



## TB Alert Strategic Plan, April 2012 – March 2017

### Introduction and Executive Summary

TB Alert has a vision of a world where tuberculosis is controlled and ultimately eliminated. Tuberculosis is a disease which, despite being curable, currently leads to almost 1.5 million deaths each year. TB is a disease of poverty and social disadvantage; it affects the most vulnerable people in society and its impact in health and social terms is immense. It is the second deadliest infectious disease in the world, is one of the three leading causes of death of women aged 15-44, and usually affects adults in their most productive years, pushing families further into poverty.

Most of these deaths could be avoided if people with TB were aware of the symptoms of the disease and able to overcome the barriers to accessing the antibiotic treatment which is available. This would not only cure them of the disease but would stop them passing on the infection to other people. This is where TB Alert focuses its work – in raising awareness of TB among people most vulnerable to the disease so they access treatment promptly, and in advocacy for policies and TB services that better meet the needs of the most vulnerable communities. We also advocate for increasing political and financial commitment to develop the new diagnostics, vaccines and drugs that are urgently needed.

TB Alert bases its field programmes within the framework of a country's nationally coordinated TB programmes. While our work is at the 'social' end of the TB spectrum, our work is always overseen by leading TB clinicians as well as public health specialists.

The social and clinical complexity of TB means the disease can rarely be tackled in isolation. For example, in southern Africa where the vast majority of people with TB are HIV+, we focus on work that helps people be cured of TB and continue healthy lives under anti-retroviral treatment. We also address TB in the context of other social risk factors such as smoking, alcohol and diabetes.

Our work is currently focused in the UK, India, Malawi, Zambia and Zimbabwe. In the UK we are the Department of Health's lead partner in raising awareness of TB and involving civil society in TB programmes. For TB Alert, civil society refers not only to charities and community-based organisations, but, crucially, to people who have had TB or been closely affected by it (referred to as *people affected by TB*); their experience and voices play a central role in our work to raise awareness of TB and advise statutory stakeholders on how to improve TB services.

In India, where 20% of the world's TB cases are found, our sister organisation TB Alert India has become a leading civil society organisation in the fight against TB. Our two organisations work in close partnership, for example by delivering large-scale projects funded by the UK Department for International Development, and we also support TB Alert India to grow as an organisation that is able independently to develop and implement its own major initiatives.



**As TB Alert embarks upon this five year strategic plan** we are committed to further developing our existing role as the UK's national TB charity across the three key areas of our work:

- Information and support: raising awareness about TB, and providing support to individuals throughout the patient journey.
- Policy development: working with partner organisations to identify the need for policy change in relation to the care of patients and the prevention and control of TB, and coordinating the development of policy and the presentation of policy recommendations to decision-makers.
- Advocacy: influencing resource mobilisation and policy for the care of patients and the prevention and control of TB.

This plan contains five overarching strategic objectives that are applicable to our work both in the UK and internationally. Under each objective we describe the key initiatives that will go towards delivering the objective – the majority of these initiatives are applicable both in the UK and internationally. We then lay out the specific work that will be carried out during the two year period of April 2012 to March 2014, mostly described in the context of a specific geographic location.

TB Alert's five strategic objectives for 2012-2017 are to:

1. Meet the needs of individuals and communities affected by TB for information and support, and raise awareness of TB among health practitioners.
2. Strengthen collaboration between health and social care systems and civil society, for the care of patients and the prevention and control of TB.
3. Influence resource mobilisation and policy for the care of patients and the prevention and control of TB.
4. Measure and demonstrate the impact and cost-efficiency of TB Alert's work.
5. Secure committed, skilled and effective staff and trustees and a diversified funding base.

There will be an in-depth review in the third year of the strategy, to review progress and ensure the strategy remains fit for purpose.

### **Vision**

The vision of TB Alert is the control and ultimate elimination of TB.

### **Mission Statement**

TB Alert works to increase access to effective treatment for all.



## Strategic Objectives

### **1. Meet the needs of individuals and communities affected by TB for information and support, and raise awareness of TB among health practitioners.**

Nearly nine million people worldwide develop tuberculosis each year, of whom 30%-40% never reach a qualified doctor who could diagnose the disease and prescribe a course of antibiotics to cure it. It is among these people that most of the 1.5 million deaths from TB each year occur – deaths that could be prevented if people could access the life-saving medical treatment that is available.

