

Changing the Conversation: Human Rights and the Power of Words in Tuberculosis Care

July 16, 2015

Sponsored by
Global Tuberculosis Institute

Rutgers, The State University of New Jersey

Faculty



Jane Carter, MD
President, The Union

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Objectives

At the end of this webinar, participants should be able to:

- Describe the human rights-based approach for patient-centered TB care;
- Assess one's use of language and its implication during interactions with TB patients; and
- Share best practices for reducing stigmatizing language and empower patients to share their voices for TB

Faculty



Mike W. Frick, MPH
Project Officer, TB/HIV
Treatment Action Group

Faculty



Barbara Seaworth, MD
Medical Director
Heartland National TB Center

Faculty



Jigna Rao
TB Health Activist & Advocate

HUMAN RIGHTS AND THE ROAD TO ZERO TB

Mike Watson Frick
TB/HIV Project

TAG
Treatment Action Group

END TB STRATEGY

WHO's END TB Strategy

- 95% reduction in TB deaths by 2035
- 90% reduction in TB incidence by 2035
- Zero catastrophic spending due to TB



What are human rights?

- Universal, inalienable
- Defined by international law
- Primarily concerned with the relationship between *individuals* and their *governments*
- Governments are charged with the obligation to respect, protect and fulfill
- Rights can be **civil and political** (e.g., freedom of movement, religion etc.)
- Rights can be **economic, social, or cultural** (e.g., the right to health)



The right to health

The right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

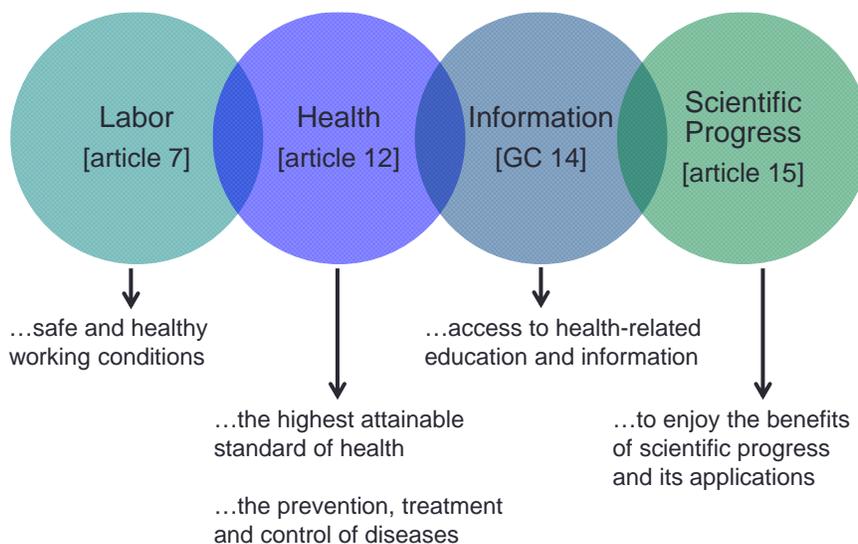
International Covenant on Economic, Social and Cultural Rights

General Comment 14

Convention on the Rights of the Child

Convention on the Elimination of All Forms of Discrimination Against Women

Human rights are interrelated



Human Rights and Tuberculosis

An old story...?

“Detainees [in Russian prisons] are subjected to conditions in which they are guaranteed increased exposure to MDR-TB. **In other words, increased TB risks should be seen as a violation of rights** TB as a form of punishment. This is due to overcrowding, ineffective infection control, tardy diagnosis and ineffective or interrupted treatment.”

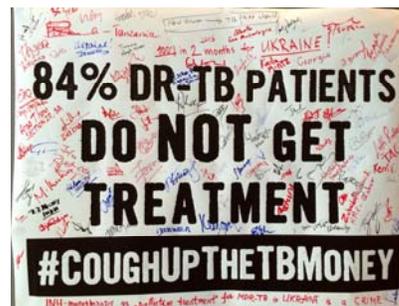
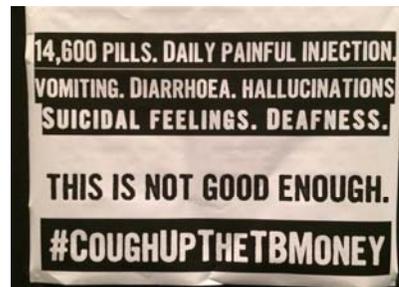
“But we want treatment that can cure us.”

Paul Farmer, Pathologies of power: rethinking health and human rights, *AJPH*, 1999
Photo: James Nachtwey

...that needs to be retold

“ TB is a disease associated with poverty and social inequality that particularly affects **vulnerable populations** with **poor access** to basic services....TB has often been depicted as a disease driven by **biomedical determinants**, but increasingly efforts are focusing on addressing the **social inequalities** by **putting affected people at the center** of the health response. ”

The Global Fund TB and Human Rights Information Note



What can human rights offer the response to TB?

