

TB Alert Strategic Plan 2017-2020

Introduction

TB Alert has for many years been recognised as an organisation that plays important and sometimes unique roles on national and international stages. Building on our core strengths and experience, this three year strategic plan will provide the framework to reach more people with the diagnosis and treatment they need to be cured of TB and to protect the health of their families and communities. At the core of this plan is the guiding principle of the WHO's End TB Strategy calling for a strong coalition with civil society organisations and communities.

While the vision and mission of TB Alert will remain unaltered, the overarching focus of this plan is to develop TB Alert's role as a knowledge-based, technical agency in order to engage more effectively with influential actors in this country and internationally, and to remain relevant in a period of challenge to the conventional NGO model. At the same time, we aim to strengthen the organisation's financial base, in part by growing sustainable fee-based income streams generated by providing technical services.

TB Alert has been recognised by recent UK governments as the national TB charity. As such, we have a responsibility not only to deliver programmes that reduce the impact of TB in this country but also to influence the UK's involvement in tackling TB on the global stage. Our international work has three main components:

- Field-based programmes in high incidence countries, supported by major British institutional funding agencies
- Supporting the activities and growth of our sister NGO TB Alert India, in the country that carries over a quarter of the world's TB burden
- Working with other Stop TB Partnership members to advocate for the UK, as one of the world's leading aid providers, to play a leading role in supporting the WHO's End TB Strategy aim of reducing TB deaths by 95% and cutting new cases of TB by 90% between 2015 and 2035.

This strategic plan provides the framework for increasing our ability to reach the people most vulnerable to TB. Although not exclusively a disease of the poor, the link between TB and poverty is well established. Poor people are at greater risk of infection due to overcrowding, sub-standard living and working conditions, poor nutrition and migration patterns. Poor people are also less likely to access government or other appropriate healthcare services and to complete treatment. Within a global setting of ambitious goals, strategies and targets set by the UN, WHO and Stop TB Partnership, and funding mechanisms such as TB Reach, there is increasing focus on the differing life circumstances and needs of specific demographic groups and the need to adapt services to meet the needs of these 'key populations'. This applies not only to high incidence countries but also to the UK.



TB Alert operates within an environment of change for UK-based NGOs. Institutional funding for international projects is increasingly focused on specific themes which often exclude TB. The role of Northern NGOs is also changing, with a potential lessening of their involvement in field project implementation. Within the context of our work in the UK, government austerity has made it more challenging to access statutory funding despite tuberculosis being one of Public Health England's seven priority areas.

These and other shifts are increasingly affecting how TB Alert must work to maximise its impact while at the same time ensuring its survival and growth. Recent years have seen the charity adapt and expand the scope of its work: historically, our focus was primarily on community-level awareness and access to services; today, while we still do not provide clinical treatment, our work increasingly considers the full public health and patient pathways and addresses multiple issues concerning prevention, diagnosis and patient care.

This three year strategic plan will take these developments forward, increasing TB Alert's role as a source of technical knowledge and assistance, focusing our work where appropriate on the needs of key populations, and seeking to reduce our reliance on institutionally-based project funding. We will also explore the feasibility of extending our work into Eastern Europe and Central Asia (EECA), building on the networks developed by our Chairman in recent years through the TB Europe Coalition. The EECA regions have specific challenges around drug-resistant TB and their governments are starting to recognise the contributions that could be made by organisations other than government medical services.

This plan will also be used as the basis for developing annual operational plans, to inform our annual budget setting and investment plans, and for ongoing review by our Board.

TB Alert's strategic objectives for 2017 to 2020 are:

- Provide information, guidance and support to individuals, communities and health and care services, so that people with TB access healthcare and receive a prompt and accurate diagnosis.
- 2 Partner health and care services to ensure people with TB receive the clinical and psychosocial support necessary for successful treatment.
- 3 Build TB capacity among civil society, and strengthen collaboration between health and care services and civil society.
- 4 Develop and use our organisational expertise to generate new partnerships and programmes and to support national and international advocacy.
- 5 Strengthen financial and staffing resources and systems to build the foundation for longterm sustainability and growth.



TB Alert's Vision and Mission Statement

<u>Vision</u>

The control and ultimate elimination of TB

Mission Statement

TB Alert works to increase access to effective treatment for all

Strategic Objectives

Provide information, guidance and support to individuals, communities and health and care services, so that people with TB access healthcare and receive a prompt and accurate diagnosis.

Prevalence studies carried out during recent years show that more people are falling ill with TB than previously thought. The original estimate of 8.6 million cases of TB in 2012 is now known to have been an underestimate, and for the most recent year for which data has been published, 2015, there were an estimated 10.4 million cases.

