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# Learning from disease registries during a pandemic: Moving toward an international federation of patient registries



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**Abstract** High-quality dermatology patient registries often require considerable time to develop and produce meaningful data. Development time is influenced by registry complexity and regulatory hurdles that vary significantly nationally and institutionally. The rapid emergence of the coronavirus disease 2019 (COVID-19) global pandemic has challenged health services in an unprecedented manner. Mobilization of the dermatology community in response has included rapid development and deployment of multiple, partially harmonized, international patient registries, reinventing established patient registry timelines. Partnership with patient organizations has demonstrated the critical nature of inclusive patient involvement. This global effort has demonstrated the value, capacity, and necessity for the dermatology community to adopt a more cohesive approach to patient registry development and data sharing that can lead to myriad benefits. These include improved utilization of limited resources, increased data interoperability, improved ability to rapidly collect meaningful data, and shortened response times to generate real-world evidence. We call on the global dermatology community to support the development of an international federation of patient registries to consolidate and operationalize the lessons learned during this pandemic. This will provide an enduring means of applying this knowledge to the maintenance and development of sustainable, coherent, and impactful patient registries of benefit now and in the future.

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## Introduction

In the hierarchy of evidence-based medicine, randomized controlled clinical trials are accepted as the standard for confirming the safety and efficacy of treatments to guide clinical practice. Although rare events may be encountered serendipitously, the stringent inclusion criteria of clinical trials exclude patients with significant comorbidities and are not powered to detect rare adverse events encountered in the “real world.” Although spontaneous reporting such as the Medicines and Healthcare products Regulatory Agency Yellow Card Scheme in the United Kingdom can detect adverse reactions to medications post-marketing, patient registries reflect “realworld” evidence more closely.<sup>1-3</sup> With large numbers of participants and long-term follow-up, registries are more suited to detect rare adverse drug events. The “realworld” data registries collections also describe a

wider range of disease severities; off-label use, including combination therapies specifically excluded in randomized controlled trials; and the natural history of diseases as comparators. Registries are also ideally placed to identify cohorts of potential clinical trial candidates and enable pharmacoeconomic evaluations.

Broad, inclusive projects, such as patient registries, that capture diverse data can be resource intensive. Incrementally, increasing data security and privacy regulatory requirements add strain in an age of ever-evolving global connectivity. Patient registries often develop as silos, created to address region-specific nuances and experiences. This pattern of development typically results in poorly harmonized datasets across different countries.<sup>4-7</sup> With high-quality patient reg-

istries and time to identify and incorporate diverse datasets, this lack of data interoperability can at times be rectified. When a pandemic strikes, a time when coherence and speed are at a premium, these weaknesses are exposed. Valuable information can be lost that might otherwise have benefited patients and the global medical community.

We briefly review the current state of dermatology patient registries and consider how we can evolve to become pandemic ready and maximize the reach and value of "real-world" data at a time when efficient use of limited resources is particularly important.

## Patient registries: international collaboration and data set harmonization

Although patient registries have existed for many years, their definition has evolved and is perhaps most robustly described as: "an organized system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition, or exposure, and that serves one or more predetermined scientific, clinical, or policy purposes. A registry database is a file (or files) derived from the registry."<sup>4</sup>

The benefit of patient registries is well recognized. The real-world evidence they generate can identify best clinical practice to improve outcomes and health care value. For example, data from the Swedish Hip Arthroplasty Register, when compared with the hip revision burden of the United States between the years 2000 and 2009, were estimated to have resulted in avoidance of approximately 7,500 hip revisions in Sweden during the same period.<sup>8</sup> Sweden achieved this by using the registry data to identify the best clinical practices and the most suitable implants, resulting in one of the lowest revision rates worldwide. The capacity of patient registries to register large numbers of patients has also been recognized as a critical component of rare disease care and as being able to identify rare side effects of medications. Efalizumab, a humanized, recombinant, monoclonal IgG1 antibody, demonstrated considerable efficacy in the treatment of psoriasis in what was, at the time, the "longest continuous study using a biologic therapy for psoriasis."<sup>9</sup> Despite following 339 patients for up to 33 months, progressive multifocal leukoencephalopathy was not identified. This rare but serious adverse effect, for which efalizumab was ultimately withdrawn after reporting by the Yellow Card Scheme in the United Kingdom, was only identified after spontaneous reporting of one suspected and three confirmed cases after more than 46,000 patients had been exposed to the medication.<sup>10</sup> Evaluation of the long-term safety of biologic therapies in psoriasis, without reliance on spontaneous reporting and randomized controlled trials alone, was the primary reason for the establishment of a number of national registries.<sup>11,12</sup> Since its origination in 2005, the collabo-

rative network, PSONET (European Registry for Psoriasis <http://psonet.eu>), has linked such independent registries for patients with psoriasis receiving systemic medications to monitor the long-term safety and effectiveness of therapy.<sup>12</sup>

