indirect costs (in PPP terms) ranged between US\$1,715 and US\$8,925 and between US\$364 and US\$4,207, respectively, per patient per year.

The Economist Intelligence Unit (EIU) carried out a study to assess the effectiveness of national policies and guidelines and their adherence to WHO recommendations through a system of scorecards for six countries—Canada, France, Germany, Italy, Spain and the UK. As a result, the report identifies critical areas where attention is needed from governments, the medical profession and academia to improve psoriasis awareness, diagnosis, treatment and support. Moreover, it assesses what policymakers, advocates, medical practitioners and researchers need to do to ease the challenges psoriasis presents to healthcare systems and to people suffering from the disease.

The key findings are:

• Awareness of psoriasis is low. The common perception is that it is an itchy skin condition and not an autoimmune, long-term condition with comorbidities. People are unacquainted with the functional, psychological effects of the disease, or indeed the negative impact psoriasis can have on daily life, educational opportunities or the ability to work. Psoriasis on the hands and feet can cause work limitations and in general affects quality of life negatively.⁴ Consequently, governments must do more to increase understanding of the disease. The unfamiliarity of many with the disease can contribute to the development of psychosocial problems and sickness absence, even in those with a mild version of the disease. People with visible psoriasis may avoid work and social situations because of entrenched stigma and discrimination.

• Psoriasis patient associations have laid the groundwork for better education to break down the stigma and discrimination associated with the disease. Good examples of such work exist in the UK, Canada, Spain, France, Italy and Germany. The interviews we conducted with the members of these organisations highlight a desire for more government support in facilitating education about psoriasis, its related physical and psychological comorbidities and its effect on individuals and their ability to work

 WHO, Global Report on Psoriasis.
Geneva, World Health Organisation, 2016. http://apps.who.int/iris/ bitstream/10665/204417/1/9789241565189_ eng.pdf

² WHO, Resolution WHA67.9. Geneva, World Health Organisation, 2014. http:// apps.who.int/gb/ebwha/pdf_files/ WHA67/A67_R9-en.pdf

³ R Burgos-Pol *et al*, "The Cost of Psoriasis and Psoriatic Arthritis in 5 European Countries: A Systematic Review", Actas Dermosifiliogr, 2016;107(7):577-590.

⁴ F Ayala *et al*, "The impact of psoriasis on work-related problems: a multicenter cross-sectional survey", *Journal of the European Academy of Dermatology and Venereology*, 28(12): 1623-32. and contribute to the economy. Additional effort is required to establish workplace environments that do not discriminate against people with psoriasis when faced with the realities of the disease. Failure to manage psoriasis better will continue to result in considerable healthcare costs and other damaging outcomes, such as lost work days.

• Medical professionals, especially general practitioners, need to be better educated about psoriasis so that it can be diagnosed at an earlier stage. This will reduce human suffering and the economic costs of the disease. Specialists are critical, but the report shows a shortage in many countries. Of the six countries covered, Germany has the highest number of dermatologists with 6.6 per 100,000 people, while the UK comes last with just one dermatologist per 100,000 people. In addition, more investment in psychological services for people with psoriasis is needed. This will help to manage anxiety, depression and other psychological problems arising from the disease.

• Patient-centred, co-ordinated care is the most effective way to manage psoriasis and its comorbidities. Successful examples of patient-centred care can be found in leading psoriasis centres in Germany, the UK and Italy, but a concentrated focus is needed to improve the quality of psoriasis care. This model of healthcare is characterised by treatment provided by multidisciplinary medical teams working in a co-ordinated and integrated way. The ultimate goal of treatment is to deliver what people with psoriasis want most—skin that is completely clear of psoriasis.

• Inequality in psoriasis management exists across all six countries surveyed. Psoriasis management depends on existing healthcare systems, and while all of the countries covered have established functioning healthcare systems, each country is unique and has unique challenges in terms of improving the lives of people suffering from the disease.

• Work is under way to create a Global Psoriasis Atlas. This will raise the profile of psoriasis further and remove stumbling blocks to advocacy, such as the lack of psoriasis data. "The goal is to establish a first-ever, worldwide, online database on psoriasis," says Sophie Andersson, executive director of the International Federation of Psoriasis Associations (IFPA) in Sweden, one of the Atlas's founding organisations. The Global Psoriasis Atlas database, which is being set up and managed by the UK's University of Manchester, will not only gather and compile all existing psoriasis research, but will also devise a standardised methodology for gathering future data. Ms Andersson notes: "It is IFPA's hope that by setting up one centralised point of psoriasis knowledge, psoriasis advocacy will be facilitated. Most of all, the Global Psoriasis Atlas is intended as a resource for people living with psoriasis across the world as well as their healthcare providers, friends and family."

Scorecard framework methodology

The countries in this study are assessed using a scorecard framework developed by The Economist Intelligence Unit. This framework assesses countries' efforts to follow national or European recommendations and improve the care of people living with psoriasis. As a starting point, we used psoriasis policy recommendations from the WHO and complemented them with data from other relevant sources to create an assessment

framework. The framework scores countries on their level of support for people with psoriasis by considering policy across all the areas relevant to improving care for people living with the disease. These areas are: access to professional medical care; access to treatment; national patient registries for psoriasis; activities to build awareness; diagnosis, monitoring and treatment guidelines; measurement of clinical indicators; continuum of care; side-effects of treatment; patient-centred care; workforce capacity; education and training on the disease; quality measures; co-ordinated and integrated care; individualised/personalised treatment; patient education; psychological support; the role of patient associations and advocacy groups; and discrimination.

SECTION I: THE CHALLENGE CHAPTER 1 THE SCALE AND SCOPE OF THE PSORIASIS CHALLENGE

There are an estimated 125m people suffering from psoriasis worldwide.^{5,6} Psoriasis presents itself in five forms—plaque, guttate, inverse, pustular and erythrodermic—and each type can be mild, moderate or severe. Psoriasis is not contagious, so cannot spread through touching someone who has it, but its effects on the skin are highly visible and can cause embarrassment, social stigma, discrimination, depression and sometimes suicide. Scientists are still trying to learn what causes psoriasis, but a person's immune system and genes play important roles. There is no cure for the disease, only a range of treatments that can improve the symptoms and the appearance of the skin. Psoriasis carries with it higher risks for developing other illnesses, including psoriatic arthritis, heart disease, abdominal obesity, high blood pressure, diabetes, cancer, depression and Crohn's Disease.⁷

Until recently, psoriasis was absent from the health agenda of the international community, eclipsed by high-profile, noncommunicable diseases such as cancer and diabetes. However, a report by the World Health Organisation (WHO) on psoriasis, published in 2013,⁸ provided a basis for discussion about the disease and potential actions to improve the care of people living with psoriasis. The report was followed by a WHO resolution in 2014,⁹ which encouraged member states to expand their advocacy efforts in order to raise awareness about the disease and help to fight against the stigmatisation often suffered by those with psoriasis. Nick Levell, president of the British Association of Dermatologists, regards the WHO's global resolution as "a major step forward in recognising that psoriasis is a serious, non-communicable disease that is complex, life-long and frequently life-ruining". Management involves recognition of the significant physical, psychological and socioeconomic consequences of the disease, he says.

Accompanying these important steps, the WHO's Global Report on Psoriasis, published in 2016, includes the following key actions to improve the care of people with psoriasis: commitment and managerial support from policymakers; improved access to services and medicines to manage psoriasis; education and training for healthcare providers, particularly in primary-care settings; and advocacy efforts to raise awareness and fight the stigma suffered by people living with psoriasis.

Initiatives such as these mark progress in raising the global profile of psoriasis, but experts interviewed for this report say that in general their governments have not acted on the WHO's recommendations. Kathryn Andrews-Clay, executive director of the Canadian Skin Patient Alliance at the Canadian Association of Psoriasis Patients, says: "The issue is that the government of Canada signed the Psoriasis resolution in May 2014 and yet has not had the resources to spend on the issue of psoriasis."

⁵ WHO, Psoriasis. Report by the Secretariat, EB133/5. Geneva, World Health Organisation, April 5th 2013. http://apps.who.int/gb/ebwha/pdf_ files/EB133/B133_5-en.pdf

⁶ IFPMA, Bringing psoriasis into the light, International Federation of Pharmaceutical Manufacturers & Associations, Geneva, 2014. Available at: http://www.ifpma.org/wp-content/ uploads/2016/01/Psoriasis_Publication-Web.pdf

⁷. Available at: https://www.psoriasis. org/about-psoriasis/related-conditions

⁸ WHO, Psoriasis, EB133/5.

⁹ WHO, Resolution WHA67.9.

In evaluating whether the WHO's actions have influenced meaningful government action to improve psoriasis care and awareness, our research found that only France provides tangible evidence of its government's commitment. Its Ministry of Social Affairs and Health granted the leading French psoriasis patient association, Association France Psoriasis, permission to use the government's logo on its awareness campaigns and patient/public educational initiatives. Patricia Jimmy, board member and the former vice president of Association France Psoriasis, explains: "In May 2015, a year after the WHO recommendation, and at our request, the minister of social affairs and health, Marisol Touraine, granted her ministry's patronage to the various information campaigns organised by France Psoriasis. The association is authorised to affix the ministry's logo to our documents and actions."

