

# Support of vulnerable patients throughout TB treatment in the UK

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## ABSTRACT

Despite well-established treatment regimens, tuberculosis (TB) remains a public health burden; it disproportionately affects poor and marginalized populations who may not have access to social support, including migrants, homeless people and those dependent on drugs or alcohol. There is a clearly demonstrated need for housing and other appropriate social support, as part of a package of integrated clinical and social care. However, TB prevention and control efforts in the UK often do not address the specific vulnerabilities of these groups and it can be a challenge to support the continued TB treatment of these underserved populations. This challenge is exacerbated by complex issues concerning funding, immigration and the law. In this paper, we have reviewed current UK guidance and legislation, discussed several case studies and highlighted examples of existing models of community support for TB patients. Finally, we lay out our recommendations for ensuring a co-ordinated, whole system approach to successful TB treatment.

**Keywords** public health, socioeconomic factors, communicable diseases

## Introduction

Despite well-established treatment regimens, tuberculosis (TB) remains a public health burden; it disproportionately affects poor and marginalized populations who may not have access to social support, including migrants, homeless people and those dependent on drugs or alcohol. TB prevention and control efforts in the UK often do not address the specific vulnerabilities of these groups and it can be a challenge to support the continued TB treatment of these underserved populations. This challenge is exacerbated by complex issues concerning funding, immigration and the law.

Although TB medication is free in the UK, evidence shows that a lack of access to funds to support vulnerable patients, who in some cases will have no recourse to public funds (NRPF), severely compromises treatment access, completion and cure.<sup>1,2</sup> Prolonged or interrupted treatment has a negative impact on the health of the individual as well as on the wider public health, and increases costs to health and social care services.

There is a clearly demonstrated need for housing and other appropriate social support, as part of a package of integrated

clinical and social care. This will vary from case to case and may include low-cost interventions such as those met by TB Alert, the UK's national TB charity, whose Patient Support Fund has provided funding for needs such as food to support the effectiveness of medication, travel costs to clinic and mobile phones/top ups for patients to maintain contact with nurses.

This paper sets out current UK guidance and legislation, together with case studies and examples of existing models of community support for TB patients. It makes UK-based recommendations for ensuring a co-ordinated, whole system approach to successful TB treatment.

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## Current guidance

The National Institute for Health and Care Excellence (NICE) provides UK national guidance and advice to improve health and social care. In 2013, NICE released a briefing on TB treatment in vulnerable groups<sup>3</sup> to local authorities. It was supported by Public Health England and stated that ‘services provided or commissioned by local public health teams and other local authority departments tackle the factors that make people vulnerable to TB and which can stop them from completing treatment. Local authority support, welfare and housing services are a vital part of TB prevention and control for vulnerable groups of people’.

In its guidance on identifying and treating TB in underserved groups,<sup>4</sup> NICE recommends that ‘commissioners of TB prevention and control programmes should fund accommodation for homeless people diagnosed with active TB who are otherwise ineligible for state-funded accommodation. Health or public health resources should be used’ and also that ‘local multidisciplinary teams have access to funds that can be used flexibly to improve adherence to treatment among hard-to-reach groups. For example, funds could be used to provide transport to clinics, to provide incentives for treatment’.

The Royal College of Nursing (RCN) guidance on Tuberculosis Case Management<sup>5</sup> also highlights the negative impact that lack of housing, transport, poor nutrition and immigration status can have on treatment outcomes. ‘For TB patients on treatment, the importance of housing cannot be understated’. The RCN recommends that ‘for the purposes of TB control, a broad and inclusive definition of homelessness is needed which incorporates overcrowded and sub-standard accommodation to include people:

- who share an enclosed air space with individuals at high risk of undetected active pulmonary tuberculosis (that is, those with a history of rough sleeping, hostel residence or substance misuse)
- without the means to securely store prescribed medication
- without private space in which to self-administer TB treatment
- without secure accommodation in which to rest and recuperate in safety and dignity for the full duration of planned treatment’.

The World Health Organization (WHO) statement on TB control in vulnerable populations<sup>6</sup> discusses a number of different groups, including refugees, asylum seekers, the homeless and those with substance addiction problems; many of these groups will have NRPF for a variety of reasons. The WHO cites evidence which demonstrates that providing

housing and other social needs may reduce hospitalization and improve treatment completion.

The King’s Fund has also recently published a paper highlighting their top 10 priorities for clinical commissioners.<sup>7</sup> Number 6 is care co-ordination through integrated health and social care teams. Although the paper highlights the benefits for patients with long-term illness, it is equally applicable to TB patients.

