

# Defining unmet need and linkage to care

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## Issue

Unmet need and linkage to care are important HIV prevention and care indicators. However, these terms may represent different calculations depending on jurisdiction and program. This causes confusion and incomparable figures. As HIV surveillance integrates with care and prevention programs, it is important to consistently define terms. Here, Michigan presents definitions of unmet need and linkage to care which may be adopted nationally.

## Key terms and concepts

**Linked to Care:** An individual newly diagnosed with HIV is considered linked to care on the specimen collection date of his/her first CD4, viral load, or genotype laboratory test (proxies for clinical care visits). The sooner individuals are linked to care and begin ARV treatment, the better their prognosis<sup>1</sup>. Additionally, in Michigan, the earlier a person is linked to care the more likely they are to be in care in the future and the better their prognosis as 82% of Michiganders receiving HIV care are virally suppressed<sup>2</sup>. This, in turn, reduces transmission risk to others.

**In Care:** Persons diagnosed with HIV who receive at least one CD4, viral load, or genotype, during a calendar year. Receiving HIV care is extremely important in improving individuals' prognoses and, in turn, reducing transmission risk to others by achieving viral suppression.

**Retained in Care** (elsewhere referred to as "in care"): Persons diagnosed with HIV who receive at least two CD4's, viral loads, and/or genotypes at least three months apart during a calendar year. Persons who are "in care" but not "retained in care" may still achieve viral suppression.

**Viral suppression:** The final, and most important, stage in an HIV care continuum. An individual is considered to be virally suppressed if he/she has less than or equal to 200 copies of HIV virus per milliliter of blood ( $\leq 200$  copies/mL). Consistent suppression of the virus in an individual is an indication that he/she has routine access to care and is adherent to treatment. Those who maintain low viral loads also have the best long term prognosis. Additionally, transmission of the HIV virus is extremely low among virally suppressed individuals – 0.4 transmission per 100 PLWH per year. The transmission rate among persons retained in care, but not suppressed is over four times higher at 1.8 transmissions per 100 PLWH per year<sup>3</sup>.

