

Report of study tour with funding provided from the
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Assessing the impact of nurse led teams employing
Directly Observed Therapy (DOT)
on TB treatment completion in Zambia & London
to inform service developments across Scotland



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I would like to offer my sincere thanks to the following:

- **TB workers & patients met in England and Zambia**
 - *Your enthusiastic and heart warming welcomes have left me with many treasured memories*
- **NHS Borders colleagues & TB Nurses in Scotland**
 - *You have cheered me on from the beginning and will be the key to driving up standards of TB care*
- **Trustees of the GNC for Scotland (Education) Fund 1983 and Margaret Callum Rodger Midwifery Award**
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The views expressed in this report are those of the author and not necessarily those of the funders.

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1. Summary

Scotland has had a relatively low and stable incidence of tuberculosis (TB) in recent years but the picture may be changing. There is evidence of an increasing incidence of disease and a background concern of emerging antibiotic resistant strains.

TB disproportionately affects vulnerable groups and a convergence of social and clinical complexity of case management presents real challenges to treatment completion. Directly Observed Therapy (DOT) is a strategy widely promoted by the World Health Organisation to improve cure rates. It is however not widely practised in Scotland and a missed opportunity perhaps exists to tackle the concern that more than 1 in 5 patients do not complete a full 6 month course of treatment.

Zambia is a country with a high burden of TB disease and yet achieves very successful treatment outcomes. London has the highest TB rate of any capital city in Western Europe and 10% of cases are thought to be drug resistant and some services have developed innovative approaches to TB control via DOT provision.

This is a report of first hand experience and knowledge of TB control gained through a travel bursary by visiting high caseload TB services that have developed innovative systems of DOT provision in Zambia & London.

Recommendations are made as to how this knowledge may be adapted and applied by nurses working with TB patients across Scotland for the benefit of their patients and wider public health.

2. Activities supported by fund

a) Introduction – background and rationale

Drugs to effectively treat tuberculosis have been available for over 70 years although with the relatively recent emergence of multi-drug resistance strains a significant public health threat hangs in the air (van Hest, 2014). Never has it been more important to ensure that effective case management strategies are in place to achieve disease cure through treatment completion. A great difficulty in TB treatment lies in the lengthy course of therapy (at least 6 months) needed and unpleasant side effect profiles which can quickly exacerbate poor adherence. Many patients do not go on to complete the prescribed course. TB services need to be not only accessible but appropriate to the complex clinical and social demands that many patients place on them (RCN, 2012). A widely accepted approach to encourage treatment completion in both developing countries and the developed world has been to assign a designated individual ((health care worker, community volunteer or family member) to personally have sight of the patient taking their drugs - Directly Observed Therapy (DOT). They are expected not only to observe and record treatment but amongst other things may be asked to look out for any treatment complications, encourage clinical follow up and take swift action when treatment is being missed (WHO, 2002).

In recent years Scotland has had a relatively low and stable incidence of tuberculosis. Compared with other parts of the UK and Europe the disease has not been a significant problem with 453 reported cases in 2011. However, the recent epidemiological evidence suggests that the picture may be changing. While tuberculosis is still at lower levels than elsewhere in the UK, the numbers of cases are suggestive of an increasing incidence. The greatest burden is borne by Greater Glasgow and Clyde NHS Board, with just under half of all reported cases and an incidence of 18.3 cases per 100,000 (HPS, 2012). My work as a Health Protection Nurse Specialist between 2009 and 2010 saw more than doubling of cases (n=15) in the Scottish Borders making this the second highest Board incidence of TB in Scotland (13.3 per 100,000) and without a local specialist TB service placed a strain on existing local services (NHS Borders, 2012). No Borders patients received their treatment using directly observed therapy due to operational difficulties in setting this up. Of the six cases notified in 2009 only four (67%) successfully completed treatment falling woefully short of the internationally set target of >85% established by the WHO to reduce transmission of TB. (WHO, 2006). Across Scotland in 2010 a total of 79.1% successfully completed treatment at 12 months with only 8.3% on a DOT programme. *Was this approach being overlooked or neglected in Scotland? A recent survey of DOT provision in London revealed that 8.8% of total of TB patients were able to access it. However more than a third of patients assessed as really needing DOT were offered it (Hemming S, personal communication, June 5, 2014).*

