HEALTHWATCH & PUBLIC INVOLVEMENT ASSOCIATION

Patient and Public Involvement in Health and Social Care

THE BATTLE AGAINST TUBERCULOSIS in the UK

TREATMENT RIGHTS AND HUMAN RIGHTS – WHO ADVOCATES FOR THE PATIENT?

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NOVEMBER 28th 2015

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EXECUTIVE SUMMARY

The shocking news about TB in the UK, is that whilst deaths and the incidence of TB infection are reducing in some local authority areas, in others the numbers are rising significantly.

It is almost unbelievable that 15 years after World Health Organisation (WHO) called for a major campaign against TB across the world, that the UK has made so little progress and indeed it is only in the past two years that PHE have prioritised TB. Whist there have been significant reductions in the number of cases in most European countries progress in the UK has been slow. There are some fantastic teams across the UK providing both outstanding inpatient and outreach care to people with TB. In some cases people with TB are provided with housing and the high level care they need to recover, become non-infectious and remain well. In other parts of the country services are poor and this may be the cause of growing epidemics in those areas.

Homelessness, poverty, living under the radar because of fears of removal by the Home Office, and in some areas inadequate primary care services are key contributory factors in the TB epidemic. As Dr Onkar Sahota AM, Chair of the Health Committee, said when the GLA reports was published on October 28th 2015: "It is astounding that TB is such a prevalent disease in London and that misconceptions about the disease are so common. We know TB disproportionately affects prisoners, homeless people and people with substance abuse issues, and high quality TB care services are not universally available to all Londoners.

Getting information about the epidemic for this report has not been easy. Whilst some workers in the field have been a fantastic source of support and information, others have been hesitant and reluctant to provide information. Requests to PHE for copies of minutes of the TB Control Board were eventually complied with, but no minutes were available for 2015 and access to TB Control Board meetings was denied. Some questions put to NHSE were never answered, and despite commissioning healthcare in Immigration Removal Centres, NHSE were unable to provide information regarding the incidence of serious illnesses suffered by people in IRCs, e.g. TB, HIV, malaria. The impression gained from PHE and NHSE was that we were asking too many questions.

Deportation/removal of people with TB appeared to be an area of confusion. Despite a partnership agreement between NHSE, PHE and the Home Office, we could not gain

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access to NHSE policy/guidelines on the treatment of people with TB who are deported/removed. We fear that following deportation/removal that people infected with TB may infect others when their medication runs out. NICE produce excellent guidelines on the treatment of TB, which should be followed in these cases, but they are not legally binding. Draft regulations are presented at the end of this report to amend the law in that respect.

We agree with the London Assembly Health Committee's report *'Tackling TB in London'* that there is a need for: better public information, more outreach work and for the Mayor to take a leading role in TB control, and that the Greater London Authority (GLA) should consider including TB services as part of its pan-London rough sleeping services. In addition we would like to see the following recommendations implemented:

1) CCGs and NHS England should ensure that all GPs re adequately trained to diagnose TB in the community and be proactive in case finding.
2) NHSE and PHE should create a pan London TB treatment/outreach team, instead of 32 teams currently providing services for people with TB in London.
3) The Secretary of State for Health should publish Directions making the NICE TB Guidance legally binding on NHSE, PHE and CCGs, in order that treatment is provided to all patients until their infection is fully treated.
4) Health Protection Regulations should require that those with TB who are most at risk have full access to antibiotics and social support throughout the entire period of their treatment – including those who are at risk of deportation/removal (see appendix for proposed draft regulations).
5) NHSE through their IRC contracts, should ensure doctors providing healthcare in IRCs, follow NICE Guidance in relation to the duration of TB treatment, and advice they give to the Home Office on deportation of detainees with TB.
6) PHE should establish a rapid response pubic information service, to provide fast, accurate information for people with TB about access to treatment and 'deprivation of liberty' in relation to infectious diseases.
7) The GMC should provide assurances that doctors breaching the confidentiality of patients who are 'irregular migrants' will be subject to disciplinary procedures.
8) PHE and local authorities should collaborate to produce an information pack for people detained on 2A detention Orders, and commission a national advocacy service to provide advice and empowerment to detained people with TB.

INTRODUCTION

Tuberculosis (TB) has become endemic in many parts of the UK, but which communities are infected, why is treatment sometimes failing and does the law on infectious diseases detention help or hinder? Stigma, poverty, migration, homelessness and the interface with illegality will be explored in this report, as well as the impact of antibiotic resistance on TB treatment, detention and deportation/removal.

London has the highest incidence of TB) in western Europe – 3000/annum (515 cases in Paris[1]), 9% of TB patients in London have a drug resistant strain, and 2% multi-drug resistance (MDR). TB incidence is rising in Brent (279), Ealing (213) and Newham (335) and falling in Hackney (86) and Camden (45) (PHE 2013).