This use of the government's logo represents progress, but that is the full extent of the government's involvement. The logo has helped to publicise psoriasis advisory counters in 3,500 pharmacies throughout France as well as other awareness initiatives. However, Ms Jimmy argues: "We want more action from our government, because in France there is no national policy on psoriasis. We plan to present our actions and studies to the health ministry so that a strategy can be implemented."

In all six countries surveyed in our report the lack of government support is a bone of contention. Psoriasis patient associations, alliances and networks co-operate with sufferers to help them cope with stigma, discrimination and a catalogue of other issues, but they all say that they need government support. David Chandler, chief executive of the Psoriasis and Psoriatic Arthritis Alliance in the UK, says: "Discrimination is a difficult area, as we know people often lose their jobs due to psoriasis, but this will never be the reason given, it will always be some other well-documented reason. If someone wants to discriminate, they will find a way to do this within the law, without it appearing to be because of psoriasis. There is little we can do to change such clever behaviour. There is also a counterproductive issue. By raising these issues, you can sometimes throw a light on the condition, which creates a negative impact and subsequent discrimination for individuals, so our activities have to be even-handed and take into account the whole psoriasis population, not just those with the worst type of psoriasis."

In addition to workplace difficulties, the economic impact of psoriasis is substantial. Christopher Griffiths, foundation professor of dermatology at the University of Manchester in the UK, says that beyond the treatment costs of psoriasis there is the cost to the economy: "There are some powerful figures around. The cost to the economy in absenteeism and presenteeism is more than £1bn [US\$1.25bn] a year in the UK, and patients with psoriasis lose about 26 days a year from work." In a recent study,¹⁰ which examines the five European countries that are also covered in our report, the cost of psoriasis, regardless of severity, is put at between US\$2,077 and US\$13,132 in purchasing power parity (PPP) terms per patient per year. The same study estimates the direct costs at between US\$1,715 and US\$8,925 and the indirect costs at between US\$364 to US\$4,207 (in PPP terms) per patient per year.

¹⁰ "The Cost of Psoriasis and Psoriatic Arthritis in 5 European Countries: A Systematic Review". Beyond hard figures, the human costs of psoriasis may be immeasurable. Richard Langley, professor of dermatology at Dalhousie University, Canada, explains: "It may impact the patient's decision to stay in school, to take certain jobs, the decision to get married, the ability to stay married, their productivity at work, absenteeism and presenteeism. We see higher rates of alcoholism, suicide, depression, and this is now recognised as having a profound negative impact on every aspect of a patient's life."

Alongside psoriasis, other health problems develop. As Dr Langley explains: "We are seeing higher rates of cardiovascular disease, but if we treat psoriasis, we can reduce that. There are increased rates of suicide, inflammatory bowel disease, psoriatic arthritis." Canadian guidelines for managing plaque psoriasis recommend that physicians manage comorbidities either directly or by an appropriate referral. *Think beyond the Skin*, an expert opinion paper,¹¹ recommends that the ultimate goal of treatment should be to achieve skin that is clear of psoriasis, as this is "a simple and measurable result that the patient and physician can clearly understand". Mr Chandler adds: "If you've got psoriasis and you see a 75% improvement, that still leaves you with psoriasis, and for some people a small amount of psoriasis can have a huge impact, so clearing psoriasis completely has to be a goal now, and it should be the gold standard that everybody is aspiring to."

CASE STUDY: FIGHTING STIGMA

Combatting the stigma that is associated with psoriasis is an everyday battle for some. Christine Hewitt, who lives in the UK and has suffered from psoriasis for the past 32 years, sums it up as follows: "People stare in the swimming baths because I have these things all over my arms, my chest, my head, my knees, and it makes you feel awful, like you're dirty, even though you know you're not... You feel uncomfortable... You try to look your best, you wear nice clothes, and you cover up every part of you even on the hottest summer days, but in the back of your mind you still feel inadequate." Psoriasis brings with it issues of selfesteem, giving rise to depression and social withdrawal.

However, the situation is changing in some countries. In Spain, Acción Psoriasis, a patient association, has spearheaded a campaign that sees people with psoriasis posting online photos of themselves wearing bikinis, vests or swimming trunks on beaches or while taking part in other outdoor pursuits. The objective of the campaign is to help normalise patients' lives.

In addition to this campaign, Acción Psoriasis uses multiple social media platforms, such as Facebook, Twitter and YouTube, to help raise awareness and offers a psoriasis telephone counselling service called Tandem, which allows patients to speak to a nurse and a psychologist about issues they are dealing with.

David Trigos, vice president of Europso, the European umbrella organisation for psoriasis movements and representative of Acción Psoriasis, says that this is the way forward, because in his opinion, little or no action has been spearheaded by

the government in Spain. "Only patient organisations have taken real action to fight the stigma being suffered by people who have psoriasis," he explains. Stigma has "a big and increasing impact on patients in Spain in terms of their mental health", he notes. Psychological help is available, but "it is not a special service for psoriasis patients". Indeed, research carried out for this report found that few hospitals in Spain offer psychological support, and those that do reserve it for the most severe cases. However, exceptions do exist. At the Hospital de Sant Pau in Barcelona psychologists work in multidisciplinary teams that are tailored to the needs of people living with psoriasis.

CHAPTER 2 PROBLEMS THAT NEED FIXING

The six countries surveyed all demonstrate that positive work is being done on psoriasis by individual groups and organisations, but all of them are experiencing the same difficulties and problems that need fixing. The issues commonly begin in primary care, where people with psoriasis go for initial diagnosis. Experts argue that people are being mismanaged or undermanaged, because general practitioners (GPs) and primarycare physicians need to be better educated about the disease. In Spain, which has 2.1 dermatologists per 100,000 people, psoriasis sufferers have to wait for lengthy period of time for a diagnosis. According to Mr Trigos, "the waiting times people have to go through in order to receive medical care or a diagnosis from a dermatologist are one to about two years (depending on the region or city)".

In the UK, Mr Levell says: "Early diagnosis is not happening routinely, and patients report being held in primary care or not being referred to specialist care and given ineffective treatment for long periods. Furthermore, the psychological problems associated with psoriasis, which may include suicidal ideation, are not being addressed."

At the heart of the problem is the fact that most GPs in the UK have little formal training in dermatology to enable them to diagnose the disease. As Mr Levell notes: "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 and postgraduate medical students. This is exemplified by the Identification and Management of Psoriasis Associated Comorbidity (IMPACT) programme, which indicates that GPs are reluctant to attend training when it is offered, as they may not see psoriasis as a significant health problem." IMPACT is a psoriasis education and training programme funded by the National Institute for Health Research, a UK government body.

The problem with diagnosis is similar in Canada. Simmle Smith, president of the Canadian Psoriasis Network, explains: "People are not being diagnosed, so those who have this condition still think of it as a skin disease and not as an autoimmune disease. Even when you go to a family doctor, they do not know that psoriasis is an autoimmune disease, so people are not being referred to specialists."

Access to treatment for mild to moderate or severe psoriasis is driven by guidelines and national policies, and each country has its own guidelines for diagnosis and treatment. Germany has two guidelines in place for physicians, one national, the other European, says Ulrich Mrowietz, head of the Psoriasis Centre at the University Medical Centre Schleswig-Holstein in Kiel, Germany. The European guideline focuses on the systemic treatment of psoriasis vulgaris and was updated in 2015. The national guideline is currently being revised. Doctors who are willing to specialise have access to specific training on psoriasis and a psoriasis certificate course, representing a national standard that is run by the German Dermatological Society, according to Professor Mrowietz.

Our research has found no official guidelines on the diagnosis and management of psoriasis in France. European guidelines have not been translated into French, and there are few signs that physicians are encouraged to use them. However, medical students preparing for their final exams have access to a psoriasis management training document prepared by the *Collège des Enseignants en Dermatologie de* France (CEDEF, the National College of Teachers in Dermatology). The document provides clear, detailed guidance on diagnosis and includes recommendations for monitoring treatment side-effects.

Some countries are more advanced in this area. The EIU scorecards rate the UK, Italy and Canada ahead of Germany, Spain and France on diagnosis, monitoring and treatment guidelines. For example, the UK has national policies in place, such as the National Health Service (NHS) England Commissioning Specialised Services, which focus on a number of areas of dermatology, including severe psoriasis. The National Institute for Health and Care Excellence (NICE) offers evidence-based advice for healthcare practitioners on the assessment and management of psoriasis in adults, young people and children. However, many GPs do not follow the guidelines. Professor Griffiths notes: "If they followed such guidance, then that may improve things significantly, but skin disease does not figure highly on their list of importance." Mr Chandler adds: "I tell people all the time to download the NICE guidelines and take them to their GP, but they come back and tell me their GP was not interested."