Zambia as a lower middle income country has a high burden of TB disease but a steady decline in TB notifications has been reported since 2005 with 347 per 100,000 population compared to 444 per 100,000 population in 2011. I first visited the country in 2012 as part of a long established twinning arrangement with NHS Borders and St Francis Hospital located in the Eastern Province close to the borders with Malawi and Mozambique (see appendix 1). On average the hospital treats 1600 of the TB patients per year. The Eastern Province of Zambia notified 2389 cases in 2012 with a treatment success rate of 86% - a remarkable achievement given the vast and remote rural area where access to health care is severely limited to the majority of the population (Zambia Ministry of Health, 2012). What was the secret to their success? *Could any lessons be learnt and applied to the Scottish context?*

With these questions in my mind I set out to see if any answers could be found by trips made possible by the travel bursary to Zambia and London.

b) Objectives & Expected Benefits

Main objectives:
<ul style="list-style-type: none"> • Gain first hand experience and knowledge of TB control in a developing country with a high burden of TB disease, excellent treatment completion rates and routine application of DOT • Compare and contrast this experience to London with high caseloads of TB patients and developed systems of active case finding and DOT provision • Develop guidance to apply the knowledge to the variety of settings across Scotland
Expected Benefits for Patients/Service User/Client Group:
<ul style="list-style-type: none"> • Patients commonly accepted as being 'hard to reach' have greater access to services that are more patient centred in their approach to delivering treatment • > 85% of TB patients in Scotland successfully complete treatment • Increase opportunities to identify contacts of TB and thus reduce the burden of disease across Scotland
Expected professional / personal benefits:
<ul style="list-style-type: none"> • Bring the applied knowledge to the TB Nurse Network (Scotland) about new ways to more effectively engage with patients • Strengthen professional links with services with a proven track record of service excellence • Develop my skills that make a valuable contribution to TB care across Scotland • TB services gain a reputation for seeking innovative ways to develop services

c) Funding

Item Description	Estimated	Actual
Travel (Zambia)	£1210	828.74
Accommodation (Zambia)	£550	554.03
Insurance	£60	98.03
Medication & vaccines	£100	150.84
Travel (UK)	£180	386.95
Accommodation (London)	£275	260
Subsistence	£375	207.51
Miscellaneous	£0	77.01
Total	£2750	£2563.11