A third of London's TB patients are treated in hospital, and since 2010, eleven people have been treated in detention under the Health Protection Regulations (DH 2010:1). In the community DOT (Directly Observed Treatment) is most common and provides assurance patients are taking medication (WHO 2006:1). Public Health England (PHE 2014:1) produces data about rates of infection, ethnicity and antimicrobial resistance, but nothing about patients detained in hospital or Immigration Removal Centres (IRCs) or deported during treatment.

There is virtually no information in the NHS for patients regarding treatment or TB detention (PALS 2015). The TB Action Group (2015) attempts to break the stigma of TB by highlighting patient's stories and produced leaflets but these are not distributed to hospital PALS and none of the bodies we contacted had seen the wide range of leaflets produced by the TB Action Group.

The World Health Organisation (WHO) called on governments to tackle the TB crisis by 2015 – the year PHE finally produced its TB strategy (WHO 1994, 2006:1, PHE-NHSE[2] 2015:A7). Substantial resources and effective organisation are needed–but London has 32 teams – whereas New York with one integrated team, successfully tackled the 1990s epidemic (London Assembly 2015:2).

Public health law may have a role in relation to the TB endemic and is examined in this report to see whether it is humane, and what impact it has on patients' rights; social and economic harm and breaches of civil liberties. The report explores the tension between

[1]Rate for London: 44.4/100,000, Paris: 23.4/100,000, Madrid/17.8/100,000
[2] NHS England – the commissioner of NHS care.

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the WHO approach: “Despite the gravity of the global problem, it is within our grasp to reverse the epidemic” (WHO 2010) and the UK approach which has failed to tackle the endemic and deports partially treated TB patients who may return to the country they fled from, without resources for continuing treatment – despite the claim that the WHO will step in and fix the treatment gap.

The report also explores reform of UK law and policy to create a system for people with TB that protects their health, social and economic interests and simultaneously protects the interests the community.

During the collection of data for this report: “Why do you want to know?” became the frequent riposte to questions put to PHE and NHSE about policy on TB. This reaction perhaps suggests anxiety and perhaps ‘stigma by proxy’ where the health system essentialises and internalises TB stigma (Hansson 2011). However, there are many very passionate and committed clinicians working to eradicate the endemic and a very rich seam of data available from PHE which includes information about antibiotic resistance, deaths from TB, failure to complete treatments and the ethnicity of patients.

This information at national, region and borough level is available from:

National Data

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/360335/TB_Annual_report__4_0_300914.pdf

Pan London Data

www.gov.uk/government/uploads/system/uploads/attachment_data/file/385823/2014_10_30_TB_London_2013_data__1_.pdf

Newham Data:

www.lho.org.uk/Download/Public/18482/1/Newham%20TB%20profile%202013.pdf

INCIDENCE

Progress in reducing TB incidence in the UK has been poor even though the PHE have declared they will halve TB cases by 2018 (London TB Control Board, 2013). UK performance is inadequate compared to other countries in western Europe (WHO 2012). Current PHE priorities include latent TB and treating the homeless/socially deprived (PHE and NHSE 2015). Incidence in Hackney and some other boroughs has reduced since 2002, but in many London boroughs incidence since has remained the same or increased (underlined figures). Barking and Dagenham, Brent, Greenwich, Harrow, Hounslow, Newham and Redbridge show a particularly worrying trend.

TB cases numbers by local authority of residence, London, 2002 – 2013

	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Bark & Dag	35	42	43	60	49	62	69	72	69	61	66	74
Brent	212	216	229	283	240	274	306	297	296	309	308	279
Camden	117	107	77	101	96	89	85	100	69	70	62	45
Croydon	109	113	118	113	102	115	111	124	110	132	120	109
Ealing	201	186	254	237	233	236	198	220	207	242	246	213
Greenwich	81	72	88	87	98	104	138	121	119	111	131	105
Hackney	146	155	155	129	133	141	123	114	92	90	88	86
Ham & Ful	73	66	70	89	80	67	67	73	53	68	46	48
Harrow	118	115	99	132	123	122	125	135	138	153	183	147
Hillingdon	106	115	117	137	124	124	151	122	125	130	139	101
Hounslow	119	102	115	167	134	134	134	170	197	181	192	163
Islington	105	94	86	85	96	93	93	91	62	82	69	64
Lambeth	158	156	126	144	134	104	126	117	114	97	98	78
Merton	55	41	62	61	66	57	63	61	55	64	73	59
Newham	218	245	241	256	261	277	283	309	301	370	367	335
Redbridge	92	111	109	120	144	135	162	147	137	161	154	151
Southwark	106	100	132	137	125	103	117	95	95	118	115	95
Tower Ham	126	148	118	128	132	153	132	139	153	140	119	100
Wal For	107	100	99	114	120	91	129	92	114	122	123	120
Wands	100	96	94	125	80	115	110	84	99	87	92	63

London 3055 - 3063 - 3111 - 3449 - 3328 - 3234 -3363 - 3404 - 3241- 3489 -3403 2985

The incidence of TB has shown a decrease in the UK since the peak in 2011, but the numbers in 2013 are about the same as 2004 which was the year when infections began to rise to their peak in 2011. Although deaths have decreased significantly, it is alarming that over 3000 people have died of TB in the past 10 years in the UK.