- Human rights—and the right to health, in particular—must be used as **tools** to increase access to TB testing and treatment.
- In contrast to traditional public health (or strictly biomedical) approaches, a rights-based approach must:
 - 1) focus on underlying social & economic determinants of TB;
 - 2) articulate the rights of people living with and vulnerable to TB;
 - 3) encourage people to claim these rights.
- Rights-based approaches also establish the legal obligations of governments and other actors (e.g., drug manufacturers) to ensure good quality TB testing and treatment are available and accessible to all.

Adapted from Brian Citro et al, *Health and Human Rights* special issue on TB and the Right to Health

How can human rights be put into Practice in TB Programs

What can someone working in a TB program do to integrate respect for human rights into individual patient care?

Here are a few—very much interrelated—starting points:

- Embrace patient-centered care
- Speak of rights alongside responsibilities
- Combat stigma and discrimination

...but first, a negative case example

“ Yellow car came to my house and ask the surname. She came out and put the gloves on and it was clear that this is bad. When she came inside the house, every thing was special and urgent...My child said, ‘We learned about this at school. It’s better when it’s MDR. When it’s X, it’s the last stage. That is when you are about to die’...I am sick of this vehicle because people knows about it...They were standing on the road, putting these things [i.e., masks] and writing names on the bottles...They don’t even come in the house. They ask while they are outside...[My son] just ran away. He doesn’t want to sleep there. It’s because they told me about XDR in his presence. ”

Daftary A, Padayatchi N, O'Donnell M. Preferential adherence to ART over TB treatment: A qualitative study of DR-TB/HIV co-infected patients in South Africa. *Global Public Health*, 2014.

Embrace patient-centered care

Human rights principles are at the root of many of the activities that make up patient-centered care:

Participation

Non-discrimination

Accountability

Transparency

Information

- Delivering care in culturally competent ways
- Supporting patient education (treatment literacy)
- De-centralizing care and limiting periods of institutionalization and isolation
- Reducing costs of treatment (where costs can be financial, psychological, social)
- Actively listening to patients and giving them a voice in decision-making

Speak of rights alongside responsibilities



“Few entitlements but plenty of duties...”

The TB Patient Charter lists rights and responsibilities

...but never names who is in charge of upholding these rights (i.e., governments)

...but never discusses what to do if rights and responsibilities conflict (i.e., deliberate, using tools like the Siracusa Principles)

The Siracusa Principles

When is it justified to limit human rights in the interest of public health or safety?

- Restrictions must be judged:
 - 1) necessary and
 - 2) proportional to the potential harm
- Restrictions on rights must be non-discriminatory and non-arbitrary
- Restricting one right cannot be used as a justification for limiting *all* rights

People with TB don't just have sick bodies, they have rights-bearing bodies

Fight stigma and discrimination

by avoiding stigmatizing language

Treatment default	→	Treatment non-completion
Tuberculosis suspect	→	Person to be evaluated for TB
Tuberculosis control	→	Tuberculosis prevention and care
Compliance	→	Adherence
Research subjects	→	Research participants



1. Frick M, von Delf D, Kumar B. End stigmatizing language in TB research and practice, *BMJ*, 2015

2. Zachariah R, Harries A, et al. Language in TB services: can we change the paradigm and stop blaming patients? *IJTL*, 2012

Photo: CA Towries for Treatment Action Campaign

Fight stigma and discrimination

by avoiding the politics of fear



Informing the public should not involve terrifying the public and turning sick people into would be TB (or HIV or Ebola or MERS etc.) terrorists.

1. Do we need to announce every case of MDR/XDR-TB?

2. When are we “raising awareness” and when are we stoking fear?

THANK YOU!

Questions / Comments / Thoughts?
(or advocacy issues you want to bring to our attention)

mike.frick@treatmentactiongroup.org

 @mwfrick



Stop the Stigma

Declaration:

Funding from TAG to support stigma reduction project

Barbara J Seaworth M.D.
Medical Director
Heartland National TB Center

EXCELLENCE EXPERTISE INNOVATION

TB is Associated with Significant Stigma



We all recognize the stigma our patients face - what I did not realize for too long is how I may have added to that with my words.



Responsibility for Successful Treatment

“...the prescribing physician, ..., is carrying out a public health function with responsibility not only for prescribing and appropriate regimen but also for successful completion of therapy.”

