Tuberculosis case management and cohort review
Guidance for health professionals
Acknowledgements

Lead Authors
Dr Alistair Story RGN MPH PhD – Consultant TB Nurse, Clinical Lead for Find&Treat
Malcolm Cocksedge BSC (Hons) RGN – Senior TB Nurse Specialist Barts and the London NHS Trust

Writing Committee
Alyson Anderton RGN – TB Nurse Specialist British Thoracic Society
Mark Edginton – National Programme Manager National Treatment Agency
Marie O’Donoghue RGN – TB Nurse Specialist London TB Workforce
Dr Onn Min Kon MD FRCP – Consultant Respiratory Physician British Thoracic Society
Surinder Tamne RGN – TB Nurse Specialist Health Protection Agency

RCN Staff
Jan Maw – RCN Public Health Adviser
Emily Pollinger – RCN Assistant Public Health Adviser
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Foreword

This practical guidance is an invaluable compendium of evidence-based best practice for nurses and social care professionals who case manage patients with suspected and confirmed tuberculosis (TB).

The Royal College of Nursing is delighted to lead on the publication and dissemination of this guidance which has been produced in collaboration with the British Thoracic Society (NTA), Health Protection Agency, National Treatment Agency and the London Find&Treat TB outreach team.

An expert multidisciplinary panel reviewed national and international guidelines and models of care to clearly define the TB case manager’s role and responsibilities and to produce standardised definitions and performance outcome measures.

Tackling the resurgence of TB in the UK is a major public health challenge. While anyone can get TB, most cases today occur among socially excluded populations such as vulnerable migrants, homeless people, problem drug users and prisoners in our large urban centres. No area of the UK is unaffected by TB and case managers in low prevalence areas can face unique challenges due to low clinical suspicion of TB and widely distributed caseloads. Finding TB cases early and supporting treatment completion is an essential public health service that benefits both individuals and the communities in which they live.

Controlling TB is founded on early diagnosis, supporting patients to complete a minimum of six months drug treatment and meticulous monitoring to ensure that TB services meet the objective of curing patients and protecting the wider community.

Nurses contribute greatly in TB control, providing screening services, expert patient care and supporting non-clinically qualified case managers. Every TB patient should receive a named case manager and their contribution is pivotal to the overall success of our efforts to regain control of TB in the UK. The care of TB patients and their contacts requires case managers to work seamlessly between hospital care and the community and across organisational and geographic boundaries.

This first edition of *TB case management and cohort review: guidance for health professionals* complements existing guidance from the National Institute for Health and Clinical Excellence, providing a clear and concise reference manual for frontline workers engaged in the challenge of TB control.

Steve Jamieson
Head of RCN Nursing Department
Introduction

This practical guidance is for any clinical or non-clinical professional involved in the case management of suspected and confirmed tuberculosis (TB) patients. The guidance aims to:

- promote standardisation of protocols and procedures
- ensure accountability for delivery
- establish clear performance measures through cohort review.

Existing guidance

This publication is consistent with the following guidance for TB professionals in England and Wales, providing a sound framework for clinical management and commissioning:


We are grateful to international colleagues who have contributed to the development of important international guidance on TB control which has informed this guidance:


The initial draft of this guidance was developed by an expert working group set up in March 2009 by the Department of Health including representation from the Royal College of Nursing, British Thoracic Society, Health Protection Agency, National Treatment Agency and Find&Treat.

For more information or to submit comments on this guidance please contact rcntbinfo@gmail.com.

Review date: April 2013
1.0 Case management

1.1 What is TB case management?

Case management is the comprehensive follow-up of a suspected or confirmed TB case. Case management requires a collaborative multidisciplinary team (MDT) approach. Where risk/needs assessment demonstrates that the patient has clinically and/or socially complex needs, an enhanced level of case management should be provided. Enhanced case management (ECM) commences from suspicion of disease and includes directly observed treatment (DOT) in conjunction with a package of supportive care tailored to patients’ needs and should be available to patients in both high and low incidence areas. All socially and/or clinically complex TB patients must be able to access ECM and should be referred to, or collaboratively managed, alongside local specialist centres where necessary.

1.2 Referral process and pathway

TB services must be accessible to primary and secondary health providers and allied agencies in the community. An essential part of the role of the TB MDT is to promote awareness of TB among local health and social care professionals and ensure that all suspected cases of TB are rapidly referred for investigations. Routes of presentation will vary according to the local case mix and populations served. Routes should be monitored to inform targeted awareness raising and active case finding activities. The most common routes by which patients access TB services include:

- primary care referrals – general practitioners and practice nurses
- other hospital medical specialties (especially HIV, renal, paediatrics, rheumatology and ENT)
- accident and emergency
- active case finding – contact investigations, new entrant screening and hard-to-reach groups
- microbiology and histopathology
- radiology
- clinical teams working with local hard-to-reach groups (drug and alcohol users, homeless people, offenders, recent entrants).

TB services should have one designated referral number and contact address. Triaging all referrals through the TB specialist nursing services promotes good case management. This also ensures that the relevant investigations necessary to inform clinical decision making are completed and results are available prior to seeing a physician.

1.3 Standard case management

Standard TB case management is co-ordinated by a named case manager and is appropriate for any non-clinically complex patient who is able to self-medicate and have monthly follow-up in a hospital or community setting. For example, standard case management for drug sensitive non-complicated pulmonary TB can be structured as follows:

<table>
<thead>
<tr>
<th>diagnostic work-up</th>
<th>initial interview including clinical history and relevant investigations ordered</th>
</tr>
</thead>
<tbody>
<tr>
<td>start of treatment</td>
<td>seen by TB physician and case manager, contact investigations initiated, given one month of medication</td>
</tr>
<tr>
<td>one week</td>
<td>home visit (assess patient environment and complete contact list within five working days)</td>
</tr>
<tr>
<td>two weeks</td>
<td>seen by case manager as an outpatient or in the community</td>
</tr>
<tr>
<td>one month</td>
<td>seen by case manager as an outpatient or in the community, given one month of medication</td>
</tr>
<tr>
<td>two months</td>
<td>seen by TB physician and case manager to switch from initiation to continuation regimen, given one month of medication. Confirmation of drug sensitivity or record that no drug sensitivity yet available (to be reviewed regularly until either culture negative or sensitivities documented)</td>
</tr>
<tr>
<td>three months</td>
<td>as for month one</td>
</tr>
<tr>
<td>four months</td>
<td>as for month one</td>
</tr>
<tr>
<td>five months</td>
<td>as for month one</td>
</tr>
<tr>
<td>six months</td>
<td>seen by TB physician and case manager, treatment stopped and outcome reported.</td>
</tr>
</tbody>
</table>

1.4 Enhanced case management (ECM)

ECM is co-ordinated by the named case manager working alongside a specialist multidisciplinary TB team able to provide expert clinical and psychosocial care and to engage effectively with the client group in the community. ECM should be provided for all socially complex cases with
suspected TB to reduce the risk of patients disengaging with services prior to a diagnostic conclusion. In addition to the standard services and expertise within a multidisciplinary TB team, centres providing ECM are able to provide patients access to:

- expert management for clinically complex cases, including spinal, CNS disease, HIV co-infection, significant other co-morbidities and rifampicin resistant disease
- negative pressure facilities appropriate for prolonged isolation
- skilled outreach and advocacy workers able to draw effectively on the services of allied agencies to address patients’ housing, addiction, welfare benefits and other social care needs
- flexible clinic opening hours, appointment systems and community DOT options.

A hub and spoke model, with all centres able to provide standard case management and onward referral to specialist centres that are able to provide enhanced case management, will ensure that all TB patients can access a level of care equal to their needs.

1.5 Who provides TB case management?

Standard and enhanced case management will usually be provided by a specialist TB nurse or (in low-incidence areas) a nurse with responsibilities which include TB. Dependent upon the patient’s particular circumstances and needs, case management can also be provided by appropriately trained and supported non-clinical members of the TB multidisciplinary team.

1.6 When does case management begin?

Case management should start as soon as possible from first presentation for all suspected cases to ensure a timely diagnostic conclusion. In some instances, the patient’s route to diagnosis will be via microbiology or another medical specialty and first contact with TB services may be shortly prior to, or after, start of TB treatment. Services should ensure that a named case manager is appointed on the same day the patient becomes known to the TB service. The case manager should follow up all suspected cases who fail to attend an out-patient appointment. (See 6.4 RTS activities – suspected cases.)

1.7 What are the responsibilities of the TB case manager?

The case manager takes responsibility for ensuring that diagnostic investigations are completed and outcomes documented; an appropriate treatment regimen is monitored and completed and contacts are identified, evaluated and treated. This will require:

- ensuring that relevant clinical investigations are completed and acted on (see 6.0 Managing lost to follow-up (LFU) and return to service (RTS) activities)
- risk/needs assessment prior to commencement of a planned course of treatment to identify cases that require ECM (including DOT) from start of treatment (see 3.1 Delivering tuberculosis treatment)
- providing patient education and advocacy
- arranging screening and contact investigation in accordance with NICE guidelines and documenting outcomes to contact investigations through cohort review
- deciding and agreeing on a care plan and co-ordinating care with allied providers where appropriate, with the aim of addressing any psycho-social barriers to treatment adherence and ensuring completion of the prescribed treatment regimen
- ensuring optimal treatment delivery including supervision of DOT and attendance for clinical assessment and follow-up care
- ensuring all new cases are notified, cohort review is completed and treatment outcomes are reported.

1.8 Ratio of suspected and active TB cases to case managers

Previous guidance from the Joint Tuberculosis Committee of the British Thoracic Society recommended a ratio of one whole time equivalent (WTE) TB nurse specialist to 40 notifications in London (equivalent to any high prevalence urban centre) and one to 50 notifications outside of London (equivalent to any low prevalence area), based on the number of new cases reported from a TB service in any given year.
It is necessary to factor in the demands of case managing all suspected cases and the additional complexity of managing socially and clinically complex cases requiring ECM. Staffing levels for all TB services should be based on one WTE TB case manager per 40 notifications annually requiring standard case management and one WTE TB case manager per 20 notifications annually requiring enhanced case management. Any fraction of a WTE beyond 0.2 should be rounded up. In practice this would mean that a TB service providing care to 60 non-complex and 40 socially or clinically complex cases per annum, would need four WTE TB case managers. A service providing care to 30 non-complex and 10 socially or clinically complex cases per annum would need two WTE TB case managers.

This proposed staffing ratio does not include essential administrative staff, health advocates, interpreters and non-clinically qualified outreach staff working alongside TB MDTs.
2.0 The initial interview

The initial interview should take place on first presentation to the TB service or as soon as practically possible for all suspected or confirmed TB patients and patients commencing preventive treatment. The interview should be conducted by the named case manager and can be undertaken in either a clinical or community setting, depending on the patient’s individual circumstances. If the patient is diagnosed with TB while in a hospital, plans for follow-up care upon discharge must be initiated at the outset, and not on the day before discharge. This will require early liaison with the inpatient nursing and medical teams (plus, awareness on their part that they must contact the TB team when the patient is admitted or diagnosed with TB).

The aim of the initial interview between the case manager and any suspected or confirmed TB patient is to:

1. establish a trusting relationship
2. educate the patient
3. identify and assess physical and psycho-social care needs and potential barriers to completion of diagnostic investigations and treatment
4. initiate contact investigation as appropriate.

Existing NICE guidance provides information on clinical assessment including potential drug interactions which will not be covered in this guidance. In addition to clinical assessment the initial interview should be structured to cover the following issues.

