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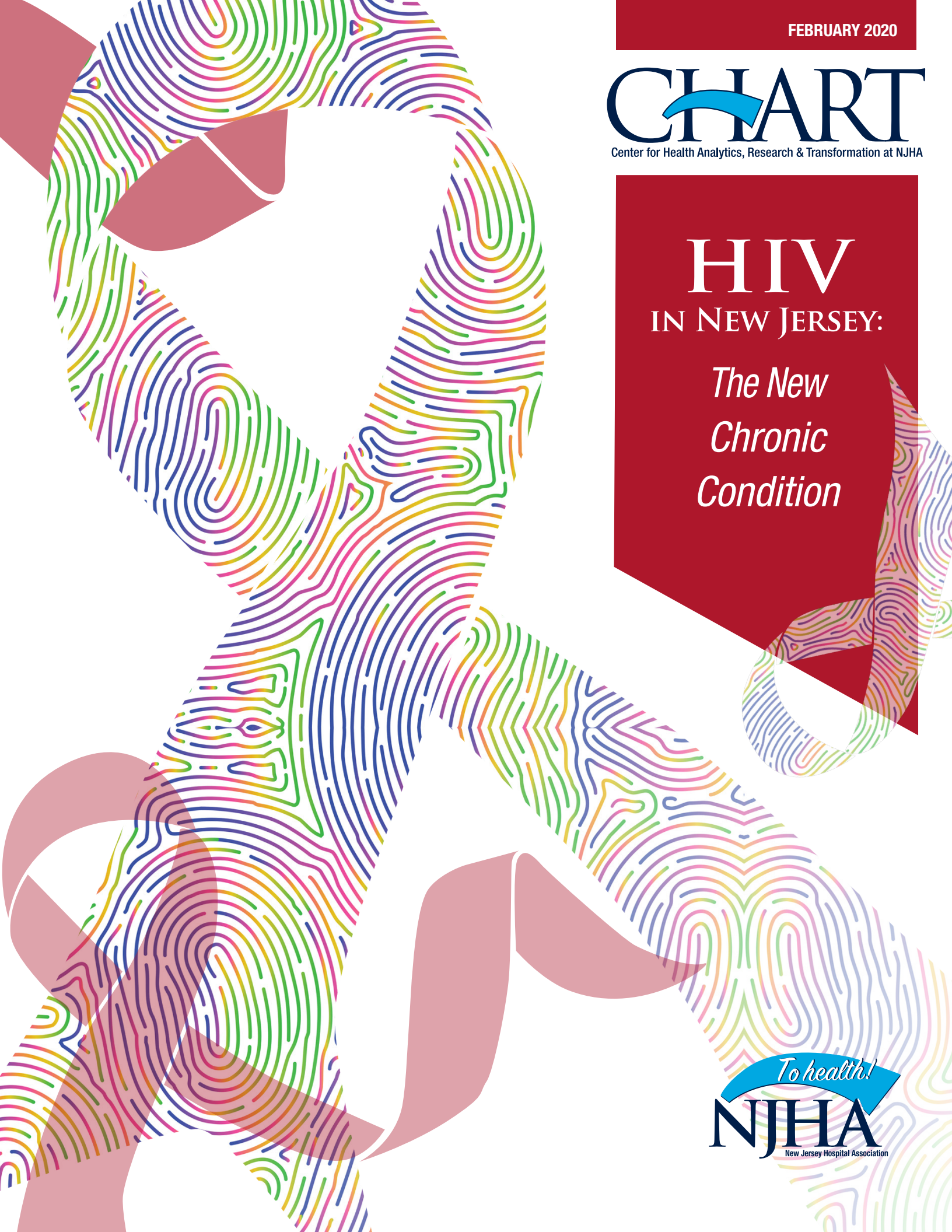
HIV IN NEW JERSEY:

The New Chronic Condition



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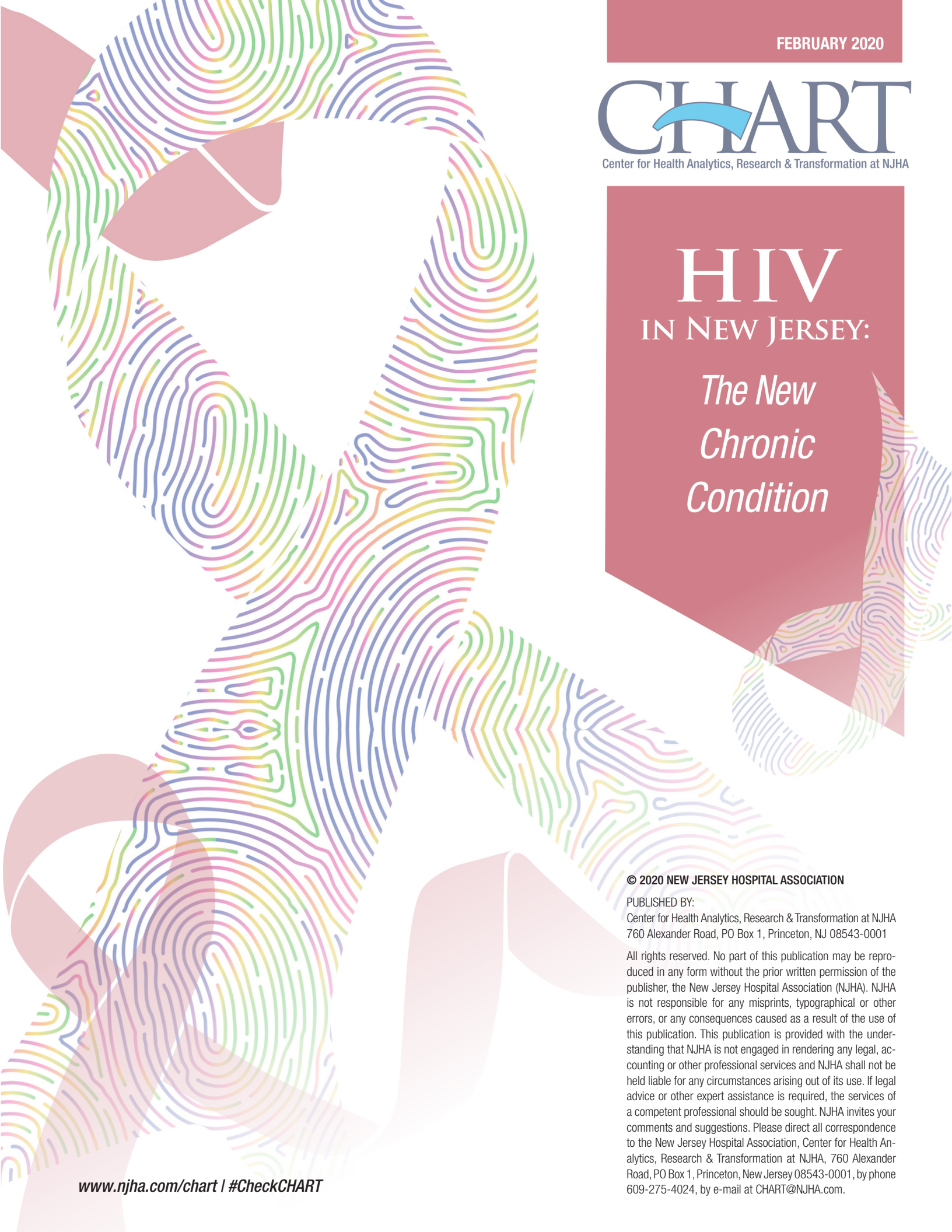

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HIV IN NEW JERSEY: *The New Chronic Condition*

In 1991, New Jersey had one of the highest AIDS rates in the United States. In recent years, both the state and the country have made great strides in reducing the number of HIV and AIDS cases through early detection and advanced treatment options. Between 2008 and 2017, New Jersey saw a 23.2 percent reduction in the rate of newly diagnosed HIV patients per year, and nearly 30 percent reduction in the rate of HIV deaths. All told, more than 37,000 people, or one out of every 235 New Jerseyans, is currently living with HIV/AIDS – a success story for an illness that was considered a death sentence just a generation ago. With medical and pharmaceutical advances, HIV has become akin to a chronic condition in which infected individuals can live a full and healthy life, with proper management of the condition.

