

2008 PatientsLikeMe HIV Community Report: *Embracing the Positive*
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Introduction

The PatientsLikeMe HIV community is growing fast. The community has grown from a handful of beta-testers at this time last year to currently include more than 1,600 patients, 50 caregivers, and 160 guests from healthcare, research and academic institutions. If you've spent any time exploring the site and looking at patient profiles, treatment and symptom reports, the forum, or connecting with others through our advanced search, you might have a pretty good idea of who is in the community and what they've been up to.

Whether you're relatively new to the community or a seasoned member interested in learning more, this report will provide you with an interesting snapshot of who has joined and what information they have shared. To create the report we pulled together data from earlier this fall at a time when we had about 1,300 patients. The report shows that those 1,300 HIV community members represented a broad set of diagnosis and treatment experience among a group of widely diverse people.

Patients are coming together at PatientsLikeMe to embrace the challenge of achieving a better understanding of how this condition is affecting themselves and others. As part of the open sharing that is happening within the community, patients are providing each other with more insights into how to make better treatment decisions with their doctors in the face of constantly changing treatment regimens.

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Summary

Experience of HIV (or Diagnosis History)

A basic part of the PatientsLikeMe experience involves answering a brief survey about your diagnosis history, which allows your charts and your badge to have more relevance.

About 75% of patients have shared the date when they first tested positive for the HIV virus.

- Before 1995: 200+ patients report being tested positive
- 1996 – 2004: About 200 report being tested positive
- 2005 – 2007: About 200 report being tested positive
- 2008 (this year): About 200 report being tested positive

So, you can see immediately you are going to find people with all kinds of experience, from the newly diagnosed to patients who have had HIV for more than 10-20 years.

Additionally, based on responses to the diagnosis history survey, we found that 25% of patients thought they were infected 3 or more years before they tested positive, while 25% thought they were infected 3 months or less before they tested positive.

Although we do not display this information, we also found that about 30% indicated they got tested because they were afraid they had been exposed to HIV, about 25% doing so because they were sick, and about 33% tested as part of a routine health screening.

Most patients (more than 70%) felt they were infected while having sex with someone who was infected, but there are also small numbers of people who think they were infected in other ways – such as while receiving blood, while injecting drugs, through accidental exposure to blood, or via transmission from their mother during pregnancy.

AIDS

HIV (Human Immunodeficiency Virus) is the virus that causes AIDS (Acquired Immune Deficiency Syndrome). AIDS is the most serious stage of HIV infection, when your immune system is so weak that you are more at risk for serious and life-threatening infections and cancers. If you are infected with HIV and your CD4 count drops below 200 cells/mm³, or if you develop an AIDS-defining condition (an illness that is very unusual in someone who is not infected with HIV), your doctor may diagnose you with AIDS. As many newly-infected patients learn, having HIV does not necessarily mean you have AIDS.

Two-hundred forty-two (242) PatientsLikeMe members (or only about one-quarter of those who report the date of their first positive HIV test) report that they have received an AIDS diagnosis. Of those patients, about half indicate they were diagnosed between 1995 and 2006, and the remaining 50% before or after that time period (25% before 1995 and 25% since 2006). Among those diagnosed with AIDS, about 40% report receiving the diagnosis the same month they tested positive for HIV. Among the rest of people with an AIDS diagnosis, more than half had tested positive five or more years before.

Personal characteristics

Basic understanding of any population group begins with the measurement of age, sex, and place of residence. Even though PatientsLikeMe is an online community, your experience is still affected in important ways by these personal characteristics. Among other things, this information helps your ease of access to providers and other face-to-face support when you need it.

PatientsLikeMe members have been a little more reluctant to report about some personal characteristics that may be of interest to others in the community or that would be helpful in understanding their situation. About half the members in our community (between 600 and 700 users at the time we put together this report) indicated their birth date, sex, or the country in which they live. In a snapshot:

- Most of these users are from the USA, but there are users in more than 30 other countries.
- 1 out of 3 (33%) of these users are women.
- Ages of users vary:
 - Under 29 years of age: 20%
 - 30-39 years of age: 25%
 - 40-49 years of age: ~30%
 - 50 years of age or older: ~25%

When you have any illness, concerns about privacy and avoiding stigma or discrimination may come to mind. Our members have discussed this from time to time in the Forum, along with the notion of [posting a picture on your profile](#). This serves to remind all users to read and understand our [Privacy Policy](#) and [Openness Philosophy](#). We hope that you'll come to share the view that providing the basic information we request in our questionnaires should not compromise your privacy in any way, but may contribute to a better understanding of the HIV community and finding effective ways to live better with HIV. Please read on to find out how we can make use of this information.