2.1 Education
Assess knowledge and misconceptions about TB, determine the most appropriate educational intervention and provide appropriate literature. For patients who are about to start treatment for either active or latent TB, the educational content should include:

- TB transmission and pathogenesis
- preventing TB
- distinguishing infection from disease
- how drug resistance develops
- length of treatment needed for sensitive versus drug-resistant TB
- standard TB medications, including names, dosages, actions and adverse effects (including possible drug interactions)
- showing medication and how to take it
- promoting ECM including DOT as required
- explaining contact investigation process.

2.2 Locating information
It is vital to obtain and document comprehensive locating information and agree with the patient on the best method of communication (e.g. mobile phone, home/work number, significant other). Identify who will always know where to find the patient and determine if the patient plans to remain in accessible proximity to the TB service for the duration of treatment. For patients with complex social needs locating information should include details of other involved agencies, and consent should be obtained from the patient to contact these agencies (see 2.5 Consent).

2.3 Psychosocial needs assessment
This assessment should be tailored to the individual patient’s needs. TB patients presenting with complex social needs such as homelessness and substance use will require detailed MDT assessment to ensure that an appropriate plan of care can be implemented. Issues to address in the initial assessment include (See TB Treatment 3.4 Who should be offered DOT?):

- housing needs and living situation
- mental, emotional and cognitive status (via referral to a mental health team and social worker as necessary)
- language and literacy barriers
- cultural and religious beliefs that may impact on acceptance of diagnosis and adherence
- substance misuse and treatment
- access, mobility and transportation
- employment and income source, including entitlement to benefits
- family/social support and dynamics
- legal or immigration issues.

2.4 Contact investigations
Emphasise to the patient why it is important that contacts be identified and evaluated as soon as possible. Enquire about all household contacts and other close (often work or social) contacts. Obtain names, demographic details, contact information, exposure history and any factors for increased risk of TB disease (see 7.0 Implementing contact investigations).
Patients should be informed about the possibility of home visits and the TB service initiating return to service activities if treatment is interrupted. Patients do not need to provide separate permission for this as it is part of the treatment package. The process is not only in their own interest but also in the interest of their contacts and the general public.

2.5 Consent

Wherever possible, case managers should seek informed consent. Patients should, “agree to follow-up care and that personal information about them may be shared with other agencies and with other professionals”. Obtaining consent is a matter of good practice.

Case managers should encourage patients to see that giving their consent to share information will help them receive the care and support that they need. Consent lasts as long as co-ordinated inter-agency services are required. Individuals have the right to withdraw consent after they have given it. If consent has not been sought, or sought and withheld, then advice from local health protection staff should be obtained, particularly when information sharing is deemed necessary in order to prevent serious harm to a child or adult and/or to provide urgent medical treatment (see Appendix 6: Simple guide to information sharing).
3.0 TB treatment

3.1 Delivering tuberculosis treatment
TB treatment can be either self-administered or directly observed. The most important factor affecting TB treatment outcomes is the patient’s ability to adhere to, and complete, a prescribed course of treatment. Adherence refers to the extent to which a patient follows the instructions given for prescribed treatment. Low adherence with any prescribed treatment is common, with typical adherence rates estimated to be about 50 per cent. Non-adherence to TB treatment results in onward transmission, severe morbidity and preventable death, and the emergence of drug resistant strains.

DOT should be considered the standard of care from the start of treatment for all TB patient groups at increased risk of poor adherence [see 3.4 Who should be offered DOT]. In addition to significantly increased completion rates, the use of DOT has been shown to reduce the rate of drug resistance and relapse when compared with self-administered treatment (SAT) 6-7. Self-administered treatment must be taken daily 8.

3.2 What is self-administered treatment (SAT)?
The patient takes responsibility to collect, organise and administer their medication. Adherence for patients administering their own treatment should be promoted by providing medication in a conveniently packaged form such as a dossette box, and delivering medication to patients in the community where appropriate. Patients undergoing SAT should be monitored regularly (at least monthly) either in the community or clinic setting. Monitoring for adherence to SAT should include:

- discussing any perceived adverse effects or problems tolerating medication as prescribed (see Appendix 5: Drug therapy – adverse effects requiring clinical action)
- tablet count – dossette boxes help with accurate tablet counts
- urine test (if available) – commercially available test strips for isoniazid or rifampicin (butanol) are a simple tool for monitoring adherence
- counselling on the importance of treatment continuity and completion
- re-supply of medications from the TB service (only one month should be given) and check arrangements for future prescriptions and clinical follow-up appointments.

3.3 What is directly observed treatment (DOT)?
A trained health professional, or responsible lay person supported by a trained health professional, provides the prescribed medication and observes the patient swallowing every dose (3.5 Who should observe DOT).

DOT is part of a patient-centred case management approach, including:

- support to attend medical appointments
- ongoing patient education
- offering incentives and/or enablers
- ensuring access to appropriate accommodation
- assisting with transport
- connecting patients with social services and other specialist support agencies as appropriate.

DOT is resource intensive and includes delivering the prescribed medication, checking for adverse effects, watching the patient swallow the medication, completing a DOT log of medications observed and incentives issued, documenting the visit and answering questions.

TB services should aim to ensure that all TB patients who are likely to benefit from DOT receive DOT.

3.4 Who should be offered DOT?
While demographic factors such as age, sex, ethnicity, education and socio-economic status are not accurate predictors of adherence, psychiatric illness, substance abuse (alcohol and drug) and homelessness do typically predict non-adherence 9. The best predictor of non-adherence is a previous history of non-adherence to TB treatment. Directly observed therapy should be considered for all TB patients with active disease since it is difficult to predict with any certainty who will comply with treatment 10-11. TB case managers should undertake a risk assessment to identify whether the person should have DOT from the start of treatment, for all children aged under 16, for people who request it and for those who:

- do not (or did not in the past) adhere to treatment
- have been treated previously for TB
- have a history of homelessness, drug or alcohol misuse
• are currently or have previously been in prison
• have a major psychiatric, memory or cognitive disorder
• are in denial of the TB diagnosis
• have multi-drug resistant TB
• are too ill to administer the treatment themselves.

Wherever practically possible, DOT should be initiated at the start of TB treatment as patients who are switched to DOT can see this as a punitive measure and there is less chance of successfully completing treatment. Both the DOT provider and treating clinician should reinforce the value of DOT.

Treatment of patients not initially on DOT should be switched to DOT if any of the following occur without clear clinical reasons:

• slow sputum culture conversion (culture still positive more than two months after treatment started)*
• slow clinical improvement or clinical deterioration while on TB therapy.

In addition, patients who experience adverse effects to medication can be reluctant to self medicate and should receive close supervision.

All patients receiving DOT should sign a contract that clearly states the agreed timing and location for DOT and includes the potential public health implications of not taking TB treatment as prescribed. This agreement must be in a language understood by the patient and should be included in medical records.

Where resources for providing DOT are limited, providers should still assess the need for DOT using the characteristics listed above and work with local commissioners, clinical TB networks and health protection staff to demonstrate the need for additional TB case management and DOT resources.

[* In practice this may only be apparent after several weeks and reinforces the need to obtain regular sputum samples if the patient is still productive.]

3.5 Who should observe DOT?
DOT is most commonly provided by a trained nurse or non-clinical outreach worker attached to the local treating clinic. In practice, DOT can be supervised by any responsible adult (with the consent of the patient) provided they receive direct regular support from the named case manager and the patient is regularly clinically reviewed. Potential DOT observers include:

• nurses
• non-clinical outreach workers
• staff working in homeless hostels (key workers)
• pharmacists
• teachers
• staff working with offenders and ex-offenders
• staff working with clients who misuse drugs or alcohol
• staff working with people with major psychiatric/memory or cognitive disorders
• occupational health staff.

All TB patients should have a named case manager (see 1.5 Who provides TB case management?). Responsibility to ensure that effective arrangements are in place to promote treatment continuity and completion remains with the case manager.

It is not usually recommended that family members be responsible for watching TB patients take their medication as they are not typically neutral or objective about the patient’s health. In some instances, it may be appropriate to include family members as DOT observers, provided they do not themselves have any risk factors for poor adherence. With a high level of community support from the named case manager, a parent or guardian can be best placed to supervise the treatment of children and younger adults living in a household setting. Virtually observed therapy (VOT) can be an effective option to promote adherence for children and young people (see 3.7 How frequently should DOT be provided?).

3.6 Where should DOT be provided?
Treatment should be arranged to be most practicable for the person with TB. DOT can take place anywhere the patient, their case manager and DOT worker agree on, provided the location is convenient and safe for both patient and provider. When agreeing the DOT location, providers should consider issues associated with accessibility and economic resources (incentives, enablers, travel costs, employment disruptions), other treatments currently underway (HIV, opioid substitution therapy) and their locations, and possible social stigma associated with having TB.
A centralised system of DOT provision from a specialist TB treatment centre is the least resource intensive model but will not be suitable for all patients. Community based DOT can be provided more efficiently by establishing effective partnerships with allied health and social care services. TB clinics providing DOT on an outpatient basis should consider extended opening hours.

3.7 How frequently should DOT be provided?
The effectiveness of anti-tuberculosis drugs is dependent on adherence to prescribed therapy and convenient dosing schedules are an important means to improve patient adherence. Treatment may be given either daily or three times each week at a larger dose for both treatment phases. A twice-weekly dosing regimen should not be used for the treatment of active TB.

There is good evidence from controlled clinical trials to show the effectiveness of daily DOT, but few studies have assessed the effectiveness of intermittent treatment regimens. Daily treatment regimens may remain effective even in the presence of minor episodes of non-adherence, however intermittent dosing regimens may be less effective if enough doses are missed. It is common practice for DOT providers to request patients taking daily DOT to self-administer their medication at the weekend. It should be noted, however, that if every weekend dose were omitted then the patient would be taking only 71 per cent of the prescribed treatment.

Where clinical management is complicated by the concurrent treatment of other morbidities such as HIV or by opiate use, then expert guidance should be sought (see Appendix 3: Methadone and anti-tuberculosis treatment containing rifamycins).

Providing DOT for patients who are prescribed complex drug regimens that include intravenous, intramuscular or more than one daily dose, is a major challenge and is highly resource intensive. TB services should aim to provide home care in collaboration with other community health providers. For some patients, virtually observed therapy (VOT) using internet-based technologies that enable every dose to be ‘virtually’ observed by a trained provider remotely have proved effective. This approach must include a component of home-based support and regular (weekly) drug studies.

3.8 How long should DOT be continued?
Ideally all patients on DOT should complete the planned treatment course with DOT. Where a reduction in the frequency of contact with the DOT provider is planned, the most prudent strategy is to step down from daily dosing to three doses a week after completion of the initiation phase of treatment. All patients receiving DOT should complete at least the initiation phase of treatment before any consideration is given to reducing the level of treatment supervision. Where patients have demonstrated good adherence and treatment is well tolerated it may be appropriate to step down from DOT to SAT, with weekly review in the continuation phase.

3.9 How should patients who will not agree to DOT be managed?
Studies have shown that the main reasons for refusing DOT are that patients felt they could self-medicate and DOT interfered with their schedule. In most cases, both of these factors can be overcome by providing education, support and ensuring that the arrangements for DOT are as convenient as possible for the patient.

While patients falling into recommended categories for DOT have the right to refuse DOT the provider must stress the potential public health implications of not taking TB treatment. Patients who refuse DOT should sign a written contract to self-administer their treatment which should be included in medical records. This agreement must be in a language understood by the patient and clearly state the potential public health implications of not taking TB treatment as prescribed.

If sputum smear positive and/or drug resistant patients refuse DOT they should be reported to the TB lead at the local Health Protection Agency (or relevant local public health body) as they present a clear threat to public health. The TB lead should work with the case manager to involve the patient in a multidisciplinary/agency case conference to address DOT need. All patients who refuse DOT should receive a high level of community support from their named case manager including weekly adherence checks.

