

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## Centre for Public Health

### Information, education or other support used in practice to support the diagnosis, treatment and management of TB: a systematic review

#### Overview

##### *Review aims and approach*

This brief report summarises evidence on UK-related practice on information, education or other support offered to support testing, diagnosis, treatment and management of tuberculosis (TB).

The report has been developed to inform the Guideline Development Group (GDG) in its update of Clinical and Public Health guidelines on tuberculosis, as outlined in Centre for Clinical Practice TB (update) review question 'NN' - that is:

What information, education or other support-based interventions are currently used in practice to support the diagnosis, treatment and management of TB?

Addressing this question provides supplementary evidence to review question 'OO' on the effectiveness of information, education or support for the diagnosis, treatment and management of TB.

This research was undertaken by the Centre for Public Health, in accordance with the [Methods for the development of NICE public health guidance](#) (Third Edition).

Systematic review methods were applied including searches of bibliographic databases, websites and consideration of submissions in response to the NICE Call for Evidence (July 2013) followed by the application of explicit inclusion and exclusion criteria. Details of the searching and methods for evidence selection are provided in the protocol (presented to the [GDG meeting on September 2013](#)).

This resulted in 22 records being selected as eligible for more detailed review, including academic papers, evaluation reports and leaflets. Following further review, a collection of 6 records was created by selecting the more detailed and likely applicable descriptions of practice. These records are highlighted as being of particular note and potential interest to the GDG.

## ***Practice identified***

Broadly, the following characteristics were observed in the included studies:

- Awareness raising, linked to annual, national campaigns. Practice Nurses expressed a need for more information on how to raise awareness in the communities in which they practice.
- Information needs around medication and nutrition for patients and a mix of general and more targeted information for providers. A mixture of preferences for mode and frequency of provision were reported for providers, including *ad hoc* arrangements.
- Education practice including peer review against national guidelines, the inclusion of TB content in medical training, but 'patchy' provision of training for GPs. Survey of users' experience suggested GP awareness and a low 'index of suspicion' of TB may be topics to address through education.
- Establishment of TB networks was reported for 8 major UK cities.
- Social care/outreach workers supporting patients as well as 'freeing-up' clinical staff. Skill mix for these roles spanned clinical, social health, management, education and 'administrative' (including research) skills.
- Support included the provision of key workers for each person with TB; educational outreach; piloting of a social outreach model of care involving link working between providers as well as between provider and service users. Support from link workers included establishing trust, assistance with housing/accommodation, accessing benefits and addressing the impact of the psychosocial aspects of TB.

Practice was generally reported for London, but there were also some data on 7 other large UK cities and nationally. Descriptions were largely from surveys and evaluations including service, worker and user experience. Reports selected as examples were completed between 2008 and 2013. Some aspects of practice were *inferred* (by the reviewers) from reports of worker or service user experience/views.

## **Results**

### ***Evidence flow***

Title and abstracts of 2764 records were screened to be excluded at this stage or retrieved as full text. This resulted in retrieval of 158 (8 records were not available/not retrieved) items for further review and subsequent inclusion of 22 items.

A summary of the [evidence flow](#) and reasons for exclusion are presented in the appendices.

Of the 144 exclusions, these were assessed not to describe: practice (80); information, education or support (36) or a population of interest (13). There were 15 'other' exclusions (including 12 which were not available, a thesis or duplicate).

### ***Included evidence***

A brief description of each of the 22 records is presented in the main evidence table accompanying this report.

The following 6 records were selected to be reviewed in more detail:

1. Pan-London tuberculosis services: a service evaluation (Belling, 2012)
2. Tuberculosis in UK cities: workload and effectiveness of tuberculosis control programmes (Bothamley, 2011)
3. Listening to those on the frontline: service users' experiences of London tuberculosis services (Boudioni, 2011)
4. Establishing a new service role in tuberculosis care: the tuberculosis link worker (Craig, 2008)
5. TB awareness activities conducted among TB clinics across the UK 2009 (TB National Knowledge Service, 2013)
6. Help reverse 20 years of rising Tuberculosis: Primary care practitioner survey UK 2010 (TB National Knowledge Service, 2013)

Each of these examples of practice are summarised in the next pages.

## Practice examples

	Pan-London tuberculosis services: a service evaluation (Belling et al, 2012)
Awareness/ I/E/S foci	Support: <ul style="list-style-type: none"> <li>• Descriptions of social care/outreach workers role and skill mix required</li> <li>• Identifying patients with complex needs</li> <li>• Description of support offered</li> </ul>
Settings/ population	London (with some non-London contributors) Service provider views
Topics/ content	Evidence of medical and non-medical TB professionals reporting social care and outreach staff being of particular assistance in areas with high levels of people with social support needs – ‘freeing up’ nursing staff, while supporting patients.  Skill mix requirements of those providing the service ( <i>thus potential areas for education/training</i> ) were reported to include: clinical, social health (advocacy, housing, dependency/addiction, immigration, treatment support), management (leadership, staff management, budgetary), educational (training, health promotion) and ‘administrative’ skills (office management, data collection, audit collection).
Media/ methods Applicability	Service evaluation and audit (including interviews, document review) London based, 23 participants including views across a range of services. Published 2012.

