



# HIV Linkage Project

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## Introduction



Ben Taub General Hospital

Much of the progress and emphasis in HIV care to date has been related to diagnostic and therapeutic advances, but issues like pharmacy, access, and patient awareness/education still require a great deal of attention. And to realize the full potential of what medicine has to offer HIV patients, the medical community should focus its efforts on those latter issues so that HIV truly becomes a disease our patients die with, rather than die from.

Unfortunately, there is still a great deal of work to be done in our community. Based on preliminary local data, approximately 60% of patients who are found to be "new HIV positives" at the Ben Taub Emergency Center – the largest screening EC in the nation that tests patients on an 'opt-out' basis – do not seek continuity of care despite availability of resources. Moreover, there has been a dearth of information as to why our patients do not 'link' to care within the HCHD system after their diagnosis.

In view of this, we aimed to serve our community through a project defined by three main, overarching goals: one that would identify barriers to care and holes in our linkage process, make changes that would improve those rates, and to create media through which patients could be educated about their condition and also express their experiences with the linkage process.

## Methods and Results

Our project can be organized into three phases:

- 1) To call patients who were lost to follow up and had not linked, so as to identify barriers to care. Linkage was defined as successfully completing their first appointment. After creating a comprehensive survey, we were able to call over 80 patients, who were lost to care since Aug 2008. Most of the barriers were different for each patient but some common themes were lack of knowledge about the disease, denial or access to the "Gold Card" – Harris County's subsidized insurance plan
- 2) To create a patient education packet that can be disseminated to new HIV positive patients who are seen in the Ben Taub Emergency Center during the weekends or between 7pm and 8am. We focused on including information about counseling/linkage services and basic descriptions about the disease process, with an emphasis on why it is so critical to follow up with a physician. Our goal is to publish this on the website and have it be readily accessible to the public.
- 3) To compile a booklet of patient stories, from the patients we interview – some who were lost to care, and others who connected to follow up – and create a collection that we will publish on the BT website and potentially in print. The purpose of this is three-fold: to raise awareness about the immense linkage needs, to remind those of us in healthcare that the patient's voice and perspectives are paramount in implementing change, and to inspire others to think creatively about issues and solutions facing our HIV+ community.



The Harris County HIV Service Linkage Team

## Excerpts from our patients stories

*. . . She told me how dumb she felt for being so careless, but how even then she never thought she would've ended up in the hospital, across from me, being told she had HIV . . .*

*. . . I pushed the heaviness in my throat into my chest with a deliberate breath. Part of me wanted to say something reassuring – to comfort her, and affirm to myself that our conversation had actually helped. Another part of me was afraid that it hadn't and wanted to hold the silence. . . .*

*. . . It is a fate I would not wish on my worst enemy. I should have continued to see my doctor, but I didn't think it would really affect me. And then my lungs got infected and I became really sick. My family and I went through some hard times, but things are better now. I haven't missed an appointment since. . .*

*. . . I saw my boyfriend go into a coma and never wake up. I wish that he had told me his HIV status, I would have encouraged him to get treated. Thankfully, I am not positive and this has motivated me to get tested at least once a year. It is my duty to warn everyone who will listen, what a silent killer HIV can be...*

## Acknowledgements

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