3.10 How should treatment for latent TB infection (LTBI) be provided?
LTBI treatment requires people who are otherwise well to complete either three or six months of daily medication. Research has shown that
adherence is even more difficult than in cases on full treatment for active TB disease and that no one strategy has been found to be successful for improving adherence to treatment for LTBI. Shorter courses of LTBI treatment and offering patients the choice of medication regimen are associated with better adherence to LTBI treatment. Patients starting preventive treatment should be risk assessed for factors likely to complicate adherence as for patients with active disease. DOT for LTBI results in higher completion rates, and should be offered to all children, any patients who have known risk factors for progression from infection to disease and any patients with complex social problems likely to complicate adherence.

3.11 Advice for home isolation

Most newly diagnosed TB patients do not require hospital admission to prevent further onward transmission provided their accommodation circumstances will not generate new household or close contacts following commencement of TB treatment. The duration of treatment required to render patients non-infectious varies between individuals and remains largely unknown. In the absence of drug resistance and extensive cavitary disease, patients with respiratory TB are usually not infectious after two weeks of treatment. Advice from the treating clinician should be sought in all cases. Where home isolation is considered appropriate, case managers should instruct patients to observe the following advice for the first two weeks of their treatment (or until such time as they are proven to be non-infectious in the event of drug resistant or extensive pulmonary disease).

- Stay at home unless you need medical care.
- Put off all non-emergency appointments (dentist, hairdresser, etc.) until you are no longer contagious.
- If you need to see a medical practitioner for any reason, inform them that you have TB.
- People who live with you will be investigated as contacts and are safe to be around. Avoid people who are not known to the TB service as a contact.
- You can go outside but avoid public transport.
- Do not go to school, work, or any other public place.
4.0 Promoting adherence

DOT works best as part of a range of supportive measures tailored to the individual needs of each patient. A package of care should include education and counselling, incentives, enablers and psycho-social care to address housing, substance misuse and other problems likely to complicate recovery.

Adherence to anti-tuberculosis therapy in drug-misusing patients who are prescribed substitute opioids may be significantly improved if the consumption of both medicines is supervised together.

4.1 Incentives and enablers
Incentives and enablers are measures that help a patient to overcome barriers and improve adherence. There is international expert consensus that use of incentives and enablers can improve case detection and treatment success. Good evidence exists for incentives and enablers to increase adherence with DOT20,21,22. Local commissioners should recognise the role that incentives and enablers can play in TB control and ensure that they are readily available to patients.

4.2 What are incentives?
Incentives are small rewards that encourage patients with both suspected and confirmed TB to attend for community TB screening, out-patient follow-up and DOT appointments. Incentives must be something that meets patients’ interests and needs. Providers should be creative and tailor incentives to the individual and make a clear written agreement on what is expected, what will be received, where and when. Incentives are usually used on an ongoing basis – weekly, monthly, or when key milestones in investigations or treatment are reached. Use incentives to motivate, not coerce.

4.3 What are enablers?
Enablers help overcome barriers to completing investigations and TB treatment. Examples of barriers that are likely to impact on outcomes include transport, housing, nutrition and immigration status. Providing assistance with transport is crucial for some patients who may not have the means to cover these costs. For TB patients on treatment, the importance of housing cannot be understated. In some areas local agreements between PCTs and local authority housing officers are in place to ensure that TB patients can access accommodation and complete treatment.

4.4 When should incentives/enablers be used?
A thorough individualised needs/risk assessment should identify barriers to care and potential adherence problems and ensure that enablers are used appropriately.

4.5 Accommodation
A safe and supportive environment is essential to recovery and prerequisite to TB treatment. All TB patients should have their housing circumstances systematically assessed by the case manager and where necessary the MDT should undertake more detailed assessment alongside other relevant housing and social care experts. For the purposes of TB control, a broad and inclusive definition of homelessness is needed which incorporates overcrowded and substandard accommodation to include people:

- who share an enclosed air space with individuals at high risk of undetected active pulmonary tuberculosis (that is, those with a history of rough sleeping, hostel residence or substance misuse)
- without the means to securely store prescribed medication
- without private space in which to self-administer TB treatment
- without secure accommodation in which to rest and recuperate in safety and dignity for the full duration of planned treatment.

TB patients who are street homeless or likely to become street homeless, for example, following release from prison, need rapid access to accommodation in hostels and in supported housing projects. TB services should forge links with local housing services to help engage and manage hard-to-treat patients, promote rapid referral and support treatment continuity and recovery. All acute hospitals should have formal admission and discharge policies for homeless people and especially those with TB23. NICE recommends that commissioners of TB prevention and control programmes should make provision to prevent ongoing transmission in the community and prolonged, unnecessary and costly hospital admission by funding accommodation for homeless patients with active TB for the full duration of their treatment. The TB MDT should stress to patients, who may not be otherwise entitled to state-funded accommodation, that funding could be withdrawn if patients disengage with TB treatment services and do not take TB treatment as prescribed.
5.0 Managing non-adherence

5.1 What is non-adherence?

- SAT patients are considered non-adherent after two consecutive missed out-patient appointments, irrespective of the amount of medication that they potentially hold.
- DOT patients on daily therapy are considered non-adherent after missing three daily doses or two doses per week in two consecutive weeks.
- DOT patients on three times per week therapy are considered non-adherent after two or more doses are missed within two weeks.

All episodes of non-adherence must be documented and action initiated by the case manager in consultation with the MDT to address any potential barriers to treatment continuity.

5.2 Managing non-adherence for active TB patients on SAT

Case managers have no objective means of verifying that SAT patients are actually taking their medication. As such they should be highly alert and responsive to potential indicators of non-adherence including:

- missed appointments
- delayed clinical improvement or clinical deterioration while on TB therapy
- slow sputum conversion
- inability to verify correct doses of medication
- discrepancies in tablet counts
- poor or non-acceptance of TB diagnosis
- adverse effects may make patients reluctant to self medicate.

The named case manager should telephone the patient within one working day of a missed appointment.

- If the patient is estimated to have enough medication to last until the new appointment date, and can confirm by phone that they are taking the medication and are not experiencing side effects, then a new appointment should be made to see the patient within five working days.
- If the patient is not contactable by telephone then a home/community visit must be made and a new appointment delivered to the patient within three working days of the first missed out-patient appointment. A standard letter reiterating the importance of treatment completion, in a language the patient understands, should be hand delivered.
- If the patient cannot be contacted or does not attend the new appointment then the case manager must inform the treating physician and continue to attempt to contact the patient with repeat phone calls and home/community visits.
- If the patient has not been contacted within 10 working days of the first missed appointment then the patient is defined as lost to follow-up (LFU). The case manager should inform the local TB lead at the health protection unit to initiate local return to service (RTS) activities for LFU patients.
- Where specialist street outreach teams are available, such as Find&Treat in London, case managers should make contact with these services and initiate RTS activities for LFU patients, i.e. those not contacted within 10 working days of the first missed appointment.

5.3 Managing non-adherence for active TB patients on DOT

The role of observing the patient take their medication is sometimes devolved by the case manager to another responsible person. However, the case manager remains ultimately responsible for monitoring adherence and ensuring that any potential barriers to treatment continuity are addressed.

- Case managers should attempt to contact patients who miss a DOT appointment within one working day.
  - Where DOT is devolved by the case manager, the person observing the patient take their medication should inform the case manager on the day of a missed DOT appointment.
  - The case manager should telephone the patient within one working day of a missed DOT appointment.
- If the phone call is unsuccessful, or if the patient has no phone number, the case manager should ensure that a home/community visit is undertaken within one working day of the missed DOT appointment. A standard letter reiterating the importance of treatment completion, in a language understandable by the patient, should be hand delivered to the contact address.
- If the patient cannot be contacted within five working days of the first missed appointment then the case manager must inform the treating physician and continue to attempt to contact the patient with repeat phone calls and home/community visits.
Patients on daily or intermittent DOT who cannot be contacted within 10 working days of the first missed DOT appointment are defined as LFU. The case manager should inform the local TB lead at the health protection unit (HPU) or specialist street outreach teams to initiate local RTS activities for LFU patients.

5.4 Managing non-adherence in TB patients on preventive treatment
Preventive treatment is not 100 per cent effective even when taken completely and carries the risk of adverse effects. As such, the potential patient and public health benefit of preventive treatment will vary. All patients who agree to take preventive treatment will require case management including regular clinical review. Where appropriate this will include DOT preventive treatment [see 3.4 Who should be offered DOT?].

In young children who are household contacts, HIV co-infected individuals and persons receiving anti TNF-alpha treatment, the benefits of preventive treatment are clear. Service providers should aim to encourage and document a high rate of uptake and achieve high rates of treatment completion (85 per cent) among these groups (see 6.3 Prioritising RTS activities – active cases). Patients or their legal guardians who elect not to start preventive treatment, or who stop treatment prior to completion, should be provided with written information and advice about TB. This should include clinic contact details should they wish to seek advice on treatment in the future. The patient’s GP should also be informed in writing. NICE recommends chest radiography at three and 12 months to exclude active pulmonary tuberculosis in patients who decline preventive treatment.

5.5 Measures to support and enable patients to take TB treatment
The following health and social interventions have been demonstrated to contribute to improved TB treatment continuity. To ensure a consistent and appropriate use of powers under public health legislation, health service providers considering application to a justice of the peace to detain a TB patient in hospital should demonstrate that these alternative interventions to support and engage patients have been tried, exhausted and failed.

1. Provide a flexible, open access one-stop TB service. (Rigid clinic times, multiple appointments in different locations and with different providers and long waiting times alienate patients).

2. Case management, including comprehensive needs assessment to inform a plan of care and identify factors known to complicate TB treatment.

3. Counselling, education and support provided in the patient’s first language (wherever possible). Involve peer groups to ensure that the appropriate approach is used.

4. Access to accommodation suitable for recovery and appropriate to the patient’s level of needs.

5. Referral to allied services relevant to unmet health and social care needs, e.g. drugs, alcohol, mental health, welfare benefits, refugee and asylum seekers advocacy and advice services.

6. A contract between the patient and provider to undergo TB treatment, accept counselling and agree to take TB treatment supervised by one or more specified person(s).

7. Directly observed treatment (DOT) from treatment onset provided in:
   - a hospital/TB outpatient clinic or other health facility
   - the patient’s home environment
   - opioid substitution therapy programmes
   - other community or institutional setting.

8. Providing non-cash incentives/enablers:
   - travel assistance
   - food and food vouchers
   - other non-cash assistance.


10. Respite through voluntary admission into acute care, intermediate care or a secure medical and psychosocial unit where available.

For more information on public health legislation see

6.0 Managing lost to follow-up (LFU) and return to service (RTS) activities

6.1 Lost to follow-up (LFU) – definition, principle and purpose

- Patients on SAT who cannot be contacted within 10 working days of the first missed outpatient appointment are defined as LFU.
- Patients on daily or three times per week DOT, who cannot be contacted within 10 working days of the first missed DOT appointment, are defined as LFU.

The principle of defining LFU is to identify confirmed (diagnosed) cases, LTBI treatment cases and suspected cases that could potentially harm either themselves or others by not completing prescribed treatment or relevant investigations.

The purpose of defining LFU is to trigger RTS action following missed doses of medication and/or missed follow-up appointments.

6.2 Return to service (RTS)

Tracing individuals who have interrupted treatment to encourage treatment completion is an essential element of effective TB treatment and effective TB control. RTS will include internal review and action by local TB service /HPU and specialist outreach teams where available.