INCIDENCE OF TB IN THE UK

	New cases - UK	New cases - London	TB deaths - UK
2004	7594	2786	346
2005	8290	3098	362
2006	8314	2968	371
2007	8268	2824	300
2008	8495	2976	339
2009	8878	2989	302
2010	8398	2832	299
2011	8923	3059	256
2012	8729	2993	261
2013	7892	2591	280
Total	83,781		3116

PHE (2014:2: Appendix 1)

A comparison with France, Germany, Greece, Netherlands and Italy shows that the UK has double the incidence in these countries and that the UK has made the least progress in reducing infections from TB.

CASES OF TB IN WESTERN EUROPE - 2006-2010 (WHO 2012)

Country	Rate **(2006)** Per 100,000	Cases	Rate **(2010)**	Cases	Annual Change 2006-10
UK	**13.8**	**8363**	**13.7**	**8483**	**-0.2**
Austria	11.0	906	8.2	688	-6.8
Belgium	10.6	1117	10.3	1115	-0.5
Czech Rep	9.3	951	6.5	678	-8.3
Denmark	7.1	387	6.5	359	-2.1
Finland	5.7	297	6.1	327	+3.4
France	8.4	5323	7.9	5116	-1.4
Germany	6.5	5378	5.3	4330	-5.0
Greece	6.1	681	4.3	489	-8.0
Ireland	11.0	463	9.6	427	-3.3
Italy	7.7	4503	5.4	3249	-7.9
Netherlands	6.3	1031	6.5	1073	+0.9
Poland	22.5	8587	19.7	7509	-3.2
Spain	18.3	8029	15.4	7089	-4.1
Sweden	5.5	497	7.2	675	+7.2
UK	13.8	8363	13.7	8483	-0.2

TB AND POVERTY

In London, 45% of TB cases occur in the most deprived social classes, and10% of patients in 2013 had one or more social risk factors: alcohol (4.1%), drugs (3.6%) homelessness (3.5%) imprisonment (2.4%) (PHE 2014:1). The deteriorating social welfare fabric, exacerbated by government plans to prevent migrants without status renting homes and working, creates a significant impediment to reducing TB incidence (Clark 2015, BBC News 2015) and promotes avoidance of TB treatment and poverty. In 2014/15, 7,581 people slept rough in London double that of 2009. Rough sleepers include 43% UK nationals, and 35% from A8/A2 Accession States, e.g. Poland and Romania, who suffer benefit limitations when unemployed. These states have high rates of TB[3] (WHO 2012). TB treatment in the UK is free (DH 2015) and doctors bound by a duty of confidentiality (PHE 2015:3), but for people with no legal status to remain in

[3] Romania reported 21,078 cases in 2010

the UK fear of disclosure to the Home Office is strong and advice from statutory agencies and the GMC to people in this situation unhelpful.

ABOUT TUBERCULOSIS

Globally, 3 million people die from TB yearly, particularly where there is poverty, malnutrition and homelessness. It is caused by Mycobacterium tuberculosis which slowly infects lungs and sometimes other organs, following inhalation of dust or human aerosols. Its waxy outer coat enables survival for long periods. Primary infection occurs if the person is unvaccinated (BCG), has no previous exposure to TB, or is immuno-suppressed. The Mantoux[4] skin test detects immunity and infection by measuring the degree of epidermal induration.

Lung infection is characterised by 'tubercles' - small granulomas containing mycobacteria, which become necrotic and initiate infection. It is not acute like pneumonia; onset is insidious and a long period pass before treatment is sought.

Primary tuberculosis (10% of infections) is indicated by a chronic productive cough, blood-stained sputum and perhaps haemorrhage; together with fatigue, weight loss, weakness and 'night sweats' (Mims et al 1998). Tubercles may persist as latent TB, especially in established migrant communities and reactivation usually occurs within 5 years, related to changes in social or health status, e.g. immunity, infection or chemotherapy. Usually, in the UK there is a stable relationship with health services, and effective medical practice should detect latent TB. PHE see latent TB as a major priority and are putting considerable resources into finding and treating patients with latent TB.

STIGMA AND AVOIDANCE OF DIAGNOSIS

Stigma occurs when: '...a trait or characteristic is identified as being undesirable or disvalued', and internalised as shame, disgust or guilt, resulting in withdrawal from relationships and risky behaviour (Courtwright et al 2010).TB stigma causes delays in diagnosis, avoidance and impedes treatment compliance. Stigma may deter patients from receiving DOT because observed interaction with nursing staff may identity a person as having TB (Courtwright ibid). Dodor and Kelly (2009) suggest it is the perceived contagiousness of TB that causes stigma. Homelessness, poverty and fear of deportation/removal cause and exacerbate stigma resulting in increased susceptibility to TB, particularly for migrants living 'under the radar'. Contact tracing with index cases

[4]Test for immunity to tuberculosis using intradermal injection of tuberculin.

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i.e. disclosing who they live and socialise with may be problematic if migrants fear immigration raids and deportation/removal (PHE/NHSE 2015).