Another problem raised by psoriasis experts interviewed for this study is that there is a workforce crisis in dermatology, with consequent negative knock-on effects on early diagnosis and treatment. The scorecards show that workforce capacity needs to improve in the UK, Spain and Canada. In the UK, the variations in psoriasis care provision across the country are made worse by a shortage of dermatologists and GPs. Mr Levell explains: "If anything, the UK government is taking a backward step in strengthening services to improve the care of people with psoriasis. Existing performance targets are prioritised towards cancer, which is a good thing, except that it limits funding for severe inflammatory disease. There is a need for an expansion in dermatology training numbers to fill the record-high number of empty consultant posts in the UK, which currently looks very unlikely to happen."

In Germany, the number of dermatologists in 2016 is estimated at 5,504, or 6.6 dermatologists per 100,000 individuals, the highest number of dermatologists per capita among the six countries surveyed in this study. Even so, these numbers fall short, and primary-care physicians have stepped up to help manage mild to moderate cases of the disease. According to Professor Mrowietz, the quality of care given by primary-care physicians is inconsistent. To raise standards and achieve best practice, courses on psoriasis management are being offered. "What we are trying to do is to educate non-dermatologists about psoriasis and how they can handle mild disease." He adds that primary-care physicians are also informed about when the criteria are fulfilled and when they need to move patients to a dermatologist.

In Canada, people suffering from the disease can find psoriasis care difficult to locate because of a shortage of dermatologists and the sheer geographical size of the country. In 2015 Canada had 1.7 dermatologists per 100,000 individuals. These numbers are expected to rise, "but it could take a decade," notes Mariusz Sapijaszko, president of Canadian Dermatology Association. The process by which Canadian physicians are reimbursed for key psoriasis treatments, such as phototherapy, complicates care and access further. According to Dr Sapijaszko, access to treatment varies by provincephototherapy, for example, is limited because "dermatologists would get a fee for administering the service, but if that fee is below the cost of administering it, that service would be hard to come by in some places". Overall, psoriasis care and access in the country is fragmented. Canada does have universal access and standards of care, but there are differences between the provinces when it comes to access to medication, availability of treatment or reimbursement for treatment. In this respect Canada is guite fragmented purely because of the nature of its federal system, where healthcare is the responsibility and domain of each province and not the federal government, according to Dr Sapijaszko.

The shortage of dermatologists has made it challenging for patients to get an appointment, says Ms Smith of the Canadian Psoriasis Network. Patients who succeed in securing a doctor's appointment face other problems. These include having to work their way through the system by using various treatment options and failing on different levels before finally receiving the treatment they needed in the beginning. Ms Smith explains: "In every province it's different. If you have severe psoriasis or psoriatic arthritis, you have to start with the first level of treatment, which might be topical ointment or oral medications, and then the ultimate treatment plan would be the biologics. Given the cost of biologics, not every province covers them, and not every patient will be covered for the biologics, so access to treatment depends on the province where you live, and also your own extended healthcare. If you are not covered for biologics, your doctors have to come up with a different treatment option for you."

Ms Smith adds: "We know there is no cure, but people should be told there are different options for them to explore. One biologic may not work for a particular patient, but there are others to choose from which may be more successful in clearing their psoriasis. In Canada the treatment has to be prescribed by a specialist, otherwise it is not always going to be covered if prescribed in primary care, she says. "Your waiting time could be a year to see a specialist, and then you finally get on a biologic, but you have suffered with the disease a lot longer than you needed to. That is part of the challenge with the condition and having access to medical help."

Ms Andrews-Clay of the Canadian Skin Patient Alliance adds: "I am concerned that the government of Canada has not been able to honour their commitment to the Psoriasis resolution. We are a very small organisation and can only do so much. I am hopeful that we can collaborate with the government of Canada to achieve some of these commitments."

CASE STUDY: THE COMPLEXITY OF TREATING PSORIASIS

Paolo Gisondi, professor of dermatology at the University Hospital of Verona in Italy, is in charge of an outpatient clinic specialising in the treatment of psoriasis and psoriatic arthritis. The clinic is a centre of excellence, attracting patients mainly from Verona but also, to a lesser degree, from other parts of Italy. It is one of several centres of excellence dotted around the country seeking to tackle psoriasis and assist in offering the best treatment possible in accordance with each patient's healthcare requirements. Psoriasis is believed to affect 2-3% of the Italian population,¹² and as in other countries, its link to comorbidities, such as cardiovascular disease and diabetes, places significant pressure on Italy's healthcare system.

In a comparison with five other European countries and Canada, Italy comes second in its number of dermatologists, with 6.4 per 100,000 people, while Germany has 6.6, France 6, Spain 2.1, Canada 1.7 and the UK just one per 100,000 people. As a result, it is essential that general practitioners (GPs) act as an intermediary between a patient with psoriasis and a dermatologist. This type of integrated approach to psoriasis treatment is not only valuable to psoriasis sufferers but also to the smooth functioning of the healthcare system, according to Professor Gisondi. Importantly, opportunities exist for primary-care professionals to receive training on psoriasis, and courses are offered by the School of Dermatology in Primary Care. According to Professor Gisondi, initiatives like these are paving the way for reducing the complexities of psoriasis care in Italy. In his own practice, Professor Gisondi works alongside a rheumatologist and sees patients with psoriatic arthritis, providing integrated care.

Italy scores highly for access to psoriasis care and treatment in our research, and this is largely due to the collaboration between GPs and specialists. Treatment costs are partially or entirely covered by Italy's National Health Service (Servizio Sanitario Nazionale, SSN). The treatment of psoriasis varies according to the individual patient, but ordinarily it is long-term and complex. The reimbursement of treatment costs can be partial or complete, as in the case of highly expensive treatments such as biologics, but topical treatment is largely reimbursed by the Italian government.

The lifelong nature of the disease can sometimes result in people with psoriasis being cautious about the possible side-effects of treatment. Because of this Professor Gisondi believes that therapeutic options should be tailored to each patient according to the severity of their condition. Moreover, he considers that the provision of information on psoriasis by medical practitioners is crucial, given the complexities of the disease and the effect it can have on a person's mental well-being. His own research includes the examination of the epidemiological and comorbidity issues of psoriasis, and his publications focus on metabolic comorbidities,

¹² Paolo Gisondi, Cardio-metabolic comorbidities of psoriasis, 2013 April-June; 2(2): 116–119. ISSN: 2282-4103. http://www.clinicaldermatology.eu/ materiale_cic/697_1_2/6022_cardio/ article.htm metabolic syndrome and other key areas associated with the disease.

Dermatologists and others involved in patient care must redouble their efforts to beat the negative impact psoriasis has on a person's life. "As professionals, we know that in the long term it is possible for every patient to achieve a good control of psoriasis. We may not know straightaway which drug is best for a particular patient, but we do have several different treatments available, and we also know that new biologics will arrive on the market, and that good control of psoriasis is a realistic and achievable outcome for every patient now," Professor Gisondi says.

Following the 2014 World Health Organisation (WHO) resolution, which encouraged member states to expand their advocacy efforts to raise awareness about the disease, Professor Gisondi hopes for more government action aimed at improving support for universities to facilitate scientific research on psoriasis, and for hospitals to receive economic resources to provide the best possible treatment for high-need patients.

CHAPTER 3 OPTIMISING CARE: TOWARDS PATIENT-CENTRED CARE

Psoriasis experts interviewed for this report say that patient-centred care—personalised medicine—is the future model for managing psoriasis. In the UK, Germany, Italy and Spain co-ordinated and integrated care occurs only in isolated patches, based at leading centres for psoriasis care in each country. Philip Helliwell, senior lecturer in rheumatology at the University of Leeds in the UK, explains: "Psoriasis is a complex, multi-organ disease, but I don't think that has been realised in the past." National guidelines for psoriasis care offer advice to healthcare practitioners to screen patients for comorbidities. According to Dr Helliwell, "this advice needs to be much more closely followed to effectively manage the progress of the disease and other conditions that run with it."

In Canada, Ina Campbell, co-chair of the Patient Research Partner Group, Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA), says that structural change of the health system is essential. "When somebody not only has psoriasis but also psoriatic arthritis and diabetes and other things as well, they need integrated care and electronic records... Right now we have independent silos of care, and that needs to change."

Co-ordinated, patient-centred care can help to identify and steer patients towards the different medical professionals they need to see to cover all their health problems. Too often healthcare professionals are missing the link between psoriasis and other illnesses, such as mental health problems. In Germany, Professor Mrowietz says that even when the connection is made, the waiting time for psychological support can stretch "from nine months to a year". The situation is especially difficult outside of major cities, where psychotherapists are few in number. "It is a major problem that we are facing, but we are running two programmes to begin to find solutions. There is ongoing work with an institute of psychology in Hamburg to develop a programme to treat the psychological problems experienced by people who have psoriasis," he says.

