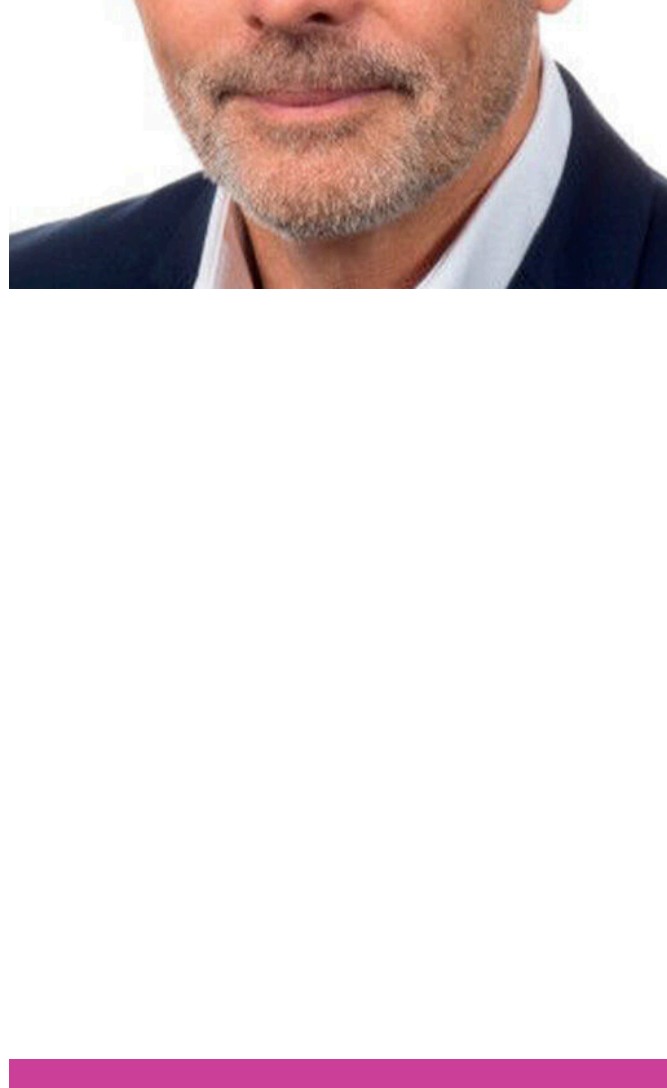


## Quarterly Newsletter - July 2022 - Issue No. 15



### Research Update



Professor Darren Ashcroft  
GPA Research Director

It's hard to believe but this is the fifteenth edition of our Global Psoriasis Atlas (GPA) newsletter – time flies. Summer, and global warming, has well and truly arrived here in the Northern Hemisphere with the UK experiencing the hottest temperatures ever recorded. Life has emerged from the COVID pandemic and for the most part travel and social restrictions are lifted, however, here in the UK, we are currently experiencing another surge of COVID cases. After our long-awaited face to face meetings at the Annual Meeting of the American Academy of Dermatology in Boston in March, we are looking forward to meeting with you again at the Congress of the European Academy of Dermatology and Venereology in Milan this September. After two long years of somewhat impersonal Zooms and Teams meetings, it is so refreshing to see so many of you in person again at these conferences. The GPA team will be holding meetings with our Steering Committee, Funders and Board of Governors.

Since March, the Research Team and our Collaborating Organisations have continued to meet and share ideas to discuss the GPA's strategy going forward into Phase III beginning in April 2023. These meetings have been highly productive sessions, ones in which we were honest about the strengths, weaknesses, opportunities and threats faced by the GPA. This is an iterative process with further meetings planned as we move into the funding cycle for Phase III.

In May, key members of the GPA research team, along with colleagues from the University of Copenhagen, travelled to the remote settlement of Tasilaq in Eastern Greenland to perform a field survey of skin disease. This was an arduous and complex trip involving stop-overs in Reykjavik and Kulusuk and a final leg completed by helicopter. The study was very insightful into access to skincare and phenotypic presentation of psoriasis in the Inuit people. We learnt a lot: you can read more about our findings and experiences in this newsletter.