d) People & agencies visited: summary & key findings

	<h1>England</h1>	<p>Leeds 17th Oct; London 8-13th Dec 2013</p>
<p>Nuffield Centre for International Health and Development, Leeds</p> <ul style="list-style-type: none"> • John Walley, Clinical Professor • Mwelwa Phiri, MPH 	<p>John has published many papers on TB within low- to middle-income country ministry of health services. He helped me to quickly access relevant literature and highlighted the importance of 'DOTS Plus' – facilitative and comprehensive case management strategy that includes, but moves beyond, the mere observation of pill taking.</p> <p>Mwela is a Zambian pharmacist with first hand knowledge of St Francis Hospital and Public Health systems. Good insight into DOT and its strategically important role within a suite of measures for TB control.</p>	
<p>Public Health England, Centre Infectious Disease Surveillance & Control</p> <ul style="list-style-type: none"> • Surinder Tamne, Snr TB Specialist Nurse • Dr Dominik Zenner, Head TB screening unit 	<p>Surinder has a vast knowledge of TB services in England, Chairs the London TB nurses network of 31 different teams and put me in touch with a variety of TB specialists. London has the highest TB rate of any capital city in Western Europe and 10% of cases are thought to be drug resistant.</p> <p>Dominik plays a strategic role in TB control. Pre-entry TB screening for new-entrants shows TB rates amongst the "non-UK born" population are more than 20 times higher than rates amongst the UK born population. The UK Border Agency is rolling out pre-entry screening implemented abroad beyond the initial 15 pilot countries. This replaces inadequate Heathrow/Gatwick chest X ray screening Home Office (2012).</p>	
<p>Homerton University Hospital NHS Foundation Trust</p> <ul style="list-style-type: none"> • Richard Ward, TB Nurse • Reg Straub, TB Outreach Worker 	<p>Gained insight through discussion and community visits into the high rates of TB in Hackney, particularly amongst Eastern European homeless people. This led the team to develop an outreach clinic to screen for TB and work innovatively through a Service Level Agreement with Social Services to secure funding to house individuals at a huge saving to the NHS by avoiding prolonged hospital admission often associated with homelessness. Cost effective strategy. Costs £10 per night to house and feed a patient compared with £650 to £1500 in an NHS bed with negative pressure facilities. Also increased DOT outcome measures due to the better social stability.</p>	
<p>Find & Treat TB Project</p> <ul style="list-style-type: none"> • Dr Al Story, Clinical Lead • Yasmin Appleby, TB Nurse Specialist 	<p>This nurse led service model funded since 2005 by Department of Health starts from suspected TB, offers a MDT package of health AND social care which is community based. It insists on DOT for all delivered through a range of options. These include pharmacists; GP's; peers; outreach & key workers; and video observed therapy (VOT). I attended a session of the mobile X-ray parked at a woman's hostel near Kings Cross. Digital images achieve a high level of sensitivity and specificity valuable in TB control by early identification of cases in targeted hard to reach populations. They work with several third sector organisations such as Groundswell who provide Peer Educators – people previously homeless with TB. They are a valuable support in educating people on the realities of TB and encouraging screening and treatment. Spent an evening out with 'The 'Connection' street team who work with people (many with TB) sleeping rough in the City of Westminster.</p>	
<p>North Central London TB Service</p> <ul style="list-style-type: none"> • Susan Dart, Clinical Team Leader • Scott Johnstone, DOT worker 	<p>Attended cohort review implemented as a tool to improve services through systematically reviewing the case management and contact investigation of every case of TB. Revealed significant variance in caseload complexity as well as capacity to provide DOT. Inconsistencies revealed about who should get DOT. The North Central London Team has a strong track record in implementing findings of cohort review that revealed DOT difficulties. I spent a fascinating day with one of their DOT workers (non nurse) employed to free up comparatively expensive and valuable TB nurse time to focus on other important aspects of case management.</p>	