The aim of RTS is to ensure that patients with active TB on treatment, LTBI treatment cases, or suspected cases who are at high risk of active disease, are rapidly re-engaged with treatment services and opportunities are not missed to prevent TB and delayed diagnosis.

Patients who are LFU should be discussed at case management team meetings and case conferences involving interdisciplinary staff with specialised expertise from local health protection units or specialist outreach teams (e.g. Find&Treat). The decision to involve local health protection teams and specialist outreach teams in RTS activities or not, should be made and documented at an MDT case conference within five working days of the patient becoming LFU.

6.3 Prioritising RTS activities – active cases

TB services should aim to locate and re-engage the following patients with active TB as a priority and refer all those not contacted within 10 working days of first missed outpatient or DOT appointment to local health protection units or specialist street outreach teams for RTS.

1. Any patient with multi-drug-resistant TB (MDR TB) with current positive bacteriology (smear or culture), regardless of the site of their disease.
2. Newly diagnosed patients, or reactivated patients, who have had AFB-positive sputum smears with no documentation of conversion to negative within the last nine months.
3. Any child younger than 16 years of age with less than six months of treatment (including preventive treatment – three months or less if prescribed 3HR chemoprophylaxis), regardless of site of disease.*
4. Any patient who is HIV-positive with current sputum AFB-negative smears, but whose culture has not converted to negative.
5. MDR TB patients with negative bacteriology (smear and culture) who have received less than 18 months of therapy.
6. Patients with single drug-resistant TB who remain culture positive.
7. Patients with drug-sensitive TB who have negative smears but remain culture positive.
8. Patients with drug-sensitive TB who have negative smears and cultures but who have received less than six months of treatment.
9. Patients with only drug-sensitive extrapulmonary TB.

* All case managers should be trained and aware of potential child protection issues with regard to management of both active disease and preventive treatment in persons under 16 years of age.

6.4 RTS activities – suspected cases

All patients with suspected TB referred to TB services for diagnostic investigations should have a named case manager appointed to ensure a timely diagnostic conclusion is reached and reported. The following suspected cases should be managed as outlined in 5.2 Managing non-adherence for active TB patients on SAT.

1. Any medically assessed person with signs or symptoms compatible with active pulmonary TB.
2. Any child (under 16 years of age) who has been medically assessed and referred for investigations.

All other suspected cases who fail to attend an outpatient appointment should be followed up (see 7.4.2 Contacts of pulmonary smear negative and all non-pulmonary cases).
6.5 RTS – Process and management

Where a local decision is made to initiate RTS activities the case manager takes responsibility for informing the local TB lead at the health protection unit or specialist street outreach teams where available. This should be done within five working days of the patient becoming LFU. It is essential to provide as much information as possible to help the patient to be reliably identified on databases and sign posted in relevant local services.

As a minimum, case managers should provide RTS teams with:

1. patient’s full name and any aliases used
2. date of birth
3. usual/last address (for patients who have no fixed abode (NFA) this should include details of places where the patient was sleeping or hanging out)
4. Next of kin (NOK) – names of person(s) known to the patient and contact addresses
5. mobile phone numbers
6. date/place first presented and date/place last seen
7. date of last verified dose of medication
8. clinical information, including route of presentation, symptoms, site of disease, risk of sputum smear positivity and drug resistance, and total amount of the prescribed regimen taken and treatment interruptions. Co-morbidities e.g. HIV, hepatitis B and C status. Previous history of TB and adherence
9. details of any psychiatric or other mental health problems
10. allied agencies involved, including details of DOT observer where devolved to allied professionals
11. social factors and history, including immigration status (date of arrival in the UK), first language and English proficiency, homelessness, drug and alcohol use and prison history
12. GP or other health provider known to the patient.

The case manager should contribute to an MDT meeting with the RTS team to provide details of all efforts and interventions made to facilitate completion of investigations and adherence to prescribed TB treatment. Case managers should be directly involved in developing and implementing relocation plans. RTS teams should not consider legal intervention using powers under public health legislation until all reasonable efforts to assist the patient in completing planned investigations and the entire course of TB treatment have failed (see 5.5 Measures to support and enable patients to take TB treatment).

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**Figure 1:** Non-adherence, lost to follow up and treatment default for active cases on treatment

- **SAT**
  - Non-adherent
    - Missed two consecutive out-patient appointments
    - Case manager informs treating physician and attempts to contact the patient with repeat phone calls and home/community visits
  - Lost to follow-up
    - Not contacted within 10 working days of the first missed out-patient appointment
    - Initiate return to service activities
  - Treatment defaulted
    - Not contacted within two months of the first missed out-patient or DOT appointment
    - Patient flagged on National TB Surveillance System as candidate for re-treatment

- **Daily DOT**
  - Missed three daily doses or two doses per week in two consecutive weeks
  - Not contacted within 10 working days of the first missed DOT appointment

- **3 x week DOT**
  - Missed two or more doses within two weeks
  - Not contacted within 10 working days of the first missed DOT appointment
7.0 Implementing contact investigations

Contact investigations are a cornerstone of TB control because they detect new TB cases and prevent future cases. Internationally, there are no standard definitions for the type, duration, closeness, and time period of exposure to an active TB case that warrant investigation; no standard criteria for expanding investigations beyond the most frequent contacts to include those with less frequent exposure; and no standard procedures for identifying, screening, and tracking contacts. A risk assessment-based approach is recommended, where the need to screen contacts is prioritised on the basis of the infectiousness of the index case, intensity of exposure and susceptibility of contacts.

The named case manager takes responsibility to ensure that contacts are identified, investigated and appropriately managed and outcomes to contact investigations are reported through cohort review. Contact investigations should not be delayed until notification.

The named case manager should compile a comprehensive list of exposed individuals for all newly diagnosed TB cases. This process begins during the initial interview, but an accurate assessment of who should be included as a contact, based on the risk of onward transmission, is best undertaken in the patient’s home or usual community setting. Case managers should undertake a home/community visit within five working days of the initial interview.

7.1 How should contact investigations be organised and prioritised?

Contact investigations should first assess those persons most likely to be infected. This will depend on the duration of exposure, the degree of infectiousness of the index case and the environment. Usually it takes many hours or days to transmit an infectious dose, but casual exposures may lead to transmission if the case is sufficiently infectious and the environmental air conditions are favourable, or if the contact is at high risk of infection.

Household and other close contacts of pulmonary smear positive cases and symptomatic individuals should be screened immediately and then six weeks later. This provides an important opportunity to demonstrate conversion caused by recent infection. Given that only a proportion of contacts return for a second screening after six weeks, local MDTs may decide to screen asymptomatic and immunocompetent contacts of pulmonary smear negative and extra-pulmonary cases only once and this should occur six weeks after any potential exposure.

Contacts with increased risk of infection and progression

The following list of groups is useful to identify high risk contacts to be assessed for screening:

- pre-school children
- immunocompromised, e.g. AIDS, lymphoma, leukaemia, cancer chemotherapy, anti-TNF alpha treatment
- diabetics
- individuals with a surgical history: solid organ transplantation, jejunoileal bypass, gastrectomy
- individuals with chronic renal failure or receiving haemodialysis
- individuals with silicosis.

In practice, an objective duration of exposure is useful in order to determine which contacts should be screened first and to limit the number of contacts who need to be identified. The “eight hour cumulative exposure rule” is generally used as a very rough rule of thumb to guide contact investigations. Household contacts are invariably those most likely to have been exposed, but for infectious cases it is necessary to screen all close contacts. The following definitions are based on NICE guidelines and international consensus where no guidance was provided by NICE.

- Household contacts of any person with active TB (any site) – persons from the same household (those who share a bedroom, kitchen, bathroom or sitting room with the index case).
- Close contacts of infectious TB cases – persons exposed for eight or more hours during the infectious period* to patients with respiratory TB and one or more of the following factors:
  - AFB pulmonary sputum positive on direct smear
  - extensive pulmonary disease, including cavitary disease on CXR
  - laryngeal TB
  - frequent cough
**Infectious period**: the time during which a person with active pulmonary TB disease is potentially infectious to others. Where there is a reliable history of onset of cough contact investigation should extend back to the date of symptom onset. If the date of onset of cough is unknown or unreliable due to lifestyle factors such as tobacco or illicit drug use, then the inclusion period for contact investigations is defined as beginning three months before the start of TB treatment. This period can be readjusted on a case-by-case basis according to epidemiological findings and clinical considerations.

Concentric circle approach to contact investigations

The ‘stone in the pond’ principle provides a method of organising and prioritising contacts in order of intensity of exposure and risk of being infected. The following concentric figure provides a useful way of organising a contact investigation.

**7.1.1 Household contacts of any person with active TB**

1a: Close contacts — persons from the same household (those who share a bedroom, kitchen, bathroom or sitting room with the index case).

1b: Persons potentially exposed in the household setting for less than eight hours during the infectious period.

1c: Contact investigations are occasionally expanded to wider family/household networks in the rare event of secondary cases or a greater than expected number of positive TST (Tuberculin Skin Test) or IGRA (Interferon-gamma release assays) results among 1b contacts. 1c investigations can occur due to undetected source cases.

**7.1.2 Workplace contacts of infectious cases (informed by individualised exposure risk assessment)**

2a: Persons exposed to infectious cases in the workplace for more than eight hours during the infectious period.

2b: Persons exposed to infectious cases in the workplace for less than eight hours during the infectious period.

2c: On the advice of local health protection teams, workplace contact investigations can be expanded in the rare event of secondary cases or a greater than expected number of positive TST or IGRA results among 2b contacts. 2c investigations can occur due to undetected source cases.

**7.1.3 Leisure contacts of infectious cases (informed by individualised exposure risk assessment)**

These commonly include social networks around pubs, clubs, sporting activities etc.

3a: Persons exposed to infectious cases for more than eight hours during the infectious period.

3b: Persons exposed to infectious cases for less than eight hours during the infectious period.

3c: On the advice of local health protection teams, investigations of leisure contacts can be expanded in the rare event of secondary cases or a greater than expected number of positive TST or IGRA results among 3b contacts. 3c investigations can occur due to undetected source cases.

**7.2 Which contacts should be assessed first?**

The first contacts ring should include all:

- household contacts of any person with active TB (any site)
- close contacts of infectious TB cases.

Potential duration of infectiousness and the environment where exposure took place also needs to be assessed. The weekly MDT meeting should be used to agree which contacts to include in the first ring for all:

- newly diagnosed patients found to have acid fast bacilli (AFB) on direct smear microscopy, with or without cavitary disease, who report cough for longer than 12 weeks before start of treatment
- infectious patients who have been resident or employed in a congregate setting (e.g. prison,
homeless shelter, hospital, nursing home, school, college) during the infectious period
• infectious patients who have spent eight or more hours with work colleagues in confined and poorly ventilated settings during the infectious period.

Where it is decided to include more than 10 non-household contacts in the first ring then expert advice from local health protection teams should be sought.

7.3 When should contact investigations be expanded beyond household and close contacts?
Where evidence of transmission between the index case and contacts in the first concentric ring can be demonstrated, then contact investigations should be expanded to include persons who have less than eight hours exposure, especially those contacts at high risk of developing tuberculosis once infected.

Assessing the probability that transmission has occurred is not straightforward. Epidemiologically linked secondary cases and documented TST or IGRA conversions among household contacts and close contacts of infectious cases, provide good evidence that recent transmission is likely to have occurred and justification to expand contact investigations. The occurrence of clusters of cases identified as having identical molecular strain types in either temporal or geographical proximity of one another, can inform the expansion of contact investigations outside of the household setting. TB MDTs should meet regularly with local health protection teams to ensure that local molecular strain typing data is used in a timely and co-ordinated way to inform expanded contact and outbreak investigations.

