Life Course Indicator: HIV Prevalence

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: HIV Prevalence (LC-51)

Brief description: HIV rate (diagnosed cases) per 100,000 total population

Indicator category: Reproductive Life Experiences

Indicator domain: Risk/Outcome

Numerator: Total diagnosed HIV cases in the population

Denominator: Total population

Potential modifiers: Race/ethnicity, sex, age, social economic status, geography, rural vs. urban, sexual behaviors, drug use

Data source: The Centers for Disease Control and Prevention (CDC) National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention (NCHHSTP) Atlas

Notes on calculation: Multiply by 100,000 for rate

Similar measures in other indicator sets: HP 2020 Focus areas HIV-1, HIV-2, and HIV-3; CDC Winnable Battle (Reduce the number of new HIV infections by 25 percent)
Life Course Criteria

Introduction
The CDC estimates that human immunodeficiency virus (HIV) prevalence increases about 4 percent each year (10). Since the 1990s HIV prevalence has been increasing, while estimated incidence has remained constant, at around 50,000 cases per year. In 2010, the prevalence of diagnosed HIV cases in the United States was an estimated 872,990 (11). When estimated undiagnosed HIV cases are included, around 1.1 million people are living in the United States with HIV. HIV directly affects individual health through the destruction of the host immune system leading to the development of acquired immune deficiency syndrome (AIDS) and subsequently, death. AIDS develops, on average, 10 years after HIV infection without treatment (42). Although treatment with antiretroviral drugs can delay onset of symptomatic HIV as well as the development of AIDS, people with HIV infection still experience emotional stress, depression, employment barriers, and medication side effects (25, 27, 31, 38, 40). Certain subpopulations are at higher risk for HIV infection than others including African Americans, Hispanics, men who have sex with men (MSM), lower socioeconomic groups, and injection drug users (IDU) (2, 15). A range of complex social and economic factors place certain subpopulations at higher risk of HIV infection including high rates of HIV within sexual networks, poverty, discrimination and stigma, incarceration rates, language barriers, and poor access to health care (44). HIV infection has a cyclical relationship with various social determinants of health. For example, low socioeconomic status is a risk factor for HIV infection, and HIV infection hinders socioeconomic advancement through employment barriers (15, 34, 38). HIV can be transmitted from mother-to-child (MTC) during delivery, although MTC transmission is nearly entirely preventable when antiretroviral therapy (ART) is given to mothers and newborns (14). Unfortunately, not only does MTC transmission still occur in the United States, large disparities exist for racial/ethnic subpopulations (14). A number of national resources and initiatives exist to lower the rate of new HIV infections and to provide care for those who are already HIV-positive. Many governmental, national and community groups have supported and promoted education and prevention activities that have contributed to the flattening of HIV incidence in recent years. While new infections contribute to the rising prevalence of HIV, it is important to note advances in treatment options have positively impacted the life span of people with HIV, also contributing to the rising HIV prevalence (10).

Implications for equity
Many disparities exist in prevalence rates of HIV across variables such as race/ethnicity, gender, sexual activity, and socioeconomic status. African American males and females have the highest prevalence rates of HIV in comparison to other racial groups (12). Although the African American population only accounts for 12 percent of the total U.S. population, African Americans are estimated to account for 44 percent of adults and adolescents living with HIV (2). The CDC estimates that one in 32 African American women will be diagnosed with an HIV infection during their lifetime, in comparison to only one in 526 White women (2). New studies are reporting that sexual networks are separated by race. Therefore increased risk of HIV could be perpetuated by the increased prevalence of HIV within different races (44). Research also indicates that increased prevalence of HIV in African American women is not due to high-risk sexual behaviors but rather the higher prevalence of HIV in the population (10). African Americans do not only have an increased prevalence of HIV, but also other sexually transmitted infections (STIs) such as gonorrhea and syphilis, which are associated with an increased likelihood of HIV transmission (46). Furthermore, the increased risk of HIV in African American males is linked with the high percentage of males in prison; 12 percent of African American males age 25-29 are presently incarcerated in jail or prison (46).

