

Global Psoriasis Atlas

Annual Report

April 2021 – March 2022



Looking back on a year of success...

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Foreword



Our Annual Report for 2021-22 reflects the encroachment of the COVID-19 pandemic on our work.

Many of us have experienced a fundamental shift to remote working, which in turn has encouraged us to find innovative ways of working to continue to achieve our goals.

The GPA has completed the second year of Phase II and, whilst travel and movement remained restricted, we seized the opportunity to expand our global network and benefit from our National and Regional Coordinators' country-specific expertise and local knowledge. This expertise gives our research a clear advantage. We are delighted that our field survey in Eastern Greenland that was postponed from 2021 will now go ahead in May 2022.

The COVID-19 pandemic has magnified health inequalities within many societies and made our work to understand the epidemiology of psoriasis, access to care and patient experience more important than ever. In 2020, colleagues in the UK launched two linked international registries to capture de-identified data about people with COVID-19 infection and psoriasis; PsoProtect is a registry for healthcare professionals to report cases of COVID-19 in psoriasis patients (psoprotect.org) and PsoProtectMe is a survey for people with psoriasis to share how the pandemic has affected them. (psoprotectme.org). The GPA continued to support both registries throughout the past year.

Notable achievements include the work of a number of our Regional Coordinators. Cristóbal Lecaros and Claudia De la Cruz led work to examine the incidence of psoriasis in Chile. This important work, published in Clinical and Experimental Dermatology, provides the first psoriasis incidence data in Chile. April Armstrong used the HANES database to examine the prevalence of psoriasis among adults in the US and a major piece of work is underway with Choon Siew Eng to investigate for the first time, the incidence and prevalence of psoriasis in Malaysia. We have also undertaken new collaborations with colleagues in Qatar and Newfoundland, using our methodology to assist them to examine epidemiology, multi-morbidities and economic impact of psoriasis using the rich datasets available.

The GPA PhD programme has contributed significantly to our research outputs. For example, we published the findings from our international e-Delphi survey, facilitated by

International Psoriasis Council, to develop clinical diagnostic criteria for chronic plaque psoriasis, in the British Journal of Dermatology in April 2021. We are now piloting use of a training tool with UK primary health care professionals to support them in making an accurate psoriasis diagnosis. In July 2021, GPA PhD student Alex Trafford published a new study examining the concordance and timing of cancer recording between primary care, hospital and death registration data for people with psoriasis. This study underpins our extensive programme of work examining cancer incidence and mortality in people with psoriasis involving cohort studies conducted in Denmark, Israel, Taiwan and the United Kingdom. Dr Alex Trafford successfully defended his PhD viva at the end of 2021 and I would like to take this opportunity to wish him all the best in his future endeavours.

We have taken time this year to enhance our digital communications and improve the GPA website and resources. Providing data and resources for use by stakeholders to influence policymakers and to engage our supporters is at the heart of what we do. You will also read about how our research outputs support the work of our three Collaborating Organisations.

I invite you to review our results and highlights from 2021 and read how our work is continuing to gather momentum in 2022. Thanks to our collaborators and supporters, we have achieved some tremendous results in global epidemiological research into psoriasis. The GPA team are always interested in hearing from clinicians, researchers and patients about new ideas for us to investigate, please do get in contact. In the meantime, I hope that 2022 continues to move towards a more normal way of life.

Professor Chris Griffiths OBE
Director, Global Psoriasis Atlas



Mission

The mission of the GPA is to ensure that people with psoriasis have access to the best available care, wherever they live in the world.

Vision

The GPA will become the leading epidemiological resource on psoriasis globally, providing the common benchmark on the burden of psoriasis in all countries and regions throughout the world. The Atlas will seek to: drive continuous improvement in understanding the natural history of psoriasis, uncover how psoriasis affects the individual and society and improve healthcare for those living with the disease.

Areas of Research Focus: Phase II

Epidemiology of Psoriasis

Implement regular updates to our large international dataset.

Collaborate with the dermatology workstream of the Global Burden of Disease.

Provide recommendations on the core data to be included in future epidemiological studies of psoriasis.

Conduct new epidemiological studies in selected countries.

Understand and Characterise the Economic Impact of Psoriasis

Conduct an extensive systematic review on the economic burden of psoriasis.

Develop data collection tools to determine the economic impact of psoriasis.

Conduct new studies to identify, and then quantify, the use of healthcare resources and associated costs to the healthcare system.

Recognising the Comorbid Disease Burden of Psoriasis

Conduct new studies to improve knowledge about the comorbid disease burden of psoriasis with a particular focus on cancer incidence and associated mortality.

Improving the Early Diagnosis of Psoriasis

Conduct a case-control study to examine the extent of misdiagnosis of psoriasis.

Conduct validation studies of our recently developed clinical diagnostic criteria.

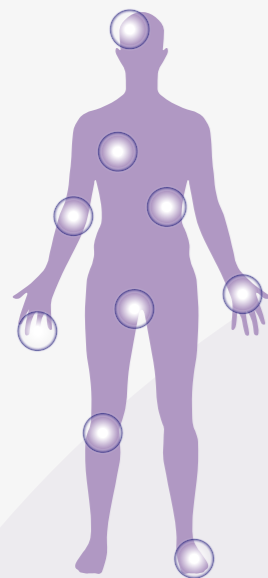
Development and feasibility testing of a training tool for psoriasis diagnosis.

GPA Highlights 2021-2022

The GPA has achieved significant success during the last year including the conduct of high-quality research, associated publications and presentations at scientific meetings.

Our ever-increasing number of collaborations with patient organisations, dermatologists and academics from around the world facilitates our field work and increases the global reach of the project.

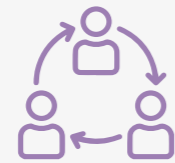
Here are a few of our progress highlights!



Development of clinical diagnostic criteria for chronic plaque psoriasis which will address issues faced by field workers in epidemiology studies and aid in preventing misdiagnosis.
(May 2021)



Alex Trafford, GPA PhD student, and colleagues published a population-based cohort study in PLoS ONE examining concordance and timing in recording cancer events in primary care, hospital and mortality records for patients with and without psoriasis.
(July 2021)



Ongoing collaboration with colleagues in Copenhagen to carry out a pilot study in Greenland.
(May 2022)



The first psoriasis incidence data ever obtained in Chile. Work led by Claudia De la Cruz and Cristobal Lecaros examining the incidence of psoriasis in Chile, published in Clinical and Experimental Dermatology.
(April 2021)



Collaboration with IRASPEN study on pustular psoriasis.
(May 2021)



Collaboration with Psoriasis Global Healthcare Study.
1,760 patients now included worldwide.
(July 2021)



Launch of Spanish version of the GPA website in partnership with Swiss4ward.
globalpsoriasiatlas.org/es
(November 2021)



Launched a LinkedIn account with the aim of connecting with more dermatologists around the world and sharing the important work of the GPA.
(July 2021)



The Atlas will provide important data on the true burden of psoriasis and its cost to the individual and to society in each country around the world.

**Professor
Chris Griffiths**



Through contact with patient organisations and those living with psoriasis, the GPA is able to amplify the voices and experiences of those with the condition, providing context beyond just the numbers.

Dr Alex Trafford



The GPA and the World Health Organization



Global report on PSORIASIS

The resolution passed by the World Health Assembly in 2014 highlighted that psoriasis should be viewed as a serious non-communicable disease and the subsequent WHO report on psoriasis¹, published in 2016, paved the way for the development of the GPA.

The resolution was aided by the 2012 systematic review from The University of Manchester reporting on the global epidemiology of psoriasis². This highlighted marked variations in the reported prevalence and incidence of psoriasis, both within and between countries. Importantly it identified knowledge gaps in our understanding of the natural history and burden of psoriasis globally. Specifically:

- Few studies focused on the incidence (new cases) of psoriasis over time.
- Most studies contributing data on disease prevalence were conducted in Europe and the USA, with far fewer identified from Asia, Africa and South America.
- No studies simultaneously compared trends in incidence, prevalence and mortality longitudinally in patients with psoriasis to determine: (i) whether the prevalence of psoriasis is increasing over time; and (ii) if so, whether this is driven by increasing trends in incidence and/or whether patients are nowadays living much longer with psoriasis due to reductions in early mortality.

These data, coupled with the identification in 2012 by the **International League of Dermatological Societies (ILDS)** that psoriasis was one of its "Grand Challenges in Global Skin Health", catalysed the tripartite partnership between **IFPA**, the **International League of Dermatological Societies (ILDS)**, and the **International Psoriasis Council (IPC)** to take forward a GPA.

¹ World Health Organization. (2016). Global report on psoriasis. World Health Organization. <https://apps.who.int/iris/handle/10665/204417>

² Parisi R, Symmons DPM, Griffiths CEM, Ashcroft DM. Global Epidemiology of Psoriasis: A Systematic Review of Incidence and Prevalence. *J Invest Dermatol* 2013;133:377-85.

“ Good epidemiological data are essential for disease control and appropriate healthcare planning... dermatology remains one of the most neglected fields of epidemiological study. There is a need for better quality data on incidence and prevalence of psoriasis to understand better the size and distribution of the problem. World Health Organization, 2016 ”

The GPA: A Strong Organisation Built to Collaborate

The GPA is a collaboration between three leading international organisations in world dermatology: **IFPA**; **International League of Dermatological Societies (ILDS)**; and **International Psoriasis Council (IPC)** and **The University of Manchester (UoM)** as the lead academic institution.

The collaborating organisations are the joint project owners of the GPA. Project success can be attributed to the integrated and synergistic interactions between the academic institution and the three partner international organisations. These organisations, represent psoriasis associations around the world, international dermatology societies and the education and empowerment of global key opinion leaders in psoriasis.

IFPA is a non-profit umbrella organisation uniting all people living with psoriatic disease - regardless of where they live, what type of psoriatic disease they have, or how it impacts their lives. IFPA was founded in 1971 and, together with international member associations, represents and advocates for over 60 million people around the world. Read more about IFPA, our members and our activities at www.ifpa-pso.org.

The **International League of Dermatological Societies** has been promoting skin health around the world for over 80 years. The ILDS represents dermatology at the highest level with 195 Member organisations from more than 90 countries they represent over 200,000 dermatologists. www.ilds.org

The **International Psoriasis Council** is a dermatology-led, voluntary, global, non-profit organization with a network of more than 125 psoriasis experts, thought leaders, and professionals, dedicated to improving patient care around the globe. www.psoriasis-council.org

“ It is thanks to the GPA Collaborating Organisations that the research and key messages from our work can be shared so readily with the global dermatology community. There is passionate support for the GPA amongst patient groups, dermatologists and funders. Rebekah Swan, Programme Manager ”




Our Team

Research Team

 **Professor Chris Griffiths**
GPA Director
The University of Manchester


 **Professor Darren Ashcroft**
GPA Research Director
The University of Manchester

 **Rebekah Swan**
GPA Programme Manager
The University of Manchester

 **PD Dr Julia-Tatjana Maul**
GPA Medical Coordinator
University Hospital Zurich

 **Dr Alison Wright**
GPA Research Associate
The University of Manchester


 **Teng-Chou Chen**
GPA Research Associate
The University of Manchester

 **Jade Kelly**
GPA Administrator
The University of Manchester

PhD Students


 **Alex Trafford**
The University of Manchester


 **Dr Maha Abo-Tabik**
The University of Manchester

 **Peslie Ng'ambi**
The University of Manchester


Collaborating Organisations

 **Arpita Bhose**
ILDS Executive Director

 **Caroline Bach**
ILDS Project Manager


 **Christy Langan**
IPC Chief Executive Officer

 **Frida Dunger Johnsson**
IFPA Executive Director

 **Sicily Mburu**
IFPA Scientific Officer


Structure and Governance

Board of Governors

 **Professor Lars French**
Chair of Board of Governors,
President of the International
League of Dermatological Societies


The Board of Governors membership includes: the Presidents of the three Collaborating Organisations and other non-voting members. The Board of Governors is chaired by the ILDS President.

