

Notification of tuberculosis: an updated code of practice for England and Wales

A code of practice for tuberculosis (TB) notifications was published in 1982 by the then British Thoracic Association¹, in response to a number of ambiguities and inaccuracies² uncovered by the 1978–79 national notification survey³. There have been further national surveys in 1983⁴, 1988⁵ and, most recently, in 1993⁶, all of which have shown that some of the same ambiguities and inaccuracies continue and that some additional problems have developed, especially in relation to TB/HIV co-infection.

The updated code of practice given here addresses the current problems (long-standing and more recent) relating to the notification of TB, giving recommendations on how they should be overcome.

The purposes of notification are threefold:

- to trigger local action and contact tracing to identify individuals who may have acquired TB or have been the source of TB infection, so that appropriate preventive measures may be taken and treatment given to any detected clinical cases
- to identify possibly related cases and outbreaks
- to allow local and national monitoring of trends in the occurrence of TB.

1. Legal basis for notifications

Notification of TB is a statutory obligation, as was made clear in the Department of Health circular of 27 April 1995⁷. A doctor making or suspecting a diagnosis of TB has a statutory duty to notify the 'proper officer' of the local authority, now normally the consultant in communicable disease control (CCDC), using the standard notification form for notifiable infectious disease (available from the local CCDC, to whom it should be returned). This applies to all forms of clinical TB, including those not felt to be infectious to others⁸, as laid down by the (Infectious Diseases) Reg-

ulations 1988. Failure to notify is a breach of the law and can be subject to a fine of up to £200 for each offence. Medico-legal consequences could follow failure to notify a case, as appropriate contact screening procedures⁸ are triggered only by notification. Contact tracing procedures detect disease in 1% of contacts, and up to 10% of notified cases are found through such tracing^{9–11}. Contact tracing also allows measures to be instituted for preventing infection (BCG vaccination) or progression to clinical disease (chemoprophylaxis). Care should be exercised in writing the notification form, with the surname and forename(s) clearly identified, as these can cause difficulties in ethnic minority patients, and the date of birth. Sputum smear status should also be on the notification form so that those with potentially higher risk of transmission of infection⁸ can be quickly identified for contact tracing. If the address of the case is a hostel for refugees or homeless persons, the CCDC should be informed by telephone to institute immediate contact tracing measures because of the potential mobility of such contacts. The notification is legally expected to be 'forthwith', and we suggest should be made no later than within three working days of the decision to treat.

2. Undernotification

The importance of notification of all cases of TB is stressed in the most recent Joint Tuberculosis Committee (JTC) code of practice on TB control and prevention⁸. It has, however, long been realised that not all cases of TB are notified despite the statutory responsibility to do so. Undernotification occurs in TB in general, and also selectively in patients with TB and HIV co-infection (see Section 12). The extent of general undernotification is not known, but probably varies widely throughout the UK. The level can be extremely high, with 27% undernotification, including 14% with sputum smear-positive disease not being reported in one area¹²; this was reduced to 7% after audit¹³. The prevention of undernotification and procedures to ensure comprehensive and rapid notification should be laid down in the local TB control policy; they should be agreed with the local CCDC who has overall responsibility for TB control, and be the subject of regular audit. These procedures should include collation of all microbiology reports showing TB, with copies sent to either the local respiratory physician or the CCDC for appropriate clinical action and notification. Also discussed in the local policy should be close liaison with the

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histopathologist and consideration of sending copies of appropriate histopathology reports to the CCDC or local respiratory physician for action.

3. Duplicate notifications

In the 1993 national survey of tuberculosis notifications in England and Wales¹⁴, over 100 duplicate notifications were identified (ie notification of the same patient for the same episode of disease). In some, this was the result of notification forms being completed by different doctors involved in the care of the same patient (eg hospital clinicians, microbiologists or general practitioners). These patients do not cause a major problem as they can usually be identified locally and are unlikely to result in unnecessary duplication of the local contact tracing procedures.

However, duplicate notifications were sometimes received of the same patient from clinicians in different districts, usually because the patient was receiving treatment in a hospital outside the district where he or she was resident. In such cases, it remains essential for the clinician to notify a case to the local CCDC, who should in turn pass on the notification to the CCDC of the patient's district of residence. Contact tracing will usually be initiated in the latter, but liaison with the district of treatment may be necessary.

Duplicate notifications may also be received when patients change their place of residence during the course of treatment. Clinicians assuming the care of such a patient should ask whether the TB has been notified previously and, if in doubt, notify the case to the local CCDC with information about the previous address and physician. The CCDC should pass this notification on to the district in which the patient was resident when treatment began. If the patient has already been notified, the duplicate can be identified and removed at this stage.