ORGANIZATION AND SUPERVISION OF TREATMENT

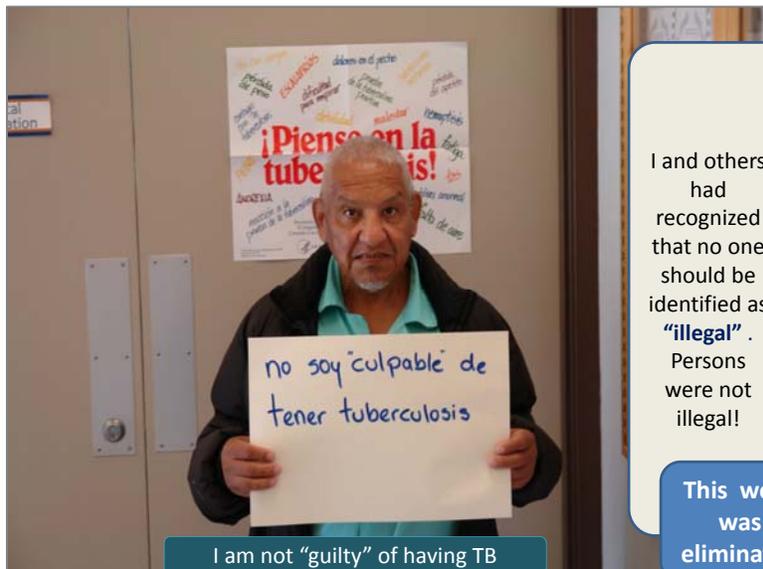
“... IT IS ESSENTIAL THAT TREATMENT BE TAILORED AND SUPERVISION BE BASED ON EACH PATIENT’S CLINICAL AND SOCIAL CIRCUMSTANCES(**PATIENT CENTERED CARE**).”

MMWR Treatment of Tuberculosis, June 20, 2003



We are Charged to Provide Medical Care that:

- Cures the individual and is non-toxic
- Respects the individual person
- Allows the patient to participate as a partner
 - It follows ... they should be **free of stigma** from their providers
 - That means all of us caring for the individual
 - That means in every facet of our care



I am not "guilty" of having TB

I and others had recognized that no one should be identified as "illegal". Persons were not illegal!

This word was eliminated





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<http://dx.doi.org/10.5588/ijtld.11.0635>

A Call to Change

PERSPECTIVES

Language in tuberculosis services: can we change to patient-centred terminology and stop the paradigm of blaming the patients?

R. Zachariah,* A. D. Harries,^{††} S. Srinath,[§] S. Ram,[¶] K. Viney,[#] E. Singogo,** P. Lal,[§] A. Mendoza-Ticona,^{††} A. Sreenivas,[§] N. W. Aung,^{††} B. N. Sharath,^{§§} H. Kanyerere,^{¶¶} N. van Soelen,^{##} N. Kirui,^{***} E. Ali,* S. G. Hinderaker,^{†††} K. Bissell,[†] D. A. Enarson,[†] M. E. Edginton[†]

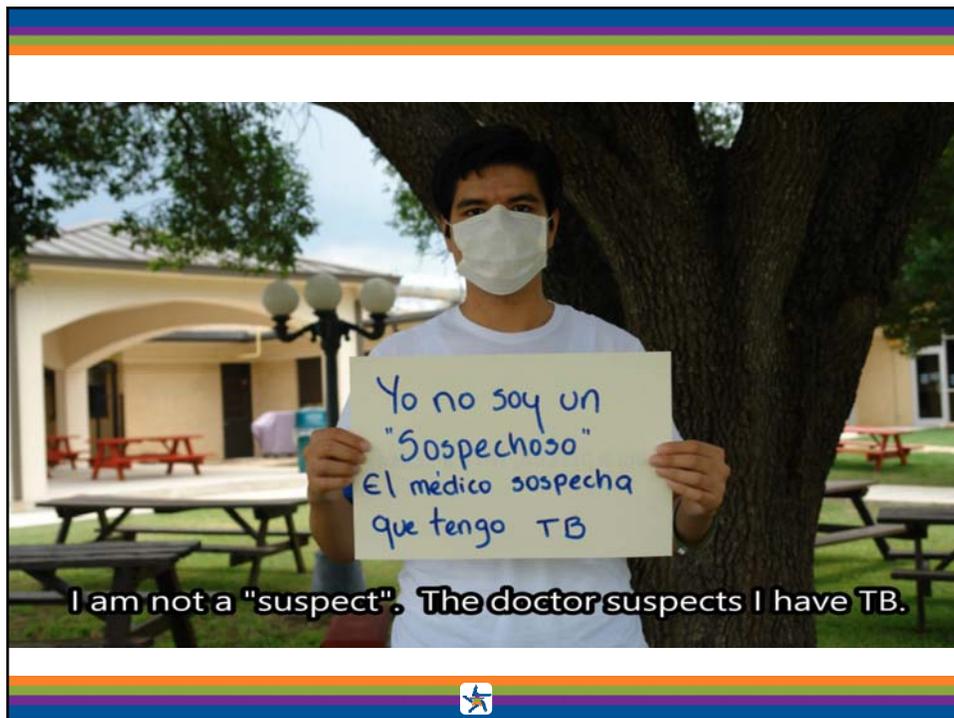
* Medical Department, Médecins Sans Frontières, Operational Centre Brussels, MSF-Luxembourg, Luxembourg; [†]International Union Against Tuberculosis and Lung Disease (The Union), Paris, France; ^{††}London School of Hygiene & Tropical Medicine, London, UK; ^{†††}The Union, South-East Asia Office, New Delhi, India; [§]Fiji National University, Suva, Fiji; ^{§§}Secretariat of the Pacific Community, Nouméa, New Caledonia; ^{**}Dignitas International, Zomba, Malawi; ^{¶¶}Instituto Nacional de Salud, Lima, Peru; ^{##}Health Services Department, PSI/Myanmar, Yangon, Myanmar; ^{§§}Revised National Tuberculosis Control Programme, Delhi, India; ^{¶¶}National Tuberculosis Control Programme, Lilongwe, Malawi; ^{##}Desmond Tutu TB Centre, Department of Paediatrics and Child Health, University of Stellenbosch, Cape Town, South Africa; ^{***}Academic Model Providing Access to Healthcare (AMPATH)/Moi Teaching & Referral Hospital, Eldoret, Kenya; ^{†††}Centre for International Health, University of Bergen, Bergen, Norway