Organisations (IFPA, ILDS and IPC), along with the members of the Project Management Team comprising the GPA Research Director, GPA Medical Coordinator, GPA Programme Manager and GPA Administrator.

 **Dr Hoseah Waweru**
President of the International
Federation of Psoriasis
Associations

Scientific Advisory Board
Membership includes: three individuals (including the Chair) with expertise in epidemiology; dermatology; health economics and global health.

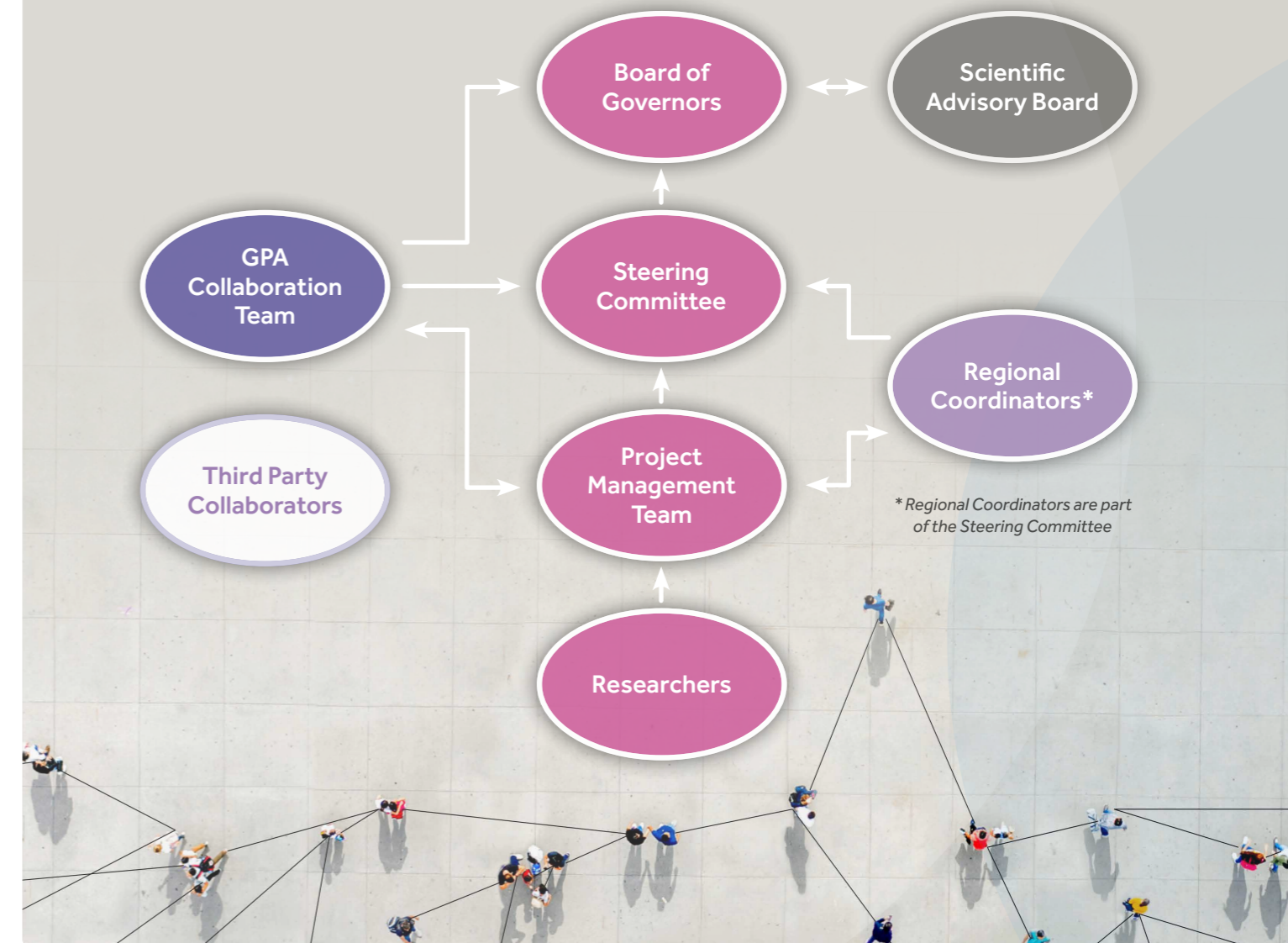
Regional Coordinators
Part of the GPA Steering Committee.

 **Professor Jonathan Barker**
President of the International
Psoriasis Council

Steering Committee
The GPA Steering Committee is chaired by the GPA Director and is composed of a lead from each of the Collaborating

Collaboration Team
Membership includes executives and members from the Collaborating Organisations and the GPA Programme Manager.

Researchers
Research Associates and PhD students.



Scientific Advisory Board

The newly appointed Scientific Advisory Board (SAB) will provide the Board of Governors with independent and international scientific oversight of the work of the GPA. They will have responsibility for reviewing research priorities and advising on significant developments which may affect the GPA.

Professor Robert Dellavalle Chair of the GPA Scientific Advisory Board



Dr Dellavalle is the Dermatology Service Chief for the US Department of Veterans Affairs Eastern Colorado Health Care System and Professor of Dermatology at the University of Colorado School of Medicine. He received undergraduate and masters degrees in philosophy at UCLA before matriculating from the MD/PhD Medical Scientist Training Program at the University of Chicago. He subsequently completed a dermatology residency, fellowship in dermatology research, and masters of science in public health degree at the University of Colorado. Dr Dellavalle

is a funded skin cancer prevention investigator and has published over 350 PubMed indexed articles.

Dr Dellavalle routinely treats patients with skin disease and witnesses firsthand the incredible disability that skin disease causes. His lab focuses on:

- dermatoepidemiology, to better monitor the incidence, prevalence, and burden of skin disease around the globe,
- skin disease prevention, to reduce and prevent major skin diseases especially skin cancer (he is currently co-PI on an NCI R01 grant testing standard versus delayed delivery of a skin cancer education intervention to tattoo clients by tattoo artists and co-PI on a VA Basal Cell Chemoprevention clinical trial grant),
- evidence-based dermatology, to determine and promote the best therapeutic options for skin disease. He serves as joint coordinating editor of Cochrane Skin, editor of JMIR Dermatology, and an editorial board member of UpToDate, the Journal of the American Academy of Dermatology and the Journal of Investigative Dermatology.

Professor Mohsen Naghavi Member of the GPA Scientific Advisory Board



Mohsen Naghavi, MD, MPH, PhD, is a Professor of Health Metric Science at the Institute for Health Metrics and Evaluation (IHME) at the University of Washington. In this role, he leads the Institute's work on cause of death, intermediate cause, natural disaster, war and terrorism death. In addition he leads estimation of burden of skin diseases and anti-microbial resistance. IHME was established at the University of Washington in Seattle in 2007 and he started his work with IHME from 2007.

Dr Naghavi was senior expert on primary health care, disease, injury, and cause of death in Iran, having spent most of his career at the Ministry of Health and Medical Education in Iran, where he ran numerous programs and initiatives. At the Ministry, he headed up the Applied Research Center for Health. He started a death registry system in Iran from one province and expanded this to 29 provinces of Iran and was in charge of disease control for both the province and the district. Prior to joining IHME, he was a Research Fellow at the Harvard Initiative for Global Health in 2007. Dr Naghavi studied at Tehran University and received an MPH, a PhD in Epidemiology, and a medical degree.









Professor Luigi Naldi Member of the GPA Scientific Advisory Board



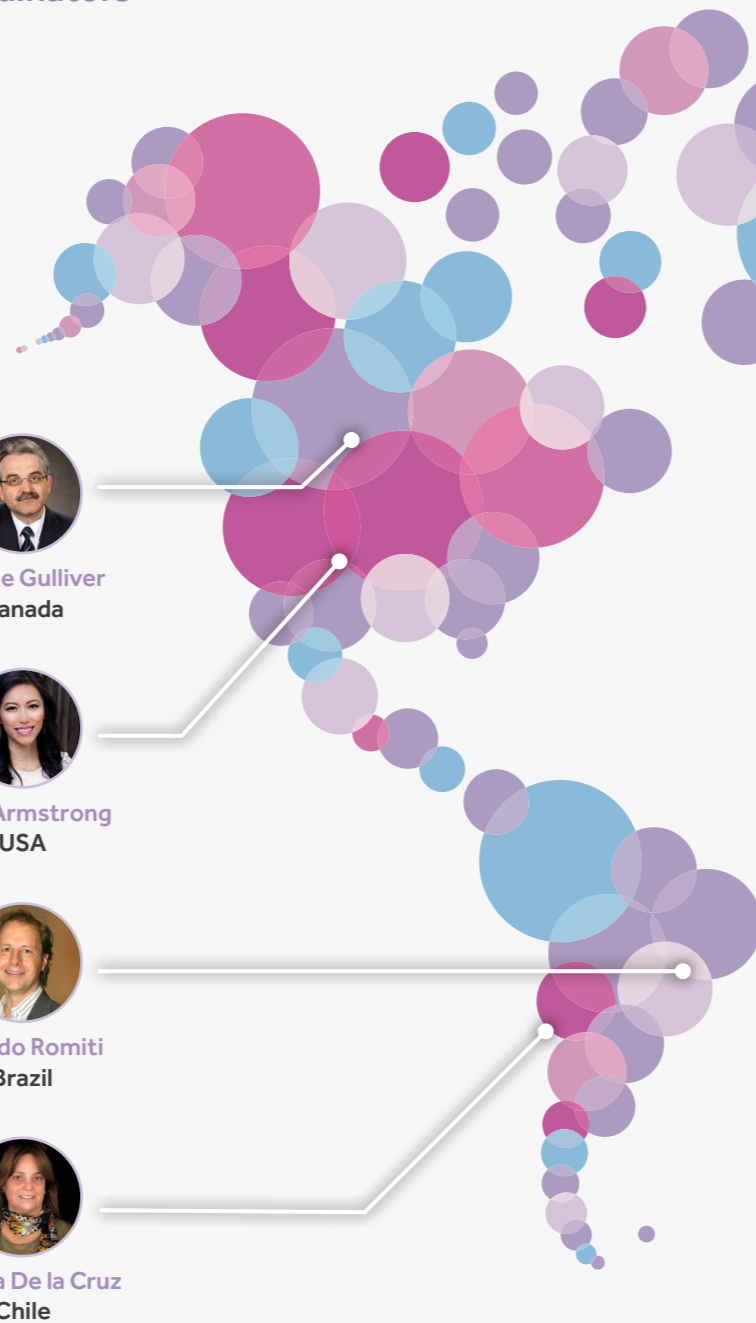



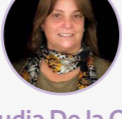
Dr Naldi took a Degree in Industrial Design at the School of Engineering and Design in Milan, before moving to Medicine. He graduated as a medical doctor at the University of Pavia in 1981 and then worked for three years in the Laboratory of Clinical Pharmacology of the Mario Negri Institute in Milan. In 1988 he moved to the Department of Dermatology of the University of Milan, Bergamo General Hospital, and qualified as a full professor of Dermatology in Italy in 2012. He is currently the Head of the Department of Dermatology at the Regional Hospital in Vicenza and the Head of the Study Centre of the Italian Group for Epidemiologic Research in Dermatology (GISED) in Bergamo. His research interests focus on classical and clinical epidemiology in dermatology on pragmatic clinical trials, on methods to assess the safety of medical interventions, and, more recently, telemedicine and big data analysis, with the final aim of improving patient care.