With my best wishes,  
Chris Griffiths

I'm pleased to report that we will be presenting our recent GPA research findings at the forthcoming 31st European Academy of Dermatology and Venereology (EADV) Congress in September. We look forward to meeting up with many of our regional and national collaborators at this conference and exploring new opportunities to take forward studies in other countries. Since my last update, the GPA team completed a field trip to Greenland to develop and test methods for a future epidemiological study examining psoriasis prevalence (and atopic dermatitis) in May 2022. This work has involved close collaboration with Professors Claus Zachariae, Jacob Thyssen and team at the University of Copenhagen.

We are delighted to report that our study examining the incidence and prevalence of psoriasis in Malaysia has recently been accepted for publication in the British Journal of Dermatology. This is important work as it is the first time that data will be reported on the epidemiology of psoriasis in south-east Asia. We are very grateful for the valuable contributions made by Choon Siew Eng and her team to make this work possible.

We have also recently completed a study examining changes in the prevalence, incidence, and mortality rates in people with psoriasis or psoriatic arthritis in Taiwan. This population-based study analysed data from the Taiwan National Health Insurance claim records over a 12-year period. These findings have been submitted for publication. Building on this, we are completing another new study using the national claims database from Taiwan examining the risks of serious infection in people with psoriasis. We look forward to sharing further details on this programme of work later in the year.

Finally, we have made very good progress in recent months with our work focussed on improving the diagnosis of psoriasis. The evaluation of our diagnostic training tool has recently been completed in which we recruited general practitioners, nurses and pharmacists to test the new resources. Our study examining missed opportunities for earlier diagnosis of psoriasis has also been accepted for publication in the British Journal of General Practice. We very much look forward to providing future updates on these new initiatives in due course.

### Medical Coordinator Update



PD Dr. Julia-Tatjana Maul  
GPA Medical Coordinator

In July, GPA Director, Professor Chris Griffiths, GPA Programme Manager, Rebekah Swan, and GPA Medical Coordinator, PD. Dr. Tatjana Maul, conducted Zoom calls with the GPA Regional Coordinators. The purpose of these meetings was to provide an update on GPA progress and discuss the role of Regional Coordinators and any ongoing work/collaborations in their regions. We also outlined the opportunities for epidemiological research with the GPA and the potential development of further National Coordinator networks. Furthermore, there will be an opportunity for Regional Coordinators to learn about progress and provide updates during the GPA Steering Committee meeting at the Congress of the European Academy of Dermatology and Venereology in Milan.

If you missed the calls and would like to contact us to arrange a meeting, please email: [rebekah.swan@manchester.ac.uk](mailto:rebekah.swan@manchester.ac.uk)

#### IRASPEN

The IRASPEN team, led by Principle Investigator, PD. Dr. Julia-Tatjana Maul, and Professor Alexander Navarini, are delighted to report the enrolment of the first patients in the study in Switzerland (Zürich and Basel) and many centres around the globe are in the process of ethical approval. We aim to gain 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 ethical 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.

**Please continue to share the following information with your colleagues and across your networks:**

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:

<https://www.iraspenn.org/>

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

**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](mailto:Julia-Tatjana.Maul@usz.ch)

#### Global Healthcare Study on Psoriasis

The Global Healthcare Study on Psoriasis has so far recruited 2078 patients.

The Global Healthcare Study on Psoriasis is an independent research project that is conducted by PD. Dr. Julia-Tatjana Maul in collaboration with the GPA and uses a data driven approach to further map psoriasis and improve the lives of psoriasis patients around the globe.