But there's more to the story. Incidence rates show that the number of New Jerseyans newly diagnosed with HIV remains high at 12.7 per 100,000 population. This is the 13th highest rate in the nation. An analysis of incidence rates reveals insight into the people most vulnerable to HIV infection. They include:

- THOSE WHO INJECT DRUGS. 11 percent of New Jersey's newly diagnosed cases were transmitted through injection use. This is nearly double the national average.
- AFRICAN-AMERICANS. Blacks comprised 45 percent of the newly diagnosed HIV patients in 2017; however, only 13 percent of New Jersey's overall population is black.
- HISPANICS. While the state has seen an overall decrease in the rate of newly diagnosed HIV patients, the rate of newly diagnosed Hispanic HIV patients remains unchanged.
- LOW-INCOME INDIVIDUALS. 38 percent of the population living with HIV/AIDS in New Jersey falls within the definition of low-income, which is 400 percent of the federal poverty level.

More than 37,000 N.J. residents are living with HIV – testament to the medical advances that have increased survivability. Despite awareness and prevention efforts, New Jersey ranks 13th highest in the nation for new HIV cases, with more than 1,100 N.J. residents infected annually.

This white paper recognizes the success in treating people with HIV in New Jersey, but – more importantly – uses data to pinpoint populations and factors that remain vulnerable to HIV infection. Examining local data on the most vulnerable populations can help direct resources to treat, manage and prevent the disease within the state.

Introduction: Identifying and Tracking AIDS

On June 5, 1981, The Centers for Disease Control and Prevention (CDC) released its *Morbidity and Mortality Weekly Report (MMWR)* which, for the first time, reported on the deaths of five homosexual men in Los Angeles who were diagnosed with Pneumocystis carinii pneumonia (PCP), an infection found almost exclusively in those with severely compromised immune systems. These cases would become the first publicly reported Acquired Immunodeficiency Syndrome (AIDS) cases in the United States.

Following this discovery, AIDS tracking programs were swiftly implemented across the nation. State departments of health began mandating that physicians and hospitals identify and track any AIDS patients by name. A majority of states adopted these tracking procedures by 1983, and all 50 states had a procedure in place by 1986. This led to the compilation of a comprehensive database of AIDS patients. However, these patients only entered the database once they were infected with AIDS and in many cases already very ill. A better tracking system is one which identifies the earliest predictor of AIDS, the Human Immunodeficiency Virus (HIV).

HIV is a virus which damages the immune system. Left untreated, the virus can progress to AIDS, a disease caused by the destruction of the immune system. AIDS is the most severe level of HIV and commonly leads to death, either from the disease

itself or from complications arising from it. With early diagnosis and proper treatments, people can live with HIV for many years without developing AIDS. Quicker identification and tracking of HIV patients would likely serve to decrease the overall incidence of AIDS as patients could receive treatments and support services earlier, delaying the development of AIDS.

New Jersey's Leadership

Starting in 1985, many states implemented anonymous HIV tracking, in contrast to the name-based AIDS tracking already adopted by most. Anonymous tracking, which kept a person's HIV status private, was preferred due to concerns of data breaches, which could lead to social stigma and discrimination.

New Jersey, with one of the highest AIDS case rates in the country, became the first state to create a name-based HIV tracking database in 1991. To address privacy concerns, this data was housed on two computers at the Department of Health (DOH). These computers were in a locked enclosure, which only three state employees were granted access to enter test data from physicians, hospitals and testing centers. New Jersey law provided further protections to those who were tested by allowing them to sue for damages if a breach of this data occurred. Tracking cases by the patient's name did not appear to discourage testing, with New Jersey's testing rates comparable with other states.

