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Learning from Disease Registries During a Pandemic: Moving Towards an International Federation of Patient Registries.

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Highlights:

- Patient registries are key means of collecting real-world evidence, particularly during pandemics.
- Successful patient registries require a high level of physician and patient engagement, with broad participation in order to be successful.

- More stringent data security, privacy and governance requirements are increasing barriers to patient registry development.
- Lessons learned from contrasting existing patient registries with those developed during the COVID-19 global pandemic are vital to the development and maintenance of patient registries that will better serve the dermatology community during and outside of future pandemics.
- This article calls on the dermatology community to commit to collaborative development, participation and maintenance of interoperable patient registries through the development of an international federation of patient registries. It also recognizes the rise of patient facing registries, and why patient involvement at all levels of registry design, deployment and data analysis is crucial.

Abstract (200 words; 200 max)

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 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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Conflicts of Interest: CF is Chief Investigator of the UK-Irish Atopic eczema Systemic TherApy Register (A-STAR). CF, AI and PS co-lead the SECURE (Surveillance Epidemiology of Coronavirus under Research Exclusion)-AD register, which studies the impact of COVID-19 infection episodes on atopic dermatitis. DW and RS co-lead the SECURE (Surveillance Epidemiology of Coronavirus under Research Exclusion)-Alopecia registry which studies the impact of COVID-19 infection on patients with all forms of hair loss. RS, DW, NM, KY and LB are leading the development of GRASS Global Registry of Alopecia areata disease Severity and treatment Safety (GRASS). CF, PS and CA are members of the international TREatment of Atopic eczema Taskforce (TREAT) Executive Committee. CEMG is Chief Investigator of the British Association of Dermatologists Biologics and Immunomodulators Register (BADBIR) and an Executive Member of the PsoProtect and Psoprotectme Registries. CHS is Research Chair of BADBIR, and joint CI of PsoProtect and PsoProtect*Me* Registries. SKM is joint CI of PsoProtect and PsoProtect*Me* Registries. Dr. Lara-Corrales are 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). BWMA is a patient representative for the SECURE (Surveillance Epidemiology of Coronavirus under Research Exclusion)-AD patient register, and the Dutch TREAT NL and BioDAY registers. PS is member of the PsoProtect International Scientific Advisory Board. Dr. Naik is a board member of the Hidradenitis Suppurativa Foundation.

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Abbreviations used:

Agency for Healthcare Research and Quality (AHRQ), British Association of Dermatologists Biologics and Immunomodulators Register (BADBIR), Core Outcome Measures in Effectiveness Trials (COMET), Core Outcome Sets (COSs), Data Protection Impact Assessment (DPIA), Electronic health records (EHRs), European Reference Network (ERN), European Medicines Agency (EMA), ENCePP (European Network of Centres for Pharmacoepidemiology and Pharmacovigilance), European Platform for Rare Disease Registries (EPIRARE), Health Level 7 Fast Healthcare Interoperability Resources (HL7 FHIR), Health Service (HS), Health Technology Assessment (HTA), Medicines and Healthcare products Regulatory Agency (MHRA), National Research Ethics Committees (NRECs), Randomized Controlled Clinical Trials (RCTs), PAtient Registries iNiTiative joint action (PARENT), Pediatric Dermatology Research Alliance (PeDRA), Surveillance Epidemiology of Coronavirus Under Research Exclusion (SECURE), Society for Pediatric Dermatology (SPD), TREatment of ATopic eczema (TREAT), United Kingdom (UK), United States of America (US).

Introduction

In the hierarchy of evidence-based medicine, randomized controlled clinical trials (RCTs) are accepted as the standard for confirming the safety and efficacy of treatments to guide clinical practice. While 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”. Though spontaneous reporting, such as the Medicines and Healthcare products Regulatory Agency (MHRA) Yellow Card Scheme in the United Kingdom (UK), can detect adverse reactions to medications post-marketing, patient registries reflect “real world” evidence more closely.[1–3] With large participant numbers and long-term follow up, registries are more suited to detect rare drug adverse events. The “real world” data they collect also describe a wider range of disease severities, off-label use, including combination therapies specifically excluded in RCTs, and the natural history of diseases as comparators. They 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 further 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.[4–7] With high-quality patient registries and time to identify and incorporate diverse datasets, sometimes, this lack of data interoperability can be rectified. Once a pandemic strike, at a time when coherence and speed is 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 the manner in which we can evolve to become pandemic-ready, while also maximizing 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 dataset harmonization