	Tuberculosis in UK cities: workload and effectiveness of tuberculosis control programmes (Bothamley et al, 2011)
Awareness/ I/E/S foci	Broad ranging evaluation of TB services, with audit against TB Action Plan, including professional training, awareness raising, provision of free medication and outreach and link/key worker roles.
Settings/ population	UK – 8 cities (Birmingham, Bradford, Glasgow, Leeds, Leicester, London, Manchester, Sheffield)  PCTs or TB clinics with greater than 100 cases per year  Service level, worker and service user data reported.
Topics/ content	Awareness raising linked to World TB day was reported for around two thirds of cities responding (5/8, less so for clinics with fewer nurses).  Practice relating to service provider education/development in cities surveyed included peer review against NICE guidance in half, all respondents' medical education included TB but GP training was 'patchy' and most had links with HIV services. All cities reported having an established TB Network.  Support to service users was reported, such as wide provision of free medication, allocation of a key worker for each TB case. Key workers were considered to include a TB Nurse (responsible for contacts and treatment) or outreach/community health worker for people who were 'hard-to-reach'. Less educational outreach was reported for Birmingham, Bradford, Manchester and Sheffield. Where staffing resources are stretched (such as beyond the 1:40 ratio) assistance with complex needs, educational outreach and screening new entrants was limited as nurses focus on contract tracing aspects of their role.
Media/ methods Applicability	Survey of TB related activity and audit; published report  UK – spanning 8 cities and multiple services; 2011

	Listening to those on the frontline: service users' experiences of London tuberculosis services (Boudioni et al, 2011)
Awareness/ I/E/S foci	Survey of service users understanding ( <i>thus indicating information effectiveness</i> ); information needs; experience of service providers/GPs ( <i>thus indicating training needs</i> ); views on communication and social-emotional impact of TB ( <i>thus indicating support needs</i> ) and 'further' support needs.  <i>Service users' views are presented to GDG to as a report of their experience of recent practice.</i>
Settings/ population	UK – London  Participants were treated through hospital for 6-13 months as inpatients, outpatients (receiving DOT) or 'home visits for complex cases'
Topics/ content	Reported barriers include GP awareness /'low index of suspicion of TB' and the attitude of some health professionals (though all respondents reported satisfaction with the care provided by TB health professionals). These may suggest areas to be addressed in professional education/development.  Respondents indicated that information provision on medication side effects, diet and nutritional status could be improved. Two (of 10) respondents reported not appreciating the importance of taking the medication as instructed.  A range social and emotional effects on people with TB were reported. Most compared TB to other conditions when diagnosed with TB (such as HIV). Fear of dying from TB and concern that the infection was life long and risked infecting others (some expressed 'feeling guilty') were also expressed. Impacts on work or education; socialising and negative reaction of family members (improved with education) were also reported.  Mixed views were expressed on nurses providing help with broader social support (including housing, financial support and travel) – some considered this would be useful, while others noted this role was 'separate' from that nurses where trained for and they are busy with their clinical duties. Managed accommodation by TB-aware professionals was identified as a positive aspect of TB service experience.  <i>Authors suggest TB services at local, national and international levels need to be more closely aligned with service users' complex needs.</i>
Media/ methods	Survey (using interviews) and thematic analysis of service users' experiences and satisfaction; published report
Applicability	UK – London; 10 users of DOT, 2011

	Establishing a new service role in tuberculosis care: the tuberculosis link worker (Craig et al, 2008)
Awareness/ I/E/S foci	<p>Support through social outreach model of care.</p> <p>Description of the roles of link workers and approaches to assessing and addressing 'social risk' factors that complicate treatment. Enabled by the integration of health and social care.</p> <p>Link working described that involved sharing of information, concerns and tasks.</p>
Settings/ population	<p>UK – London</p> <p>Patients referred to link worker. These patients were described as 'marginalised'/with challenging health and social care needs.</p>
Topics/ content	<p>Among the participants, reasons for referral to link worker (<i>thus indicate support needs</i>) included housing need (56%), welfare benefits (42%), immigration (29%) and 'clinical management' issues (28%) – a third were referred to other agencies.</p> <p>Link working encompassed more 'holistic approach to care', sharing of information, concerns and tasks.</p> <p>Communication between patient and care provider was described.</p> <p>Reported that link workers improved understanding of patient circumstances and were more likely to prioritise enabling approaches such as mobile X-ray and to assess and enable housing allocation.</p> <p>Evaluation tool used in study outlines components of the link worker model</p> <p>Risk referral tool outlines information collected by nurses at first contact</p> <p>Evaluation proforma outlines information to collect and feeds into profile of a service user's needs and directs link worker activities (<i>thus support need and provision</i>)</p> <p>Report suggests social outreach model provides opportunity for establishing trust with those most socially excluded; offering assistance with housing/accommodation; accessing entitled benefits and impact on psychosocial aspects of TB through enhanced social support.</p>
Media/ methods	Process evaluation of pilot model of care using a cohort of 100 patients and survey (interviews) of 8 agencies; published report
Applicability	UK – London; 100 patient cohort and 8 agencies; pilot project conducted 2003-2005, report published 2008

	TB awareness activities conducted among TB clinics across the UK 2009 (TB National Knowledge Service, 2013)
Awareness/ I/E/S foci	Information materials used and available to TB nurses to raise awareness and educate primary care staff.
Settings/ population	UK TB nurses and case workers
Topics/ content	<p>Provision of information to GPs – both targeted and general information provided.</p> <p>More likely in high incidence areas. Sessions delivered to GPs through standard talks, informal meetings, email and other means (such as leaflets/information resources), but generally <i>ad hoc</i> or annually.</p> <p>High prevalence areas tend to focus information provision to GPs rather than Practice Nurses. Where this is provided, mostly general TB information via variable delivery methods (such as standard talks, leaflets, World TB Day). Often <i>ad hoc</i> with some half yearly or annual sessions.</p> <p>Participants report time and resource constraints as main barrier to delivery of the service. Poor access to GPs reported in some areas.</p> <p>Agreement that a standard resource would be useful with a preference for electronic resource.</p>
Media/ methods	Survey (questionnaire) of TB nurses and case workers; unpublished - available online (produced by national agency, with programme board)
Applicability	UK; conducted 2009