Zambia

19th Oct – 2nd Nov 2013

<p>Jhpiego – an affiliate of Johns Hopkins University</p> <ul style="list-style-type: none"> • Dr Joseph Banda Assistant Project Director 	<p>High profile NGO with extensive programmes across Africa. Stressed the importance of strengthening the integration of HIV/TB services due to the high rates of HIV and TB co infection resulting in TB being one of the leading causes of death among people living with HIV/AIDS. Support to patients through DOT volunteers invaluable to treatment completion. Rely heavily on family to support treatment (“health is a family issue”) except in cases of MDRTB. Launched ‘SmartCare’ electronic patient health records system – provides better continuity of care by tracking medical history and treatment information for HIV clients</p>
<p>FHI 360</p> <ul style="list-style-type: none"> • Amos Nota, Senior Technical Officer 	<p>Well respected long standing NGO. Programmes to support the Zambia Ministry of Health in efforts to control TB and TB/HIV-related disease. Ambitious 50% reduction goal of TB prevalence and mortality by 2015. Success to date – 73% case detection rate for all forms of TB (target 70 percent); 91% treatment success rate (target 85 percent). Produce excellent TB Infection Control training resources and Training Needs Analysis of community based volunteers. ‘Cough to cure’ pathway detailed barriers to be tackled if a high rate is to be achieved. Incentives to volunteers supporting the DOT programme can be motivational.</p>
<p>St Francis Hospital</p> <ul style="list-style-type: none"> • Dennis Makowe – TB Clinical Officer • Merina Musonda – Lead Nurse for TB service • Mathew Mwale – Hospital Administrator • Kennedy Mbewe – TB treatment supporter 	<p>Severely under resourced team. Nurse led but only one full time clinical officer to co-ordinate care of 1600+ patients diagnosed per year. All put on DOT. Limited input from other hospital staff. Rely heavily on 36 (18 active) DOT volunteers. 3 of them previous TB patients. Support an average of 12 patients. Refer TB suspects for screening, trace contacts and defaulters, recognise side effects. Provide basic counselling and provide health education to patients, family members and the wider community. Many also volunteer for other patient support programmes. Enlist the support of community leaders (Chief, head man) to put forward names of potential volunteers and conduct ‘Community Sensitisation’ meetings to raise awareness of TB and HIV through music and drama. 1 week training programme with refreshers based on national and WHO guidelines & delivered by 2 different agencies. Volunteering has led on to employment within the hospital for a few. Each provided with bike to visit clients – a big engagement incentive. 90% treatment completion.</p>
<p>Ministry of Health</p> <ul style="list-style-type: none"> • Dr Kennedy Malama, Eastern Provincial Medical Officer 	<p>Zambia has a TB notification rate of 375/100,000 with an estimated case detection rate of 58% while Eastern Province has a notification rate of 166/100,000. Latest national figures show that nearly 86% of the 50,000 cases notified annually were tested for HIV (WHO, 2014). 64% of these were HIV positive and the country attained 82% cure rate, 87% treatment success and 4% mortality rate. TB case detection remains a challenge in the Eastern Province due to long distances, few diagnostic centres, and shortage of qualified staff. A comprehensive provincial plan to stop TB (2011-2015) is underway. It aims to dramatically reduce the burden of TB by 2015 in line with Millennium Development goals, the Stop TB partnership targets and the sixth National TB strategic plan. Crucial objective - coordinate provincial level efforts to expand DOTS to include use of volunteers to actively case find through community sputum collection.</p>
<p>Riders for Health</p> <ul style="list-style-type: none"> • Essau Mbewe, Programme Accountant 	<p>Help outreach health workers to travel to rural communities and provide services such as health education, disease surveillance, immunisations, maternal and child health services and HIV counselling. Usual mode of transport for these health workers is the motorcycle which is a relatively low cost solution to a logistical problem to reach people in remote locations and help them to access life saving medical services. Without their input a delay of one month would be common in achieving a diagnosis for TB This has significant implications for TB control.</p>



Scotland

TB Nurses (Scotland) Network



I received responses from 16 nurses involved in TB care across most of the 14 Health Boards in Scotland to an online survey conducted prior to my visit to Zambia and London. It set out to capture various elements of local practice in the light of the 2012 published RCN document 'Tuberculosis case management and cohort review: Guidance for health professionals'. The views from 6 Health Boards were collected from a follow up survey undertaken after my return to look a little more at DOT provision. In addition I visited TB nurses in Glasgow who undertook DOT from time to time. The main findings were as follows:

- 20% said that not all TB patients have a named case manager
- Nearly half did not conduct home visits
- DOT (using a daily or thrice-weekly dosing regimen) was rarely employed as a treatment strategy
- 75% never used incentives to encourage clinic attendance
- 40% reported that treatment completion rates in their Board were less than 85%

Commonly cited obstacles to DOT are:

- Recruiting DOT observers particularly from pool of community nurses and other health care workers
- Patients reluctant to come to clinic
- Lack of real incentives offered to patients to attend
- Outright refusal by patients
- Complex drug regimens
- Limited out of hours services
- Remote or distant locations make HCW observation challenging

The World Health Organisation has been recommending DOT for many years for all patients to ensure treatment compliance and limit the development of drug resistance. The first WHO endorsed DOTS-Plus programmes began in 2000 as a particular response to limit emergence of drug resistance. DOTS lies at the heart of their six point "Stop TB Strategy" and has been embraced by many countries with high burdens of disease such as India and Zambia (Zambia Ministry of Health, 2014).

