### Global Psoriasis Atlas Annual Report

Year 2: April 2018-March 2019







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# Foreword

### I am delighted to present the second annual report of the Global Psoriasis Atlas (GPA).

You will see the huge amount of work that is now taking place under the auspices of the GPA teams and how truly global the enterprise has become in a relatively short period. Our Work Streams, under the leadership of Darren Ashcroft and Matthias Augustin, are now producing novel data, presented at international scientific meetings and in the process of submission for publication. Thus, we have new information on the worldwide epidemiology of psoriasis and on the access to psoriasis care in Latin America. The humanistic aspects of the GPA work are brought to life by Dr Tatajana Maul's journey through South America on behalf of the GPA. We also have grant funding to expand our work into Sub-Saharan Africa an area that our systematic review highlighted as having a dearth of data on psoriasis prevalence.

All of this will be encapsulated by the launch of the web-based Atlas in October of this year. Watch this space – the Atlas is moving rapidly.

With my best wishes,

**Professor Chris Griffiths OBE** Director, Global Psoriasis Atlas

www.globalpsoriasisatlas.com

🎾 @PsoriasisAtlas

GPA







# Vision

The Global Psoriasis Atlas is the leading epidemiological resource on psoriasis globally; thus informing research, policy and health care provision for the disease worldwide.

# Mission

The mission of the Global Psoriasis Atlas (GPA) is to provide the common benchmark on the complete burden of psoriasis in all countries and regions throughout the world. The GPA will leverage existing data from publications and registries; where gaps are identified, additional studies will be commissioned. The GPA is a long-term project that seeks to drive continuous improvement in the understanding of psoriasis and to uncover how it affects both the individual and society at large. Whilst the first edition of the GPA will focus on the incidence and prevalence of psoriasis, future additions will be expanded to include access to treatment, comorbidities and cost to society.

GPA

www.globalpsoriasisatlas.co



## Global Impact

The GPA will maximise the value of epidemiological research into psoriasis by facilitating international collaboration and greater standardisation in study methodology whilst meeting the highest scientific standards for epidemiological data collection and estimation.

The scope of this project incorporates scientific publications including: a methodology paper and; studies conducted to form a foundation for development of the GPA.

The two phases are designed to allow comparisons of the incidence and prevalence of psoriasis between populations in different countries, and create a first time global 'picture' of the disease burden.

#### Through two work streams we will:

- conduct an extensive systematic review of currently available literature with the desired outcome of a publication(s) in suitable high impact journal(s).
- determine a methodology to serve the framework for compiling the GPA, thus providing a Standard Operating Procedure to execute the GPA under a "hub and spoke" model.

As a team we are all committed to pursuing the goal of the atlas, which is to ensure that people with psoriasis have access to the best available care wherever they live.

**Rebekah Swan**, **Programme Manager** 

## The Collaborating Organisations

The GPA is a collaboration between three leading international organisations in world dermatology: International Federation of Psoriasis Associations (IFPA); International League of Dermatological Societies (ILDS); and International Psoriasis Council (IPC).



#### The International **Federation of Psoriasis** Associations (IFPA)

IFPA is a nonprofit organisation comprising psoriasis associations from around the world. IFPA unites psoriasis associations so that their global campaign for improved medical care, greater public understanding and increased research will improve the lives of people who live with psoriasis and psoriatic arthritis.

To learn more about IFPA please visit www.ifpa-pso.org



#### The International League of Dermatological Societies (ILDS)

ILDS is a non-governmental organisation that brings together over 170 member societies from more than 80 countries.

It was formed to:

- Stimulate the cooperation of societies of dermatology and societies interested in all fields of cutaneous medicine and biology throughout the world
- Encourage the worldwide advancement of dermatological education, care and sciences
- Promote personal and professional relations among the dermatologists of the world
- Represent dermatology in commissions and international health organisations
- Organise a World Congress of Dermatology every four years
- To learn more about ILDS please visit www.ilds.org





#### The International **Psoriasis Council (IPC)**

Founded in 2004, the International Psoriasis Council (IPC) is a dermatology-led, voluntary, global, nonprofit organization with a network of more than 100 psoriasis experts, thought leaders, and professionals, dedicated to improving patient care around the globe.

Our vision is a world free of psoriasis. We believe that psoriasis patients, no matter where they live in the world, no matter how complex their symptoms, should have access to the best care available to them, and that ultimately a world without psoriasis is possible.

Our mission is to improve the care of people with psoriasis world-wide through education, research and advocacy.

To learn more about IPC please visit www.psoriasiscouncil.org

## Structure and Governance



### GPA and the World Health Organization

In 2014, Member States recognized psoriasis as a serious non-communicable disease (NCD) in the World Health Assembly resolution WHA67.9

The resolution highlighted that many people in the world suffer needlessly from psoriasis due to incorrect or delayed diagnosis, inadequate treatment options and insufficient access to care, and because of social stigmatization. The resolution requested that WHO publish a global report on psoriasis, including the global incidence and prevalence, emphasizing the need for further research on psoriasis.







www.globalpsoriasisatlas.com

### Work Stream 1 Progress





Darren Ashcroft

Ireny Iskanda

I am delighted to report that we have taken some major steps forward this year in Work Stream 1. Specifically, we have made excellent progress in completing two extensive systematic reviews.

The first is the largest ever review examining the international data on the incidence and prevalence of psoriasis from population-based studies. This has involved extensive searches of 11 electronic and regional databases, with over 130 studies now identified examining the prevalence of psoriasis. We have also completed a second detailed systemic review examining the risks of developing or dying from cancer among people with psoriasis. These are important data resources that will underpin the development of the Global Psoriasis Atlas.

We have worked closely with our GPA Regional Coordinators to identify electronic health record data sources, with clear plans to take forward new studies examining the epidemiology of psoriasis. Specifically, we have recently completed new work reporting on time trends in the incidence and prevalence of psoriasis in Israel, in collaboration with Professor Arnon Cohen. Planning for further new research studies in other countries is well underway too. We having been working closely in partnership with the ILDS and have recently received additional funding support from the UK Global Research Challenge.

This support will allow us to spend time at the Regional Dermatology Training Centre in Moshi, Tanzania later this year to better understand the healthcare systems and data collection methods throughout Sub-Saharan Africa. We are very grateful to all our international dermatology colleagues who have recently completed the e-Delphi survey that we launched to establish consensus on clinical examinationbased diagnostic criteria for psoriasis in adults. We are looking forward to reporting on all these new insights in the coming months, and implementing the diagnostic criteria in our international field studies.

