

EDITORIAL

INTERNET-BASED REGISTRIES (IBR)-DO THEY HAVE A ROLE IN PEDIATRIC RHEUMATOLOGY IN 2004?

The article of Philip Hashkes and colleagues from Israel demonstrates that an internet-based disease registry can be quite successful. It must be said at the beginning that this success does not necessarily translate to easy use of internet-based registries in large countries with many more pediatric rheumatologists or on an international scale. There are obviously advantages and disadvantages over paper registries and a number of obstacles as well. Let's discuss it.

Advantages:

- 1) **Data access:** An internet-based registry (IBR) allows easy access of multiple centers (national or international) to anonymous data of multiple other centers and clearly may facilitate research at local, regional, national, and international levels. Based upon the large data base, pediatric rheumatology centers may have an easier time identifying the best potential sister centers for research collaboration and initiating the collaboration.
- 2) **Data input easier:** An IBR allows easier input of data in one step and avoids the two steps needed in paper registries, first filling out forms, and then inputting the data into a computer program.
- 3) **Forced data collection:** The IBR would make every participating center collect patient data in a systematic, computer-based program. The effort may be painful initially but well worth the time and personnel in the long run.

- 4) **Incidence and prevalence:** Assuming the success of such an IBR, the most obvious potential result is better information on true incidence and prevalence of pediatric rheumatic diseases. Valid incidence and prevalence data is critical to obtaining the resources to provide the optimum clinical care, center support, and research funding in every country.

Disadvantages:

- 1) **Time, personnel, and money:** Where will this personnel, time, and money come from to establish an IBR? Many pediatric rheumatology centers are understaffed at this time and participating in an INR may be just one more added burden. It might work with outside funding from research grants, educational contributions from drug companies, or philanthropy.
- 2) **Privacy issues:** The medical community in the USA is laboring under new privacy constraints (HIPPA) that will make an IBR more complicated but feasible nonetheless. Other countries may have similar concerns. The authors discuss this issue, how it was addressed in Israel, and suggest that this problem can be surmounted. But it may not be so simple. The new HIPPA regulations in the USA have been interpreted differently in a number of medical systems and varying interpretations may mean some centers in the USA may not be able to participate in the short or long term.
- 3) **Institutional Review Boards (IRB):** These internal committees usually require any data collection effort with research potential to go through their committee and a formal application process. This effort also takes time, personnel, and money.
- 4) **Agreement on data collection format:** This effort would require much negotiation and political will to come up with a form that everyone will use and be happy with. This form could be created by e-mail.
- 5) **Computer glitches:** Hacking and computer viruses may make computer data input and evaluation an on-again, off-again experience. This problem

comes with the territory of internet-based programs and may be frustrating, but ultimately acceptable.

6) **Politics:** Last but not least is getting everyone or nearly everyone to participate. Integration of an IBR into the existing organizations of pediatric rheumatology would take time and political savvy. Some organizations such as PRINTO already obtain data from many international centers, but have not yet moved to an IBR.

I believe that internet-based registries have many positive attributes. However, the larger the country and the more centers involved, the larger the obstacles may be. Yet the potential for international collaboration, data collection, and multicenter research based upon an IBR is both intriguing and exciting and merits discussion of the IBR within the pediatric rheumatology community. It's a small world and getting smaller. We need to work together for our kids. Let's consider IBR's.

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