

Registration of Health Data: A Gold Mine for Research about Health Service Utilization¹

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In a recent issue of Central European Journal of Paediatrics, Michelsen et al. provided a comprehensive overview of health care services use among persons who have cerebral palsy (CP) in Denmark (1). The results suggested that children with CP more often visited general practitioners as well as specialist physicians at primary, secondary and tertiary health care level compared to adults with CP. Nevertheless, there was no appreciable difference between children and adults with CP in terms of the admissions to the emergency department (1).

Similar to all former Yugoslav republics, all permanent residents in Denmark have universal health care access and a unique personal identification number through which each individual could be traced within the health care system. Organized and systematic data collection by means of registers, such as the National Patient Register or the National Health Service Register in Denmark (2) allows for an almost complete insight into the patterns of health care utilization and needs of specific groups as well as the population as a whole.

A recent study by Klawonn et al. (3) suggested that research focusing on CP has been increasing,

particularly over the last decade. Depending on the level of impairment, persons with CP may have similar life expectancy to that of the general population (4). Therefore, one of the main topics in CP research nowadays is related to aging and functioning (3). The systematic long-term collection of data about persons with CP using registers provides important information about the issue of aging with CP. The study by Michelsen et al. (1) was based on data from the Danish Cerebral Palsy Register, which has been in use since 1967 (5). This Register initially covered the population residing in Eastern Denmark, but as of 1995, the entire population of Denmark was included. The long-term follow-up of persons with CP through the Register brings health care workers and researchers better understanding of their health needs from childhood to older age.

Analyses of register-based data, such as the one by Michelsen et al. (1), are necessary for all health care systems to organize, improve, adjust or refine the existing health care services. Furthermore, examination of health care services utilization can highlight which departments and specialists have higher workload and how to, therefore, reorganize the health care staff. Finally, optimal organization directly leads to lower health care costs.

¹Invited commentary on "Health Care Usage among Children and Adults with Cerebral Palsy" by Michelsen et al. Central Eur J Paed 2020;16(1):46-59.

Indeed, the foundation of health registers requires a collaborative effort from the government, health care institutions as well as the entire medical community. It also requires considerable investments of financial and human resources. However, despite these setbacks, the benefits of having health registers for health care workers, researchers, governmental organizations and, most importantly, users of health care services, far outweigh the disadvantages associated with their organization and management.

Conflict of Interest: The author declares that she has no conflict of interest.

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