THEME: Engaging the community and building public trust in health research.

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

Authors: Luz Quevedo Cruz [1,2,3] , Rosario Montoya [1,2], Carlos Pozo [1,2], Adelina Lozano [1,2], Eric S Ramos [1,2], Lenin Bernaola [1,2], Jonathan Gómez [1,2], Maribel Rivero [1,2] , Carlton A Evans[1,2,3], Sumona Datta[1, 2,3,4]

Author affiliations:
[1] IFHAD: Innovation For Health And Development, Universidad Peruana Cayetano Heredia LID416, Lima, Peru

[2] IPSYD: Innovación Por la Salud Y el Desarrollo, Asociación Benéfica Prisma, Lima, Perú

[3] Infectious Diseases & Immunity, Wellcome Trust Imperial College Centre for Global Health Research, London UK

[4] Department of Clinical Sciences, Liverpool School of Tropical Medicine, Liverpool, UK.
Body of the abstract:

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 to 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, verbal autopsies defined the cause of death to be tuberculosis for 25% (15/59) patients who died after completing tuberculosis therapy, 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 all but three of them (or their families) 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 of what health outcome to expect. We propose that global policy is changed to assess tuberculosis treatment outcome by asking patients (or if they died, their relatives) their tuberculosis-related health several months after treatment ends, replacing the current programmatic assessment of treatment completion with a self-reported evaluation of actual health.