

A new era for collaboration?

Clinical, academic and patient consortiums

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For clinicians and clinical academics with an interest in less common diseases, there is an ongoing challenge of how to promote best practice and encourage the development of research studies to inform evidence-based clinical practice. By combining expertise and resources and providing a central focus of activity, clinicians specializing in treating and researching these diseases can beneficially influence disease awareness across patients, health care professionals and politicians. Working as a collaborative network should ensure the quality and clinical utility of new research ideas and improve research participant recruitment, enhancing the likelihood of developing successful research studies with funders and pharmaceutical companies.

A new collaboration of academically interested clinicians and patients across the UK [British Psoriatic Arthritis Consortium (Brit-PACT)] acting as a focus for disease education and a platform for epidemiological, biomarker and pharmaceutical studies may provide a blueprint for success in other disease areas. Early successes include the prioritization of unmet needs in PsA research, care and management and Brit-PACT input into National Health Service choices for patient information on PsA. The consortium acts as a national hub to liaise with worldwide PsA research groups and with other linked disease-specific groups such as BRITSpA (a sister UK clinical academic research group for axial SpA) and dermatology stakeholders. The steering group includes many of the active clinical researchers across the UK, patient partners and an international advisor from Ireland. Brit-PACT's strength lies in the combination of patient and professional input, with a strong focus on a single disease and associated comorbidities. This allows the group an immediate advantage in the development, submission and promotion of research studies that are relevant to patients and clinicians alike. Linking with similar existing groups (or helping develop these in countries without an established collaborative infrastructure) will promote independent group/country initiatives and enhance collaborative work at a European level or wider. Linking groups may be a valuable method of developing internationally collaborative research designed to answer important clinical-, epidemiological- and pathogenesis related questions and enhance clinical care.

It is perhaps surprising that for many chronic inflammatory diseases there is a real paucity of research to support widely accepted clinical practices. These areas are often highlighted by experts in the condition while clinical decision aids such as EULAR, Group for Research and Assessment of Psoriasis and Psoriatic Arthritis, British Society for Rheumatology or National Institute for Health and Care Excellence guidelines are being developed. However, often there is no established infrastructure to develop or fund research into these highlighted areas of unmet need to improve the potential for truly evidence based practice. Collaborative groups of clinical academics and patients working together have the potential to refine and prioritize research questions that make a real difference to patient care in the future. The strategy of patients playing an equal part within the consortium ensures patient and public involvement in all activities, at each stage and at all levels.

A variety of patient and professional organizations along with charities work hard to raise awareness of rheumatological conditions for patients, health professionals and decision makers. However, these bodies often have to promote across the wide spectrum of musculoskeletal diseases. This understandably results in the more commonly occurring musculoskeletal diseases, such as back pain, OA and RA, receiving the focus of attention. Diseases that occur less frequently, such as PsA, axial SpA, SLE and scleroderma may be championed enthusiastically by disease-specific organizations (often patient groups), however, these groups often come under umbrella organizations, such as the Arthritis and Musculoskeletal Alliance (ARMA) in the UK. ARMA has been particularly successful in raising the profile of musculoskeletal diseases with politicians and decision makers, but by coming together to improve visibility and being representative of a larger population, there is a risk that disease-specific focus may be lost. Although national grant-awarding charities often have dedicated clinical studies groups providing strategic direction for the development of clinical research ideas, they are often limited by the relatively tight remits. For example, some groups focus on interventional studies to the exclusion of biomarker or cohort collection, and most have a country-limited focus. Groups such as Brit-PACT, with a strong partnership between patients and research-interested health professionals, can be an invaluable resource to ensure study design and grant applications are of high quality with appropriate focus on areas important to both patients and clinicians. This potentially improves the likelihood of not only successful study funding and completion, but also implementation of research into clinical practice for the benefit of patients.

Both charities and national/international funding bodies experience difficulties in their relationships and potential partnerships with the pharmaceutical industry [1]. Research-related relationships between the pharmaceutical industry and clinical academics are already considerable and have played an essential role in translating the discoveries of basic biological research into new therapies [2]. However, there is a dissonance in understanding the need for such collaborations and their endorsement. We believe that the wider rheumatology community would support academics collaborating with pharmaceutical companies if this resulted in research that benefits patients. However, without maintaining academic independence, researchers run the risk of being accused of bias. Academics and industry need to find practical and durable solutions for the best and most appropriate ways to work together and be productive while maintaining both real and perceived independence. A possible answer to this problem is for nationally collaborative groups, rather than individual academics, to work with industry to develop mutually beneficial studies with a wider remit than simply providing proof of therapeutic response, and with more of a focus on patient benefit.

Patient and health professional disease education can also be championed by collaborative groups like Brit-PACT. They can act as a resource of clinical expertise for patient groups, providing patient information and education. Their independent status provides the opportunity to provide quality certification of the educational activities of others [3] (such as patient organizations and pharmaceutical companies).

Brit-PACT was created to bring together patients and professionals with an interest in PsA. We believe this is a good exemplar of how clinicians working in rheumatology can both promote disease awareness and also lead and inform clinically relevant research across different countries and clinical areas.

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