"On yer bike!" - NHS Borders supports TB treatment & control in Zambia: an evaluation

Tuberculosis in Zambia is a major public health problem.[i]
Did you know……?

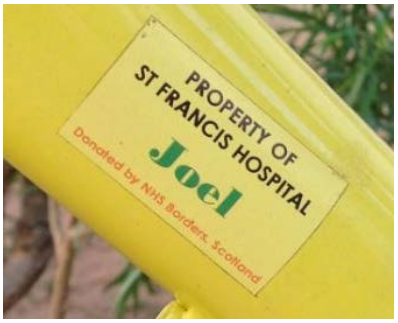
- Every day in Zambia more than 30 people die needlessly from TB
- 64,000 new TB cases are diagnosed each year: (6,000 in UK)
- 406 per 100,000 of the population have TB (10 per 100,000 in UK)
- 6 cases out of 10 have HIV too. This makes treatment even more difficult
- It takes at least 6 months of treatment with a combination of antibiotics to treat TB
- This stretches out to 18 months if it is a drug resistant strain
- Side effects are common and unpleasant putting people off completing treatment
- St Francis Hospital[ii] is formally twinned with NHS Borders. It treats over **1600** new cases every year (Scotland - 300, Borders General Hospital - less than 5 per year). Despite this excessive workload, 85% of patients complete treatment in line with WHO targets[iii]. (80.3% in Scotland in 2014[iv]).

When Chris Faldon, Nurse Consultant, NHS Borders, first visited the hospital in 2012 he could see that the TB workload was overwhelming. A team led by a few nurses but largely delivered by Dennis Makowa, Clinical Officer and a team of volunteers (many of them had been previous TB patients) worked tirelessly to help men, women and children to complete their treatment. These 'Treatment Support Volunteers' are an amazing group of men and women who give of their own time to work with TB patients. This could involve a variety of tasks ie encouraging them to keep appointments, Direct Observed Therapy (DOT) of medications, delivering drugs to those who cannot travel, giving advice on diet and nutrition and generally just being there when times are tough. They face many challenges as they try hard to support the patients. When asked what would make their work easier the loud cry came back – "**a bicycle!"**

What did we do?

1. Raised funds (quiz nights, cake sales, gifts from Galashiels, Gateshead, Germany and elsewhere!)
2. Researched and then discussed good practice models with various agencies, individuals and NGO's (Jhpiego – an affiliate of Johns Hopkins University[v]; FHI 360[vi]; Riders for Health; Ministry of Health[vii]; Nuffield Centre for International Health and Development, Leeds); Eric Bing[viii].
3. Purchased 36 bikes (and tool kits) from Zambikes[ix]. A robust model for difficult terrain.
4. Delivered bikes in 2013 along with a tee shirt each. A service was held in the hospital chapel.
5. Paid for building improvements to the TB patient waiting area
6. Went back in 2016. Ran a bike maintenance course with Zambikes and provided each volunteer with a new tee shirt. Asked them what they would benefit from now. Answer – a back pack for their community visits
7. Over £6,300 raised since 2012 to help with the volunteers requests for assistance

How are the bikes being used?



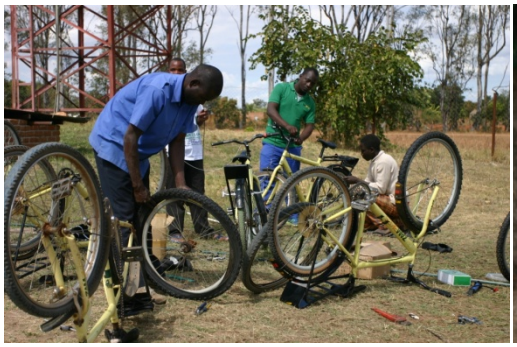
Fantastically! One of the bikes was stolen and another was recovered by the police. Each bike was given an identity with the name of a book in the Bible. Volunteers who provided **regular reports** and **maintained the bike** at their own expense were promised ownership would transfer to them after 3 years of use. Each volunteer was interviewed in 2016 to get a feel for what their work was like, what pressures they faced and what difference their bike had made.

These are some of the pressures they identified and suggestions for future support:

- **Poverty** – many people do not have enough food to give themselves the proper nutrition to build themselves up and get better. The volunteers could benefit from teaching programmes so that they can give advice to patients on good nutrition from a small income.
- **Lack of protective clothing** – this is particularly a problem in the rainy season. They could benefit from raincoats, boots and bags.
- **Poor hygiene** – many people do not have basic Community Health Education. This is something the volunteers could have training in.
- **Expectations of patients –** Many patients think that the volunteers get paid for what they do or at least get incentives. This is not the case. Patients often expect volunteers to bring them food.
- **Patients want to stop taking their medication –** This can be due to side effects or that they begin to feel better. The volunteers try and persuade them of the importance of finishing a full course of treatment and encourage them to come into hospital to have this explained to them.
- **Issues over ownership of the bikes –** There can be a feeling that it is a community bike so is available for anyone to use. This puts pressure on the volunteers. There is a need to bring on board the village headmen/chairmen so that they understand the ethos behind the work of the volunteers.
- **Lack of encouragement –** There is a need for emotional support for the volunteers as they face many difficult situations when they visit the patients in their own homes. Regular meetings together would help.
- **Traditional medicine –** Many people who fall ill seek the help of traditional healers and not medicine from the hospital.
- **Labelling** – Being labelled as people who work with those who have TB and HIV.