Stigma is less problematic in latent TB, because discovery is later, and discrimination less common (Liefooghe et al 1995). When identified through routine medical practice e.g. Mantoux test, or during treatment for other illnesses, antibiotic treatment provided in confidence, is unlikely to be observed.

TB DRUG RESISTANCE

Mycobacteria are resistant to antibiotics, but usually respond to 8 months treatment with isoniazid, rifampicin and ethambutol. In 2013, 9% of London TB isolates were resistant to one or more first-line drugs (8% in 2012) and MDRTB (isoniazid and rifampicin resistance) occurred in 2% of infections. Resistance emerges due to poor prescribing or non-compliance, and those with social risk factors are vulnerable to multi-drug resistant infections (28% of isolates in this group) (PHE 2014:1). MDRTB is treated with fluoroquinolone, and at least one of three injectable TB drugs. Treatment lasts for 2 years and imposes extreme economic and social burdens, e.g. homeless people with MDRTB are most likely to experience extended hospital treatment. Long-term treatment in negative-pressure hospital rooms is inimicable to emotional wellbeing, and patients may self-discharge when symptoms reduce.

Enforced treatment is unlawful in the UK, but detention of non-compliant patients in hospital is lawful, but if the patients self-discharges during treatment this can result in transmission of resistant mycobacteria to others, especially in overcrowded poorly ventilated accommodation (DH 2010:1, TB Alliance 2015).

THE LAW ON DETENTION OF PEOPLE WITH INFECTIOUS DISEASES

Infectious patients may be detained in hospital under the Health Protection Regulations (2A Orders) of the Public Health Act 1984 (DH 2010:1). Coker (2000) examined human rights implications for people detained under the original 1984 Act (DH 1984) and its failure to show regard for the European Convention of Human Rights(ECHR:1953). He suggested that: ’detention of ‘unco-operative’ individuals with tuberculosis may be ineffective as a public health measure. He highlighted the paucity of legal support to challenge detention. Fidler and Gostin (2007) reviewed attempts to detain of Andrew Speaker, who “absconded” from the USA (for vacation) following diagnosis of resistant TB. He travelled widely, pursued by USA officials with no concern for his human rights

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or powers of detention. He was demonised for his apparent lack of concern for the threat he posed to others.

In Enhorn v Sweden (ECHR 56529/00, 2005) a breach of Article 5 of the ECHR was found. Enhorn had HIV and was detained without due regard to finding less restrictive ways of preventing him infecting others. The court prioritised Enhorn's right to liberty, over the potential risk of infection and determined that Swedish law lacked appropriate criteria to assess risk (Martin 2005).

The UK Public Health Act was similarly deficient until amended (DH 2008) and the subsequent Regulations (DH 2010:1) were designed to: 'prevent, protect against, and respond to infection diseases'. Doctors are required to inform local authorities of persons with notifiable infections who pose a risk to others (SI 2010/659), authorities may seek 28 day, 2A Orders from a Justice of the Peace to detain a person who is then subject to medical examinations, abstaining from work (SI 2010/658), and acting to reduce risk of transmitting infection.

Consistent with Articles 5.4 and 6 of ECHR, the Regulations require that detained persons understand the: 'effect of the order, reasons it was made, right to an appeal and public hearing, and access to support services (DH 2010:1(8(2)(a)(b)). A person can be 'restricted' but not locked, and in response to self-discharge: "A constable may ... return the person to that place" (DH 2010:1(45O(5)). London has 50% of the UK's TB patients, and since 2010, eleven Part 2A Orders have been granted including 2 for 224 days. TB patients are also treated in hospitals for long periods without 2A orders (LA 2015).

By way of comparison, Section 2 of the Mental Health Act (MHA) (DH 1983), allows for a single 28 day compulsory admission, right of appeal, and compulsory medical treatment, if assessment suggests this would safeguard the person's health and safety, and protect others. There is no difference between compulsory admission and restriction (Jones 2015) as defined in the two Acts and persons can be detained in open wards. In Supreme Court judgements: P v Cheshire West and Chester Council and P and Q v Surrey County Council (2014), Lady Hale observed that in Ashingdane v UK (1985) the court accepted that a patient is deprived of his liberty in the hospital where he is 'detained', irrespective of the openness of the conditions there. Following these cases NHS guidance was issued in relation to 'deprivation of liberty':

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> "Where a potential deprivation of liberty is identified, a full exploration of the alternative ways of providing the care and/ or treatment should be undertaken, to identify less restrictive ways of providing care which will avoid a deprivation of liberty". (DH 2014)

Thus Coker's (ibid) criticisms of the Public Health Act were ultimately answered with amendments to the Act in 2008 and the Health Protection Regulations. The findings in Enhorn (ibid) support and reinforce a more progressive approach to liberty for people who are infectious (DH 2014).