New Jersey's pioneering name-based HIV tracking system was eventually replicated nationwide. By 2003, 39 states had adopted a name-based system. The other 11 states were using a code-based system which assigns a unique identifier to each patient without revealing their actual name. However, by 2008 all 50 states adopted the name-based HIV tracking system. The 11 remaining states transferred to this system as federal funding from the Ryan White HIV/AIDS Program was contingent on having a name-based system in place.

Since the creation of New Jersey's name-based system in 1991, HIV tracking has evolved, with the standardization of definitions and collection methodologies across all 50 states. Thanks to this work, the last decade has provided the most reliable data on HIV in the nation. Examining this data both on a national and state level helps identify trends in prevalence, death rates and methods of transmission.

In the past three decades, researchers have collected a vast range of data and information on HIV and AIDS, helping to educate the public on modes of transmission and prevention strategies. Numerous federal programs such as the Presidential Advisory Council on HIV/AIDS; U.S. President's Emergency Plan for AIDS Relief (PEPFAR); the Global Fund to Fight AIDS, Tuberculosis and Malaria; the Housing Opportunities for People with AIDS (HOPWA) Program and the Ryan White HIV/AIDS Program have devoted funding and resources to the cause.

These resources provide greater insight into trends and allow for the improved allocation of resources and treatments as the face of the HIV patient continues to evolve and change.

Newly Diagnosed Patients

Nationally, the annual number of newly diagnosed HIV patients has decreased nearly 20 percent between 2008 to 2017 (47,290 cases in 2008 versus 38,226 cases in 2017). After accounting for changes in population size, the rate of newly diagnosed cases nationwide was 11.8 per 100,000 population in 2017, a 24.4 percent decrease from 15.6 in 2008.

New Jersey's rate of newly diagnosed HIV patients during that time period decreased by approximately 23.2 percent, close to the national average. Although encouraging, New Jersey's rate remained high in 2017 at 12.7 per 100,000 population, the 13th highest in the nation. While states surrounding New Jersey also showed large decreases in raw numbers of HIV cases, their rates were still higher than the national rate of 11.8.

	2008 Rate per 100,000	2017 Rate per 100,000	% Change
Maryland	36.1	17.0	-53.1%
New York	23.6	13.9	-40.8%
Delaware	17.5	13.2	-24.9%
New Jersey	16.5	12.7	-23.2%
Nationwide	***15.6***	***11.8***	***-24.4%***

While states in the Northeast are making strides to reduce the overall number of newly diagnosed patients, more work is needed to reduce the high rates in relation to the total nationwide population.

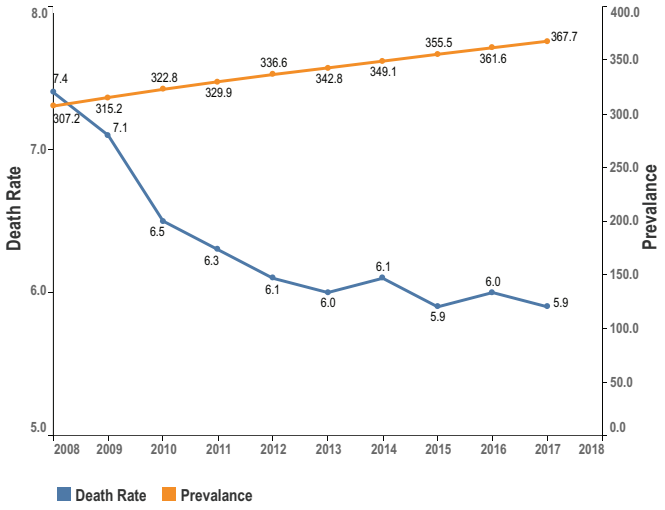
Prevalence and Death Rates

Decreasing trends in the incidence (number of newly diagnosed cases) of HIV are promising. As incidence rates decrease across the nation, the prevalence of HIV, defined as the number of patients living with HIV in a given year, has been on the rise. In 2008, there were 771,038 HIV patients nationwide, increas-

ing by approximately 30 percent in 2017 to just over 1 million. All states, including Washington D.C., saw an increase in the prevalence of HIV patients over this time period.