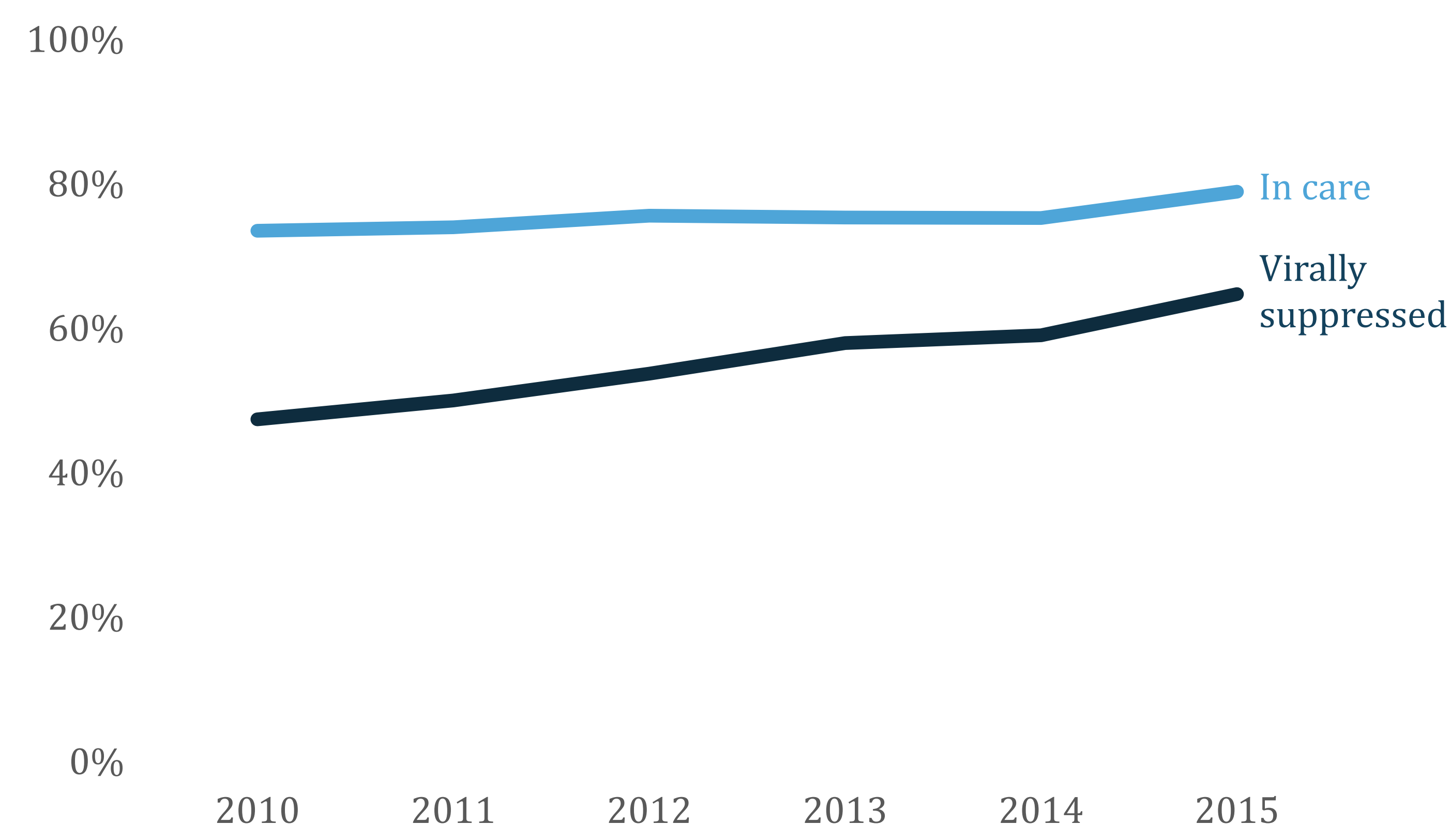


Viral suppression is the ultimate goal of care and prevention programs, therefore program indicators such as unmet need and linkage to care should be reflective of the steps necessary to achieve viral suppression.

## Setting

Compulsory HIV lab reporting in Michigan was implemented in 2005. Since 2013, the Michigan surveillance program has explored various care and linkage to care definitions that take advantage of successful lab reporting. The motivation behind this exploration is demonstrated by Michigan's care and viral suppression trends. Though care rates among PLWH leveled off between 2010 and 2014, the proportion of virally suppressed individuals continued to rise. The stagnation of care and increase of viral suppression is observed across populations, race, risk, age, geography, etc. Additionally, the improvement of viral suppression appears to be occurring without targeted interventions. This improvement, however, is limited by the proportion in care. Therefore, the Michigan surveillance program advocates focusing on improving care rates as a means to allow the continued improvement of viral suppression. Ultimately, the usefulness of this strategy depends on how care and linkage to care are defined as demonstrated henceforth.

Proportion of Michiganders living with HIV in care and virally suppressed, 2010-2015



References  
<sup>1</sup>Lundgren JD, Babiker AG, Gordin F, et al. (2015) Initiation of Antiretroviral Therapy in Early Asymptomatic HIV Infection. *N Engl J Med*.373(9):795-807  
<sup>2</sup>Michigan Department of Health and Human Services. (2017) The 2020 National HIV/AIDS Strategy (NHAS) Indicators: Assessment of Michigan's Progress 2010-2015.  
<sup>3</sup>Skarbinski J, Rosenberg E, Paz-Bailey G, Hall I, Rose C, Viall A, et al. (2015) Human Immunodeficiency Virus Transmission at Each Step of the Care Continuum in the United States. *JAMA Intern Med*.doi:10.1001/jamainternmed.2014.8180  
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# Unmet Need