Though patient registries have existed for many years, their definition has evolved over time 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."*[4]

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 (US) between 2000-2009, were estimated to have resulted in avoidance of approximately 7,500 hip revisions in Sweden over the same decade.[8] 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 identified as a critical component of rare disease care and identifying rare side effects of medications. Efalizumab, a humanized, recombinant, monoclonal IgG1 antibody, showed considerable efficacy in the treatment of psoriasis in what was, at the time, the “longest continuous study using a biologic therapy for psoriasis.”[9] Despite following 339 patients for up to 33 months, progressive multifocal leukoencephalopathy was not identified. This rare but serious side effect, for which efalizumab was ultimately withdrawn after reporting by the Yellow Card Scheme in the UK, was only identified following spontaneous reporting of one suspected and three confirmed cases, after over 46,000 patients had been exposed to the medication.[10] Evaluation of the long-term safety of biologic therapies in psoriasis, without reliance on spontaneous reporting and RCTs alone, was the primary reason for the establishment of a number of national registries.[11,12] Since its origination in 2005, the collaborative network, PSONET (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.[12]

The value of patient registries has been recognized at the governmental level. In the U.S. the Department of Health and Human Services, through the Agency for Healthcare Research and Quality (AHRQ) produces comprehensive registry development and maintenance guidelines.[4] 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.”[5] PARENT (PAtient Registries iNiTiative joint action) also received significant funding to identify best practice registry development, producing, amongst other deliverables, Methodological Guidelines and Recommendations for Efficient and Rational Governance of Patient Registries.[7] The European Medicines Agency (EMA) has also recognized the value of utilizing patient registries and their networks of stakeholders in facilitating Health Technology Assessment (HTA). This resulted in the development of a cross-committee task force to facilitate harmonization of data collected in disease registries and encourage utilization of existing patient registries "to measure the safety and efficacy of medicinal products in routine clinical practice."[13,14]

The values 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; UK and Republic of Ireland; http://badbir.org/) and BIOBADADERM (Spain; https://biobadaderm), in psoriasis have emerged on a national level. Beyond national borders, collaborations across Europe, such as the PSONET initiative (http://psonet.eu) for psoriasis registries, and the TREAT (TREatment of ATopic eczema) registry taskforce (https://treat-registry-taskforce.org/), who have established atopic dermatitis registries in multiple European countries, aim to facilitate closer harmonization of patient data.[15,16] Further patient registries are emerging in the rare disease area; for example, ectodermal dysplasias plus mosaic and DNA repair disorders. Patient registries for epidermolysis bullosa and hidradenitis suppurativa have existed for a number of years,[17–19] and rare disease registries are expected to grow significantly in population coverage within the E.U. due to the emerging European Reference Networks (ERNs). These represent virtual networks that connect highly specialized experts in over 900 healthcare units from more than 300 hospitals across 26 Member States in the European Union (EU) to provide care for rare diseases. Sites within the UK, which has recently left the E.U., continue to participate 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, while sharing common data points. In addition to disease focused-registries, treatment-related international registries are in development, such as the LEAD (Laser trEAtments for Dermatology) registry.[20]

COVID-19 patient registries

In 2020, a novel RNA virus, SARS-CoV-2, causing a disease known as 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.[21] At a time of unprecedented demands on physicians and healthcare 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 designated.[22]

Of those described, a number of which are global in reach, one is patient-facing (PsoProtectMe, https://psoprotectme.org/) and one has both patient and physician entry options (Global Hidradenitis Suppurativa COVID-19 registry, https://hscovid.ucsf.edu),[23,24] whilst the others are physician-entered only. A third patient-facing survey, SECURE-AD Patient Survey, (https://www.secure-derm.com/secure-pad/) has also emerged. Analysis of datasets shows a remarkable coherence across COVID-19 related data collected. This contrasts with prior experience of poor patient registry interoperability, improvement of which was a key principle underlying the PARENT and EPIRARE projects.[4–6,25,26] The coherence of the COVID-19 patient registries is likely to have been contributed to by each registry utilizing the core concept developed by the COVID-19 Inflammatory Bowel Disease Registry (SECURE-IBD; Surveillance Epidemiology of Coronavirus Under Research Exclusion, https://covidibd.org).[27,28] A further contributor is likely to be the experience in patient registry development and maintenance by the registry teams.

