Tuberculosis in the UK: what is being done?

Board of Science

October 2011

At the 2008 Annual Representative Meeting (ARM), BMA members expressed their concern at the increasing incidence of tuberculosis (TB) and of multi-drug resistant TB (MDR-TB) in the UK. Initial scoping research identified that there is already much work being undertaken in the UK with regard to tackling TB. The Board of Science agreed that the best way forward was to contact a number of relevant organisations in order to ascertain their current or planned activities in relation to TB.

The following organisations were contacted:

- UK Health Departments
- Medical Royal Colleges and Faculties
- UK Chief Medical Officers
- relevant stakeholders.

A full list of organisations contacted is provided in Appendix 1.

Background information

In the UK, TB remains a major public health problem. According to the Health Protection Agency (HPA), a total of 9,040 cases of TB were reported in the UK in 2009, equivalent to a rate of 15 per 100,000 population [Reference 1]. While the number of cases of TB have remained relatively stable since 2005, rates remain at their highest since the late 1980s. The UK has one of the highest incidence rates of TB in Western Europe [Reference 2].

The main burden of disease remains concentrated in certain urban areas, with 38 per cent of all cases in London, giving this region a rate of 44.4 per 100,000. In 2009, the majority of cases occurred in young adults and among non-UK born black African and Indian/Pakistani/Bangladeshi ethnic groups.

Levels of drug resistance in the UK have also remained stable in recent years. In 2009 the proportion of cases resistant to isoniazid rose to 6.9 per cent, and the target limit of 7 per cent was exceeded in London and the East Midlands. Drug resistance was more common among cases in those born outside the UK, those with a previous history of TB, and cases in those aged less than 45 years.
In October 2004, the Department of Health (DH) published the TB Action Plan for England which set out clear steps for tackling the high levels of TB. The immediate aims of the national TB programme were to:

- reduce the risk of people being newly infected with TB
- provide high quality treatment and care for all people with TB
- maintain low levels of drug resistance, particularly MDR-TB.

A similar action plan has also been developed in Scotland and a TB framework for action is currently being developed for Wales. Northern Ireland does not have an equivalent national programme.

In March 2006, the National Institute for Health and Clinical Excellence (NICE) and the National Collaborating Centre for Chronic Conditions (NCCCC) launched the NICE clinical guidelines Clinical diagnosis and management of tuberculosis, and measures for its prevention and control to help the NHS identify, prevent and treat people with TB in England and Wales. The guidelines:

- aim to reduce the number of patients developing multi-drug resistance by recommending that all patients have a risk assessment for adherence to treatment regimens
- recommend that everyone with TB has a named key worker who is easily contactable
- advise that BCG vaccinations be considered for all new-born babies in areas with a high incidence of TB, for individuals at increased risk in other areas and for selected new entrants from high incidence countries
- recommend that new entrants be identified for TB screening based on Port of Arrival reports, new registrations with primary care, entry to education (including universities) and through links with statutory and voluntary groups working with new entrants
- recommend that active case finding be carried out among street homeless people (including those using direct access hostels for the homeless) by chest X-ray screening on an opportunistic and/or symptomatic basis.
- call for patients with suspected or known infectious MDR-TB to be isolated in a negative pressure room (Negative pressure rooms are used to prevent the release of Mycobacterium tuberculosis from the space in which it is generated).

The following provides a summary of the current and planned activities of the individual organisations contacted based on the responses received.

The British Thoracic Society

The British Thoracic Society (BTS) receives funding from the DH in order to ensure that the 2004 TB Action Plan for England is implemented. As a part of this work, the BTS is currently undertaking a mapping exercise and recruiting pilot centres in order to develop a multi-disciplinary clinical advice network.
In 2008, the BTS and the All-Party Parliamentary Group on Global Tuberculosis (APPG-TB) published *Putting tuberculosis on the local agenda* following a survey of all Primary Care Trusts (PCTs) in England. This was followed up in 2009 when the BTS, APPG-TB, Royal College of Nursing (RCN) and TB Alert carried out a second national TB audit to consider the progress made.

The 2009 report found that there had been some progress, however, deficiencies still exist in local NHS planning and delivery of TB services. Sixty per cent of PCTs highlighted that funding had increased for TB services over the past three years. In addition, 93 per cent have a senior designated ‘lead’ to tackle TB – nearly double the amount reported in 2007. TB awareness initiatives have increased, however these activities vary in scope and depth. The number of PCTs screening ‘high-risk groups’ has dropped by 10 per cent since 2007 and, although TB screening for ‘new entrants’ has increased, there appears to be no unified national standard in place. Results also showed that only 40 per cent of PCTs had a strategy in place for TB, a necessity if TB is to be made a priority.