Age (and Age at First Positive Test)

The table below shows the number of patients in each age grouping, according to their age at first HIV-positive test. (The same basic pattern holds up for men and women separately.) The thing that's interesting is that no matter what your age, you can find someone your own age who has recently tested positive or who has been positive for several years or more. So, if you have recently tested positive, you can find support with the issues you are facing right now as a new 'patient', but you can also benefit from the experience of those who were diagnosed at about the age you are and have lived with HIV. For those of you who were diagnosed several years ago and have lived through changes in the medical management of HIV there is also an opportunity to compare notes about what has gone better or worse in your experience with people who understand what it's all about. And for everyone, the likelihood of living into old age with HIV has increased dramatically and presents new challenges ([Newsweek, 9/18/2008](#)).

Current age	Age when first tested positive				Total
	Under 29 years	30 to 39 years	40 to 49 years	50 years or older	
Under 29 years	113	-	-	-	113
30 to 39 years	77	108	-	-	185
40 to 49 years	52	97	75	-	224
50 years or older	5	43	44	22	114
Total	247	248	119	22	636

Disease Measurement (CD4 Count and Viral Load)

The CD4 count refers to the CD4+ T-lymphocyte count. The CD4+ T-lymphocyte is the primary target for HIV infection. As the number of CD4+ T-lymphocytes decreases, the risk and severity of serious infections and cancers increases. Viral load tests are reported as the number of HIV copies in a milliliter of blood. If the viral load measurement is high, it indicates that HIV is reproducing and that infections may occur more often or be more severe than if the viral load is low. A high viral load can be anywhere from 5,000 to 10,000 copies and can range as high as one million copies or more. A low viral load is usually between 200 to 500 copies, depending on the type of test used, and indicates that HIV is not actively reproducing and that the risk of disease-related infections is low. A viral load result that reads “undetectable” does not mean that you are cured. It may mean that the level of HIV virus in your blood is below the threshold needed for detection by the test.

One out of four (~25%) of all users of the site had reported their CD4/Viral Load test results in the period May-August 2008, so this smaller group is one for which we have some relatively recent measure of disease status. However, as the table below shows, this information is far from definitive. Each row of the table represents a group of patients defined by CD4 count. For each group the table reports the number of patients at that level, the median viral load, and the minimum and maximum viral load values reported in the group. (The median is a kind of average, representing the value dividing the group in half. For example, half of those with a CD4 of 100 or less had a viral load below 36,500, and half had a viral load above 36,500.). Notably, in each group defined by CD4 level at least some patients reported viral load of zero. This highlights one of the problems patients face, which is even when antiviral medications apparently wipe out the HIV, the immune system can still be compromised (as indicated by the low CD4 count), making the patient susceptible to AIDS-related infections.

CD4	Number of Patients	Viral load		
		Median	Minimum	Maximum
0-100	10	36500	0	Over 1,000,000
101-200	20	13520	0	550000
201-300	33	50	0	60000
301-400	50	50	0	498000
401-500	46	49	0	340000
501-600	54	48	0	452000
601 or above	123	0	0	168000
Total	336	50	0	Over 1,000,000

Treatments

The U.S. Department of Health and Human Services recommends that treatment of HIV with antiretroviral medications be initiated when CD4 counts are less than 350.¹ It also recommends that after treatment is started that there should be no long term interruption of treatment. At the time we pulled the data for this report (September 2008), there were over 2,200 treatment reports about interventions that about 530 PatientsLikeMe members were currently using or had used in the past 6 months. (Members can always get up-to-date information on top treatments by going to the [treatments tab](#) on your profile.)

About 40% of those reports referred to an antiretroviral medication, and were being taken by 429 community members at the time we analyzed data in this report. The top 10 antiviral medications in use by community members were:

Treatment	# taking
Atripla	171
Truvada	135
Ritonavir (Norvir)	105
Atazanavir (Reyataz)	89
Kaletra (Lopinavir/Ritonavir combination)	64
Epzicom	47
Efavirenz (Stocrin, Sustiva)	39
Nevirapine (Viramune)	34
Tenofovir (Viread)	33
Combivir	32

¹ Panel on Antiretroviral Guidelines for Adults and Adolescents. Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents. Department of Health and Human Services. January 29, 2008; 1-128. Available at <http://www.aidsinfo.nih.gov/ContentFiles/AdultandAdolescentGL.pdf>. Accessed (10/4/2008) [page 12]

Treatments (cont'd)

Many people who have just tested positive for HIV wonder how long they should wait before starting treatment with anti-retroviral medications. Because of concern about treatment side-effects, many patients want and are sometimes advised to delay treatment until there is evidence of a higher viral load. Among those reporting, the average time from testing positive to first use of antiviral treatment is about 2,250 days (a little over 6 years). However, you should not read too much into this number, because users of the site who have been positive for a long time may not have filled in their full treatment history.