The occurrence of secondary cases and positive TST and IGRA test results among exposed children (under 16 of age) is likely to reflect recent transmission. Interpreting the results of TST and IGRA testing among adult contacts is complicated as, in the absence of documented conversion, it is not possible to differentiate between recent and remote infection. The proportion of persons with positive test results will vary considerably according to age and previous exposure risk of those tested. This must be taken into consideration when assessing whether or not the proportion of contacts tested, who have positive TST or IGRA results, is greater than expected.

Contact investigations should be expanded beyond household contacts and close contacts of infectious cases if one or more of the following is demonstrated:
• epidemiologically linked secondary cases
• documented TST or IGRA conversions
• the proportion of contacts tested who have positive TST or IGRA results is greater than expected
• clusters of cases with indistinguishable molecular strain types (on the advice of local health protection teams).

7.4 How should adult contacts who did not attend (DNA) be managed?

7.4.1 Contacts of pulmonary smear positive cases
• 1st missed out-patient appointment
  ° Repeat appointment for next out-patient clinic (within five working days).
  ° Assign case manager and contact the patient by telephone within one working day to explain in an appropriate language the importance of attendance.
  ° Confirm contact details and address.
  ° If a patient has moved out of area, then refer the contact to the most accessible local TB service.
  ° Document in patient’s notes.

• 2nd missed out-patient appointment
  ° Repeat appointment for next out-patient clinic (within five working days).
  ° Case manager undertakes a home/community visit.
  ° Hand deliver letter, explaining importance of attending.
  ° Document in patient’s notes.

• 3rd missed out-patient appointment
  ° Discharge.
  ° Record outcome for cohort review.
  ° Send second letter to patient.
  ° Copy of second letter to local HPU and GP.
  ° Copy of this in patient’s notes.
  ° If index case is being treated elsewhere, send the same letter to referring TB service.
7.4.2 Contacts of pulmonary smear negative and all non-pulmonary cases

- **1st missed out-patient appointment**
  - Repeat appointment for next out-patient clinic (within five working days).
  - Assign case manager and contact the patient by telephone within one working day to explain, in an appropriate language, the importance of attendance.
  - Confirm contact details and address.
  - If patient has moved out of area then refer the contact to most accessible local TB service.
  - Document in patient’s notes.

- **2nd missed out-patient appointment**
  - Discharge.
  - Record outcome for cohort review.
  - Send second letter to patient.
  - Copy of second letter to local HPU and GP.
  - Copy of this in patient’s notes.
  - If index case is being treated elsewhere, send the same letter to referring TB service.

7.5 How should child (under 16 years of age) contacts who DNA be managed?

The risk of developing TB disease after infection in children under five, especially in infants, is as high as 40 per cent\(^34,35\), and disease can develop within weeks of infection\(^36\). All child contacts who DNA should be managed as adult contacts of pulmonary smear positive cases who DNA (See 7.4 How should adult contacts who DNA be managed?). Failure to investigate and clinically assess children who have been potentially exposed to TB raises issues around child protection. All frontline staff engaged in the management of TB cases should have received the relevant child protection training.

7.6 How should timeliness, completeness and yield of contact investigations be reported?

(See 8.4.2 Contact investigation outcome indicators.)

7.7 Source case investigations

The diagnosis of TB in a child under 16 should initiate a source case investigation to evaluate all persons (adults and children) who have had close or household contact with the paediatric index case. All close or household contact in the one year prior to the time that the paediatric case was diagnosed, should be located. The source case investigation aims to identify the individual with active TB disease who may have infected the child and any other high-risk contacts who may have been infected in the same setting.

The source case is most commonly an adult in the home, a frequent visitor or an adult with whom the child spends significant periods of time such as a relative, nursery worker, childminder or teacher.

Rarely, the paediatric index patient is considered to be potentially infectious (i.e. strongly AFB positive on gastric lavage, cavitary disease or positive respiratory cultures). This should initiate a contact investigation to identify any secondary cases (See 7.1 How should contact investigations be organised and prioritised?).
8.0 Communication and monitoring

8.1 Weekly MDT meetings
The TB service MDT should meet weekly to discuss and plan care for:

- all newly diagnosed TB cases
- all suspected TB cases who have DNA outpatient appointments
- all other socially and/or clinically complex cases
- contact/source case investigations (including incident and outbreak investigations).

The MDT meeting provides an opportunity to co-ordinate care across the different professional disciplines and ensure timely and appropriate action. MDT meetings must be attended by the physician and case manager overseeing the care of the patient. Attendance from allied service professionals contributing to the care of patients under ECM should be encouraged.

8.2 What is a cohort review?
Cohort review is a systematic quarterly review of the management of every case of TB for treatment completion and contact investigation. The ‘cohort’ is a group of cases counted over a specific time, usually three months.

Details on the management and outcomes of each case are reviewed in a group setting. The case manager presents the cases for which they are responsible, giving the opportunity to bring up problems and difficulties in case management, reveal service strengths and weaknesses, and staff training needs.

Cohort review is an essential method of program evaluation and provides a multidisciplinary forum to review the management of each case and ensure accountability at all levels of the service, while linking to local, regional and national targets.

While TB services differ in both TB epidemiology and service provision, the principles of systematic review and accountability that are central to the cohort review are applicable to any setting.

Objectives of the cohort review process are to:

- ensure the implementation of comprehensive case management procedures for all TB patients
- improve promptness of appropriate interventions
- maintain reliability of data on the national Enhanced TB Surveillance System and local TB registers
- provide immediate analysis of treatment outcomes and contact investigation efforts, measured against previous cohorts
- assess efforts compared to local and national TB control targets
- identify, track and follow up on important case management issues
- provide ongoing training and education for staff
- provide staff with a forum for open discussion.

8.3 How to organise a cohort review
All TB clinical networks or local TB service administrative sectors should undertake a cohort review of every active case of TB diagnosed during a given quarter of the year. The review should be scheduled for each sector approximately six months after the close of each quarter (so cases are presented six to nine months after starting treatment). These should be attended by all sector staff and other key allied professionals.

Cohort review meetings should be chaired by the local TB lead, local director of public health or similar professional. At the meeting case managers present standardised information on each case, including information on contact investigations. The chair and medical reviewer are responsible for raising questions about the management of each case, and ensuring standards of care are adhered to. Issues or problems that arise during cohort, are systematically documented and followed up, and will be reviewed at the following cohort review.

Immediately following the case presentations, the epidemiologist will calculate and give a preliminary presentation on the sector completion data for treatment and contact investigation outcomes at the time of cohort. Updated completion data on cases and contacts presented at prior cohort reviews will also be presented to sector staff.

8.4 Performance standards – what information should be collected?
In order to assess progress, targets must be set for particular indicators which can be measured at each review. Outcome indicators for both case management and contact investigation are given below. These indicators will be measured using data in the TB surveillance system, and presented on the day by the epidemiologist.
Case management
1. 100 per cent of TB patients assessed as requiring DOT will be offered DOT.
2. 100 per cent of TB patients will be offered HIV testing.
3. At least 85 per cent of TB cases will successfully complete a recommended treatment regimen within 365 days. Treatment outcomes will be reported separately for the following categories of patients:
   a. patients receiving DOT from treatment onset
   b. patients who have had AFB-positive sputum smears
   c. patients with any first line drug resistance.
4. Less than five per cent of TB cases will be LFU at time of cohort review.

Contact investigation
1. Among pulmonary sputum smear positive cases:
   a. at least 95 per cent will have one or more contacts identified
   b. at least 80 per cent will have five or more contacts identified.
2. At least 90 per cent of contacts of smear positive cases will receive clinical evaluation.
3. At least 85 per cent of contacts with LTBI, who are started on treatment, will successfully complete.
Appendix 1: Case management forms

All the forms in appendix 1 can be downloaded from www.rcn.org.uk/phresources

**Form 1: Suspected TB case**

<table>
<thead>
<tr>
<th>Hospital number:</th>
<th>Case manager:</th>
<th>Date referred to TB service: / /</th>
<th>Date 1st seen by TB service: / /</th>
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<tbody>
<tr>
<td>Last name:</td>
<td>First name:</td>
<td>Other names (if any): Designation:</td>
<td></td>
</tr>
<tr>
<td>Sec: DOB:</td>
<td>Ethnicity:</td>
<td>Religion: Country of birth:</td>
<td></td>
</tr>
<tr>
<td>NHS no.:</td>
<td>Work or school details and address:</td>
<td>Language: Needs interpreter: Yes No</td>
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</tr>
<tr>
<td>Occupation:</td>
<td>Nearest of kin/ parental responsibility (name and contact details):</td>
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<td></td>
</tr>
<tr>
<td>Address (usual place of residence or 'where can be found'):</td>
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<td></td>
</tr>
<tr>
<td>Telephone:</td>
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<td></td>
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<tr>
<td>GP details:</td>
<td>School Nurse:</td>
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<tr>
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<tr>
<td>Symptoms (AUDIT): Date onset: / /</td>
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<td>LTBI?</td>
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<td>TB Investigations:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date:</td>
<td>Results:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical history/ medication/screening summary:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Initial assessment by (Name): ____________________________________________

Signature: ____________________________ Date: ____________________________

Designation: ____________________________
**Form 1: Suspected TB case (reverse)**

<table>
<thead>
<tr>
<th>Name</th>
<th>hospital no.</th>
</tr>
</thead>
</table>

**COMMENTS** eg: other TB risk factors and issues that may complicate diagnosis
eg: history of non adherence to TB or any medical treatment

**Recall for further investigations**
- **Date**: / / 
- **Signature**:  

**Mantoux (1)**
- **Date**: / / 
- **Live vaccine post 4/52**: Yes ☐ No ☐
- **Batch No.**:  
- **Expiry Date**:  
- **Signature**:  
- **Induration**: mm  
- **Site**:  
- **Read by**: (signature)  
- **Date**: / / 

**Mantoux (2)**
- **Date**: / / 
- **Batch No.**:  
- **Expiry Date**:  
- **Signature**:  
- **Induration**: mm  
- **Site**:  
- **Read by**: (signature)  
- **Date**: / /

**BCG**
- **Date**: / / 
- **Live vaccine post 4/52**: Yes ☐ No ☐
- **Site**:  
- **Batch No.**:  
- **Expiry Date**:  
- **Signature**:  

**Diagnostic outcome**
- 1 No evidence of active TB
- 2 Not TB atypical - REFERRED
- 3 Active TB - TREAT
- 4 Latent TB - TREAT
- 5 Latent TB - Not treated/declined
- 6 LTE prior to diagnostic decision

**Action**
1. Inform and advise - discharge
2. Where referred? (Details in comments)
3. Complete FORM 2: Initiate Rx (audit)
4. Complete FORM 2: LT: Initiate Rx
5. Inform, advise and arrange follow up
6. Refer to Find & Treat: Action / Info (audit)

**Audit**
- A Seen within 2 weeks of referral (if GP suspected paTB) Yes ☐ No ☐
- B All sputum smear results within 1 working day Yes ☐ No ☐
- C ECM Initial assessment completed Yes ☐ No ☐
- D Referred to Find & Treat if: High risk (see *) or LTE prediagnosis of AFB-TB contact Yes ☐ No ☐
- E (Calculate in days for Active TB cases only – see definitions sheet)
  1. Patient delay: ___ days
  2. Health Service delay: ___ days
  3. Total delay: ___ days