In 1992, AIDS was the number one cause of death for men aged 25-44. By 2016, HIV had fallen to the 9th most common cause of death among men 20-44, accounting for just 1 percent of deaths in that population. Nationwide, the rate of death for HIV patients per 100,000 population declined 20 percent in the time period from 2008 to 2017. Even as incidence rates decline, the declining death rate has pushed the prevalence rate higher as people live longer with HIV infection.

HIV Prevalance and Death Rates per 100,000 Population



Research indicates HIV patients are living longer as a result of better treatment options. Antiretroviral therapy (ART) is medication taken on a daily basis to reduce the HIV patient's viral load and is commonly called "Treatment as Prevention (TasP)". If taken consistently, according to the CDC, most patients will no longer have detectable HIV antibodies six months after beginning treatment. As a result, the HIV patient is at a lower risk of developing the more advanced form of HIV and subsequently AIDS. Per the CDC's 2018 *"HIV Treatment as Prevention Technical Fact Sheet"*, as a patient has "effectively no risk" of sexually transmitting the disease when their viral load is at undetectable levels, ART also acts as a preventative measure. While ART doesn't cure HIV, it has demonstrated effectiveness in stopping the virus from reproducing and spreading.

According to a 2017 study from *Lancet HIV*, an online research journal, life expectancy for a person with HIV in Europe and North America increased by approximately 10 years between 1996 to 2010, largely due to increased access to ART and early diagnoses. Based on this research, a 20-year-old HIV patient using ART has a life expectancy of 78 years, close to national averages for those not infected with HIV.

HIV in New Jersey

HIV statistics in New Jersey have greatly improved over the past decade, with the rate of new diagnoses and death rates decreasing rapidly. According to the New Jersey DOH, there are currently more than 37,000 people, or one out of every 235 New Jerseyans, living with HIV/AIDS. Although the annual number of newly diagnosed patients continues to decrease as noted above, in 2017 alone, over 1,100 people were newly diagnosed with HIV in New Jersey.

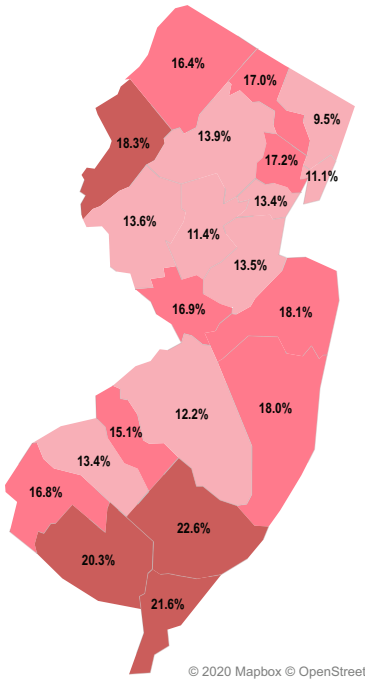
When AIDS was first identified in the 1980s, it was predominantly in the male, homosexual population. In the 30 years since, this population still remains at-risk. Male-to-male (MTM/MSM) sexual contact is the most common route of transmission in the nation, accounting for approximately two-thirds of newly diagnosed HIV cases nationwide in 2017. This is followed by heterosexual contact (close to 24%) and injection (6%).

In New Jersey, 55 percent of newly diagnosed HIV cases in 2017 were through MTM sexual contact. While lower than the national proportion of approximately 66 percent, MTM sexual contact is the only category of transmission that has experienced an increase in its proportion from 2008 to 2017. In 2008, only 43 percent of newly diagnosed HIV cases were through MTM sexual contact.