Expanding Global Network

National Coordinators

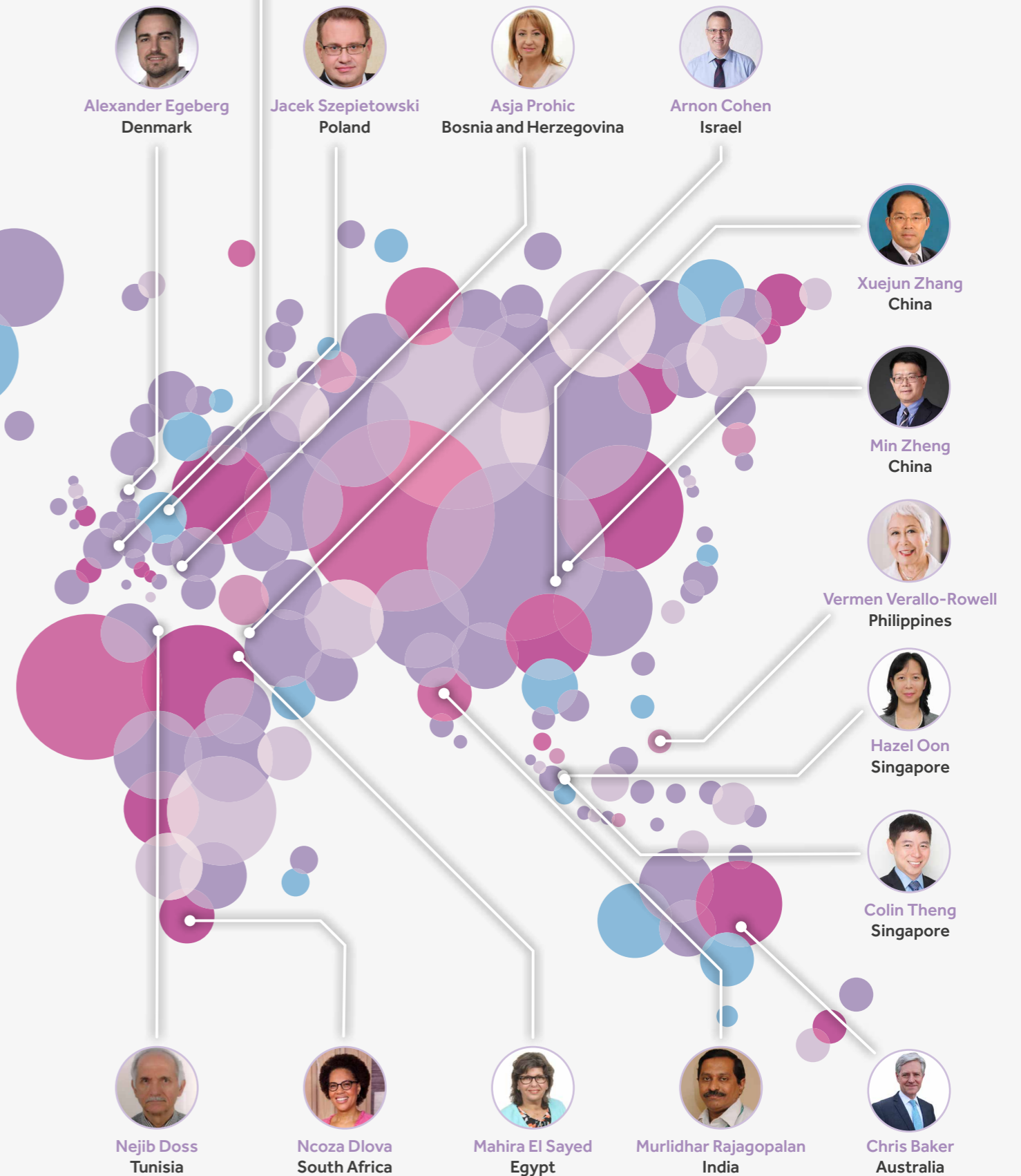






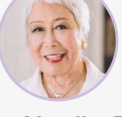







-  Mario Amaya Guerra
Mexico
-  Andre Carvalho
Brazil
-  Cristina Echeverria
Argentina
-  Benjamin Hidalgo-Matlock
Costa Rica
-  Cesar Gonzalez
Colombia
-  Farah Novoa Boza
Peru
-  Enrique Rivas
Guatemala
-  Fernando Valenzuela
Chile

Regional Coordinators

- 
-  Wayne Gulliver
Canada
 -  April Armstrong
USA
 -  Ricardo Romiti
Brazil
 -  Claudia De la Cruz
Chile



GPA Medical Coordinator, PD Dr Julia-Tatjana Maul, is responsible for coordinating the work of our specialist global network.
Switzerland

- 
-  Alexander Egeberg
Denmark
 -  Jacek Szepietowski
Poland
 -  Asja Prohic
Bosnia and Herzegovina
 -  Arnon Cohen
Israel
 -  Xuejun Zhang
China
 -  Min Zheng
China
 -  Vermen Verallo-Rowell
Philippines
 -  Hazel Oon
Singapore
 -  Colin Theng
Singapore
 -  Nejib Doss
Tunisia
 -  Ncoza Dlova
South Africa
 -  Mahira El Sayed
Egypt
 -  Murlidhar Rajagopalan
India
 -  Chris Baker
Australia

Bold Advocacy

The GPA has been incredibly fortunate to have an extraordinary team around the world to help drive each phase of growth. Each of these individuals has contributed to the project with enthusiasm and skill. Thank you to Claudia De la Cruz, April Armstrong and Wayne Gulliver for sharing updates on their progress this year.



Claudia De la Cruz Regional Coordinator Chile



During 2021, Dr Claudia De la Cruz, Director of Clínica Dermacross, in Santiago, Chile and Dr Daniela Armijo, launched the campaign "Treating Psoriasis", with the aim of providing information about all aspects of the disease and the treatments available to patients with psoriasis and their families.

We developed a web page (lpsoriasis.cl) and a book and we expect to deliver 1000 copies to patients with psoriasis, free of charge. We also developed an online survey that was available to be completed on the webpage. The objective was to collect sociodemographic data and information about access to treatment for psoriasis patients in order to contribute to the Global Psoriasis Atlas. We obtained 3192 valid answers, 69% were female and

31% male. 42% answered that they have at least 1 relative with psoriasis – psoriasis vulgaris and scalp psoriasis were the most common types. 65% of patients reported comorbidities, and obesity (26%), hypertension (20%), depression (16%), insulin resistance (15%), dyslipidaemia (12%) were the most common. 14% reported psoriatic arthritis. The majority were being treated with topicals, 30% said they were not receiving any treatment, and 9% were on methotrexate. Only 50 out of 3192 patients said they were on biologics: secukinumab > golimumab > etanercept > adalimumab > infliximab > guselkumab > risankizumab and the majority of them also had psoriatic arthritis ($p < 0.001$). 20% of patients responded they had stopped working due to the disease; the majority had psoriatic arthritis ($p < 0.001$). These results suggest that access to biologics is limited, most likely due to the associated high costs. We aim to continue with the campaign in 2022, collecting new data about the epidemiology of psoriasis.

April Armstrong Regional Coordinator USA



We recently found the prevalence of psoriasis amongst adults in the United States (U.S.) to be 3.0%. This was determined from the 2011-2014 NHANES survey cycles. We used NHANES datasets because NHANES uses a multistage, stratified survey methodology and over-samples minority and low-income populations to ascertain prevalence data that are representative of the general U.S. adult population.

Using the 2020 U.S. Census data, we estimated over 7.5 million U.S. adults have psoriasis. This shows that psoriasis remains one of the most common immune-mediated diseases suffered by many adults in the U.S. Overall, compared to those without psoriasis, psoriasis patients tended to be older. For example, the prevalence of psoriasis was 1.6% amongst 20-29 year-olds, whereas it was 4.3% amongst 50-59 year-olds. Additionally, psoriasis was most common amongst whites (3.6%) and least prevalent among blacks in the U.S. (1.5%). However, those with and without psoriasis had similar levels of other sociodemographic factors such as marital status, education, income, or medical insurance status. Of note, psoriasis prevalence was similar between women (3.2%) and men (2.8%).

Wayne Gulliver Regional Coordinator Newfoundland



It is an extreme pleasure and honor to be the Canadian Regional Coordinator for the Global Psoriasis Atlas. We are continuing to make progress with the GPA Global Healthcare Study as well as the psoriasis epidemiology study in Newfoundland and Labrador. With respect to the GPA Global Healthcare Study, the initial ethics application has been submitted and we have received feedback. This has been reviewed and resubmitted. We are expecting approval in the next two weeks and then we will be pleased to start enrolling psoriasis patients from Newfoundland and Labrador. Our goal is to enroll up to 400 patients. We have hired a new Research Coordinator and Clinic Nurse, Ms. Peggi Cousens, who will be joining the team to help enroll these patients.

With respect to the psoriasis epidemiology study in Newfoundland and Labrador, we have been working with the Newfoundland Centre for Health Information (NCLHI) and Kendra Lester, BsC, MSc, PhD(c), is leading the NILCHI team. We have signed off on the variable list and have received feedback from Kendra and the NILCI. We are now able to finalize and move forward with this study.

With respect to the IRASPEN registry, we have been slow to make progress on this front as the lead research coordinator has taken an early leave of absence and is now spending time with her baby daughter. We are in the process of hiring another coordinator to help move this project forward.

Thank you to the research team at the Global Psoriasis Atlas for their continued support and understanding.

Global Reach

2021: A year of growth and expanding networks

The value of the Global Psoriasis Atlas network: enabling research into the epidemiology of psoriasis around the world.

Research collaborations

Chile

The GPA has collaborated on work led by Dr Cristóbal Lecaros and Dr Claudia De la Cruz to examine the incidence of psoriasis in Chile. This work provides the first incidence data on psoriasis in the country and has been published in *Clinical and Experimental Dermatology*.

Denmark

One of our major collaborative projects with GPA Regional Coordinator, Associate Professor Alexander Egeberg, has focused on cancer incidence and cancer mortality in people with psoriasis. We have conducted population-based epidemiological studies in Denmark, Israel, Taiwan and the United Kingdom.

Greenland

In May 2022, the GPA team will conduct a pilot study in Tasiilaq on the East coast of Greenland with Professors Jacob P. Thyssen and Claus Zachariae, University of Copenhagen.

Malaysia

The GPA research team is working closely with Associate Professor Choon Siew Eng to examine the incidence and prevalence of psoriasis in Malaysia. This is the first time that data will be reported on the epidemiology of psoriasis in South-East Asia.

Myanmar

The political situation in Myanmar has resulted in a delay to our plans for a pilot research study and workshops with local dermatologists. In 2022, the plan is to continue to work with Dr Su Lwin to provide educational support via webinar and to facilitate discussions on a future large-scale epidemiological skin disease survey.

Newfoundland

The GPA research team will be undertaking several new studies (epidemiology, comorbidities and economic impact) this year in collaboration with GPA Regional Coordinator, Professor Wayne Gulliver.

Qatar

Plans to carry out a validation study (demographic data) in collaboration with Professor Martin Steinhoff. The GPA research team will advise on a cohort study of incidence/prevalence and multi-morbidity work, diabetes and cardio-metabolic disease.

Taiwan

The GPA research team completed a study examining changes in the prevalence, incidence and mortality rates in people with psoriasis or psoriatic arthritis in Taiwan. These findings have been submitted for publication. The team are completing a new study using the national claims database from Taiwan examining the risks of serious infection in people with psoriasis.