**The aim of the Global Healthcare Study on Psoriasis 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 – based on ethnicity and gender
- Differences in quality of life
- Burden of disease
- Influence of the level of education on the treatment response

Our Regional and National Coordinators have all received an email with detailed guidance on how to sign up and register and an increasing number of centres around the world are now involved. We are grateful to all our colleagues around the globe for their efforts in sharing the survey with dermatologists in their region – thank you! **The registration process is quick and easy and takes less than five minutes to complete.**

During this important phase of work, we are asking GPA Regional and National Coordinators to sign up for the study and to link us with colleagues that might be interested in participating, thus widening the GPA research network. Thank you all for your engagement with this process so far and your hard work in identifying dermatology colleagues in your regions. This is a truly exciting phase of work and the enthusiasm globally is excellent.

Please do send us a list of potential collaborating partners. If you require any further information regarding the Global Healthcare Study on Psoriasis or the ethical approval process, please contact:

PD. Dr. Julia-Tatjana Maul (University Hospital of Zürich, Switzerland)

[julia-tatjana.maul@usz.ch](mailto:julia-tatjana.maul@usz.ch)

If you would like to arrange a call regarding any other GPA related work, please contact:

GPA Administrator, Jade Kelly (University of Manchester, UK):

[jade.kelly@manchester.ac.uk](mailto:jade.kelly@manchester.ac.uk)

### Greenland

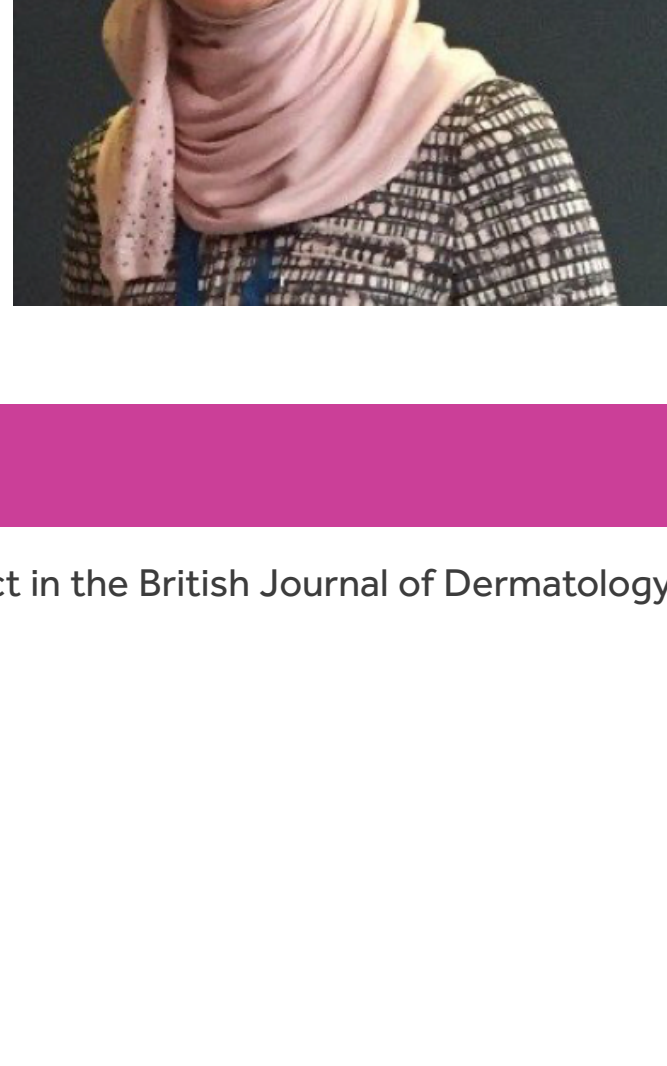
The GPA research team joined colleagues from the University of Copenhagen to conduct a pilot survey of skin disease in Tasilaq, Greenland, during the first two weeks of May. Throughout the duration of the study the teams screened a total of 295 participants and saw a range of skin diseases including psoriasis, hand eczema and a small number of atopic dermatitis cases. Both teams observed that the phenotype of psoriasis in Inuit people was mainly of the thin plaque phenotype with a seborrheic pattern. The group is working on the preparation of abstracts for the World Congress of Dermatology, Singapore and the International Societies for Investigative Dermatology Tokyo meeting, both in 2023. Work also continues to understand how we can use our study insights to inform the 2023 National Census in Greenland. We are also preparing a narrative report about the trip and this will be shared via the GPA Collaborating Organisations in September 2022.