Anonymized or de-identified data collection in several COVID-19 patient registries has enabled exemption from ethics committee review in most jurisdictions. Despite these exemptions, some academic centers still require data use agreements, and full ethical approval has been required in others (for example in Australia, Ireland, and Canada). The latter requirement hints at the volume of work that is required to develop a patient registry that adheres to current standards in an era of increasing demands with for data protection and security. Each ethical application requires considerable resources and expertise. A data protection impact assessment (DPIA), 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 dataset.[29–32] Newly emerging COVID-19 patient registries, despite the considerable requirements outlined above, 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 enter further waves. It is also likely that future, unrelated, pandemics will occur. It is essential to reflect on patient registries prior to and during the current pandemic, to consider the lessons learnt, and to determine how they may benefit the dermatology community now, and in the future.

Evolving patient registries

Undoubtedly, chief amongst these lessons, 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 take considerable time and expertise, even when expedited by COVID-specific national research ethics committees (NRECs) and streamlined pathways that have emerged during the pandemic.

While the response to the current pandemic has been impressive in some countries, it will need to be even faster 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 penetration of registries beyond highly resourced countries and expert centers is needed. Both require 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 datasets with clear definition of data terms. It should incorporate the work of relevant groups such as the COMET (Core Outcome Measures in Effectiveness Trials; http://www.comet-initiative.org/)[33] initiative, who have generated core outcome sets (COSs) for use in COVID-19 research. Where new datasets need to be generated, a rapid process of term definition and broad agreement to implement them needs to be established.

For those who intend to build new patient registries, visibility of standard datasets 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, will need to be readily available. Ethics applications will be required to be considered in advance, particularly to facilitate non-anonymized patient registries needed to avert 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 in order to make it capable of being incorporated within a registry.[34]

Inter-registry interoperability will also be important, to enable use of existing pharmacovigilance registry data that can act as a denominator 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.[35–37]

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, IRB templates, communication tools, and other components of its blueprint with multiple autoimmune focused groups, including several international dermatology and rheumatology efforts.[27] Given 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 though 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 to the corresponding physician-reported patient registries (https://psoprotect.org,[38] https://www.secure-derm.com/secure-ad-physician,[39] and https://hscovid.ucsf.edu[24]). While 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 amongst new and “pre-COVID” registry communities. Such a collaboration would utilize and build on the experience gained during this challenging time. This will aim to address many of the challenges identified above 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 and standardized datasets 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. While promoting interoperability, the federation would not seek to host patient data that might compromise data sovereignty, yet 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.[6,40] Orphanet is a resource that gathers and improves knowledge on rare disease. Initially established by the French National Institute for Health and Medical Research (INSERM) in 1997, it has evolved to become a global Consortium of 41 countries. While it lists a number of dermatology-relevant patient registries, these are within a large directory that focuses on all rare diseases.[41,42] An inventory of disease registries already exists, supported by the ENCePP (European Network of Centres for Pharmacoepidemiology and Pharmacovigilance) Resource database of data sources, although it is incomplete with respect to dermatology patient registries.[13,43–46] 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, it funding ended in 2019,.[40,47,48]

This is a timely reminder that such valuable resources may benefit from being located within the care of the networks which 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 the authors envisage a more detailed, live registry to be maintained by the proposed federation. Initially published in 2016, following a literature review of dermatology patient registries, this table has been expanded to incorporate a number of omitted registries and those that have emerged during the COVID-19 era.[49]

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 further 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 though 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, the authors envisage some work, but perhaps less than would have been envisaged pre-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, that 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 generation of patient registries capable of providing data to EMA and FDA mandated post-marketing surveillance studies. Supporting such a project would be of notable value to the pharmaceutical industry.

Importantly, 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, 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 is not 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.

While 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 for outcomes data, is a powerful incentive to collaborate and adopt such pioneering solutions.