The value of patient registries has been recognized at the governmental level. In the United States, the Department of Health and Human Services, through the Agency for Healthcare Research and Quality (AHRQ), produces comprehensive registry development and maintenance guidelines.<sup>4</sup> In the European Union, registries have been identified as "key instruments for developing rare disease (RD) clinical research, improving patient care and health service (HS) planning," resulting in the funding of the European Platform for Rare Disease Registries (EPIRARE) project "to improve standardization and data comparability among patient registries and to support new registries and data collections."<sup>5</sup> The PATient Registries iNiTiative (PARENT) joint action also received significant funding to identify best practice registry development, producing, among other deliverables, "Methodological guidelines and recommendations for efficient and rational governance of patient registries."<sup>7</sup> The European Medicines Agency has also recognized the value of using patient registries and their networks of stakeholders in facilitating the Health Technology Assessment. This resulted in the development of a cross-committee task force to facilitate harmonization of data collected in disease registries and encourage the use of existing patient registries "to measure the safety and efficacy of medicinal products in routine clinical practice."<sup>13,14</sup>

The value of patient registries in the dermatology community has become increasingly more apparent, generating an ever-expanding volume of real-world evidence. Patient registries, such as the British Association of Dermatologists Biologics and Immunomodulators Register (BADBIR; United Kingdom and Republic of Ireland; <http://badbir.org/>) and BIOBADADERM (Spain; <https://biobadaderm>), in psoriasis have emerged on a national level. Reaching across national borders, collaborations across Europe, such as the PSONET initiative for psoriasis registries, and the TREATment of ATopic eczema (TREAT) registry taskforce (<https://treat-registry-taskforce.org/>), which have established atopic dermatitis registries in multiple European countries, aim to facilitate closer harmonization of patient data.<sup>15,16</sup> Additional patient registries are emerging in the rare disease area (eg, ectodermal dysplasias plus mosaic and DNA repair disorders). Patient registries for epidermolysis bullosa and hidradenitis suppurativa have existed for a number of years,<sup>17-19</sup> and rare disease registries are expected to grow significantly in population coverage within the European Union owing to the emerging European Reference Networks (ERNs). These represent virtual networks that connect highly specialized experts in over 900 health care units from more than 300 hospitals across 26 member states in the European Union to provide care for rare diseases. Sites within the United Kingdom, which recently left the European Union, continue to partic-

ipate in ERNs. Dermatology is represented by ERN-Skin, which is currently developing a generic registry capable of capturing numerous skin conditions at a high level and sharing common data points. In addition to disease-focused registries, treatment-related international registries are in development, such as the Laser Treatments for Dermatology (LEAD) registry.<sup>20</sup>

## COVID-19 patient registries

In 2020, a novel RNA virus, severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), causing a disease known as coronavirus disease 2019 (COVID-19), resulted in a global pandemic that, to date, has claimed the lives of an estimated 850,000 people and infected more than 25 million.<sup>21</sup> At a time of unprecedented demands on physicians and health care providers, a number of new dermatology patient registries have been developed to assess the outcomes of dermatology patients with COVID-19. Ten of these registries have recently been established.<sup>22</sup>

Many of these registries have a global reach. One is patient-facing (PsoProtectMe, <https://psoprotectme.org/>), one has both patient and physician entry options (Global Hidradenitis Suppurativa COVID-19 registry, <https://hscovid.ucsf.edu>),<sup>23,24</sup> but the others are physician-entered only. A third patient-facing survey, Surveillance Epidemiology of Coronavirus Under Research Exclusion (SECURE)-AD Patient Survey, (<https://www.secure-derm.com/secure-pad/>) has also emerged. An analysis of datasets demonstrates a remarkable coherence across COVID-19-related data collected. This contrasts with prior experience of poor patient registry interoperability, the improvement of which was a key principle underlying the PARENT and EPIRARE projects.<sup>4-6,25,26</sup> The coherence of the COVID-19 patient registries is likely to have been contributed to by each registry using the core concept developed by the COVID-19 Inflammatory Bowel Disease Registry (SECURE-IBD; <https://covidibd.org>).<sup>27,28</sup> In addition, the creators of these registries met early in the epidemic to establish a collaborative framework, and the American Academy of Dermatology/International League of Dermatological Societies COVID-19 Dermatology Registry, PsoProtect and SECURE-AD, have already shared data with one another.<sup>22</sup> An additional contributor is likely to be the experience in patient registry development and maintenance by the registry teams.

Anonymity or the de-identification of data in several COVID-19 patient registries has enabled exemption from ethics committee review in most jurisdictions. Despite these exemptions, some academic centers continue to require data use agreements, and full ethical approval has been required in others (eg, in Australia, Ireland, and Canada). The latter requirement hints at the volume of work required to develop a patient registry that adheres to current standards in an era of increasing demands for data protection and security.

Each ethical application requires considerable resources and expertise. A data protection impact assessment, study protocol, ethics application, and evidence confirming insurance coverage and financial sustainability of the registry project are often required. Information technology expertise with experience in registry development to create an appropriate platform is critical. Considerable effort is then necessary to recruit and manage steering and advisory boards to develop a dataset, user-test the registry platform, and establish data analysis strategies. Continuous liaison with multiple physician and patient organizations to mobilize endorsements and drive patient recruitment is then essential.