### New PhD Publication

Congratulations to GPA PhD student, Maha Abo-Tabik, who has had her paper "Mapping opportunities for the earlier diagnosis of psoriasis in primary care settings in the UK" accepted for publication in the British Journal of General Practice. This is a novel and important piece of work as patients often experience delays when being diagnosed with psoriasis and are frequently even misdiagnosed.

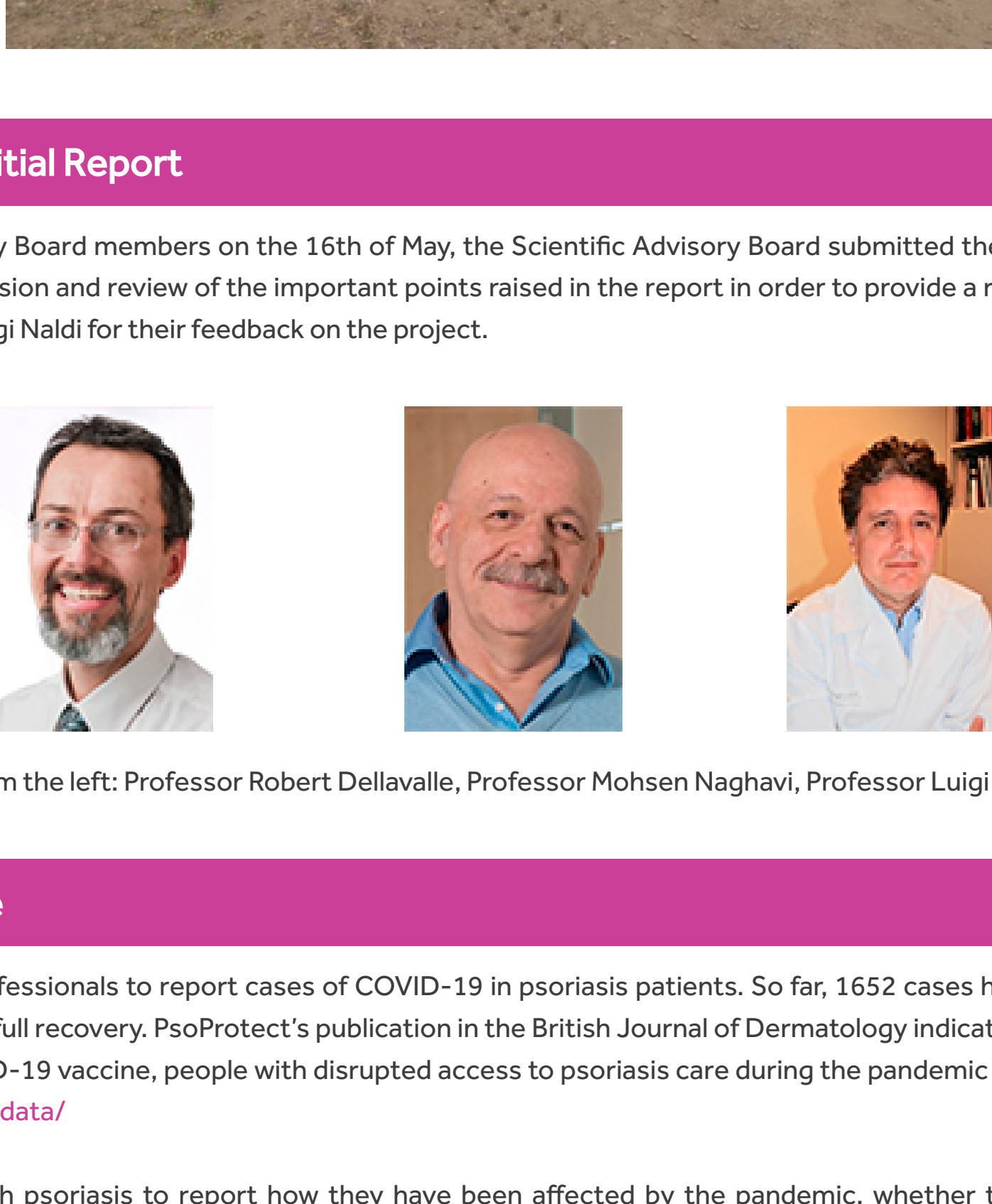
Once published, we will post the link on our Twitter page so please do make sure you're following us at [@PsoriasisAtlas](https://twitter.com/PsoriasisAtlas) for the latest GPA updates.