	Help reverse 20 years of rising Tuberculosis: Primary care practitioner survey UK 2010 (TB National Knowledge Service, 2013)
Awareness/ I/E/S foci	Training and development needs of GPs and Practice Nurses
Settings/ population	UK - England GPs and Practice Nurses
Topics/ content	<p>Diagnosis – GPs had preference for information on tests for diagnosing TB; Nurses had a preference for information on all aspects of TB.</p> <p>Management – GPs had an information requirement for all aspects of TB management; nurses in particular wanted information on treatments and social aspects of TB management. Both groups interested in information on undocumented migrants.</p> <p>Laboratory-related information – minority of respondents identified a need. Preference for general information.</p> <p>Public health measures – all welcomed information on effectiveness of BCG and screening of high risk groups. Also requirement for information about cluster/outbreak investigations; surveillance; epidemiology and contact tracing.</p> <p>GPs preferred updates delivered in the format of guidelines, followed by web-based tutorials, self-study modules. Nurses had a preference for half day educational events, off site presentations. Annual basis was the preferred option for receiving information, followed in preference by an <i>ad hoc</i> basis.</p> <p>GP – majority of comments related to awareness raising, diagnosis and referral pathways. Emphasis on quality of communication and ease of access was noted in relation to referral pathways. Needs for information on local TB incidence/high risk groups was also reported.</p> <p>Practice nurses – mostly commented on how to raise awareness with their community and referral pathways. Noting need for clear information on signs and symptoms of TB, more local information about referral pathways.</p>
Media/ methods  Applicability	<p>Survey (questionnaire) of primary care practitioners (GPs and Practice Nurses); unpublished - available online (produced by national agency, with programme board)</p> <p>UK; conducted 2010</p>

## Appendices

### Evidence flow

Stage	Number of records	Description
Databases	3150	Results of searches of bibliographic databases and websites (including the <a href="#">NICE SLP</a> ) and the NICE call for evidence. Reported separately for each source.
Websites	322	
Call for evidence	40	
Combined search results	2764	De-duplicated results of searches
Screened	2764	Considered as title and abstract, for retrieval of full text for further consideration
Considered as full text	158	Considered as full text against inclusion/exclusion criteria
Included in brief report	22	Full text records satisfying the inclusion criteria

### Included items

Brief details of the 22 included 'descriptions of practice' are presented in the evidence table.

Bibliographic details are provided in the [references](#) section.

Awareness/I/E/S content Setting/focus Medium/methods	Main messages/practice points Applicability	Citation *practice example
<p><b><u>Information Education or support (I/E/S) content</u></b></p> <p>Supporting measures to detect TB in people entering the UK</p> <p>Improving information collection and exchange systems</p> <p>Support for hard to reach groups to negotiate the health and social care system</p> <p><i>Setting/focus</i></p> <p>UK and international comparisons (NYC, Netherlands)</p> <p><i>Medium/methods</i></p> <p>Non-systematic review/opinion piece</p>	<p>Reference made to:</p> <p>Mobile chest X-ray screening (<i>help address barriers/awareness in hard-to-reach groups</i>) used in London within a case control study showing reduced diagnostic delay.</p> <p>PHAST recommendations (see row 19 of this table)</p> <p>Units based in local authorities combing outreach with one stop clinic as in 'Dutch experience'.</p> <p>Improvement of treatment outcomes by ensuring safe and secure housing in rough sleepers/those with unstable housing.</p> <p>Applicability – overview/opinion piece; includes comparisons; 2011</p>	<p>Abubakar (2011)</p>
<p><b><u>I/E/S content</u></b></p> <p>Awareness raising activities reported by 45%, but when asked for examples – these were limited to informing population about changes in schools BCG vaccination policy.</p> <p>Some evidence of good practice and pro-active awareness raising.</p> <p>Survey explored themes within DH TB Action Plan, NICE guidance, TB toolkit</p> <p><i>Setting/focus</i></p> <p>UK – England</p> <p>Survey of TB service providers/commissioners</p>	<p>Survey exploring themes in explored themes within DH TB Action Plan, NICE guidance, TB toolkit.</p> <p>Awareness raising may be limited to information on BCG policy with a minority of providers/commissioners using proactive awareness raising.</p> <p>Applicability – Wide survey, sent to all PCTs (98 responses), but little I/E/S practice; conducted 2007</p>	<p>All Party Parliamentary Group on Global TB; BTS (2008)</p> <p>Putting tuberculosis on the local agenda</p>