## Traditional compared with emerging pandemic registries

Patient registries, particularly those with international recruitment, have traditionally taken years to develop, even with considerable budgets. For example, in atopic dermatitis and alopecia areata, global eDelphi projects have both taken more than a year to facilitate the development of a common data set.<sup>29-34</sup> Newly emerging COVID-19 patient registries, despite the considerable requirements outlined earlier in this report, have been developed far more rapidly through the considerable collective goodwill, energy, and diligence of the dermatology community.

There is, unfortunately, an increasing likelihood that the current COVID-19 pandemic will persist and possibly cause additional waves. It is also likely that future, unrelated, pandemics will occur. It is essential to reflect on patient registries before and during the current pandemic to consider the lessons learned and to determine how the knowledge gained may benefit the dermatology community now and in the future.

## Evolving patient registries

Undoubtedly, chief amongst the lessons learned regarding patient registries during the COVID-19 pandemic, is the need to rapidly deploy new or adapt existing patient registries in the event of future pandemics. Existing approval mechanisms are not designed to meet the pressing urgency demanded by a pandemic. Ethics committee meetings, data sharing agreements, and data protection impact assessments are critical elements of patient registry approval. These activities take considerable time and expertise, even when expedited by COVID-specific national research ethics committees and streamlined pathways that have emerged during the pandemic.

Although the response to the current pandemic has been impressive in some countries, it will need to be even quicker in the future. Otherwise, the benefit of answering clinical questions, such as the safety of the initiation, discontinuation,



or continuation of immunosuppression/immunomodulation for such immune-mediated diseases as psoriasis and atopic dermatitis, will be lessened. Greater permeation of registries beyond countries with many resources and expert centers is needed. This requires the availability of pre-existing registry infrastructures, which the current emerging COVID-19 patient registries may provide.

To maximize data utilization, its harmonization will be essential. Even the most seemingly simple variables can be interpreted and recorded differently between countries. Defining standard, understandable, and cohesive reporting variables early on is of paramount importance. This will require broad agreement on standard data sets with clear definition of data terms. It should incorporate the work of relevant groups, such as the Core Outcome Measures in Effectiveness Trials (COMET, <http://www.comet-initiative.org/>)<sup>34</sup> initiative, which has generated core outcome sets for use in COVID-19 research. Where new data sets need to be generated, a rapid process of term definition and broad agreement to implement them should be established.

For those who intend to construct new patient registries, visibility of standard data sets must be prioritized. The reusable building blocks of patient registry development, such as standardized ethics templates, patient information leaflets, committee membership, and authorship agreements, as well as expertise regarding data protection, security, governance, software development, and implementation, must be readily available. Ethics applications will be required to be considered in advance, particularly to facilitate non-anonymized patient registries needed to avoid problems with data double entry from removal of patient identifiable data. There should be mechanisms to facilitate easier collaboration of patient registry groups across time zones, languages, cultures, and physician-patient boundaries. Considerable work will need to be undertaken to ensure that patient registries can integrate with existing information systems.

Electronic health records (EHRs), for example, contain valuable patient-level data, export of which could reduce some of the data entry burden of patient registries. Unfortunately, EHRs have traditionally connected inefficiently and expensively with patient registries or contain data that require significant processing to make it capable of being incorporated within a registry.<sup>35</sup>

Inter-registry interoperability will also be important to enable use of existing pharmacovigilance registry data that can act as denominators or even identify patients who might require recall upon identification of risk modifiers. Such connectivity is likely to rely heavily on ensuring that registries embrace open standard data models, such as openEHR, that encourage recording of data in a similar manner from system to system and by utilizing messaging standards, such as HL7® FHIR®, that enable structured data exchange between them.<sup>36-38</sup>

Beyond dermatology, harmonization and shared data infrastructure across specialties will be an important driver of research efficiency and effectiveness. For example, in the

early stages of the COVID-19 pandemic, the SECURE-IBD registry shared its data dictionary, institutional review board (IRB) templates, communication tools, and other components of its blueprint with multiple autoimmune focused groups, including several international dermatology and rheumatology efforts.<sup>27</sup> Because patients across immune-mediated conditions share similar medication exposures, harmonized data collection will facilitate studies of the effect of various immune suppressant medications on COVID-19-related outcomes across conditions. Ultimately, pooling data across conditions will provide important answers to emerging safety conditions much faster than single disease or specialty registries working independently.

Patient involvement is a critical component of success. A feature of COVID-19 patient registries has been patient involvement at a steering committee level and the establishment of robust communication with patient organizations. This has reconfirmed the immense value of a patient-centric approach, evidenced through considerable benefits in all aspects of patient registry development and deployment, including improved communication, dataset generation, advocacy, visibility, and endorsement.

