

Involving affected people in the fight against TB in low incidence countries:



UK's TB Action Group

A real life TB journey



Authors

A McConville ¹, T Marshall ², D Olapoju ¹, N Winter ¹, R Dukes ², P Davies ³, E Okereke ⁴,
¹ TB Action Group, Brighton; ² TB Alert, Brighton; ³ Liverpool Heart and Chest Hospital, Liverpool;
⁴ Public Health England, Leeds

Background

Rates of tuberculosis (TB) have recently begun to stabilise in the UK, following a 60% rise in cases since the late 1980s. However, despite efforts to improve TB prevention, care and control, the incidence of TB in the UK remains high compared with most other Western European countries. Cases of TB are reducing worldwide and have halved in most Western European countries over the last ten years. Yet in 2012 there were 8,751 new diagnosed cases of TB in the UK, and if the situation continues on its current trajectory, by 2015 the UK will have more cases of TB than the whole of the US.

TB patient advocacy is a relatively new concept in the UK. However, changes in the culture of the NHS mean that governmental health policy now aims to make shared decision making between health services and patients the norm in both individual patient care and the design of health services. This has provided the opportunity to build upon established service user involvement strategies to create meaningful patient advocacy at a national and local level.

TB patient advocacy in low incidence countries is required due to:

- Low levels of understanding among the public leading to stigma and isolation
- Low levels of awareness among medical staff leading to delayed diagnosis and treatment complications
- Patients lacking support networks and their needs not being adequately reflected in service design and delivery

Intervention

TB Action Group (TBAG) was established in 2008 through the work of TB Alert, the UK's national TB charity. TBAG was formed to provide a voice to people in the UK who have been personally affected by the illness and therefore have valuable insight into TB services. TBAG is the only network of people affected by TB (PATB) in the UK, and has been at the forefront of the development of the civil society response to TB in the UK.

TBAG members are active in:

- contributing to consultations on TB policy and service design and delivery
- increasing knowledge of the patient experience among health professionals
- training community representatives at TB workshops
- raising awareness through media advocacy
- providing telephone and online peer support to patients

Results

TBAG is evolving from a network of PATB engaged in awareness and peer support activities, to become a nationally and internationally recognised patient advocacy organisation.

- TBAG is an integral part of TB Alert's awareness programme, *The Truth About TB*. Members have helped deliver 28 awareness seminars and training workshops for staff of community-based organisations (CBOs) that support people most at risk of TB
 - Members of TBAG are working towards civil society engagement in TB care and control in England through TB Alert's local TB partnerships, which bring together state partners, CBOs and PATB to support local services
- In order to increase the influence of PATB, TBAG members are expanding upon their strategic policy and parliamentary activities at both a national and European level.
- TBAG gave evidence at a parliamentary inquiry into the threat of drug-resistant TB in the UK, as part of a select panel of experts
 - TBAG members have been selected by the National Institute of Health and Care Excellence (NICE) to help develop national recommendations on the diagnosis and treatment of TB in the UK, including identifying and managing the illness in "hard-to-reach" groups
 - TBAG members have addressed the European Parliament as key-note speakers at a variety of events, including a symposium on childhood vaccination



Conclusion

No country can effectively respond to TB without engaging affected individuals, and TBAG's work means that health services and other state partners increasingly value the contribution of PATB. A structured national mechanism is required to recruit, train and build the role of PATB to enable meaningful patient advocacy in TB care and control in the UK.

Contact

To find out more about the TB Action Group please contact
 Tessa Marshall at TB Alert: +44 (0)1273 234770, tessa.marshall@tbalert.org



www.tbalert.org
www.thetruthabouttb.org

TB Alert is the only TB-specific NGO addressing issues of TB in the UK and overseas. With funding from the Department of Health, TB Alert raises awareness among affected communities in the UK in line with the Department's TB Action Plan (2004). TB Alert also support grass-roots programmes in India, Malawi, Zambia and Zimbabwe, and works internationally to advocate for greater global priority and resources for combating TB. The TB Action Group (TBAG) was established by TB Alert in 2008; TB Alert provides facilitation and funds the group's expenses.

What the TB journey should be like