In centres of excellence where research findings are being implemented—such as the Manchester Psoriasis Service, the St John's Institute of Dermatology at the Guy's and St Thomas' NHS Foundation Trust in London, the Kiel University Psoriasis Centre in Germany and the University Hospital of Verona in Italy—people are offered patient-centred care within a multidisciplinary team, which includes psychological care for psoriasis.¹³ These hospital teams tailor any treatment to the patient's specific needs and are seen as models of optimal care for the future.

¹³ RC Lamb et al, "Screening for anxiety and depression in people with psoriasis: a cross sectional study in a tertiary referral setting", *British Journal of Dermatology*, 2016 Jul 1. doi: 10.1111/ bjd.14833. Available at: https://www. ncbi.nlm.nih.gov/pubmed/27363600

CASE STUDY: RAPID-ACCESS PSORIASIS CLINICS

In the UK, clinicians in Greater Manchester are seizing a "once in a lifetime opportunity to do something on a political level", according to Christopher Griffiths, foundation professor of dermatology at the University of Manchester in the UK. Under the UK's "Devolution Agenda", the city's £6bn health and social-care budget has been transferred from central government to the city. With this freedom to test new pathways of care, people living with psoriasis could be fast-tracked into rapid-access psoriasis clinics. For some patients, this could end years of waiting for a correct diagnosis and management plan. Professor Griffiths explains how the new pathway works: "As soon as patients present to their GP, they are referred to a rapid-access clinic, where they are assessed for severity of disease. They can be assessed for psoriatic arthritis and whether they are at risk for cardiovascular disease and so on, and whether they need to go rapidly onto a systemic therapy rather than trying all the topical treatments. We can also educate them about what psoriasis is and tell them how to self-manage. Most patients could then go back to primary care, and we could follow them up with mobile devices or apps so they feel connected."

psoriasis "could be managed in a much more accelerated fashion than would otherwise have been the case," he adds. "It's about improving quality of care and improving productivity, and obviously health economics is important to the NHS. Usually, taking innovation into practice in the NHS can take up to 15 years, but we think we can do this in 3-4 years in Manchester."

Moves such as these could change the outlook for psoriasis care across the UK. Currently, patients encounter multiple barriers to best care outside the specialist dermatology centres, says Jonathan Barker, professor of medical dermatology at the St John's Institute of Dermatology at King's College London. "The majority of patients with psoriasis are treated in primary care and never see a dermatologist. Sometimes referrals to dermatology centres are sometimes delayed and sometimes local dermatology services are patchy." Another issue, he says, is that "many GPs will not have any specific dermatology training over and above what they learned at medical school, so the possibility exists that patients with psoriasis may not be made aware of some of the advances in treatment that there have been." Rapid access to high quality psoriasis services looks to change this.

Patients with moderate to severe

CASE STUDY: DELIVERING INTEGRATED CARE

Similar to the other countries in this report. Germany scores poorly for the delivery of co-ordinated and integrated care, but an exception to this rule is the Psoriasis Centre in Kiel, a division of the University Medical Centre Schleswig-Holstein. The Centre takes a multidisciplinary approach to managing moderate to severe psoriasis. "We have integrated care, where rheumatologists and dermatologists work together, and we have a nurses team. We have at least two people trained in nutritional medicine, so we can offer a broad spectrum of care for the psoriasis patient, but in Germany that is unique to the Kiel situation," says Professor Mrowietz, the head of the Centre. For people living with psoriasis who are overweight, the Centre offers a behavioural intervention programme to encourage weight loss.

The Centre participates in scientific research and clinical trials and is an example of gold-standard psoriasis care. Ear, nose and throat (ENT) specialists are also showing an interest in psoriasis care, a move that is being supported by the Centre. Professor Mrowietz explains: "We teach them that tonsillitis is a trigger factor for psoriasis, and we have a local campaign here in Germany to raise awareness among ENT doctors, so that when they are sent people living with psoriasis for tonsillectomy, they don't refuse them because their tonsils are not inflamed. We give them the knowledge that removing the tonsils is a very helpful procedure to get rid of a potential trigger."

By connecting patients with different health professionals, the Centre is aiming to deliver the best in patient experience.

CONCLUSION

The WHO has recognised psoriasis as a serious noncommunicable disease. It has raised questions about who receives access to care, the true prevalence and incidence of psoriasis globally, its costs to healthcare systems, and the risk of comorbidities. Being able to provide complete answers to these questions is imperative for the organisation. It is equally essential for the future management of the disease in Europe and Canada as well as in underdeveloped countries, where treatments for psoriasis are not yet available.

Overall, health policies provide a good foundation for the care of people living with psoriasis. The main difference in this domain between countries is the existence—or indeed absence—of a national patient registry for psoriasis, which can promote a better understanding of successful strategies and also support communication among physicians.

National patient registries guarantee a way forward by helping to gather data. Progress in this area is already being made in France, Italy, Spain, Germany and the UK. In Germany for example, people with moderate to severe psoriasis are tracked on PsoBest, the German psoriasis registry, when they first begin treatment with a conventional systemic agent or biologic. Patients of dermatology practices and clinics are included in the registry for five years, and data are gathered about their age, comorbidities, treatment regimen, the severity of their condition and its duration.¹⁴

The countries in this study are contributing to global efforts to combat psoriasis. Work is under way to generate a better understanding of the epidemiology and natural history of the disease. The International Federation of Psoriasis Associations (IFPA), the International League of Dermatological Societies (ILDS) and the International Psoriasis Council (IPC) have begun to set up a Global Psoriasis Atlas. "The Atlas will create a global epidemiological psoriasis database for psoriasis research, policy and healthcare provision worldwide and comes in response to the WHO's actions," says Professor Griffiths, who is leading the work at the University of Manchester.

Ms Andersson of the IFPA explains: "As pointed out in the WHO's Global Report on *Psoriasis*, we are very well aware that data are missing regarding psoriasis prevalence, incidence and care in many countries. To fill that gap, the Global Psoriasis Atlas was launched during the European Academy of Dermatology and Venereology Congress in September 2016. What is also missing globally are data about the economic burden of psoriasis disease, which would be a great tool for advocacy."

In response to the WHO report, the IFPA is also building a coalition to gain the support of members of the European Parliament and policymakers everywhere. The coalition consists of "global psoriasis advocates, including the European Academy for Dermatology and Venereology and other medical societies as well as actors from the private sector and representatives from other non-governmental organisations," says Ms Andersson. "It is everyone's business to take action—healthcare practitioners,

¹⁴ M Augustin et al, "German psoriasis registry PsoBest: objectives, methodology and baseline data", Journal der Deutschen Dermatologischen Gesellschaft, 12(1) (2014): 48–57.

policymakers, industries, non-governmental organisations and patients themselves must contribute, and the media is needed to spread the information."

The coalition will focus on raising awareness about psoriasis and linking it to other major noncommunicable diseases (NCDs). "The IFPA's psoriasis coalition will therefore be advocating for the inclusion of psoriasis as a way to control and prevent other NCDs, such as diabetes and cardiovascular diseases, in the WHO's *Global Action Plan for the Prevention and Control of NCDs 2013-2020*. The IFPA has identified a window for revision and expansion of the scope of the current plan in 2018," says Ms Andersson.

As momentum builds, policymakers will need to focus on healthcare improvements. People with psoriasis need to be diagnosed early and have access to treatment that is patient-centred and designed to treat them holistically, taking into account all the conditions they have. GPs must be better educated about psoriasis, and patient associations need to be supported in their efforts to eliminate stigma and discrimination. Policymakers can support awareness campaigns and anti-discrimination legislation to help dispel the stigma experienced by people who have psoriasis.

Ms Andersson says that the IFPA played a significant role in the writing and publication of the WHO's *Global Report on Psoriasis*. Consequently, she adds, "we naturally support the WHO's recommendations, and if fully implemented by all associated stakeholders, living conditions for people with psoriasis could be vastly improved across the world." However, the WHO recommendations are non-binding and reach out to a wide range of stakeholders, from policymakers to civil society activists, healthcare professionals and academia. Ms Andersson notes: "To ensure the recommendations will be effective, the IFPA and other psoriasis advocates rely on the will of these stakeholders to make a difference for people with psoriasis. The IFPA is convinced that the recommendations and practical solutions, if implemented, will contribute to improving the situation for people living with psoriasis. But all recommendations should be considered, because to implement only a few will not be enough."

This EIU research shows that much more can be done to identify psoriasis earlier and manage patients sooner to prevent them from developing complications that are costly in both human and economic terms. With an estimated 125m people worldwide living with psoriasis and its stigma, it is time for governments and policymakers to deliver on the WHO recommendations, so that the lives of people living with psoriasis can be improved in the same way as the lives of people suffering from cancer or diabetes. Until governments and policymakers make this commitment, the WHO's resolution and vision of better psoriasis care around the globe will not be realised.