A notable feature of the self-reporting COVID-19 patient surveys for psoriasis (PsoProtectMe), atopic dermatitis (SECURE-AD Patient Survey), and hidradenitis suppurativa (Global Hidradenitis Suppurative COVID-19 registry) is the considerably greater speed of recruitment reported, compared with the corresponding physician-reported patient registries (<https://www.psoprotect.org/>,<sup>23</sup> <https://www.secure-derm.com/secure-ad-physician><sup>39</sup> and <https://www.hscovid.ucsf.edu><sup>24</sup>). Although PsoProtectMe and SECURE-AD Patient Survey enable registration of patients who have not experienced COVID-19 and questions typically arise regarding privacy, security, and data validity, it is clear that patient-centric registries are key to better patient engagement and registration.

## Future direction

COVID-19 has generated seismic ripples that continue to disrupt the fabric of our societies and the manner in which we practice medicine. With great challenges, however, come opportunities to evolve. We suggest an international federation of dermatology registries as a means to harness the foundations of registry collaboration among new and pre-COVID registry communities. Such a collaboration would use and build on the experience gained during this challenging time. This will aim to address many of the challenges identified earlier in this report and provide an entity capable of catalyzing rapid, international deployment if and when future pandemics emerge.

Such a federation would aim to develop the reusable blueprints of registry creation, standardized data sets, and definitions to better align existing and future patient registries. As an independent organization, the federation would

aim to impartially facilitate cohesion, rather than act as a regulator. Although promoting interoperability, the federation would not seek to host patient data that might compromise data sovereignty, but still facilitate data merging where consent to data sharing exists.

Such a federation could enable greater visibility of registries and their characteristics through the development and maintenance of a registry of registries, a concept described by PARENT and the AHRQ.<sup>6,40</sup> Orphanet is a resource that gathers and improves knowledge on rare disease. Initially established by the French National Institute for Health and Medical Research in 1997, it has evolved to become a global consortium of 41 countries. Although Orphanet lists a number of dermatology-relevant patient registries, these are within a large directory that focuses on all rare diseases.<sup>41,42</sup> An inventory of disease registries already exists, supported by the European Network of Centres for Pharmacoepidemiology and Pharmacovigilance (ENCePP) Resource database of data sources, although it is incomplete with respect to dermatology patient registries.<sup>13,43-46</sup> The AHRQ developed a similar concept to act as a patient registry equivalent of ClinicalTrials.gov that is “a database of privately and publicly funded patient registry studies conducted around the world;” however, its funding ended in 2019.<sup>40,47,48</sup>

This is a timely reminder that such valuable resources may benefit from being located within the care of the networks that will most benefit from them, such as a federation of dermatology registries, to facilitate awareness, utilization, and sustainability. A simplified example of such a registry of registries (Table 1) is presented, although we envision a more detailed, live registry to be maintained by the proposed federation. Initially published in 2016, after a literature review of dermatology patient registries, Table 1 has been expanded to incorporate a number of omitted registries and those that have emerged during the COVID-19 era.<sup>49</sup>

This proposed federation would provide a hub capable of fostering the continued connectivity of patient registries with relevant stakeholders, including patient and physician organizations that have been so impressive during the COVID-19 era. This may increase the capacity for patient organizations to advocate for physicians to engage more broadly with relevant patient registries. It would facilitate fast tracking of applications to regulatory authorities and ethics boards through the provision of reusable templates and group experience to provide guidance to steering committees committed to swift registry development. Ultimately, streamlining and collaborating on registry development in this manner could translate into the speedier provision of real-world information. Subsequently, this might reduce the time taken to address clinical hypotheses, for example, the effectiveness of hydroxychloroquine in patients exposed to COVID-19 and the impact of systemic medications on prognosis.

To develop a federation of dermatology registries, we envision additional work, but perhaps less than would have been envisaged, before COVID-19 given the significant effort undertaken already by registry groups. The blueprint

of such an organization has been outlined by the structures created for each of the patient registries. In the first instance, a steering committee with global representation from existing stakeholders, nominated experts with specific expertise in pharmacoeconomics, epidemiology, health informatics and data protection; and patient representation would be required. A larger scientific advisory board, which can be expanded to ensure democratic representation when new patient registries emerge, would also be invited. The time expenditure of committee members is likely to be significantly rewarded by the outputs the federation would be able to generate in terms of simplifying registry development and maintenance.

Although funding for sustainability would be required, much of the large infrastructure costs have already been borne by the development of the registries the federation seeks to support. Such a federation would also provide a valuable conduit to facilitate the generation of patient registries capable of providing data to the European Medicines Agency and the US Food and Drug Administration–mandated post-marketing surveillance studies. Supporting such a project would be of notable value to the pharmaceutical industry.

It is important to note that the federation would require broad endorsement. Given the wide-ranging support by international patient and physician groups that have already endorsed a number of the newly developed COVID-19 patient registries, this should not be a significant hurdle. Undoubtedly, an international federation of patient registries will require considerable debate and more formalized structures; however, it is critical that the opportunity not be lost.