In the UK, where rates of TB have been rising for 25 years, the diagnosis of many patients takes place much later than it should. This damages the patient's own health and risks onward transmission to their loved ones and other close contacts. There are two main reasons for this delay, both of which are addressed by TB Alert.

First, patients may not present to their GP or other health services until their illness is quite severe. This is usually for similar reasons to those we find in developing countries: a lack of awareness of the symptoms of TB, high levels of stigma about TB within their communities, and not knowing that diagnosis and effective treatment – usually free – is available. TB Alert addresses this by raising awareness among the most vulnerable communities and tackling the complex issues that confront different demographic groups in relation to TB. Our work is usually delivered in partnership with local civil society organisations that already work with people at high risk of TB. We help these organisations gain the knowledge and access the resources to integrate TB issues into their work programmes, enabling them to provide support to and advocate for the needs of the communities they assist. In the UK we also offer an information service from our office in Brighton, responding by phone and email to people who have specific concerns about TB.

Second, the symptoms of TB are often not immediately recognised in primary care settings, leading to missed or delayed diagnosis. We therefore raise awareness of TB among primary care practitioners, for example by providing resources for TB specialist nurses to use when conducting training sessions for local GPs and practice nurses.

As TB overwhelmingly affects poorer people, we also provide crucial help during the six months or more of treatment. These initiatives help ensure patients are fully cured and that their TB does not return in a drug-resistant form. Depending on the country, this can involve supporting patients through directly observed treatment, offering peer support, or providing financial support for needs such as nutritional food or the costs of travelling to the clinic; in the UK the latter is delivered through our Patient Support Fund.

In countries with high levels of TB/HIV co-infection, TB Alert focuses on internationally recognised strategies to reduce the burden of TB, such as intensified case finding, infection control and TB prevention therapy.

#### **To achieve Strategic Objective 1, TB Alert will:**

- 1.1.1 Continue to develop and implement models of awareness raising that are appropriate to individual countries, specifically intending such models to be recognised by key programme stakeholders in those countries as representing best practice.



- 1.1.2 Provide accurate and accessible information to people affected by or concerned about TB.
- 1.1.3 Make the Patient Support Fund accessible, through TB nurses and caseworkers, to all patients in the UK requiring financial assistance within the Fund's remit.
- 1.1.4 Raise awareness of TB among primary care practitioners.

**In 2012-14 TB Alert will:**

- 1.2.1 Develop and begin implementation of Country business plans, designed to enhance the impact of and provide a basis for the expansion of TB Alert's international programme.
- 1.2.2 Improve access to treatment through increased community awareness, via our large-scale DfID-funded projects – COTHAZ (in Zambia) and APCHIP and TAP (in India).
- 1.2.3 Further build TB Alert's reputation in working with civil society organisations across all of the main demographic groups affected by TB in the UK.
- 1.2.4 Review and update the formats and channels used to disseminate our awareness messages in the UK, including the use of new media, to ensure target populations are most effectively reached.
- 1.2.5 Review our information service to ensure it meets the needs of people affected by or concerned about TB.
- 1.2.6 Pilot an expansion of the Patient Support Fund demonstrably to meet the needs of all patients.
- 1.2.7 Develop and deliver a programme to raise awareness of TB in primary care settings in England, in collaboration with the Royal College of GPs and through TB specialist nurses.

**2. Strengthen collaboration between health and social care systems and civil society, for the care of patients and the prevention and control of TB.**

Tuberculosis is a highly complex public health issue that involves the interaction of many social and medical issues. These involve the prevention, transmission, activation, detection, diagnosis, treatment and cure of TB. Yet TB programmes have historically been tackled within an overwhelmingly medical paradigm, with limited focus on the social aspects of the disease.

There is increasing recognition among those responsible for developing and delivering TB services, that TB programmes should be addressed within a social model of health – a model which, alongside clinical care, addresses the wider socio-economic issues which impact on people's health. This can be most effectively achieved by encouraging and supporting partnerships between civil society and statutory health sector stakeholders.



