

## LETTERS

### Real-world data really matter

We read with interest the editorial by Morin and Flegel highlighting the benefits that a Canadian national health care data network could provide.<sup>1</sup> National patient registers from Nordic countries provide clear examples of the advantages of having access to data on a country-wide level.<sup>2</sup>

Real-world data, which is defined by the Association of the British Pharmaceutical Industry as data collected outside the controlled constraints of conventional randomized clinical trials to evaluate what is happening in routine clinical practice, is an essential component for health care decision-making.<sup>3</sup> Real-world data are used to understand disease epidemiology, patterns of care and patient need, information that is important for policy-makers in deciding health care provision.

A previous study of admissions to the National Health Service in England that used real-world data reported a “weekend effect”<sup>4</sup> (i.e., admission at the weekend was associated with an increased risk of subsequent death). This led to controversial policy changes by the government of the United Kingdom to increase weekend staffing levels, perhaps showing one of the most striking examples of the importance of real-world data. However, a more recent study by Walker and colleagues that used real-world data from the Infections in Oxfordshire Research Database (IORD) showed that any apparent weekend effect on mortality arises from patient-level differences at admission.<sup>5</sup>

Data from IORD have been available for many years and if the database were openly accessible for researchers to analyze, perhaps the negative impacts of policy

changes could have been prevented. However, unlike for clinical trials where strong movements are taking place for more open access to data,<sup>6</sup> there are few champions for the sharing of real-world data. The IORD is one of a number of different data sets across the world that could be shared for researchers to analyze for improvement of patient care. Although privacy issues may need to be addressed, sharing of real-world data should become the norm.

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