SUMMARY

The words 'defaulter', 'suspect' and 'control' have been part of the language of tuberculosis (TB) services for many decades, and they continue to be used in international guidelines and in published literature. From a patient perspective, it is our opinion that these terms are at best inappropriate, coercive and disempowering, and at worst they could be perceived as judgmental and crimi-

words 'defaulter', 'suspect' and 'control' and argue why it is detrimental to continue using them in the context of TB. We propose that 'defaulter' be replaced with 'person lost to follow-up'; that 'TB suspect' be replaced by 'person with presumptive TB' or 'person to be evaluated for TB'; and that the term 'control' be replaced with 'prevention and care' or simply deleted. These terms are





Member: clinicians, public health workers & researchers working in tuberculosis



Website of the Global Tuberculosis Community Advisory Board



- [Civil society calls for the retirement of stigmatizing and criminalizing language from the global TB discourse](#)

An **March 10, 2015** open letter requests that The Union take steps to retire the use of stigmatizing and criminalizing terminology from the papers published in its journals and the abstracts submitted to its conferences.

‘Language is very powerful — it is important for all of us to change the way we speak and write about this disease. We hope that this letter and actions taken by the Union will open a dialogue between advocates, members of civil society, researchers, health professionals, and academics necessary to truly eliminate stigmatizing terminology in TB.



The Union’s response to the open letter by [José Luis Castro](#) (Executive Director of The Union), Mach 12, 2015:

Thank you for voicing your concerns ... **The Union fully acknowledges that some of the terms that have been used for many years to describe TB activities can serve to stigmatize people affected by TB.** Ultimately the responsibility for providing TB effective and high quality treatment and care falls on the healthcare system, not on individuals impacted by the disease. ...

The Union is committed to communicating in a manner that embodies respect for all people affected by TB. We will include guidance and a [link](#) to the Stop TB Partnership’s language guide in our abstract submission guidance for our conference participants. We have also shared your letter with the Editors in Chiefs of our journals, [International Journal of Tuberculosis and Lung Disease](#) and [Public Health Action](#), and will pursue appropriate language guidance.

Thank you.
José



National Society of TB Clinicians supported the letter

Sent letters to each speaker at the national conference asking them to avoid stigmatizing language.