This has several implications. First, many more people than we thought are dying of TB out of sight of healthcare services. TB is killing 1.8 million people a year, which once again makes it the leading global cause of death from an infectious agent. Second, we no longer have to find 3 million people who are not receiving the care they need; instead there are now an estimated 4.3 million missing people¹. And third, rather than fewer people passing on the infection within their families and communities, we instead have more infectious people than previously thought.

A range of social and structural barriers prevent people receiving an accurate and prompt diagnosis. Social issues include people not recognising the symptoms of TB or not knowing the illness is curable, experiencing TB-related stigma, or not being able to afford costs such as diagnostic x-rays or travel to clinic. Structural issues include geographically inaccessible clinics, primary care staff not considering TB as a possible cause of the patient's symptoms, or a lack of diagnostic equipment. In developing countries this leads to millions of people not being diagnosed at all; in the UK it is more likely to lead to delayed diagnosis, with an average of over 70 days passing from the onset of symptoms of pulmonary TB to the start of treatment. In Eastern Europe and Central Asia, where there are high levels of multi-drug resistant tuberculosis (MDR-TB), delayed diagnosis often leads to onward infection with a strain of the disease which is much more difficult to cure.

¹ The World Health Organization's Global Tuberculosis Report 2016, which provides data for 2015, reported a gap of 4.3 million between notifications of new cases and the estimated number of incident cases.



Among many key populations the situation is especially severe: miners, mobile populations, people who use drugs, prisoners and homeless people face specific challenges, while for people co-infected with HIV a prompt diagnosis is critical since the disease is likely to progress more rapidly. Even within 'mainstream' populations, different approaches need to be taken in urban and rural areas, and to address the specific barriers to healthcare faced by women and children.

Various other country-specific issues must also be taken into account. In India, for example, poor people who fall ill usually visit unqualified practitioners whose knowledge is rudimentary and who cannot properly diagnose or treat tuberculosis. TB programmes in India increasingly recognise the private sector as key stakeholders, both the informal sector of unqualified practitioners as well as the formal sector of well-resourced hospitals.

In England, a new programme to treat latent TB among new entrants to the country means explaining to people who are not currently ill why they should consider taking a course of antibiotic preventive treatment². There is also a need for better collaborative working between the NHS, local government and civil society to address the social determinants of TB, improve TB-related public health measures, ensure all people with TB promptly access NHS services, and receive appropriately integrated health and psychosocial care.

TB Alert has always placed issues of access – reaching the missing millions – at the core of its work. Internationally, we have primarily approached this through grants from institutional donors such as DfID, for multi-year projects delivered through partner NGOs. We know that tackling stigma within communities, supporting community-based groups and strengthening the links between communities and government health services is key to ensuring sustainable impact beyond the project lifespan.

During the period of this strategic plan, we will increase our focus on tackling issues that prevent different key populations from accessing diagnosis and treatment. Our current involvement on the TB in the Mining Sector programme across Southern Africa demonstrates how our skills and experience can be adapted to different countries and demographic groups. We will also support TB Alert India's work to increase public-private involvement initiatives which protect the health of people who initially present to unqualified/informal practitioners.

In the UK, TB Alert continues to be seen by health and public health professionals as a key source of advice and resource on awareness raising and addressing social factors related to TB. Our reach and profile will continue to grow through our work with Public Health England and NHS England to progress the successful delivery of the national TB strategy. We have produced high quality publications such as a toolkit to support localities in planning and delivering latent TB testing and treatment programmes for new entrants, and have expanded the range of resources

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² Healthcare in the United Kingdom is a devolved matter, with England, Northern Ireland, Scotland and Wales each having their own systems. Hence, while TB Alert is the national TB charity for the entire UK, the programmes within the Collaborative Tuberculosis Strategy for England 2015 to 2020 (often referred to as the 'national TB strategy') do not extend beyond England's borders.



through *The Truth About TB* brand. We continue to provide various forms of information to the public, support to patients, and have developed training for GPs in partnership with the Royal College of GPs.

Individual localities, however, still struggle to plan and deliver TB awareness and health promotion programmes due to a lack of expertise and resource and, compared to many other conditions, low prioritisation in the eyes of commissioners. We will therefore increase our support to individual localities, advising them on developing multi-stakeholder partnerships involving the NHS, PHE, local government and third sector agencies, and providing resources and support to help ensure these programmes are effectively delivered.