### A skin disease survey of the Maasai in Northern Tanzania

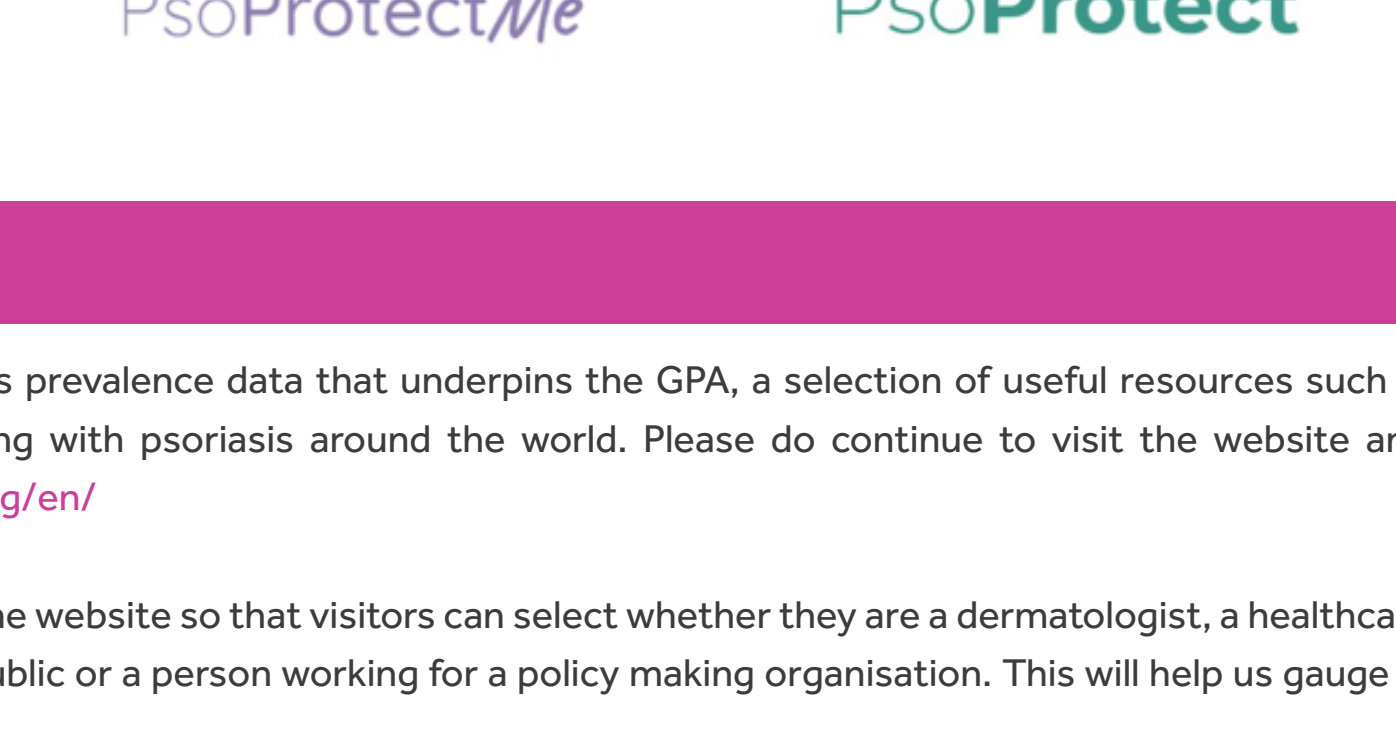
Following our trip to Tanzania in 2019 to conduct a pilot skin disease survey, GPA advocate, Sidra Khan, has published an abstract in the British Journal of Dermatology looking at skin disease amongst Maasai adults and the potential barriers faced when accessing dermatological care.

