

Consensus Statements for The Use Of Administrative Health Data In Rheumatic Disease: Research And Surveillance

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Administrative health data (i.e., physician billing and hospitalization databases) are potentially a key resource for research and surveillance of rheumatic disease, co-morbidity and adverse events. In Canada, physician billing and hospitalization data have helped estimate the prevalence of systemic autoimmune rheumatic diseases, rheumatoid arthritis, polymyalgia rheumatic, and osteoarthritis. Administrative data held by each province in Canada can be used to study almost any rheumatic disease, from rheumatoid arthritis (RA) to systemic lupus (SLE) to osteoarthritis(OA), and everything in between.

Unfortunately, the findings from administrative data-based studies may be inconsistent or difficult to compare across studies because of differences in design and methods. If studies were done using more standard and comparable methods, stakeholder groups (professional bodies, decision-makers, advocacy groups) would better understand the medical burden faced by the arthritis community, and hence be in a better position to address it. Moreover, conflicting results from observational databases creates great distrust amongst clinicians and others, who may not have the analytical sophistication to understand why differences in such observational studies may arise.

A common goal shared by many researchers, policy-makers, and other stakeholders in Canada, is the application of well-defined case definitions for arthritis and related diseases. We brought together policy makers and researchers who had been working on these issues, particularly as they relate to surveillance and observational research in arthritis and other rheumatic disease. Using Canadian administrative data sources, these individuals have produced novel findings in the past several years, related to disease prevalence and access to quality care. Recently, our group developed best-practice consensus statements about the use of administrative data for rheumatic disease research and surveillance in Canada. With the input of 52 decision makers, epidemiologists, clinicians, and researchers, we developed 13 best-practice consensus statements, separating them into three distinct categories, which were endorsed by a group consensus at our February 2011 meeting. The goal was to identify a 'benchmark' set of recommendations. That is, the guidelines were to present recommendations for a core set of approaches to definitions and analyses. Future work on rheumatic disease research and surveillance may use alternative definitions and analyses in their work, but they should be sure to include at least one set of analyses that use the approaches recommended by the established guidelines.

The first category of consensus statements addressed validation of case definitions and ascertainment. The group discussed the justification of definitions for rheumatic disease based on purpose. Validation studies of rheumatic disease case definitions in administrative data should adhere to published guidelines on their conduct and reporting and authors should acknowledge the limitations of their administrative data when ascertaining cases of rheumatic disease and the implications on their findings. The second category focused on confounding and drug exposure measurement. Administrative data are often used to evaluate potential effects of medications (e.g. disease-modifying agents, biologics). The third category focussed on co-morbidity and

outcomes measurement: consensus statements were developed for osteoporosis and fragility fractures, cancer, infections, cardiovascular disease, and renal disease

The consensus statements generated from our team during our February 2011 meeting will soon be published in the Journal of Rheumatology . Ongoing work will disseminate these consensus statements, and potentially expand the project to focus on applications in potentially vulnerable populations such as the First Nations, Métis and Inuit as well as paediatric groups in Canada.

The physical infrastructure of our platform is largely 'virtual', which takes advantage of existing electronic resources and media in novel and creative ways. During our October 2011 meeting, our team discussed the next steps in creating a website would help in the exchange of best practices in research and surveillance. This will substantially advance the efficiency of arthritis research and surveillance across our nation, and aid in the uptake and use of new data as it is produced. The website will be representative of our team's view and a way to share research, guidelines, articles, case definitions, abstracts etc. Our team members will be listed on the website, opening up opportunities for networking and meeting new potential team members. We hope to archive our team members' publications, reviews and articles which discuss rheumatic disease using Canadian administrative data.

Recently, we have formed working groups within our team that might better aid in identify issues and opportunities related to different areas of research. The working groups will be related to First Nations/Métis/Inuit arthritis surveillance, pediatric populations, the linkage of electronic health records and administrative data, the linkage of Statistics Canada data and administrative data, as well as a methodology subgroup and the groups will be lead and made up of the team members whose specialties match the goals of each working group. Our next planned meeting in 2013 will be spent exploring and expanding these working groups. Between now and the meeting, each group will begin to collect information and begin to form ideas of what direction the group should head in. The groups will each give a presentation or an update on the group activities at the meeting, and helping contribute to dissemination activities.