Hispanics also are disproportionately affected by HIV and account for 16 percent of people in the United States (2). While Hispanics represented only 16 percent of the U.S. population in 2009, they accounted for 21 percent of the new infections recorded in 2009 (2). Behavioral and cultural factors are hypothesized to contribute to the increased risk (59). Undocumented Hispanic immigrants also have limited access to HIV prevention services, including care and testing which adds to the burden of HIV in Hispanic communities (59). Increased prevalence of HIV in African American and Hispanic women contributes to the disparity in perinatal HIV infections (14). Between 2004 and 2007, 69 percent of perinatal HIV cases were among African American women (45). These statistics are disturbing because theoretically perinatal transmission could be eliminated due to the available intervention in the United States. (14).

Men who have sex with men of any race or ethnicity are the group most affected by HIV in the United States (2). Contributing to the sustained high prevalence rate in MSM populations is a continued high risk of infection. Although MSM represent only an estimated 4 percent of the U.S. male population, they account for nearly 78 percent of all estimated new
HIV infections (2). In looking at prevalence data, by the end of 2011, 52 percent of all U.S. HIV cases were among MSM (2). The largest number of new HIV infections occurred in White MSM (11,200) while 10,600 occurred in African American MSM (2). When stratified by age, young African American MSM aged 13-24 were at highest risk of infection(2).

Low socioeconomic status (SES) is a social factor highly associated with HIV prevalence rates. In some low SES urban areas HIV prevalence is as high as 2.1 percent; these rates are comparable to developing countries such as Haiti, Ethiopia and Angola (15). In 2007, 81.6 percent of the newly diagnosed HIV cases lived in urban areas with populations over 500,000 (10). Some investigators argue that low SES is positively correlated with the practice of riskier health behaviors, such as earlier sexual debut in comparison to higher SES groups (18). Other research suggests that unstable housing is positively correlated with risky behaviors, such as unsafe sexual behaviors and drug use (17). Not only does low SES increase the risk of HIV infection, it also can impede HIV treatment, which in turn increases risk of transmission. In comparison to higher SES individuals, treatment and testing is delayed, which decreases survival rates (18). Furthermore, the lack of health insurance of many low-SES HIV-positive individuals creates disparities between survival rates of high-SES and low-SES HIV positive individuals (19).

Public health impact
Since 1981, an estimated 1.8 million people have been infected with HIV in the United States, more than 650,000 of whom have died, leaving approximately 1.1 million U.S. residents currently living with HIV (47). HIV-related mortality rates have declined since the 1980s due to treatment advances and stabilized infection rates; however, in 2010, HIV was still the seventh leading cause of death among people ages 25-44, individuals who should otherwise be in the prime of their lives (47).

The economic burden of HIV is high. Individually, the annual cost of HIV treatment is $20,000, and in 2012 it was estimated that the U.S. government spent $15 billion on HIV care and medication (21). The lifetime cost for just one person who receives an early HIV diagnosis (CD4 count above 500 cells per microliter) and subsequently enters into treatment is an estimated $402,000 (37). Early entry into treatment is costly but necessary as people who enter into care with a CD4 count above 500 cells per microliter lose 44 percent fewer quality adjusted life years (QALYs) of illness, gain additional life expectancy, and transmit almost 50 percent fewer HIV infections than people who receive a late diagnosis (37). Not only does HIV impact the United States financially by direct medical cost, but other costs are involved such as lost productivity (23). Persons living with HIV/AIDS experience multiple perceived barriers to employment including health insurance availability, physical ability, health concerns related to the work environment, and current job skills (38). These barriers impede short- and long-term financial independence and emotional well-being of persons living with HIV/AIDS.