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References:

1. Yiu ZZN, Mason KJ, Barker JNWN, et al. A standardization approach to compare treatment safety and effectiveness outcomes between clinical trials and real-world populations in psoriasis. *Br J Dermatol*. 2019;181(6):1265-1271. doi:10.1111/bjd.17849
2. Mason KJ, Barker J, Smith C, et al. Comparison of drug discontinuation, effectiveness, and safety between clinical trial eligible and ineligible patients in BADBIR. *JAMA Dermatology*. 2018;154(5):581-588. doi:10.1001/jamadermatol.2018.0183
3. Medicine and Healthcare products Regulatory Agency. Yellow Card Scheme. https://yellowcard.mhra.gov.uk. Accessed August 31, 2020.
4. Gliklich R, Dreyer N, Leavy M, eds. *Registries for Evaluating Patient Outcomes: A User's Guide. Third Edition. Two Volumes.* (Prepared by the Outcome DEcIDE Center [Outcome Sciences, Inc., a Quintiles company] under Contract No. 290 2005 00351 TO7.) AHRQ Publication No. 13(14)-EHC111. Rockville, MD: Agency for Healthcare Research and Quality.; 2014. http://www.effectivehealthcare.ahrq.gov/ registries-guide-3.cfm.
5. Taruscio D, Mollo E, Gainotti S, de la Paz MP, Bianchi F, Vittozzi L. The EPIRARE proposal of a set of indicators and common data elements for the European platform for rare disease registration. *Arch Public Heal*. 2014;72(1):1-8. doi:10.1186/2049-3258-72-35
6. Zaletel M, Kralj MM. *Methodological Guidelines and Recommendations for Efficient and Rational Governance of Patient Registries.* Ljubljana: National Institute of Public Health, Slovenia; 2015.
7. Meglič M, Doupi P, Pristaš I, Skalkidis Y, Zaletel M, Orel A. PARENT joint action:

Increasing the added value of patient registries in a cross-border setting. *Stud Health Technol Inform*. 2013;192(1-2):1161. doi:10.3233/978-1-61499-289-9-1161

8. Larsson S, Lawyer P, Garellick G, Lindahl B, Lundström M. Use of 13 disease registries in 5 countries demonstrates the potential to use outcome data to improve health care's value. *Health Aff*. 2012;31(1):220-227. doi:10.1377/hlthaff.2011.0762
9. Leonardi C, Menter A, Hamilton T, Caro I, Xing B, Gottlieb AB. Efalizumab: Results of a 3-year continuous dosing study for the long-term control of psoriasis. *Br J Dermatol*. 2008;158(5):1107-1116. doi:10.1111/j.1365-2133.2008.08548.x
10. Seminara NM, Gelfand JM. Assessing Long-Term Drug Safety: Lessons (Re) Learned from Raptiva. *Semin Cutan Med Surg*. 2010;29(1):16-19. doi:10.1016/j.sder.2010.01.001
11. Burden AD, Warren RB, Kleyn CE, et al. The British Association of Dermatologists' Biologic Interventions Register (BADBIR): Design, methodology and objectives. *Br J Dermatol*. 2012;166(3):545-554. doi:10.1111/j.1365-2133.2012.10835.x
12. Ormerod AD, Augustin M, Baker C, et al. Challenges for synthesising data in a network of registries for systemic psoriasis therapies. *Dermatology*. 2012;224(3):236-243. doi:10.1159/000338572
13. European Medicines Agency. *EMA Patient Registry Initiative Strategy and Pilot Phase*.; 2015. https://www.ema.europa.eu/en/documents/other/initiative-patient-registries-strategy-pilot-phase_en.pdf.
14. European medicines agency. Patient Registry Initiative- Strategy and Mandate of the Cross-Committee Task Force. 2017;EMA/180341(May):1-8. https://www.ema.europa.eu/en/documents/other/patient-registry-initiative-strategy-mandate-cross-committee-task-force_en.pdf.

15. Bosma AL, Spuls PI, Garcia-Doval I, et al. TREatment of ATopic eczema (TREAT) Registry Taskforce: protocol for a European safety study of dupilumab and other systemic therapies in patients with atopic eczema. *Br J Dermatol*. November 2019:bjd.18452. doi:10.1111/bjd.18452

16. Spuls PI, Gerbens LAA, Apfelbacher CJ, et al. The International TREatment of ATopic Eczema (TREAT) Registry Taskforce: An Initiative to Harmonize Data Collection across National Atopic Eczema Photo- and Systemic Therapy Registries. *J Invest Dermatol*. 2017;137(9):2014-2016. doi:10.1016/j.jid.2017.05.014

17. Daxhelet M, Suppa M, Benhadou F, et al. Establishment of a European Registry for hidradenitis suppurativa/acne inversa by using an open source software. *J Eur Acad Dermatology Venereol*. 2016;30(8):1424-1426. doi:10.1111/jdv.13267

18. Kimball AB, Crowley JJ, Papp K, et al. Baseline patient-reported outcomes from UNITE: an observational, international, multicentre registry to evaluate hidradenitis suppurativa in clinical practice. *J Eur Acad Dermatology Venereol*. 2019:1302-1308. doi:10.1111/jdv.16132

19. de Souza MP, Rangel Miller V. Significance of patient registries for dermatological disorders. *J Invest Dermatol*. 2012;132(7):1749-1752.