You can read Sidra's abstract here: <https://onlinelibrary.wiley.com/doi/10.1111/bjd.12140>



### Scientific Advisory Board Initial Report

Following a call with the Scientific Advisory Board members on the 16th of May, the Scientific Advisory Board submitted their final report for its first year of operation. The GPA team are in the process of discussion and review of the important points raised in the report in order to provide a response. We would like to thank Professors Robert Dellavalle, Mohsen Naghavi and Luigi Naldi for their feedback on the project.

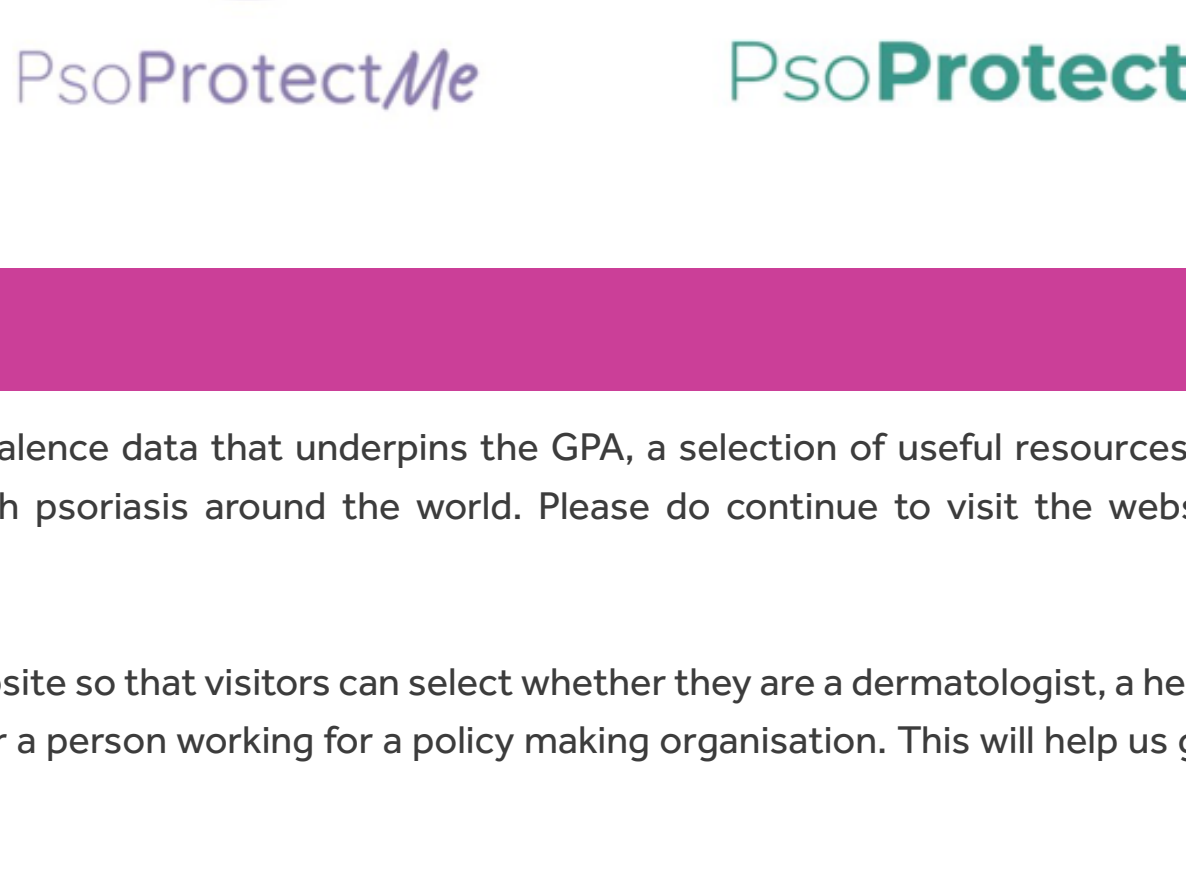


From the left: Professor Robert Dellavalle, Professor Mohsen Naghavi, Professor Luigi Naldi

