

February 2022 Newsletter



The MSDA Catalogue – An Important Tool in the Search for a Cure

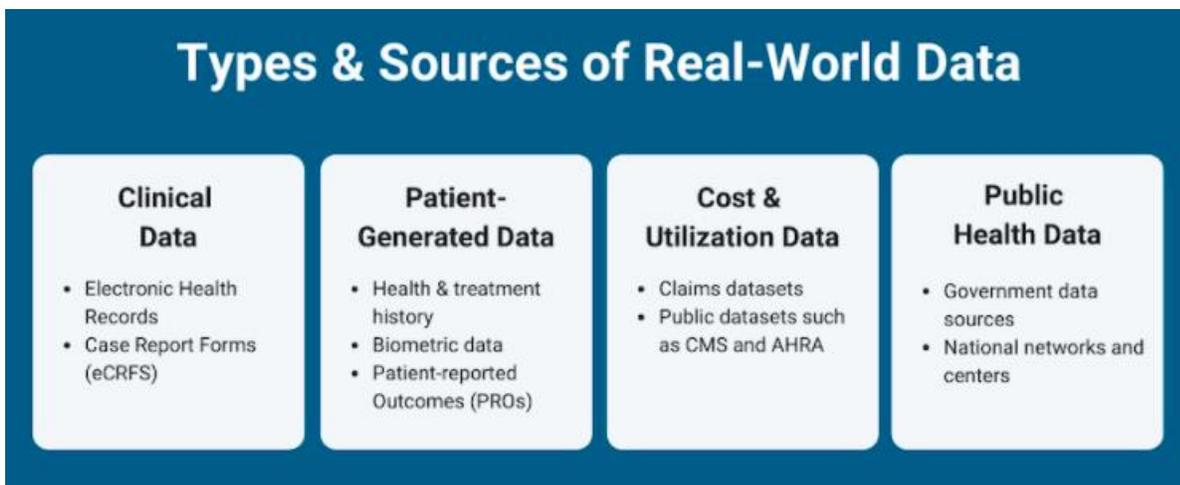
We, at ACP, believe that research is the only way to greatly improve the outlook for people with MS and one day find a cure. Data collection and sharing are key in the research process. Our two main initiatives are important tools for obtaining the necessary data to understand not only the causes of MS, but also the full scope of impact the disease has on those living with it. The [ACP Repository](#) is a



collection of thousands of biosamples and associated data that also has millions of returned data points deposited for the benefit of all researchers. [iConquerMS](#) engages people with MS and their loved ones to participate in research by sharing their health information, completing questionnaires on a variety of subjects and connecting with researchers by an online portal. Both datasets hold great potential for accelerating efforts toward determining what causes MS, improving treatments and finding a cure.

As discussed in our [March 2018 newsletter](#), physicians rely on changes in [health status](#) (otherwise known as health outcomes) to determine a course of treatment. Health outcomes are classified according to the source from which they are collected. A

physician reported outcome is one collected by a physician in the course of clinical care (for example, the physical exam, imaging scans or lab tests). A **patient reported outcome** (PRO) is one directly reported by the person who experienced it. PROs are most often factors that matter most to an individual, such as symptoms, functioning and quality of life. PRO and physician reported outcomes measure different components of a person's well-being and should ideally be used together to assess their health status and to provide individualized treatment. Physician reported outcomes and PROs are types of **real-world data** (RWD). RWD relate to the health status of and the delivery of healthcare to an individual. They come from sources other than traditional clinical trials, such as electronic health records, claims and billing activities, product and disease



registries, and individuals themselves. The ACP Repository and iConquerMS databases contain RWD that are readily available for research, giving investigators an accurate picture of MS from both the clinical and personal perspectives. Using this type of data, therapies can be developed and evaluated under real-world conditions more cost effectively and in a wider population than would be possible in clinical trials.



The [Multiple Sclerosis Data Alliance](#) (MSDA) is a global multi-stakeholder collaboration that was founded on the belief that data can transform the care of people with MS. They encourage all participants in the research process, including clinicians, researchers and people with MS, to contribute and use RWD collaboratively to address important knowledge gaps that clinical trials may not address, thereby facilitating the development of new and effective MS treatments. The MSDA has two initiatives in place to step up the use of MS RWD. The [MSDA Academy's](#) mission is

to raise awareness about the importance of research using this type of data. This initiative is working to build an MS data community and promote the trustworthy and transparent usage of MS RWD within it. The [MSDA Toolbox](#), as the name implies, develops tools to reduce the time and effort needed to access MS RWD. One recently developed tool is the [MSDA Catalogue](#), which is a listing of MS RWD sources and datasets. Registry recruitment for the MSDA Catalogue started in June 2019 and has been ongoing. Investigators with particular study requirements or research questions can browse the catalogue for the information they need for their studies. This valuable resource not only reduces the time needed to discover MS RWD sets, but also promotes collaboration in the research community.

The [status](#) of the MSDA Catalogue was recently published in the International Journal of MS Care. To date, 38 data sources across 5 continents are included, including the ACP Repository and iConquerMS databases. The participating registries were initiated between 1956 and 2020, and enrollments range from a few hundred to more than seventy-five thousand



people with MS. Of the 38 registries, 18 are sponsored by academic/research institutions, 8 by health care organizations, 6 by patient organizations, and 11 by other institutions or organizations, such as the government or private companies. There are 15 languages used among the 38 registries, but English is the most common (used in 21 of them). Participants were included for data collection if MS was diagnosed based on the [McDonald criteria](#) in 30 of the 38 registries. Twenty-two cohorts include participants with possible MS/clinically isolated syndrome, and 8 collect data on individuals with self-reported MS that is not clinically validated.



Personal and basic disease data are the most collected variables across registries in the MSDA catalogue, whereas information on fatigue measurements and cognition scales are the least collected. Of note, data regarding COVID-19 and MS are collected by 26 of the registries. The source of data for most of the cohorts (89%) is health care services. Information was collected on paper forms in 12 of the registries. Other sources include manual merging of data sets and remote (web-based) data entry. Data was entered

by a neurologist in 31 of the web-based registries and in a little over half of those it was also entered by a medical assistant or nurse. Participants did data entry in 16 of 38 registries. Other reported sources include a pharmacist, data manager, study coordinator, neurology resident or research assistant. Electronic health technologies were used to collect data in 11 of the registries, the most commonly used were mobile apps and wearable devices.

There are many existing and arising RWD sources in MS that are unique in their purpose, maturity and content. The MSDA Catalogue aligns and organizes this valuable information in such a way that it is at researchers' fingertips as they strive to answer specific research questions. Ready access to RWD has the potential to speed up collaborative efforts that are working toward better treatments and a cure for MS. We'd like to extend a heartfelt thank you to all that have participated in the ACP Repository and are members of the iConquerMS community. We are excited to contribute your data to this collective effort and look forward to seeing the advances in MS research that are made as a result. According to ACP's CEO Sara Loud, "To me, the collaborative nature of our work is most exciting... A complex disease like MS is unlikely to be cured in a fragmented research environment. There is a tremendous need for collaboration in order to accelerate MS research toward better ways to diagnose, treat, and eventually cure the disease."