Darren Ashcroft

### Epidemiology of psoriasis

Psoriasis is a common disease which can occur at any age, equally in men and women. The disease is more common in adults than children. The estimates in children vary between 0.7% (Augustin et al, 2010) in Europe to almost none in Asia (Chen et al, 2008; Yang et al, 2007); whereas the prevalence of psoriasis in adults can affect up to 8.50% in Norway (Bo et al, 2008). The variation in the prevalence of psoriasis has also been linked to geographical location, being less common in countries closer to the Equator (Egypt, Sri-Lanka, Taiwan) and compared to countries more distant from it (Europe, Australia and North America) (Parisi et al, 2013). Existing literature also highlights that variation in estimates might be due to different methologies in aspects of study design, such as definitions of prevalence, diagnostic methods and age groups studied (Parisi et al, 2013).

Despite the number of studies aiming to estimate the prevalence of psoriasis in different countries of the world, research on the incidence of the disease is still limited. Incidence appears to be higher in Europe (Egeberg et al, 2017; Springate et al, 2017) than in the USA (Eder et al, 2019; Icen et al, 2009) and increased with age.

Findings have consistently reported an increasing trend of the prevalence of psoriasis (Danielsen et al, 2013; Eder et al, 2019; Egeberg et al, 2017; Springate et al, 2017), whereas existing studies on the incidence of psoriasis have yielded conflicting results with an increasing (Egeberg et al, 2017; Icen et al, 2009) or decreasing (Springate et al, 2017) trend of the disease over time. We have worked closely with our GPA Regional Coordinators to identify electronic health record data sources, with clear plans to take forward new studies examining the epidemiology of psoriasis.

Darren Ashcroft, Lead, Work Stream 1





### Work Stream 1 **Progress**

#### Summary of results from a systematic review on the global epidemiology of psoriasis

One of the key aims of the Global Psoriasis Atlas is to inform on the worldwide epidemiology of psoriasis. This process was performed in two stages. The first stage consisted of carrying out a systematic review of the incidence and prevalence of psoriasis by searching and identifying all the available published literature; the second stage consisted of developing a statistical model able to use the data from the systematic review and generate a single estimate of the prevalence of psoriasis for each country of the world.

Eleven electronic and regional databases (MEDLINE; EMBASE, Web of Science, SciELO, Korean Journal Database, and Russian Science Citation Index. Regional databases: WPRIM. SaudiMedLit. Informit, IndMed and HERDIN) were systematically searched from their respective inception dates to November 2017. Eligible studies reported data on individuals with

psoriasis from the general population and provided sufficient details to calculate the prevalence and/or incidence rates. No restriction on the type of population regarding age, gender and severity of psoriasis or regarding type of diagnosis (self-reported, physician diagnosis or dermatologist diagnosis) was applied. Studies from any country of the world or in any language were included provided they met the inclusion criteria. All included studies were critically appraised for the risk of bias using a validated tool (Appraisal tool for Cross-Sectional Studies [AXIS]). Variations in the incidence and prevalence of psoriasis according to age, gender, diagnostic methods (dermatologists, physician or self-reported diagnosis), geographical region, and type of estimate (point, period or life-time prevalence) were explored.

In total 30,461 records were identified from searching the databases and 139 papers were critically appraised. Fourteen studies reported on the incidence of psoriasis, while 131 reported on its prevalence from 32 countries (Figure 1).

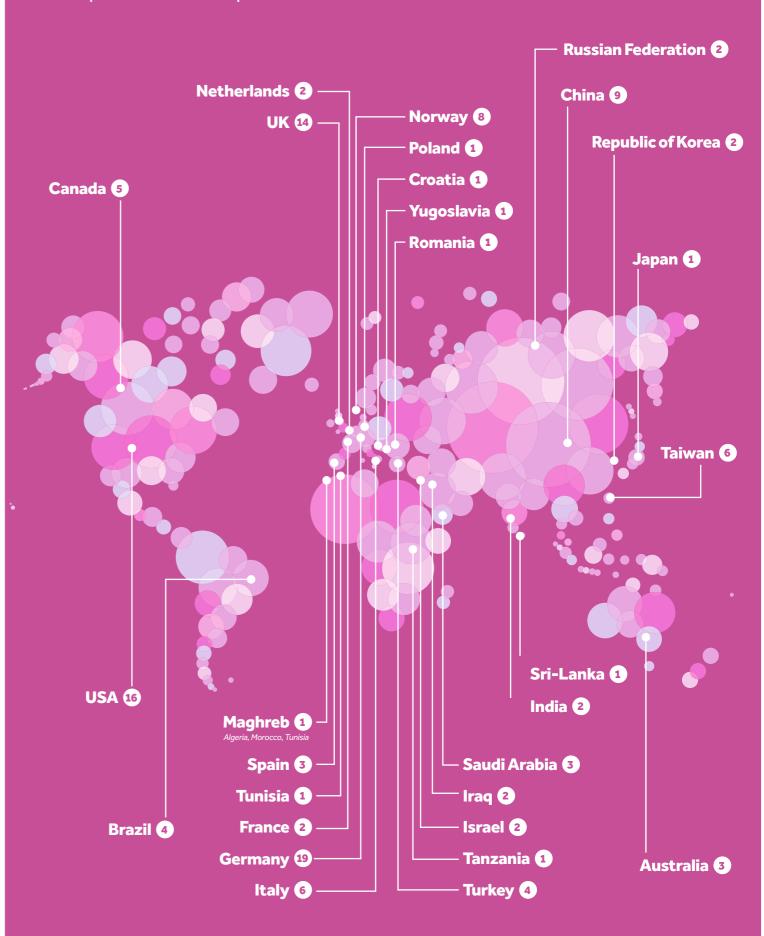
Of the 131 studies that report on the prevalence of psoriasis: 25 studies reported on the prevalence of psoriasis in children; 47 studies reported on the prevalence of psoriasis in adults; and 64 studies reported on the prevalence of psoriasis in the overall population (Figure 2). Of the 14 studies that report on the incidence of psoriasis: 2 studies reported on the incidence of psoriasis in children; 5 studies reported on the incidence of psoriasis in adults; and 7 studies reported on the incidence of psoriasis in the overall population (Figure 3).

Existing studies highlighted marked variation in the occurrence of psoriasis according to age, diagnostic method, and type of prevalence estimate. In addition, geographic location and ethnicity were important contributing factors being more frequent in white Caucasians and countries at higher latitude. Despite existing epidemiological studies, there is still a need for future international collaborations using standardized methodology to address knowledge gaps that exist about trends in the prevalence and incidence of psoriasis over time.

36%



Figure 1: Distribution of studies reporting on the prevalence and incidence of psoriasis



## Work Stream 1 Progress

#### **Statistical modelling**

Using the results from the systematic review, only studies reporting on the prevalence of psoriasis were included in the statistical analyses. The total number of studies on the prevalence of psoriasis was 131, however due to studies reporting on overlapping data sources only 101 single data points were included in the statistical model (Figure 4).

