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Empowering patients with tuberculosis to build public trust in treatment outcome data.

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Tuberculosis has killed more people than any other infection since records began. According to World Health Organization policy and global practice, tuberculosis treatment outcomes are reported as “good” if patients complete all their treatment without persisting positive laboratory tests; or “bad” if treatment is not completed, and/or laboratory tests remain positive. Globally, most patients treated for tuberculosis never have any positive laboratory test, so usually treatment outcome simply assesses whether patients have completed their standardised course of treatment. In an ongoing cohort of 15,000 patients with tuberculosis disease treated in 32 Peruvian shantytowns we have compared programmatic and patient-reported outcomes. Amongst 2152 consecutive patients with tuberculosis, half of the 6.1% of patients whose treatment outcome was “bad” because of death during treatment actually died from unrelated causes, so “good” tuberculosis outcomes were underestimated. Furthermore, patients who die after completing tuberculosis therapy are not included in outcome data, but verbal autopsies defined their cause of death to be tuberculosis for 25% (15/59), so “good” outcomes were overestimated. In a group of 1622 patients, 0.86% (14) were considered programmatically to have “bad” outcome because they were lost to follow-up, but our research team were able to contact them or their families in all but three cases and 91% (8/11) actually had good treatment outcomes, so “good” outcomes were underestimated. Similarly, we completed detailed follow-up for 607 patients who were considered to have had a “good” tuberculosis outcome, but 7.9% of them were diagnosed with tuberculosis again, so “good” outcomes were overestimated. We assessed wellbeing with the EUROHIS-QOL questionnaire for 836 patients after being considered to have had a good treatment outcome and 38% were not satisfied with their overall health, so “good” outcomes were overestimated. Because of these issues, patients with tuberculosis cannot be confident that current statistics indicate what health outcome to expect. We propose that global policy is changed to empower patients (or if they died, their relatives) to report several months after treatment ends their actual tuberculosis-related health, making tuberculosis treatment outcome statistics more meaningful.