The recently published Collaborative Tuberculosis Strategy for England (2015–20)<sup>8</sup> will establish regional TB Control Boards. One of the responsibilities of these boards will be to track the outcomes of the strategy to demonstrate progress and identify areas requiring greater focus. One of the four ways success will be measured is through the existence of ‘systematic, joined-up care between health services, health and social care, public health and housing that specifically reaches underserved or vulnerable groups’.

## Legislation

The *National Assistance Act 1948* was established to ensure appropriate care was provided for people who did not pay National Insurance. Section 21 of the Act gives local authorities a duty of care towards any person who has a connection with the locality so long as the need for care is not due to destitution alone. In 2002, an amendment removed this duty of care for persons who were in the UK illegally. In practice, this excludes many vulnerable TB patients who have NRPF.

For people who do have a right to remain in the UK, to gain access to certain means-tested benefits including income support, housing benefit and universal credit requires demonstrating *habitual residence*. Habitual residence has no statutory definition and is determined on a case-by-case basis. In general, a person must be resident in the UK and there must be a degree of permanency about this residence.

For patients who are homeless or have insecure housing but who would be eligible for assistance, it can be extremely difficult to demonstrate residence within a local authority, despite having lived in an area for many years. In some cases, articles of the *European Convention on Human Rights* can be used to support an application for housing and subsistence support, but this can be a very lengthy process and demonstrating eligibility can, again, be difficult.

With recent changes, and tighter immigration and benefits eligibility rules in force from 1 April 2014, this process has become even more challenging and politically sensitive. It can be extremely difficult to support TB treatment in the community for non-EU residents with NRPF. Recent examples have shown that this can also be problematic for EU Accession

Citizens who have a right to remain in the UK but are not eligible for any benefits.

The case study below highlights many of these complexities which, at the time of writing, remain unresolved; some details have been changed to protect the anonymity of the patient.

A 40-year-old Lithuanian female with smear-positive pulmonary multidrug-resistant tuberculosis (MDR-TB) had been living and working in the UK for 5 years. She lost her job prior to being diagnosed with TB and her housing situation became insecure. She ended up either sofa surfing or sleeping on the street. Treatment for MDR-TB is complex and this particular patient required the addition of a trial drug which was made available on a compassionate release basis. After 5 months of treatment in a negative pressure room at a neighbouring hospital, she was discharged back to her local hospital. Despite efforts by the health services to have the local authority house, this patient for the remainder of her treatment, she continued to remain in hospital for a further 10 weeks at significant cost to the NHS.

Although, as an EEA national, this woman had a right to remain in the UK, she could not demonstrate habitual residency. However, there is no need to demonstrate habitual residency for individuals who are no longer in work due to incapacity or those who are already receiving Jobseeker's Allowance. This particular patient had lost her job just prior to her diagnosis with MDR-TB, possibly due to her illness. She did not immediately claim Jobseeker's Allowance after being made unemployed, which later created difficulties in proving her housing eligibility. It is also worth noting that her drug treatment regimen is unavailable in her home country and, as such, deportation might put her life at risk. This may fall within the remit of Article 2 of the European Convention on Human Rights, which declares that the state has, in some circumstances, a positive duty to prevent a foreseeable loss of life. Despite all this, she was deemed ineligible for support following an assessment by the local authority social services team.

This patient's TB was complex and should she have defaulted from treatment, she was likely to become infectious again and pose a health protection risk. This case highlights the legal complexities and the importance of supporting vulnerable patients throughout their TB treatment, taking into account the overall cost to the public purse and the public health risk.

### **Benefits of providing support to vulnerable patients**

Without access to public funds, treatment access, completion and cure are compromised. This can lead to increased illness of the individual and even death, higher rates of transmission to the wider public and higher costs.

The following excerpt is from unpublished work conducted by Sue Collinson, TB outreach worker at Homerton Hospital, London,<sup>9</sup> and based on London costs:

Patients with no recourse to public funds or services such as temporary accommodation could remain on hospital wards as 'bed blockers' at considerable expense to the NHS. Alternatively, they could self-discharge and discontinue treatment. The two case studies below are real, and based on the cost of a hospital bed per night (£500).

#### Case study 1

This was a 46-year-old Jamaican man, with smear positive pulmonary tuberculosis. Whilst an in-patient, it became clear that he had NRPF. He spent over five months 'bed blocking' because there was nowhere to discharge him to. At £500 a night, this cost the NHS at least £77,500.