APPENDIX I: COUNTRY PROGRESS COUNTRY REPORTS

Canada

In Canada, a number of decisions regarding the health system are made at the regional level. Canada has 18 different healthcare plans, because each province has its own system. This means that access to medical care and treatment within the country can vary; for example, biologic drugs for the treatment of psoriasis are not covered by the health plan in all provinces. Canada has a national guideline for the management of plaque psoriasis published in 2009, and in 2016 relevant additional information was published in an addendum. However, by requiring the consultation of two documents instead of one, the recommendations are not communicated in the most lucid and objective way. In addition, the guidelines lack clear criteria for the assessment of the disease or the management of adverse reactions, although they do include measures to determine treatment failure or success.

There is a considerable lack of awareness of psoriasis among the general population and the medical community in Canada. This lack of awareness is seen as the reason behind the difficulty in having a psoriasis diagnosis and receiving adequate treatment. There are specialised training sessions for healthcare professionals mostly organised by nursing associations or the American Academy of Dermatology, which focusses on dermatologists from the U.S. and Canada; however, these sessions can be difficult to access. Patient advocacy groups are involved in raising psoriasis awareness, but more campaigns are required. These associations focus on reducing discrimination against people living with psoriasis and develop informative sessions for patients, making an effort to educate them and help them to get involved in their own treatment. However, management of psoriasis is not yet patient-centred in Canada. Some provinces have specialised clinics, such as the Psoriasis and Phototherapy Clinic in Vancouver, British Columbia, where it is common to see joint efforts between different healthcare professionals, but in other areas it can even be challenging to find a dermatologist.

France

Health policies in France and a strong dermatology workforce provide a good foundation for the care of people living with psoriasis. Consultations with general practitioners or specialists are covered by the national plan, and psoriasis drugs are reimbursed. However, France lacks official guidelines on the diagnosis and management of the disease. European guidelines have not been translated into French, and there are no signs that physicians are encouraged to use them. The Collège des Enseignants en Dermatologie de France (CEDEF, the National College of Teachers in Dermatology) has made a training document on psoriasis care available. The document, which targets medical students, is very detailed on diagnosis and includes clear recommendations for monitoring the side effects of phototherapy and systemic drugs other than biologics.

The French psoriasis registry, PsoBioteq,¹⁵ focuses on effectiveness and safety of treatment with biologics. ResoPso, a network of dermatologists specialising in psoriasis, is a non-profit organisation which runs regular meetings aimed at sharing good practice with specialists and general practitioners treating people who live with psoriasis. Despite this initiative to promote integrated care, however, there is no emphasis on a multidisciplinary approach to psoriasis management. Similarly, despite a mention in the CEDEF document regarding the importance of involving patients in treatment decisions as a way to increase their adherence to treatment, no practical recommendation is made on how to achieve this. People living with psoriasis are not usually involved in their treatment plan unless they are proactive in the search for information on the disease or when specialised physicians are involved, as they are aware of the importance of patient insight.

For patients who need it, psychological support is available in France, but this is usually the result of a personal, proactive approach. Psoriasis patient associations are active in reducing stigma and discrimination of patients at work and in social life and are currently collecting data on the impact of psoriasis at work. Association France Psoriasis, the leading French psoriasis patient association, has developed an educational game, Théo et les Psorianautes, to help both children and adults gain a better understanding of the disease.

Germany

Germany's healthcare system covers primary and secondary care, and psoriasis treatments are accessible and covered. In addition to using the approved medical indications to prescribe a treatment, physicians need to make economic decisions. Physicians have access to two guidelines for the diagnosis, management and treatment of psoriasis in Germany: one national and one European. The European guideline, focused on the systemic treatment of psoriasis vulgaris, was updated in 2015; the national guideline is not up to date and is currently under revision. Doctors willing to specialise have access to specific training on psoriasis, and the German Dermatological Society (DDA) awards a psoriasis certificate, which represents a national standard. These strengths are also supported by the Care Goals that have been set by the professional medical societies.

That said, multidisciplinary care is still not widely available outside of specialised centres, such as the Psoriasis Centre at the University Medical Centre in Kiel. Physicians there have developed a weight-loss programme specifically for people living with psoriasis, which has been made available to other dermatology clinics. Although psychological support for people living with psoriasis has been overlooked in Germany, some attention has been given to patients' quality of life, and the German psoriasis registry, PsoBest,¹⁶ includes a quality-of-life index. The initiative provides a platform for communication between physicians both online and in person through the organisation of meetings and training sessions.

¹⁵ https://clinicaltrials.gov/ct2/show/ NCT01617018

¹⁶ https://clinicaltrials.gov/ct2/show/ NCT01848028?term=PsoBest&rank=1 Getting access to and being referred for psychological support is not common practice, and waiting times for this service can be up to a year, particularly in the countryside. The German patient advocacy group, Deutscher Psoriasis Bund, is focusing on the areas defined in the Care Goals, including, for example, specific websites for children and teenagers and offering camps for teenagers. In addition, it contributes to raising awareness of psoriasis, notably by distributing a bi-monthly magazine to its members that includes articles about the stigma faced by people living with psoriasis and attempts to involve physicians in this aspect of management of psoriasis.

Italy

In Italy, people living with psoriasis are well covered, as consultations with general practitioners and specialists are included in the National Health System, the Servizio Sanitario Nazionale (SSN). The reimbursement of treatment costs can be partial or complete, as in the case of highly expensive treatments like biologics. Notwithstanding this encouraging public policy approach, the SSN is still lagging in providing patients with the best possible care; for example, only a few centres prescribe biologics for treatment of psoriasis. The current Italian guidelines only cover treatment options and lack recommendations regarding the monitoring of side effects and a patient-centred approach. The Psocare project, which took place from 2005 to 2008, was a national registry promoted by the Italian Medication Agency, Agenzia Italiana del Farmaco (AIFA). Psoreal¹⁷ has recently been launched as a continuation of Psocare, but it is only active in a few centres and communication around it is limited. Psoreal aims to describe the long-term results of treatment with new systemic drugs, estimate risks and benefits, and identify groups of patients who are expected to respond (or fail to respond) to the treatment. At the moment, the long-term treatment outcomes are covered in reports that resulted from the Psocare collaborative project.

Italy has a significant number of dermatologists, and there are training opportunities for healthcare professionals, including for primary care. The School of Dermatology in Primary Care offers a specific course on psoriasis. However, there is room for improvement regarding the provision of integrated and co-ordinated care, which is only available in specialised centres. Awareness of the importance of self-management is rising among doctors, and they provide patients with information to support their empowerment, such as lifestyle advice on foods that may impact their condition, and provide encouragement to track their own symptoms and identify triggers. Still, the approach could be more patient-centred; for example, there is a lack of psychological support for people living with psoriasis. Dermatologists do not usually refer patients to specialised psychological services, and these are not reimbursed. Patient associations are therefore the main source of psychological support for patients and play a very important role in raising awareness of psoriasis through the organisation of initiatives such as the World Psoriasis Day.

Spain

The management of the Spanish National Health System takes place both at the national and the regional level; treatment protocols, as in other countries, are usually designed at a hospital level. Patients are provided with capped topical treatment drugs and free systemic treatments. The Spanish Psoriasis Group of the Spanish Academy of Dermatology and Venereology (AEDV) provides guidelines on the treatment of psoriasis with biologics. Additional treatment options are not covered in the guideline and are discussed in independent documents from the AEDV. The AEDV also promotes a Spanish registry of psoriasis patients receiving treatment with biologic drugs, Biobadaderm,¹⁸ a project that receives support from the Spanish Agency for Medicines and Health Care Products and several pharmaceutical laboratories. Biobadaderm focusses on adverse events and had over 2,000 patients listed in 2016. Surveys run by patient groups, such as Barometer Psoriasis, provide additional data to better understand patients' views about their treatment and their relationship with health professionals. Barometer Psoriasis was conducted among 1,085 patients in Spain in 2013.

The management of psoriasis is not usually provided by multidisciplinary teams—there are only about ten specialised centres in the country which take this approach. A few centres have psychological support available for people living with psoriasis, such as the Hospital of Sant Pau in Barcelona, and patient associations are aiming to fill this gap. Acción Psoriasis, for example, has set up a psychological support service delivered over the phone. Patients are increasingly getting involved in their treatment, but this can still vary between individual hospitals or specialists, and the national guideline does not stress the importance of patient empowerment in psoriasis.

Patient associations play an important role in communicating the benefits of a patientcentred approach and patient insight in psoriasis. For example, Acción Psoriasis provides patients with guidance documents, including indications for self-management of their disease. Online courses are also made available for patients seeking information. Psoriasis patient associations are active in raising awareness and reducing the stigma around psoriasis. In one such initiative—Destápate—which has been running since 2012, the association invites patients to share pictures of themselves on the beach or in the open air, showing the psoriasis. The goal is to promote acceptance of the disease and normalise patients' lives.