**Initial assessment by (Name):**  
**Designation:**  
**Signature:**  
**Date:**  

Form 2: Active TB treatment

<table>
<thead>
<tr>
<th>Field</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHS no.</td>
<td>Hospital no.</td>
</tr>
<tr>
<td>Last name:</td>
<td>Other names:</td>
</tr>
<tr>
<td>Telephone:</td>
<td>DOB: ___ / ___ / ___</td>
</tr>
<tr>
<td>Address (usual place of residence or “where can be found”):</td>
<td></td>
</tr>
</tbody>
</table>

**Diagnosis**

- Active Pulmonary TB
  - Smear: (date: ___ / ___)
  - positive: ___
  - negative: ___
  - not done: ___
  - unknown: ___
  - Culture: (date: ___ / ___)
  - positive: ___
  - negative: ___
  - not done: ___
  - unknown: ___

- Active Extra-Pulmonary TB
  - Smear: (date: ___ / ___)
  - positive: ___
  - negative: ___
  - not done: ___
  - unknown: ___
  - Culture: (date: ___ / ___)
  - positive: ___
  - negative: ___
  - not done: ___
  - unknown: ___

**In patient at diagnosis:**

- Yes □ No □
- Date admitted: ___ / ___ / ___
- Consultant: ____________________

**Site(s) of disease:**

- Pulmonary
- Lymph node
- CRS
- Bone
- Spinal
- Milary
- Other (below)

**Drug resistance risk factors (Audit 6):**

- Previous TB treatment (year: ___)
  - (where: ___ for how long: ___)
  - Contact of known resistant case
  - Problem drug use (ever)
  - Problem alcohol use (ever)
  - Imprisonment (ever)

**Drug sensitivity (tick any as known):**

- Fully sensitive
- Isoniazid resistant
- Rifampicin resistant
- Ethambutol resistant
- Pyrazinamide resistant
- Other: ____________________

**Other relevant clinical issues, including:**

- History of any treatment non-adherence

**Weight (kg) (at Rx start):**

<table>
<thead>
<tr>
<th>LFTs</th>
<th>Abnormal</th>
<th>Normal</th>
<th>BMI</th>
<th>Visual acuity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal</td>
<td>Abnormal</td>
<td>VH D level</td>
<td>Aid/ausaid</td>
<td>Left: ___</td>
</tr>
<tr>
<td>NAD</td>
<td>Not done</td>
<td>No ETH</td>
<td>Abnormal</td>
<td>Ishihare:</td>
</tr>
</tbody>
</table>

**Referral to eye clinic:** Yes □ No □

**Planned treatment start:** ___ / ___ / ___

**Planned date continuation phase:** ___ / ___ / ___

**Actual: treatment start:** ___ / ___ / ___

**Continuation phase date:** ___ / ___ / ___

**Treatment completion date:** ___ / ___ / ___

**Treatment Outcome at 1 year:**

**Clinic TB patient information leaflet supplied:** Yes □ No □

**OPD F/U appointments arranged and given to patient:** Yes □ No □

**Medical factors (tick any):**

- known HIV +ve HAART
- Hepatitis B +ve (test this episode Yes □ No □)
- Hepatitis C +ve (test this episode Yes □ No □)
- TNF-alpha treatment planned
- Diabetes
- Long-term corticosteroid therapy
- Low B& (<=20, <=18.3)
- Pregnant / postpartum at time of diagnosis
- Possible drug interactions

**Other TB/regular medication:**

- Possible drug interactions:

<table>
<thead>
<tr>
<th>Other TB/regular medication:</th>
<th>Possible drug interactions:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of treatment start: ___ / ___ / ___</td>
<td>Date of treatment completion: ___ / ___ / ___</td>
</tr>
</tbody>
</table>
### Form 2: Active TB treatment (reverse)

<table>
<thead>
<tr>
<th>Psychosocial assessment:</th>
<th>(Audit H)</th>
<th>Agencies known to/ referred to:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housing (current situation)</td>
<td>□ Urgent housing problem (NFA) give details</td>
<td>Housing officer:</td>
</tr>
<tr>
<td></td>
<td>□ Housing problem(no immediate action) give details</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ No housing problem</td>
<td></td>
</tr>
<tr>
<td>Immigration concerns</td>
<td>Yes □ No □ details</td>
<td>Immigration support worker:</td>
</tr>
<tr>
<td>History of prison (in past 5 yrs)</td>
<td>Yes □ No □ details</td>
<td>Probation officer:</td>
</tr>
<tr>
<td>Substance misuse</td>
<td>Is the client scripted for methadone Yes □ No □ details</td>
<td>Drug / alcohol worker:</td>
</tr>
<tr>
<td></td>
<td>Alcohol Yes □ No □ details</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Illicit drug Yes □ No □ details</td>
<td></td>
</tr>
<tr>
<td>Mental health</td>
<td>Give details including diagnosis</td>
<td>CPN/ CMHT</td>
</tr>
<tr>
<td>Communication</td>
<td>Needs interpreter Yes □ No □ Language:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sensory impairment Yes □ No □</td>
<td></td>
</tr>
<tr>
<td>Financial (income/benefits)</td>
<td>Nil income □ On benefits □ Other(50/80) □ Employed □</td>
<td></td>
</tr>
<tr>
<td>Mobility problem</td>
<td>Yes □ No □</td>
<td></td>
</tr>
<tr>
<td>Access &amp; Transport</td>
<td>Needs help with transport Yes □ No □</td>
<td></td>
</tr>
<tr>
<td></td>
<td>If yes : Provision □ Finance □</td>
<td></td>
</tr>
<tr>
<td>Directly Observed Therapy (DOT) (Audit H)</td>
<td>offered Yes □ No □</td>
<td></td>
</tr>
<tr>
<td></td>
<td>if No, reason</td>
<td></td>
</tr>
<tr>
<td></td>
<td>if Refused, reason</td>
<td></td>
</tr>
</tbody>
</table>

**Other info:** health beliefs, history of non-adherence to TB or any medical treatment, lack of social/ family support or any other complicating factors

### Any other places of regular contact (district nurses, social services, probation services, drop-in centres, church/mosque/terreto etc)

### Treatment delivery & support (at Rx start)

<table>
<thead>
<tr>
<th>Audit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Offered HIV test (all 18+ not already known) Yes □ No □</td>
</tr>
<tr>
<td>Assessed for risk of drug resistance Yes □ No □</td>
</tr>
<tr>
<td>DOT from onset or at risk Yes □ No □</td>
</tr>
<tr>
<td>LIFU at any time during tx Yes □ No □</td>
</tr>
<tr>
<td>If 1 = &quot;Yes&quot; referred to Find &amp; Treat Yes □ No □</td>
</tr>
</tbody>
</table>

Initial assessment by (Name): ___________________ Date: __________
Signature: ___________________ Designation: ___________________
# Form 2a: TB patient review record

<table>
<thead>
<tr>
<th>Field</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Clinic</strong></td>
<td></td>
</tr>
<tr>
<td><strong>NHS no.</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Hospital no.</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Case manager</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Consultant</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Date next F/U</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Nursing</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Date</strong></td>
<td></td>
</tr>
<tr>
<td><strong>MD</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Anatomy</strong></td>
<td></td>
</tr>
<tr>
<td><strong>DOB</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Other names</strong></td>
<td></td>
</tr>
<tr>
<td><strong>LTBR / ETS no:</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Estimated date change to dual therapy</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Weeks on TB/LTB treatment</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Estimated treatment completion date</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Interpretor used</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Language</strong></td>
<td></td>
</tr>
<tr>
<td><strong>ID code</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Symptoms &amp; Progress</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Appetite</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Weight loss</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Fever</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Coughing</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Night sweats</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Lethargy</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Feeling better</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Request sputum</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Lymph node changes</strong></td>
<td></td>
</tr>
<tr>
<td><strong>No</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Yes</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Comment</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Side effects</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Nausea/vomiting</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Rash</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Itchy skin</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Joint pain</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Weight</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Increase</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Decrease</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Liver function test</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Previous</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Normal</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Abnormal</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Checked today</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Yes</strong></td>
<td></td>
</tr>
<tr>
<td><strong>No, not due/indicated</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Visual disturbances</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Etambutol</strong></td>
<td></td>
</tr>
<tr>
<td><strong>N/A</strong></td>
<td></td>
</tr>
<tr>
<td><strong>No</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Yes</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Comments</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Medication: Self administered/supervised</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Frequency</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Doses missed</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Yes</strong></td>
<td></td>
</tr>
<tr>
<td><strong>No</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Reason for non-adherence</strong></td>
<td></td>
</tr>
<tr>
<td><strong>DOT</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Switched to DOT</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Recommended B&amp;V screening</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Prescription</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Replied on time</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Repeated late</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Rx Rifadin</strong></td>
<td></td>
</tr>
<tr>
<td><strong>mg</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Rx Ethambutol</strong></td>
<td></td>
</tr>
<tr>
<td><strong>mg</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Rx INH</strong></td>
<td></td>
</tr>
<tr>
<td><strong>mg</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Rx Pyrazinamide</strong></td>
<td></td>
</tr>
<tr>
<td><strong>mg</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Rx Other</strong></td>
<td></td>
</tr>
<tr>
<td><strong>mg</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Due date next prescription</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Other medication</strong></td>
<td></td>
</tr>
<tr>
<td><strong>HIV outcome documented</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Hepatitis outcome documented</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Rx other</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Chest X-ray date</strong></td>
<td></td>
</tr>
<tr>
<td><strong>New contacts identified</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Assessment date</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Assessor: Name</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Designation</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Signature</strong></td>
<td></td>
</tr>
</tbody>
</table>
Form 3: TB contact investigation/risk assessment

- **Clinic n°:**
- **Case manager:**
- **Consultant:**
- **Data start treatment:**
- **DOB:**

**Define investigation**
- Identify secondary cases
- Contact investigation in institutional setting (*refer HPU)
- Date referred to HPU:
- HPU ref No:
- Identify source case(s) AND secondary cases
- Community investigations
- Details of education/ workplace:

**Date 1st assessed:**
- **Assessed by:**
- **Where assessed:**

**Infectivity risk assessment - factors specific to index case**
- PTB sputum smear +ve
- PTB sputum smear -ve
- Laryngeal TB
- Cavitation on CXR
- Sputum culture +ve
- Bronch. washings smear +ve
- Induced sputum smear +ve
- Sputum PCR +ve
- Cough on presentation
- MDR TB

- Estimated period of infectivity:
- Last date school/work:
- Number AFB seen:
- Overall infectivity risk assessed as:
  - High (PTB smear +ve &/ cavitating)
  - Medium (PTB culture +ve & cough)
  - Low (PTB culture -ve & extra-pulmonary)

**Exposure risk assessment:**
- *If no contacts identified or less than 5 contacts for PTB, comments:

**Please use sheets provided to enter contact details (see overleaf)**

**Comments:**

**Final audit**
- Total no. of contacts identified:
- I No. contacts screened
- J No. non-attenders
- K No. contacts Mantoux/IGT +ve
- L No. contacts commenced on preventive Rx
- M No. contacts commenced on TB Rx
- N All high risk contacts seen within 2 weeks