High level evidence generated by eleven randomised controlled trials in low-, middle, and high income countries on the impact of DOT programmes has been conducted by the Cochrane Collaboration (Volmink & Garner, 2009). It is interesting to note that no assurance could be found that DOT compared favourably to self administration of treatment on cure or completion rates. More recent similar conclusions were made from a systematic review and meta-analysis of treatment outcomes from community-based drug resistant tuberculosis treatment programmes (Weiss et al al, 2014). Many studies however have been published that indicate a 90% cure rate and decreased odds of drug resistance when DOT is effectively deployed (Peruhype et al, 2014).

The impracticality of an approach relying on all patients returning daily for supervised treatment to a health facility is widely cited (Khogali et al, 2014). My study visits have revealed however an almost universal acceptance of the valuable place modified versions of DOT has in the management of TB. Each Zambian service equally emphasised the importance of integrating tuberculosis and HIV services within the community due to the high co infectivity rates as stressed in the ZAMSTAR trial involving over 1 million people across 24 communities in Zambia and South Africa, (Ayles et al, 2013).

e) Implications for practice

A ½ day workshop of the Scottish TB multidisciplinary network held in May 2014 explored issues around 'hard to reach' groups and acknowledged that current services were often not geared to patient centred care thus making many TB patients 'hard to serve'. An example of this is the observation that current low levels of DOT provision for patients in Scotland has changed little from an earlier review of TB services in Scotland (Hamlet, 2001). The TB Action Plan for Scotland (Scottish Government, 2011) explicitly supports the pursuit of high quality DOT expansion and enhancement as promoted by the WHO six point "Stop TB Strategy". Innovative approaches adopted by several agencies visited during this study tour may have some direct application to the Scottish context.

This study tour has reinforced the challenge to find more creative and innovative ways to offer and actively encourage DOT for anyone whose social circumstances or lifestyle makes it difficult to recognise TB symptoms, access health services, self-administer treatment and attend regular hospital appointments. These will typically include:

- Homeless people and those in insecure/overcrowded accommodation
- Substance users
- Detainees – previous and current
- Destitute migrants

Further consideration therefore should be given to the following:

1. Ensure all TB patients have a nurse case manager (key worker) to facilitate education and involvement of the patient and significant others in achieving adherence
2. All 'TB teams' audit DOT assessment and record outcomes of patients against Scottish & NICE guideline criteria (Health Protection Network HPN, 2009)
3. All aspects TB care traditionally undertaken by nurses should be closely scrutinised to see if some routine tasks (DOT provision) could be delegated to other competent colleagues or volunteers to allow more targeted and skilled nursing interventions to take priority
4. Promote more engagement with Third Sector organisations in order to exploit the potential of mobilising trained volunteers to support TB patients throughout their treatment, educate contacts/wider public and assist in active case finding.
5. As Scotland prepares to reform services for Health and Social Care integration, Boards and Local Authorities will need to explore mechanisms to develop packages of health and social care through Service Level Agreements for 'hard to serve' TB patients in order to reduce need for hospital admission and promote successful treatment outcomes
6. TB services embrace the opportunities that smart phone and internet technology bring to a subset of patients amenable to video observed treatment (National Institute for Health Research, 2013)

f) Dissemination Plan

Share findings, encourage further discussion and identify solutions with:

- TB Nurse Network (Scotland) – Chair : Lesley Ritchie, NHS Lanarkshire
- National Multidisciplinary TB network – Chair: Dr Kirsty Licence, NHS Tayside
- Scottish Government Health Department - Dr Duncan McCormick & Ros Moore

Submit presentation for the Scottish Annual TB Conference.