A global network of experts committed to understanding the epidemiology and burden of psoriasis and facilitating access to the best care for people living with the disease worldwide.



-  Regional Coordinators
-  National Coordinators
-  Research Collaborations
-  Research Team (UK)
-  Medical Coordinator (Switzerland)

GPA Research Progress

**Professor
Darren Ashcroft**
GPA Research Director
The University of Manchester



Over the last year, we have made very good progress with our research plans.

Dr Alison Wright
GPA Research Associate
The University of Manchester



The following synopsis reports on studies that have recently been completed and those that will get underway in the coming months.

Teng-Chou Chen
GPA Research Associate
The University of Manchester



Epidemiology of psoriasis in Taiwan

The World Health Organization recognised psoriasis as a serious non-communicable disease, and emphasised the need to better understand the global burden. Due to a rapidly ageing population, it is important to quantify the social and economic burden of psoriasis and psoriatic arthritis (PsA). However, previous studies from Taiwan provided limited information on the temporal trends of the incidence, prevalence and mortality of psoriasis and PsA. We used the Taiwan National Health Insurance (NHI) claim database and national death certificates to examine these issues further. The Taiwan NHI is a single-payer mandatory enrolment programme that started in 1995, and hence more than 99.99% of the Taiwan population were enrolled. We identified patients with a diagnosis of psoriasis or PsA recorded by dermatologists or rheumatologists and each patient was matched to 10 comparators from the general population by sex and age. Annual age- and sex-standardised prevalence and incidence rates were calculated and the risk of mortality was analysed. During the study period, Taiwan NHI registrants increased from 22,502,536 in 2006 to 23,583,524 in 2017, and

overall, we included 123,303 people with psoriasis and a further 12,933 with PsA. The incidence of psoriasis and PsA in Taiwan remained stable between 2009 and 2017, however, the prevalence increased steadily between 2006 and 2017 (psoriasis: 0.18% - 0.86%; PsA: 0.01% - 0.08%). The increasing prevalence of psoriasis and PsA in older age groups may be attributable to overall improvements in life expectancy. Nevertheless, the risk of mortality remained higher in patients with psoriasis (hazard ratio 1.16; 95% confidence interval: 1.13 - 1.19) compared with the general population.

Psoriasis and severe infection and its mortality

Building on our findings examining the epidemiology of psoriasis in Taiwan, we have recently completed a new study examining the association between psoriasis and severe infection. Specifically, we conducted a population-based cohort study using the Taiwan National Health Insurance (NHI) claims database with linkage to national death registration from 2000 to 2017. The NHI claims database provides anonymous longitudinal records from both outpatient visits and inpatient hospitalization in Taiwan. For each adult psoriasis patient, we matched to 10 comparators by age and gender. Overall, we included 185,434 adult psoriasis patients with a median age of 45. Compared to matched comparators, higher risks of severe infection (HR:1.209, 95%CI: 1.194,1.224) and death due to infection (HR:1.147, 95%CI: 1.114,1.182) were found in psoriasis

patients, especially for patients with moderate-to-severe psoriasis. In addition to respiratory infections, psoriasis was also related to higher risks of severe tuberculosis (HR:1.288, 95%CI: 1.100,1.508) and hepatitis B (HR:1.176, 95%CI: 1.062,1.302).

Psoriasis and Multimorbidity

Psoriasis is associated with several important medical conditions which can affect disease burden and outcomes, treatment strategies and quality of life. By gaining an understanding of the patterns of comorbidities in people with psoriasis, and groups of conditions which typically occur together, this may facilitate earlier and more targeted screening of specific conditions and appropriate management and treatment to improve quality of life.

The medical conditions we are observing include connective tissue disorders, cardiovascular disease, diabetes, cancer, respiratory disorders, autoimmune disorders, liver disorders, renal and intestinal diseases, neurological disorders, mental health conditions, sleep disorders and eye problems.

We are using electronic health record data from the Clinical Practice Research Datalink (CPRD) to estimate the prevalence of individual conditions and comorbidities in people with psoriasis between 1998 and 2020 and to identify any clustering of these comorbidities. We will also evaluate if there are distinct patient profiles for these disease clusters. We look forward to reporting on these findings later this year.

Epidemiology of Psoriasis

A systematic review of the worldwide epidemiology of psoriasis, carried out by GPA researchers (Parisi et al., 2020), identified that 81% of the countries of the world lack information on the incidence and prevalence of psoriasis. Reliable data is important to determine disease burden and to ensure adequate resource allocation for risk management and the management of patients with psoriasis. We have been collaborating with teams in Malaysia (Dr Choon Siew Eng), Newfoundland (Professor Wayne Gulliver) and Qatar (Professor Martin Steinhoff) to estimate the incidence and prevalence of psoriasis in these areas for the first time.

Global research collaborations

1. Malaysia

There have been no population-based epidemiological studies on psoriasis in Southeast Asia including Malaysia. We have been collaborating with Associate Professor Choon Siew Eng and her team to analyse trends in the incidence and prevalence of psoriasis in multi-ethnic Malaysians in the Johor Bahru district in the state of Johor between 2010 and 2020.

We used electronic health records routinely captured in the Teleprimary Care (TPC®) clinical information system. TPC is a locally developed clinical information system that links public primary and secondary care facilities providing information on routine medical examinations, diagnoses and disease surveillance,

laboratory results and pharmacy data. From 1 January 2005 till 31 December 2020, the TPC system contained data on 1,290,205 individuals residing in the Johor Bahru district with 4,893 patients with dermatologist-diagnosed psoriasis. The study period 2010-2020 was chosen when the TPC data was more mature and to ensure prevalent psoriasis cases were not misclassified as incident ones.

Between 2010 and 2020, 3,932 patients had dermatologist confirmed psoriasis in a population of 1,164,724, prevalence 0.34%. The period incidence of psoriasis was 33.8 (95% confidence interval 32.3 to 35.4) per 100,000 person-years, with higher rates observed in men than women; 40.2 (37.8 to 42.7) and 28.1 (26.1 to 30.0) per 100,000 person years, respectively. This pattern was consistent across the years. Patients from Indian and Chinese ethnic groups had the highest incidence rates; Indian 52.2/100,000 person years, Chinese 37.6/100,000 person years, Malay 29.6/100,000 person years and Others 15.0/100,000 person years.

An increasing trend in psoriasis prevalence with age was observed throughout the study period, peaking in age groups 50-59 and 60-69 years and then decreasing for 70 years and above.

2. Newfoundland

The prevalence of psoriasis in Canada is around 2-3%; however, this is likely to be higher in the Canadian province of Newfoundland and Labrador due to specific population differences and is also thought to be 5- to 10-fold higher than in most other Caucasian populations. Due to the genetically isolated founder population in

GPA Research Progress

Newfoundland and Labrador, there is an elevated incidence of several genetic disorders. This founder effect and/or genetic drift has also led to an increased incidence of several complex diseases including psoriasis (in particular type 1 early-onset psoriasis).

In collaboration with Professors Wayne Gulliver and Proton Rahman, we will establish the incidence and prevalence of psoriasis in Newfoundland and Labrador between 2001 and 2020 and examine variation in onset of psoriasis by age, gender, ethnicity and rural secretariat region.

Electronic health records for the province will be obtained from The Newfoundland and Labrador Centre for Health Information (NLCHI). The database contains demographic and clinical data for individuals receiving inpatient care in the province and data on physician claims (diagnoses and fee codes).

People with psoriasis will be identified from the NLCHI and The NewLab Psoriasis Clinical Database. The NewLab database comprises medical, demographic, and genetic data on patients with psoriasis attending the dermatology clinic at NewLab Clinical Research Inc. (St John's, NL). The diagnosis of psoriasis is confirmed by a dermatologist. The NewLab Psoriasis Clinical Database includes over 5,000 patients diagnosed with psoriasis between 1989 and 2021.

3. Qatar

We have been collaborating with Professor Martin Steinhoff to assist in the development of a cohort study on the incidence and prevalence of psoriasis in Qatar.

The prevalence of psoriasis in Middle Eastern countries is believed to be similar to that observed in Western countries, affecting ~3% of the Qatari

population; however, there is a lack of data on psoriasis and guidelines for dermatologists practicing in these countries. Accurate and timely information on the epidemiology of psoriasis in Qatar is needed in order to understand the impact of this disease and to ensure appropriate allocation of resources to reduce morbidity, disability, and mortality associated with the disease.

Patient data will be obtained from the Hamad Medical Corporation (HMC), the principal public healthcare provider for the State of Qatar, which contains clinical data from secondary and tertiary care. Between 1st January 2016 and 30th September 2021, there were 5,898 patients with dermatologist confirmed psoriasis.

Psoriasis and Cancer

Though potentially underpinned by a number of plausible mechanisms, the association between psoriasis and cancer lacks clarity, particularly with regards to whether risk is increased at specific sites. In order to summarise the existing literature, we conducted a systematic review and meta-analysis of cancer development and mortality risk in psoriasis. Whilst associations were found between psoriasis and a number of cancers, an additional important finding of the work was the frequent variation in the strength of the associations found by different studies.

In order to address this variation and bring greater clarity, we have conducted two further studies across population-based health records in Denmark, England, Israel and Taiwan - one exploring cancer development and one exploring cancer mortality (excluding Israel). In each study, a common study design has been applied across all countries as a means

to ensure consistency. The risk of development and mortality has been considered for cancer overall and for 26 site-specific cancers. Furthermore, the role of psoriasis severity in any modification of risk has also been explored. Work pertaining to both cancer development and cancer mortality is well developed, and we hope to share the results in the next year.

Understanding the comorbidities present in psoriasis is key for the provision of optimal care. A notion evidenced by the focus given to psoriatic arthritis and cardiovascular disease in those with psoriasis. We hope that the results of these collaborative studies will bring greater clarity to the relationship between psoriasis and cancer, with the eventual objective of informing the best possible care for individuals with psoriasis.



The GPA is a melting pot for highly talented people from around the world who focus on achieving the best care possible for people with psoriasis, wherever they may live.

**Professor
Darren Ashcroft**



At the GPA, it is important to us to hear from people with psoriasis and consult with them on our upcoming research studies and results so that our work can contribute meaningfully to the care and treatment of this condition.

Dr Alison Wright



PhD Progress Review: Peslie Ng'ambi



Tell us about yourself

I graduated from the University of Zambia with a Bachelor of Pharmacy degree in 2011. After graduating, I practised as a pharmacist within Zambia for 3 years before moving to Germany for my postgraduate study. In 2016, I graduated with a joint Master of Science in International Pharmacoeconomics and Health Economics from Fresenius University of Applied Science (Germany) and Cardiff University (UK). After a year of working in a medical device company, I moved to the UK in 2017 to take up a research associate position in Health Economics at the University of Manchester.

What inspired you to undertake a PhD with the GPA?

When I learnt of the PhD opportunity with the GPA, I was inspired by the global reach of the GPA, the multi-disciplinary team and the breadth of work being undertaken. The idea of working on a project with a far-reaching impact in both high and low-income countries to contribute solutions on easing the burden of psoriasis inspired me even more to join the GPA. At the time, most of the work under the GPA was focused on the epidemiology of psoriasis and I was excited to come in and work on the health economics side of the project.

What is the focus of your PhD?

My PhD focused on quantifying the economic impact of psoriasis. This looked at the financial impact of psoriasis on the health care system, and health and beyond health consequences of psoriasis on the individual. One of the aims was to estimate the cost of illness of psoriasis using linked Clinical Practice Research Datalink and Hospital Episodes Statistics (CPRD-HES) data to estimate primary and secondary resource use in the English National Health Service (NHS).