SOCIAL EXCLUSION AND INFECTIOUSNESS

In evidence to the London Assembly, Alistair Story who leads London's 'Find and Treat' service described TB as a social disease:

> '...intrinsically linked to income and opportunity...which correlates almost perfectly with the seas of deprivation in every major urban conurbation in the western world. In London the highest rate is amongst rough sleepers who represent the tip of the iceberg in terms of the broader homeless population. Infection is related to, poor diet, malnutrition and stress on the immune system caused by drug and alcohol.' (London Assembly 2015:2)

In 2012 NICE Guidance on identifying and managing pulmonary tuberculosis among hard-to reach groups recommended:

- Ensuring housing for those entitled to state-funded homes.
- Funding and supporting homeless people with active pulmonary TB, who are ineligible for state-funded accommodation.
- Ensuring patients have accommodation throughout TB treatment.
- Making plans to continue housing once TB treatment is completed.
- Collaboration between housing departments, TB teams, prevention programmes, and hostels to ensure housing is available (NICE 2012).

These guidelines have not generally been implemented (London Assembly 2015:2), with notable exceptions, e.g. Hackney, where local authority homes are provided during TB treatment, and through the pan-London Find and Treat service (PHE 2015:1, Potter et al 2015, UCHL 2014).

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In practice the government sometimes simultaneously excludes by denying employment, housing and income; detaining infectious people; failing to ensure GPs are proficient in diagnosing TB; under-resourcing 'find and treat' services and deporting people to infect others (NHS London 2011, Belling et al 2012, Tower Hamlets Council 2012). It will need a powerful and assertive NHSE-PHE alliance to stop harmful Government policies, which are currently undermining eradication of TB and exporting it though deportation/removal.

CONTRADICTIONS IN UKs TB TREATMENT POLICY

The WHO (2008) requires people with TB to have two negative sputum smears before flying, and for MDRTB two negative cultures. The Home Office doesn't appear to follow NICE guidelines for completion of treatment before deportation/removal, or current WHO guidelines – it deports after complying with redundant guidance requiring 2 weeks of treatment (and negative cultures for MDRTB) (Home Office 2013, WHO 2006:2). The PHE/NHSE strategy based on NICE and WHO guidance requires that:

- undocumented migrants with TB be supported to complete treatment
- homeless people with TB are provided with fast-track access to social care and accommodation for the length of their treatment
- identification and management of active TB in prisons and IRCs is carried out in line with NICE guidance. (PHE 2015, NICE 2012)

DEPORTATION/REMOVAL OF PEOPLE INFECTED WITH TB

Most front-line health staff endeavour to create a safe, therapeutic environment for the treatment of TB, e.g. "To keep patients with high risk factors adherent to meds over 6 months, we have developed a care package for them, which introduces stability into their chaotic lives. Our most complex patients are typically homeless and 'living under the radar', with NRPF[5]". (Homerton Hospital 2015)

The Home Office may deport people receiving TB treatment who are potentially infectious, following advice of IRC doctors that the person is 'fit to fly' (IRC doctors are not TB experts and there is no evidence that the prisons policy for TB is used in IRCs). Doctors cannot foretell the consequences of deportation/removal and may prescribe short term TB medication and give the 'safe to deport' tick. (Home Office 2015).

[5] No Resource to Public Funds

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The position of NHSE is that:

"With regard to managing the longevity of treatment for those patients being returned or removed from the detained estate, the World Health Organisation (WHO) have ensured that TB medications are accessible worldwide so whichever country someone is returned to they should be able to continue any pharmacological treatment started in this country. Therefore an individual being returned to their originating country would be prescribed an appropriate level of medication to allow them time to locate and access medication in their home country".

IRC doctors who are accountable to NHS England cannot possibly know if a deported person with TB will be able to access medication via the WHO, especially if the person has a highly resistant strain of TB. In many countries accessing appropriate TB therapy is near impossible and this is reflected in the extremely high incidence of TB in those countries, e.g. Pakistan. Even if TB drugs are prescribed by the IRC medical service, they would probably be insufficient to complete treatment particularly in the case of MDRTB. Thus, NHSE the healthcare commissioner for all IRCs, which has a strategy that requires patients to be supported with completion of treatment and accommodation, in practice cannot require that to happen and doctors advising the Home Office that a person is 'fit to fly', but ignoring NICE guidelines, might breach 'Good Medical Practice'16b:"to provide effective treatments based on the best available evidence" (GMC 2009,2013).

The agreement between the Home Office, PHE and NHSE is described in their Partnership Agreement (April 2015): "9.15 … We have a collective understanding that the decision to detain/maintain detention is always made by Home Office but healthcare has a key role in providing advice, where appropriate, to help inform this decision making".

Some questions put to NHS England (FOI-008385) on this issue initially received a hostile response from Health and Justice Department, but later led to the following exchange:

1) Please provide a copy of your guidance in relation to people detained in IRCs who have been treated for TB and are regarded as fit for deportation/removal?
2) Is there guidance that explains the procedure and what medication is given to them?

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3) In relation people with resistant TB that will take up to two years to be completely cured, what guidance do you follow? I am aware of your guidance based on WHO recommendations (Home Office appears to follow the second edition rather than the third) but not on the actual process in relation to medication."