Awareness/I/E/S content Setting/focus Medium/methods	Main messages/practice points Applicability	Citation *practice example
<p><i>Medium/methods</i></p> <p>Survey of PCTs</p>		
<p><b><u>I/E/S content</u></b></p> <p>Awareness raising activities reported by 1/3 of BTS TB Networks – 68% of respondents’ trusts members of a network</p> <p>Data systems were considered adequate by 1/2</p> <p><i>Setting/focus</i></p> <p>UK</p> <p>Survey of TB service providers</p> <p>Covered Awareness raising; Data systems</p> <p><i>Medium/methods</i></p> <p>Research – report</p> <p>Survey of British Thoracic Society (using TB leads contact database and BTS website) and RCN (using RCN TB Forum attendees and other methods)</p> <p>Aim of survey to assess implementation of ‘central policy’ and barriers to TB prevention and control</p>	<p>Survey of practice reported:</p> <p>From BTS (124, commonly consultants)</p> <p>1 clinical lead suggested they took on care for people with TB as a lone physician and were unable to attend regional or national TB meeting – due to workload (echoed in quote of another TB lead)</p> <p>1 quote stated that the ‘great interest’ in TB of selected physicians resulted in patients being provided with appropriate care (‘well sorted’) and suggested that ‘Low prevalence tends to makes GPs forget about the possibility of TB’</p> <p>From RCN (49, nurses)</p> <p>Quotes suggested coordination with GUM and access to patient records (results) would be helpful, as would sharing skills between HIV and TB services. It was also suggested that a dedicated paediatric nurse should focus on TB work [service not identified] and (in a separate quote) that there was lack of experience due to ‘sporadic nature of the cases’ and that ‘Expert resource is needed’.</p> <p>It was reported that the service ‘Need more patient focused care rather than disease focused’</p> <p>Reports of low implementation and awareness of TB policy in low incidence areas (BTS and RCN surveys)</p> <p>Awareness raising activities reported for 35% of BTS survey (14% in areas with 10 TB case/year)</p> <p>A set of recommendations are made, including:</p>	<p>All Party Parliamentary Group on Global TB; BTS; RCN TB Forum (2009)</p> <p>Turning UK TB policy into action: the view from the frontline</p>

Awareness/I/E/S content Setting/focus Medium/methods	Main messages/practice points Applicability	Citation *practice example
	<p>Trusts (Primary care) provide effective local awareness raising programmes in all high risk communities</p> <p>Adequate information in areas of low incidence – to support TB prevention and control</p> <p>Commissions (of primary care) should use the TB Commissioning Toolkit and national standards developed for use in managing commissioned services</p> <p>Report states that a third BTS survey intends to explore impact</p> <p>Applicability – UK wide survey, but limited I/E/S practice and abstraction (above) partly based on quotes from individuals, some breakdown of responses by TB incidence; conducted 2009</p>	
<p><b><u>I/E/S content</u></b></p> <p>Risk assessment tool to support clinical decision making about treatment adherence strategies</p> <p><i>Setting/focus</i></p> <p><i>UK – London TB Network</i></p> <p><i>Medium/methods</i></p> <p>Pilot project evaluation (north central London) using patient profile study across London cohort and London TB treatment register</p> <p>Research – published</p> <p>Abstract only</p> <p>Comparison between two arms (no control)</p>	<p>Risk assessment tool (which summarises characteristics into a risk of non adherence score) discriminates those patients who could receive self-administered therapy</p> <p>Applicability - Limited: abstract only, with relatively speculative findings and little I/E/S focus</p>	<p>Barrett (2011)</p> <p>Tuberculosis outcome following pre-treatment assessment for directly observed or self-administered therapy: Still room for improvement?</p>

Awareness/I/E/S content Setting/focus Medium/methods	Main messages/practice points Applicability	Citation *practice example
<p><b><u>I/E/S content</u></b></p> <p>Social care/outreach workers</p> <p>Performance management to indentify patients with complex needs</p> <p>Role of social care/outreach workers and reported principle support offered</p> <p><i>Setting/focus</i></p> <p>UK – London; (non-London contributors)</p> <p><i>Medium/methods</i></p> <p>Research – publication</p> <p>Service audit evaluation (including interviews, document review)</p>	<p>Social support</p> <p>Stated that involvement of social care/outreach workers role within TB services is new</p> <p>Evidence (process evaluation) of social outreach model in North London. Majority of needs were housing or welfare claims. 'Agencies involved reported 17 separate benefits of the link worker post, including additional time, intensive support, information sharing and disease awareness raising. Community education and resources were recommended to support link workers where nurses were unable to perform educational outreach and in this instance a nursing post was subsequently reconfigured to provide continued funding.'</p> <p>Evidence of medical and non medical TB professionals reporting social care and outreach staff being of particular assistance in areas of high levels of 'homeless patients, immigrants, refugees, asylum seekers, prison populations and patients with drug abuse, freeing up nursing staff from some of the most labour-intensive activities, while supporting difficult to reach patients in taking prescribed medication and staying on treatment'</p> <p>DOT and [attending to] social care needs most frequently mentioned as appropriate roles for non-medical staff. Benefits included relieving workload but also offer 'non-nursing' view, provide home vists and help with better understanding of patients and acess issues</p> <p>Some reported that although patients reported a preference that outreach workers share ethnic group, there was recognition an outreach worker cannot be representative of a full range of ethnicities in a service area</p> <p>The report noted a range of terms in use outreach worker, support worker, social care worker, social worker, case worker, link workers and advocates – some interchangably whether or not performing similiar tasks</p> <p>Skill mix requirements of those providing the service (<i>thus potential areas for education/training</i>) were reported to include:</p> <ol style="list-style-type: none"> <li>1. Clinical skills: assessment, nursing care, planning and research</li> <li>2. Social health skills: advocacy, housing, dependency/addiction, immigration, treatment support</li> </ol>	<p>Belling (2012)*</p> <p>Pan-London tuberculosis services: a service evaluation</p>