In the first instance, methodological heterogeneity and conceptual shortcomings were identified in several economic impact of disease studies. This motivated the development of a framework to conceptualise the economic impact of disease as comprising two elements, cost of illness (CoI) and burden of disease (BoD), and the need to take account of welfarist and extra-welfarist approaches to identify, measure and value costs and consequences. The framework formed the basis for the critical appraisal component of two subsequent systematic reviews of studies reporting the cost of illness and burden of disease for psoriasis.

Another aim was to estimate the burden of disease of psoriasis using a survey that was designed and administered to people living with psoriasis in the UK. Validated questionnaires in health economics and dermatology were used in this survey to estimate the impact on health, wellbeing, and disease severity. Using the UK study as the template, the study is intended to be replicated in other countries.

Why did you choose this particular project?

This project was interesting because of the breadth of health economics methods and the scant knowledge of the economic impact of psoriasis. I took an interest in looking deeper into psoriasis and how it impacted people's lives after knowledge of a possible PhD topic in psoriasis. At the same time, I learnt a lot concerning the different methods in health economics such as analysis of routinely collected administrative data.

Tell us about your most notable achievements

One overarching notable achievement under this project was adding to the evidence on the financial cost of psoriasis and the health and non-health consequences it poses in individuals. Up to a much as 40% of health care costs were estimated to be attributable to psoriasis. During this project, I also noted that obesity and existence of multimorbidity was a significant driver of costs. This highlights the need of modifying individual lifestyles to control obesity and managing other chronic conditions to minimise the financial impact on the health care systems. It was also notable to realise the deeper psychological health and non-health impact the condition has on individuals such as the daily struggle of choice of clothes, the annoying need for constant moisturising, the low self esteem and low confidence, and the extent of stigmatisation.

What challenges have you encountered and how have you overcome them?

It has probably become a common highlight, but the COVID-19 pandemic did not spare me. Due to the pandemic I had to have an interruption of my PhD which meant I had to get an extension of about 3 months to be able to finish my research.

What would you like the impact of your project to be?

I would like to see this project replicated in other countries and ultimately contribute to the advocacy for improved management of people living with psoriasis. There is need to have a holistic approach in alleviating the burden of psoriasis on individuals by taking into consideration both the health and non-health consequences of psoriasis.

PhD Progress Review: Maha Abo-Tabik



Tell us about yourself

I graduated from The University of Baghdad, College of Medicine, with an MBChB in 2012. After graduation I practiced medicine in my home country. In 2015, I was awarded the Chevening scholarship to undertake a master's degree in clinical dermatology. I graduated from the University of Hertfordshire in 2016, with a distinction.

What inspired you to undertake a PhD with the GPA?

The starting point of my project is a genuine belief that people with psoriasis are not receiving the best medical care. Psoriasis affects around 60 million people worldwide; however, many people suffer needlessly from the disease due to missed or delayed diagnosis. Until recent years, available epidemiological data assessing the burden of psoriasis were scarce. Hence, the GPA took the first steps to build an evidence-based resource for psoriasis where clinical and epidemiological data are easily accessible by healthcare professionals, policymakers, and the public.

What is the focus of your PhD?

My PhD research involves developing and piloting clinical examination based diagnostic criteria for psoriasis and subsequently applying them to improve early diagnosis of psoriasis. "One way to reduce the burden of psoriasis on people's lives is through early diagnosis and appropriate treatment," WHO (2014). Moreover,

part of my PhD project involved the conduct of retrospective analysis of the medical records of people with and without psoriasis using UK's largest healthcare database, the Clinical Practice Research Datalink (CPRD) in an attempt to identify missed opportunities for the earlier diagnosis of psoriasis in primary care settings in the UK.

Why did you choose this particular project?

My project documents a stepwise approach that aims to improve psoriasis diagnosis in clinical and research settings. My professional background as a clinician relates very well to my PhD project. Coming from a country where the healthcare system is not very well developed encourages me to further explore potential opportunities to improve psoriasis diagnosis in settings where access to specialist dermatology care is restricted, such as in the lower and middle income countries.

Tell us about your most notable achievements

One of the most distinguished achievements during my PhD studies is the development of clinical diagnostic criteria for chronic plaque psoriasis in adults. Findings of this study were published in one of the highly ranked journals in the world of dermatology, the British journal of dermatology (BJD).

What challenges have you encountered and how have you overcome them?

Given that my PhD consists of three separate projects with different methodologies, I faced multiple challenges. One of the most significant challenges was the knowledge gap that has been identified during my review of the literature, as to date only limited data are available on the clinical diagnosis of psoriasis. We overcame this challenge by working in association with the International Psoriasis Council (IPC) and relying on their expert opinion to build a diagnostic tool for psoriasis. The diagnostic tool was then used to develop an educational resource to help improve psoriasis diagnosis by non-dermatologists such as primary care professionals.

What would you like the impact of your project to be?

I hope that my project identifies key areas for improvement in the clinical diagnosis of psoriasis. Subsequently, improving early diagnosis and avoiding a potentially detrimental delay in establishing an appropriate treatment regimen.



Evaluation of a newly developed training resource for psoriasis

Background

To provide better medical care, we developed an educational resource for psoriasis based on the findings from our recent e-Delphi study¹. The developed tool is intended to be used by primary health care professionals to improve their knowledge about psoriasis presentation and hence support them in making an accurate diagnosis.

What does the study involve?

This is an online study which involves completing the following tasks:

- Short demographic questionnaire
- Training package
- Feedback survey

Be part of our study

We are trying to evaluate an e-learning tool for primary care doctors, nurses and pharmacists to improve their diagnostic skills for psoriasis.

How will you benefit from the study?

- You will improve your diagnostic skills for psoriasis.
- You will receive a shopping gift voucher in return for your participation.

What I will need to do:

- A short demographic questionnaire.
- A training package.
- A feedback survey.

Version 01; Date 20/12/2021 IRAS ID: 293734

Study advertisement

Design of the training tool

Working with Swiss4ward, we designed a virtually delivered training tool for psoriasis. A specific website was designed for the purpose of this study. The training tool is supported by illustrations and clinical images of psoriasis.

training tool for chronic plaque psoriasis

Intro First: What do psoriasis lesion look like? Second: most commonly affected body parts Third: Nail changes Fourth: key clinical information Example clinical images

Your ID: [input field]

Pre-training Training Post-training

Example clinical images

Please view these additional images to support your understanding

Chronic plaque psoriasis ▾

Psoriasis on skin of colour ▾

Scalp psoriasis ▾

Nail psoriasis ▾

Example of the clinical images used to enhance understanding

training tool for chronic plaque psoriasis

Intro First: What do psoriasis lesion look like? Second: most commonly affected body parts Third: Nail changes Fourth: key clinical information Example clinical images

Your ID: [input field]

Pre-training Training Post-training

Identifying clinical signs of psoriasis using consensus agreed clinical diagnostic criteria for CPP in adults

What follows?

- What follows is the training part which consists of visual illustration of each diagnostic criterion with a plain language explanation.
- This aims to improve your diagnostic skills for chronic plaque psoriasis.
- Following the training there will be a test to check your understanding of the material.

Background

The diagnostic criteria

Hints and tips

Next Page >

A screenshot from the interactive training tool

¹ Abo-Tabik M, Parisi R, Willis S.C, Griffiths C.E.M, Ashcroft D.M. Development of clinical diagnostic criteria for chronic plaque psoriasis: an international e-Delphi study. British Journal of Dermatology 2021.

Developing clinical diagnostic criteria for chronic plaque psoriasis in adults

Research motivation

Lack of clinical diagnostic criteria for psoriasis in adults.

Method

Three rounds e-Delphi study

50 Dermatologists from 27 countries

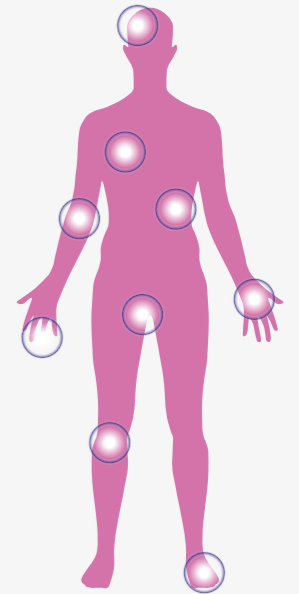


Argentina, Australia, Belgium, Brazil, Canada, Chile, China, Colombia, Denmark, Egypt, Germany, Iran, Ireland, Israel, Italy, Japan, Malaysia, Philippines, Poland, Portugal, Singapore, South Africa, Spain, Switzerland, The Netherlands, UK, USA.

Results

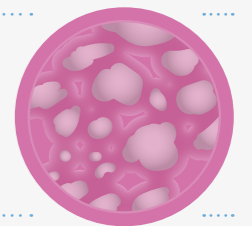
Definition

Chronic plaque psoriasis is systemic, inflammatory disease that predominately affects the skin. Skin lesions can occur on any part of the body and particularly affects extensor surfaces of the limbs, especially the **elbows** and **knees**. Other common sites for psoriasis to appear include the **trunk**, the **umbilicus**, over the lower back (**sacrum**), on the **scalp** involving the hairline, skin inside and behind the **ears**, the **palms** of the hands, **soles** of the feet and **nails**. **Skin folds** such as **armpits**, between the **buttocks**, **genitals** and **under the breast** may also be affected.



Essential clinical diagnostic criterion

Well demarcated lesion with or without silvery/white scales.



Supportive clinical examination diagnostic criteria

1. Lesions are pink to red in colour. In deeply pigmented skin, lesions may be grey in colour
2. Lesions vary in size
3. Lesions are palpable
4. Lesions are symmetrically distributed
5. Family history of psoriasis in first degree relatives
6. Nail involvement (such as pitting, onycholysis and subungual hyperkeratosis of the nails)
7. Joint pain and/or stiffness
8. Itching



Clinical diagnosis of chronic plaque psoriasis in adults requires the presence of the essential criterion and at least four out of the eight supportive criteria listed above.

The consensus exercise included recommendations for the clinical diagnosis of CPP across diverse ethnic groups.

Our Impact

A note from our Collaborating Organisations

IFPA: Global leader in fighting psoriatic disease



Global Psoriasis Atlas – Bringing value to patient advocacy groups

The GPA is making a valuable contribution to patient advocacy groups by addressing the research call put forward in the WHO Global Report on Psoriasis. The publications presented on the Atlas website have been tremendously useful to IFPA and our member associations.

As an example, the open-access disease prevalence comparator tool, a mapping initiative focussed on comparing regional and national burden, has served as a key resource in advocating for better treatment

for all. In addition, GPA's free-to-use data have also been essential to the advancement of IFPA's mission related to psoriatic disease policy. These data have been referenced in IFPA advocacy publications.

In its role as trusted convener of the psoriatic disease community, IFPA has used the latest findings from the GPA as a focal point for multiple discussions in stakeholder events. An important example is the annual regional member meetings where GPA Regional Coordinators have shared insights on the latest data.

Additionally, the GPA has served as a reliable source for accurate messaging in IFPA research projects and recently in the IFPA Strategy launched in 2021.

During the past few years, the GPA has been involved in several joint activities with IFPA with notable success. These include World Psoriasis Day campaigns

which attracted worldwide attention. Furthermore, the GPA research team has been attending and presenting at IFPA's World Conference since the congress was established in 2006. These presentations have inspired a new generation of researchers to discover more about psoriasis.