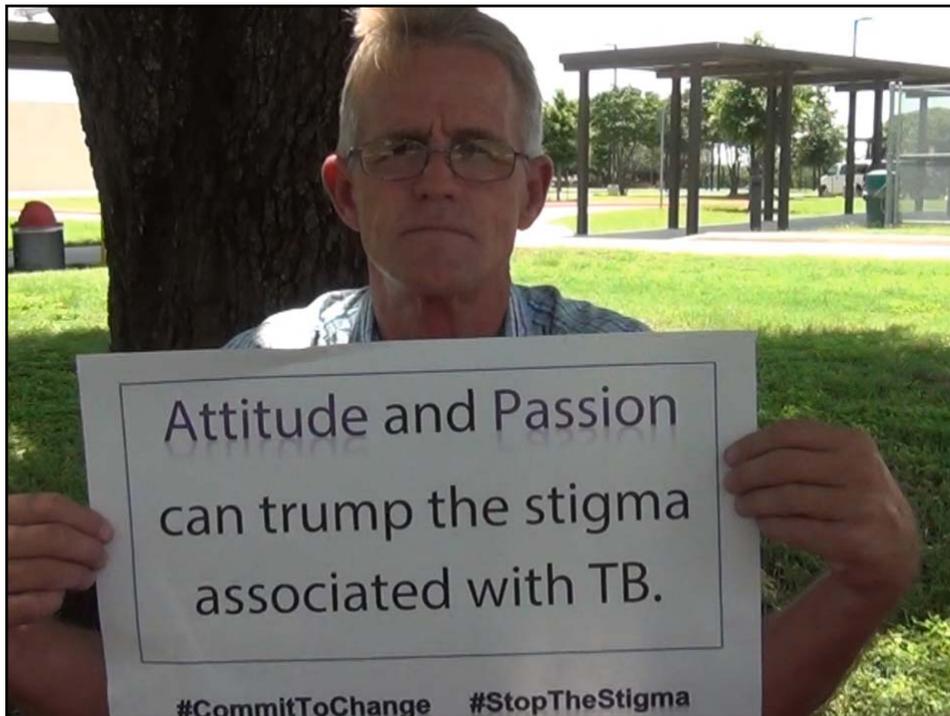


EXCELLENCE • EXPERTISE • INNOVATION

I asked myself - "What More Can Be Done to Make an Impact?"



...and with the help of the staff at Heartland National TB Center and patients at the Texas Center for Infectious Disease



We launched our campaign at the National TB Conference in Atlanta, June 9, 2015



Heartland Staff and Heartland's Advisory Committee Started the Day by Wearing Our T-Shirts



I pledge to stop the use of language that is stigmatizing in the care of patients and their families affected by #TB. Because #LanguageMatters I will encourage others to #CommitToChange and #StopTheStigma by #SpeakingFromTheHeart.



We Asked Others to Pledge to Join Us



We Passed Out Calendars and Armbands

Calendars

Instructions: Click on a calendar to download the PDF file. Print on an 11x17 sheet of paper.



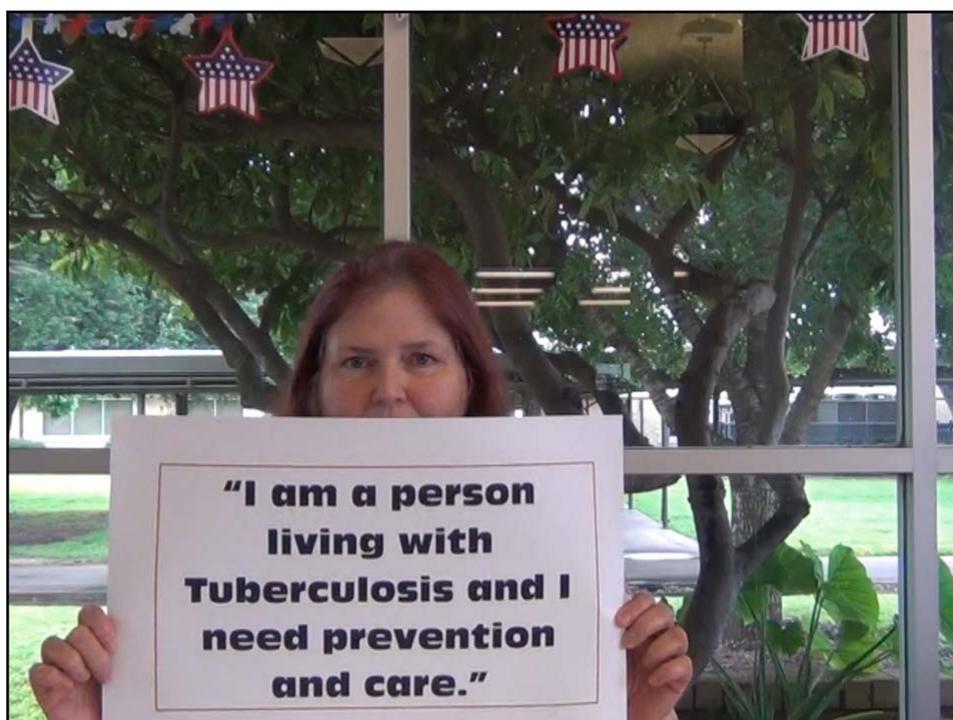
The image shows four 2015 calendars arranged in a 2x2 grid. Each calendar features a photograph of a person and the text 'Stop the Stigma'. The top-left calendar shows a person holding a sign that says 'STOP THE STIGMA'. The top-right calendar shows a person holding a sign that says 'HEARTL & NO STIGMA'. The bottom-left calendar shows a person holding a sign that says 'HEARTL & NO STIGMA'. The bottom-right calendar shows a person holding a sign that says 'HEARTL & NO STIGMA'. Each calendar also includes a monthly calendar grid for the year 2015.