Awareness/I/E/S content Setting/focus Medium/methods	Main messages/practice points Applicability	Citation *practice example
	3. Management skills: leadership, staff management, budgetary 4. Educational skills: training, health promotion 5. Administrative skills: office management, data collection, audit collection Applicability – London based, 23 participants including views across a range of services; 2012	
<p><b><u>I/E/S content</u></b></p> <p>Use of World TB day to raise awareness of TB (though less likely for clinics with fewer nurses)</p> <p>Limitations of terms used to describe people of 'Black African' ethnic origin.</p> <p><i>Setting/focus</i></p> <p>UK – cities (Birmingham Bradford Glasgow Leeds Leicester London Manchester Sheffield)</p> <p>TB service evaluation</p> <p><i>Medium/methods</i></p> <p>Research – published</p> <p>Analysis of epidemiological data from TB services</p> <p>Audit against national guidance and TB action plan</p>	<p>Data presented for UK cities for 'workload' and 'effectiveness'</p> <p>Reported that:</p> <ul style="list-style-type: none"> <li>• TB networks established in all cities</li> <li>• Key worker for each TB case</li> <li>• Free treatment offered</li> <li>• Arrangements for HIV co-infection</li> </ul> <p>Less outreach in Birmingham, Bradford, Manchester and Sheffield.</p> <p>Key worker – a TB Nurse (contacts and treatment) or outreach/community health worker for people who are 'hard to reach' (description from methods)</p> <p>Indicates key worker for each TB case, provision of medications free of charge implemented widely across UK TB services</p> <p>Medical education included TB, but postgraduate provision for GPs was 'patchy'.</p> <p>Audit of services against national TB action plan – reported by city and included data on: peer review against NICE guidance, GP training, use of World TB day, educational outreach, medical school teaching on TB, frequency of TB Network meetings, named key worker, free medication, joint TB-HIV clinics, ratios of nurses/notification (1:40)</p> <p>Suggestion (in discussion) that social support varies for illegal immigrants and that decline in TB cases in NY linked to 'legal framework' to ensure collaboration and collaboration with</p>	<p>Bothamley (2011)*</p> <p>Tuberculosis in UK cities: workload and effectiveness of tuberculosis control programmes</p>

Awareness/I/E/S content Setting/focus Medium/methods	Main messages/practice points Applicability	Citation *practice example
	<p>'social organisations' offering support</p> <p>Findings in relation to nurse to case ratios suggest provision of DOT was 'patchy' and loss to follow-up was 'significantly greater' in areas with fewer nurses. The authors suggest where resources are stretched (such as where the 1:40 ratio is not achieved) assistance with complex needs, educational outreach and screening new entrants will be limited and nurses focus on contract tracing aspects of their role.</p> <p>Applicability – UK, spanning 8 cities and multiple services; 2011.</p>	
<p><b><u>I/E/S content</u></b></p> <p>In patient, outpatient and home visits for 'complex cases'</p> <p><i>Setting/focus</i></p> <p>UK – London</p> <p>TB service user experience</p> <p><i>Medium/methods</i></p> <p>Research – published</p> <p>Qualitative research – thematic analysis of TB service user interviews</p> <p>10 Users of DOT</p> <p>Experience of barriers and facilitators described</p>	<p>TB service users' experience indicate areas where I/E/S may be supportive or address areas for improvement. Barriers include GP awareness/'low index of suspicion of TB', the attitude of some health professionals and restricted referral routes were barriers.</p> <p>Information provision on medication side effects, diet/nutritional status</p> <p>A range social and emotional effects on people related to TB diagnosis are reported</p> <p>Views on support, including nurses providing help with broader social support are reported.</p> <p>Managed accommodation by TB-aware professionals was identified as a positive aspect of their TB service experience by some users</p> <p>Authors suggest TB services local, national and international need to be more closely aligned with service users' complex needs</p> <p>'First in depth study of TB service users experience in London'</p> <p>Applicability – limited to 10 users, but in depth qualitative method used to capture recent, London-based experience</p>	<p>Boudioni (2011)*</p> <p>Listening to those on the frontline: service users' experiences of London tuberculosis services</p>
<p><b><u>I/E/S content</u></b></p> <p>TB link worker – access to housing, specialist allied services (drug and alcohol services), mental health and HIV services, advocacy and advice, implementing models of care.</p>	<p>TB link worker role described</p> <p>TB link worker facilitates access to services outside of healthcare (such as housing, substance use treatment)</p> <p>Reported that TB link worker focuses on underlying social and economic needs in addition</p>	<p>Craig (2003)</p> <p>The missing link</p>

Awareness/I/E/S content Setting/focus Medium/methods	Main messages/practice points Applicability	Citation *practice example
<i>Setting/focus</i> UK – London based TB Link Project  <i>Medium/methods</i> News item	to treatment  Applicability - News item only, dating back to 2003	
<u><b>I/E/S content</b></u>  Social outreach  <i>Setting/focus</i> UK - London ‘Marginalised groups’ with TB Service mapping Migration of factors that complicate treatment  <i>Medium/methods</i> Social outreach model of care  Link worker  Interprofessional practice	Social outreach model of care  Inter professional practice (figure presented) and link working (patient and service link worker)  Link working encompasses more ‘holistic approach to care’, sharing of information, concerns and tasks. Roles in communication between patient and care provider, improved understanding of patient circumstances and more likely to prioritise enabling approaches such as mobile X-ray and to assess and enable housing allocation  Opportunity for establishing trust with those most socially excluded, assistance with housing/accommodation and access to entitled benefits, impact on psychosocial aspects of TB through enhanced social support  Applicability – Report dates back to practice prior to 2008	Craig (2008)*  Establishing a new service role in tuberculosis care: the tuberculosis link worker
<u><b>I/E/S content</b></u>  Raising awareness Reducing stigma  <i>Medium/methods</i>  <i>Setting/focus</i> UK – London, Hackney	News item on promotion of TB (and HIV) testing involving work with voluntary and community sectors  Description of:  Work with voluntary sector and NHS to develop and coordinate pathways  Contact community leaders, leaflets, radio, visiting organisations, stall at cultural ‘fete’ (Stoke Newington).  Community clinics in community venues (testing offered as part of Health Check) and soup	Dean (2012)  Removing the stigma