To achieve Strategic Objective 1 we will:

- Continue to expand our strategies to increase awareness, reduce stigma and tackle false beliefs about TB, working with key influencers and stakeholders and using forms of media appropriate to different audiences and settings
- Raise awareness of TB among formal and informal healthcare providers and key workers
- Support localities in England to develop and deliver multi-stakeholder awareness and health promotion programmes for latent and active TB and to reach under-served populations
- Increase the focus of our international programme on helping different key populations access diagnosis and treatment.

2 Partner health and care services to ensure people with TB receive the clinical and psychosocial support necessary for successful treatment.

A diagnosis of any illness is only the first step on the path to recovery. For tuberculosis, the path can be especially laden with obstacles which not only prevent a successful cure but can subsequently result in the patient developing drug-resistant TB and remaining infectious to other people. TB Alert's mission statement of increasing access to *effective* treatment recognises the need to help people overcome the obstacles they might encounter.

Support needs to be tailored to patients' individual circumstances and communal settings. This might include ensuring patients have nutritious food to ensure their medicine is effective and can be tolerated; establishing directly treatment observation (DOT) or other support networks within their communities; and helping patients remain in contact with clinicians, including migrants who are often 'lost to follow-up' when they cross borders.

Although TB treatment is usually free, the illness can incur catastrophic costs for patients and their families. In developing countries this is especially common and severe, causing patients to stop treatment or resulting in their dropping out of school to care for a sick parent or to seek paid work. This can have profound social and public health impacts which perpetuate poverty and disadvantage; the End TB Strategy aims that by 2020 no families face catastrophic costs due to TB.



A patient's treatment should always be provided by appropriately trained clinicians with access to the necessary diagnostic equipment and medicines. Psychosocial support, however, can be provided by a range of people within the patient's family or community, and through NGOs or local community organisations.

TB Alert works with its partners to understand the support that patients need, providing it directly where appropriate or advocating for clinical teams or other responsible agencies to ensure patients' needs are met.

In India, for example, we used data that showed how low BMI (body mass index) can prevent patients being successfully treated, and we used this to advocate effectively for the government to provide extra food rations. In Africa, we support patients and their families to plant small vegetable gardens to provide a regular supply of nutritious food. Here in the UK, our Patient Support Fund helps the most vulnerable patients overcome challenges such as not being able to afford basic foods or the bus fare to attend clinic.

Our patient information leaflets in the UK are the standard form of printed information given by nurses to patients. Co-branded NHS and TB Alert and available in 20 languages, these leaflets will be updated and refreshed, and we also plan to make information available to patients through other media such as mobile phone apps.

To achieve Strategic Objective 2 we will:

- Link TB patients and their families to existing government and non-government social safety nets
- Work with health and care services, communities and civil society to develop patientcentred care programmes which support successful treatment and prevent catastrophic cost to patients or their families
- Develop a new range of NHS co-branded multi-media patient information and support resources for the UK.
- Build TB capacity among civil society, and strengthen collaboration between health and care services and civil society.

In recent years there has been increasing recognition among those responsible for developing and delivering TB programmes, that these 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.

Tackling TB effectively and holistically needs to involve all organisations that can have a significant positive impact on people's health. This will typically include health services, other government departments such as housing, environmental health and social services, and civil society.



Civil society is a broad spectrum which, in general terms, can be seen to include two types of organisations: first, professionally staffed and resourced NGOs; second, more informal community-based organisations led by community members.

While the UK has a vibrant civil society sector whose views are often valued and sought out by government and TB service providers, the situation in developing countries is typically very different. Civil society may be seen by government as a threat rather than as a service provider and critical friend, and may be prevented from undertaking projects or receiving funds from overseas without specific permissions. Alongside this, the capacity of Southern civil society is not always high, with organisations often unable to attract high calibre staff or grow their organisational expertise.

Another key group within civil society is people personally affected by TB: the voice of one person who has suffered badly from the impact of TB and poor TB care can be stronger than the voices of 100 NGO spokespeople. People affected by TB can advocate for improved resourcing, advise on the provision of truly patient-centred services, offer peer support to people currently undergoing treatment, and use their personal stories to raise awareness.

A parallel issue is that the role of NGOs is changing, with a move towards more funding going directly to low- and middle-income countries. This increases the urgency to build TB-related technical and management capacity among Southern NGOs so they can successfully bid for and effectively spend this funding.

While *TB Alert* is not a medical charity providing clinical treatment, our work is framed by a detailed understanding of patients' treatment. The presence of experienced clinicians and public health specialists on our Board and as advisers ensures this is so, and reassures government TB services that TB Alert is a credible strategic and operational partner. This also means we have insight into how different parts of health and care systems can work most effectively together to benefit communities and patients.