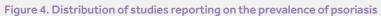
The first step was to map countries according to the classification used by the Global Burden of Disease. Here, countries are nested into regions and regions in super-regions, therefore the world map is divided in 191 countries nested in 21 regions nested in 7 super-regions (Figure 5); grouping of which is based on income. This clustering was helpful in order to inform and generate estimates for countries with missing information.

A Bayesian statistical framework was used in order to model the data. This is the preferred statistical method when data is sparse and the level of heterogeneity is high (Figure 6). Taking into account the wide age groups (such as children, adults or overall population) of prevalence estimates and variability across studies, the statistical model generated an estimate of the prevalence of psoriasis for the overall population for each country of the world.

The first set of results highlighted that as much as 83% of the countries of the world lack estimates and information on the epidemiology of psoriasis (Figure 6).

Despite the advanced statistical methods used, challenges still remain in the reporting of epidemiological studies of psoriasis in the published literature. For example, studies don't always provide raw numbers for people with the disease or breakdown by age groups.

The prevalence of psoriasis appears to vary according to genetic background and geographic location. Therefore, the prevalence of psoriasis is more common in high-income countries North of the Equator and less common (except Australasia) in less developed countries South of the Equator.



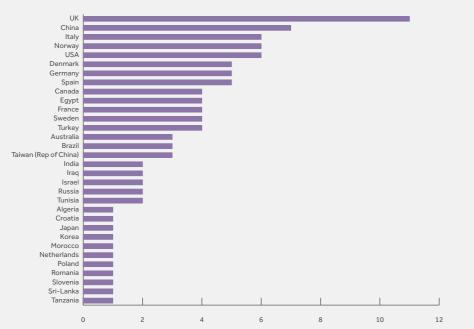
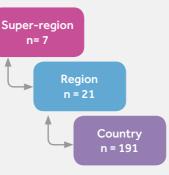


Figure 5. Classification of countries used in the statistical model





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Egeberg A, Skov L, Gunnar G, Thyssen J, Mallbris L (2017). Incidence and Prevalence of Psoriasis in Denmark. *Acta Dermato-Venereologica*: 808–12.

Icen M, Crowson CS, McEvoy MT, Dann FJ, Gabriel SE, Maradit Kremers H (2009). Trends in incidence of adult-onset psoriasis over three decades: a population-based study. *Journal of the American Academy of Dermatology* 60: 394-401.

### Figure 6. Countries reporting on the prevalence of psoriasis and countries with no information

Parisi R, Symmons DPM, Griffiths CEM, Ashcroft DM (2013). Global Epidemiology of Psoriasis: A Systematic Review of Incidence and Prevalence. Journal of Investigative Dermatology 133: 377-85.

Springate DA, Parisi R, Kontopantelis E, Reeves D, Griffiths CEM, Ashcroft DM (2017). Incidence, prevalence and mortality of patients with psoriasis: a U.K. population-based cohort study. *British Journal of Dermatology* 176: 650-58.

ang YC, Cheng YW, Lai CS, Chen W (2007). Prevalence of childhood acne, ephelides, warts, atopic dermatitis, psoriasis, alopecia areata and keloid in Kaohsiung County. Taiwan: a community-based clinical survey. *J Eur Acad Dermatol Venereol* 21: 643-9.

### Global Collaborations: Israel

Work Stream 1 of the Global Psoriasis Atlas (GPA) has been working in collaboration with Dr. Yochai Schonmann and Professor Arnon Cohen.

Yochai is a General Practitioner at Clalit Health Services and an epidemiologist, with a special research interest in analyses of routinely collected data of skin diseases. Professor Arnon Cohen is the director of the Department of Quality Measures and Research and head of the Dermatology Service (Southern Region) of Clalit Health Services in Israel. He is a professor at the Faculty of Health Science at Ben-Gurion University, Israel and also a regional coordinator for the Global Psoriasis Atlas.

Together they performed a study on the descriptive epidemiology and comorbidities of psoriasis in Israel, looking at the trends of psoriasis incidence and prevalence in Israel during 2011-2017. It was observed that, whereas the annual psoriasis incidence rate remained prevalence is on a substantial rise (from 2.5% in 2011 to 3.9% in 2017). This important observation demonstrates the increased burden of psoriasis and mandates the importance of allocation of public health resources to the research and treatment of psoriasis. The preliminary findings were presented to the GPA executive team and a number of Regional Coordinators at a meeting in Stockholm, Sweden in June, 2018. Dr Yochai Schonmann and Professor Arnon Cohen are currently working on describing risk

factors and outcomes of psoriasis by

age of psoriasis onset.

identical over the years (280 per

100,000 person-years), psoriasis



Dr Yochai Schonmann



Professor Arnon Cohen





It was observed that, whereas the annual psoriasis incidence rate remained identical over the years (280 per 100,000 person-years), psoriasis prevalence is on a substantial rise (from 2.5% in 2011 to 3.9% in 2017).

## Work Stream 2 **Progress**





of the Global Psoriasis Atlas in 2019.

Matthias Augustin

Nirohshah Trialonis-Suthakharan

We are pleased to present the Work Stream 2 progress with development of the Global Psoriasis Atlas (GPA). We are currently engaged in finalizing the results of the subprojects, global desk research and GPA online survey, all of which identified data sources.

From desk research, we identified 687 single sources which were further classified based on whether they provided information on psoriasis or not. Of 687 data sources, only 44% had psoriasis specific information from 139 countries and provided contact or potential Data source information. data sources were health ministries, national registries, NGO's, statistical/ public health and research institutes and claims data. They were reviewed for accessibility, methodologies and data quality. The GPA online survey focused on dermatologists was developed and a pilot trial was conducted to validate it. It was sent

to a maximum of 5 dermatologists per country. 44 countries responded to the survey and the analysis shows that there is no suitable data collection system (in most countries). Due to lack of quality data from many countries, it was decided to conduct field studies.

Parallel to this, our team completed the analysis of the field study on psoriasis healthcare in 16 Latin American countries. In total, 76 surveys were received and, out of these, 71 were included in the final analysis. For any doubtful or incomplete information, the dermatologists were contacted back and the respective corrections were made. Currently, we are in the process of evaluating the PsoHealth survey on psoriasis treatment. A total of 93 surveys were returned from two centres in Chile. Each survey represents data from one patient. We are looking forward to presenting significant results of these subprojects in the first version

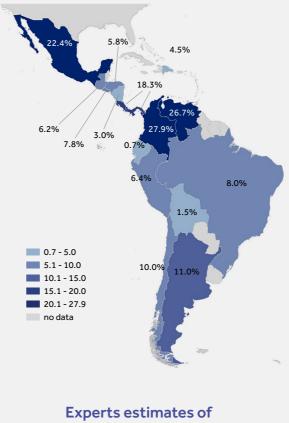
Furthermore, Work Stream 2 is currently engaged in web meetings with the regional coordinators and several other dermatologists around the world to obtain more detailed information on the country-specific profile and to begin field studies in the rest of the world. These subprojects will help us attain our prime objective of developing epidemiological field studies. A thorough understanding of potential data sources, the health care system and treatment of psoriasis in each country is required to define the gaps in the data. Based on this understanding, a methodology for field studies on the epidemiology of psoriasis will be developed and implemented. In addition, technologies for data adaptation and interpolation (e.g. for hard-toreach areas) will be developed and incorporated into the GPA.