“ The Global Psoriasis Atlas informs bold new steps in psoriatic disease advocacy. Essential insights into prevalence, comorbidities, and economic impact allow us to target our efforts towards the issues that matter most. IFPA Secretariat ”



International League of Dermatological Societies (ILDS)



The theme for the ILDS 2020-2023 Strategy is Global Partnerships for Skin Health. ILDS recognises the importance of working in partnerships to increase awareness, cooperation and communication within the global dermatology community and to promote high quality education, clinical care, research and innovation that will improve skin health globally. The GPA has been used as a paradigm for other skin disease atlases and a research study has been commissioned into a proposed atopic dermatitis atlas. The GPA reflects ILDS core values of collaboration, impact, communication, evidence and leadership.



International Psoriasis Council (IPC)



One of IPC's key strategies is to increase our work on a regional level. During 2021 and 2022, Professor Griffiths has participated in regional IPC masterclasses in Middle East Africa, North Africa, Asia and Latin America with 208 participants from 54 countries. The information the GPA is collecting on psoriasis around the globe is critical to better understanding the burden of the disease globally and allows us to target our programs and activities to address regional specific needs.



The GPA community is facilitating our global research impact.

The GPA facilitates the coordination of networks of dermatologists all striving to obtain high quality epidemiological data from around the world.

From our global team of experts and researchers, to our Collaborating Organisations and patients, we are shifting the landscape of psoriasis research together.



"One disease - millions of individuals. Millions of stories of heartache, frustration, pain and dealing with a lack of understanding and access to adequate healthcare. The Global Psoriasis Atlas project provides the data and information needed to effect real change and has the potential to truly improve the health and quality of life for people with psoriasis. Not just in one place - all over the world."

Barbra Bohannon
from Sweden



"The GPA is doing fantastic work and offers all of us who have this condition hope for a brighter and healthier future."

Russ Cowper
from the UK



Global Research Collaborations

Burma Skincare Initiative and the GPA – Myanmar

Following the military coup on 1 February 2021, the humanitarian crisis in Myanmar has deepened, compounded by the COVID-19 pandemic.

The junta continues to arrest, torture and kill healthcare workers (HCWs); indeed, Myanmar is currently the most dangerous country in the world for HCWs. Consequently, our dermatology colleagues are struggling to provide skincare services with merely a third of their usual workforce. Most of the dermatology services are being delivered by non-specialist frontline HCWs. The Burma Skincare Initiative (BSI) has therefore reorganised its short-term goals by: addressing the immediate and essential unmet

needs of people with skin disease; and educating non-specialist HCWs in the diagnosis and management of common and emergency skin diseases. Nevertheless, the primary objective of the BSI-GPA collaboration is still to hold the psoriasis webinar series (instead of the in-person workshop, owing to the travel restrictions and the unstable political state in Myanmar) and to conduct a survey on the management of psoriasis in the country. Since the coup, the BSI designed and delivered online education and training, including diagnosis and management of psoriasis by Professor Chris Griffiths, specifically tailored to non-specialist HCWs in Myanmar (Figure 1); developed one-page clinical algorithms to guide the frontline HCWs; and is in the process of developing a teledermatology

service and video lecture series for both specialist and non-specialist colleagues in the country. It is intended that the video lecture series will also be of educational value to other low-and-middle-income countries beyond Myanmar in the wider context of Global Health Dermatology. We plan to deliver the webinar series on psoriasis in collaboration with the International Psoriasis Council in Quarter 4 of 2022. By this time, it is hoped that our Myanmar dermatology colleagues will be in a position to participate in this tailored webinar programme, although the political situation in the country continues to be of grave concern.

“ Over the past 13 months of the military coup takeover in Myanmar, we have lost many of our colleagues in the country, either due to being arrested and tortured by the junta or the Covid-19 pandemic. Those who survived these unprecedented challenges continue to help their patients, albeit the increasingly limited resources and workforce. Now is the time when the international community needs to continue providing their solidarity and support for our colleagues in Myanmar. The BSI, in partnership with the GPA and the international dermatology community, is committed to providing exactly the support needed on the ground under these rapidly evolving circumstances. ”

Dr Su Lwin

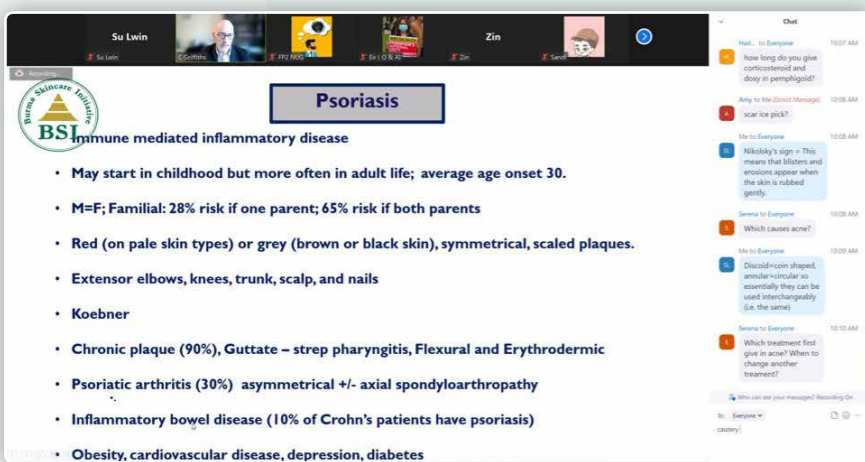


Figure 1. Professor Griffiths delivering an online lecture on psoriasis as part of the common and emergency skin disease lecture series for the final year medical students and frontline healthcare workers in Myanmar.

Global Research Collaborations

Cross-Sectional Study – Greenland



Professor Jacob P. Thyssen and Associate Professor Claus Zachariae

Psoriasis, pustulosis palmoplantaris, atopic dermatitis and chronic hand eczema in Greenland.

Greenland is the world's largest island and is a self-governing entity within the constitutional monarchy of Denmark. There are about 56,000 persons living in the country of which approximately 90% are of Inuit heritage¹. There are currently no studies that have examined the prevalence of psoriasis among Inuits and their descendants. In collaboration with the GPA, we plan to perform a cross-sectional study of Greenlandic adults from Tasiilaq, Eastern Greenland, to determine the prevalence of frequent dermatological conditions, including psoriasis, pustulosis palmoplantaris, atopic dermatitis and chronic hand eczema. Furthermore, we will attempt to identify specific phenotypes, genotypes and specific risk factors tied to these diseases among Greenlanders. Each participant will be asked to complete a questionnaire and, in case report of skin symptoms, we will offer a clinical examination to determine the diagnosis, and sample DNA for genetic analysis. Our study offers a unique opportunity



to investigate psoriasis and other inflammatory skin diseases in a small and historically isolated population in a secluded environment. Moreover, we hope to bring one of the final pieces of the puzzle in the mapping of global psoriasis. Approvals are now

in place for our study which will take place in May 2022. This pilot study will be followed by a larger scale inclusion in 2023 as part of the national population health survey.

UNIVERSITY OF COPENHAGEN



¹ Moltke I, Fumagalli M, Korneliussen T, et al. Uncovering the Genetic History of the Present-Day Greenlandic Population. *Am J Hum Genet.* 2015;96(1):54-69. doi:10.1016/j.ajhg.2014.11.012.



IRASPEN

The International Rare and Severe Psoriasis Expert Network – a global Pustular Psoriasis registry

The IRASPEN-Registry is a global, prospective registry, investigating the genotype-phenotype correlation of pustular psoriasis (PP).

IRASPEN comprises the prospective collection of data and biological material from multiple, global sites and is led by PD Dr Julia-Tatjana Maul and Professor Alexander Navarini.

The sub-study IRASPEN-CS is a cross-sectional design comprising a one-time collection of data and photographs, based on the first visit of the IRASPEN main project.

Patients suffering from PP, regardless of the subtype, namely generalized pustular psoriasis (GPP), palmoplantar pustulosis (PPP), Acrodermatitis continua of Hallopeau (ACH) or a mixed phenotype, meeting the inclusion criteria such as primary sterile, macroscopically visible epidermal pustules (persistent over three months for PPP and ACH and relapsing or persistent over three months for GPP) will be invited to participate. At the time point of inclusion, active pustulation must be present. A minimum of 180 patients will be included (minimum 140 PPP, 20 GPP, 20 ACH) in the main registry and an unlimited number of PP-patients for IRASPEN-CS.

Since we hypothesise that the majority of pustular psoriasis patients have at least one episode of increased (50%) activity per year and that the majority of these patients (>50%) require active treatment, the main objective is to describe the natural course of this rare disease (frequency and severity of flares) in order to gain more detailed information about their phenotype. In addition, we aim

to describe the response to already established treatments to define the genetic background of PP, as well as its transcriptional profiles.

The duration of the registry trial is five years and consists of 14 visits per patient (60 minutes). At each visit, the attending physician will characterise the clinical features (phenotypic description) and perform a lesion count. Several modified assessment scores such as the Physician Global Assessment (PGA) for palmoplantar pustulosis (PPP PGA), for generalized pustular psoriasis (GPP PGA) as well as an adapted Psoriasis Area and Severity Index Score (PASI), namely GPPASI and PPPASI, are used to quantify the extent of the various diseases. To objectify the subtype ACH, the GPPGA and the standardised Nail Psoriasis Severity Index (NAPSI) are going to be applied. Personal evaluation of the patient's quality of life, health, illness symptoms, work productivity and activity as well as pain and disease intensity are assessed via various questionnaires (DLQI, EuroQol EQ-5D, WPAI-GH, PSS, VAS scores for pain and disease activity).

In total, we collect two skin biopsies (4mm size) – one at baseline and one at the follow up visit. In addition, three blood samples (3x30ml) will be taken; one baseline, one at a follow-up visit with inactive disease and one at a follow up with active disease. If relatives can be included, a single sample (1x 30ml) will be collected at one-time (baseline), without follow-up visits.

Professor Alexander Navarini is the Principal Investigator (PI) of IRASPEN together with GPA Medical Coordinator, PD Dr Julia-Tatjana Maul. Among others, Professor Griffiths and Professor Ashcroft are

members of the IRASPEN Steering Committee Board. The GPA team is working in collaboration to assist with dissemination of information about the project to key stakeholders and across its social media platforms. It is important to understand the immunology and epidemiology of this disease in order to make a difference to the lives of people with PPP.

Newest Inclusion Numbers

We are delighted to report enrolment of the first 15 patients in the study in Switzerland (Zürich and Basel). This is an important first step towards gaining insights into the natural course of pustular psoriasis, disease burden, therapeutics and genetics. The team also hope to open two study sites in the UK, working with Professor Jonathan Barker and Professor Chris Griffiths. A number of other sites around the world are at various stages of the ethics approval process and will be joining the study in the near future.

We are grateful to all the Regional Coordinators who have expressed an interest in assisting with recruitment to the IRASPEN registry and look forward to working with you on this study.

www.iraspen.org

PD Dr Maul is keen for all GPA Regional and National Coordinators and dermatologists from around the world to contribute to the study. The electronic case report form, information on ethical approval and reimbursement for the study can be provided on request. **For further information, please contact: Julia-Tatjana.Maul@usz.ch**



Psoriasis Global Healthcare Study

Total number of patients included in study to March 2022
1760

The Psoriasis Global Healthcare Study is an independent research project that is conducted by PD Dr Julia-Tatjana Maul in collaboration with the Global Psoriasis Atlas.



The study uses a data driven approach to further map psoriasis and improve the lives of psoriasis patients around the world.

Our Regional and National Coordinators have been provided with detailed guidance on how to sign up and register for the study. An increasing number of centres around the world are now taking part, including Chile, Brazil, Switzerland, Singapore, Peru, South Africa, Senegal, Burkina Faso, China and Costa Rica. We are grateful to all our colleagues around the world for their efforts in sharing the survey with interested dermatologists in their region.