#### Case study 2

This was a 47-year-old Polish man who spoke no English. He had no recourse to public funds. He stayed in a hospital side room for about three weeks because there was nowhere safe to discharge him to, and became an expensive bed blocker, but once he felt fit and well he became bored and self-discharged. The team continued directly observed treatment (DOT) at his squat, but within a few weeks he disappeared, because his squat was closed down and he was lost to follow up. He died about two months later, but in the meantime had infected four other people with TB. Death is expensive; the average cost of a death in London is £9556—almost the price of two standard six-month courses of TB treatment.

The standard six-month course of TB treatment costs in excess of £5000. Six months of local authority temporary accommodation costs £350 per week. The cost of housing a patient with TB in temporary accommodation and keeping them adherent on the standard six-month course is approximately £14,100.

### **Current models**

Local authority support of patients with NRPF is, at best, *ad hoc* and relies on local discretion. A number of local authorities, such as Islington Council, have established specialist teams to manage complex cases. The NRPF network, a network of local authorities and partner organizations focusing on the statutory response to migrants with care needs who have NRPF, and which provides training and practice guidance, notes in its 2011 report<sup>10</sup> that:

Social services departments in 51 local authorities across the UK supported approximately 6,500 people with NRPF in

the financial year 2009/10 at a cost of £46.5 m. Support in the form of accommodation, subsistence and in some circumstances additional social care, is provided owing to statutory duties under community care and children's legislation and remains unfunded. Local authorities must therefore meet these costs from existing budgets. This shortfall will become increasingly acute following cuts to local authority budgets as part of the Comprehensive Spending Review, particularly for authorities supporting large numbers of NRPF clients.

Owing to current legislation, individuals with NRPF who require support need to be discussed on a case-by-case basis with the local authority concerned. The delay in accessing funds is variable as is the success of each application.

The TB Team at Homerton Hospital, London, has negotiated a service level agreement with Hackney Council's Homeless Person Unit to provide rapid access to accommodation for TB patients with NRPF. This project has been running for over 4 years and has demonstrated clear cost-effectiveness and a near 100% treatment completion record. However, no funding is provided for food, travel to clinics or basics such as bedding and cooking equipment. Currently, the Homerton TB team provide a small sum on a weekly basis through charitable donations and previously with the support of TB Alert's Patient Support Fund.

Another example of the need for housing has been highlighted in Ealing's Joint Strategic Needs Assessment (JSNA) 2012–13 which stated:

TB is often associated with lower socio-economic status and is quite prevalent in people who are homeless, have been in prison, have mental health issues and have underlying chronic diseases such as diabetes and heart disease that makes them more vulnerable for TB disease.

Therefore treatment can often be complex due to additional complex medical conditions or it can be complex due to difficult social conditions. Treatment should not be seen solely as taking medication for six months or more, it should be seen as providing holistic care taking into account ability to take medication, ability to make the right life choices and supporting vulnerable people in their circumstances in order that the health of the whole community will improve as a result. This means that, in some circumstances, a multi-stakeholder approach needs to happen to ensure good adherence to treatment and an improvement of the quality of life.

In the list of commissioning priorities they suggested: 'Consider commissioning emergency housing for homeless patients for the duration of their TB treatment'.

In London, the Find & Treat specialist outreach team works alongside over 200 NHS and third sector front-line services to tackle TB among homeless people, drug or alcohol users, vulnerable migrants and people who have been in prison. The service screens almost 10 000 people a year using mobile digital chest radiology; locates patients who have stopped TB treatment before completing the full course; sets up and supports directly observed treatment in the community; and provides practical assistance and advice on accommodation, working in partnership with other services to provide residential TB treatment and care for homeless and destitute patients.

## Conclusion

It is vital to address the treatment of TB in conjunction with related health and social care issues. This requires a co-ordinated approach to commissioning that includes not only clinical services but also community support throughout the duration of treatment, with a special focus on poor, marginalized and disadvantaged groups who bear the main burden of the disease. There is clear evidence that following NICE and RCN guidance results in cost-effective treatment outcomes and is in the best interests of wider public health.

## Recommendations

- (i) Local TB commissioners should ensure integrated treatment and care programmes are established through a multi-agency approach, involving clinicians, relevant local authority teams, public health professionals and appropriate community organizations.
- (ii) Local TB control strategies should address all aspects of TB prevention, care and control including housing and social support.
- (iii) Joint strategic needs assessments in areas with high incidence of TB should highlight local authorities' dual roles: their responsibility for public health, and the need to provide housing and appropriate social care to TB patients.

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