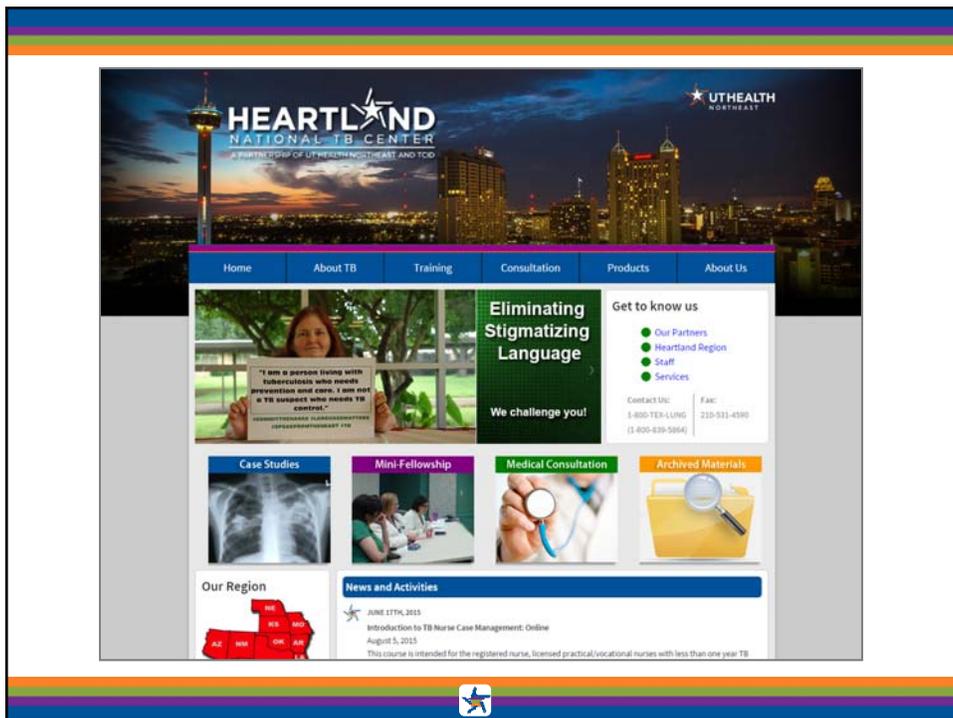


Testimonials of persons affected by TB Disease who participated in the **“Stop the Stigma”** Project were shown on large screens as attendees entered the meeting.

Their Stories Were Powerful!







HEARTLAND NATIONAL TB CENTER
A PARTNERSHIP OF UTHEALTH NORTHEAST AND TCID

UTHEALTH NORTHEAST

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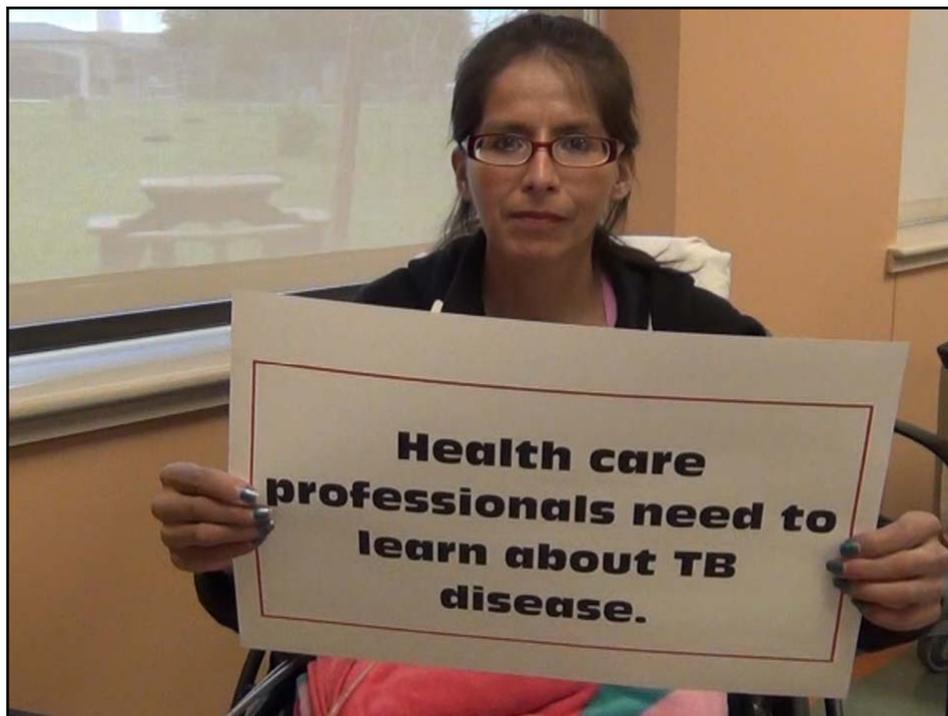
Eliminating Stigmatizing Language

Members of the public health community worldwide have been working for almost five years to promote the avoidance of harmful and stigmatizing language used in TB care. Language such as "defaulter", "suspect", and "control" is not only hurtful but also judgmental, criminalizing, and places blame on patients. Heartland has committed to join forces with patient advocates from the Global TB Community, the International Union Against TB and Lung Disease, and the National Society of TB Clinicians to eliminate stigmatizing language. We are proud to introduce "Stop the Stigma", a campaign to spread awareness and promote elimination of the use of stigmatizing language by the public health workforce. We would like to invite you to join us and pledge yourself, your organization, and challenge others to pledge as well.