## Conclusions

COVID-19 has placed exceptional demands on societies and economies globally, but it has provoked a coherent response from the international dermatology community. One encouraging occurrence has been the rapid harmonization and development of international patient registries to collect relevant COVID-19 data from cohorts of dermatology patients. We urge the international community to build on this work and suggest the establishment of an international federation of dermatology registries to generate new standards and practices. Such a cohesive approach may also establish more rapid and sustainable avenues for funding these registries and provide more affordable solutions at times where economic capabilities are under strain.

Although such an undertaking would be of particular significance during pandemics, the value to facilitating harmonization and improving the quality of existing and future non-pandemic registries would also be significant. Despite such an undertaking being viewed as resource hungry and necessitating considerable innovation and input, much of the groundwork has already been done. The rapidly increasing human toll of COVID-19 and the continued, pressing need

**Table 1** Dermatology patient registries\*

COVID-19 registries			
Name	Disease	Scope	Website
<b>AEDV COVID-Piel</b>	COVID-19/Dermatology	National (Spain)	<a href="https://aedv.es/covid-piel">https://aedv.es/covid-piel</a>
<b>COVID-19 Dermatology Registry</b>	COVID-19/Dermatology	International (Global)	<a href="https://www.aad.org/coronavirus">https://www.aad.org/coronavirus</a>
<b>FSD (Société Française de Dermatologie) COVIDSKIN</b>	COVID-19/Skin Lesions	National (France)	<a href="https://evenements-sfd.fr/coronavirus">https://evenements-sfd.fr/coronavirus</a>
<b>Global Hidradenitis Suppurativa COVID-19 Registry</b>	COVID-19/Hidradenitis Suppurativa	International (Global)	<a href="https://hscovid.ucsf.edu/">https://hscovid.ucsf.edu/</a>
<b>PedRA (Pediatric Dermatology Research Alliance)</b>	COVID-19/Acral Ischemia/Perniosis in children	International (Global)	<a href="https://pedraresearch.org/covid">https://pedraresearch.org/covid</a>
<b>PsoProtect</b>	COVID-19/Psoriasis	International (Global)	<a href="https://psoprotect.org">https://psoprotect.org</a>
<b>PsoProtectMe</b>	COVID-19/Psoriasis	International (Global)	<a href="https://psoprotectme.org">https://psoprotectme.org</a>
<b>SECURE-AD</b>	COVID-19/Atopic dermatitis	International (Global)	<a href="https://www.secure-derm.com">https://www.secure-derm.com</a>
<b>SECURE-AD Patient Survey</b>	COVID-19/Atopic dermatitis	International (Global)	<a href="https://www.secure-derm.com/secure-pad/">https://www.secure-derm.com/secure-pad/</a>
<b>SECURE-Alopecia</b>	COVID-19/All forms of hair loss	International (Global)	<a href="https://www.secure-derm.com">https://www.secure-derm.com</a>
General dermatology registries			
Name	Disease	Scope	Website
<b>A*STAR (The UK &amp; Ireland Atopic eczema Systemic Therapy Register)</b>	Atopic dermatitis	International (United Kingdom and Ireland)	<a href="https://astar-register.org">https://astar-register.org</a>
<b>AtopyReg</b>	Atopic dermatitis	National (Italy)	<a href="https://www.atopyreg.it/">https://www.atopyreg.it/</a>
<b>Biobadatop</b>	Atopic dermatitis	National (Spain)	No link available
<b>BioDay</b>	Atopic dermatitis	International (Netherlands and Belgium)	<a href="https://www.bioday.nl/">https://www.bioday.nl/</a>
<b>GREAT (Groupe de Recherche sur L'Eczéma ATopique)</b>	Atopic dermatitis	National (France)	<a href="https://www.sfdermato.org/site/groupe-de-recherche-sur-l-eczema-atopique-great.html">https://www.sfdermato.org/site/groupe-de-recherche-sur-l-eczema-atopique-great.html</a>
<b>Japan AD Registry (ADDRESS-J)</b>	Atopic dermatitis	National (Japan)	<a href="https://upload.umin.ac.jp/cgi-open-bin/ctr_e/ctr_view.cgi?recptno=R000025749">https://upload.umin.ac.jp/cgi-open-bin/ctr_e/ctr_view.cgi?recptno=R000025749</a>
<b>Pediatric Elective Eczema Project</b>	Atopic dermatitis	National (US)	<a href="https://enroll.thepeerprogram.org/">https://enroll.thepeerprogram.org/</a>
<b>SCRATCH</b>	Atopic dermatitis	National (Denmark)	No link available
<b>SwedAD (Svenskt kvalitetsregister för Atopisk Dermatit)</b>	Atopic dermatitis	National (Sweden)	<a href="http://swedad.nu/">http://swedad.nu/</a>
<b>TREATgermany (TREATment of ATopic eczema, Germany)</b>	Atopic dermatitis	National (Germany)	<a href="http://www.treatgermany.org/">http://www.treatgermany.org/</a>
<b>TREAT NL (TREATment of ATopic eczema, the Netherlands)</b>	Atopic dermatitis	National (Netherlands)	<a href="https://treatregister.nl">https://treatregister.nl</a>