UK

The UK's National Health Service (NHS) covers appointments with general practitioners (GPs) and specialists. Access to treatment is driven by the guidelines from the National Institute for Health and Care Excellence (NICE), giving access to advanced treatments for severe cases after having attempted other treatment options. The psoriasis guidelines in the UK are comprehensive, and NICE also sets national quality standards specifically for psoriasis. Special attention is given in the guidelines to the need to involve patients in their treatment decisions. Against this backdrop, the UK's number of dermatologists, just as the number of physicians in general, is lower than the OECD average. For physicians

¹⁸ https://clinicaltrials.gov/ct2/show/ NCT02075697

seeking specialised training in psoriasis, there are opportunities of training organised by associations of physicians, patient associations and the IMPACT programme, a collaboration between the Salford Royal NHS Foundation Trust, the University of Manchester and the UK Psoriasis Association. The national psoriasis registry in the UK, BADBIR,¹⁹ was established in 2007 and focuses on assessing long-term safety of biologic treatments.

In practice, variations in the care provision appear across the country, with generally less specialised services offered in the countryside. In specialised centres, some patients are offered individualised treatment approaches, where the hospital team may design a treatment plan for a patient taking into account their specific circumstances, such as a planned wedding, for example. In these centres, such as the Manchester Psoriasis Service, a multidisciplinary approach is taken, but this is not the norm across the country. Outside these centres, the management of psoriasis is not usually provided by multidisciplinary teams, although some initiatives, such as the leaflets made available by the British Association of Dermatologists and the Psoriasis and Psoriatic Arthritis Alliance (PAPAA), focus on patient education. These associations also work together to organise live events for patients to learn and talk about their disease. There have been several awareness campaigns for psoriasis in the UK; one example is Psoriasis Shout Out, an initiative that aims to raise awareness about the disease among the public and bring psoriasis patients together with professionals working in the field of psoriasis management and research.

APPENDIX II: SCORECARD METHODOLOGY

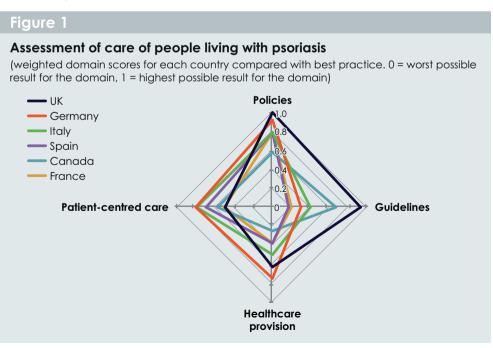
In this study we assess the actions taken to address the psoriasis challenges for patients in Canada and five European countries. The final scorecard is presented in Table 1, and a graphical presentation is included in Figure 1. The scorecard framework is split into four distinct domains, each of which includes a number of indicators scored for each country.

1. Policies: Policy-driven initiatives, notably around policies enabling access to care and activities to build awareness of psoriasis.

2. Guidelines: Focusing on the existence of recognised guidelines and the areas covered in detail by the guidelines or reference documents provided to healthcare professionals looking after people with psoriasis.

3. Healthcare provision: Addressing the critical aspects of the healthcare provided to psoriasis patients, including the provision of co-ordinated and integrated care specifically for these patients.

4. Patient-centred care: Elements in place to ensure that patients have the opportunity to make informed decisions about their care and treatment in partnership with healthcare professionals.



The UK is the country with the best overall score, although there is still significant room for improvement, notably regarding the provision of co-ordinated care and patientcentred care. In Germany, the policy environment is strong as well, with more emphasis on training for both patients and healthcare providers, but the guidelines for treating psoriasis, an essential aspect of the effort, have been out of date since the end of 2014.

Overall, health policies provide a good foundation for the care of people living with psoriasis. The main difference in this domain between countries is the existence or absence of—a national patient registry for psoriasis, which can promote a better understanding of successful strategies and also support communication among physicians. Some countries still lack psoriasis guidelines, such as France, where there is no national guideline and no reference is made to the European guideline.

In the UK and Germany, national quality standard assessments and objectives have been set. These enable the development of a better understanding and set targets for

Table 1– Scorecard for the care of people living with psoriasis in Canada, France, Germany, Italy, Spain and the UK.

Summary of sco	ores					······································	*		
		Indicator	United Kingdom	Germany	Italy	Spain	Canada	France	Max Score
1. Policies	1.1	Access to professional medical care	2	2	2	2	2	2	2
1. Policies	1.2	Access to treatment	3	3	3	3	2	3	3
1. Policies	1.3	National patient registry for psoriasis	2	2	1	1	0	1	2
1. Policies	1.4	Activities to build awareness	3	2	2	2	2	2	3
2. Guidelines	2.1	Diagnosis, monitoring and treatment guidelines	2	1	2	1	2	0	2
2. Guidelines	2.2	Measurement of clinical indicators	2	0	0	1	1	0	3
2. Guidelines	2.3	Continuum of care	1	0	1	0	1	0	1
2. Guidelines	2.4	Side effects of treatment	1	1	0	0	0	1	1
2. Guidelines	2.5	Patient-centred care	1	0	0	0	1	0	1
3. Healthcare provision	3.1	Workforce capacity	1	2	2	1	1	2	2
3. Healthcare provision	3.2	Education and training on disease	2	2	2	2	1	1	2
3. Healthcare provision	3.3	Quality measures	1	1	0	0	0	0	1
3. Healthcare provision	3.4	Coordinated and integrated care	0	0	0	0	0	0	1
4. Patient- centred care	4.1	Individualised treatment	0	1	1	1	0	0	1
4. Patient- centred care	4.2	Patient education	1	2	2	1	2	1	2
4. Patient- centred care	4.3	Psychological support	1	1	1	1	1	1	2
4. Patient- centred care	4.4	Role of patient associations and advocacy groups	1	1	1	1	1	1	2
4. Patient- centred care	4.5	Patient associations and advocacy groups - discrimination	1	1	1	1	1	1	1
			25	22	21	18	18	16	

the improvement of service design. They can therefore be an effective tool to enable progress.

All countries seem to be taking initial steps towards a patient-centred approach to psoriasis, as seen in efforts to educate patients or in actual individualised treatment strategies in dedicated centres or hospital services. However, there is still a long way to go to achieve true patient-focused care.

The member states of the World Health Organisation (WHO) recognised psoriasis as a serious, noncommunicable disease at the 67th World Health Assembly. It is now time for individual governments and policymakers to acknowledge the significance of psoriasis and work in collaboration with patient associations to improve the quality of life of people living with psoriasis, from providing more comprehensive medical care to expanding efforts to increase acceptance by the general public.

Aim

The psoriasis project aims to assess current practice regarding the provision of care for people living with psoriasis in six countries.

Methods

The scorecard was developed through a review of the relevant literature. Information specialists at EIU Healthcare searched across the grey literature and databases, such as MEDLINE, Embase and the Cochrane Library, to identify programmes and processes to assess psoriasis care and recommend improvements. The review covers psoriasis care in a comprehensive sense, inclusive of diagnosis, care and angles such as stigma reduction, for example.

After rounds of appraisal based on relevance, authority and reliable methodology, we extracted data from five documents:

• The **WHO Global Report on Psoriasis**, published in 2016, which provides a thorough review of the disease and its impact on quality of life and intends to empower policymakers with practical solutions to improve the healthcare and social inclusion of people living with psoriasis in their populations;

• The report **Bringing Psoriasis into the Light**, published in 2014 by the International Federation of Pharmaceutical Manufacturers & Associations (IFPMA), which is a call to action for policymakers;

• The 214 report *Implementing best practice in psoriasis: a Nordic expert group* **consensus**, by K Kragballe and colleagues, which aims to provide Nordic recommendations for improving the treatment and quality of life of people living with psoriasis;

• The guideline from the National Institute for Health and Care Excellence (UK NICE), **Psoriasis: assessment and management** (CG153), published in 2012, which aims to

provide clear recommendations on the management of all types of psoriasis in people of all ages;

• The 2012 white paper **German psoriasis registry PsoBest: objectives, methodology and baseline data**, by M Augustin *et al*, which outlines goals and actions based on the opinions of the European Expert Working Group for Healthcare in Psoriasis that aim to improve access to high-quality care for people with psoriasis in Europe.

Thematic analysis of the identified literature revealed four major areas of psoriasis care that should be prioritised by healthcare systems. They are:

- 1. Policies
- 2. Guidelines
- 3. Healthcare provision
- 4. Patient-centred care

These four themes (domains) formed the basis of the scorecard.

An additional dimension that is important to improve care of psoriasis patients is research. There are currently unmet needs for the treatment of psoriasis, from aetiology and epidemiology of the disease to understanding the association with comorbidities and finding global and affordable treatment options. Clinical parameters also need to be improved to better evaluate the severity of the disease and its impact on quality of life. As this dimension is of a global nature, it is not included in the framework for our country assessment.

Scoring

The scorecard marks each domain from very weak to very strong, with bespoke scales for each (0 or 1, 0 to 3 for example). The information used to mark each domain for each country was gathered from national policy documents, interviews with experts and literature sources. Given the qualitative nature of the scorecard, the scores assigned represent a judgment based on the evidence available. All scores were also adjusted based on evidence from the expert interviews conducted for the white paper; these interviews were used to fill in gaps where no published data were available. The final marks are therefore a combination of desk research and expert opinion and should be viewed as indicative in nature.

