



# Neuropathic Pain Registries Improve Pain Management and Provide More Efficacious Planning of Healthcare Services

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## ABSTRACT

The first official health registry dates back to the 19th century and was proven to be very useful for gathering important information regarding a specific disease. Since then, data collection through registries is gaining more popularity, as it can offer useful information not only to health providers but also to healthcare planning services. Health registries could come along with randomized controlled trials and support or reject their findings in the “real world”. Pain registries and neuropathic pain registries have proven to be very potent weapons in the armory of the pain specialist and are growing rapidly, offering substantial information for this challenging pain entity.

**Keywords:** Healthcare services design; Neuropathic pain registries; Pain management improvement

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## Key Summary Points

In the last few years, the use of registries and the recognition of their importance is witnessing an increase.

The roots of register-based medicine can be identified to Norway in 1856.

Registries could be an advantageous alternative to randomized controlled trials as they gather information from the real world, with greater sample size and no time limitations.

Pain registries lead to a better understanding of treatment benefits in certain populations or different pain entities and identify the effectiveness of specific treatment procedures or polypharmacy remedies as well.

The high prevalence of neuropathic pain in surviving cancer patients as well as the continuously rising numbers of patients with chronic pain with a neuropathic component highlights the importance of neuropathic pain registries.

## COMMENTARY

Regardless of the disease, health registries are valuable tools for ameliorating clinical conditions and supporting clinical and epidemiological research [1]. Recently, the lack of resources for development of new treatments has led to the development of big data analysis, where registries could prove very useful [2]. Apart from supporting the latter, health registries can be vital for the planning of healthcare services [1].

Over the last few years, the use of registries and the recognition of their importance are increasing. Notably, the United States Food and Drug Administration risk minimization action plan has identified health registries as important tools to significantly reduce identified product risk [3, 4]. Moreover, in a survey conducted by the International Society for Pharmacoeconomics and Outcomes Research, a high percentage of interviewees responded that institutional agencies (academia, a contract research organization, the pharmaceutical industry, medical device industry, etc.) are presently associated with the establishment and management of at least one patient registry [5].

When it comes to establishing a register, it is worth looking into the origin of register-based medicine. Historically, a collection of individual patient data may have served as a well-established tool in medicine [6] and in order to create a register, a permanent record should be established, according to the World Health Organization nomenclature [7]. This requires longitudinal follow-up of patients and basic statistical analyses for epidemiological data and information on clinical history [7]. Hence, improving vigilance, health care, and research should be the primary aims of a health-register.

The roots of register-based medicine can be identified to Norway, namely the National Leprosy Registry, which was created in 1856, and represents the first national patient register in the world [8, 9]. As in the 19th century leprosy was a severe health problem in the rural western regions of Norway, an important decision was made that all the patients examined and found to be infected with leprosy would be systematically registered, resulting in the

establishment of a National Leprosy Register, a complete medical innovation, not only in Norway but also in an international perspective. It is worth mentioning that some patients were apprehensive of social exposure because of the register and tended to avoid registration [10]. The main aim of that register was to understand better the spread of the disease and influence disease control programs [8].

Moreover, another important use of registries is to enhance the medical information that we get from randomized controlled trials (RCTs). In medical research, it is well recognized that RCTs are the gold-standard procedure to prove the efficacy of interventions. However, it might be difficult to generalize the results obtained from these trials in routine clinical practice. Particularly, RCTs impose strict criteria for the inclusion and exclusion of patients during the selection process. Furthermore, the assessment of interventions is performed under highly controlled settings [11] and in some occasions RCTs do not detect all the possible adverse events due to limited sample size or time limitations [12]. Therefore, patient registries are worthy alternatives to effectively resolve the above-mentioned difficulties and to initiate best practices in pain medicine. Moreover, it is a fact that the “real-world” data incorporated in patient registries, during the course of patient care, could provide considerable advantages that complement the findings of RCTs. Thus, significant information can be obtained to ascertain the safety and efficacy of interventions, especially with diversified patient populations (different ages, multiple comorbidities, etc.) and clinical situations [13]. According to the above, registries can provide invaluable information about the utility of a treatment and its efficacy, but the data must be examined with caution. As a result, it is suggested that a registry could not provide the same level of control and interpretation as RCTs, since a registry’s data might be undermined by missing data or a host of confounding factors that could interact with the recorded adverse events.