About 20% of users indicate that their first treatment began within about 2 months of testing positive for HIV. At the other extreme, about 20% did not report a first treatment until 13 years or more after first testing positive. That is a huge range of experience, which makes it easy to find people like you and learn from their experiences.

A lot of the discussion that you will have with your physician will depend on your viral load and the state of your immune system, as measured by your CD4+ counts and as indicated by your experience of HIV and AIDS-related infections. Among those users who had recently updated their CD4 data, we found patients with lower CD4 counts were more likely to be taking antiretroviral medications. Overall, we also found that at least half (50%) of community members at any level of CD4 were taking these medications. There was little difference in the number of antiviral medications being used.

CD4 level	Number of patients	Percent taking antiretroviral medications	Average number of medications taken by those using antiretroviral medications	Minimum	Maximum
0-100	10	70	2.29	1	5
101-200	20	90	2.39	1	6
201-300	33	88	2.34	1	5
301-400	50	66	1.58	1	4
401-500	46	50	1.91	1	3
501-600	54	50	2.33	1	5
601 or above	123	53	2.23	1	5
Total	336	60	2.13	1	6

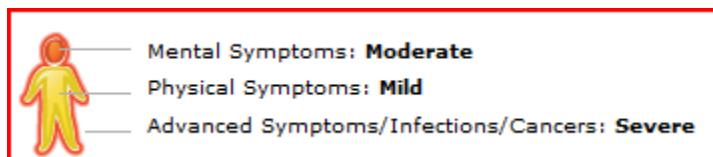
Current Symptoms

The PatientsLikeMe profile also includes charts showing results of symptom surveys that are designed to ask about symptoms that HIV patients are more likely to experience when their viral load is high or their immune system is not working well. Users are encouraged to periodically report on 10 primary symptoms. (So, just as with treatments, you can always get up-to-date information on symptoms by going to the [symptoms tab](#) on your profile.) At the time we conducted this present study (September 2008), the proportion reporting moderate or severe levels for each symptom was:

Symptoms	% moderate or severe
Aches and pains	34%
Anxiety	32%
Chills/fever	6%
Decreased appetite	17%
Depression	38%
Diarrhea	17%
Fatigue	33%
Night sweats	12%
Rash/skin problems	9%
Swollen glands	8%

Fatigue, diarrhea, and aches and pains were somewhat more likely among patients taking antiretrovirals. While these symptoms are among the common side effects of some classes of antiviral drugs, they may also occur for other reasons. As a result they have been the topic of discussion in the Forum (97 posts about fatigue, 37 posts about diarrhea, and 47 posts about aches and pains) with community members sharing useful tips for avoiding problems with these symptoms or reducing their impact (for example, see the threads regarding: [New here and I have a question or two \(what can I do about fatigue and low energy?\)](#), [A Delicate Subject but the tasty way to ease Diarrhea](#), [Information to share about aches and pains](#)).

The site also includes short, standard surveys about HIV-related infections, HIV-related Cancers, and HIV-advanced symptoms. Most users report this information less frequently, but when it is reported, we use the information to change the coloring of your 'stickman' so that others can tell at a glance if you're having problems and might benefit from some support or additional information.



The Forum

The PatientsLikeMe Forum is a simple, time-ordered list where you can reach out to the entire community to make a statement or request help for a problem, and receive and share the responses. [The Forum](#) has grown to be active and widely used, with nearly 1,000 distinct threads encompassing over 7,500 posts. There are multiple posts in nearly every thread, so if you have a question, information to share or are looking for support, check out the Forum.

Conclusion

We hope this overview of the community has been interesting. Today, on the occasion of World AIDS Day 2008 (when this paper is released), the PatientsLikeMe HIV community has established a foundation of caring and hope. We're ready to start work with our users on the next generation of tools and data visualizations to provide better insight into how to better care for oneself, take better care of each other, and make better treatment decisions with doctors.

If you have suggestions about how we can make the site more helpful, please let us know. Email me at mmassagli@patientslikeme.com or the research team at research@patientslikeme.com.