TB Alert also believes that people affected by TB can make a key contribution to raising awareness and advising on how TB services can be more patient-centred. In recent years we have helped establish the TB Action Group (TBAG) in the UK as the key network of people affected by TB; TBAG is today a recognised stakeholder in key TB policy arenas.

In England, *The Truth About TB* programme, launched in 2010, has focused initially on raising awareness by providing training and resources to civil society organisations that work with communities vulnerable to TB. This work has all been delivered in close partnership with local NHS stakeholders. In the next stage of the programme we will explore the wider roles that civil society can play in local TB programmes, for example in providing community-based DOT, supporting contact tracing, offering case management and providing peer support. There are clear opportunities to work with local authorities as they take over responsibility for public health, to improve the social dimensions of the care of patients and the prevention and control of TB.

In India, we shall continue to build the capacity of our sister organisation TB Alert India to make a major contribution to India's national TB programme. TB Alert India has established a strong reputation among government and other leading NGOs, delivering work in partnership with ourselves as well as independently of TB Alert, for example as part of Project Axshya, a national programme funded by the Global Fund to Fight AIDS, TB and Malaria.

In Africa, we currently work through in-country partner organisations rather than through a direct presence in the continent. We shall keep this model under review and, through the development and delivery of Country business plans, establish mechanisms that best allow us to deliver our country and regional objectives.

**To achieve Strategic Objective 2, TB Alert will:**

- 2.1.1 Provide training and access to resources to develop the ability of civil society organisations that work with affected communities to integrate TB activities into their programmes.
- 2.1.2 Develop the role and strengthen the voices of people affected by TB in the care of patients and the prevention and control of TB, and work with civil society partner organisations to integrate people affected by TB into their work more effectively.
- 2.1.3 Actively promote the role of civil society to key stakeholders responsible for the planning and delivery of TB programmes.

**In 2012-14 TB Alert will:**

- 2.2.1 Develop and begin implementation of Country business plans, designed to enhance the impact and provide a basis for the expansion of TB Alert's international programme.
- 2.2.2 Build the capacity of partner NGOs to integrate TB into their community-based and advocacy programmes through our large-scale DfID-funded projects – COTHAZ (in Zambia) and APCHIP and TAP (in India).

- 2.2.3 Pilot Local TB Partnerships in the UK as a mechanism to develop the role of civil society in working with local statutory stakeholders for the care of patients and the prevention and control of TB, and establish a national network of civil society organisations working in TB programmes.
  - 2.2.4 Develop and seek to launch a pilot project in the UK for expanding the role of community-based organisations in the care of individual patients as well as within local programmes for the prevention and control of TB.
- 3. Influence policy and the mobilisation of resources for the care of patients and the prevention and control of TB.**

Since its launch in 1999, TB Alert has been an active player within UK and international TB advocacy arenas. The charity is contracted by the global Stop TB Partnership to coordinate advocacy activities at the annual World Conference on Lung Health; is a lead partner in the TB Europe Coalition; holds a funded Memorandum of Understanding with Aeras, the product development partnership for vaccines, to promote the case in the UK for funding and support of vaccine development; was a founding partner and is a Steering Group member of the UK Coalition to Stop TB; works closely with the UK All Party Parliamentary Group on Global TB; and plays a central role in influencing the commissioning of TB services under the post-2010 health service restructure in England.

As the UK's national TB charity, TB Alert aims to ensure there are effective programmes of TB advocacy in the UK. We do this by working with other civil society organisations, with colleagues in health services and with people affected by TB. In the international arena, we work closely with the Stop TB Partnership and other partners to ensure the UK fulfils its responsibilities to global TB resourcing and control. In delivering this strategic plan, we shall ensure that we live up to our role as the only TB-specific charity working in the UK, by establishing a more pro-active role in leading policy analysis and development and in advocacy for the plans, systems and resources necessary to fight TB.

This focus on advocacy is also reflected in our international field-based programme, where the empowerment of communities to advocate for their rights in relation to health and for improvements in TB systems is a common thread throughout our work.

**To achieve Strategic Objective 3, TB Alert will:**

- 3.1.1 Strengthen TB Alert's role in harnessing public and professional opinion to inform government and influence the agenda within TB policy development in the UK.
- 3.1.2 Encourage and support partner community-based organisations to advise health services and advocate on the design and delivery of local TB services, highlighting the special contributions provided by civil society to the care of patients and the prevention and control of TB.
- 3.1.3 Build the role of people affected by TB within national and local TB advocacy in the UK and in our international programme countries.



