



## **A new management model for Tuberculosis**

An overview of the BTS project supported by the Department of Health

This is an extract from the project proposal which was sent to the Department of Health in early 2008.

### **Background**

Effective management of tuberculosis is vital not just for the individual concerned, but also in the wider interests of the public health. Inappropriate management increases the risk of morbidity and mortality in the index case, increases the risk of producing drug resistant organisms, and increases the risk of spread of the disease to others.

National guidelines are in place (formerly the BTS Guidelines, now the NICE Guideline) to assist in optimal management. However, as with all Guidelines not every eventuality can be covered and their interpretation and application to the individual case requires the exercise of professional judgment, based on knowledge and experience.

Even the most experienced healthcare professional involved in Tuberculosis will encounter circumstances where very difficult decisions must be made. Indeed, these individuals may be frequently in such a position, since they are likely to have a complex case mix in their patient population. At the other end of the spectrum of experience, many doctors practice in parts of the country where there is relatively little TB and may have difficulty acquiring the experience base necessary for the best management of those cases for which they do find themselves responsible.

It is now uncontroversial that – despite the existence of NICE guidelines - cases of cancer should not be managed “solo”, but that professional decision-making should be a shared process not just with the patient but with other healthcare professionals: the “MDT” model (multi-disciplinary team. Since optimal management of TB may have consequences for the morbidity and even mortality of others and not just for the original patient, the argument for a move towards some form of MDT model for TB care would seem to be a compelling one.

Discussions with the Department of Health in mid-2007 led to the proposal that the Department would provide funds to enable the Society to establish a multi-disciplinary TB Advice Network. In a letter dated 30 November, the Department states:-

“The Department in no way wishes to interfere with or disrupt existing advisory mechanisms. However, we would like to see provision and advertisement of a structured network of expert clinical contacts to whom colleagues could turn for advice. The key here seems to be ensuring that the existence of the network is widely communicated amongst the relevant clinical communities to whom TB may present, so that colleagues who may see TB are aware of the network, and know how to contact an appropriate expert”.

## **Project outline**

This document proposes an incremental development of MDTs within Clinical Advice Network(s).

It is clear from the NICE guidelines, from the Chief Medical Officer's TB Action Plan for England, from the TB Commissioning Toolkit, and from all locally formulated guidance that effective management of tuberculosis involves close working relationships between primary and secondary care, between doctors and specialist nurses and health visitors, and between TB clinicians, their colleagues in laboratory services and those in health protection. Indeed, there are important relationships other than these. *The importance of this principle is explicitly recognised and repeated here.*

This document proposes an incremental development of clinical advice networks(s), initially clinician-led, and based on the establishment in year 1 of a number of pilot MDTs; evaluation at the end of the first year; and development of the model across England in years 2-3. The model will include suggested operating procedures and related financial implications for each MDT. At the core of the proposed work will be the establishment of central support at the Society's headquarters in London for the MDTs and related web-based advice, updating and, in due course, monitoring tools, plus support for the role of the Society's Specialist Advisory Group for Tuberculosis, which will act as the supervisory body for the development of this project. (The model could then also be made available throughout the UK, although the Society is aware that the DH will not expect to provide additional funds to specifically enable this).

By the end of year 2, it is proposed that a feasibility study will have taken place by the Society to amalgamate the TB CAN (Clinical Advice Network) with the specialised work of the Aintree-based Multi-Drug Resistant MDRTB Service (see below). It may also be possible for the Society to host and run a separate project which is looking at the treatment of those patients who have complex and challenging needs, and in particular using the web-based methods of communication and promotion of best practice, so that by the end of the 3<sup>rd</sup> year a comprehensive TB Advice Network will be achieved, covering all points on the spectrum of TB treatment and the needs of all practitioners involved in the treatment and care of people with Tuberculosis in the UK.

The added value of this approach is the Society's ability to develop and promote a series of related educational activities (including e-learning) linked to this initiative, and to future Guidelines. The Society is currently in discussions with NICE about how both organisations might work together in promoting dissemination of key messages in treatment Guidelines and HTAs.

## **Project Aims**

- It should become the norm for the clinical management of all cases of tuberculosis to be discussed between clinicians, rather than all decisions about such management being taken solely by one doctor.
- Clinicians should have a readily identifiable pathway through which they may seek advice when (including after discussion with local colleagues) they find themselves with a difficult clinical decision.