**Completed audit by:**
- **(Name):**
- **Designation:**

**Signature:**
- **Date:**
### Form 3: TB contact investigation/risk assessment (reverse)

<table>
<thead>
<tr>
<th>Contact list:</th>
<th>Index case name:</th>
<th>LTBR No.</th>
<th>Final Outcome:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name:</td>
<td></td>
<td></td>
<td>No evidence of active TB</td>
</tr>
<tr>
<td>DOB:</td>
<td></td>
<td></td>
<td>Not TB Atypical – REFERRED</td>
</tr>
<tr>
<td>Relationship to index:</td>
<td></td>
<td></td>
<td>Active TB – TREAT</td>
</tr>
<tr>
<td>Date last contact:</td>
<td></td>
<td></td>
<td>Latent TB – TREAT</td>
</tr>
<tr>
<td>Contact risk code:</td>
<td></td>
<td></td>
<td>Latent TB – Not treated/declined</td>
</tr>
<tr>
<td>Date referred:</td>
<td></td>
<td></td>
<td>LFU prior to diagnostic decision</td>
</tr>
<tr>
<td>Date screened:</td>
<td></td>
<td></td>
<td>BCG to be given</td>
</tr>
<tr>
<td>Comments:</td>
<td></td>
<td></td>
<td>Other:</td>
</tr>
<tr>
<td>Address 1:</td>
<td></td>
<td></td>
<td>No evidence of active TB</td>
</tr>
<tr>
<td>Address 2:</td>
<td></td>
<td></td>
<td>Not TB Atypical – REFERRED</td>
</tr>
<tr>
<td>Tel:</td>
<td></td>
<td></td>
<td>Active TB – TREAT</td>
</tr>
<tr>
<td>GP:</td>
<td></td>
<td></td>
<td>Latent TB – TREAT</td>
</tr>
<tr>
<td>Hospital No:</td>
<td></td>
<td></td>
<td>Latent TB – Not treated/declined</td>
</tr>
<tr>
<td>LTBR No:</td>
<td></td>
<td></td>
<td>LFU prior to diagnostic decision</td>
</tr>
<tr>
<td>BCG to be given:</td>
<td></td>
<td></td>
<td>Other:</td>
</tr>
</tbody>
</table>

**Note:** This form is meant to document the contact investigation and risk assessment for TB. It includes fields for the contact details, index case name, and LTBR No. for each contact. The final outcome section includes options for no evidence of active TB, not TB atypical, active TB, latent TB, latent TB not treated/declined, LFU prior to diagnostic decision, and BCG to be given, with additional space for other outcomes.
Form 4: Directly observed therapy (DOT)

<table>
<thead>
<tr>
<th>TB Medication</th>
<th>Rifater</th>
<th>Rifampicin</th>
<th>Isoniazid</th>
<th>Pyrazinamide</th>
<th>Ethambutol</th>
<th>Pyridoxine</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Month/date</td>
<td>Dose</td>
<td>Dose</td>
<td>Dose</td>
<td>Dose</td>
<td>Dose</td>
<td>Dose</td>
<td>Dose</td>
</tr>
<tr>
<td>1</td>
<td>Frequency</td>
<td>Frequency</td>
<td>Frequency</td>
<td>Frequency</td>
<td>Frequency</td>
<td>Frequency</td>
<td>Frequency</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>3</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>4</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>5</td>
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Appendix 2: Outreach and safe practice

Source: information adapted from Find&Treat Outreach Safety Protocol developed by Joe Hall (TB Social Worker) and Al Story (Clinical Lead)

Community outreach is an essential activity for frontline staff working in tuberculosis control. It is important that workers who undertake home visits and outreach in the community feel safe when carrying out their duties.

Statistics show that there is a very low risk of attacks on outreach staff. Common sense, a raised awareness of potentially difficult situations and taking simple precautions will reduce any potential risk even further. It is important that all staff complete relevant in-house training, such as courses in personal safety or dealing with difficult, dangerous and disturbing behaviour.

Safe practice procedures should be followed when preparing, during and at the end of any home visits or community outreach activities. Under no circumstances should workers compromise their safety. If you feel unsafe at any point remove yourself from the situation.

1. Before

Before carrying out a home visit to an unknown patient, it is important to gather as much information as possible about the patient and the location you are visiting. Useful sources include: the referrer, GPs, discharge co-ordinators, colleagues, and other allied agencies. Use this information to assess any potential risks. Points you should consider include:

- patient’s background (i.e. increased risk of aggression/violence due to alcohol/drug use or mental ill-health)
- nature of visit (i.e. could the reason for the visit cause the patient serious distress or potentially incite extreme behaviour)
- location/type of accommodation (i.e. is it a flat, bedsit or hostel in an ‘at risk’ area?). It may be appropriate to arrange to meet a patient who lives in shared accommodation, such as squats, in a neutral location such as a GP practice, community centre or café.

If planning to visit a patient in the community for the first time, it is often useful to do a joint visit with a professional already known to the person (i.e. drug worker, community psychiatric nurse (CPN), housing key worker).

Any staff undertaking community outreach activities should have a mobile telephone provided by their employer. It is your responsibility to ensure that your telephone is charged and functioning and that your contact number is known to your manager, team members and other relevant co-workers. You must carry your identity card with you at all times when undertaking outreach in the community.

Always keep a diary record of any planned visits, preferably in a shared calendar that can be viewed by your team. Always inform a team member shortly before you enter a property that is not known to you. Estimate the time that the visit will take and tell your team member to expect a call from you in a specified number of minutes and to call you if they do not receive your call.

Make every effort to inform the patient that you are planning to visit them prior to the visit. This may not be appropriate for patients who are deliberately evading services. In this instance, advice from the local HPU or specialist outreach service should be sought.

2. During

As you approach the location, assess the situation to determine if anything is unusual or if anything makes you feel uneasy. Do not enter areas or properties if you have any doubts or concerns.

If any person answering the door gives you cause for concern (e.g. they appear very intoxicated, high or aggressive in nature) do not enter and/or if appropriate speak with the person on the doorstep. It is not usually appropriate to disclose the purpose of your visit to an unknown third party. Be tactful, show your identity card and request to speak with, or find out, the whereabouts of the person you are trying to contact. If you are unsure, you should withdraw immediately from the area and inform your line manager, document findings in notes and, where appropriate, complete an incident report form.

3. After

Check in with your manager, team members or other relevant co-workers at the end of the visit. Make specific arrangements to check in if the visit is likely to continue after normal hours.

Document the visit, including the time of arrival and departure, according to local practice.

Regularly review procedures for outreach in MDT meetings and update information on patients whenever there is a change in circumstances or new information obtained from external agencies.

Remember – Your personal safety is paramount.
Appendix 3: Methadone and anti-tuberculosis treatment containing rifamycins

**Principles**

Serum methadone levels can be markedly reduced by rifampicin (rifampin), and withdrawal symptoms have occurred in some patients. Methadone levels in the plasma can fall by up to 50 per cent if on rifampicin. Rifabutin appears to interact similarly, but to a lesser extent. The serum levels of other opioid substitutes may also be reduced by rifampicin.

There will often need to be a significant increase in methadone dose to counterbalance the effects of anti-tuberculosis drugs (especially rifampicin). Likewise, for those on buprenorphine treatment, the daily dose may need to be increased in response to the anti-TB treatment.

There is no good pharmacokinetic data to be able to provide specific guidance on the increased doses of opioids needed. Hence, the dose of methadone/buprenorphine should be increased so as to abolish any emergent withdrawal symptoms and signs. This is done by titrating the dose in response to clinical assessment of any withdrawal features with a view to achieving an adequate final dose that also re-establishes the patient.

In the community this might well be carried out by the prescribing clinician who is managing the patient's opiate substitution treatment; while for inpatients it may well be carried out by TB clinicians taking the advice of the specialist addiction service. Whatever the arrangement locally, it is important that there is agreement on who is managing this element.

The speed of the titration will mainly depend on the level of clinical supervision that is feasible and the severity of withdrawal syndrome observed. Additional doses can be given more than once a day in inpatient settings and in the presence of clear continued withdrawals. Greater caution is required for more frail patients and for those remaining in the community, but close monitoring can mitigate the risks. The appropriate concerns about risk of overdose from opioid treatment must be balanced with the risks of return to illicit drug use if inadequately treated.

Care is needed to monitor ongoing compliance with rifamycins. When the dose of anti-tuberculous treatments is again reduced and stopped, care is needed also to reduce methadone (or buprenorphine) dosage to prevent overdose; although this can usually be carried out more slowly.

There is consensus that methadone is only given if on DOT and the taking of rifampicin is established, given the risk of overdosing if rifampicin is not taken.

(a) Rifabutin

A study in 24 HIV-positive patients taking methadone, found that rifabutin 300mg daily for 13 days had only minimal effects on the pharmacokinetics of methadone. However, 75 per cent of the patients reported at least one mild symptom of methadone withdrawal, but this was not enough for any of them to withdraw from the study. Only three of them asked for, and received, an increase in their methadone dose. The authors offered the opinion that over-reporting of withdrawal symptoms was likely to be due to the warnings that the patients had received.1

(b) Rifampicin (Rifampin)

The observation that former diamorphine (heroin) addicts taking methadone complained of withdrawal symptoms when given rifampicin, prompted a study2 in 30 patients taking methadone. Withdrawal symptoms developed in 21 of the 30 patients within one to 33 days of starting rifampicin 600 to 900 mg daily and isoniazid daily. In six of the seven patients most severely affected, the symptoms developed within one week, and their plasma methadone levels fell by 33 to 68 per cent. Of 56 other patients taking methadone with other anti-tubercular treatment (which included isoniazid but not rifampicin), none developed withdrawal symptoms.2-4 Other cases of this interaction have been reported.5-9 Some patients needed two to threefold increase in their methadone dose, while taking rifampicin, in order to control the withdrawal symptoms.5-2,9

**Mechanism**

Rifampicin is a potent enzyme inducer, which increases the activity of the intestinal and liver cytochrome P450 isoenzymes concerned with the metabolism of methadone, resulting in a marked decrease in its levels.10 In four patients in the study cited, the urinary excretion of the major metabolite of methadone rose by 150 per cent.2 Rifabutin has only a mild enzyme-inducing effect and therefore the effects are not as great.
Importance and management

The interaction between methadone and rifampicin is established, adequately documented and of clinical importance. The incidence is high: two-thirds (21) of the narcotic-dependent patients in one study developed this interaction, 14 of whom were able to continue treatment. Withdrawal symptoms may develop within 24 hours. The analgesic effects of methadone would also be expected to be reduced. Concurrent use need not be avoided, but the effects should be monitored and appropriate methadone dose increases (as much as two to threefold) made where necessary.

Adherence to anti-tuberculosis therapy in drug-misusing patients prescribed substitute opioids may be significantly improved if the consumption of both medicines is supervised together. However, the effects of the concurrent use of drugs for anti-tuberculosis and opioid substitution therapy should be monitored and appropriate opioid dose increases made where necessary. When the dose of anti-tuberculosis treatments is again reduced and stopped, care is also needed to reduce methadone (or buprenorphine) dosage to prevent overdose.

Rifabutin appears to interact to a much lesser extent than rifampicin, so that fewer, if any, patients are likely to need a methadone dose increase.

References for Appendix 3

Appendix 4: Managing treatment interruptions

There are no controlled studies evaluating regimens addressing this clinical situation. The recommendations from the ATS are empiric and based on best perceived practice. The figure below outlines the ATS suggested protocol.

Figure: Managing treatment interruptions

- Interruption in Initial Phase
  - Duration of interruption
    - <14 days: Continue treatment; If total not completed in 3 months restart from beginning
    - ≥14 days: Restart from the beginning
  - % planned doses in continuation phase completed
    - <80%: Duration of interruption
      - <3 months [B]: Continue treatment [C] If total not completed in 3 months restart from beginning
      - ≥3 months [B]: Restart 4-drug regimen from the beginning [D]
    - ≥80%: Additional treatment may not be necessary

[A] Patients who were initially smear positive should receive additional therapy
[B] Recheck smears and cultures (if positive, check drug susceptibility results). Start DOT if not already being used
[C] If repeat culture is positive, restart four-drug regimen while waiting for drug susceptibility results. If repeat culture is negative, continue therapy to complete regimen within nine months of original start date.
[D] If repeat culture is positive, restart four-drug regimen while waiting for drug susceptibility results. If repeat culture is negative, consider stopping therapy if patient has received a total of nine months of therapy.
The principles guiding an approach

- When the interruption occurred is a key arbiter, i.e. initiation or continuation phase. Initiation phase breaks are more crucial (given that there are likely to be more viable organisms and therefore may warrant a more robust restart).