20. Fransen F, Spuls P, Alam M, et al. Generic outcome set for the international registry on Laser trEAtments in Dermatology (LEAD): a protocol for a Delphi study to achieve consensus on what to measure. *BMJ Open*. 2020;10(6):e038145. doi:10.1136/bmjopen-2020-038145

21. Johns Hopkins University. No TitleCOVID-19 Dashboard by the Center for Systems Science and Engineering (CSSE) at Johns Hopkins University (JHU). https://coronavirus.jhu.edu/map.html. Accessed August 31, 2020.

22. Freeman EE, McMahon DE, Hruza GJ, et al. International Collaboration and Rapid Harmonization across Dermatologic COVID-19 Registries. *J Am Acad Dermatol*. June 2020. doi:10.1016/j.jaad.2020.06.050

23. PsoProtectMe. https://psoprotectme.org/. Accessed July 20, 2020.

24. Global Hidradenitis Suppurative COVID-19 registry. https://hscovid.ucsf.edu. Accessed July 21, 2020.

25. Nicholson N, Perego A. Interoperability of population-based patient registries. *J Biomed Informatics X*. 2020;(April). doi:10.1016/j.yjbinx.2020.100074

26. Sernadela P, González-Castro L, Carta C, et al. Linked Registries: Connecting Rare Diseases Patient Registries through a Semantic Web Layer. *Biomed Res Int*. 2017;2017. doi:10.1155/2017/8327980

27. SECURE-IBD (Surveillance Epidemiology of Coronavirus (COVID-19) Under Research Exclusion - Inflammatory Bowel Disease. https://covidibd.org. Accessed August 31, 2020.

28. Brenner EJ, Ungaro RC, Gearry RB, et al. Corticosteroids, but not TNF Antagonists, are Associated with Adverse COVID-19 Outcomes in Patients With Inflammatory Bowel Diseases: Results from an International Registry. *Gastroenterology*. 2020;(July):1-11. doi:10.1053/j.gastro.2020.05.032

29. Meah N, Wall D, York K, et al. The Alopecia Areata Consensus of Experts (ACE) Study: Results of an International Expert Opinion on Treatments for Alopecia Areata. *J Am Acad Dermatol*. 2020;(March). doi:10.1016/j.jaad.2020.03.004

30. Gerbens LAA, Apfelbacher CJ, Irvine AD, et al. TREatment of ATopic eczema (TREAT) Registry Taskforce: an international Delphi exercise to identify a core set of domains and domain items for national atopic eczema photo- and systemic therapy registries.

Br J Dermatol. 2018;18(1):1-12. doi:10.1111/bjd.16714

31. Vermeulen FM, Gerbens LAA, Bosma AL, et al. TREatment of ATopic eczema (TREAT) Registry Taskforce: consensus on how and when to measure the core dataset for atopic eczema treatment research registries. *Br J Dermatol*. 2019;181(3):492-504. doi:10.1111/bjd.17715

32. Gerbens LAA, Boyce AE, Wall D, et al. TREatment of ATopic eczema (TREAT) Registry Taskforce: Protocol for an international Delphi exercise to identify a core set of domains and domain items for national atopic eczema registries. *Trials*. 2017;18(1):1-12. doi:10.1186/s13063-016-1765-7

33. Core Outcome Measures in Effectiveness Trials (COMET) Initiative. http://www.comet-initiative.org/. Accessed July 20, 2020.

34. Blumenthal S. Improving Interoperability between Registries and EHRs. *AMIA Jt Summits Transl Sci proceedings AMIA Jt Summits Transl Sci*. 2018;2017:20-25. http://www.ncbi.nlm.nih.gov/pubmed/29888033%0Ahttp://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC5961768.