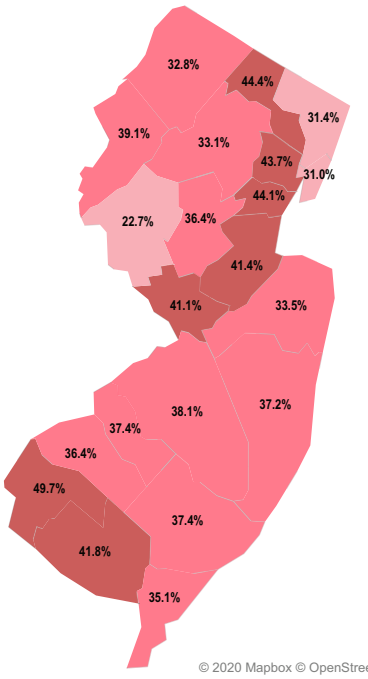
Compared to the nation as a whole, New Jersey has a higher proportion of transmissions from both heterosexual contact (33%) and injection use (11%). However, unlike MTM sexual contact, these proportions have been decreasing over the past decade. The proportion of newly diagnosed cases transmitted heterosexually decreased from 36 percent in 2008 to 33 percent in 2017, while injection cases decreased from 17 percent in 2008 to 11 percent in 2017.

Injection cases, although the smallest proportion, are found at a higher rate in New Jersey versus nationwide. CHART examined data from the New Jersey DOH regarding living HIV cases by county. Living HIV cases are those diagnosed at any point between 1990 and 2018, and not deceased as of Dec. 31, 2018. The maps below show the percentage of living cases by county for the following categories of transmission: injection use, heterosexual contact, and MTM sexual contact.

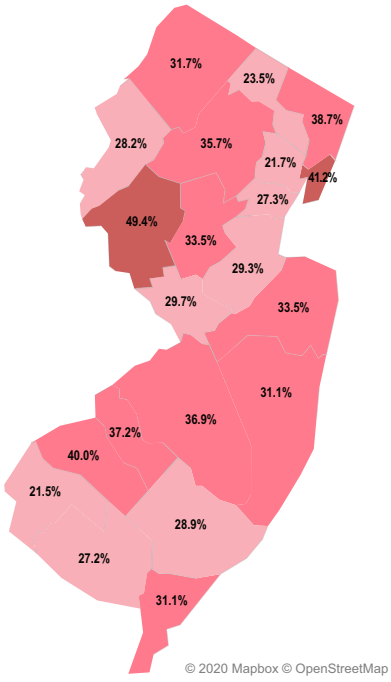
Percent Transmission by Injection



Percent Transmission by Heterosexual Contact



Percent Transmission by Male-To-Male Sexual Contact



As of 2018, approximately 15 percent of living HIV cases in New Jersey were transmitted via injection. The top three counties with the highest proportion of injection cases are located in the southern part of the state – Atlantic (22.6%), Cape May (21.6%) and Cumberland (20.3%) counties. Higher-than-average rates are also observed in shore counties (Monmouth - 18.1% and Ocean - 18.0%) and northwestern New Jersey (Warren – 18.3%). These findings echo data from CHART's October 2018 report *A Broader View*, which identified growing hospital use rates for mental health and substance use services in the southern and northwestern parts of the state.

Racial and Ethnic Disparities

On a national level, CDC statistics show that HIV disproportionately affects the black population. While blacks compose approximately 13 percent of the U.S. population, they accounted for 43 percent of new HIV diagnoses in 2017. Data from New Jersey demonstrates a similar trend, with blacks comprising around 13 percent of the population and 45 percent of New Jersey's newly diagnosed HIV patients in 2017. Thus, faced with a higher incidence of HIV, the black community also had the highest prevalence of HIV in New Jersey, with 13 out of every 1,000 blacks living with HIV in 2017 compared to 1 out of every 1,000 whites.