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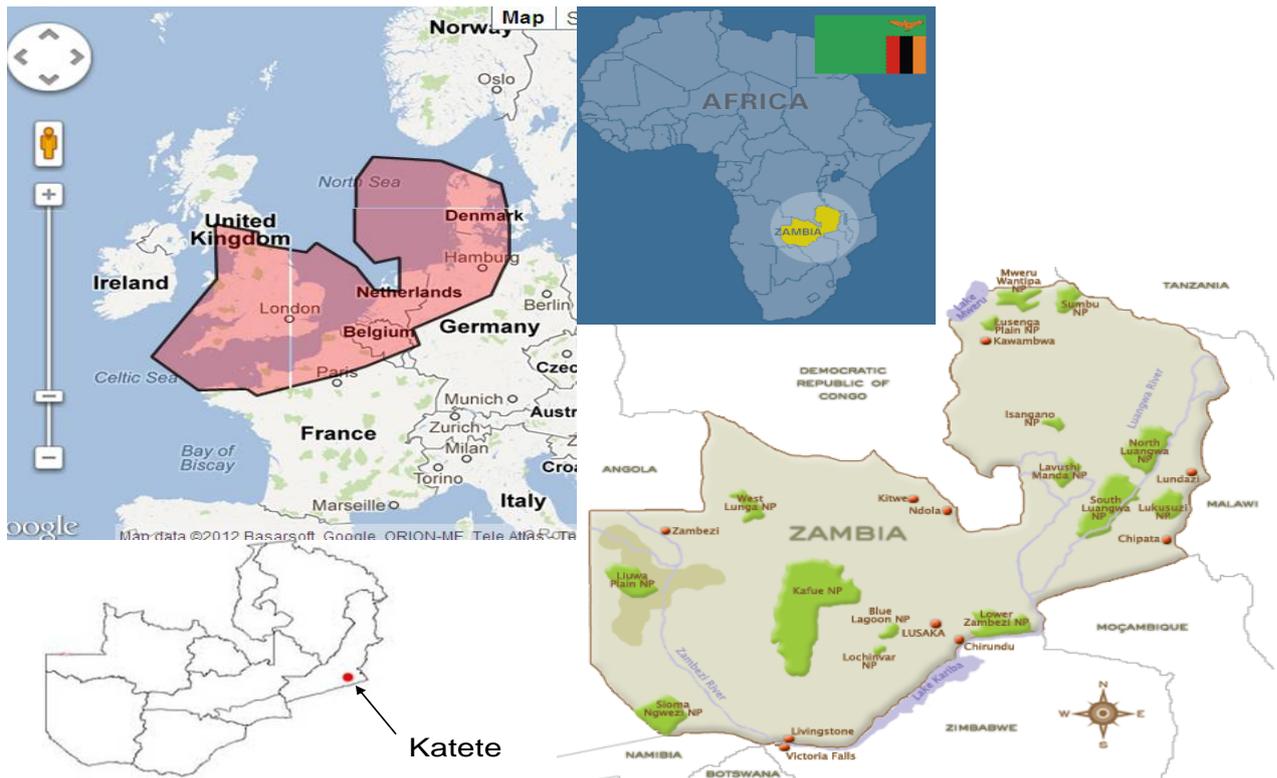
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5.0 Appendices

Appendix 1 – St Francis Hospital & NHS Borders

For almost 20 years the Borders General Hospital and St Francis' Hospital in Eastern Province, Zambia have been linked, and in January of 2009 the two hospitals were formally twinned. Over the past few years, there have been projects involving the sexual health team, pharmacy, radiology, maternity and public health as well as visits by GPs, paediatricians, and numerous medical students.



St Francis' Hospital is a mission hospital situated in a very poor rural area of Eastern Province near the Malawian border, 7 hours drive from the capital, Lusaka. It was founded in 1948, is administered by a Joint Anglican Catholic Management Board, and is funded as a Zambian Ministry of Health second-level referral hospital. The majority of patients are poor peasant farmers living in traditional villages.

The hospital has 360 beds with recognized training schools for enrolled nurses and enrolled midwives. It is a busy general hospital for an immediate population of 180,000 and it is also a referral hospital for 1.5 million people living in the Eastern Province - an area the size of Scotland. Patients are referred for surgery, serious medical, paediatric conditions and obstetrics by 14 rural health centres in Katete District and seven other hospitals and rural health centres in the Province.

Chris Faldon is a Health Protection Nurse Specialist and has chaired the NHS Borders TB committee for a number of years. He is actively engaged in supporting water and sanitation programmes as well as the TB service. Fund raising efforts has enabled the purchase of 36 bicycles in Zambia for the TB Volunteers Community Supporters at St Francis to assist in their work. It has also funded building improvements to the TB clinic waiting area.