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**Table 1** (continued)

COVID-19 registries			
Name	Disease	Scope	Website
<b>CARPE (Chronic Hand Eczema Registry on Long-term Patient Management)</b>	Chronic hand eczema	National (Germany)	No link available
<b>RegiSCAR</b>	Cutaneous drug reactions	National (US)	<a href="http://www.regiscar.org">http://www.regiscar.org</a>
<b>Cutaneous Lupus Registry</b>	Cutaneous lupus	National (US)	<a href="https://www.utsouthwestern.edu/education/medical-school/departments/dermatology/research/cutaneous-lupus-registry/">https://www.utsouthwestern.edu/education/medical-school/departments/dermatology/research/cutaneous-lupus-registry/</a>
<b>Central Cutaneous Lymphoma Registry</b>	Cutaneous lymphoma	National (Germany)	<a href="https://www.orpha.net/consor/cgi-bin/OC_Exp.php?lng=EN&amp;Expert=231889">https://www.orpha.net/consor/cgi-bin/OC_Exp.php?lng=EN&amp;Expert=231889</a>
<b>UK and Ireland Juvenile Dermatomyositis Cohort Biomarker Study and Repository</b>	Dermatomyositis	International (United Kingdom and Ireland)	<a href="https://www.orpha.net/consor/cgi-bin/ResearchTrials_RegistriesMaterials.php?lng=EN&amp;data_id=45340&amp;RegistryMaterialName=English-juvenile-dermatomyositis-registry-and-repository">https://www.orpha.net/consor/cgi-bin/ResearchTrials_RegistriesMaterials.php?lng=EN&amp;data_id=45340&amp;RegistryMaterialName=English-juvenile-dermatomyositis-registry-and-repository</a>
<b>Ectodermal Dysplasias International Registry</b>	Ectodermal dysplasias	International	<a href="https://nfed.patientcrossroads.org">https://nfed.patientcrossroads.org</a>
<b>EBCare Patient Insights Network</b>	Epidermolysis bullosa	International	<a href="https://ebcare.patientcrossroads.org">https://ebcare.patientcrossroads.org</a>
<b>EB Registry Austria</b>	Epidermolysis bullosa	National (Austria)	<a href="https://www.orpha.net/EB-RegisterAustria">https://www.orpha.net/EB-RegisterAustria</a>
<b>C1 Inhibitor Registry in the Treatment of Hereditary Angioedema Attacks</b>	Hereditary angioedema	International	<a href="https://clinicaltrials.gov/NCT01397864">https://clinicaltrials.gov/NCT01397864</a>
<b>English hereditary angioedema patient registry – part of the HAE European registry</b>	Hereditary angioedema	National (United Kingdom)	<a href="https://www.orpha.net/consor/cgi-bin/ResearchTrials_RegistriesMaterials.php?lng=EN&amp;data_id=35474N&amp;RegistryMaterialName=English-hereditary-angioedema-patient-registry—part-of-the-HAE-European-registry">https://www.orpha.net/consor/cgi-bin/ResearchTrials_RegistriesMaterials.php?lng=EN&amp;data_id=35474N&amp;RegistryMaterialName=English-hereditary-angioedema-patient-registry—part-of-the-HAE-European-registry</a>
<b>Firazyr Patient Registry Protocol (Icatibant Outcome Survey)</b>	Hereditary angioedema	International	<a href="https://clinicaltrials.gov/NCT01034969">https://clinicaltrials.gov/NCT01034969</a>
<b>HAE-registry: European hereditary angioedema patient registry</b>	Hereditary angioedema	International	<a href="https://www.orpha.net/consor/cgi-bin/ResearchTrials_RegistriesMaterials.php?lng=EN&amp;data_id=28343&amp;RegistryMaterialName=HAE-registry—European-hereditary-angioedema-patient-registry">https://www.orpha.net/consor/cgi-bin/ResearchTrials_RegistriesMaterials.php?lng=EN&amp;data_id=28343&amp;RegistryMaterialName=HAE-registry—European-hereditary-angioedema-patient-registry</a>
<b>Hereditary Angioedema Association Scientific Registry</b>	Hereditary angioedema	National (US)	<a href="https://www.haea.org/pages/p/LearnMoreSR">https://www.haea.org/pages/p/LearnMoreSR</a>
<b>Spanish Patient Registry of Hereditary Angioedema</b>	Hereditary angioedema	National (Spain)	<a href="https://www.orpha.net/consor/cgi-bin/ResearchTrials_RegistriesMaterials.php?lng=EN&amp;data_id=30532&amp;RegistryMaterialName=Registro-espa-ol-de-pacientes-con-angioedema-hereditario">https://www.orpha.net/consor/cgi-bin/ResearchTrials_RegistriesMaterials.php?lng=EN&amp;data_id=30532&amp;RegistryMaterialName=Registro-espa-ol-de-pacientes-con-angioedema-hereditario</a>