35. Li M, Leslie H, Qi B, et al. Development of an openEHR Template for COVID-19 Based on Clinical Guidelines. *J Med Internet Res*. 2020;22(6):e20239. doi:10.2196/20239

36. Stanimirovic D, Murko E, Battelino T, Groselj U. Development of a pilot rare disease registry: A focus group study of initial steps towards the establishment of a rare disease ecosystem in Slovenia. *Orphanet J Rare Dis*. 2019;14(1):1-13. doi:10.1186/s13023-019-1146-x

37. Physical Consortium for Performance Improvement. Registries on FHIR. https://www.thepcpi.org/page/RegistriesOnFHIR?&hhsearchterms=%22registries+and+fhir%22. Accessed August 31, 2020.

38. PsoProtect. https://psoprotect.org. Accessed July 20, 2020.

39. SECURE-AD. https://www.secure-derm.com/secure-ad-physician/. Accessed July 20, 2020.

40. Heger M. A registry of registries? The us backs the idea for patients. *Nat Med*. 2011;17(1):4. doi:10.1038/nm0111-4a

41. Orphanet. Search for a registry/biobank. https://www.orpha.net/consor/cgi-bin/ResearchTrials_RegistriesMaterials.php?lng=EN. Accessed August 31, 2020.

42. Orphanet. About Orphanet. https://www.orpha.net/consor/cgi-bin/Education_AboutOrphanet.php?lng=EN. Accessed August 31, 2020.

43. European Network of Centres for Pharmacoepidemiology and Pharmacovigilance (ENCePP). ENCePP Resources Database. http://www.encepp.eu/encepp/resourcesDatabase.jsp. Accessed July 10, 2020.

44. European Medicines Agency. Patient registries. https://www.ema.europa.eu/en/human-regulatory/post-authorisation/patient-registries. Accessed July 10, 2020.

45. European Medicines Agency. ENCePP Resource Database. Inventory of Patient Registries. 2017. https://www.ema.europa.eu/en/documents/regulatory-procedural-guideline/encepp-resource-database-inventory-patient-registries_en.pdf.

46. Kurz X, Perez-Gutthann S. Strengthening standards, transparency, and collaboration to support medicine evaluation: Ten years of the European Network of Centres for Pharmacoepidemiology and Pharmacovigilance (ENCePP). *Pharmacoepidemiol Drug Saf*. 2018;27(3):245-252. doi:10.1002/pds.4381

47. Agency for Healthcare Research and Quality. Registry of Patient Registries. https://www.ahrq.gov/ropr/index.html. Published 2019. Accessed July 10, 2020.

48. U.S. National Library of Medicine. ClinicalTrials.gov. https://clinicaltrials.gov. Accessed July 10, 2020.

49. DiMarco G, Hill D, Feldman SR. Review of patient registries in dermatology. *J Am Acad Dermatol*. 2016;75(4):824-829. doi:10.1016/j.jaad.2016.03.020

Table 1: Dermatology patient registries, adapted from DiMarco et al to include COVID-19 era patient registries.[49]

COVID-19 Registries			
Name	**Disease**	**Scope**	**Website**
AEDV COVID-Piel	COVID-19/Dermatology	National (Spain)	https://aedv.es/covid-piel
COVID-19 Dermatology Registry	COVID-19/Dermatology	International (Global)	https://www.aad.org/coronavirus
FSD (Société Française de Dermatologie) COVIDSKIN	COVID-19/Skin Lesions	National (France)	https://evenements-sfd.fr/coronavirus
Global Hidradenitis Suppurativa COVID-19 Registry	COVID-19/Hidradenitis Suppurativa	International (Global)	https://hscovid.ucsf.edu/
PeDRA (Pediatric Dermatology Research Alliance)	COVID-19/Acral Ischemia/ Perniosis in children	International (Global)	https://pedraresearch.org/covid
PsoProtect	COVID-19/Psoriasis	International (Global)	https://psoprotect.org
PsoProtectMe	COVID-19/Psoriasis	International (Global)	https://psoprotectme.org
SECURE-AD	COVID-19/Atopic dermatitis	International (Global)	https://www.secure-derm.com
SECURE-AD Patient Survey	COVID-19/Atopic dermatitis	International (Global)	https://www.secure-derm.com/secure-pad/

SECURE-Alopecia	COVID-19/All forms of hair loss	International (Global)	https://www.secure-derm.com