**Matthias Augustin** 

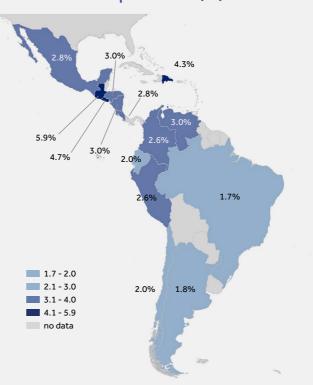
Work Stream 2 is currently engaged in web meetings with the regional coordinators and several other dermatologists around the world to obtain more detailed information on the country-specific profile and to begin field studies in the rest of the world.

Matthias Augustin, Lead, Work Stream 2

Proportion of dermatologists prescribing biologics (%)

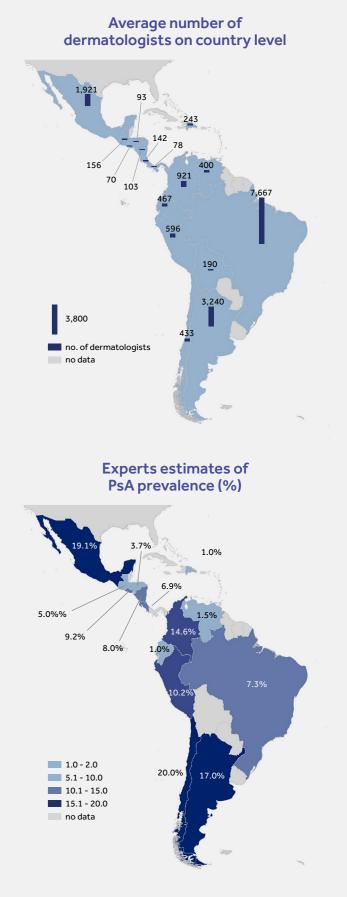


Psoriasis prevalence (%)





With the support of PsoNet, Dr. Julia-Tatjana Maul was funded for her three month trip to Latin America to collect data on the health care of psoriasis on behalf of the GPA.

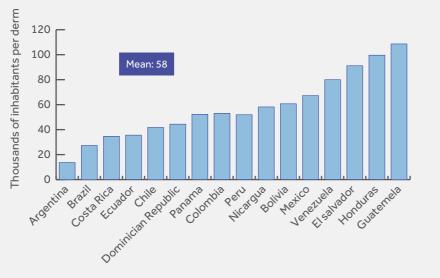


## Work Stream 2 Progress

#### Latin America (LA) -Health care Survey Results

Average number of inhabitants per dermatologist was calculated by taking the ratio of population of each country and the mean number of dermatologists observed in the survey, shown in Figure 1.

Figure 1. Average number of inhabitants per dermatologist in LA



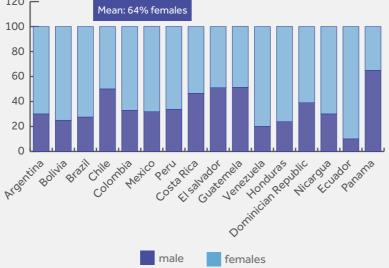
#### **Gender differences**

Figure 2 shows that about 64% of all dermatologists are female. Other than Panama, which has a higher percentage of male dermatologists, all other countries had an equal or higher percentage of female dermatologists.

Data pending for the following countries: Paraguay, Uruguay, Cuba or Puerto Rico. Hard to reach areas include: Belize, Guyana, French Guianna, or Suriname.

120 r Mean: 64% females

Figure 2. Percentage of male and female dermatologists in LA countries



#### Waiting times

Regardless of simple and effective formal access to dermatology health care, treatment by a dermatologist can be limited by long waiting times. We evaluated the waiting times for regular visits in different Latin American countries.

Regular visits: Waiting period was zero for regular visits in Dominican Republic as seen in Figure 3. In some countries there was waiting period exceeding 3 months like Costa Rica (98 days), Ecuador (135 days) and Guatemala (145 days).



#### Drug prescription by dermatologists

Since drug prescription might differ depending on the structure and financing of health systems as well as the patient population treated by dermatologists, we have tried to get distinct information about the proportion of dermatologists prescribing topical drugs, individual formulations, systemic drugs and biologics for psoriasis treatment. Descriptive statistics for all 16 LA countries are summarized in Figure 4.

- Topical drugs are prescribed by almost all the dermatologists in LA
- Only 11% prescribe biologics for psoriasis

National guidelines for

**Treatment of Psoriasis** 

Data about the availability of a national guideline was collected in all 16 countries. As seen in Figure 5, 37 dermatologists responded that a national guideline exists in their country. Data was limited by the participants' knowledge about the guideline.

**37** (52%)

### 150 -

120

90

60

30

dav

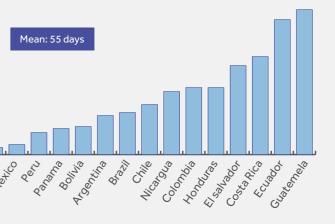
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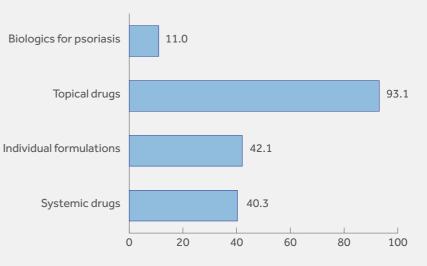


dermatologists

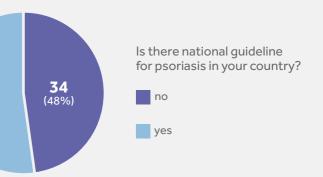


#### Figure 3. Average waiting period for an elective appointment with a dermatologist

Figure 4. Percentage of dermatologists prescribing the different types of drugs in LA



#### Figure 5. Responses to question on if there is a national guideline in a country



# Showcasing **Performance**

Year 2

#### We collaborate

Through collaboration with our regional coordinators and dermatologists from around the world, we can identify priority areas for future research.

#### We research and develop

Through our research, we can identify gaps in understanding and develop methodology/ research tools to support future international field studies examining the epidemiology of psoriasis.

#### COLLABORAN Maximising MPAC7 the value of epidemiological research

GPA

Year 1

#### Our impact

DEVELOD Through our work, we will uncover the true burden of psoriasis worldwide and work towards enabling people with psoriasis to access the best available care wherever they may reside.