Patient registries represent interesting and alternative research avenues and are becoming increasingly popular in many areas of medicine,

including pain medicine, as well as in the management of acute postoperative pain [14] and postsurgical neuropathic pain [15]. Taking all the above into consideration, in our opinion, pain registries would lead to better understanding of treatment benefits in certain populations and different pain entities and also the effectiveness of specific treatment procedures or polypharmacy remedies. There are quite a few examples of patient registries in pain medicine, of which the PAIN OUT is the first international acute pain registry [14]. Other examples include the “Oslo University Hospital Pain Registry” [16], a valuable existing digital chronic pain registry that provides data of thousands of patients, and the Quebec Pain Registry (QPR), a large research database of patients suffering from various chronic pain (CP) syndromes in the province of Quebec (Canada). The above registry constitutes a comprehensive tool for conducting research in a “real-world” context. It contains data on the clinical evolution of thousands of patients and provides the opportunity of answering important research questions on various aspects of CP (or specific pain syndromes) and its management [17]. Another pain registry that was established in 2015 in Denmark, the PainData, aims to assist clinical decision-making, and facilitate quality assurance and research projects to improve understanding and optimize treatment of patients with chronic pain [18]. Finally, the “Special Registry for Patients with Chronic Neuropathic Pain” was also established by the Hellenic Society of Pain Management and Palliative Care (PARH.SY.A) with the data of thousands of patients with chronic neuropathic pain in Greece [19, 20]. For example, the Greek Pain Neuropathic Registry includes patient information such as baseline patient data (demographics and social-financial data), medical history, relevant family history, type of chronic pain, type of neuropathic pain, history of neuropathic pain, pain medication, interventional techniques, and other treatments [19].

Besides the obvious clinical benefits, these registries might be used for conducting pharmaco-economic studies. Cost-effectiveness of interventions is important in the planning and

use of health care services and available resources [21].

To further support the aforementioned and to highlight the importance of neuropathic pain registries specifically, we provide one example from a Spanish neuropathic pain registry. Data from this registry were analyzed in order to assess the etiology and the cost of management of patients with neuropathic pain. The results showed that neuropathic pain results in substantial utilization of health resources, particularly by those who were referred by primary care specialists to pain clinics for pain management [22]. However, the writers compared these results with patients whose pain is primarily managed in pain clinics and it seems that the extra health care cost for medication for the referred patients is being offset by the lower costs of other components of pain management, eventually generating similar mean monthly total costs [22]. Moreover, a recent big cohort study that was conducted in Norway and included data from two nationwide registers, the Cancer Registry of Norway and the Norwegian Prescription Database, revealed that in cancer survivors there is a high prevalence of gabapentinoids. The latter, according to the writers, is indicative of increased prevalence of neuropathic pain and further supports the importance of the existence of neuropathic pain registries [23].

Taking all the above into consideration, the existence and usage of neuropathic pain registries to their full extent could not only lead to better patient management but also serve as a useful tool for the development and planning of pain management services. Useful information, apart from the prevalence and the treatment costs, than could be gathered from neuropathic pain registries could be medication usage for specific types of neuropathic pain, medication tolerance or failure, medication side effects, coping strategies of patients (like distraction strategies or trigger point massaging for myofascial pain), usage of health care and pain services, success or failure of pain procedures, and many other important information [24–26].

Of utmost importance is that along with the many benefits of health registries in research

and health planning, we should also acknowledge the sensitive nature of information stored in such registries and the potential risk of information leak [27]. The valid recent concerns about privacy and data protection could limit a registry's use and affect the willingness of patients to share their information [28]. For instance, many patients have concerns regarding the potential economic harm resulting from discrimination in health insurance and employment or that they would have to pay out of pocket for care that is covered by insurance [29]. Therefore, as clinicians and researchers, we should be extremely grateful to our patients for sharing their information and treat these sensitive data with due respect. Clinicians and researchers should always look for ways to improve data sharing that would minimize the risk of information leak. Establishment and maintenance of pain registries are crucial for clinical and research applications. Epidemiological, clinical, and economical studies will be feasible with the data obtained by them; however, more importantly, patients will receive better and personalized care for pain management.

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