In 2009, the BTS and the RCN carried out concurrent surveys of TB Leads and TB nursing staff respectively to ascertain the degree to which central policy had been implemented and to identify the barriers to effective TB prevention and control. The results of these two interconnected surveys were published in *Turning UK TB policy into action: the view from the frontline*. The report noted that much progress had been made, however, it identified a number of areas that require further attention, including:

- TB nursing staff - only three quarters of respondents to the BTS survey were aware that there was advice on matching nursing staff with TB caseload
- administrative support - only 44 per cent of BTS respondents stated that their TB service had a specifically funded admin or clerical post
- data systems - only 52 per cent of BTS respondents felt that they had a robust data recording system in place even though TB is a notifiable disease.
- awareness raising - only 35 per cent of respondents to the BTS survey indicated that there was a local programme aimed at raising awareness of TB in high risk areas
- TB in low incidence areas - responses to both the BTS and RCN surveys indicated that TB policy and recommendations are often not being implemented in areas of low TB burden, while in some cases TB staff are not even aware that these policies exist
- TB Commissioning Toolkit - only 17 per cent of RCN respondents stated that it had been fully implemented in their area. Forty five per cent of respondents to the BTS survey commented that TB services in their area were specifically commissioned by their local PCT
- TB service standards - 88 per cent of BTS respondents stated that all TB patients with suspected pulmonary TB are seen by the TB team within two weeks of first presentation to health care
• local priority - approximately a quarter of BTS and RCN respondents regarded the priority given to TB by their local PCT as inadequate

• national priority - 43 per cent of BTS respondents gave the DH in England a rating of poor or very poor in the priority they give to TB.

In light of these results, the BTS and RCN made a number of recommendations, including that:

• people who commission or fund TB services in all parts of the UK should ensure that those services are in line with the recommended 1:40/1:50 nurse to patient ratio, and ensure all nursing staff treating TB are adequately trained and that their skills are regularly updated

• clear guidelines should be produced to govern the workload of consultants treating TB cases

• all Trusts should have robust data systems in place to ensure that TB incidence data are reported to the DH

• all TB services should be staffed by a multi-disciplinary team (including admin support) and all Trusts, irrespective of TB burden, should be part of a local clinical network that shares best practice and advice

• Trusts should ensure that effective local awareness raising programmes are run in all high risk communities

• adequate information and support should be given to areas with low incidence of TB to enable effective prevention and control services to be put in place and sufficiently resourced

• new technologies should not only be accessible but also adequately funded to allow optimum benefit to TB patients

• clear guidelines should be produced indicating where responsibility lies for giving routine BCG vaccinations and the impact that this has on TB nurse specialist work load

• PCTs should specifically commission TB services and ensure that the TB Commissioning Toolkit is fully implemented

• national standards on TB should be agreed and implemented to allow local PCTs and service providers to be held to account on the services they commission and provide for TB patients.

Department of Health

The DH strategy for tackling TB is to help the NHS strengthen TB services in order to detect cases of TB early, and ensure completion of treatment. In addition to developing the TB Action Plan for England, the DH has:

• developed a set of resources, the ‘TB Toolkit’, on what constitutes a good TB service with advice on how to assess local needs and commission appropriate services in line with NICE clinical
guideline. The Toolkit has been presented to PCT commissioners and their local service providers/public health teams via a series of regional workshops

- provided funding for the BTS to establish a national clinical advice network, with a multidisciplinary make-up, offering peer support and best practice advice for the management of TB cases
- implemented improvements to the current HPA surveillance system to enable local services to have rapid, timely and accurate information, allowing them to monitor TB cases and outcomes in their locality
- funded an evaluation of the use of mobile X-ray screening in London as a tool for active case-finding
- provided funding for a TB ‘Find & Treat’ programme to support TB services in London in following-up suspected cases of TB, and diagnosed cases who have been ‘lost to follow-up’
- introduced X-ray screening equipment in a number of key prisons in order to improve detection of cases among prisoners
- commissioned research on awareness of, and knowledge about, TB among certain migrant groups at higher risk of TB, and among primary care professionals. This forms the basis of further work to raise awareness of TB. For example, the DH is funding TB Alert to develop materials to raise awareness among higher risk groups, and work closely with PCTs to target these materials locally
- reduced the cost of TB drugs to patients who would normally pay a prescription charge. A small amendment to the medicines charging regulations allows TB drugs to be given via TB clinics or patient group direction without a prescription charge being levied
- held an expert meeting to review the TB Action Plan in England in order to identify gaps and priorities for further action.