#### Work in progress

Submission and publication of the systematic review on incidence and prevalence of psoriasis.

A methodology for field studies on the epidemiology of psoriasis will be developed and implemented.

Implementation of an international e-Delphi exercise to develop diagnostic criteria for psoriasis in adults (aged 18 years and above).

#### Meeting the Milestones in Year 2

In March 2019, the prototype "Global Psoriasis Atlas" was launched at the GPA Steering Committee, Board and Funders meetings at the AAD in Washington DC. This prototype atlas is based on findings from the updated and extended systematic review.

We have completed a second large-scale epidemiological study, using electronic health care datasets, in collaboration with colleagues in Israel.

Through our work, we will uncover the true burden of psoriasis worldwide and work towards enabling people with psoriasis to access the best available care wherever they may reside.

### PhD Q&A: Peslie Ng'ambi



#### Where were you born and where did you go to school?

I was born and went to school in Lusaka, Zambia,

I did my undergraduate at the University of Zambia, school of medicine where I pursued a Bachelor of Pharmacy degree (BPharm) from 2006 to 2011. After graduating I joined the Ministry of Health-Zambia as a Pharmacist where I worked for 3 years before embarking on my postgraduate. In 2014, I enrolled for a Master of Science (MSc) in International Pharmacoeconomics and Health Economics at Cardiff University (UK), school of pharmacy and pharmaceutical sciences. Although this programme was offered by Cardiff University, it was delivered by the Fresenius University of Applied Science (Germany), School of Business and Media studies.



Whilst the 1st edition of the GPA will focus on incidence and prevalence of psoriasis, future editions will be expanded to include access to treatment. comorbidities and cost to society.



#### How did you decide to go into the field of **Health Economics?**

My days as a pharmacist saw me working in a hospital, community pharmacy and later as a district pharmacist where I explored aspects of health care financing and resource allocation. It was a combination of all these factors that got me interested in pursuing a deeper understanding of health systems as a whole, resource allocation and financing. After a search for several programmes, I became fascinated with what health economics offered.

#### What made you specialise in psoriasis?

I have a keen interest in quantifying the economic impact of illnesses and when I got a chance to work on psoriasis I took it. This interest in psoriasis and the impact it has on peoples' lives led me to pursue a PhD in this area.

#### How did you get involved with GPA?

It was in 2017, whilst working as a research associate in the Manchester Centre for Health Economics, that I was informed about the Global Psoriasis Atlas. My line manager asked me if I was interested in applying for this PhD and I started my studies in September 2018.

#### How will your research contribute to GPA?

My research aims to quantify how much psoriasis (ill health) economically impacts on individuals, households, firms and governments. Of particular interest is the impact of psoriasis on people's participation in income generating activities (productivity) as well as healthcare expenditure. This research will establish methods of identifying, measuring and valuing how psoriasis impacts on people. Quantifying the economic impact of psoriasis will help in casting a spotlight on the disease. In addition, this will contribute to information required by the GPA to advocate for improved access to treatment for people in different settings.



#### What inspires you the most every day in your work with GPA?

It's the enthusiasm of everyone on the team and the professional diversity of the members. The common goal that we are all working towards is in itself inspiring. The passion that people share and the anticipation of the difference we aim to make to contribute to easing the burden of psoriasis patients. The global nature of the organisation is yet another thing that inspires me because I know the knowledge we generate is not bound by national borders.

## **Fellowships**

#### International Psoriasis Council Fellowship 2018

The GPA was fortunate to host Daniela Armijo as part of her IPC Fellowship.



Daniela said..

It was a great experience to get involved in the Global Psoriasis Atlas project during my clinical observation period in Manchester, mentored by Professor Griffiths.

During this period I had the pleasure of meeting Rebekah Swan and the Work Stream 1 team at The University of Manchester. There, I learnt about the interesting research work that has been carried out by Professor Darren Ashcroft, Dr Rosa Parisi and Dr Maha Abo-Tabik. I also had the honour of being invited to participate in the meeting for the GPA website development, which was fascinating. I also had the opportunity to meet Nirohshah Suthakaran at Hamburg and Dr Julia-Tatjana Maul in Zurich, members of the Work Stream 2 team.

In Hamburg, I visited the CVderm department and the University Medical Centre Hamburg-Eppendorf, where I learnt about data collection and data processing.

Working with Dr Julia-Tatjana Maul was a wonderful experience. During her trip throughout Latin America, we worked together collecting data, from the University of Chile, on patients with psoriasis. During my stay in Manchester, I visited the hospital where she works in Zurich and we worked together there for three days.

I'm very grateful to have had the opportunity to meet the GPA team and to get involved with the project. I think it is a great initiative that will provide important information about the prevalence and burden of psoriasis, which is essential to improve the access to both, the health care systems and to the best available treatments.

#### International Psoriasis Council Fellowship 2019

We are delighted that Dr Julia-Tatjana Maul has been awarded the 2019 IPC Fellowship.

Dr Maul will complete her fellowship in Latin America in 2020. She has already contributed to the Global Psoriasis Atlas through a 3-month study of psoriasis epidemiology and access to healthcare for psoriasis patients in South America.

Dr Maul will be placed with Professor Ricardo Romiti of the University of São Paulo, Brazil and Dr Claudia de la Cruz of Clinica Dermovein in Santiago, Chile. Dr Maul will attend the Reunión Anual de Dermatólogos Latinoamericanos (RADLA) in Buenos Aires, Argentina as a part of the fellowship program.



I'm very grateful to have had the opportunity to meet the GPA team and to get involved with the project. I think it is a great initiative that will provide important information about the prevalence and burden of psoriasis.