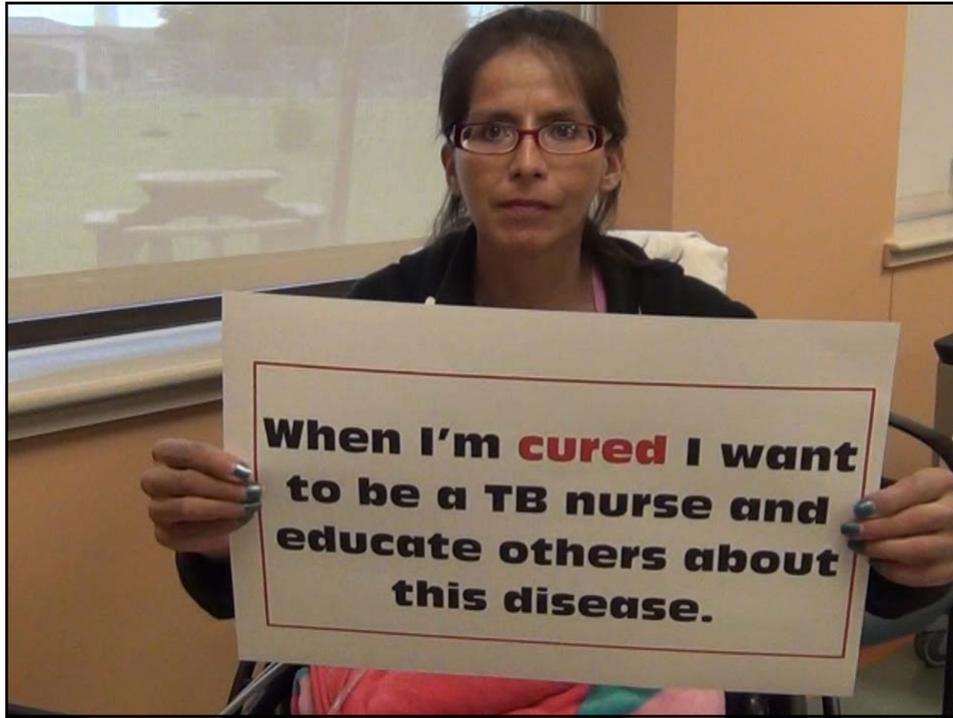
Supporting Documents

- [Stop TB Partnership](#)
- [IUATLD - Language in TB](#)
- [Open Letter](#)
- [STOP Stigmatizing](#)
- [Brochure](#)
- [Pledge Form](#)
- [Pledge Sign](#)

"Stop the Stigma" - Eliminating Stigmatizing Language







She was passionate about The Stigma Project. She served others her entire life. Her life made a difference.

IN MEMORY OF
July 15, 2015

With Heartfelt Sympathy

Please know that you are in our thoughts and prayers

HEART Land
HEALTHCARE SERVICES

EXCELLENCE • EXPERTISE • INNOVATION

HEARTLAND HAS ISSUED THE CHALLENGE

What is holding you back?

<http://www.heartlandntbc.org/stopthestigma/index.php>



Our Challenge to You

Commit to using language that is patient centered, appropriate and sensitive and represents the dignity of people with TB and their families.

Sign the pledge: By signing the pledge, you are committing to stop the use of stigmatizing language when caring for persons and their families whose lives have been affected by TB. As a public health worker and leader in the field of tuberculosis, you pledge to adopt patient centered terminology that is appropriate, sensitive, and represents the dignity of people with TB and their families.



We will fill out a pledge card with your name on it and add it to other pledges. This banner is located at Heartland National TB Center on the campus of Texas Center for Infectious Disease a TB hospital located in San Antonio, Texas. This banner is visible to patients, health care workers, and visitors to the Heartland center.

Take a picture: Take a picture holding your "I Pledged" sign and email it to edgar.salinas@uthct.edu. We will add you to our Facebook page and Twitter feed.

Challenge others: Challenge others to join in your commitment. Let them know that you have made the commitment and would like to encourage them to do the same.

- Brochure
- Pledge Form
- Pledge Sign

Download and print the project brochure to display or present the project to your partners. Print a copy of the pledge form for them to sign and email to edgar.salinas@uthct.edu.

Pledge Today!

* Email Address

* First Name

* Last Name

* Company

HNTC can use your picture to promote project? y/n



San Antonio Metro Health Accepts the Challenge



National Level



What Can a Training Center Do?

Ask our speakers to eliminate stigmatizing language from their presentations.