Awareness/I/E/S content Setting/focus Medium/methods	Main messages/practice points Applicability	Citation *practice example
Community  Hard-to-reach groups  Promotion of TB (and HIV) testing  Normalise testing in groups that prove to be Hard-to-reach  <i>Medium/methods</i>  News item	kitchens for homeless people  Activities summarised as 'Small steps in a journey.'  Applicability – news item only; 2012	
<u><b>I/E/S content</b></u>  Training peer educators (former TB patients with history of homelessness and drug/alcohol dependence)  <i>Setting/focus</i>  <i>UK – London</i>  Peers working within TB clinics and mobile X-ray screening service  <i>Medium/methods</i>  Research – published  Before and after evaluation	Aim to 'harness the voice and experience' of people that had used TB service users  Peer educators working alongside TB clinics and mobile X-ray screening service  Suggests importance of peer educators in raising TB awareness and promoting service access  Reported that peers recruited over 3200 hard-to-reach clients during 2009-2010  Applicability – Abstract only, with limited description of I/E/S practice, but report of service recruiting over 3000 clients, in London, 2009-2010.	Hall (2010)  Evaluation of TB peer educators essential partners in metropolitan TB control
<u><b>I/E/S content</b></u>  A guide for all those who work with children  <i>Setting/focus</i>  UK	Leaflet (available online) for those who work with children on exposure to TB and to support children and young people with TB  Includes management pathway for children, young people and adults who may have been infected with TB and educational establishments	Health Protection Agency (2013)  TB and Children: Guidance for all those who work

Awareness/I/E/S content Setting/focus Medium/methods	Main messages/practice points Applicability	Citation *practice example
<p><i>Medium/methods</i></p> <p>Leaflet/Brief guide</p>	<p><i>Headings on</i></p> <ul style="list-style-type: none"> <li>• How to advise those who may have been exposed to TB</li> <li>• How to support children and young people with TB</li> </ul> <p>Information on TB, children at risk of TB, BCG immunisation and the protection offered, symptoms of TB in children, action in TB is suspected, next steps if TB suspected, healthcare professional responsible for care of children, TB at school/nursery, contract tracing and screening for TB</p> <p><a href="http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/Tuberculosis/NationalKnowledgeServiceTB/ResourcesDevelopedByNKSTB/010tbknowTBandChildrenGuidance/">http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/Tuberculosis/NationalKnowledgeServiceTB/ResourcesDevelopedByNKSTB/010tbknowTBandChildrenGuidance/</a></p> <p>Applicability – leaflet with limited description of I/E/S practice; 2013</p>	<p>with children.</p>
<p><b><u>I/E/S content</u></b></p> <p>Information for families affected by substance misuse and TB</p> <p><i>Setting/focus</i></p> <p>UK</p> <p><i>Medium/methods</i></p> <p>Leaflet/Brief guide</p>	<p>Leaflet (available online) on information for family members on TB and issues related to substance misuse</p> <p>Information on symptoms, what is my role (as a family member), continued use of drugs or alcohol during treatment, process for investigating co-infection with HBV, HCV, HIV, address concerns about need for home decontamination, contact tracing and sources of help for families and the person with TB</p> <p><a href="http://www.hpa.org.uk/Publications/InfectiousDiseases/Tuberculosis/09010710Substancemisuetteforfamilies/">http://www.hpa.org.uk/Publications/InfectiousDiseases/Tuberculosis/09010710Substancemisuetteforfamilies/</a></p> <p>Applicability – leaflet with limited description of I/E/S practice; 2013</p>	<p>Health Protection Agency; NHS National Treatment Agency (2013)</p> <p>Substance misuse and TB: Guidance for families affected</p>
<p>I/E/S content</p> <p>Provision for basic social needs for migrants (undocumented /with no recourse to public funds)</p> <p><i>Setting/focus</i></p> <p>UK – London – Find and Treat service</p>	<p>Evidence on the importance of social support</p> <p>Suggests that lack of access to social support compromises treatment access, completion and cure. This includes being ‘unable’ [quote] to pay for transport to clinic appointments or food and access accommodation</p> <p>Applicability – Abstract only, specific interest group. Indication of needs, but little description of I/E/S practice</p>	<p>Hemming (2010)</p> <p>Treating TB patients with no entitlement to social support-welcome to the</p>

Awareness/I/E/S content Setting/focus Medium/methods	Main messages/practice points Applicability	Citation *practice example
<p><i>Medium/methods</i></p> <p>Research – published</p> <p>Case review</p>		social jungle
<p><b><u>I/E/S content</u></b></p> <p><i>Advisory service for multi-drug resistant (MDR) TB</i></p> <p><i>Specialist advice on individual cases</i></p> <p><i>Setting/focus</i></p> <p>UK – national service (coordinated from 1 location, Liverpool)</p> <p><i>Medium/methods</i></p> <p>Service description and characteristics</p>	<p>Advice and support for clinicians managing patients with multi drug resistant TB</p> <p>Coordination through secure web site and access restricted to designated experts</p> <p>Patient's case is discussed 'virtually' with their consent. Experts review case notes and provide comments</p> <p>Summary of advice provided to the referring clinician</p> <p>Noted that it is 'too early' to determine impact on patient outcomes</p> <p>Applicability – UK wide, I/E/S practice limited to system for advice and support for clinicians described; 2012</p>	<p>Jordan (2012)</p> <p>A centralised electronic Multidrug-Resistant Tuberculosis Advisory Service: the first 2 years</p>
<p><b><u>I/E/S content</u></b></p> <p>Specialist TB Nurse Service using community-based nurses</p> <p><i>Setting/focus</i></p> <p>UK – Bristol PCT</p> <p><i>Medium/methods</i></p> <p>Research – published</p> <p>Abstract only</p> <p>Audit by case note review of organisation of care (monthly clinic visits or nurse-led system)</p>	<p>Reported community based TB nurse led system demonstrated improvement in all standards audited</p> <p>TB nurse led system provided better care than the hospital-based clinic and reduced non-attendance rates (addressing barrier)</p> <p>Applicability – Abstract only, little description of I/E/S practice</p>	<p>King (2009)</p> <p>Does a specialist TB nurse service improve outcome?</p>