Lowering the prevalence of HIV in the U.S. population is in line with multiple national initiatives. In 2010, the National HIV/AIDS Strategy (NHAS) proposed goals such as lowering the annual number of new infections by 25 percent, decreasing the proportion of HIV-positive individuals who are unaware of their status to 10 percent, and increasing the proportion of HIV-diagnosed MSM with undetectable viral load by 20 percent (48). The CDC plans to meet these goals by maximizing limited resources and prioritization of highest risk sub-populations. Presently the CDC is focusing on using a High-Impact Prevention approach to reducing the transmission of HIV (24). The approach consists of a proven and cost-effective intervention focused on high-risk populations (African Americans, Latinos, MSM, transgender and injection drug users), for the largest impact on HIV transmission (24).

MTC HIV transmission is preventable, and part of the strategy for reducing MTC transmission is reducing the incidence of HIV in women and girls of childbearing age, specifically among African American and Hispanic women (14). Adherence to highly active ART of HIV positive women during pregnancy is important in preventing perinatal transmission, but identifying all HIV positive pregnant women during pregnancy can be a challenge as most jurisdictions in the United States lack resources and the framework to identify these women during their pregnancy (14). HIV also affects breastfeeding as it is strongly recommended that HIV positive women do not breastfeed due to the increased risk of MTC transmission. The HIV transmission rate can increase by as much as 30 to 45 percent when breastfeeding is prolonged (25).

Leverage or realign resources
Current science points to the possible success of a “treatment as prevention” approach to HIV (49). Proper adherence to ART medications can create an undetectable viral load, which vastly reduces the chances of transmission (49). In sero-
discordant couples, ART reduces the risk of HIV transmission to an HIV negative partner by 92 percent (50). Sero-discordant couples are particularly important as approximately 54 percent of HIV positive men and 52 percent of HIV positive women with primary partners or spouses have partners that are HIV negative, and an estimated 140,000 want to conceive (20). The HIV Treatment Cascade, defined by Gardner et al, consists of the following steps to undetectable viral load: 1) tested and diagnosed, 2) linked to HIV care, 3) retained in HIV care, 4) need for ART, 5) on ART, and 6) adherent to ART/undetectable viral load (49). An estimated 19 percent of HIV-positive people in the United States have reached the adherent/undetectable viral load stage (49). Support is needed for HIV testing, linkage to care, retention in care, and adherence behaviors to ART medications (51). The CDC provides an online resource for locating free local HIV testing sites at http://hivtest.cdc.gov/ and also sponsors the National HIV Testing Day (NHTD) campaign (http://caponinpin.org/nhtd/).

Opportunities for funding programs to improve care of HIV-positive individuals exist through the Ryan White Comprehensive AIDS Resources Emergency Care (CARE) Act, which has become a critical part of health care delivery to HIV-positive individuals (51). More than half a million people with HIV are provided with care services through city and state programs and local community-based organizations funded by the Ryan White CARE Act (52). While a number of Ryan White CARE Act clients will now be eligible for health insurance after implementation of the Affordable Care Act, the Ryan White CARE Act will remain crucial in filling coverage gaps, assisting with copayments, and supporting HIV-positive individuals through each stage of the HIV treatment cascade (51). Medicaid is also a crucial partner in delivery of care to people with HIV. Half of all HIV positive people in the United States are insured through Medicaid (26), and this percentage may increase due to Medicaid expansion (53). Costs of HIV treatment may begin to decrease as a number of patents for HIV medications are set to expire between 2010 and 2017. Generic treatments for HIV are only slightly less effective than the current treatments, and this small decrease in effectiveness would be overshadowed by the overall improved care for people with HIV (22). As drug patents expire, generic versions of the drugs will become available, hopefully resulting in lowered treatment costs and an increased proportion of individuals treated for HIV (22).

MTC transmission is almost entirely preventable through testing during pregnancy and maintaining ART adherence through birth (14). In New York State the Maternal-Pediatric HIV Prevention and Care Program (MPHPCP) has been successful in reducing MTC HIV transmission (54). Main components of the program include prenatal HIV counseling and testing, ART medication for HIV-positive pregnant women, routine HIV screening for newborns, and rapid HIV tests if a mother's HIV status is unknown at delivery(54). As a result, the New York State Department of Health found prenatal HIV testing has risen to 95 percent to 96 percent in 2010 from 64 percent in 1997 and the number of cases of MTC transmission has fallen from 97 cases in 1999 to 3 cases in 2010 (54).