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**Table 1** (continued)

COVID-19 registries			
Name	Disease	Scope	Website
<b>International Rare Histiocytic Disorders Registry</b>	Histiocytic disorders	International	<a href="https://clinicaltrials.gov/ct2/show/NCT02285582">https://clinicaltrials.gov/ct2/show/NCT02285582</a>
<b>National Registry for Ichthyosis and Related Diseases</b>	Ichthyosis	National (US)	<a href="http://www.firstskinfoundation.org/">http://www.firstskinfoundation.org/</a>
<b>Network for Ichthyosis and Related Keratinization Disorders</b>	Ichthyosis	National (Germany)	<a href="https://www.medizin.uni-muenster.de/">https://www.medizin.uni-muenster.de/</a>
<b>KINDLERNET: Central patient registry Kindler syndrome</b>	Kindler syndrome	International	<a href="https://www.orpha.net/consor/cgi-bin/OC_Exp.php?lng=EN&amp;Expert=242250">https://www.orpha.net/consor/cgi-bin/OC_Exp.php?lng=EN&amp;Expert=242250</a>
<b>French Certified Patient Registry for Langerhans Cell Histiocytosis</b>	Langerhans cell histiocytosis	National (France)	<a href="https://epidemiologie-france.aviesan.fr/en/epidemiology/records/french-langerhans-cell-histiocytosis-registry">https://epidemiologie-france.aviesan.fr/en/epidemiology/records/french-langerhans-cell-histiocytosis-registry</a>
<b>German Registry for Langerhans Cell Histiocytosis in Childhood</b>	Langerhans cell histiocytosis	National (Germany)	<a href="https://www.orpha.net/Deutschen-Registers-fur-Langerhanszell-Histiozytosen">https://www.orpha.net/Deutschen-Registers-fur-Langerhanszell-Histiozytosen</a>
<b>Great Ormond Street Hospital Congenital Melanocytic Naevus Registry for Congenital Melanocytic Nevi and Neurocutaneous Melanocytosis</b>	Melanocytic nevi	National (United Kingdom)	No link available
	Melanocytic nevi; neurocutaneous melanocytosis	National (Germany)	No link available
<b>Morphea in Adults and Children</b>	Morphea	National (US)	<a href="https://clinicaltrials.gov/ct2/show/NCT01808937">https://clinicaltrials.gov/ct2/show/NCT01808937</a>
<b>International Pachyonychia Congenita Research Registry</b>	Pachyonychia congenita	International	<a href="https://www.pachyonychia.org/patient-registry/">https://www.pachyonychia.org/patient-registry/</a>
<b>Pemphigus-Pemphigoid Registry</b>	Pemphigus; pemphigoid	International	<a href="http://www.pemphigus.org/pemphigus-pemphigoid-registry/">http://www.pemphigus.org/pemphigus-pemphigoid-registry/</a>
<b>Italian Registry of Patients and Families Affected by Pseudoxanthoma Elasticum</b>	Pseudoxanthoma elasticum	National (Italy)	<a href="https://www.orpha.net/Pseudoxanthoma-elasticum">https://www.orpha.net/Pseudoxanthoma-elasticum</a>
<b>PXE International BioBank and Clinical Data Registry</b>	Pseudoxanthoma elasticum	International	<a href="https://www.pxe.org/registry">https://www.pxe.org/registry</a>
<b>AMC Psoriasis Registry</b>	Psoriasis	National (Netherlands)	No link available
<b>Australasian Psoriasis Registry</b>	Psoriasis	International (Australia and New Zealand)	<a href="http://www.psoriasis.asn.au">www.psoriasis.asn.au</a>
<b>BADBIR (British Association of Dermatologists Biologics and Immunomodulators Register)</b>	Psoriasis	International (United Kingdom and Republic of Ireland)	<a href="http://www.badbir.org">http://www.badbir.org</a>
<b>Biobadaderm</b>	Psoriasis	National (Spain)	<a href="https://biobadaser.ser.es/biobadaderm/">https://biobadaser.ser.es/biobadaderm/</a>
<b>BioCAPTURE</b>	Psoriasis	National (Netherlands)	<a href="https://biocapture.nl">https://biocapture.nl</a>

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**Table 1** (continued)