**In 2012-14 TB Alert will:**

- 3.2.1 Commence work to establish a policy and advocacy department within TB Alert.
- 3.2.2 Continue to work with the partner organisations and coalitions to build global advocacy impact.
- 3.2.3 Advocate for the Department of Health to set a national target for the reduction of TB incidence.

**4. Measure and demonstrate the impact and cost-efficiency of TB Alert's work.**

TB Alert is committed to maximising its impact in saving lives, improving health and helping relieve the poverty that results from TB among poor people and communities. As the organisation has grown, we have built our experience in tailoring programmes to have the greatest impact in different settings.

We are committed to monitoring and continually improving our programmes in the global fight against tuberculosis. As we further expand the scale and enhance the impact of our work, we shall increase our focus on providing demonstrable evidence of improved health outcomes. We shall publish more details of our work, evidencing the impact of addressing tuberculosis through a social model of health and seeking to assist others to adapt or replicate our approaches.

**To achieve Strategic Objective 4, TB Alert will:**

- 4.1.1 Integrate high quality monitoring and evaluation processes throughout our activities.
- 4.1.2 Increase the focus on publishing details of our programmatic approach and the outcomes of our work.

**In 2012-14 TB Alert will:**

- 4.2.1 Establish monitoring standards intended to be recognised as authoritative by key stakeholders in TB programme management in the UK and internationally.
- 4.2.2 Develop a process for independent review of our impact.
- 4.2.3 Develop an evidence base to demonstrate the contribution of civil society in the UK towards the care of patients and the prevention and control of TB.

**5. Secure committed, skilled and effective staff and trustees and a diversified funding base.**

TB Alert has long been seen as an organisation that punches above its weight. In 2007, despite only having two members of staff, it was already recognised as making a significant contribution in the field of TB, largely due to the knowledge and reputation of its Chairman and key Trustees.



As the organisation has grown, people with additional areas of experience and skill have joined the staff team (which currently numbers 13), the Board of Trustees and advisory committees. We shall continue to keep our internal structures under scrutiny, in the first instance by reviewing organisational governance, advisory mechanisms and staff structures to deliver the objectives contained in this strategic plan. Our existing annual appraisal process for staff will become linked to the achievement of our new strategic objectives and the workplans that flow from them. To ensure the team can operate to maximum effectiveness, we are conscious of the need to ensure that our systems and resources meet the needs of a growing organisation.

The organisation's expenditure has increased from £401,000 in 2007-08 to over £1m in 2011-12. The largest part of our income is through statutory grants from the Department of Health and Department for International Development. While this demonstrates the high level of confidence the UK government has in TB Alert, it creates a financial risk for the organisation, especially in the present global financial climate. It also creates a potential risk of the charity needing to tailor its work to changing government priorities rather than being led by its own strategic priorities.

For both these reasons, TB Alert will aim to diversify its income so as to be less reliant on major statutory grants. In autumn 2012 we will launch the Sir John Crofton Fund to Fight TB, which aims to raise £250,000 of unrestricted funds annually to underpin our infrastructure and activities. We will also expand our fundraising from grant-making trusts and introduce fundraising around World TB Day, to establish a secure and diversified funding base for the consolidation and expansion of our work.

**To achieve Strategic Objective 5, TB Alert will:**

- 5.1.1 Ensure the Board and advisory committees reflect the technical and social dimensions of our work, including representation of people and communities affected by TB.
- 5.1.2 Continue to build and empower a skilled staff team, valuing diversity and initiative.
- 5.1.3 Establish a diversified funding base that balances growth and risk.

**In 2012-14 TB Alert will:**

- 5.2.1 Carry out a review of governance and of the terms of reference of the Board's advisory committees, and ensure TB Alert is strategically guided and operationally advised by people with the necessary range of competencies.
- 5.2.2 Launch the Sir John Crofton Fund to Fight TB, and develop other major donor and trust funding initiatives.
- 5.2.3 Develop fundraising initiatives from individuals and companies on and around the annual World TB Day.

*Approved by TB Alert's Board of Trustees, June 2012*