Partnering with educational systems such as middle schools and high schools can help to increase prevention efforts, testing, linkage to care in young populations. Adolescents need to be informed about HIV and other STIs to increase the probability of being tested and safe sexual practices (27). The CDC Division of Adolescent and School Health (DASH) provides a network of nationwide HIV prevention leaders that include state and local health departments as well as state education agencies and school districts. DASH provides funding and technical assistance to school based HIV prevention programs in 49 states and the District of Columbia (55).

**Predict an individual’s health and wellness and/or that of their offspring**

While multiple effective treatments exist, there is still no known cure for HIV/AIDS. Without treatment, HIV generally stays clinically latent (asymptomatic) for a period of eight to 10 years (47). Development of AIDS is marked by severe deterioration of the immune system and a decline in the body’s ability to fight infection, creating susceptibility to opportunistic infections that eventually lead to death (47). Compared with adults who have other chronic conditions (epilepsy, clinically localized prostate cancer, depression, or diabetes), persons living with symptomatic HIV or those who meet the clinical criteria for AIDS have worse physical functioning (40). Medications taken to delay the onset of AIDS can have serious side effects including liver damage, bone loss, kidney problems, diabetes, nerve problems, and cardiovascular problems (39).

HIV has been noted to cause many mental and cognitive problems. Research has shown that HIV increases the risk of anxiety and depression (29). HIV-positive persons can also be affected with a loss in cognitive ability, although researchers do not know the exact mechanism in which HIV injures the central nervous system, studies show that HIV
can cause HIV-associated dementia (29). The depression and poor cognitive and physical function, resulting from HIV or treatment, only increases with age (30).

Risk of comorbidities in an HIV-positive person increases with age, smoking, duration of antiretroviral use, and previous immunodeficiency (43). Among HIV-positive IDUs, 80 percent are also co-infected with hepatitis C (57). HIV-positive women are at an increased risk for contraction of human papillomavirus (HPV), which can result in cervical cancer and severe pelvic inflammatory disease (56). HIV greatly increases the risk of latent TB infection to become active TB disease, which is noteworthy as TB is an AIDS-defining condition and one of the worldwide leading causes of death among HIV-positive people (58). HIV-positive individuals are also at an increased risk of heart attack and certain types of cancer (29).

HIV also can impact intergenerational health. Presently, there is less than a 2 percent chance that an HIV-positive woman will deliver an HIV-positive baby if she is treated early and takes her medication properly (14). Unfortunately, not all pregnant HIV-positive women receive treatment, which increases the risk to 25 percent that the woman will deliver an HIV-positive baby (31). Studies have also shown that HIV-related stressors on parents have the ability to negatively affect the psychological adjustment of children (32). Furthermore, a study following HIV positive parents with children reported that 50 percent of the children at one point in the two year study were not living with their HIV positive parent (33). Disruption of living arrangement can lead to negative health outcomes especially when it involves the child entering into foster care (33).

SES and HIV status can be considered to have a cyclic relationship. Low SES can increase the risk for HIV; also HIV can negatively affect SES. Many studies argue that positive HIV status negatively affects SES, because it decreases the individual’s productivity. For example, one study showed that 45 percent of HIV positive individuals were unemployed (34). As mentioned above, HIV can negatively impact cognitive ability and create barriers to employment; this loss in cognitive ability directly leads to loss of productivity in the workforce (36). It has been argued that cognitive ability of HIV positive children is even more affected by deficiencies, which decreases their earning potential and learning ability throughout life (23).