Awareness/I/E/S content Setting/focus Medium/methods	Main messages/practice points Applicability	Citation *practice example
<p><b><u>I/E/S content</u></b></p> <p>Awareness raising and information for health professionals</p> <p><i>Setting/focus</i></p> <p>UK – Norfolk NHS Trust</p> <p><i>Medium/methods</i></p> <p>Leaflet/publicises Community TB Service</p>	<p>Information for professionals on TB</p> <p>Information on symptoms of TB; advice, information and support provided by the Community TB service (for patients, domiciliary support and awareness raising in the community; other services provided (vaccination, TB screening)</p> <p>Norfolk</p> <p>Applicability – Leaflet only, with brief overview of service - but provides example from outside London; 2013</p>	<p>Norfolk Community Health and Care NHS Trust (2013)</p> <p>Community TB service. Information for health professionals</p>
<p><b><u>I/E/S content</u></b></p> <p>Indication of support needs</p> <p>[Tool to identify in the review]</p> <p><i>Setting/focus</i></p> <p>UK – London</p> <p>Commissioned by London TB Commissioning Board</p> <p><i>Medium/methods</i></p> <p>Report – London TB Service</p> <p>Health needs assessment, Service review</p> <p>Including literature review and service user survey</p>	<p>Health needs assessment</p> <p><i>General discussion/recommendations</i></p> <p>Refers to Find and Treat – referral to and advice and support offered by this service</p> <p>Speculates that more community based outreach may help reduce loss to follow-up</p> <p>States Find and Treat based on extensive outreach approaches and developed important role for peer educators</p> <p>Suggests provision of care close to patients is supportive, particularly for vulnerable groups</p> <p>Literature review cites experience in NY and Amsterdam</p> <p><i>User survey</i></p> <p>Respondents cited</p> <ul style="list-style-type: none"> <li>• Improved GP training</li> <li>• Rising awareness among public</li> </ul> <p>Applicability - Cross London assessment, multiple services (30) but conducted before recent changes to NHS.</p>	<p>Public Health Action Support Team (2010)</p> <p>London TB Service Review and Health Needs Assessment</p>

Awareness/I/E/S content Setting/focus Medium/methods	Main messages/practice points Applicability	Citation *practice example
<p><b><u>I/E/S content</u></b></p> <p>Information on TB (wide range)</p> <p>Support – financial support for charges and transport, administered by TB nurses</p> <p><i>Setting/focus</i></p> <p>UK</p> <p>Public, patients, high risk groups</p> <p><i>Medium/methods</i></p> <p>Posters, awareness card, awareness events</p> <p>Leaflets</p> <p>Patient diaries (Genus Pharmaceuticals)</p> <p>Videos</p> <p>Support to patients through industry sponsored grants</p>	<p>Leaflets ‘help explain, inform, reassure and remind’ backing up information provided by health professional and ‘providing something for the patient to take away and read at home’</p> <p>Working with DH</p> <p>Industry sponsorship of materials</p> <p>Awareness events, including TB Awareness Officer, Annual ‘World stop TB day’ (March).</p> <p>Support to patients (in ‘hardship’) through industry sponsored grants, including prescription charges, transport and awareness raising activities</p> <p>Leaflets in languages other than English</p> <p>Online availability of leaflets</p> <p>Applicability – news item, broad range of TB Alert activities mentioned, but limited description of practice; 2005</p>	<p>TB Alert (2005)</p> <p>TB Alert: working with health professionals to eradicate T</p>
<p><b><u>I/E/S content</u></b></p> <p>Materials used and available to TB nurses to provide awareness and support to primary care staff</p> <p><i>Setting/focus</i></p> <p>UK</p> <p><i>Medium/methods</i></p> <p>Research – NKS - HPA</p> <p>Report of questionnaire survey (TB nurses/case)</p>	<p>Summary of findings include:</p> <ol style="list-style-type: none"> <li>1. Provision of information to GPs – both targeted and general information provided More likely in high incidence areas. Sessions delivered to GPs through standard talks, informal meetings, email and other (such as leaflets/information resources), but generally <i>ad hoc</i> or annually</li> <li>2. High prevalence areas tend to focus information provision to GPs rather than Practice Nurses. Where this is provided, mostly general TB information via variable delivery methods (e.g. standard talks, leaflets, World TB Day). Often <i>ad hoc</i> with some biannual/annual sessions</li> </ol>	<p>TB National Knowledge Service (2013)*</p> <p>TB awareness activities conducted among TB clinics across the UK 2009</p>