### PsoProtect & PsoProtectMe

PsoProtect is a registry for healthcare professionals to report cases of COVID-19 in psoriasis patients. So far, 1652 cases have been reported and, out of these cases, 13.5% were hospitalised and 93% made a full recovery. PsoProtect's publication in the British Journal of Dermatology indicated that, while only a minority of people with psoriasis were hesitant towards the COVID-19 vaccine, people with disrupted access to psoriasis care during the pandemic were more likely to be hesitant. Explore the data here: <https://psoprotect.org/current-data/>

PsoProtectMe is a registry for people with psoriasis to report how they have been affected by the pandemic, whether they've had COVID-19 or not. So far, 5360 participants have completed the survey and 14% of participants had been diagnosed with COVID-19. 2136 participants felt that their psoriasis had worsened during the pandemic, 1845 felt that it had stayed the same and 354 felt that it had improved. Explore the data here: <https://psoprotectme.org/current-data/>

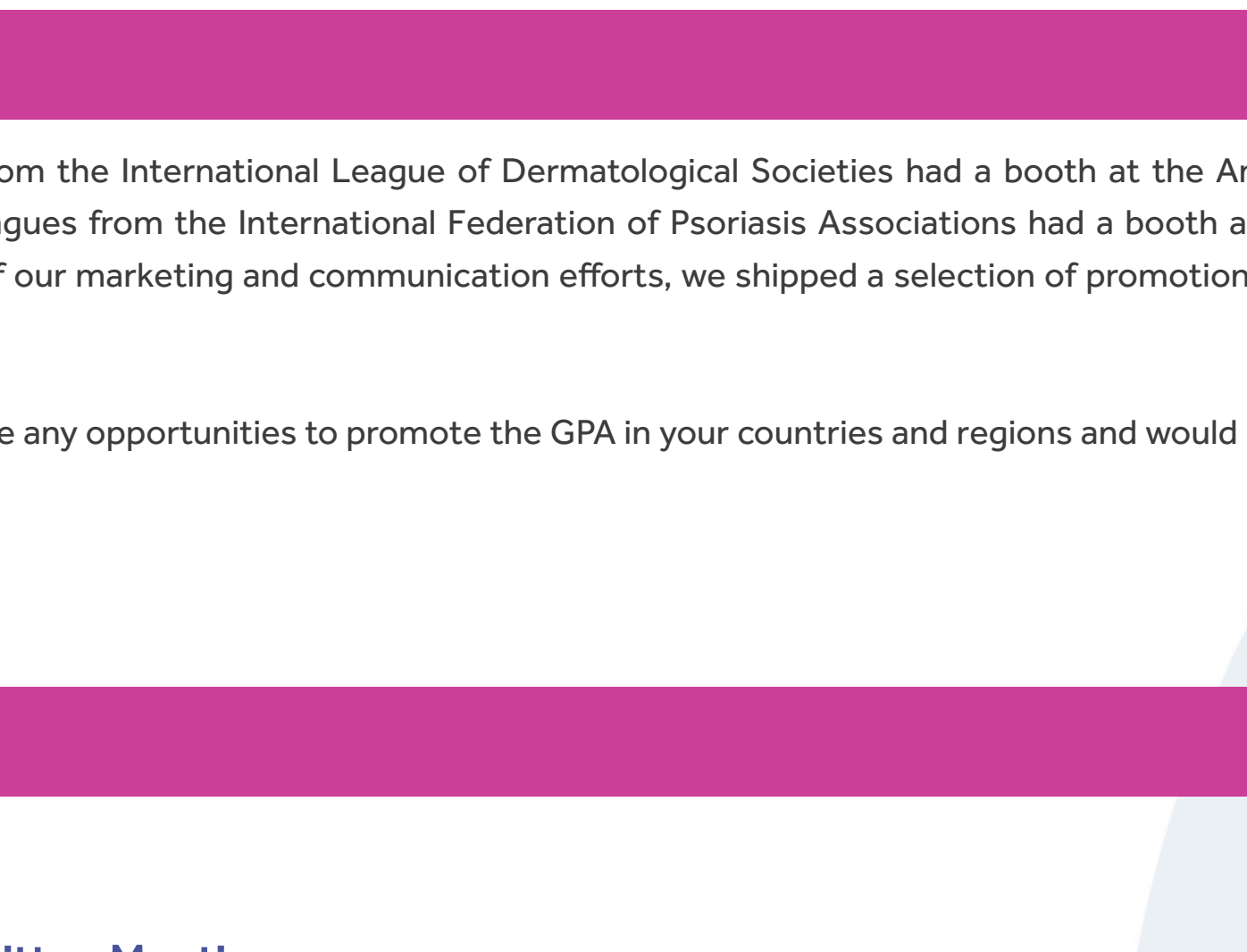


### Website Update

On our website, you can find the psoriasis prevalence data that underpins the GPA, a selection of useful resources such as our annual report and blog posts, and a diverse range of stories from people living with psoriasis around the world. Please do continue to visit the website and share the link where possible on social media: <https://www.globalpsoriasisatlas.org/en/>

We have recently added a pop-up box to the website so that visitors can select whether they are a dermatologist, a healthcare professional, a researcher, a person living with psoriasis, a member of the general public or a person working for a policy making organisation. This will help us gauge the type of user that visits our website and enable us to tailor our content accordingly.

Following discussion with the Scientific Advisory Board, we are working on plans to update the website and present the prevalence data on an interactive heat map. Watch this space...



