Journal of Cystic Fibrosis
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CYSTIC FIBROSIS FOUNDATION
ADDING TOMORROWS

Cystic Fibrosis Research News

Citation:

Mendelsohn AB, Dreyer NA, Mattox PW, Su Z, Swenson A, Li R, Turner JR, Velentgas P. Characterization of missing data in clinical registry studies. Therapeutic Innovation & Regulatory Science 2015; 49:146-154.

What was your research question? (50 words maximum)

The primary objective of this study was to get a better idea of how much data is missing from registry-based studies. We examined three registries, including the CF Foundation Patient Registry (CFFPR). We also investigated whether patient, site, or data collection characteristics may predict which data is missing in the registries.

Why is this important? (100 words maximum)

Missing data can threaten the likelihood of obtaining valid conclusions from all research studies, both experimental (where patients are taking a study drug) and observational (where patients are taking surveys or allowing researchers to use test results). To date, there has been limited effort to characterize missing data in observational studies, including studies which have used data from the CFFPR. The research that has been conducted has generally been limited in terms of variable types evaluated and/or disease areas considered.

What did you do? (100 words maximum)

Missing values were evaluated for demographic, clinical, and patient-reported outcome (PRO) data from three different registries: a procedure registry (TOPS); a rare disease (cystic fibrosis) registry (Port-CF); and a comparative effectiveness registry (glaucoma, RiGOR). Statistical models were used to assess whether patient characteristics or follow-up methods predicted the likelihood of missing data. Data from 156,707 surgical procedures, 32,118 cystic fibrosis patients, and 2373 glaucoma patients were analyzed.

What did you find? (100 words maximum)

Data were rarely missing for demographics, treatments, and outcomes. Missing data for clinical variables varied by registry and measure and depended on whether a variable was required. Within RiGOR, PRO forms were missing more often when collected by e-mail compared with office-based paper data collection. In Port-CF, missing data varied based on insurance status and sex.

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What does this mean and reasons for caution? (100 words maximum)

This study suggests some opportunities for better understanding missing data in observational studies. Reasons for missing data should be strategically considered prior to data collection and assessed periodically during study conduct.

What's next? (100 words maximum)

Expanding the analyses to examine other registry types, (device, global, pregnancy, etc.) including registries in other diseases, is warranted. Further work needs to be conducted to examine the impact of missing values on our study findings and how the interpretation of data may change based on different strategies, (e.g., for handling missing data).