General Dermatology Registries

Name	**Disease**	**Scope**	**Website**
A*STAR (The UK & Ireland Atopic eczema Systemic Therapy Register)	Atopic dermatitis	International (UK & Ireland)	https://astar-register.org
AtopyReg	Atopic dermatitis	National (Italy)	https://www.atopyreg.it/
Biobadatop	Atopic dermatitis	National (Spain)	No link available
BioDay	Atopic dermatitis	National (Netherlands)	https://www.bioday.nl/
GREAT (Groupe de Recherche sur L'Eczéma ATopique)	Atopic dermatitis	National (France)	https://www.sfdermato.org/site/groupe-de-recherche-sur-l-eczema-atopique-great.html
Japan AD Registry (ADDRESS-J)	Atopic dermatitis	National (Japan)	https://upload.umin.ac.jp/cgi-open-bin/ctr_e/ctr_view.cgi?recptno=R000025749
Pediatric Elective Eczema Project	Atopic dermatitis	National (US)	https://enroll.thepeerprogram.org/
SCRATCH	Atopic dermatitis	National (Denmark)	No link available

SwedAD (Svenskt kvalitetsregister för Atopisk Dermatit)	Atopic dermatitis	National (Sweden)	http://swedad.nu/
TREATgermany (TREatment of ATopic eczema, Germany	Atopic dermatitis	National (Germany)	http://www.treatgermany.org/
TREAT NL (TREatment of ATopic eczema, the Netherlands)	Atopic dermatitis	National (Netherlands)	https://treatregister.nl
CARPE (Chronic Hand Eczema Registry on Long-term Patient Management)	Chronic hand eczema	National (Germany)	No link available
RegiSCAR	Cutaneous drug reactions	National (US)	http://www.regiscar.org
Cutaneous Lupus Registry	Cutaneous Lupus	National (US)	https://www.utsouthwestern.edu/cutaneous-lupus
Central Cutaneous Lymphoma Registry	Cutaneous lymphoma	National (Germany)	https://www.orpha.net/kutane-Lymphome-in-Deutschland
UK and Ireland Juvenile Dermatomyositis Cohort Biomarker Study and Repository	Dermatomyositis	International (UK and Ireland)	https://www.orpha.net/consor/cgi-bin/ResearchTrials_RegistriesMaterials.php?lng=EN&data_id=45340&RegistryMaterialName=English-juvenile-dermatomyositis-registry-and-repository

Ectodermal Dysplasias International Registry	Ectodermal dysplasias	International	https://nfed.patientcrossroads.org
EBCare Patient Insights Network	Epidermolysis bullosa	International	https://ebcare.patientcrossroads.org
EB Registry Austria	Epidermolysis bullosa	National (Austria)	https://www.orpha.net/EB-RegisterAustria
C1 Inhibitor Registry in the Treatment of Hereditary Angioedema Attacks	Hereditary angioedema	International	https://clinicaltrials.gov/NCT01397864
English hereditary angioedema patient registry – part of the HAE European registry	Hereditary angioedema	National (UK)	https://www.orpha.net/consor/cgi-bin/ResearchTrials_RegistriesMaterials.php?lng=EN&data_id=35474&RegistryMaterialName=English-hereditary-angioedema-patient-registry---part-of-the-HAE-European-registry
Firazyr Patient Registry Protocol (Icatibant Outcome Survey)	Hereditary angioedema	International	https://clinicaltrials.gov/NCT01034969

HAE-registry: European hereditary angioedema patient registry	Hereditary angioedema	International	https://www.orpha.net/consor/cgi-bin/ResearchTrials_RegistriesMaterials.php?lng=EN&data_id=28343&RegistryMaterialName=HAE-registry--European-hereditary-angioedema-patient-registry
Hereditary Angioedema Association Scientific Registry	Hereditary angioedema	National (US)	https://www.haea.org/pages/p/LearnMoreSR
Spanish Patient Registry of Hereditary Angioedema	Hereditary angioedema	National (Spain)	https://www.orpha.net/consor/cgi-bin/ResearchTrials_RegistriesMaterials.php?lng=EN&data_id=30532&RegistryMaterialName=Registro-espa-ol-de-pacientes-con-angioedema-hereditario
International Rare Histiocytic Disorders Registry	Histiocytic disorders	International	https://clinicaltrials.gov/ct2/show/NCT02285582
National Registry for Ichthyosis and Related Diseases	Ichthyosis	National (US)	http://www.firstskinfoundation.org/
Network for Ichthyosis and Related Keratinization Disorders	Ichthyosis	National (Germany)	https://www.medizin.uni-muenster.de/