### Strategic Review Meetings

In March, key members of the GPA Research Team and Collaborating Organisations met to review progress during Phase II of the Atlas and to begin to consider short, medium and long term strategic planning moving into Phase III. This initial meeting presented an opportunity to discuss the strengths and weakness of the GPA as well as any opportunities and threats facing the project. The Strategic planning process continued with additional meetings in May and June 2022; it has been an insightful process coming together as a team to solidify the GPA's research goals for Phase III.

### Promoting the GPA

During the past month, our colleagues from the International League of Dermatology Societies had a booth at the Annual Meeting of the British Association of Dermatologists in Glasgow and our colleagues from the International Federation of Psoriasis Associations had a booth at the Congress of the Skin Inflammation & Psoriasis International Network. As part of our marketing and communication efforts, we shipped a selection of promotional GPA materials to our colleagues at these events to be handed out to the attendees.

Please remember to let us know if you have any opportunities to promote the GPA in your countries and regions and would like us to provide you with any GPA branded materials.

Contact: [jade.kelly@manchester.ac.uk](mailto:jade.kelly@manchester.ac.uk)

### Upcoming meetings

**Saturday 10<sup>th</sup> September**

- 13.30-14.45: **Steering Committee Meeting**
- 15.00-16.00: **Board of Governors Meeting**
- 16.15-17.00: **Funders Briefing**

*(During the Congress of the European Academy of Dermatology and Venereology, Milan, Italy)*

#### THE GPA

About the GPA

Collaborating Organisations

The Home of GPA

Funders

Team Map

CONTACT

FAQs

PRIVACY POLICY

#### EXPLORE THE DATA

Prevalence Heat Map

Healthcare Data

Key Messages

#### PSORIASIS STORIES

#### EVENTS

#### RESOURCES

What is Psoriasis

Industry Sponsorship Information

GPA Articles

Newsletters

Annual Reports

Posters

Publications

SPI

PSO WELL®

#### HOW CAN I SUPPORT GPA?

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 collaborations across regions and countries.**

Contact us