RESPONSE FROM NHS ENGLAND

"Public Health England (PHE) has produced TB guidance for prisons, which is available at the following web link: https://www.gov.uk/government/publications/managing-tuberculosis-tb-in-prisons. Whilst we recognise this document is designed for the secure estate we are able to cross reference it to support our management of people in the detained estate. PHE have also recently established a Cross-Directorate Collaborative Working Group on Latent TB Infection (LBTI) in Immigration Removal Centre (IRC) Populations chaired by Éamonn O'Moore and Hilary Kirkbride. This work informs the overarching TB strategy and all the TB control work which is taking place. NHS England also work to the relevant National Institute for Health and Care Excellence (NICE) guidance, which can be accessed at the following web link: https://www.nice.org.uk/guidance/ph37"

There is no evidence that the TB guidance for prisons (Management of Tuberculosis in Prisons) has been implemented in IRCs and there is no parallel guidance for IRCs.

UNANSWERED QUESTIONS

1) I would be very grateful for a response. Could you also tell me if there is data recording any serious illness suffered by people in IRC, e.g. TB, HIV, malaria? (September 9th 2015). Sent to: christine.kelly14@nhs.net, hayley.weaver1@nhs.net

The Partnership Agreement makes the following statements:

8.3 Detainees should expect continuity of care between establishments, and with community services as permitted, if given leave to remain in the UK or otherwise released from detention. Those being deported who have been diagnosed and treated

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for HIV or **TB infections should be clinically assessed and be in receipt of an appropriate supply of medication from the healthcare providers in their IRC to allow time for them to seek healthcare in their home country upon their return.**

Priority 2

9.5 Improve the pro-active detection, surveillance and management of infectious diseases in IRCs and improve capability to detect and respond to outbreaks and incidents; and to acknowledge and address the pathway challenges that this patient cohort is presented with in respect of **where they might access on-going treatment, particularly in respect of Hepatitis C treatment and the active identification and management of active and latent TB within this population.**

9.6 The greater prevalence of infectious disease, especially blood-borne viruses (BBVs) and tuberculosis (TB), amongst detainees and the ability to deliver active case finding programmes among traditionally under-served populations passing through the IRC estate provides an opportunity to make significant improvements to both the health of detainees, their family and social networks, as well as **public health gains for the wider population- the community dividend.**

9.7 In support of this priority during 2015/16 we will:
Continue to improve the detection of TB at or near reception and improve treatment for those who are infected (including provision of Directly Observed Therapy (DOT) and **treatment completion in detention, in the community and following removal or deportation/removal through the appropriate provision of medication on removal)**

Evidence will be required to demonstrate that these aspirations are being met. The failure of PHE to provide access to meetings of the TB Control Board for London, or copies of the minutes of the Board is a cause of great concern. Transparency and public accountability are essential is PHE is to have credibility in relation to its much delayed assault on the TB endemic.

ADVICE AND ADVOCACY FOR VULERABLE AND DETAINED PEOPLE

A homeless Lithuanian woman with MDR/TB had been treated in a negative- pressure hospital room for five months. She was discharged to her local hospital, but the local authority would not house her, so she remained in hospital for a 10 more weeks. She had a 'right to remain 'in the UK, but couldn't demonstrate 'habitual residence' in her local area and was therefore denied housing (Potter et al 2015).

TB Control Boards were established in 2013 to achieve a 50% reduction in TB by 2018, using 'whole system' approaches, but their 'terms of reference' failed to include promoting relief of homelessness and deprivation for people with TB who have NRPFs. Neither do they promote access to advocacy and advice for vulnerable people.

Despite the growing TB endemic and homelessness, there is a paucity of advocacy and advice from statutory and voluntary agencies. TB Alert won't provide advocacy or challenge deportation/removal of TB patients (TB Alert 2015), whilst PHE provide more general and helpful advice, but takes a week to respond to members of the public requesting advice on TB treatment (PHE 2015:3).
NHS independent advocacy (NHS Complaints Advocacy 2015) may provide advice - two agencies responded to our requests regarding information on 2A Orders. Medical Justice (MJ 2015) provides advice and legal support for those detained in IRCs but not advocacy. Doctors of the World (DOTW 2015) provides free access to healthcare: "whatever the person's status and wherever they live" – invaluable for migrants needing medical treatment but fearful of accessing mainstream services.

Although a statutory duty is laid on local authorities to provide information to patients in relation to Part 2A Orders, none of the 13 authorities contacted were able to provide any information to enable a person to understand the consequences of the Order, why it has been made and their right of appeal. The author of the Health Protection Regulations Toolkit, asked about absence of support for detained patients replied: "we expect Local Authorities to be compassionate at every stage" (Hele 2011, 2015). Inquiries to several hospitals, PHE and TB Alert failed to produce access to sources of advocacy or advice for detained patients (Advocacy Inquiries 2015).

Thus it is difficult to say: 'who advocates for the patient'. Despite clear regulations, and guidance from NICE and WHO/StopTB Partnership (2010) there are no expert agencies

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ready to provide support to people on Part 2A Orders and those with TB fearing deportation/removal would struggle to find an agency able to assist them.

