

Electronic Databases, Data Quality and Loss to Follow-up: Survey of Antiretroviral Treatment Programmes in Resource Limited Settings

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Objectives

To examine the electronic databases used in antiretroviral therapy (ART) programmes in lower-income countries and assess strategies to maintain and improve data quality and reduce loss to follow-up.

Methods

Using the WHO Web Data Collector System, a cross-sectional survey was performed (2006) in 21 treatment programs located in Africa, South America and South-East Asia. The questionnaire focused on critical human and electronic resources devoted to EMRs. The data quality of selected sites from the ART-LINC Collaboration, a multinational network of HIV treatment programs, was also assessed by computing proportions of missing data for ART key-variables (age, sex, clinical staging, CD4 counts, and year of ART initiation). Patients not seen during the past 12 months were considered lost to follow-up. Associations between site characteristics as assessed by the survey and actual data quality were investigated using multivariable maximum-likelihood logit models using robust standard errors.

Findings

Twenty-one sites that provided ART to 50,060 patients were included (median 1,000 patients, interquartile range [IQR] 72 to 19,320). Eighteen sites (86%) used an electronic database; most (n=15; 83%) relied on software intended for personal or small business use. The median proportion of missing data in key variables was 10.9% (IQR 2.0 to 18.9%); it declined with training (odds ratio [OR] 0.58, 95% confidence intervals [CI] 0.37-0.90) and person-time of data staff (OR 0.95, 95% CI 0.90-0.99 per hour/week/100 patients). About 10 hours/week/100 patients were required to reduce missing data in key variables to below 10%. The median percentage of patients lost to follow-up at one year was 8.5% (IQR 4.2-19.7%). Strategies to reduce loss to follow-up included outreach teams, community based organizations and checking death registry data: implementation of all three strategies substantially reduced loss to follow-up (OR 0.17; 95% CI 0.15-0.20).

Conclusions

The quality of data collected and the retention of patients in treatment programmes is unsatisfactory for many sites involved in the scale up of ART in resource limited settings. Our study suggests that promoting appropriate and sustainable databases and systems to trace patients should be a priority in the context of scaling up ART. Patients could both directly and indirectly benefit from improvements of data quality, since accurate clinical data are a prerequisite for high standards of care and monitoring, and good care and good data support programme retention. These issues may not have received sufficient attention from the governmental and non-governmental organisations driving the scale up of ART in resource limited settings.