Who have the volunteers been supporting?

- **Joseph** was sick for 5 years before he received any treatment. He is looked after by his grandma and is recovering well.
- **Rhodea** has 14 children and started taking TB medicines 4 years ago. She has problems with her eyes and begs for food to feed her family.
- **Eunice** has 4 children and sells roofing material. Her husband is a builder but has TB. He is too weak to work and they struggle to feed their family. Having a volunteer visit them means that they do not need to travel to hospital for the medicines.
- **Tenford** has been well for a while although his wife died. He encourages other people to take their medicines and visit hospital.
- **Catherine** had TB when she was 6 months old. The volunteers helped the family with her medicines and gave advice on looking after her. She is better now but her mother has died. She helps look after the younger children
- **The list goes on and on……**



Volunteer snapshots

Loveness became volunteer in 2005 when she saw a great need in her own community. She wanted to see people recover from TB so as a volunteer felt she would be able to offer advice. 4 members of Loveness' family had TB. They are all better now. The bike has made it safer for her travelling out to the villages as the journey time is shorter.

Moses has only been a volunteer for 2 years. He has a passion to help those suffering from TB and HIV. The bike has made it much easier for him to follow up clients. He can see many more than he used to with the time available.

Loveness (a different one!) has been a volunteer for 11years. Her husband died from TB and she wanted to tell others how to stop the spread of TB and encourage them to take their medicine. The bike helps her save time when transporting patients to hospital, taking sputum specimen for testing, attending monthly meetings

Monica became a volunteer in 2008. She saw how devastating a disease this had within her own village and wanted to help people get better. Monica loves visiting people and although she had a stroke last year she has made a good recovery and has found that the bike has made it possible for her to continue volunteering.

Catherine worked as a cleaner in the hospital for 26 years. She became a volunteer in 2005 after seeing how ignorant people were about the disease. She wanted to teach them and encourage them to go to the hospital and not rely on traditional medicines. She helps clients with practical tasks. The bike makes it quicker for her to visit patients and she is less tired.

Justin has been a volunteer for 11 years. He started because he wanted to stop the spread of the disease. He works in the hospital laboratory but volunteers in his spare time. The bike enables him to travel much further to support clients at a greater distance

Mary has been a volunteer for 10 years. She has looked after family members who have suffered from TB. She nursed her own sister with HIV and when she came to Katete as a nurse she contacted the TB co-coordinator to see if she could help with the project in anyway. The bike has made it much easier for her to take medicines out to patients.

Loveness (a third one!!) has been a volunteer since 2005 She saw many people suffering in the Community. People were begging for food as they were too sick to grow it themselves. She helps with practical tasks such as sweeping, getting water and cooking. The bike means she can keep in touch more often with clients.