DISCUSSION AND CONCLUSION

"I should like to die from consumption, helping to popularize the disease as the disease of artists". Lord Byron.

In the pre-antibiotic era, TB was romanticised by association with art, trips to Switzerland to take 'the air' and south coast sea-bathing hospitals, where patients 'could catch the sun' (Kirby 2004). Once treatment was available, TB's 'social class' changed and it relocated "...with the seas of deprivation in every major urban conurbation in the western world" (London Assembly, 2015:2). TB follows social movements and demography, inserting itself when the social infrastructure frays and safety nets deteriorate. It feeds on lack of compassion, stigma and neglect (Goffman 1963).

The UK TB endemic is catastrophic - 85,000 people treated in the UK between 2002-12, with 3000 deaths. Following WHO's declaration of a 'Global TB Emergency' in 1994 and the 'Stop TB Strategy' in 2006 (WHO 1994, 2006) it took the UK government 18 years to formulate a strategy to eliminate 50% of TB by 2018 (PHE 2013, 2015). During the 'great inertia', infection rates increased in many boroughs, e.g., Brent, Newham and Redbridge suffered the largest outbreak of drug-resistant TB in western Europe.

Without a massive strategic reorganisation of TB services, the 50% target is unlikely to be achieved. The Health and Social Care Act 2012 created a chaotic model of NHS leadership (HSJ 2015) and London now has 32 TB teams, but no pan-London leadership. MDRTB which requires two years of treatment (London Assembly 2015:1, Clark 2015) is directly related to homelessness, so public health and local authorities must fund housing. The New York model shows that one team focussed on systematic outreach with homeless and destitute people, effective contact tracing and sufficient resources, can be highly effective.

Achieving this transformation may require the Secretary of State for Health to create a legal enforcement framework, by publishing Directions[6] to public bodies, that would make NICE TB Guidance legally binding (DH 2010:2). This can be done under Part 8 of the Health and Social Care Act 2012 (DH 2012) and would place duties on NHSE, PHE and CCGs to fund and implement the Directions - including housing, food and other support. NHSE could ensure that CCGs work jointly to eradicate TB, by forming a single outreach and treatment team, and press government to reverse policies that promote avoidance of TB outreach teams (GLA 2009, NHS London 2011:2, Story 2015).

People who are homeless, must feel safe when interacting with 'find and treat' teams and health bodies, e.g. all interactions must be confidential and secure. Bodies like PHE, NHSE, CCGs and the GMC should build the trust of service users by becoming sources of useful information - some information requests to PHE and the GMC received unhelpful responses and some information could not be obtained, e.g. copies of minutes of the London TB board(GMC 2009, PHE 2015:3).

Stigma is another major disincentive to accepting treatment and is related to social attitudes about TB. For homeless communities, meeting a TB worker in an abandoned building, may feel less stigmatizing than a hospital clinic: fear of infection, discrimination and being labelled as a TB sufferer contribute to avoidance and stigma. Disclosing names of TB contacts can feel like an act of betrayal (Douglas 1994, Dodor and Kelly 2009, Courtwright et al 2010).

For those with highly resistant TB who distance themselves from services, most are persuaded by 'public health' to accept voluntarily treatment. Rarely for people who are infectious and refuse TB treatment, 2A Orders may be used. Detention never happens for other infections like influenza, which cause many more death – 5000 per year from flu compared to 300 from TB; is this due to the troubled history of TB, or simply that TB has become an 'underground' disease that associates it with coercive powers?

It is surprising that while public health infrastructure for 2A Orders is very sophisticated, extensive enquiries about empowerment, advocacy and support for detained people in line with the regulations, yielded no information for patients whatsoever from public or voluntary sector sources, despite the Public Health Act having been amended to reflect

[6] Delegated legislation

the ECHR in 2010. Comparisons with the Mental Health Act provide a useful lens on how human rights have been successfully embedded into the law of detention for people with mental health problems, e.g. clear structures of review and appeal and a code of practice.

Any act of detention must in law be subject to the' least restrictive principle', however a patient can be detained for long periods in hospital to prevent the transmission of infection, presumably with a security guard at their door. Whilst they cannot be obliged to accept treatment, they must remain in a hospital ward of vulnerable people, where there is an increased risk of infection transmission.

A disturbing finding was the confusion at government /arm's length body level about the direction of some aspects of TB prevention policy. NHSE and PHE follow NICE guidance which contradicts Home Office policy in relation to 'irregular migrants'. Despite signing the Partnership agreement the Home Office appears to be indifferent towards a deterioration in the social welfare infrastructure and their approach would appear to be consistent with the development of TB antibiotic resistance. Secondly, the deportation/removal of people on treatment for TB, directly contradicts the policy of NICE/NHSE/PHE to support the patient until treatment is finished. The accountability of IRC doctors in relation the NHSE-IRC healthcare procedures and NICE guidelines, need to be made contractually transparent and if the prison guidance is relevant to IRC it should state in the document that this is the case.