- The length of the lapse in treatment is important but the regime reintroduced is dependent on when the break occurred (e.g. restart all four drugs if the break is more than two weeks at induction phase and three months at continuation phase).

- Always attempt to obtain samples in any break of treatment to guide sensitivity – any positive cultures mean that full treatment has to be completely restarted (i.e. ignore all previous dosing).

- Other factors to take into account include the potential for immunosuppressive states (e.g. HIV), where rapid replication may occur despite short interruptions in treatment – i.e. consider full retreatment even if below the standard time criteria.

- A ‘full’ course of therapy (completion of treatment) is determined more accurately by the total number of doses taken, not solely by the duration of therapy (e.g. six-month daily regimen given seven days/week – should consist of at least 182 doses of INH and RIF, and 56 doses of PZA). Aim to get a minimum of six months of drug doses over a maximum of nine months.

- If the patient has completed over 80 per cent of the planned course, cessation of treatment can be considered but only in initial smear negative and non-cavitary cases.

The following approach (summarised in Figure: Managing treatment interruptions) is modified from the New York City Bureau of Tuberculosis Control Clinical Policies and Protocols, and is presented as an example.

“If the interruption occurs during the initial phase of treatment and the lapse is 14 days or more in duration, treatment should be restarted from the beginning. However, if the lapse is less than 14 days, the treatment regimen should be continued. In either instance the total number of doses targeted for the initial phase should be given. If the interruption in treatment occurs during the continuation phase after the patient has received more than 80 per cent of the planned total continuation phase doses given by DOT, further treatment may not be necessary if the patient’s sputum was AFB smear negative on initial presentation. However, for patients who were smear positive initially, continued treatment to complete the planned total number of doses is warranted. If the patient has received less than 80 per cent of the planned total doses and the lapse is three months or more in duration, treatment should be restarted from the beginning. If the lapse is less than three months in duration, treatment should be continued to complete a full course. At the time the patient is returned to treatment sputum cultures should be obtained and repeat drug susceptibility testing performed. If the cultures are still positive, the treatment regimen should be restarted. If sputum cultures are negative the patient could be treated as having culture-negative tuberculosis and given an additional four months of combination chemotherapy. Regardless of the timing and duration of the interruption, DOT should be used. If the patient was already being managed with DOT, additional measures will be necessary to ensure completion of therapy. Consultation with an expert is recommended to assist in managing treatment interruptions.”

References for Appendix 4

Appendix 5: Drug therapy – adverse effects requiring clinical action

As is true with all medications, TB treatment can cause adverse effects in some patients. This section covers the important adverse effects to standard TB treatment and is aimed at non-clinical professionals, carers of TB patients and persons who have been trained to act as DOT observers.

Named case managers should provide all TB patients and their carers, including DOT observers, with education and information leaflets on the commonly reported adverse effects to TB treatment.

Patients and their carers, including DOT observers, should report any of the following adverse effects. This should happen on the same day, to the named case manager who will inform the treating physician, provide advice on whether to continue or stop the treatment and make arrangements for the patient to be reviewed urgently (ideally within one working day).

1. Trouble breathing – stop treatment and seek urgent medical help.
2. Yellow skin or eyes or very dark-coloured urine – stop treatment and seek urgent medical help.
3. Stomach pain, nausea or vomiting.
4. Any eye problems: vision changes, blurring, colour blindness, trouble seeing, or eye pain.
5. Pain or swelling in the face or joints.
6. Numbness, pain, or tingling in hands or feet.
7. Skin rash, severe itching or hives.
8. Headache or dizziness.
9. Fever or chills.
10. Unusual tiredness or loss of appetite.
Appendix 6: Simple guide to information sharing

Information sharing with consent

If you have a person's consent then it is ok to share personal information about them with other health and social care professionals. Obtaining explicit consent for information sharing is best practice in most situations but it is not always possible.

The seven golden rules for information sharing

Where you are considering sharing information with other health and social care professionals but you do not have the person's consent (and there isn't an information sharing protocol in place to govern that exchange of information), follow these golden rules. This should ensure that you strike the correct balance between protecting a person's privacy, protecting the public, and ensuring that fellow practitioners have the information they need to deliver services.

1. **Remember that the Data Protection Act is not a barrier to sharing information** but provides a framework to ensure that personal information about living persons is shared appropriately.

2. **Be open and honest** with the person from the outset about why, what, how and with whom information will, or could be shared, and seek their agreement, unless it is unsafe or inappropriate to do so.

3. **Seek advice** if you are in any doubt, without disclosing the identity of the person where possible.

4. **Share with consent where appropriate** and, where possible, respect the wishes of those who do not consent to share confidential information. You may still share information without consent if, in your judgement, that lack of consent can be overridden in the public interest. You will need to base your judgement on the facts of the case.

5. **Consider safety and wellbeing.** Base your information-sharing decisions on considerations of the safety and wellbeing of the person and others who may be affected by their actions.

6. **Necessary, proportionate, relevant, accurate, timely and secure.** Ensure that the information you share is necessary for the purpose for which you are sharing it, is shared only with those people who need to have it, is accurate and up-to-date, is shared in a timely fashion, and is shared securely.

7. **Keep a record** of your decision and the reasons for it — whether it is to share information or not. If you decide to share, then record what you have shared, with whom and for what purpose.

Glossary

**Case management** – Case management is the comprehensive follow-up of a suspected or confirmed TB case. It requires a collaborative, multidisciplinary approach. Case management commences as soon as possible after a suspected case has been discovered to ensure a timely diagnostic conclusion.

**Case manager** – Standard and enhanced case management is overseen by a case manager who will usually be a specialist TB nurse or (in low-incidence areas) a nurse with responsibilities which include TB. Dependent upon the patient’s particular circumstances and needs, case management can also be provided by appropriately trained and supported non-clinical members of the TB multidisciplinary team.

**Directly observed therapy (DOT)** – A trained health professional, or responsible lay person supported by a trained health professional, provides the prescribed medication and observes the patient swallowing every dose.

**Enablers** – These are methods of helping someone to overcome barriers to completing diagnostic investigations and TB treatment. Examples of barriers that may need to be overcome include: transport, housing, nutrition and immigration status.

**Enhanced case management (ECM)** – Provided when a patient has clinically or socially complex needs. Enhanced case management commences as soon as TB is suspected. It includes directly observed treatment (DOT) in conjunction with a package of supportive care tailored to the patient’s needs.

**Hard-to-reach groups** – Adults, young people and children, whose social circumstances, language, culture or lifestyle, or those of their parents or carers, make it difficult to:
  - recognise the clinical onset of TB
  - access diagnostic and treatment services
  - self-administer treatment (or in the case of children and young people, have treatment administered by a parent or carer)
  - attend regular appointments for clinical follow-up.

**High incidence** – High incidence includes any country or area with an incidence of more than 40 per 100,000 per year, as listed by the Health Protection Agency (go to [www.hpa.org.uk](http://www.hpa.org.uk) and search for ‘WHO country data TB’ for country data or look up the incidence for each UK district).

**Homelessness** – This definition incorporates the issue of overcrowded and substandard accommodation and goes beyond statutorily homeless. People with one or more of the following should be considered homeless:
  - share an enclosed air space (for non-occupational reasons) with individuals at high risk of undetected active pulmonary TB (persons with a history of rough sleeping, hostel residence or substance misuse)
  - without the means to securely store prescribed medication
  - without private space in which to self administer TB treatment
  - without secure accommodation in which to rest and recuperate in safety and dignity for the full duration of planned treatment.

**IGRA (Interferon-gamma release assays) test** – A blood test carried out after, at the same time as, or instead of the Mantoux test. If the result is positive, more tests are undertaken to see if the person has TB.

**Incentives** – Incentives are small rewards that encourage patients with both suspected and confirmed TB to attend for community TB screening, out-patient follow-up and directly observed therapy appointments.

**Index case** – The first case of TB in a family or another defined group to come to the attention of the medical investigator.

**Latent TB infection (LTBI)** – LTBI means someone is infected with mycobacteria of the *M. tuberculosis* complex, where the bacteria are alive but not currently causing active TB.

**Lost to follow-up (LFU)** – TB patients are defined as lost to follow-up if they have not completed a planned course of TB treatment and:
  - cannot be contacted within 10 working days of their first missed outpatient appointment (SAT)
  - cannot be contacted within 10 working days of their first missed DOT appointment (daily or three times per week DOT).

**Multidisciplinary (MDT) TB team** – A team of professionals with a mix of skills to meet the needs of someone with TB who also has complex physical and psychosocial issues. The team will meet regularly to plan, implement and evaluate a care pathway. Specific members should be able to meet to deal with urgent issues. Team members will include a social worker, voluntary sector and
local housing representatives, TB lead physician and nurse, a case manager, a peer supporter/advocate and a psychiatrist.

**Multi-drug-resistant TB (MDR TB)** – TB that is resistant at least to isoniazid (INH) and rifampicin (RMP).

**Non-adherence**
- SAT patients are considered non-adherent after two consecutive missed out-patient appointments irrespective of the amount of medication that they potentially hold.
- DOT patients on daily therapy are considered non-adherent after missing three daily doses or two doses per week in two consecutive weeks.
- DOT patients on three times per week therapy are considered non-adherent after two or more doses are missed within two weeks.

**Outbreak investigation** – An epidemiological investigation into the occurrence of disease in a population to identify transmission sources and prevent additional cases.

**Peers** – Peers are members of the affected community who may have experienced TB. They are often in a good position to help convey, with empathy, the need for screening or treatment. They may be recruited and supported to communicate health messages, assist with contact investigations or screening and to offer people support while they are being tested or treated.

**Return to service (RTS)** – The process of locating LFU suspected and confirmed TB cases and re-engaging them with diagnostic and treatment services. RTS activities are arranged locally by TB MDTs in collaboration with health protection staff or specialist outreach teams such as Find&Treat in London. The TB MDT should make a decision whether or not to initiate RTS activities within five working days for:
- any patient on TB treatment not contacted within 10 working days of their first missed appointment
- any medically assessed person with signs or symptoms compatible with active pulmonary TB who has not attended for planned investigations
- any child (under 16 years of age) who has been medically assessed and referred, but has not attended for planned investigations.

**Self-administered treatment (SAT)** – The patient takes responsibility to collect, organise and administer their TB medication.

**Substance misuse** – Substance misuse is defined as intoxication by – or regular excessive consumption of and/or dependence on – psychoactive substances, leading to social, psychological, physical or legal problems. It includes problematic use of both illegal and legal drugs (including alcohol) in such a way as to affect the person’s ability to recognise the clinical onset of TB, access diagnostic and treatment services, self-administer TB treatment and/or attend regular appointments for clinical follow up.

**TST (Tuberculin Skin Test)** – This test involves intra-dermal injection of tuberculin and is now performed in the UK using the Mantoux method which has now replaced the multiple-puncture Heaf method. Tuberculin is a poorly-defined, complex mixture of antigens which can cause a hypersensitivity reaction resulting in a raised area of skin (induration) among people with previous exposure to mycobacteria including BCG immunisation.

**Virtually observed therapy (VOT)** – Using internet-based technologies to enable every dose of medication to be ‘virtually’ observed by a trained provider remotely.
References


8 A recommendation of the Canadian Thoracic Society’s Tuberculosis Committee.


Notes
The RCN represents nurses and nursing, promotes excellence in practice and shapes health policies

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