During this important phase of work, PD Dr Maul is asking all GPA Regional and National Coordinators to sign up for the study and to connect her with colleagues interested in participating in order to further widen the GPA research network. The engagement with this process so far has been excellent and the GPA Coordinators have worked hard to identify dermatologists in their regions. This is an exciting piece of work and the enthusiasm globally is excellent.

The screenshot shows the 'Global Healthcare Study' interface. At the top, it displays 'GH Study MAPPING PSORIASIS GLOBALLY' and 'Add Center' button. Below, it shows 'Global Healthcare Study Centers that are participating in the study.' with statistics: Centers 88, Patients 1457, Surveys 1457, Users 4. A search bar is present. The main section is 'CENTERS BY NAME' with a table listing various centers and their patient recruitment status. A 'Global Psoriasis Atlas' map is visible on the right.

Center Name	Recruited Patients	Included Patients	Status
Ain Shams University, Egypt (EG)	0 of 0 (0%)	recruited patients included	✓
CIEC Santiago de Chile, Chile (CL)	37 of 37 (100%)	recruited patients included	✓
Clínica Dermacross, Chile (CL)	84 of 84 (100%)	recruited patients included	✓
Clínica Dermatológica Universidad de Valparaíso, Chile (CL)	0 of 0 (0%)	recruited patients included	✓
Clínica Las Condes, Chile (CL)	12 of 12 (100%)	recruited patients included	✓
Consultorios Echeverría, Argentina (AR)	0 of 0 (0%)	recruited patients included	✓
DERMOS S.A., Guatemala (GT)	0 of 0 (0%)	recruited patients included	✓
Grupo Novaderm N&C, Peru (PE)	1 of 1 (100%)	recruited patients included	✓
Hospital Clínico Universidad de Chile, Chile (CL)	0 of 0 (0%)	recruited patients included	✓
Hospital San Borja, Chile (CL)	0 of 0 (0%)	recruited patients included	✓

The purpose of the Psoriasis Global Healthcare Study is to enable further mapping of psoriasis on a local and regional level and to help us gain a better understanding of common psoriasis characteristics:

- **Severity**
- **Characteristics and frequency of comorbidities**
- **Available treatment options**
- **Differences in quality of life**
- **Burden of disease and**
- **Influence of the level of education on the treatment response**

For information regarding the Psoriasis Global Healthcare Study and the ethical approval process, please contact: PD Dr Julia-Tatjana Maul (University Hospital of Zürich, Switzerland) onboarding@gpastudy.org

PsoProtect and PsoProtectMe

PsoProtect and PsoProtectMe are global collaborative research efforts involving a large interdisciplinary team of clinicians, academics and patient partners.

Their research findings have identified immediate global priorities for the clinical care of individuals with psoriasis, which has potential to mitigate risks of direct and indirect excess morbidity arising from the COVID-19 pandemic.

PsoProtect is an international registry for clinicians to report outcomes of COVID-19 in individuals with psoriasis. Since its launch in April 2020, PsoProtect has rapidly improved our understanding of how factors such as systemic immunosuppressant therapies, comorbidities and demographic variables including age, sex and ethnicity affect outcomes of COVID-19 in psoriasis. PsoProtectMe, the aligned patient self-report registry, has helped to characterise the impact of behavioural and environmental changes associated with the pandemic on health outcomes in psoriasis.



PsoProtect



PsoProtectMe

View PsoProtect's scientific publications at www.psoprotect.org/publications

- 47 partner organisations
- 9 scientific publications
- 8 podcasts & videos
- 9 conference presentations

PsoProtect logo in top right and PsoProtectMe logo in bottom right.

PsoProtect

Clinicians worldwide are invited to enter data on their patients with COVID-19 and psoriasis using the clinician facing case report form: psoprotect.org



PsoProtectMe

Individuals with psoriasis are invited to complete the global PsoProtectMe survey (psoprotectme.org), whether or not they have had COVID-19.



Digital Developments

Spanish Translation

The plan is for the GPA website to be available as a multi-lingual resource to ensure that the data and resources are accessible to a global audience. Using our website analytics we identified which countries users were accessing the GPA website from most frequently. After English-speaking users, we found that the remaining majority of users were from Spanish speaking countries. Our website and all accompanying resources are now available to view in Spanish! Thank you to our Spanish speaking Regional and National Coordinators who helped to review the translation of the website before it went live.



www.globalpsoriasisatlas.org/es

PsoWell®

The GPA team are delighted to have worked in collaboration with Dr Lis Cordingley, Senior Lecturer in Health Psychology at the University of Manchester, to develop the PsoWell® resources into a web- app. PsoWell® resource sets focus on issues that people with psoriasis have asked us about. They contain useful information and activities to help people to live well with psoriasis.

This digital development, led by software consultancy company, Swiss4ward, provides people with psoriasis around the world access to resources that were previously only available in the UK. The GPA research team will now develop research projects to examine the value of the resources in countries beyond the UK.

The team are also in the process of developing the PsoWell® resources into a mobile app and we will work with IFPA to ensure that the resources are culturally relevant and appropriate to people with psoriasis in different

countries and regions around the world. The aim is to continue to translate the resources into different languages.

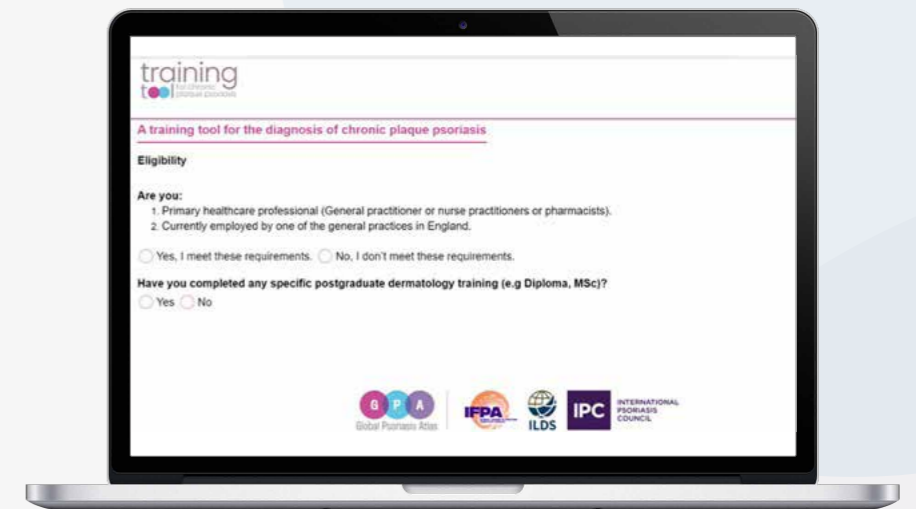


Access the web-app here: psowell.org



Training Tool

The diagnostic criteria developed by Maha Abo-Tabik has been used to develop an educational resource to help improve psoriasis diagnosis by non-dermatologists such as primary care professionals. This tool is currently being piloted in the UK amongst Practice Nurses, General Practitioners and Pharmacists. (see page 26).



The Simplified Psoriasis Index

The Simplified Psoriasis Index (SPI) is a tool which has been developed to enable either health care professionals or patients with psoriasis to make regular assessments of disease severity and its impact on well-being. It also incorporates a summary of past behaviour and treatment. It was developed at the Dermatology Centre, Salford, Greater Manchester, UK, based on an earlier prototype, the Salford Psoriasis Index, but was made much simpler to score using a novel scoring system. Unlike the former tool, the Simplified Psoriasis Index is available in two complementary versions, one for use by health care professionals (proSPI) and one for self-assessment by psoriasis sufferers (saSPI). The two versions are essentially the same except that technical language is avoided for the patient self-assessment version.

The SPI is available on the GPA website. It is available in English, French, Spanish and Thai and work is ongoing to translate the tool into Arabic. www.globalpsoriasisatlas.org/en/simplified-psoriasis-index

Psoriasis Assessment

Simplified Psoriasis Index (SPI)

- Professional assessment versions proSPI
- Self-assessment versions saSPI
- Information and references ?



World Psoriasis Day

Patient involvement is at the heart of the GPA. For World Psoriasis Day 2021, we worked with Platform Worldwide to record a new series of patient videos where people with psoriasis from around the world shared their experience of living with the disease. We posted some of these stories on our social media channels to promote the launch of the digital PsoWell® resources during Psoriasis Awareness Week and we are continuing to develop content using the topics explored during the

interviews. These themes include the messages that people with psoriasis would like to convey to healthcare professionals and how people with psoriasis manage the psychological effects of living with psoriasis. We would like to take this opportunity to thank all participants for taking the time to share their story and thanks to IFPA for their support in recruiting the video participants.

The Spanish translation of the website was released in collaboration with IFPA and to coincide with Psoriasis Awareness Week in order to maximise our reach. A special thank you to Silvia Barrio (President, AEPSo / Psoriasis Association of Argentina) and Josef de Guzman (President, Psoriasis Association of Philippines) who recorded the promotional video for us!

Digital Communications

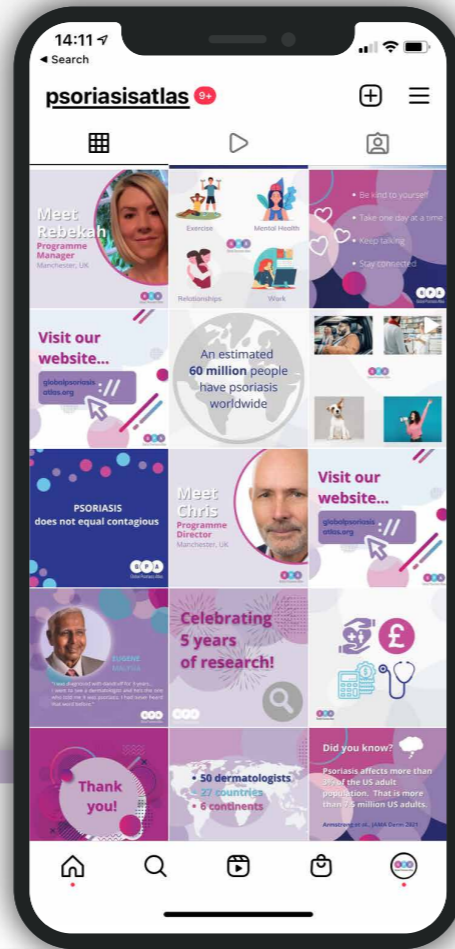
The Global Psoriasis Atlas project has established itself as a recognised and respected brand across a variety of digital platforms.

Over the last year, the GPA team have continued to build on that foundation by improving engagement with dermatologists and healthcare professionals via LinkedIn.

Social media is an important vehicle for communicating our research data and resources, as well as raising awareness of psoriasis and its effect on the individual and society.

The GPA has used its online platforms to share information and build rapport and trust with followers. The GPA launched its Twitter account in October 2018, followed by Instagram, Facebook and YouTube in 2019 and LinkedIn in 2021. During that time, our strategy has been to have a consistent online presence by utilising a bank of GPA branded content that we share with followers across all platforms.

The GPA team regularly assesses analytics across all digital outputs with the aim of increasing followers, engagement, impressions and brand awareness. We have seen steady increases in all of these metrics on the GPA website, social media and subscription to the GPA newsletter.