Domains

Policy has four indicators:

Access to professional medical care, scored from 0 to 2, where 0 = no consultations covered by national health plan; 1 = general practitioner consultations covered

by national health plan but no specialists; 2 = general practitioner and specialist consultations covered by national health plan.

Access to treatment, scored from 0 to 3, where 0 = treatment is not reimbursed or only a small amount is refunded, which generates a very high cost for the patient; 1 = systemic treatment is not reimbursed or only a small amount is refunded, which generates a very high cost for the patient for treatment other than topical or phototherapy options; 2 = treatment is reimbursed but criteria for usage of biologics or other advanced therapies reflect significant access barriers, such as penalties for doctors or a very limited budget per patient, which determines the choice of more accessible treatment options even if less effective; 3 = no reimbursement or issues that undermine the appropriate use of systemic treatment, including biologics or advanced therapies.

National patient registry for psoriasis, scored from 0 to 2, where 0 = no; 1 = yes, but information is limited, eg, only for patients with certain characteristics or on certain treatments (such as biologics) or no Dermatology Life Quality Index (DLQI) included; 2 = yes, a detailed registry for all patients that includes registering DLQI scoring.

Activities to build awareness, scored from 0 to 3, where 0 = no awareness campaign; 1 = there was an awareness campaign but the scope was not national or the campaign targeted only the general public, or the campaign targeted only healthcare professionals; 2 = there was a national campaign targeted at the general public and healthcare professionals but the results were not positive or not measured; 3 = there was a national campaign targeting the general public and healthcare professionals with positive results, eg, the World Psoriasis Day on October 29th 2016.

Guidelines has five indicators:

Diagnosis, monitoring and treatment guidelines, measuring the actual availability of guidelines from 0 to 2, where 0 = no guidelines; 1 = national guidelines available but not up to date; 2 = yes, up-to-date national guidelines available, or the European guidelines are considered.

Measurement of clinical indicators, assessing the presence of clear criteria for assessment in the guideline and definition of a timeline for assessment, scored from 0 to 3, where 0 = no to both; 1 = there is a definition of a timeline for assessment of disease but there are no clear criteria for assessment of disease; 2 = there are clear criteria for assessment of disease but there is no defined timeline for re-evaluation; 3 = yes, the guideline includes clear criteria for assessment of disease and the definition of a timeline for re-evaluation.

Continuum of care, assessing the inclusion of screening for comorbidities in the guidelines, scored 0 or 1, where 0 = no; 1 = yes.

Side effects of treatment, assessing if the guideline for psoriasis includes a clear recommendation for monitoring side effects of treatment, scored 0 or 1, where 0 = no; 1 = yes.

Patient-centred care, assessing the inclusion in the guideline for psoriasis of recommendation for a patient-centred care approach, scored 0 or 1, where 0 = no; 1 = yes.

Healthcare provision has four indicators:

Workforce capacity, assessing the number of dermatologists per population, scored from 0 to 2, where 0 = less than or equal to one per 100,000 individuals; 1 = between one and three per 100,000 individuals; 2 = more than three per 100,000 individuals.

Education and training on disease, assessing the availability of courses or training on psoriasis or dermatological diseases for healthcare providers, scored from 0 to 2, where 0 = none or only one identified; 1 = yes, courses or training on dermatological diseases in general but not psoriasis in particular, or limited offer of courses on psoriasis; 2 = yes, good-quality courses or training on psoriasis in particular.

Quality measures, assessing the presence of a national quality standard; scored 0 or 1, where 0 = no; 1 = yes.

Co-ordinated and integrated care, exploring the provision of co-ordinated and integrated care by multidisciplinary teams as part of the management of disease; scored 0 or 1, where 0 = no; 1 = yes.

Patient-centred care has four indicators:

Individualised treatment to understand if patients are involved in the decision-making about treatment options and treatment goals; scored 0 or 1, where 0 = no; 1 = yes.

Patient education, aimed at measuring if healthcare providers offer people living with psoriasis information or self-management programmes specific for psoriasis; scored from 0 to 2, where 0 = no; 1 = yes, online; 2 = yes, in visits to the clinic.

Psychological support, exploring the availability of psychological support to people living with psoriasis; scored from 0 to 2, where 0 = no; 1 = yes, but the services are of low quality or low availability; 2 = yes, support of good quality and/or with increasing availability.

Role of patient associations and advocacy groups, assessing if patients associations and advocacy groups have an active voice in the defence and support of patients; scored from 0 to 2, where 0 = it is difficult to reach governments, policymakers and health entities; 1 = meetings or any form of planned contact once a year; 2 = meetings or any form of planned contact more than once a year.

Patient associations and advocacy groups—discrimination, looking at associations' and advocacy groups' activities in reducing stigma and discrimination of people living with psoriasis; scored 0 or 1, where 0 = no; 1 = yes.

Number	Indicator	How to measure	Score	Score
			scale	
1.1	Access to professional medical care	Are consultations with general practitioners or specialists as dermatologists or rheumatologists covered by the national health plan?	0-2	2
1.2	Access to treatment	Is the access to treatment limited in terms of reimbursement or criteria of usage?	0-3	2
1.3	National patient registry for psoriasis	Is there a national patient registry for psoriasis?	0-2	0
1.4	Activities to build awareness	Have there been campaigns raising awareness for psoriasis among the general public and/or health professionals since 2014?	0-3	2
2.1	Diagnosis, monitoring and treatment guidelines	Are there national guidelines for psoriasis?	0-2	2
2.2	Measurement of clinical indicators	Are there criteria for assessment of disease and is there a definition of a timeline for assessment?	0-3	1
2.3	Continuum of care	Is screening for comorbidities such as cardiovascular disease, metabolic disease, depression or chronic pulmonary obstructive disease included in the guideline?	0-1	1
2.4	Side effects of treatment	Does the guideline for psoriasis include a clear recommendation for monitoring side effects of treatment?	0-1	0
2.5	Patient-centred care	Does the guideline for psoriasis recommend a patient-centred care approach?	0-1	1
3.1	Workforce capacity	What is the number of dermatologists per 100,000 individuals?	0-2	1
3.2	Education and training on disease	Are there courses or training on psoriasis or dermatological diseases for healthcare providers?	0-2	1
3.3	Quality measures	Is there a national quality standard assessment?	0-1	0
3.4	Coordinated and integrated care	Is coordinated and integrated care provided by multidisciplinary teams part of the management of disease?	0-1	0

4.1	Individualised treatment	Are patients involved in the decision making about treatment options and treatment goals?	0-1	0	
4.2	Patient education	Do healthcare providers offer people living with psoriasis information or self- management programmes specific for psoriasis (e.g. lifestyle advice and information about side effects of treatment)?	0-2	2	
4.3	Psychological support	Is psychological support available to people living with psoriasis?	0-2	1	
4.4	Role of patient associations and advocacy groups	Do patients associations and advocacy groups have an active voice in the defence and support of patients?	0-2	1	
4.5	Patient associations and advocacy groups - discrimination	Are patients associations and advocacy groups active in reducing stigma and discrimination of people living with psoriasis?	0-1	1	

Number	Indicator	How to measure	Score	Score
			scale	00010
1.1	Access to professional medical care	Are consultations with general practitioners or specialists as dermatologists or rheumatologists covered by the national health plan?	0-2	2
1.2	Access to treatment	Is the access to treatment limited in terms of reimbursement or criteria of usage?	0-3	3
1.3	National patient registry for psoriasis	Is there a national patient registry for psoriasis?	0-2	1
1.4	Activities to build awareness	Have there been campaigns raising awareness for psoriasis among the general public and/or health professionals since 2014?	0-3	2
2.1	Diagnosis, monitoring and treatment guidelines	Are there national guidelines for psoriasis?	0-2	0
2.2	Measurement of clinical indicators	Are there criteria for assessment of disease and is there a definition of a timeline for assessment?	0-3	0
2.3	Continuum of care	Is screening for comorbidities such as cardiovascular disease, metabolic disease, depression or chronic pulmonary obstructive disease included in the guideline?	0-1	0
2.4	Side effects of treatment	Does the guideline for psoriasis include a clear recommendation for monitoring side effects of treatment?	0-1	1
2.5	Patient-centred care	Does the guideline for psoriasis recommend a patient-centred care approach?	0-1	0
3.1	Workforce capacity	What is the number of dermatologists per 100,000 individuals?	0-2	2
3.2	Education and training on disease	Are there courses or training on psoriasis or dermatological diseases for healthcare providers?	0-2	1
3.3	Quality measures	Is there a national quality standard assessment?	0-1	0

3.4	Coordinated and integrated care	Is coordinated and integrated care provided by multidisciplinary teams part of the management of disease?	0-1	0
4.1	Individualised treatment	Are patients involved in the decision making about treatment options and treatment goals?	0-1	0
4.2	Patient education	Do healthcare providers offer people living with psoriasis information or self- management programmes specific for psoriasis (e.g. lifestyle advice and information about side effects of treatment)?	0-2	1
4.3	Psychological support	Is psychological support available to people living with psoriasis?	0-2	1
4.4	Role of patient associations and advocacy groups	Do patients associations and advocacy groups have an active voice in the defence and support of patients?	0-2	1

