

‘Reservoir of infection’ or ‘fount of knowledge’? Forging equal partnerships and shifting power to address LTBI

IN THIS ISSUE of the *IJTL*, Berrocal-Almanza et al. grapple with the needs and expectations of community organizations recruited to help boost treatment for latent tuberculous infection (LTBI).¹ Engaging users in health programme planning has now become a legal or donor requirement. Berrocal-Almanza et al. show that overtures toward affected communities are sometimes perceived as half-hearted or instrumental, particularly when community-based organizations are used only as sources of referrals or tools to fill gaps in otherwise inflexible services. Although it has long been understood that marginalised, criminalised and stigmatised communities are key to tuberculosis (TB) elimination, adapting public health services to the specific needs of these communities has lagged (and ceding any real power has been even more reluctant).

Berrocal-Almanza et al.’s work shows that communities often face more pressing threats than LTBI. The authors highlight how structural issues (e.g., fear of deportation, the cost of living and employment precarity) represent overriding concerns for these community members. These competing agendas are not unique to the United Kingdom. Vertical disease programmes aimed at increasing coverage of a specific service often ignore the health and survival priorities of community members.

A question raised by Berrocal-Almanza et al.’s work is to what extent TB programmes are willing to fully partner with communities at risk. If partnership means simply endorsing their right to pick their own treatment supporter, there will be no opposition. However, if it means recognising communities as being capable of assessing their own health needs, and developing the humility to learn about (and defer to) community priorities, including defending against attacks on their right to privacy, freedom of association, freedom of movement or human rights, the quality of the partnerships may be tested. This question is not simply theoretical—clashes between public health interests, civil liberties and the criminalisation of migrants are on the rise in many settings.

While LTBI diagnosis and treatment are fundamental to TB elimination, the authors concede that the risks and benefits of LTBI treatment vary at the individual level. Forging equal partnerships with at-risk communities may thus have unintended conse-

quences. For example, it may mean that once fully informed, individuals with LTBI may decline prophylaxis. Representatives of these communities have begun to demand more direct involvement in LTBI service design.² Almost certainly a true partnership will prompt hard questions: we may question why there is not yet a predictive screening test for TB, or why shorter LTBI treatment regimens have not yet been registered in those countries that need them. Questions are already being asked as to why community members are forced to take medication under surveillance and why children in some settings continue to suffer family separation for the treatment of an asymptomatic, non-infectious condition.³

Berrocal-Almanza et al.’s work shows that engaging community organisations is fundamental, but that the process may be disruptive. It is important to remember that disruption often feels uncomfortable, but when undertaken in the service of bringing those at the margins into the centre, disruption is a sign of progress.

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