However, encouraging trends are emerging. From 2008 to 2017, the number of newly diagnosed black patients has substantially decreased by around 26 percent, from 677 patients in 2008 to 504 patients in 2017, outpacing the state's overall decrease during that time period (22%). This decrease occurred despite the overall black population in New Jersey increasing slightly (3%) over that time period. A similar trend can be seen in regard to the number of HIV deaths in the black population, with 509 deaths in 2008 decreasing to 322 deaths in 2017. This 37 percent reduction in the number of deaths was again higher than the statewide reduction of 27 percent during that time.

While the number of new diagnoses in the black community has been steadily decreasing, the Hispanic/Latino community in New Jersey is experiencing a less robust trend. During the 2008-2017 time period, the annual number of newly diagnosed HIV patients in this group decreased only slightly (4%), while whites and blacks experienced decreases of approximately 28 percent and 26 percent, respectively. As a result, Hispanic/Latino patients made up the second largest portion of newly diagnosed patients in 2017 (35.3%), right behind the proportion of black patients (44.8%). HIV in the Hispanic/Latino community in New Jersey is therefore a growing threat.

Proportion of Newly Diagnosed HIV Patients in New Jersey

Race/Ethnicity	2008	2017	Variance
White	16.3%	14.9%	-1.4%
Black	47.2%	44.8%	-2.4%
Hispanic/Latino	28.9%	35.3%	+6.4%
Asian	0.5%	2.8%	+2.3%
All Other/Multiple Race	7.2%	2.2%	-5.0%

(Starting in 2003, the HIV surveillance data presented utilizes new classification standards and the following racial/ethnic categories (each race category is non-Hispanic): American Indian or Alaska Native, Asian, black or African American, Hispanic or Latino, Native Hawaiian or other Pacific Islander, white and multiple races.)

Zip Code-Level Analysis

With New Jersey residents living longer with HIV, nearly 8,000 inpatient admissions to New Jersey acute care hospitals in 2018 were from patients who had either asymptomatic or symptomatic HIV.

CHART examined inpatient hospital claims data to determine the most common zip codes among these patients. The top five zip codes are:

Zip Code	City	Inpatients
07305	Jersey City	204
07103	Newark	191
07501	Paterson	174
07712	Asbury Park	164
08401	Atlantic City	161

Four of these zip codes (Jersey City, Newark, Paterson and Atlantic City) appear on the New Jersey DOH's list of the top 10 cities with the highest number of HIV/AIDS cases. The remaining zip code, Asbury Park, has a much smaller population than the other cities on the list. However, Asbury Park has unique characteristics which may be contributing to a high HIV/AIDS population per capita. According to 2010 census data, Asbury Park has one of the highest rates of same sex couples per 1,000 population. In addition, drug/substance abuse may also be contributing to HIV transmission and illness in the city. Per New Jersey DOH data, of the nearly 1,000 HIV cases reported in Asbury Park since 1990, 35 percent were transmitted through injection use. This is much higher than the statewide proportion of 11 percent. Compounding this factor, city residents may face several challenges in regard to aspects of social determinants of health, which may impact their ability to prevent certain diseases and therefore avoid hospitalization, as evidenced in the table below.

Geography	Median Household Income	Percent Unemployed	Percent No High School Diploma	Percent Uninsured
07712 - Asbury Park	$62,846	7.4%	10.6%	13.8%
Statewide Median	***$87,209***	***5.9%***	***6.9%***	***6.3%***

Hospital claims data also showed that chronic conditions are commonly present among patients with HIV. Out of the 8,000 inpatient claims, two of the top five primary diagnosis codes were chronic conditions (COPD and kidney failure). HIV patients also have an enhanced risk of developing renal failure. Kidney problems can result from either the HIV virus itself, or through the use of ART. Some ART medications have been shown to affect kidney function; therefore, HIV patients and their physicians must balance the benefits of treatment with potential side effects. While this study cannot discern whether kidney disease among these HIV hospitalizations is a result of the virus itself or treatments, the common presence of this diagnosis helps emphasize the need for careful monitoring of kidney disease in HIV patients.