Number	Indicator	How to measure	Score scale	Score
1.1	Access to professional medical care	Are consultations with general practitioners or specialists as dermatologists or rheumatologists covered by the national health plan?	0-2	2
1.2	Access to treatment	Is the access to treatment limited in terms of reimbursement or criteria of usage?	0-3	3
1.3	National patient registry for psoriasis	Is there a national patient registry for psoriasis?	0-2	2
1.4	Activities to build awareness	Have there been campaigns raising awareness for psoriasis among the general public and/or health professionals since 2014?	0-3	2
2.1	Diagnosis, monitoring and treatment guidelines	Are there national guidelines for psoriasis?	0-2	1
2.2	Measurement of clinical indicators	Are there criteria for assessment of disease and is there a definition of a timeline for assessment?	0-3	0
2.3	Continuum of care	Is screening for comorbidities such as cardiovascular disease, metabolic disease, depression or chronic pulmonary obstructive disease included in the guideline?	0-1	0
2.4	Side effects of treatment	Does the guideline for psoriasis include a clear recommendation for monitoring side effects of treatment?	0-1	1
2.5	Patient-centred care	Does the guideline for psoriasis recommend a patient-centred care approach?	0-1	0
3.1	Workforce capacity	What is the number of dermatologists per 100,000 individuals?	0-2	2
3.2	Education and training on disease	Are there courses or training on psoriasis or dermatological diseases for healthcare providers?	0-2	2
3.3	Quality measures	Is there a national quality standard assessment?	0-1	1

3.4	Coordinated and integrated care	Is coordinated and integrated care provided by multidisciplinary teams part of the management of disease?	0-1	0
4.1	Individualised treatment	Are patients involved in the decision making about treatment options and treatment goals?	0-1	1
4.2	Patient education	Do healthcare providers offer people living with psoriasis information or self- management programmes specific for psoriasis (e.g. lifestyle advice and information about side effects of treatment)?	0-2	2
4.3	Psychological support	Is psychological support available to people living with psoriasis?	0-2]
4.4	Role of patient associations and advocacy groups	Do patients associations and advocacy groups have an active voice in the defence and support of patients?	0-2	1
4.5	Patient associations and advocacy groups - discrimination	Are patients associations and advocacy groups active in reducing stigma and discrimination of people living with psoriasis?	0-1	1

Number	Indicator	How to measure	Score	Score
			scale	
1.1	Access to professional medical care	Are consultations with general practitioners or specialists as dermatologists or rheumatologists covered by the national health plan?	0-2	2
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2.1	Diagnosis, monitoring and treatment guidelines	Are there national guidelines for psoriasis?	0-2	2
2.2	Measurement of clinical indicators	Are there criteria for assessment of disease and is there a definition of a timeline for assessment?	0-3	0
2.3	Continuum of care	Is screening for comorbidities such as cardiovascular disease, metabolic disease, depression or chronic pulmonary obstructive disease included in the guideline?	0-1	1
2.4	Side effects of treatment	Does the guideline for psoriasis include a clear recommendation for monitoring side effects of treatment?	0-1	0
2.5	Patient-centred care	Does the guideline for psoriasis recommend a patient-centred care approach?	0-1	0

3.1	Workforce capacity	What is the number of dermatologists per 100,000 individuals?	0-2	2
3.2	Education and training on disease	Are there courses or training on psoriasis or dermatological diseases for healthcare providers?	0-2	2
3.3	Quality measures	Is there a national quality standard assessment?	0-1	0
3.4	Coordinated and integrated care	Is coordinated and integrated care provided by multidisciplinary teams part of the management of disease?	0-1	0
4.1	Individualised treatment	Are patients involved in the decision making about treatment options and treatment goals?	0-1	1
4.2	Patient education	Do healthcare providers offer people living with psoriasis information or self- management programmes specific for psoriasis (e.g. lifestyle advice and information about side effects of treatment)?	0-2	2
4.3	Psychological support	Is psychological support available to people living with psoriasis?	0-2	1
4.4	Role of patient associations and advocacy groups	Do patients associations and advocacy groups have an active voice in the defence and support of patients?	0-2	1
4.5	Patient associations and advocacy groups - discrimination	Are patients associations and advocacy groups active in reducing stigma and discrimination of people living with psoriasis?	0-1	1

Number	Indicator	How to measure	Score	Score
			scale	
1.1	Access to professional medical care	Are consultations with general practitioners or specialists as dermatologists or rheumatologists covered by the national health plan?	0-2	2
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1.4	Activities to build awareness	Have there been campaigns raising awareness for psoriasis among the general public and/or health professionals since 2014?	0-3	2
2.1	Diagnosis, monitoring and treatment guidelines	Are there national guidelines for psoriasis?	0-2	1
2.2	Measurement of clinical indicators	Are there criteria for assessment of disease and is there a definition of a timeline for assessment?	0-3	1
2.3	Continuum of care	Is screening for comorbidities such as cardiovascular disease, metabolic disease, depression or chronic pulmonary obstructive disease included in the guideline?	0-1	0
2.4	Side effects of treatment	Does the guideline for psoriasis include a clear recommendation for monitoring side effects of treatment?	0-1	0
2.5	Patient-centred care	Does the guideline for psoriasis recommend a patient-centred care approach?	0-1	0
3.1	Workforce capacity	What is the number of dermatologists per 100,000 individuals?	0-2	1
3.2	Education and training on disease	Are there courses or training on psoriasis or dermatological diseases for healthcare providers?	0-2	2
3.3	Quality measures	Is there a national quality standard assessment?	0-1	0
3.4	Coordinated and integrated care	Is coordinated and integrated care provided by multidisciplinary teams part of the management of disease?	0-1	0

4.1	Individualised treatment	Are patients involved in the decision making about treatment options and treatment goals?	0-1	1	
4.2	Patient education	Do healthcare providers offer people living with psoriasis information or self- management programmes specific for psoriasis (e.g. lifestyle advice and information about side effects of treatment)?	0-2	1	
4.3	Psychological support	Is psychological support available to people living with psoriasis?	0-2	1	
4.4	Role of patient associations and advocacy groups	Do patients associations and advocacy groups have an active voice in the defence and support of patients?	0-2	1	
4.5	Patient associations and advocacy groups - discrimination	Are patients associations and advocacy groups active in reducing stigma and discrimination of people living with psoriasis?	0-1	1	

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Number	Indicator	How to measure	Score scale	Score
1.1	Access to professional medical care	Are consultations with general practitioners or specialists as dermatologists or rheumatologists covered by the national health plan?	0-2	2
1.2	Access to treatment	Is the access to treatment limited in terms of reimbursement or criteria of usage?	0-3	3
1.3	National patient registry for psoriasis	Is there a national patient registry for psoriasis?	0-2	2
1.4	Activities to build awareness	Have there been campaigns raising awareness for psoriasis among the general public and/or health professionals since 2014?	0-3	3
2.1	Diagnosis, monitoring and treatment guidelines	Are there national guidelines for psoriasis?	0-2	2
2.2	Measurement of clinical indicators	Are there criteria for assessment of disease and is there a definition of a timeline for assessment?	0-3	2
2.3	Continuum of care	Is screening for comorbidities such as cardiovascular disease, metabolic disease, depression or chronic pulmonary obstructive disease included in the guideline?	0-1	1
2.4	Side effects of treatment	Does the guideline for psoriasis include a clear recommendation for monitoring side effects of treatment?	0-1	1
2.5	Patient-centred care	Does the guideline for psoriasis recommend a patient-centred care approach?	0-1	1
3.1	Workforce capacity	What is the number of dermatologists per 100,000 individuals?	0-2	1
3.2	Education and training on disease	Are there courses or training on psoriasis or dermatological diseases for healthcare providers?	0-2	2
3.3	Quality measures	Is there a national quality standard assessment?	0-1	1
3.4	Coordinated and integrated care	Is coordinated and integrated care provided by multidisciplinary teams part of the management of disease?	0-1	0

4.1	Individualised treatment	Are patients involved in the decision making about treatment options and treatment goals?	0-1	0	
4.2	Patient education	Do healthcare providers offer people living with psoriasis information or self- management programmes specific for psoriasis (e.g. lifestyle advice and information about side effects of treatment)?	0-2	1	
4.3	Psychological support	Is psychological support available to people living with psoriasis?	0-2	1	
4.4	Role of patient associations and advocacy groups	Do patients associations and advocacy groups have an active voice in the defence and support of patients?	0-2	1	
4.5	Patient associations and advocacy groups - discrimination	Are patients associations and advocacy groups active in reducing stigma and discrimination of people living with psoriasis?	0-1	1	

While every effort has been taken to verify the accuracy of this information, The Economist Intelligence Unit Ltd. cannot accept any responsibility or liability for reliance by any person on this report or any of the information, opinions or conclusions set out in this report.

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