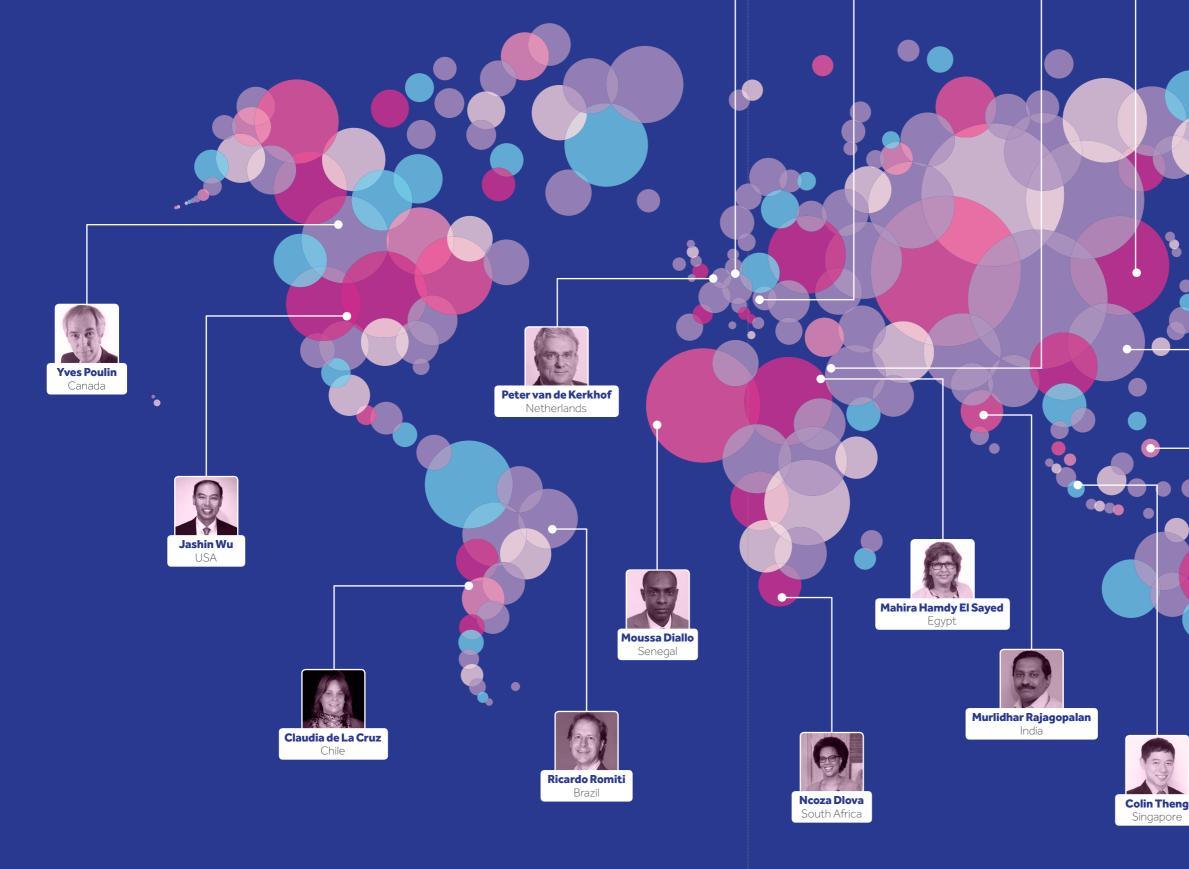
Daniela Armijo











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# Regional Coordinators **Updates**

### Xuejun Zhang

**Report from China** We are on the way

to fight against psoriasis in China

We all know that psoriasis is a serious global problem that is endangering human health. Currently, there are more than 100 million people with psoriasis in the world, and more than 6 million in China. Due to wrong diagnosis, untimely diagnosis, inappropriate treatment, inadequate medical care and social bias, many psoriasis patients suffer unnecessary pain.

To promote the development of psoriasis prevention and treatment, and improve the life quality of psoriasis patients in China, the Psoriasis Committee of Chinese Society of Dermatology (CSD) was founded in 2002. I was selected as the fourth chairman of the committee. The Psoriasis Committee has held more than 60 psoriasis health education activities all over China, which is also called "Dandelion Action". As well as this, we have held 2 sessions of the Chinese Psoriasis Conference and Hundreds of Chinese Dermatologists and Thousands of Psoriasis Patients Free Face to Face Consultation and Clinic Service, in Hefei on October 2017 and 2018. There were more than 500 psoriasis experts from the dermatology departments of nationwide hospitals present. Many media representatives and nearly one thousand psoriasis patients also attended the academic conference and volunteer activities. Up to now,

we have developed 20 National Specialised Psoriasis Demonstration Clinics and nearly 200 Specialised Disease Clinics for Psoriasis in China. However, there isn't a nationwide epidemic study of psoriasis in China at this point.

It is a good opportunity for us to join the project of the Global Psoriasis Atlas (GPA). This project will inform research, policy and health care provision of psoriasis. It is a long, difficult and meaningful task and my colleagues and I are ready to meet the new challenges.



**Report from Egypt** 

#### The problem of psoriasis in Egypt has recently gained interest among general dermatologists due to increased awareness among both patients and physicians.

In a population of 100 million people, there are roughly more than 2-3% of people afflicted with psoriasis, distributed all over the country among both rural and urban areas.

Psoriasis in Egypt is associated with several co-morbidities and is also seen frequently among children. Our main problem is the lack of registries, except a few present in the main university hospitals and referral centres where they run regular psoriasis clinics. There is a very heavy burden of the disease with lack of funding for the newer biological treatment, so there are a lot of unmet needs concerning epidemiological studies and management strategies.

GPA

Nirohshah Suthakharan, researcher for Work Stream 2 along with Professor Matthias Augustin and Professor Marc Radtke, started by recruiting dermatologists from Egypt to help with the different preliminary surveys. We have received 3 questionnaires; 2 to be filled in by dermatologists and the 3rd for patients. After studying the surveys in detail with Dr Sherry Labib, a dermatologists from Egypt, we amended some of the questions to suit our part of the world and we will also translate the patients' questionnaire to Arabic.

We are very excited about starting our work here in Egypt and will recruit more dermatologists to help with the surveys.

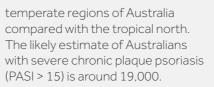
#### **Chris Baker**

#### **Report from Oceania** Diverse multicultural populations

#### characterise the people who live in the countries of our region.

Limited data are available on the true incidence and prevalence of psoriasis in the Australasian region and this highlights the need and value of the Global Psoriasis Atlas. Regional dermatology colleagues and I are pleased to be contributing to this important initiative.

It is estimated that 700,000 Australians suffer from psoriasis (prevalence of 2-3%) and a slightly lower prevalence in the Australian Aboriginal and Torres Strait Islander people (1.3%). There are higher rates of psoriasis prevalence and severe psoriasis reported in the southern



Recently, the Australian Government completed a review of psoriasis to analyse the post market use of biologic therapies. The review was far reaching and critically looked at available epidemiological data on psoriasis in this country, geographical patterns, disease subtypes and severity, and treatment patterns. This was a useful current assessment of psoriasis in the Australian population.

Valuable real world data on patients with moderate to severe psoriasis is being collected in the Australasian Psoriasis Registry (APR). This is an online registry is currently available for use by dermatologists in Australia and New Zealand and was established by my colleagues and I in 2008. There are over 2,000 patients registered and important information on life impact of psoriasis and associated comorbities, as well as geographical variation, are being collected and will provide a valuable contribution to the GPA

The findings of the Government review, APR registry outputs and other local initiatives, we expect, will provide useful information to demonstrate the breadth, distribution and patient impact of psoriasis in our region. This information will add to the world picture of psoriasis that is the GPA.

#### Claudia de La Cruz

**Report from** Latin America



#### Last year was a very productive year for Work Stream 2 of GPA in Latin America.

We have started to consolidate our work team and we have achieved some significant advances as a result of this.