New regulations may be needed to ensure that the Home Office cannot deport people when this would result in the international transmission of TB. Deporting a person with MDRTB or XDRTB without assurance of adequate medication, accommodation and support at the destination could be a death sentence for the deportee and perhaps for their family.

There is a need to amend the Health Protection Regulations to ensure that those who are most vulnerable and their families are protected throughout the course of treatment, and this must include those whom the state has decided should ultimately be deported. There might be merit in making the NICE TB guidelines legally binding on all government agencies.

RECOMMENDATIONS

1) CCGs and NHS England should ensure that all GPs re adequately trained to diagnose TB in the community.

2) The Secretary of State for Health should publish Directions making the NICE TB Guidance legally binding on NHSE, PHE and CCGs in order that treatment is provided to all patients until their infection is fully treated.

3) Health Protection Regulations should require that those with TB who are most at risk have full access to antibiotics and social support throughout the entire period of their treatment – including those who are at risk of deportation/removal (see appendix for proposed draft regulations).

4) NHSE through their IRC contracts, should ensure that doctors working for healthcare providers in IRCs, follow NICE Guidance in relation to the duration of TB treatment, and the advice they give to the Home Office on deportation/removal of detainees with TB.

5) PHE should establish a rapid response pubic information service, to provide fast, accurate information for people with TB about access to treatment and 'deprivation of liberty' in relation to infectious diseases.

6) PHE and local authorities should collaborate to produce an information pack for people detained on 2A Orders, and commission a national advocacy service to provide advice and empowerment to detained people with TB.

7) The General Medical Council should provide public assurances that doctors breaching the confidentiality of patients who are 'irregular migrants' will be subject to disciplinary procedures.

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APPENDIX – PROPOSED DRAFT STATUTORY INSTRUMENT

THE HEALTH PROTECTION (CONTINUITY OF CARE) REGULATIONS

DRAFT STATUTORY INSTRUMENT

2016 No. 000

PUBLIC HEALTH ENGLAND

The Health Protection (Continuity of Care) Regulations 2016

Made - - - - - - - - - - - - - - - 000

Coming into force - - - - - - - - 000

The Secretary of State makes these Regulations in exercise of powers conferred by Sections 45B (1)(c), 45B(2)(b), 45C(1), 45F(3) of the Public Health (Control of Disease) Act 1984.
for the purpose of preventing, protecting against, controlling or providing a public health response to the incidence or spread of infection or contamination in England and Wales (whether from risks originating there or elsewhere).

A draft of this instrument has been approved by resolution of each House of Parliament pursuant to section 45Q(2), (3) and (4) of the Public Health (Control of Disease) Act 1984.

Citation, commencement and application

(1) These Regulations may be cited as the Health Protection (Continuity of Care) Regulations 2015 and shall come into force on 000

(2) These Regulations apply in relation to England only.

Interpretation

2. In these Regulations-

"the Act" means the Public Health (Control of Disease) Act 1984;

"practitioner" means a registered medical practitioner or a registered nurse practitioner;

"P" means a patient.

Duty on practitioner to give notice of inadequate care for infectious diseases

3.- (1) This regulation applies where a registered medical practitioner or nurse practitioner, having made reasonable inquiries, and having made reasonable attempts to arrange for care to be provided to P, considers that P is not receiving appropriate and adequate care and treatment for an infectious disease.

(2) In relation to the care that the practitioner is of the opinion that P should receive for the treatment of an infectious disease, that care should in the opinion of the practitioner have been provided in a way that shows due regard to the relevant clinical Guidelines produced by the National Institute for Health and Care Excellence in Health and Social Care, consequent upon the provisions of the Health and Social

Care Act 2012 paragraphs 236 and 237.

(3)The practitioner is of the opinion that the failure of those responsible for the care for P to show due regard to Clinical Guidelines produced by the National Institute for Health and Care Excellence, is having or is likely to have a deleterious effect on the health and safety of P and/or the health of those with whom P is or may be in contact with.

Duty on practitioner to advise when care for an infectious disease is inadequate

4.- In relation 45B (1)(c) of the Act these regulations allow the practitioner to advise :

a) the clinical commissioning group for the area where the P has habitual residence in a local authority area;
b) NHS England where P does not have habitual residence in a local authority area;
c) Public Health England, and the
d) Secretary of State for the Home Department, where the person is detained in one of Her Majesty's Prisons or an Immigration Removal Centre or a youth offender institution

Whenever it is the opinion of the practitioner that P's care and treatment is such that P's health and safety are being or may be compromised.

Appointment of an Appointed Person

5.- In relation to 45B(2)(b) of the Act, these regulations enable the practitioner to advise all or any of the bodies in 4.- a) - d) that in the view of the practitioner P's care and treatment are such that P's health and safety are being or may be compromised. In that event NHS England shall appoint an 'appointed person' for the purpose of:

i) ascertaining whether in the opinion of the 'appointed person' P's treatment is such that P's health and safety is being compromised.
ii) deciding where P's care should be provided if in the opinion of the 'appointed person' P's treatment is such that P's health and safety are being or could be compromised.

Signatory text Name (Minister) Department of Health
Address
Date