TB Alert has always placed civil society at the core of its ethos and work: we have supported international efforts to build recognition of the importance of civil society in tackling TB; built TB-related capacity among civil society organisations in the UK and developing countries; and involved these organisations as key delivery partners in many of our programmes.

One of our most significant achievements has been to support the establishment and growth of TB Alert India. Based in Hyderabad, our sister organisation today works in four states – Andhra Pradesh, Telangana, Tamil Nadu and Delhi. TB Alert India is recognised as an important stakeholder by India's national TB programme and is currently a partner in delivering major projects funded by USAID and the Global Fund, as well as working as our partner over many years on projects funded by DfID, Big Lottery Fund and others. We are committed to continue supporting TB Alert India to reach more people and save more lives.



During recent years we have sought to increase our focus on working with major Northern NGOs that have extensive programmes in developing countries. By integrating TB into their programmes, for example when they tackle HIV in Southern Africa, such organisations can have much greater reach than TB Alert can achieve through our own projects. We intend to continue exploring opportunities to increase these organisations' understanding of TB and to support them to integrate TB issues into their work.

Although the incidence of TB among the general UK population is now falling, TB services are seeing an increased proportion of patients with complex needs who require joined-up health and social care. So, with public health now the responsibility of local government and a national TB strategy highlighting the importance of partnership working, TB Alert will work to increase the involvement of local government at strategic, political and operational levels, and strengthen partnerships between health services, local government and civil society organisations to improve patient outcomes.

A reduction in statutory funding of TB Alert in recent years for its work in England has led to the scaling back of our work facilitating the TB Action Group (TBAG) of ex-patients and other people personally affected by TB. Originally established by TB Alert, TBAG is recognised as an important stakeholder, contributing to NICE guidance development processes and giving evidence to parliamentary enquiries into TB. During the coming years we aim to expand our core staff and, through this, reinvigorate the support we provide to TBAG, including examining the potential of online communities for awareness raising and peer support.

In Eastern Europe and Central Asia, WHO Europe and other partners are encouraging and supporting national TB programme managers to make TB care more people-centred, with a focus on providing ambulatory (non-hospital-based) care wherever possible, especially for non-infectious patients. Recognition is building that civil society can play important roles in providing such care, as well as supporting wider TB prevention and control efforts, and the TB Europe Coalition provides an appropriate forum to progress these roles of civil society.

To achieve Strategic Objective 3 we will:

- Promote the development and support the delivery of multi-stakeholder partnership approaches, adapted to regional and country settings
- Continually adapt our work to reflect the changing role of Northern NGOs in tackling TB in high incidence countries
- Work to increase the engagement of local authorities in England in meeting their public health, housing and social care responsibilities in relation to TB
- Support the development of the TB Action Group and the delivery of sustainable activities
- Support the continued growth, reach and effectiveness of TB Alert India
- Work through the TB Europe Coalition to increase understanding within EECA government services of the potential roles of civil society in TB care and control.



4 Develop and use our organisational expertise to generate new partnerships and programmes and to support national and international advocacy.

Earlier sections of this strategic plan described some of the ways that national and global TB policy and delivery environments are changing. We are seeing a greater focus on the social complexity of TB, the need to adapt interventions to key populations, and the increased involvement of non-clinical stakeholders. These changes have come about through the work of various organisations and coalitions including the Stop TB Partnership, WHO, TB Europe Coalition and the parliamentary Global TB Caucus.

Turning these positive developments – many of which are still at relatively early stages – into consistent, evidence-based practice will not be straightforward. There is a need to engage new stakeholders, change the policy and political environment, ensure funding is available, develop new ways of working and provide evidence of effectiveness.

Alongside this, the need for new and improved vaccines, diagnostics and drugs remains critical if we are to achieve the ambitions of the End TB Strategy.

For organisations at the forefront of this change movement, new ways of working will be required. One of the key needs is to develop the knowledge base about how to reach at-risk communities – especially the missing 4.3 million people – by providing evidence to demonstrate the most effective and cost-efficient interventions that can be scaled up and mainstreamed.

The potential exists to work towards ending TB. Scientific research is starting to provide tools to tackle TB more effectively and there is growing consensus on the direction the multi-sectoral global fight should take. This momentum needs to be further upscaled, and every organisation with a track record of expertise and influence needs to assess how to maximise its contribution.

TB Alert, with its established record and reputation in this country and internationally, has begun adapting to this new environment.

The last year has seen us develop a new role as a provider of high level technical assistance. Working on the TB in the Mining Sector programme, we oversee the delivery of screening and active case finding work in eight Southern African countries. This major Global Fund programme focuses particularly on migrant workers in South Africa's gold mines. It tackles the exceptionally high rates of TB among miners and the inadequate provision of healthcare within the mining industry. In 2016 we worked with a regional partner agency to develop a project proposal for this work; that agency's grant application was successful and we now advise and support their project management team on the project's delivery.