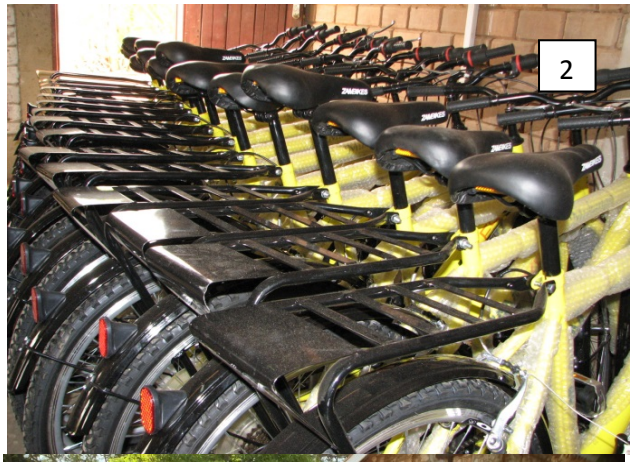
Monitoring & Evaluation

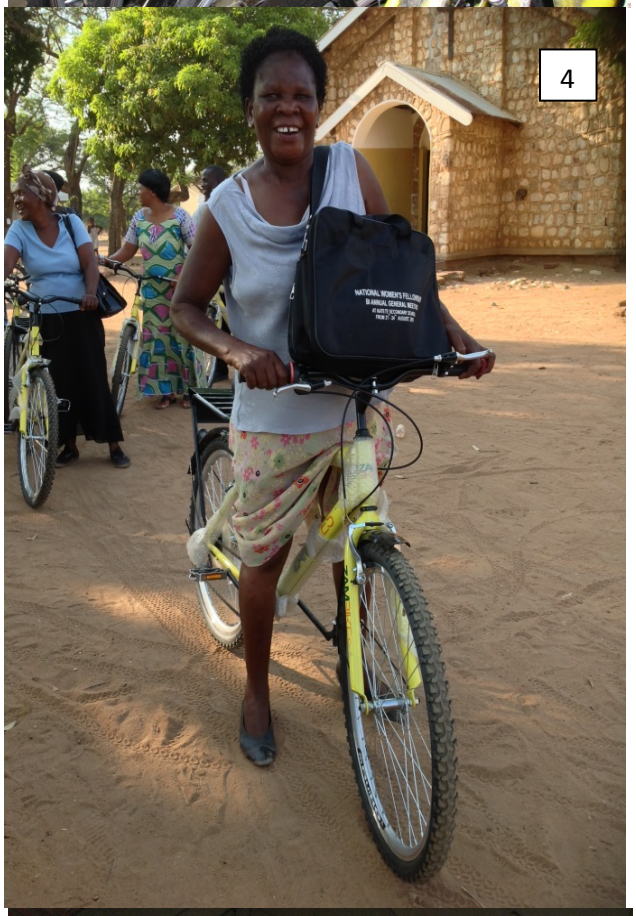
1. **What has been achieved?**
    - A severely under resourced team of volunteers have been each given a bike (at their request). This in turn has helped significantly in retaining their services
    - Over £6,300 raised from a variety of individuals, groups and businesses https://www.justgiving.com/fundraising/zambiabikes
    - Strong working relationships with variety of individuals and agencies with encouraging spin off for future projects
    - Business boosted in Zambia through Zambikes and local suppliers for repairs
    - Bike maintenance workshop funded and minor repairs made. 35/36 bikes still in working order after 3 years.
    - Hundreds of patients better supported to enable successful completion of medication
    - New patients identified with TB due to the better geographical coverage from the bikes
    - Travel bursary from General Nursing Council for Scotland (Education) Fund awarded to bring lessons back to Scotland from TB control in Zambia[x]. Findings presented at Scottish Annual TB Conference.
2. **What worked well?**
    - Listening and responding to identified needs from staff and volunteers in Zambia
    - Establishing an agreed model to encourage responsible use of the resource. This included a signed volunteer agreement and log book of useage
    - Excellent working relationship with the bike manufacturer
3. **Where could improvements been made?**
    - Better monitoring of the use of each bike. Log book not consistently kept. Very few updates were received over the 3 years.
    - More accountability for regular maintenance of the bikes by enforcing the terms of conditions of their use. The standards of bike maintenance were variable.
    - The bikes that were not deployed immediately could have been distributed to other volunteer programmes – ie HIV, Malaria
4. **What does the future hold?**
    - Explore how to support the patients in more remote locations and distant locations from the hospital ie Motorbike, trailers for bike to bring in sick patients to hospital
    - Follow up visit later in 2017 to further monitor progress, deliver the Lusaka sourced backpacks and provide written teaching materials on good nutrition for TB patients

The Logie Legacy is a newly formed charity to support the twinning work of NHS Borders with St Francis Hospital. We aim to uphold key principles for effective involvement in global health. These are ownership; alignment; harmonisation; evidence-based; sustainability; and mutual accountability. Its purposes are:

- To support the formally established twinning partnership with NHS Borders to achieve improvements in education, service delivery and patient experience at St Francis Hospital, Zambia
- To promote the value of voluntary engagement in global health for NHS Borders staff and partners in bringing knowledge, skills and ideas back to the UK
- To raise income and monitor expenditure in the support of the above.

This project actively demonstrates these purposes starting from the principle of listening to the needs of staff and volunteers in Zambia. Significant health benefits have been delivered by people *getting on their bikes.* It shows that a small project can make a big difference.





1 – Zambike team (Lusaka) 2- Bikes ready for delivery 3- Catherine (Volunteer) & TB patient

4 – Monica (Volunteer) 5 – Community visit 6 – Service at Hospital Chapel

Special thanks go to:

- all the generous donors, family members and colleagues who caught the vision and made this project possible
- all the dedicated staff and TB treatment support volunteers at St Francis Hospital
- all the patients who invited us into their homes and shared with us their stories
- Dennis Sakala Makowa, Clinical Officer for his inspirational work at 'TB Corner' SFH
- Tiki Mambwe and the team at Zambikes for their 'can do' approach to life
- the many individuals and agencies who were consulted and helped to shape this project

Sources and further reading

[i] TB Alert http://www.tbalert.org/what-we-do/our-work-in-zambia/
[ii] St Francis Hospital https://www.supportstfrancishospital.org/
[iii] WHO http://www.who.int/tb/strategy/en/
[iv] Health Protection Scotland Enhanced Surveillance of Mycobacterial Infections (ESMI) in Scotland: 2016 tuberculosis annual report for Scotland http://www.hps.scot.nhs.uk/ewr/article.aspx
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[vii] Republic of Zambia Ministry of Health http://www.moh.gov.zm/
[viii] Bing & Epstein (2013) Pharmacy on a Bicycle: Innovative Solutions for Global Health and Poverty
[ix] Zambikes http://zambikeszambia.com/
[x] Faldon (2014) 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

Chris Faldon: March 2017
Nurse Consultant (Health Protection) NHS Borders
Secretary, The Logie Legacy
Scottish Charitable Incorporated Organisation: SC47148