## **Advantages of this approach**

- Clinicians who feel they need advice on the management of a case will be able to readily access that advice. Advice will be available from allied health professionals as well as clinical colleagues, and it

is envisaged that this service will begin to capture best practice in relation to case management in the community and other settings.

- Clinicians may be happy with their management of a case, but discussion with others may identify or prevent suboptimal management.
- Sharing of experience enlarges the base of experience upon which the responsible clinician will take future decisions.
- The training of junior doctors – the next generation of doctors with full clinical responsibility for TB patients – is facilitated, as is the concept of multi-disciplinary working.
- Complex and difficult cases are a particular concern amongst the growing numbers of TB cases in the country today. What constitutes “complex and difficult” is a reflection not just of the characteristics of the patient, but also of the resources - knowledge and experience, as well as physical and financial - of the treating clinician and his/her immediate colleagues. This proposal will help lift at least some of those patients currently regarded as being complex and difficult out of that category.

### **Problems envisaged with the achievement of above aims**

- There will be understandable issues relating to self-perception of individual competence and of professional independence.
- In low incidence areas, the priority afforded TB may be low and the drive to set up such a system might be limited.
- Even where there is the will, there will be practical difficulties setting up the mechanisms for such discussion.
- Those practical difficulties include the allocation of time by clinicians, most of whom are experiencing ever-increasing demands upon that resource.
- In high incidence areas, the additional workload could potentially be very great if all cases are to be discussed.

### **Overcoming the problems**

The attempted imposition in a single step, of an MDT model for TB will fail without a highly prescriptive approach from the highest levels of Government, backed up by large-scale funding. Both of those necessities were forthcoming for cancer services, but the Society thinks it a safe assumption that they will not be available to the same degree for TB.

The two principles underpinning the proposed developments will therefore be:

- There should be an incremental approach, learning from experience.
- There is no “one size fits all” solution.

## Specific proposals

It is proposed that actions should proceed along two fronts

**Pilot MDT schemes should be set up around the country.** There are already several such initiatives, although some do not correspond to this present proposal in that “MDT” is interpreted as implying just one TB clinician meeting the nurses and other non-medical individuals involved in TB care. It is to be stressed that what is being proposed here is the discussion of management between clinical doctors, as well as discussion with healthcare professionals from other disciplines.

**A clinical advice network should be developed.** This should not only be of value to patients but should demonstrate to clinicians the advantages of discussing complex cases, or indeed any case where – perhaps because of low local workload and consequent relative inexperience - the clinician may benefit from such discussion.

It is recognised that DH invited the BTS to apply for funding for the setting up of a clinical advice network. This is extremely welcome, but in our view this is only one component of a move towards the transformation of the way in which clinical decision making in TB is carried out. Given the pressing problems of TB in the country, the development of the advice network should proceed hand in hand with another other initiative – the development of an MDT model of care - aimed at achieving that transformation.

The vision of the present proposal is thus wider than that of the pilot MDRTB service (see below). Its aim is ultimately to bring about a change in the way in which all cases of TB are managed, with the norm being that each case is managed to the highest possible standards, and that each case is in itself an opportunity for the treating clinician, no matter how experienced, to benefit from discussions with others.

At the core of this project is the development of a system at the Society’s head office that will support the development of the networks effectively and efficiently. Developments include using the BTS website, and the related ability to collect data and support on-line discussion forums (in addition to, and never meaning to substitute for, the acquisition of practical advice by speaking to colleagues).

### **The MDT**

Informal discussions have already led to expressions of interest from clinicians practising in low-incidence areas who are keen to commence discussing management of TB cases with colleagues in adjacent trusts. It is proposed that in the first year, ten pilot schemes should be set up: six in geographically separated areas of low incidence, and four in areas of high incidence (at least one of which should be in London). Expressions of interest should be sought. As is set out above, the detailed format of the MDT should not be rigidly prescribed, not least because the system as a whole needs to learn from experience.

One simple guideline as to the patients to be discussed might be that in a Trust with fewer than 15 new patients a year, *all* cases should be discussed within 4 weeks of diagnosis, midway through treatment, and at the end of the proposed treatment. The forum for the discussion should be a grouping with a critical mass of new patients each year: the number is for debate: thirty? forty?

In a high incidence area, it would in the first instance be difficult to deal with the workload imposed by discussion of all cases, and indeed such would probably not be necessary for entirely straightforward cases given the presumed degree of experience of the clinicians involved. Again, the criteria for discussion of cases are themselves a matter for discussion and refinement in the light of experience. One possible

approach would be for discussion of cases where there was drug resistance, drug intolerance or TB other than in lungs or lymph nodes.

