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Dear Professor Benger

Need for Review of NICE Guidelines on Tuberculosis (NG33 agreed in 2016)

I write on behalf of TB Alert, the only charity in Britain specifically concerned with TB both in this country and worldwide. I apologise that we are past your initial deadline of 10th January for submissions but hope that our views may nonetheless be made known to members of the NICE Prioritisation Board for their meeting on 24th January 2025.

Context

Tuberculosis (TB), now that Covid has receded, is back to being the greatest cause of death worldwide from an infectious disease. In Britain, after some years of decline in incidence, TB numbers have been rising again in recent years.

Nonetheless, the past decade has been a period of excitement in the World of TB care. New diagnostic tools and new drugs, especially for the treatment of multi-drug resistant (MDR) TB, have been developed and brought into use. As a result NG33 is out of date and no longer helpful in ensuring that people in need of diagnosis and treatment get the most up-to-date and effective care.

Diagnostics

As regards diagnostics, rapid molecular assays such as Gene-Xpert have entered standard use around the World yet Britain trails behind other countries. The global percentage of individuals diagnosed with TB who have been tested with such assays is 48% while the British figure is only 37%.

Treatment developments

As regards treatment, the greatest progress has been for MDR-TB. It is now 2 years since WHO recommended a regimen, BPAL/M, that is more effective than past regimens and brings treatment length down from 2+ years to only 6 months, the same as the standard regimen for regular drug-sensitive TB (DS-TB). It is iniquitous that individuals in Britain, where MDR rates are rising, still face the older regimens, meaning a heightened danger of death and of serious side effects such as blindness.



Another major step is that WHO has recommended a regimen for drug sensitive TB (DS-TB) that requires only 4 months of treatment, a reduction by a third from the standard regimen of 6 months. Here in Britain it is hardly talked about. The only country to include it in its standard practice is the USA.

There is a problem that this 4-month regimen includes Rifapentine, a drug that is relatively expensive and with, at present, poor availability.

This drug is also central to the best available treatment for latent TB, control of which is seen as critical to improving TB control in Britain.

Non-availability of newer TB drugs

Together with some other key TB drugs as well as child formulations of the normal DS-TB regimen, Rifapentine is not registered in the UK or the EU. As TB numbers are relatively low in Western Europe, the producers of the latest TB drugs do not see a sufficiently large market and so are reluctant to engage in the procedures and costs for obtaining registration. WHO-Europe is hosting a major meeting in Copenhagen on 28-27 January 2025 specifically on the issue of access in Western Europe to newer TB drugs. Hopefully, the UK will be well represented at this event.

Request

The present situation is ridiculous. If a person has TB today, they are more likely to get the best up-to-date treatment from the national TB programmes of poor, developing countries, than here at home in Britain.

NICE support and up-to-date recommendations would greatly help to create more of a market and stimulate whatever is necessary to ensure that best up-to-date practice in TB diagnosis and care becomes standard within Britain.

We very much hope that NICE will now prioritise TB, explore latest developments from WHO and other agencies, and develop recommendations that help bring UK practice back to best in the World.

Your sincerely,

Paul SOMMERFELD

Executive Trustee, TB Alert