Knowledge=Power

Larry Kramer's HIV Treatment Data Project

December 1, 1998 By Gabi Horn

Leave it to Larry. The indefatigable cofounder of GMHC and ACT UP, Kramer has found a way to electronically harness the massive energy and dosing habits of PWAs. Once up and running, the HIV Treatment Data Project (TDP) will be a website that records, analyzes and explains the clinical data of thousands of PWAs.

If all goes according to plan, HIVers worldwide will key their drug regimens, lab reports and health conditions into an anonymous database. Although self-reported stats don't pass scientific muster, the tabulated results could indicate general trends, detect side effects and guide patients toward informed decisions.

Hopes are high, but so is skepticism. Will TDP prove a high-tech vehicle for patient self-empowerment or sink into a morass of invalid data? Will it revolutionize research or maximize opportunities for errors and fraud?

Four test sites are underway in New York and California, but it'll be some time before the public can hit the keys. Rather than put TDP to the test prematurely, POZ took a behind-the-scenes peek at the birth of a database.

ACT I

Larry Kramer, TDP Founder: How did I come up with the idea? I didn't wake up and scream "eureka!" PWAs are desperate to facilitate our own wellness. It just seemed logical that we collect our own data. All the people taking protease inhibitors are walking data that's going down the toilet.

I hate clinical trials and people who say they're the only way to get valuable data. We can tell in three months if a drug is working; we don't have to waste three years and billions of dollars to confirm it. Which combo to take is a crapshoot, but PWAs don't have time to waste.

This database is specific to the times we're in; so was GMHC, so was ACT UP. Like those, TDP has been incredibly easy to set up. There were lots of steps to get it started. It's like casting a play: You choose your actors, then start rehearsal.

First, I interviewed **Mike Stocker** for a *New York Times Magazine* article about the anti-protease. I had the idea of collecting data from hundreds of thousands of PWAs and I challenged him to do *something*.

Michael Stocker, Prez and CEO of Empire Blue Cross and Blue Shield: When I met Larry, I'd just cancelled his indemnity and health care policy. So he wasn't too happy with me. But he had a twinkle in his eye. He was all geared up for a "conversation," as he put it. He spoke about PWAs' dire need for data. The project grew intuitively from that.

TDP is very American, very democratic: You enter data and get data back. It's consumer driven. Its success depends on the users and the info they enter.

Kramer: I wrote a piece in POZ ["5,985 and Counting," March 1997] that argued for the need to capture data directly from PWAs. After it ran, Sean Strub told me that **Bruce Brothers** from Lotus desperately wanted to get a hold of me. "I know what you want," Bruce said, "and I can get my company to do it for you." It was like a gift from heaven.

Bruce Brothers, Senior Manager of Lotus Consulting: I was feeling lucky. I just barely survived lymphoma, thanks to a Crixivan cocktail, but I became resistant to it and switched to Viracept. I realized how tentative my good health was, began to explore research on alternative therapies and found it lacking.

After I read Larry's article, I called Sean, who passed my number on. Larry called the next day. Despite his reputation, I find Larry extremely reasonable—impatient but reasonable. Corporate America is well served by someone like him forcing a look beyond the ledger sheets.

This method of data collection could revolutionalize research for so many diseases. Tools like TDP will take medical research out of dark, mysterious labs and bring it out into the open, allowing for uncloseted scrutiny and debate.

Kramer: I called **Tony Fauci**. He was the first important person who said, "Yes, this is a good idea." That was all I needed to hear. Fauci was a name I could bandy about: "*Tony* thinks it's a good idea."

Anthony Fauci, Director of the National Institute of Allergy and Infectious Diseases: From the start, I was enthusiastic about it. The important thing is to understand TDP's advantages and limitations: It cannot conduct clinical trials, but it can detect toxicities, general trends and long-term clinical outlooks.

ACT II

Kramer: So I had Fauci's approval, Mike waiting in the wings for a challenge and Bruce, who had technological know-how. I worked on getting the pieces in place. **Rodger McFarlane** didn't want to run it initially, but when he saw how revolutionary it was, he agreed. We've done this before—at GMHC. Rodger's the details man, I'm the idea man.

Rodger McFarlane, TDP Project Director: They hired me because I asked “what if” questions: What if the data’s useless? What if we can’t get the damn interface to work? It’s a monumental task that I radically underestimated. If it works, TDP will be a historic contribution toward evaluating new drugs. But it could also confuse the living hell out of everyone.

TDP is a unique—and incredibly complex—collaboration of managed care, computing, scientists, PWAs, HMOs, CEOs and activists. The beauty of it is how they got together: I remember sitting in a Boston bar with a bunch of straight guys from IBM and Lotus who’ve poured their hearts into this project. Here are people who normally work for banks, working for PWAs. I asked them why they were doing this. “Because I love Bruce,” they said. They’re fighting for someone they love; they learned it the same way we did. That makes me trust them deeply.

ACT III
Kramer: The detail shit has taken lots of time. It’s hard to get doctors and researchers to agree on anything. Mike met with the American Association of Health Plans, a big Washington-based lobby for HMOs. The exec flipped for the idea.

AAHP and Lotus fronted most of the $2.5 million. Bruce put together a team to design a website. Rodger assembled a team of doctors and statisticians, led by **Sherrie Kaplan**, to design the questionnaire and crunch the data. Sherrie’s a great lady. I’m a little in love with her.

Sherrie Kaplan, PhD, New England Medical Center and Tufts University: TDP will give feedback on how many of which PWAs are on various combinations. Say you’re male, 45, on protease combo A/B/C. You can go into TDP and find the average age of people on your combo. In other words, are they like you or not?

The questionnaire requires info that PWAs may not have at their fingertips. That’ll help them get answers from their doctors and understand their medical reports. If TDP only serves as a catalyst for improving dialogue between patients and docs, it’ll be worth it. In randomized trials, you have control; TDP represents what’s going on in the real world. What PWAs tell us could generate clinical trials or focus our efforts on specific groups.

The test sites will validate patients by testing their ability to accurately report medical results and compare their reports with medical records.

[Enter two of the docs running the test sites.]

Jeannine Bookhardt-Murray, MD, Morris Heights Health Center, Bronx, NY: My first reaction to TDP? Skepticism. I wasn’t sure our patients would be interested: Most have never used a computer. But once we spoke, I was surprised by how receptive they were to the idea and willing to learn how to use it. [Lotus will provide computer training.] They’re hungry for info and eager to make themselves better.

Howard Grossman, MD, private Manhattan practice: I have more-radical patients—some are on eight antiretrovirals. Many are treatment activists with access to info and drugs that others don’t have. They’re on the Net and use e-mail—they’ll be aggressive about using TDP.

Now, docs interview patients, then transfer data onto a form. But it’s hard to get them to fill out forms. Sometimes info gets lost and sometimes people aren’t honest, because they want to be “good patients” or stay in a clinical trial. TDP lets them be honest in an anonymous way. We may get an idea about how patients *feel*. The danger is anecdotal treatment. If people jump without clear-cut scientific evidence, it could be dangerous.

Kramer: The question is: How do we make it *the* thing to do, like it was the thing to do to belong to ACT UP? We’re making up the rules as we go along. If it doesn’t work this year, it’ll work next year or the year after. But I never thought it *wouldn’t* work: My mind doesn’t work like that. You have a challenge, a task and a goal. Call it luck or the right moment. The right people just need to show up.