Consider now the first MDT grouping above, with a caseload of (say) thirty to forty cases a year. The expectation could be that cases of a certain degree of complexity should in addition be discussed outside the group. Certainly MDR would be a specific example, and it could be argued that cases of central nervous system disease, spinal disease and complex drug intolerance should be discussed. It can be seen that this is an example of the MDT System linking into the Clinical Advice Network. Although they are being considered apparently separately in this document it is stressed that they are both part of the same initiative.

### **The Clinical Advice Network**

A pilot scheme is already running, in the form of a multi-drug resistant TB (MDRTB) service co-ordinated from the Cardiothoracic Centre, Liverpool. This scheme has support in principle of the BTS and the HPA, but for organisational reasons it is not at present an initiative formally "owned" by the BTS. The service offers advice on the management of the 50 or so new cases of MDRTB each year.

Funding for the MDRTB service is secure for the next two years. It is envisaged that initially the new BTS clinical advice network will run side by side with the MDRTB service, dealing with cases other than multi-drug resistant tuberculosis. As time passes, the two "strands" will merge, and the MDRTB service will become subsumed within the clinical advice network. Clearly, the experience gained by each of these two initiatives running side by side will be used to inform the development of the other.

Many, but not all, clinicians dealing with TB already have their own informal pathways through which they seek advice. Similarly, other disciplines also have informal networks, and have been discussing with the Society the best way of capitalising on these to move this agenda forward. The aim of the clinical advice network is to supplement these pathways and not to be rigidly prescriptive in replacing them. The goals are twofold: ensuring clinicians and others know where they can turn for advice and, supplementary to this, educating them (over the course of time) as to when they should seek advice.

It is important to avoid simply setting up a list of self-styled and self-perpetuating "experts". The aim of the advice network is to raise standards of TB management as a whole, and that includes amongst those currently regarded as experts. For the MDRTB service, it is expected that those offering the advice do so after discussion with others on the MDRTB "panel". A summary of that advice, as it was given to the requesting clinician, is kept by the MDRTB service and is available to those who have registered an interest with the service: they can thus see the clinical problem, and the advice that was offered.

Note that in the MDRTB service strict attention is given to confidentiality, including the issue of inadvertent constructive disclosure. Neither the identity of the patient *nor the identity of the referring clinician* is known to anyone other than the expert who was first consulted. This keeps the geographical location of the patient unidentified, effectively eliminating the chance of their identification by secondary clues contained in the clinical history. Issues relating to Caldecott principles and the security of patient data if it is (as is desirable for audit) also held centrally by the MDRTB service co-ordinating centre are currently in their final stages of resolution.

At least initially, and in contrast to the MDRTB service, it is *not* envisaged that a detailed central record of patients discussed and advice given be kept. If the advice network is the success that it should be, the numbers of cases will be too great for this to be achieved with currently envisaged resources. The advising clinician will, of course, be expected to have their own record of the clinical problem and the advice

offered, as will the clinician seeking the advice. As in the past, responsibility for the action taken rests ultimately with the consultant with clinical charge of the case: this is *advice* which is being offered, just as written *guidelines* offer advice.

### **Initial steps**

Appointment of a project manager at BTS responsible for setting up secure web-based communications, co-ordination of meetings, maintenance of above databases of clinicians, collection and analysis of data regarding usage of the advice network, and liaison with the MDRTB service.

BTS TB leads will be sent a global email to invite applications to contribute to the project; in the first instance as a pilot MDT.

Alongside this, to support the clinical advice network, clinicians with substantial current experience (perhaps divided into >100 new cases year under personal supervision, and 50-100 new cases year) will aim to be identified. Clinicians with areas of particular expertise (TB/HIV, paediatric TB, spinal TB, CNS TB, MDRTB, TB in renal disease etc) will also be recruited to the project.

The project is keen to identify trainees and recently appointed consultants who are hoping to develop a special interest in TB, and TB nurse specialists, to ensure that they are kept in the closest touch with developments and progress, and to ensure succession planning for those currently identified as having special expertise.

Invite representation from relevant societies, for example the British Infection Society, British Paediatric Respiratory Society and BHIVA (British HIV Association) to the core group supervising the project.

**A session at the Society's Summer Meeting in York on Friday 4 July 2008** will be held at which the selected pilot sites and the TB Advisory Group can review progress and make adjustments if necessary.