**Data Criteria**

**Data availability**

HIV is a reportable disease. Data is sent to the CDC from all 50 states and the District of Columbia and does not require the linkage of datasets for complete information (1). The CDC HIV/AIDS surveillance provides data on the national prevalence and incidence rates of the HIV/AIDS epidemic, as well as data on major metropolitan areas annually. The numerator for the prevalence of HIV is the total diagnosed HIV cases during the given calendar year (2). While an estimate of undiagnosed cases would be of value in examining HIV prevalence, only statistics on diagnosed HIV cases are available through the CDC National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention (NCHHSTP) Atlas. CDC uses a back calculation to estimate the number of undiagnosed HIV cases in the adult population (over age 13) and provides these statistics on the CDC HIV Statistics web site (http://www.cdc.gov/hiv/statistics/basics/index.html). However, undiagnosed HIV prevalence is not readily available for each state or for the national adult and child population. For data availability reasons, the numerator of this indicator is total diagnosed HIV cases during the given calendar year. The denominator is the population from the U.S. Census Projections. MCH programs can easily gain access to diagnosed HIV prevalence data annually. NCHHSTP Atlas provides annual data at http://www.cdc.gov/nchhstp/atlas/. The CDC also releases HIV prevalence and incidence data across demographic information and states.

**Data quality**

Since 1998, the CDC has recommended the use of confidential name-based reporting for all HIV surveillance programs (3). With confidential name-based reporting, the state health departments receive names of HIV and AIDS cases; then the data is forwarded to federal health agencies with an alphanumeric code replacing the name (4). The CDC believes that confidential name-based HIV reporting provides the most efficient and effective surveillance; thus improving the monitoring of the epidemic (5). The CDC also suggests that name-based reporting improves the efficiency of the allocation of funds for treatment and prevention programs, and the targeting of high risk populations (6). In 2008 confidential name-based reporting became the standard used to collect HIV data in all 50 states and the District of Columbia (7). The 2011 HIV Surveillance Report was the first year that name-based reporting data from all 50 states were used to estimate the rates of HIV diagnoses and prevalence in the United States (2). The regulation of data collection
means that data accuracy has been improving over the past few years. It is important to note that new diagnoses do not equate to incidence, as diagnosis can occur at different points in the course of disease (2). The data validity should continue to improve in the future as all states have been using name-based reporting for the last four years. The CDC also notes that it is important to assess the validity and reliability of the data when it is collected, managed and analyzed to guarantee the accuracy of the data (6). Furthermore, as of 2010, 25 states have funded population-based HIV incidence data collection by using serologic testing that allows HIV surveillance programs to identify how recently the HIV infection occurred and improve incidence data (2).

There are several ways to calculate prevalence of HIV including analyzing data from national probability-based surveys, antenatal clinic surveys, back-calculation and cohort studies. The CDC uses back calculation and serologic testing data information to calculate prevalence and incidence; with the regulation of name-based reporting, back-calculation is becoming more accurate. Also with the increase of serologic testing, incidence rates will become more accurate as well. Consequently, this will help to improve the accuracy of prevalence estimations from the data collected and analyzed by the CDC.

**Simplicity of indicator**

HIV prevalence, as defined as diagnosed cases of HIV in the U.S. population, is easy to explain and calculate. This indicator is already calculated and available through the NCHHSTP Atlas. Reducing new HIV infections is a common focus among many governmental, national and community groups that have supported and promoted education and prevention. These groups include:

- Greater Than AIDS aims to increase knowledge about HIV/AIDS particularly among black Americans and gay and bisexual men, and is a collaboration between the Black AIDS Institute (founding partner), CDC, the Kaiser Family Foundation, the Ford Foundation, Elton John AIDS Foundation and MAC AIDS (9).
- Magic Johnson Foundation, develops and support community-based organizations in urban communities (10)
- The Act Against AIDS Leadership Initiative (AAALI) is a coalition of predominantly African American organizations that aim to intensify HIV prevention efforts in African American, Latino and MSM communities (10)
- CDC (10)
- The Kaiser Family Foundation(10)
- The Ford Foundation(10)
- Elton John AIDS Foundation(10)
- MAC AIDS(10)

Of note, while the incidence of HIV has remained constant, the prevalence of HIV has been increasing since the 1990s partly due to longer survival rates (as a result of improvements to HIV treatment) and improved data collection and assessments.

**References**


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