GPA Social Media

Followers | New Followers 2021-2022

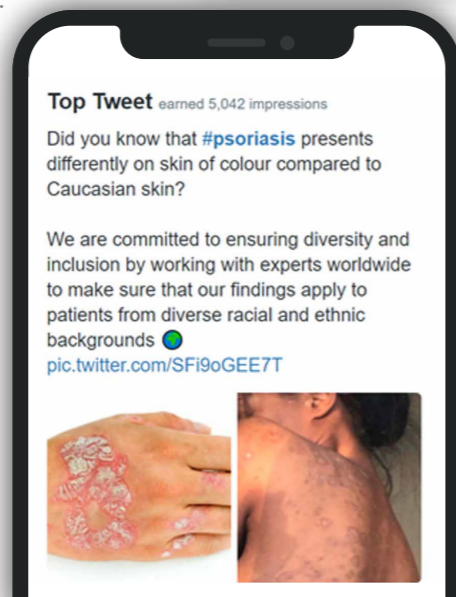
Twitter **2029** | **505**

Instagram **1234** | **155**

Facebook **876** | **48**

Launched June 2021 LinkedIn

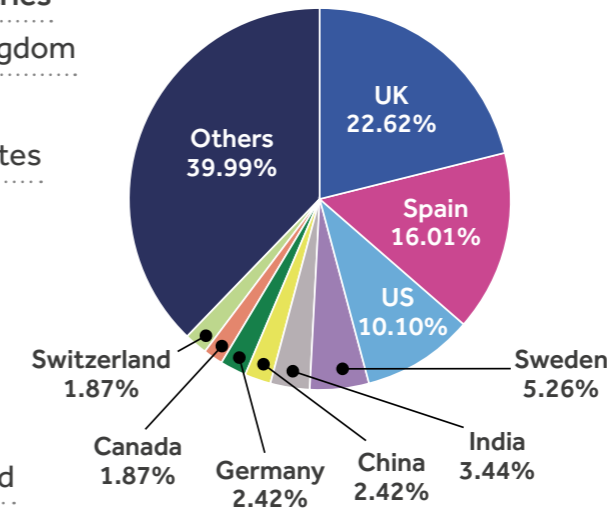
431 Followers | **35%** hospital/healthcare workers
22.9% medical practitioners



GPA Website Analytics 2021-2022

Top 10 countries

1. United Kingdom
2. Spain
3. United States
4. Sweden
5. India
6. China
7. Germany
8. Canada
9. Switzerland
10. Others



Visitor numbers
3,842



Time on page
4 minutes 3 seconds
average visit duration

GPA Quarterly Newsletter Subscription

January 2022 **96**

October 2021 **86**

July 2021 **74**

April 2021 **64**

Subscribe to our newsletter:
www.globalpsoriasisatlas.org/events



News Bulletin

9th Congress of Psoriasis: from Gene to Clinic

In December 2021, members of the GPA team attended the 9th Congress of Psoriasis: From Gene to Clinic, co-organised and co-chaired by Professor Chris Griffiths and Professor Jonathan Barker (St John's Institute of Dermatology). Professor Darren Ashcroft and Dr Alex Trafford presented on the epidemiology of psoriasis at the event.



Dr Alex Trafford



Thank you

Thank you to Dr Yves Poulin for the time and effort he spent as Regional Coordinator for Canada. We would like to wish him all the best for his retirement.



Welcome

Welcome to Professor Wayne Gulliver (Newfoundland, Canada) who we are excited to have join the GPA team as Regional Coordinator.



Members of GPA team and the RDTC team with some of the local Maasai tribe.

Tanzania

Following our skin disease survey in Tanzania in 2019, Dr Sidra Khan is in the process of writing an abstract about our survey of the Maasai people in Northern Tanzania. Furthermore, the GPA is now collaborating on a study with Dr

Doriane Sabushimike, Dr Sidra Khan and the team at the Regional Dermatology Training Centre in Moshi. The main objectives of this new study are to analyse data on the range of distances travelled by the patients attending RDTC and the common skin conditions they present with.



ILDS Webinar

During October 2021, the International League of Dermatological Societies and the International Alliance of Dermatology Patient Organizations held a collaboration webinar series. One of the webinars included presentations from GPA Director, Professor Griffiths, who spoke about the Global Psoriasis Atlas model between the ILDS, IFPA and the IPC and how to effectively engage patients in the process.

Congratulations Dr Alex Trafford



During his PhD, Alex has been an integral member of the GPA team. Accumulating a number of impressive achievements since 2017 he has made a significant contribution to the project. The team would like to take this opportunity to celebrate his successes and wish him the best of the luck in his future endeavours.

“ Understanding the true burden of psoriasis, both to the individual and to society, is a complicated undertaking. By connecting researchers and policymakers from different fields, the GPA improves our understanding of the condition through the sharing of expertise and resources. Furthermore, through contact with patient organisations and those living with the condition, the GPA is able to amplify the voices and experiences of those with the condition, providing context beyond just the numbers.

Dr Alex Trafford

Completed a systematic review on the **Association of Psoriasis with the Risk of Developing or Dying of Cancer** which was published in the scientific journal, JAMA Dermatology¹.

JAMA Dermatology publication referenced in the **New York Times** article².



Presented PhD findings at the Psoriasis: **Gene to Clinic** conference in December 2021

Published a new study in **PLOS ONE** examining the concordance and timing of cancer recording between primary care, hospital and death registration data for people with psoriasis³.

Presented an oral e-poster on his work at the **European Academy of Dermatology and Venerology** in September 2018: Psoriasis and Cancer Mortality: A systematic review and meta-analysis of observational studies

Altmetric Attention Score

Association of Psoriasis with the Risk of Developing or Dying of Cancer: A Systematic Review and Meta-analysis.

20,415 views

3,356 downloads

30 citations

250 altmetric score

¹ <https://bit.ly/3leRZWN>

² <https://www.nytimes.com/2019/10/16/well/live/psoriasis-tied-to-increased-cancer-risk.html>

³ <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0254661>

Engagement

The work of the Global Psoriasis Atlas would not be possible without the financial support we receive from our Industry partners.

The **LEO Foundation** are the lead supporter of the Global Psoriasis Atlas and we are grateful for the core, key funding that they have provided throughout Phase I and II.

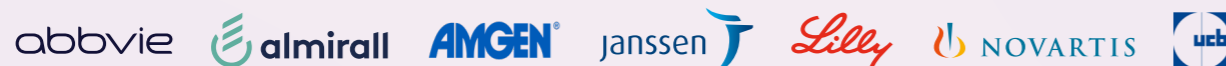


The Global Psoriasis Atlas (2017-2022) has also been supported by grants and sponsorship from **Abbvie, Almirall, Amgen, Celgene, Eli Lilly and Company, Janssen, Novartis Pharma AG** and **UCB**.

2022/23 will be a big year for the Global Psoriasis Atlas; join us in making it possible.

Partnership is a crucial step towards achieving the ambition of the GPA, to ensure that people around the world have access to the best available care and treatment for their psoriasis. We recognise that innovative and strategic partnerships with organisations are key to delivering our milestones and achieving the aims of the Atlas.

The GPA work in 2021-2022 has been made possible thanks to grants and sponsorship from **Abbvie, Almirall, Amgen, Eli Lilly and Company, Janssen, Novartis Pharma AG** and **UCB**.



We always welcome new connections and partnerships!



Here are some of the ways you can get involved;

- Provide financial support
- Collaborate with us
- Support the collection of data on the global burden of psoriasis
- Support our research
- Engage with us on social media

Establishing a high quality GPA requires the support of industry, organisations with relevant data sets and collaboration across regions and countries.

The GPA Partnership Brochure provides details of the types and levels of financial support packages and highlights unique opportunities for involvement in the project.



For further information contact, GPA Programme Manager, Rebekah Swan: rebekah.swan@manchester.ac.uk

Would you like to learn more about the work of the GPA?



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Publications, Presentations and Abstracts

Publications

Trafford AM, Parisi R, Rutter MK, Kontopantelis E, Griffiths CEM, Ashcroft DM. Concordance and timing in recording cancer events in primary care, hospital and mortality records for patients with and without psoriasis: A population-based cohort study. *PLoS ONE* 16(7): e0254661

Nymand LK, Andersen YMF, Thyssen JP, Egeberg A. Limitations of Using Questionnaires for Assessing the Prevalence of Psoriasis and Atopic Dermatitis Among Adults. *JAMA Dermatol.* 2021;157(8):971-977

Lecaros C, Dunstan J, Villena F, Ashcroft DM, Parisi R, Griffiths CEM, Härtel S, Maul JT, De la Cruz C. The incidence of psoriasis in Chile: an analysis of the National Waiting List Repository. *Clin Exp Dermatol.* 2021 Oct;46(7):1262-1269

Armstrong AW, Mehta MD, Schupp CW, Gondo GC, Bell SJ, Griffiths CEM. Psoriasis Prevalence in Adults in the United States. *JAMA Dermatol.* 2021 Aug 1;157(8):940-946

Abo-Tabik M, Parisi R, Willis SC, Griffiths CEM, Ashcroft DM; Global Psoriasis Atlas (GPA). Development of clinical diagnostic criteria for chronic plaque psoriasis: an international e-Delphi study. *Br J Dermatol.* 2021 Aug;185(2):455-456

Abstracts and Poster Presentations

Access to psoriasis treatment in Brazil and Chile: A Global Psoriasis Atlas study, Maul JTM, De la Cruz C, Romiti R, Maul LV, Valezuela F, Armijo D, Carvalho A, Riveros T, Didaskalu J, Ashcroft D, Griffiths CEM, European Academy of Dermatology and Venereology Congress, Vienna, 2021

Differences in access to psoriasis treatment in Brazil and Chile: A cross-sectional Global Psoriasis Atlas study, Maul JTM, De la Cruz C, Romiti R, Maul LV, Valezuela F, Armijo D, Carvalho A, Riveros T, Didaskalu J, Galvao W, Ashcroft D, Griffiths CEM, Swiss Society for Dermatology and Venerology Congress, Geneva, 2021

Mapping opportunities for the earlier diagnosis of psoriasis in primary care: a large retrospective analysis of general practice electronic health records in the United Kingdom, Abo-Tabik M, Parisi R, Morgan C, Willis S, Griffiths CEM, Ashcroft DM, The 6th World Psoriasis & Psoriatic Arthritis Conference, 2021

Presentations

The Global Psoriasis Atlas, Professor Chris Griffiths, RDTC International CME Conference, 2022

Access to psoriasis treatment in Brazil and Chile: A prospective multi-centre Global Psoriasis Atlas Study, PD Dr Julia-Tatjana Maul, RDTC International CME Conference, 2022

Psoriasis and the risk of cancer: pooled population-based cohort studies from Denmark, England, Israel and Taiwan, Dr Alex Trafford, Psoriasis Gene to Clinic 9th International Congress, 2021

GPA Research Update, Professor Darren Ashcroft, Psoriasis Gene to Clinic 9th International Congress, 2021

The Global Psoriasis Atlas, Professor Chris Griffiths, IPC Masterclass for Southeast Asia, 2021

Introduction on the Global Psoriasis Atlas, Professor Chris Griffiths, ILDS Webinar, 2021

GPA Global Healthcare Study, PD Dr Julia-Tatjana Maul, ILDS Webinar, 2021

How dermatologists can influence the global health agenda, Professor Chris Griffiths, BAD Global Health Dermatology Day, 2021

Fertility rates in women with psoriasis and psoriatic arthritis: a population-based cohort study, Teng-Chou Chen, International Conference on Pharmacoepidemiology and Therapeutic Risk Management, 2021

GPA Research Update, Professor Darren Ashcroft, IFPA's 6th World Psoriasis and Psoriatic Arthritis Conference, 2021

Global burden of psoriasis, epidemiology and the GPA, Professor Chris Griffiths, IFPA's 6th World Psoriasis and Psoriatic Arthritis Conference, 2021

The Global Psoriasis Atlas, Professor Chris Griffiths, IPC Middle-East and North Africa Psoriasis Masterclass, 2021



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