This work only came about because of the experience and reputation we have developed through our own field projects. This demonstrates the potential to develop synergies between our field-based projects and technical consultancy roles, based on our understanding of the real-life experiences of patients and affected communities. This approach has the potential to



significantly increase the impact of our work: by working in partnership with governments and other policy- and decision-makers, our knowledge and skills can lead to TB programmes and services being planned and delivered by agencies with significant reach into communities affected by TB.

In England, TB Alert is the only civil society member of the TB Programme Board that oversees delivery of the national TB strategy, and of the TB Delivery Board responsible for its implementation. We are recognised as a key stakeholder and source of expertise, demonstrated most recently through our development of a toolkit (published in collaboration with NHS England and Public Health England) to advise TB services on how to maximise uptake of new entrant screening for latent TB and to provide patient-centred testing and treatment services.

To embed these ways of working, TB Alert will develop new knowledge management systems to embed learning within the organisation. We will increase the systematic monitoring of the impact and value of our programmes, documenting lessons learned from our field work and our partnerships. We will disseminate this information through conferences, publications and other channels, thus increasing our profile and reach. We will also explore ways to increase our role in operational research carried out by key TB stakeholders. This approach will involve TB Alert India, assessing how they can develop as an agency to provide technical assistance within India and potentially to other South Asian countries.

Our understanding of ground realities also supports our advocacy work. Through our involvement in the TB Europe Coalition, WHO Civil Society Task Force and Stop TB Partnership we can advocate for policies and programmes that respond to challenges experienced on the ground and identify solutions to deliver more effective TB programmes.

To achieve strategic Objective 4 we will:

- Incorporate impact and value for money measures into our major programmes, focusing where possible on measuring health outcomes among specific demographic groups
- Focus on maximising the synergies between our field projects and technical advisory work, growing and embedding our knowledge in the process
- Document our work and disseminate its learnings through publications, conferences and other appropriate fora
- Further our involvement in international working groups and partnerships.
- 5 Strengthen financial and staffing resources and systems to build the foundation for longterm sustainability and growth.

The size of TB Alert and the nature of our traditional project-focused work means we exist within what is often referred to as the 'squeezed middle' of NGOs: large enough to have fixed overheads, yet without reliable income streams. As one multi-year international project ends, another is needed to take its place and provide the overhead recovery to meet our core costs.



Additionally, as the role of Northern NGOs changes with more funding going direct to the South, along with funding calls from the main UK donors (DfID, Comic Relief, BLF) becoming more targeted and generally less frequent, the risk to our portfolio of work and security of income increases. Grants are therefore an increasingly unreliable source of income while voluntary donations are difficult to raise for the cause of tuberculosis.

In the UK, we operate within a constrained funding environment in the NHS and public health. Generating earned income will be challenging, but commissioners may respond positively to offers that improve outcomes, reduce health inequalities and save health services money.

At the time of writing, TB Alert employs a staff team of six people working a combined 4.6FTE hours. For an organisation that works in several settings and has ambitions to develop its role as a source of technical expertise, we are highly reliant on individual staff members.

TB Alert will work to develop new funding streams to increase stability and provide a secure basis for future planning. While developing fee-based income from consultancies and technical assistance is a competitive sector subject to cyclical changes, our recent experience demonstrates that it provides a realistic route to diversification. We will pursue this route and also explore being a partner on major grant applications led by larger agencies.

While TB Alert does not currently employ a fundraising team, we will increase our work to obtain multi-year grants from trusts and foundations, partly to ensure we provide a consistent standard of information and advice services in the UK.

While we cannot fully treat the risk associated with having a small staff team, we will put in place plans to minimise it, for example through seeking to develop a small network of consultants and by embedding knowledge within the organisation through the development of knowledge management systems and tools.

Internationally, we have for some years considered the need to have an organisational presence in Africa, either through a staffed office or by one or more individuals working in a similar way to how, in India, we originally had an Asia representative. As we develop the new shape of our international programme we will re-visit this question.

To achieve Strategic Objective 5 we will:

- Develop our role as an international technical agency generating fee income
- Expand our international partnerships with agencies with access to large scale funds
- Develop offers of commissioned services to UK statutory bodies
- Develop a rolling programme of funding applications to grant-making trusts
- Seek to develop a small network of associates consultants or contract staff for delivering short-term contracts or programmes
- Develop a feasibility plan and, if appropriate, a business plan for having an organisational or staff presence in Africa.