Low-Income HIV Patients in New Jersey

Income is one of the most impactful social determinants of health, potentially influencing an individual's ability to acquire insurance and access care. Low-income HIV patients and their characteristics can be studied using data from the Ryan White HIV/AIDS Program. This federal program provides medical care and support services for the uninsured and underserved HIV population.

The data from this program demonstrates the level of income vulnerability among the HIV population in New Jersey. In 2018 the Ryan White HIV/AIDS program served 15,204 clients in New Jersey. This represents 40 percent of the total number of people living with HIV in New Jersey. Eighty-five percent of these clients have an income 250 percent or less than the federal poverty level. These low-income patients display the following demographic characteristics:

- Older age – 66 percent of the clients are aged 45 and over.
- A higher proportion of females – 36.5 percent of low-income clients are female. Statewide, females make up approximately 32 percent of all HIV patients.
- Heterosexual transmission dominates – over half of the low-income HIV clients acquired the disease through heterosexual contact. This compares to the statewide proportion of 33 percent for this mode of transmission.

Examining the low-income HIV population helps identify different subgroups which may require additional resources. Females and the heterosexual population are not commonly an area of focus among those with HIV. However, the Ryan White data indicates these groups may be some of the most vulnerable populations in need of greater attention.

Conclusion

New Jersey and the nation have made tremendous gains in controlling both the spread and impact of HIV. For an illness that was once incurable, the prevalence of HIV in the population shows the advances that have been made in helping individuals with HIV live longer. However, incidence rates, while decreasing, remain in the double-digits. Within New Jersey, resources should be directed toward the groups and causes identified in this report such as:

- Drug/substance abuse assistance in areas where injection rates are high.
- Expanded resources in Hispanic/Latino communities such as PrEP or pre-exposure prophylaxis. PrEP is a daily medicine which can be used by those at risk for HIV. PrEP can stop HIV from taking hold and spreading throughout the body. When taken daily, PrEP is highly effective for preventing HIV from sex or injection drug use. PrEP is much less effective when it is not taken consistently.
- Continued dedication to New Jersey's top 10 cities, including Asbury Park.

Additionally, the New Jersey HIV/AIDS Planning Group (NJHPG), the state's primary statewide planning group for the Division of HIV, STD, and TB Services (DHSTS), is responsible for the development of the state's HIV/AIDS comprehensive services plan. Its recommendations align well with the National HIV/AIDS Strategy (NHAS), with both emphasizing that each newly diagnosed case should have all contextual factors that lead to the infection identified and monitored. This information can lead to the development of strategies and funding that are adapted around emerging evidence. In addition, multiple prevention and care strategies must be used across the state to improve the health and well-being of both HIV-infected and uninfected people. By improving access to care, treatment and adherence services, which address contextual factors through co-located supportive services, the goal of sustaining undetectable viral loads for HIV-positive individuals may be within reach, helping begin the process of ending HIV in New Jersey. Details on strategies and interventions can be found in The Integrated HIV Prevention Care Plan 2017-2021.

HIV is receiving renewed attention at the national level. The U.S. Department of Health and Human Services has proposed the initiative *Ending the HIV Epidemic: A Plan for America,* which seeks to end the HIV epidemic in the United States within 10 years. The initiative was designed to leverage critical scientific advances in HIV prevention, diagnosis, treatment and care by coordinating the efforts of programs contained within, but not limited to, the CDC; the Health Resources and Services Administration; National Institutes of Health; and the Substance Abuse and Mental Health Services Administration. These efforts would be focused on the 48 most critical counties in the country, including Essex and Hudson counties, as well as those in several highly impacted states.

By recognizing the continued presence of HIV, and leveraging funding and strategies designed to lessen its spread, the magnitude of HIV could be significantly mitigated over the next decade.

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