Last year, the first survey on availability of epidemiological information at regional level was performed which was a major milestone. This was the first objective measure that allowed us to quantify the epidemiological gap among the region with the rest of the world. This difference in epidemiological data was finally transferred into access and opportunities to care. None of the countries have national registries of psoriasis and information comes mainly from academic research. In most cases, population level studies have 20 or more years of publication. Regarding this, we have stretched bonds with local researchers to offset this issue

In association with the Center of Medical Informatics of University of Chile, we have calculated the first estimation of incidence rates at a population level for one of the countries of the region (Chile). The results corroborate the established observation that in Latin America, incidence rates could be lower than in Europe. We also observe an increase of the rates as we move toward the pole. It still has to be elucidated whether this has a genetic, environmental and/or methodological component. The preliminary results will be presented in the next World Congress of Dermatology in Milan 2019.

For three months, Dr Tatjana Maul from Zurich, traveled through Latin America, visiting Chile, Argentina, Bolivia, Brazil, amongst others. She visited hospitals, contacted





dermatologists and patients, studying how psoriasis is treated in these regions. She identified many differences and barriers amongst the different countries therefore making a very important network for future research. Her work was very productive and will continue through 2019.

Additionally, in collaboration with the International Psoriasis Council, we conducted a survey to study the access to biologics therapy in developing countries, including many Latin American countries. The response from dermatologists showed us the following facts: in almost every Latin American country there is at least one option of biologic therapy available. Nevertheless, price and lack of insurance coverage are still the main barrier in every country. Even though some countries have biosimilars available, the differences in price with the innovator drugs is less than 20%, so it has no impact on the accessibility of treatments for psoriasis patients.

We are delighted with what has already been achieved and we are excited for our future endeavors. As psoriasis is such a relevant and heavy burden disease, we are optimistic about how we are getting close to the scope of the Atlas in this second iteration and how the project is getting into shape globally. We hope to get in touch with relevant stakeholders in the public health domain very soon to convert this initiative into concrete interventions for our patients.

### PhD Q&A: Maha Abo-Tabik



#### Where were you born and where did you go to school?

I was born and went to school in Baghdad, Iraq.

#### How did you decide to go into the field of dermatology/ epidemiology?

I graduated in medicine from the University of Baghdad, in 2012, with a MBChB degree. My passion to pursue a career in dermatology started mainly during my undergraduate studies. After graduation I practiced medicine for three years in Baghdad as a junior doctor. During this time my interest in dermatology increased and so as I was planning the early steps of my career path, I decided also to gain academic and research experience in addition to being a clinician. In 2015 I applied to study an MSc in clinical dermatology at the University of Hertfordshire and I have been awarded with the Chevening scholarship award which is the UK Government's international awards scheme aimed at developing global leaders. I graduated from the University of Hertfordshire in 2016 with a distinction.

#### What made you want to specialise in psoriasis?

Psoriasis was one of the main focuses during my master studies.

#### How did you get involved in the Global **Psoriasis Atlas?**

As I was applying for PhD at the University of Manchester, I got in touch with Professor Griffiths because I was very interested in his work on psoriasis. He suggested that my PhD project could be part of the GPA and this was a great opportunity for me because it would not only improve my skills as researcher but also as a team member in a large project aimed at providing a global benchmark for psoriasis.

#### How will your research contribute to the Global **Psoriasis Atlas?**

My research project aims to examine the epidemiology of psoriasis. Currently I am working on developing and piloting training tools to support the accurate diagnosis of psoriasis. These tools can then be applied to help determine the disease burden associated with psoriasis, taking account of patient demographic characteristics.

#### What challenges have you faced during your research?

The main challenge is the knowledge gap that has been identified during my review of the literature, as to date there is no valid clinical examination-based diagnostic tool for psoriasis. Previous literature suggested a wide range of diagnostic tools for psoriasis but none of these were clinical examination-based diagnostic criteria.

#### How did you overcome these challenges?

We are conducting an e-Delphi study, in association with the International Psoriasis Council, to develop diagnostic criteria for psoriasis. As the evidence is scarce we need to rely on expert opinion to build a diagnostic tool and the developed tool will then be validated in a separate validation study.

#### What do you hope your project will achieve?

I hope that the developed diagnostic criteria will be applied in future epidemiological studies of psoriasis.

#### What inspires you the most every day in your work with the GPA?

is the team work spirit and that everybody is willing to help to achieve better results in a short period of time. In addition, the concept that the GPA work is not only about recording numbers of patients with psoriasis worldwide but it is about finding solutions to help reduce the burden of psoriasis globally.



The thing that inspires me the most

"

*My* research project aims to examine the epidemiology of psoriasis. Currently I am working on developing and piloting training tools to support the accurate diagnosis of psoriasis. These tools can then be applied to help determine the disease burden associated with psoriasis.



### GPA in **Tanzania**

#### The UK government provided £1.5 billion to support projects in developing countries.

A portion of this money had been devolved to The University of Manchester from the Global Challenges Research Fund (GCRF) and we have successfully secured a grant of almost £40,000. We will be taking a team of approximately 10 people to Moshi, Tanzania, to the Regional Dermatology Training Centre (RDTC). Working with students and staff at the RDTC, we plan to carry out workshops on the GPA, teach research methods in epidemiological studies and also carry out



small surveys on psoriasis prevalence in and around Moshi. We have received support for this research venture from Daudi Mavura, Director at the RDTC and it has been agreed that we will start work on the 8th July, 2019. Successfully securing these funds has placed us in a strong position to pursue further grant funding in the future.







Border Crossing -Echador to Colombia

University of



Psoviasis clinic under the trees: Villa Tunari, Bolivia

### Travels through Latin America

Dr Julia-Tatjana Maul, a dermatologist able to establish new collaboration from the university hospital in Zürich, Switzerland and member of the Global Psoriasis Atlas Work Stream 2, travelled through Latin America for 3 months from June to August 2018. She travelled on behalf of the Global Psoriasis Atlas (GPA) and the German psoriasis network PsoNet under the lead of Professor Matthias Augustin, University Hospital of Hamburg. Tatjana visited 10 countries and 24 cities. Her aim was to identify epidemiological data sources on psoriasis from health care data and to find out more about the common psoriasis treatments and characteristics in Latin America. The intention was to use the data gathered to contribute to the development of the Global Psoriasis Atlas.

During these 3 months, Dr Maul worked closely with Claudia de la Cruz from Santiago de Chile, Chile and Ricardo Romiti from São Paulo, Brazil. Together, they were

prospects with dermatologists from Argentina, Peru, Bolivia, Colombia, Ecuador, Uruguay, Mexico and Panama, who showed a keen interest in the GPA.