COVID-19 registries			
Name	Disease	Scope	Website
<b>BIOREP</b>	Psoriasis	National (Czech Republic)	No link available
<b>Child-CAPTURE</b>	Psoriasis	National (Netherlands)	No link available
<b>Chronic Plaque Psoriasis Registry</b>	Psoriasis	International	<a href="https://clinicaltrials.gov/ct2/show/study/NCT00799877">https://clinicaltrials.gov/ct2/show/study/NCT00799877</a>
<b>Clalit Health Services Registry</b>	Psoriasis	National (Israel)	No link available
<b>Corrona Psoriasis Registry</b>	Psoriasis	National (US)	<a href="https://www.corrona.org/registry/psoriasis">https://www.corrona.org/registry/psoriasis</a>
<b>Dermbio</b>	Psoriasis	National (Denmark)	<a href="https://www.dermbio.dk">https://www.dermbio.dk</a>
<b>MPR (Malaysian Psoriasis Registry)</b>	Psoriasis	National (Malaysia)	<a href="https://www.dermatology.org.my/DermReg/index.htm">https://www.dermatology.org.my/DermReg/index.htm</a>
<b>PsoBest</b>	Psoriasis	National (Germany)	<a href="https://www.psobest.de/">https://www.psobest.de/</a>
<b>PSOBIOTEQ (French Psoriasis Registry)</b>	Psoriasis	National (France)	<a href="https://epidemiologie-france.aviesan.fr/en/epidemiology/records/cohorte-multicentrique-de-patients-recevant-un-traitement-systemique-conventionnel-ou-biotherapie-pour-un-psoriasis-cutane-moderne-a-severe">https://epidemiologie-france.aviesan.fr/en/epidemiology/records/cohorte-multicentrique-de-patients-recevant-un-traitement-systemique-conventionnel-ou-biotherapie-pour-un-psoriasis-cutane-moderne-a-severe</a>
<b>PsoCare</b>	Psoriasis	National (Italy)	No link available
<b>Psodit</b>	Psoriasis	National (Italy)	No link available
<b>PSOLAR (Psoriasis Longitudinal Assessment and Registry)</b>	Psoriasis	International	<a href="https://clinicaltrials.gov/ct2/show/NCT00508547">https://clinicaltrials.gov/ct2/show/NCT00508547</a>
<b>PsoNet</b>	Psoriasis	International	<a href="http://www.psonet.eu/cms/">http://www.psonet.eu/cms/</a>
<b>PsoRA</b>	Psoriasis	National (Austria)	<a href="https://psora.medunigraz.at">https://psora.medunigraz.at</a>
<b>PsoReg</b>	Psoriasis	National (Sweden)	<a href="https://www.psoreg.se">https://www.psoreg.se</a>
<b>SDNTT (Swiss Dermatology Network of Targeted Therapies)</b>	Psoriasis	National (Switzerland)	<a href="https://my.derma.ch/en/spec/SDNTT.html">https://my.derma.ch/en/spec/SDNTT.html</a>
<b>Slovenian National Registry of Psoriasis</b>	Psoriasis	National (Slovenia)	No link available
<b>Hospital for Special Surgery Scleroderma Registry</b>	Scleroderma	National (US)	<a href="https://www.hss.edu/clinical-trials_scleroderma-registry-repository.asp">https://www.hss.edu/clinical-trials_scleroderma-registry-repository.asp</a>
<b>Scleroderma Registry</b>	Scleroderma	National (US)	<a href="https://clinicaltrials.gov/ct2/show/NCT00074568">https://clinicaltrials.gov/ct2/show/NCT00074568</a>

COVID-19, coronavirus disease 2019; US, United States.

\* Adapted from DiMarco et al.<sup>49</sup> to include COVID-19 era patient registries.

for outcomes data are a powerful incentive to collaborate on and adopt such pioneering solutions.

## Conflict of interest

C.F. is Chief Investigator of the UK-Irish Atopic eczema Systemic Therapy Register (A-STAR). C.F., A.I., and P.S. co-lead the SECURE-AD register, which studies the impact of COVID-19 infection episodes on atopic dermatitis. D.W. and R.S. co-lead and are members of the Steering Committee, along with L.B., N.M., D.J.T., and K.Y., of the SECURE-Alopecia registry, which studies the impact of COVID-19 infection on patients with all forms of hair loss. R.S., D.W., N.M., K.Y., and L.B. are leading the development of Global Registry of Alopecia areata disease Severity and treatment Safety (GRASS). C.F., P.S., and C.A. are members of the international TREATment of Atopic eczema Taskforce (TREAT) Executive Committee. C.E.M.G. is Chief Investigator of the British Association of Dermatologists Biologics and Immunomodulators Register (BADBIR) and an Executive Member of the PsoProtect and Psoprotectme Registries. C.H.S. is Research Chair of BADBIR, and joint Principle Investigator (PI) of PsoProtect and PsoProtectMe Registries. S.K.M. is joint Principle Investigator of PsoProtect and PsoProtectMe Registries. I.L.C. is part of the Pediatric Dermatology Research Alliance COVID-19 Response Task Force, a collaboration between the Society for Pediatric Dermatology (SPD) and the Pediatric Dermatology Research Alliance (PeDRA). B.W.M.A. is a patient representative for the SECURE-AD patient register, and the Dutch TREAT NL and BioDAY registers. P.S. is member of the PsoProtect International Scientific Advisory Board. H.B.N. is a board member of the Hidradenitis Suppurativa Foundation. R.A., J.R.I., and H.B.N. are members of the Steering Committee of the Global Hidradenitis Suppurativa COVID-19 Registry.

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