4. Chemoprophylaxis

Chemoprophylaxis for TB is the administration of one or more anti-TB drugs to prevent an individual developing clinical disease, and can be either primary or secondary:

- *Primary prophylaxis* is given to persons known to have been exposed to infectious TB to try to prevent acquisition of infection. In the UK, this applies to household contacts of sputum smear-positive disease under two years of age⁸, until the results of serial tuberculin tests are known.
- *Secondary prophylaxis*, the more usual form of chemoprophylaxis, is that given after acquisition of infection as judged by a positive tuberculin test, but without clinical or bacteriological evidence of disease.

It is advised that chemoprophylaxis be given to all inappropriately tuberculin-positive children aged 0–16

found as close household contacts and all tuberculin converters, irrespective of age, and be considered for those aged 16–34 with inappropriately positive tuberculin tests found in household contacts or new immigrant screening from countries of high prevalence⁸. Chemoprophylaxis is also advised for inappropriately tuberculin-positive children aged 0–16 from high prevalence countries, as defined by an annual incidence of 40 per 100,000 or greater, which in practice means all of Asia, Africa, South America and the Caribbean, and Eastern Europe⁸.

Recommended regimens for chemoprophylaxis in the UK are either isoniazid for six months or rifampicin and isoniazid for three months¹⁵.

Persons receiving chemoprophylaxis are not notifiable as they are not suffering from clinical disease. If the CCDC is informed, or wishes to be informed, of chemoprophylaxis cases, this should be by letter and not by an official notification form. When such cases are included in the notification returns from the CCDC, the Office for National Statistics (ONS) separates the returns which state chemoprophylaxis and does not count them as cases of TB.

5. De-notification

Disease subsequently shown to be due to a cause other than TB should be de-notified. Opportunist mycobacterial infections are a common cause of disease appropriately notified as TB on clinical suspicion (including identification of acid-fast bacilli on microscopy), but should be de-notified when the result of culture is obtained. The purpose of de-notification is to curtail local contact examination activities and to ensure that local and national statistics reflect as accurately as possible the true TB incidence. The ONS is informed of a small number of de-notified cases of TB, but the detailed information collected in the national tuberculosis notifications survey in 1993¹⁴ revealed that only approximately half the notified cases which should have been de-notified had actually been de-notified. Although de-notification is simple, the lack of a formal mechanism may often hinder it being done. A telephone call or letter to the local CCDC is sufficient.

6. Posthumous notification

Occasionally TB is diagnosed after death, either at post-mortem or from cultures taken before death. Patients in whom it is considered that the TB was active at the time of death should be notified. Those likely to have been potentially infectious in life – that is, those patients with positive cultures from pulmonary sites (see Section 8), or involving the lung histologically – would justify contact tracing⁸. Cases with non-respiratory TB seldom require contact tracing⁸.

7. Previous treatment

When TB recurs in persons with a history of past (including recent past) treatment for TB, there may be uncertainty whether the new event should be notified. The overriding principle is that the case should be notified if the person is considered to have a new episode of TB and/or when a recurrence of pulmonary disease requires a re-examination of household contacts. A relapse with positive cultures from a pulmonary site should be notified as a separate episode.

Lymph node disease represents approximately half of the non-respiratory sites of disease: 30% of cases have a degree of persistent lymphadenopathy at the end of treatment¹⁶, and 10% develop new nodes or the enlargement of residual nodes after cessation of therapy¹⁷. Such events are thought to be due to immunological response to tuberculo-proteins; they do not require notification unless there is a positive culture. For other non-respiratory sites, it is advised that notification should be carried out only if there is bacteriological or strong clinical evidence of relapse 12 months or more after the previous treatment was completed.

8. Site of disease

The information required for notification of a case of TB includes site of disease. In most cases this is straightforward, but particular difficulties arise in a small proportion.