Scottish Government Health Directorate

The number of people diagnosed with TB in Scotland increased from 362 in 2005 to 485 in 2009. In March 2011, the Scottish Government Health Directorate (SGHD) and Health Protection Scotland (HPS) developed a TB Action Plan for Scotland. This guidance aims to provide clinicians and NHS Boards in Scotland with a framework for action when managing and responding to TB incidents.

The Action Plan identifies where current practices and services can be improved or enhanced; specific recommendations address standards of surveillance, diagnostic testing, rapid testing for drug resistance, ascertainment in excluded groups, contact screening, and treatment. It also considers how to reach out to high-risk groups such as immigrants, homeless people, problem drug users, and prisoners.

Welsh Assembly Government
The Welsh Assembly Government, via the National Public Health Service (NPHS), provides professional advice on TB services, including standards of care. This is developed through the NPHS TB Group, which aims to:

- facilitate and promote best practice in the control and prevention of TB by healthcare professionals across Wales
- promote a culture of collaborative working among healthcare professionals involved in the management of TB
- advise on strengthening the provision of specialist microbiological TB diagnostic tests available in Wales
- enhance TB surveillance in Wales.

Clinical guidance for the management of TB in Wales is based on the 2006 NICE guidelines and the BCG vaccination policy from the Joint Committee on Vaccination and Immunisation (JCVI) [Reference 3].

The NPHS TB Group considers both the TB Action Plan for England and the DH TB Commissioning Toolkit in advising which services should be available in Wales to control TB. The group is producing advice on planning TB services for Local Health Boards (LHBs). The emphasis will be on collaborative working between different TB services to encourage a joined-up approach to the management of TB. The Wales Centre for Mycobacteriology has introduced new TB diagnostic technologies in recent years, including strain typing, and the NPHS TB Group is working with the Centre to incorporate them into mainstream NHS services. BCG vaccination services are provided through the NHS. LHBs and Trusts in Wales are funded and encouraged to arrange BCG vaccination services that ensure high uptake rates in children from Ethnic groups where TB rates are high.

**Department of Health, Social Services and Public Safety, Northern Ireland**

Northern Ireland does not have an equivalent to the 2004 TB Action Plan for England, however, the Department of Health, Social Services and Public Safety (DHSSPS) has developed robust arrangements for the detection, diagnosis and management of TB cases. The Communicable Disease Surveillance Centre in Northern Ireland (CDCSNI) undertake the surveillance of TB infection. There is also a Regional Committee that meets annually to discuss TB in Northern Ireland and make recommendations for further action. A working group has also been convened to develop an interim care pathway for patients with MDR-TB.

**Royal College of General Practitioners**

The Royal College of General Practitioners (RCGP) has developed close links with the Society for Academic Primary Care (SAPC) and the School of Community and Health Sciences at City University who offer education to healthcare professionals working with TB. The School of Community and Health
Sciences is currently revising and strengthening their programme to try to meet the needs of the TB community, with a view to providing robust, high quality and relevant TB education.

The School aims to ensure that their generic pre-registration and postgraduate curricular have a strong presence of TB to meet the needs of generalist staff, with a standalone TB module that can be taken as part of wider BSc or MSc programmes. The standalone module will be available to all staff groups working within TB and includes classroom and web-based teaching combined with a work-based application project to enhance the application of the course. The aim over the medium term is to develop a programme that develops practitioners’ community and public health focus. The School is closely aligned with the Barts and the London Medical School (Queen Mary University of London) which runs jointly validated MSc programmes and will be offering a TB option.

Royal College of Nursing

The Royal College of Nursing (RCN) has established an active TB forum whose membership includes a significant proportion of the nurses currently working in the TB field. In recent years TB forum members have been involved in a number of initiatives including:

- contributing to the development of the 2006 NICE guidelines
- working with the BTS TB subgroup
- working with the APPG-TB on Global TB (including responding to questionnaires relating to progress on the implementation of the TB Action Plan in England)
- holding an annual conference focussing on the prevention and control of TB.

