

Allergic diseases, such as asthma, hay fever, eczema, and food allergies, affect around 20% of children in European countries and early onset severe disease often persists into adulthood. The impact on quality of life and health care resources is comparable to diabetes and rheumatoid arthritis. Furthermore, immediate allergic reactions, for instance to foods and drugs, can be life threatening.

Over past years, patient, disease and treatment registries have become increasingly recognised as important tools to improve standards of clinical care, for instance through data on the short and long-term efficacy and safety of therapies, especially where running a clinical trial is difficult due to the need for long-term follow up and also in case of rare conditions. Registry data also allow to analyse quality of care, for instance by benchmarking medical care against current evidence-based guidelines.

While a number of medical specialties developed disease and treatment registries years back, for instance for diabetes and cardiovascular disease, there is still a lack of such registries within the allergy field, although a few national initiatives have recently been started (eg. drug allergy (Pascal Demoly, France; <http://www.dahd.net/>), anaphylaxis (Margitta Worm, Germany; <http://www.anaphylaxie.net>), and chronic hand dermatitis (Christian Apfelbacher, Germany; <http://www.carpe.dermis.net>). Even where such national projects exist, there clearly is potential and need to extend such registries across European countries, using a standardised methodology to optimise the potential benefit of these registries for clinicians and researchers but also to ensure patient safety across European country borders.

We therefore set up a Task Force on allergic disease registries in late 2011 with the overall objective to provide a platform for the formation of allergic disease registries across EU country borders to develop suitable monitoring tools for use in both clinical practice and research. We also want to help standardisation of data collection on allergic diseases, diagnosis and treatment and ultimately improve allergic disease and allergen exposure management.

The A-reg project will initially focus on two national allergic disease registries to grow into pan-European projects, namely anaphylaxis (Prof M Worm) and drug allergy (Prof Pascal Demoly). Two further therapy-related projects are planned to be started *de novo*, one on cutaneous and systemic side effects of immunotherapy (Dr Moises Calderon) and one on immunosuppressive therapies in patients with severe atopic dermatitis (Dr Carsten Flohr). The main advantage of starting a registry in several European reference centres at the same time is that the same methodology ensures direct comparability from the start. We also plan to incorporate biobanking in all of these

registries for research purposes.

It is anticipated that these four projects will inform the development of further allergic disease/therapy registries, especially with regard to methodology (data collection, software use, data analysis and ethics).

One of the remits of the EAACI Allergy Registry (A-Reg) Task Force is to collect data on existing allergy registries across Europe. EAACI was proud to be a collaborating partner of the European Joint Action PARENT (May 2012-May 2015), an important EU-funded research programme aiming to provide documents and tools for implementation of interoperable and cross-border enabled patient registries. Over the course of the PARENT JA, The Methodological Guidelines and Recommendations for Efficient and Rational Governance of Patient Registries (<http://parent-wiki.nijz.si/>) have been developed as well as two complete versions of the Registry of Registries/RoR (<http://www.parent-ror.eu>). The first one was based upon an online questionnaire, which collected metadata on EU-level patient registries and included a complete directory with various browsing functions. The second version of RoR included the Nomination function which allows registry holders to nominate new organisations and registries. It consisted of Assessment/Improvement and Comparison tool which enables registry's quality and interoperability assessment (based on knowledge compiled in the Guidelines) and registry information comparison.

Although PARENT JA project has officially ended, PARENT JA team continues to develop project's deliverables. PARENT JA team invites registry holders and administrators to join the Registry of Registries platform and use tools and documents of significant utility, not only for those involved in the work in patient registries, but also for those trying to create a new one.

A-reg Task Force members:

Dr Christian Apfelbacher, Chair
Dr Carsten Flohr, Secretary
Prof Nikos Papadopoulos
Prof Peter Burney
Dr Moises Calderon
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Prof Pascal Demoly
Prof Aziz Sheikh
Prof Margitta Worm

If you would like to learn more about A-reg, please contact This email address is being protected from spambots. You need JavaScript enabled to view it. `document.getElementById('cloakc26c0f14192b6e296b64f4aea741244b').innerHTML = ''; var prefix = 'ma' + 'il' + 'to'; var path = 'hr' + 'ef' + '='; var addyc26c0f14192b6e296b64f4aea741244b = 'carsten.flohr' + '@'; addyc26c0f14192b6e296b64f4aea741244b = addyc26c0f14192b6e296b64f4aea741244b + 'kcl' + '.' + 'ac' + '.' + 'uk'; var addy_textc26c0f14192b6e296b64f4aea741244b = 'carsten.flohr' + '@' + 'kcl' + '.' + 'ac' + '.' + 'uk';document.getElementById('cloakc26c0f14192b6e296b64f4aea741244b').innerHTML += '+addy_textc26c0f14192b6e296b64f4aea741244b+'; .`