The lack of large epidemiology and treatment registries is a common issue that was found in most of Latin American countries. To solve this problem, surveys and questionnaires (PsohealthCare, PsoHealth) were developed by the WS2 team and adapted to the Spanish and Portuguese languages with the aim of collecting prospective and retrospective data. Finding new collaboration partners was not always easy so Dr Maul gave lectures in different hospitals and universities to promote the work of the GPA. As a collaboration project, a group of scientists from the Institute of Biomedical Science from the University of Chile, led by Professor Härtle and Dr Dunstan, will work on developing an artificial intelligence-

Cochabamba, Bolivia

*My trip to Latin America* wouldn't have been possible nor successful without the great help of the GPA team, especially Professor Griffiths and Professor Augustin as well as the warm welcome of the Latin American colleagues and psoriasis patients. In all host countries, I received great support and this enabled me to identify global data sources, collect raw data and find new cooperating partners. I look forward to revisiting for a 2 month follow up next year. Dr Julia-Tatjana Maul

based model to extract data from the existing electronic resources. The aim is to transfer this new technology to other Latin American countries in order to collect data more efficiently.

From June to August 2018, Dr Maul ascertained that health care pathways for patients with psoriasis were slow and there was a lack of access to systemic and biologic therapies. Access to these therapies remains limited due to the comparatively high costs in many Latin American countries. One of the main objectives of the GPA is to provide evidence for public health decision makers, as the treatment with biologics is not currently covered by health care systems in most Latin American countries. Psoriasis affects productivity, quality of life, mental health and has many comorbidities. Therefore, it is important to have this information in order to improve the access to treatment for the population.

### PhD Q&A: **Alex Trafford**



#### Where were you born and where did you go to school?

I was born in Bolton, just outside Manchester, UK. I went to a local school before going on to study Geography at Lancaster University with a year spent abroad in the US. After finishing my undergraduate degree I moved to London to complete a Master's degree at the London School of Hygiene and Tropical Medicine.

#### How did you decide to go into the field of dermatology/ epidemiology?

In the course of my time at school, I found myself most interested in both geography and biology. However, I struggled to find the right intersection between the two subjects and opted to focus on geography at university. During the final year of my undergraduate degree, I took part in a module looking at health geographies. Within this module, I was introduced to the field of epidemiology and realised that it contained both the biological and wider societal aspects that I had found most interesting during my time at school. Following a Master's degree with a significant focus on epidemiology, I decided that this was the field that I wanted to go into.

#### What made you want to specialise in psoriasis?

During my postgraduate degree I covered a large number of noncommunicable diseases and I began to realise the growing challenge that they present. Whilst exploring ways that I might be able to help work on these challenges in the future, I came across a PhD opportunity looking at psoriasis and the risk of developing cancer. At the time, my understanding of psoriasis was not comprehensive and so I decided to try to learn more about the condition. Through this research, I not only learned how many people are affected by psoriasis, but also the challenges that the condition can pose through the variety of ways in which it impacts people. Understanding these factors, and finding the enlightening stories of people with psoriasis, allowed me to see how much benefit further research could still bring.

#### How did you get involved in the Global **Psoriasis Atlas?**

I got involved with the GPA through my current PhD, which is fully supported by the project.

#### How will your research contribute to the Global **Psoriasis Atlas?**

The focus of my research is to understand the risk of developing cancer or dying from cancer in people with psoriasis. The results of this research should contribute to the future aim of the GPA to understand the comorbidities of psoriasis.

#### What challenges have you faced during your research?

The biggest challenge that I have faced so far during my research is trying to draw a single conclusion on the risk of cancer in psoriasis from a number of past studies. Although research into psoriasis in the past has been considerable, the variation in how the condition presents, from mild to severe, and the many different ways this can be classified, creates difficulty in truly understanding any associations with psoriasis. In addition to the difficulty in classifying psoriasis, trying to understand the possible roles of psoriasis-related inflammation, treatment methods and lifestyle behaviours, such as smoking, in any increased cancer risk is also challenging.

#### How did you overcome these challenges?

The challenge presented by varied psoriasis classification in previous studies was addressed through communication with other members of the GPA and consequently grouping studies according to the severity of psoriasis they considered. Understanding the roles of different factors in the association between psoriasis and cancer is much more complex and less simply overcome. In my meta-analysis of cancer risk in psoriasis, studies that controlled for lifestyle factors in their analysis were analysed separately from studies that did not in order to gain some understanding as to the influence of these factors. In future work, different methodologies will be required to best understand the roles of these factors.



#### What do you hope your project will achieve?

Most simply, I hope that my project will provide a better understanding of the association between psoriasis and cancer in order to guide further research on the topic and improve care for people with psoriasis.

#### What inspires you the most every day in your work with the GPA?

In my work with the GPA I am most inspired by the stories of people with psoriasis, and the chance to potentially influence positive changes to psoriasis care.

I hope that my project will provide a better understanding of the association between psoriasis and cancer in order to guide further research on the topic and improve care for people with psoriasis.

### Focused **Future**

Develop research tools to support future international field studies examining the epidemiology of psoriasis

#### Complete systematic reviews

Complete third large-scale epidemiological study using electronic health care datasets

Update Global Psoriasis Atlas to incorporate new evidence

Dates for the diary



#### 23rd/24th May 2019 Meeting with Leo Foundation to present the GPA

10th-15th June 2019 The World Congress of Dermatology; Regional Coordinators update meeting (Milan, Italy)

7th-12th July 2019 GPA trip to Tanzania

#### 9-13th October 2019

The GPA Board of Governors and Steering Committee will meet during the 28th Congress of the European Academy of Dermatology and Venereology (Madrid, Spain)

#### 20th-24th March 2020

The GPA Board of Governors and Steering Committee will meet during the 78th annual meeting of the American Academy of Dermatology (Denver, Colorado)

### About the **Partners**

The Global Psoriasis Atlas project is delivered by the academic project staff based at The University of Manchester and University Medical Center Hamurg- Eppendorf.



#### **The University** of Manchester

The University of Manchester's research has real-world impact beyond academia. We are at the forefront of the search for solutions to some of the world's most pressing problems, seeking to be a global force for positive change.

#### The Global Psoriasis Atlas has been supported by grants and sponsorship from the LEO Foundation, Abbvie, Eli Lilly UK and Company Limited, Novartis Pharma AG, UCB and Almirall.

Lead supporter 

LEO FOUNDATION



Engaging industry in multi year partnerships with the GPA supports our efforts to be the leading epidemiological resource on psoriasis globally. Industry partners are invited to join us bianually at our "Funders Briefing" held at the EADV and the AAD, in conjunction with the GPA meetings. Details of these meetings can be found at: www.globalpsoriasisatlas.com.











#### **University Medical Center** Hamburg-Eppendorf

Research topics and expertise, which are present at the UKE in particular, have been identified in recent years. This increasing scientific focus is supported by the Faculty of Medicine and is reflected in the research centers and joint projects at national and European level.

Other supporters











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