A 2009 report from the RCN entitled ‘Learning from success – TB case management in New York City (NYC)’, studies TB case management in NYC. The aim was to observe the successful NYC TB case management model and undertake training in the cohort review process to inform the implementation and evaluation of an effective case management system to control TB in London. As a result of the study, a five point plan was developed looking at how good practice can be transferred to the UK.

British Lung Foundation

The British Lung Foundation (BLF) produces a patient information leaflet on TB that is translated in to various languages. The BLF also has a helpline that is manned by a variety of staff including respiratory nurses who are able to handle calls on TB. In supporting research into TB, the BLF are currently funding several active grants including:

- Does Vitamin D decrease infectiousness in lung TB? Dr Adrian Martineau Clinical Lecturer, Queen Mary University of London
• **Targeting refractory cell populations in TB by monitoring mycobacterial lipid bodies.** Professor Mike Barber, Chair of Clinical Microbiology, University of Leicester.

In 2008, the BLF announced a specific call for TB research applications in the BLF ‘TB Funds’ award scheme, with successful applications being chosen in mid-November 2008. Half a million pounds of its research grant budget is restricted to support TB research and has been allocated to the following grants:

• *Finding new drugs for tuberculosis: boosting natural immunity to kill TB.* (Amount Awarded: £249,297. Proposed Start Date: 01.03.09. Duration: 24 months)

• *Developing new tools to manage TB by understanding how the body fails to control TB in the setting of HIV infection.* (Amount Awarded: £ 249,949. Proposed Start Date: 01.04.09. Duration: 36 months)

**Target TB**

Target TB is a UK-based international non-governmental organization (NGO) that supports local partner organisations in Africa and Asia in the planning and effective delivery of TB control programmes. While most of its work is aimed at supporting TB control in developing countries, Target TB is increasingly playing a role in efforts to raise awareness in the UK about the global epidemic.

Target TB is a member of the UK Coalition to Stop TB - an alliance of UK-based organisations and individuals sharing a commitment to fighting TB. This coalition aims to increase levels of awareness, commitment and political will to stop TB through a unified voice and coordinated actions. Target TB is also a member of the APPG-TB.

**TB Alert**

In the UK, TB Alert’s work centres around raising awareness of the disease, both in the UK and globally. By providing small grants to TB patients, TB Alert aims to encourage concordance with treatment, thereby helping to prevent the development of drug resistance. Part of the grants fund is specifically ring-fenced for patients with or at very high risk of MDR-TB. TB Alert is also currently developing a national template of TB awareness materials (funded by the DH). These materials include:

• a multi-lingual DVD suitable for use in prisons, drug and homeless projects, schools, to train health professionals, at community events, refugee centres and projects

• a multi-media campaign produced in conjunction with, and for, the Somali community

• a school pack aimed at providing broad public awareness to school age children

• flip charts in specific languages with appropriate artwork and design

• locally targeted radio campaigns
• targeted internet advertising/advertorials
• peer educator packs
• key staff educator packs.

Further information

Professor Peter Davies Lecture
In July 2008 Professor Peter Davies (Tuberculosis Unit, Cardio-Thoracic Centre, Liverpool) presented a lecture at the BMA ARM Victor Horsely Scientific Sessions in Edinburgh entitled 'TB: resurgence, therapy and drug resistance'. See the slides from the presentation.

BMJ Learning Module on Tuberculosis

BMJ Learning offers online learning resources to help doctors meet their continuing professional development (CPD) and continuing medical education (CME). In collaboration with NICE, BMJ Learning have developed an interactive case history module on tuberculosis.

References

(1) Tuberculosis in the UK: Annual report on tuberculosis surveillance in the UK 2010: http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1287143594275

(2) EuroTB and the national coordinators for tuberculosis surveillance in the WHO European Region. Surveillance of Tuberculosis in Europe: Report on tuberculosis in Europe: Report on tuberculosis cases notified in 2006-2008


Appendix 1

A list of organisations contacted

Department of Health

Department of Health, Social Services and Public Safety, Northern Ireland

Scottish Government Health Directorate

Welsh Assembly Government
Chief Medical Officer, England
Chief Medical Officer, Northern Ireland
Chief Medical Officer, Scotland
Chief Medical Officer, Wales
Royal College of General Practitioners
Royal College of Nurses
Royal College of Nurses Northern Ireland
Royal College of Nurses Wales
Royal College of Pathologists
Royal College of Physicians
Royal College of Physicians and Surgeons of Glasgow
Royal College of Physicians of Edinburgh
Faculty of Public Health
British Lung Foundation
Target Tuberculosis
TB Alert