Pulmonary/respiratory disease

'Pulmonary' should be used to describe the site of the disease when the lung parenchyma, bronchi or trachea are involved. Disease of the larynx and upper respiratory tract, as well as intrathoracic lymph nodes and involvement of the pleura, diaphragm or chest wall (other than superficial skin involvement), should be described as 'non-pulmonary' respiratory disease. Microscopic identification or culture of *Mycobacterium tuberculosis* complex from sputum, bronchial washings, broncho-alveolar lavage fluid or bronchial biopsies all confirm pulmonary involvement. However, the term 'sputum smear-positive' disease should be reserved for those cases where acid-fast bacilli have been identified by microscopy of spontaneously expectorated sputum. This distinguishes the group most likely to pose a significant infection risk to others⁸ and permits comparison of sputum smear-positive numbers with data from earlier years or other geographical areas. Identification of acid-fast bacilli on microscopy in specimens obtained by sputum induction should be classed as sputum smear-positive. Acid-fast bacilli on microscopy in washings or broncho-alveolar lavage fluid obtained at bronchoscopy may indicate the possibility of infec-

tiousness in certain circumstances⁸, but should not be classified as sputum smear-positive.

Cryptic disease and trials of treatment

In both adults and children, symptoms suspected to be due to TB may not be specific and a trial of therapy may be warranted. The following recommendations are made for reporting cases:

- Subjects of any age, given one or two drugs because of evidence of acquisition of infection (eg tuberculin conversion) but no clinical evidence of disease should not be notified. In some districts, it is recommended that such cases be notified to the CCDC for local purposes, but such notifications should be given by letter rather than on an official form and the details should not be forwarded by the CCDC to ONS.
- Patients suspected of TB, but with non-specific symptoms and started on full therapy (2–4 drugs), should be described as having 'cryptic disease' unless positive cultures are obtained. The term 'cryptic miliary' disease is generally reserved for such cases where the organism has been isolated from blood, bone marrow or multiple organ systems.
- Individuals, with or without symptoms, but suspected of having clinical TB and started on a trial of therapy should be notified. If the suspected diagnosis is subsequently changed and treatment stopped, the case should be de-notified (Section 5).

9. Diagnosis in children

The diagnosis of TB in children is often difficult, and bacteriological confirmation of infection may be lacking. In surveys of TB cases, distinction between chemoprophylaxis and trial of treatment in children is hampered by the fact that some paediatricians use two drugs only as treatment, whilst others use two drugs for prophylaxis. The recommendations of the JCT on chemotherapy¹⁵ are the following:

- for *chemoprophylaxis*: isoniazid alone for six months, or rifampicin and isoniazid together for three months
- for *treatment of clinical disease*, the preferred regimen is rifampicin and isoniazid for six months, supplemented initially by pyrazinamide for two months.

It is clear from this that cases given rifampicin and isoniazid together for longer than three months are receiving treatment rather than chemoprophylaxis. Hence, if the two drugs are given for longer than three months, a notification as a case of clinical disease should be made; if, however, the two drugs are commenced as a trial of therapy, notification should be

made initially and later withdrawn, if appropriate (as in Section 5). In the light of increasing drug resistance, and because the majority of clinical cases in children are from ethnic minority groups, it is no longer justifiable to use only rifampicin and isoniazid throughout for treatment.

10. Notification of tuberculosis among short-term visitors, asylum seekers and recent immigrants

Rates of TB in the UK are especially high among recent immigrants from countries with a high prevalence of TB. The purpose of notification is to ensure that local contact tracing procedures are carried out; this may be appropriate even for people spending only a short time in the UK as details can be passed on to the health authorities in their country of residence. It is therefore recommended that TB diagnosed in short-term visitors to the UK and asylum seekers be notified, as well as in recent immigrants. A small number of foreign residents comes to the UK solely for the purposes of treatment; notification is not

required in these cases unless there are considered to be specific reasons for believing that examination of contacts in this country is necessary.

11. Tuberculosis diagnosed abroad in a UK resident

Occasionally someone normally resident in the UK may be diagnosed as having TB while abroad (the number of patients in this category is small). Any such patient who continues treatment on return to this country should be notified. Steps can then be taken to ensure that appropriate screening has been carried out for contacts such as family members who may have been exposed to infection before treatment was initiated. Notification of TB in patients who commenced and completed their treatment whilst abroad is not necessary.

12. Undernotification of tuberculosis/HIV

There is now ample evidence that undernotification of TB is considerably higher in HIV-positive patients than