Awareness/I/E/S content Setting/focus Medium/methods	Main messages/practice points Applicability	Citation *practice example
workers)	<p>3. Participants report time and resource constraints as main barrier to delivery. Poor access to GPs in some areas</p> <p>4. Agreement that a standard resource would be useful; preference for electronic resource</p> <p>Applicability – UK wide survey, both recruiting TB-related nurse/case workers (TB Alert contacts) and primary care organisations (such as PCTs) in general; N = 100. Conducted by national health agency; 2009</p>	
<p><b><u>I/E/S content</u></b></p> <p>Training and development needs of GPs and Practice Nurses</p> <p>Setting/focus UK – England</p> <p>Medium/methods Research – NKS - HPA</p> <p>Report of questionnaire survey</p>	<p>Summary of findings include:</p> <ol style="list-style-type: none"> <li>1. Diagnosis – GPs had preference for information on tests for diagnosing TB; Nurses had a preference for information on all aspects of TB</li> <li>2. Management – GPs had an information requirement for all aspects of TB management; nurses in particular wanted information on treatments and social aspects of TB management. Both groups interested in information on undocumented migrants</li> <li>3. Lab updates – Minority of respondents identified a need. Preference for general information</li> <li>4. Public health measures – all welcomed information on effectiveness of BCG and screening of high risk groups. Also requirement for information about cluster/outbreak investigations, surveillance and epidemiology, and contact tracing</li> <li>5. GPs preferred updates delivered in the format of guidelines, followed by web-based tutorials, self-study modules. Nurses had a preference for half day educational events, off site presentations. Annual basis was the preferred option for receiving information, followed by <i>ad hoc</i></li> <li>6. GPs open-ended answers – majority of comments related to awareness raising, diagnosis and referral pathways. Emphasis on communication and easy access noted in relation to referral pathways. Need for information on local TB incidence/high risk groups</li> <li>7. PN open-ended answers – mostly comments on how to raise awareness with their community and referral pathways. Clear information on signs and symptoms of TB, more</li> </ol>	<p>TB National Knowledge Service (2013)*</p> <p>Help reverse 20 years of rising Tuberculosis: Primary care practitioner survey UK 2010</p>

Awareness/I/E/S content Setting/focus Medium/methods	Main messages/practice points Applicability	Citation *practice example
	<p>local information about referral pathways</p> <p>Questionnaire content presented as appendix</p> <p>Applicability – UK wide survey, both GPs and practice nurses in primary care (varying rates of TB) in general; N = 427. Conducted by national health agency; 2010- January 2011</p>	
<p><b><u>I/E/S content</u></b></p> <p><i>Improvement strategies for case management (CM)</i></p> <p><i>Appointment of DOT working group</i></p> <p><i>Setting/focus</i></p> <p><i>USA – New York City</i></p> <p>Revision of protocols and training for supervisors on tasks and standards</p> <p><i>Medium/methods</i></p> <p>Research – published</p> <p>Follow-up review of confirmed TB cases within service 2002 and 2003</p>	<p>Protocols and training for 'supervisors' (New York) – in [what appears to be] a programme of interventions to support 'supervisory management' of TB case management service. [Reviewer comment: May suggest need for ongoing education for staff, as multiple and varied interventions used to bring about improvements and needs may change]</p> <p>Reported improvement in some case management indicators (quality of patient education, DOT enrollment and documentation of CM activities), but that implementation of supervisory activities remained poor</p> <p>Top up of supervisory management skills training and workshops were offered [Reviewer comment: seems that multiple inventions where used /needed]</p> <p>Applicability – New York-based study dating back to 2002-3. Overall, diffuse I/E/S links as evaluation of range of work practices involved and various interventions used to support quality of practice,and, in turn, quality of case management</p>	<p>Udeagu (2007)</p> <p>Evaluation of case management in tuberculosis control: A three-year effort to improve case management practices in New York City</p>

## Leaflets and Videos reviewed by Lay members of the GDG including the questions Lay members were asked to consider.



TB\_NHSGrampian.pdf



RespiratoryTB\_East&PanMerseyTB\_LiverpoolPCT.pdf



TB\_LincolnshireCommunityHealthServices.pdf



TB\_TeesEsk&WearValleys.pdf



TBInfectionControl\_Sandwell&WestBhamNI

- Stop TB: Explain TB: [http://explaintb.fz-borstel.de/?page\\_id=118](http://explaintb.fz-borstel.de/?page_id=118)
- TB Awareness. The video is available on Dropbox: <https://www.dropbox.com/en/login>
  - Username: [tbvideo59@gmail.com](mailto:tbvideo59@gmail.com)
  - Password: nice2014

### Questions

#### Q1. Did you receive any printed materials or other types of information when you were suspected of/diagnosed with TB?

- What was it?
- Was it written, printed other i.e. picture based, verbal/advice from someone, a video or a variety or something else?
- Was it useful? In what way? Which was best if you had more than one and why?
- How could it (or the others) have been improved?
- Overall what did you think of it?

#### Q2. What about during treatment?

- Did you receive any further information?
- Was it written, printed other i.e. picture based, verbal/advice from someone, a video or a variety or something else?
- Was it useful? In what way?
- How could it have been improved?
- Overall, what did you think of it?

#### Q3. We have found 3 leaflets and 2 videos giving information to the public on TB . For each item (or if easier in general):

- What was it?
- Did you think the leaflets or videos were better? What about your peers? Which format did you think they would find most useful?
- Would you find it useful? What about your peers? What do you think they would think?
- Do you think it could be improved? If so, how?
- Overall what did you think of it?
- What other things would you like to see available?

## Excluded items

Reason for exclusion	Number of records
Population not of interest	13
- not TB	(8)
- setting not in scope	(5)
Not a description of practice	80
No description of information, education or support (no information of interest reported)	36
Other exclusion	15
Not available, thesis or duplicate	(12)
Total excluded records from search and screening	144

Further details of exclusions are held on file.

## Review project team

Catherine Swann	CPH	Associate Director
Emily Aidoo		Project Manager
Ruaraidh Hill		Analysts
Andrew Hoy		
Rachel Kettle		
Claire McLeod		
Lakshmi Murthy		
Alastair Fischer		Technical Adviser
Paul Levay	gIS	Information specialist
Samantha Licence		Administrator

giS Guidance Information Services, NICE

Reviewing and report preparation was conducted in February to April 2014.

## Declarations of interest

No contributor has a competing interest with the topic considered.

All are employees of NICE.

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\*Selected descriptions of practice