KINDLERNET: Central patient registry Kindler syndrome	Kindler syndrome	International	https://www.orpha.net/consor/cgi-bin/OC_Exp.php?lng=EN&Expert=242250
French Certified Patient Registry for Langerhans Cell Histiocytosis	Langerhans cell histiocytosis	National (France)	https://epidemiologie-france.aviesan.fr/en/epidemiology/records/french-langerhans-cell-histiocytosis-registry
German Registry for Langerhans Cell Histiocytosis in Childhood	Langerhans cell histiocytosis	National (Germany)	https://www.orpha.net/Deutschen-Registers-fur-Langerhanszell-Histiozytosen
Great Ormond Street Hospital Congenital Melanocytic Naevus	Melanocytic nevi	National (United Kingdom)	No link available
Registry for Congenital Melanocytic Nevi and Neurocutaneous Melanocytosis	Melanocytic nevi; neurocutaneous melanocytosis	National (Germany)	No link available

Morphea in Adults and Children	Morphea	National (US)	https://clinicaltrials.gov/ct2/show/NCT01808937
International Pachyonychia Congenita Research Registry	Pachyonychia congenita	International	https://www.pachyonychia.org/patient-registry/
Pemphigus-Pemphigoid Registry	Pemphigus; pemphigoid	International	http://www.pemphigus.org/pemphigus-pemphigoid-registry/
Italian Registry of Patients and Families Affected by Pseudoxanthoma Elasticum	Pseudoxanthoma elasticum	National (Italy)	https://www.orpha.net/Pseudoxanthoma-elasticum
PXE International BioBank and Clinical Data Registry	Pseudoxanthoma elasticum	International	https://www.pxe.org/registry
AMC Psoriasis Registry	Psoriasis	National (Netherlands)	No link available
Australasian Psoriasis Registry	Psoriasis	International (Australia and New Zealand)	www.psoriasis.asn.au

BADBIR (British Association of Dermatologists Biologics and Immunomodulators Register)	Psoriasis	International (UK & Republic of Ireland)	http://www.badbir.org
Biobadaderm	Psoriasis	National (Spain)	https://biobadaser.ser.es/biobadaderm/
BioCAPTURE	Psoriasis	National (Netherlands)	https://biocapture.nl
BIOREP	Psoriasis	National (Czech Republic)	No link available
Child-CAPTURE	Psoriasis	National (Netherlands)	No link available
Chronic Plaque Psoriasis Registry	Psoriasis	International	https://clinicaltrials.gov/ct2/show/study/NCT00799877
Clalit Health Services Registry	Psoriasis	National (Israel)	No link available
Corrona Psoriasis Registry	Psoriasis	National (US)	https://www.corrona.org/registry/psoriasis
Dermbio	Psoriasis	National (Denmark)	https://www.dermbio.dk
MPR (Malaysian Psoriasis Registry)	Psoriasis	National (Malaysia)	https://www.dermatology.org.my/DermReg/index.htm

PsoBest	Psoriasis	National (Germany)	https://www.psobest.de/
PSOBIOTEQ (French Psoriasis Registry)	Psoriasis	National (France)	https://epidemiologie-france.aviesan.fr/en/epidemiology/records/cohorte-multicentrique-de-patients-recevant-un-traitement-systemique-conventionnel-ou-biotherapie-pour-un-psoriasis-cutane-modere-a-severe
PsoCare	Psoriasis	National (Italy)	No link available
Psodit	Psoriasis	National (Italy)	No link available
PSOLAR (Psoriasis Longitudinal Assessment and Registry)	Psoriasis	International	https://clinicaltrials.gov/ct2/show/NCT00508547
PsoNet	Psoriasis	International	http://www.psonet.eu/cms/
PsoRA	Psoriasis	National (Austria)	https://psora.medunigraz.at

PsoReg	Psoriasis	National (Sweden)	https://www.psoreg.se
SDNTT (Swiss Dermatology Network of Targeted Therapies)	Psoriasis	National (Switzerland)	https://my.derma.ch/en/spec/SDNTT.html
Slovenian National Registry of Psoriasis	Psoriasis	National (Slovenia)	No link available
Hospital for Special Surgery Scleroderma Registry	Scleroderma	National (US)	https://www.hss.edu/clinical-trials_scleroderma-registry-repository.asp
Scleroderma Registry	Scleroderma	National	https://clinicaltrials.gov/ct2/show/NCT00074568