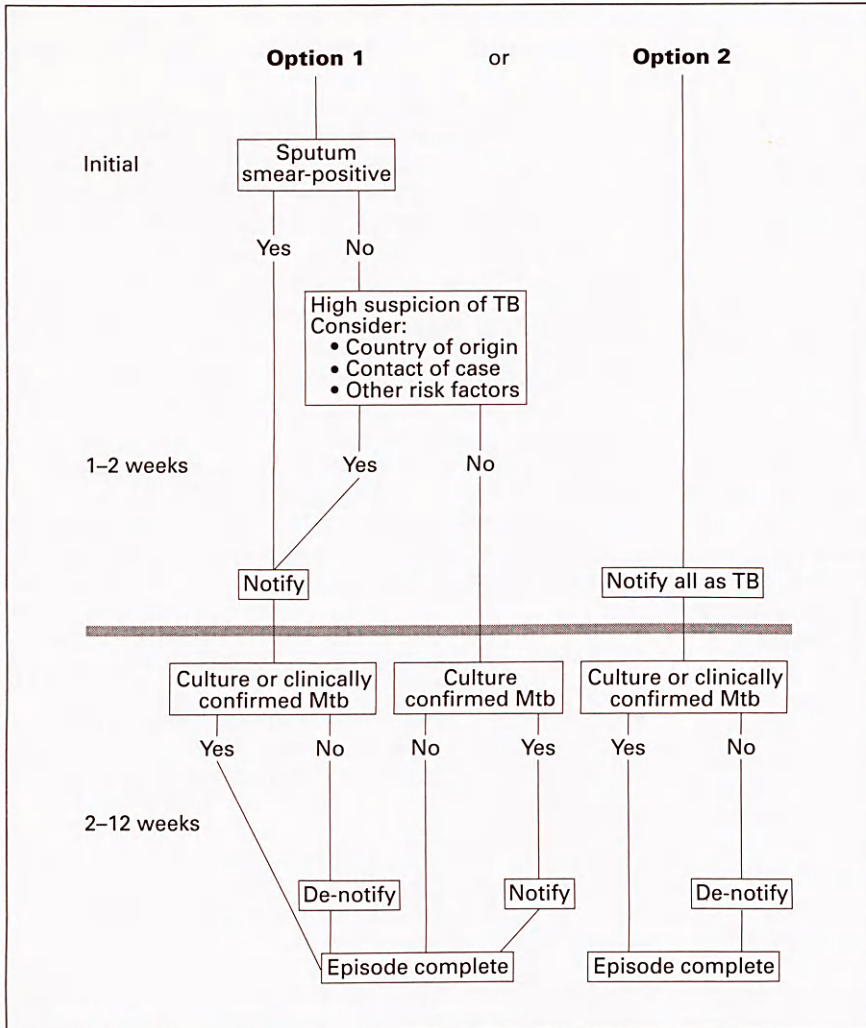


Fig 1. Flow diagram for notification of tuberculosis in HIV-positive patients: suspected mycobacterial disease, clinical ± acid-fast bacilli (Mtb = Mycobacterium tuberculosis; TB = tuberculosis).

in those known, or thought, to be HIV-negative. Undernotification rates of between 70%^{18,19} and 94%²⁰ of HIV-positive patients have been reported. The 1993 national survey of TB notifications⁶ showed that 2.2% of TB cases were HIV-positive by anonymised unlinked testing, but when the TB and AIDS registers were matched only about 50% of patients with TB known to be HIV-positive had been notified. Notification is an important part of TB control whatever the setting, particularly in HIV treatment centres where nosocomial outbreaks of TB are well documented²¹⁻²³. The threefold purposes of notification set out in the introduction apply equally to HIV-positive cases.

Even if a patient is HIV-positive, proven or suspected TB should be notified. Confusion about who should be notified may arise when acid-fast bacilli are seen in specimens but the mycobacteria may be non-tuberculous. A flow diagram with alternative pathways is given to simplify the decision about whom to notify (Fig 1). One of these pathways should be adopted as the procedure for notification in all centres treating HIV-positive cases or for cases found sporadically in low-incidence districts. Each HIV centre should keep TB notification forms.

Notification of TB does not breach the Venereal Diseases (1974) Act. If deductive disclosure about a patient's HIV status is an issue because a genitourinary physician is signing the notification form, local arrangements can be made for a chest or infectious disease physician or the CCDC to complete the form.

Although the TB notification form does not mention HIV status, it is important that those carrying out contact tracing, usually the local chest service, are – with the patient's consent – made aware informally of the dual infection. This is because the possibility of contacts also being HIV-positive needs to be known, as this alters some of the actions needed for a proper assessment of contacts²⁴. HIV-positive persons found to be inappropriately tuberculin-positive or requiring chemoprophylaxis on other grounds²⁴ are not notifiable, as with other groups receiving chemoprophylaxis (see Section 4).

When an HIV-positive patient suspected of having TB has been notified, but the diagnosis proves not to be TB (eg non-tuberculous mycobacteria are diagnosed by culture or genetic probes), the patient should be de-notified as advised in Section 5.

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