Commit to eliminate stigmatizing language from our products

Teach our participants about the negative effects that language can have on those affected by TB



State Level



Local Level



Tommy Camden
Tuberculosis Health
Program Manager
San Antonio City Chest
Clinic



Mary Ann Rodriguez
Medical Director,
Communicable Disease Unit
City of Austin Health and
Human Services

Are you
next?



Who can you challenge?



Thank you HNTC Staff and TCID Patients
You Have Truly Made a Difference!





Language Matters: The Power of Words

Jigna Rao
TB Activist & Advocate



TIME TO CHANGE THE LINGO

- TB bacteria is within a person's body
- Diagnosis does not mean that the person is now defined by the bacteria he or she carries

TB Can Affect Anyone .. Even YOU

THEY



WE



STOP the "HUNTING" ..

Definition | HUNT : To pursue and kill (a wild animal)

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Severe TB case triggers hunt for possible victims

John Bacon and Tyler Page, USA TODAY 9:03 a.m. EDT June 12, 2014



A woman with a severe form of tuberculosis was being treated at the National Institutes of Health in Maryland Tuesday while health officials were searching for people she may have infected.

The woman was admitted to NIH's hospital in Bethesda on Friday with an "extremely drug-resistant" form of the disease, the NIH said in a statement. She was in stable condition Tuesday.

"The patient is staying in an isolation room in the NIH Clinical Center specifically designed for handling patients with respiratory infections," NIH said.

The National Institute of Allergy and Infectious Diseases, part of the NIH, is providing treatment. NIAID has treated other so-called XDR-TB patients in the past, NIH said.

"NIH is taking every precaution to ensure the safety of all concerned, and the situation is of minimal risk to other Clinical Center patients, NIH staff, and the public," the statement said.

Bruce Hirach, a physician and infectious diseases specialist at North Shore University Hospital in Manhasset, N.Y., told USA TODAY that monitoring potentially exposed patients is "essential" to keeping Americans safe.

"The treatment of this resistant strain of tuberculosis is challenging and prolonged," he warned.

CDC spokesman Tom Skinner told nbcwashington.com that health officials in Illinois are working with the Centers for Disease Control and Prevention to find people with

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25 July 2014 US & Canada



..and the Dehumanization

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South Africa **Hunt for escaped TB patients**

David Beresford in Johannesburg
Monday 16 Jun 2008 16:01 EDT

Health authorities in South Africa said yesterday they were sending out a team in protective clothing to hunt for tuberculosis patients who escaped from hospital.

The missing patients are suffering from a drug-resistant strain of the illness, and three have the extremely dangerous XDR-TB.

The breakout from the Jose Peanson hospital in Port Elizabeth reportedly took place after a security guard allowed one patient with XDR-TB to go shopping. The others protested when they were not allowed out, overpowered the guards and ran off.

The provincial health authority said that three of the 16 patients who escaped had returned to their families, who would bring them back to hospital. National radio reported that 12 had returned to the hospital.

In December 43 patients with drug-resistant TB escaped from the same hospital, cutting through a fence. Police were sent to catch them and court orders were obtained to force them back into hospital.

A few months ago TB patients at the hospital were given TV sets, pool tables and soccer and netball kit to try to persuade them to stay.



Experts call for new drugs and return of sanatoriums to halt TB in South Africa

17 Jan 2014 27



How do you catch an escaped crocodile?

25 Jan 2013 31

South African police hunt couple after officer killed in shooting

19 Jan 2011

The dilemma of a deadly disease: patients may be forcibly detained

23 Jan 2007

Language is not static Modernize TB-related language

- ~~▪ Defaulter~~
- ~~▪ Suspect~~
- ~~▪ Non-compliant~~
- ~~▪ TB-Control~~
- ~~▪ TB-Patient (label)~~
- ~~▪ TB-Suspect (label)~~
- ~~▪ Infected (associated with corrupt, dirty, tainted)~~

The BIG impact of little things

✓ Person affected by TB | ~~TB-Patient~~

✓ Persons affected by TB | ~~People~~

✗ Acronyms= Loss of identity as human beings

✗ Limited use of the word “infection”

WHO is responsible for changing the language?

- Researchers and Scientists
- Medical Experts
- Clinicians, Healthcare providers
- Public Health Officials
- Media
- Health Advocates
- Community

WHAT do we do ?

- ✓ **STOP:** Stigmatizing language and blame-game
- ✓ **RECOGNIZE :** People affected by TB are best suited to created this manifesto
- ✓ **BRING:** Multi-disciplinary scientists and experts together to find effective solutions

**Sticks and stones may break my bones
But names will never hurt me !**

- No one can control the air they breathe - but we can all control the words we use ..
- Words are powerful -As Emily Dickinson writes, "I know nothing in the world that has as much power as a word..."
- Change the words used to form the language around TB = End the stigmatization.

THANK YOU !

raojigna@gmail.com