## Proposed Definition

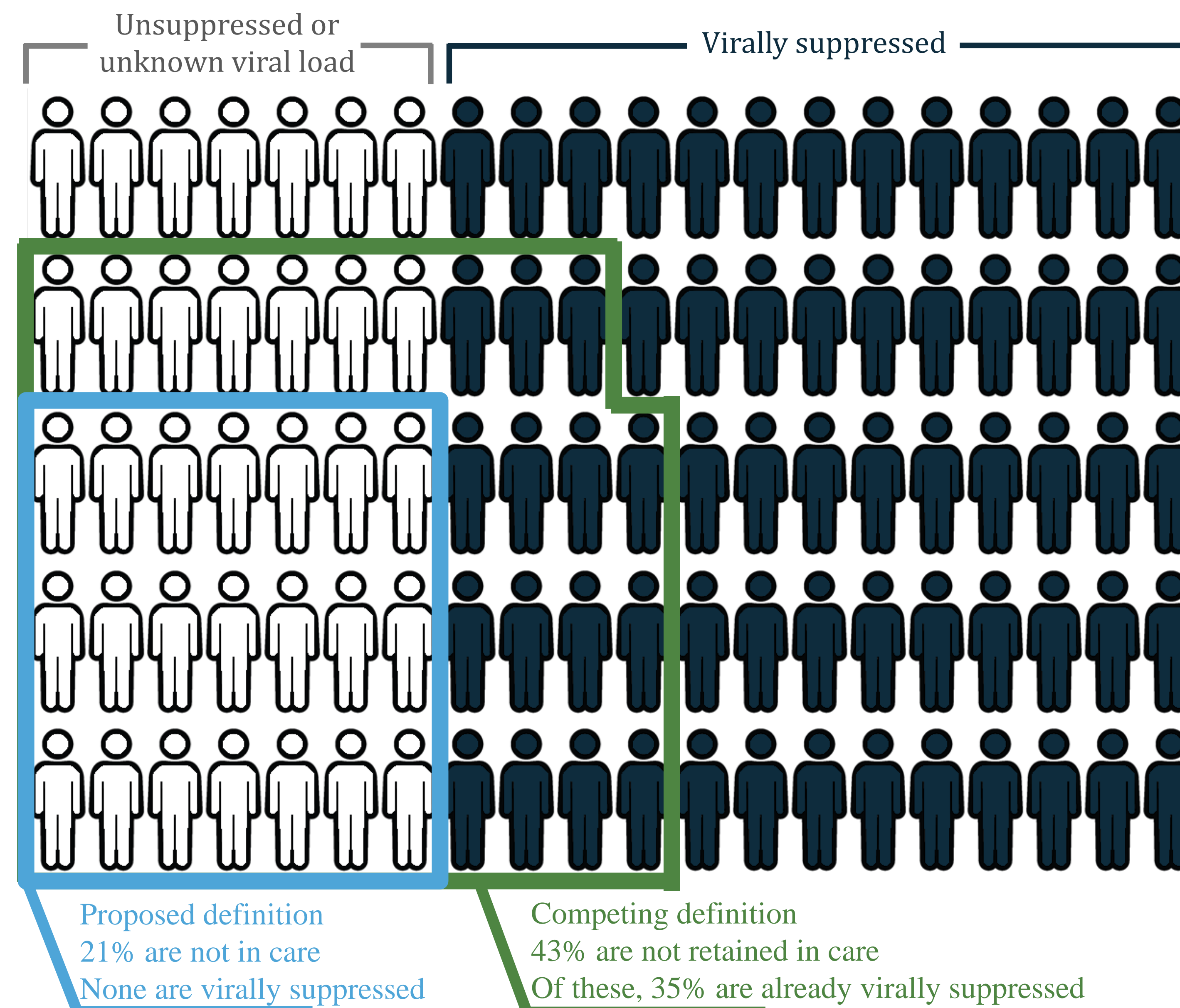
Persons diagnosed with HIV who did not receive a CD4, viral load, or genotype during a calendar year (not in care). Includes persons living with HIV for the entirety of the year.

**Primary competing definition:** Persons diagnosed with HIV who did not receive at least two CD4's, viral loads, or genotypes at least three months apart during a calendar year (not retained in care). Includes persons living with HIV for the entirety of the year. This definition was included in the Ryan White Part B Funding Opportunity Announcement, FY 2017. This calculation, named the HIV Care Continuum Framework, was proposed to better align Ryan White Program measures with the CDC Care Continuum.



The proposed definition encourages improved viral suppression while the competing definition does not. Below is a visual representation of the definitions' differences as they relate to viral suppression.

Unmet need and viral suppression among Michiganders living with HIV, 2015



**Consequences of the competing definition:** Two medical visits per year ("retention in care") are not necessary to achieve viral suppression. Patients who consistently achieve viral suppression may be instructed by their physicians to only visit once per year. If unmet need is defined as those not retained in care, states could reduce unmet need by motivating virally suppressed persons to schedule a second physician visit. This would only serve to take up valuable clinic time without improving community viral suppression.

Additionally, defining unmet need as those not retained in care dilutes need disparities observed among black and Latino persons, persons who inject drugs (PWID) ( $p < 0.05$ ) and 13-19 year olds (table below). It is critical to attribute appropriate need measure to these populations as they also consistently achieve lower levels of viral suppression compared to white persons, MSM, and persons 25 and older.

Unmet need and disparity ratios

| Demographics        | Not in care |                  | Not retained in care |                  |
|---------------------|-------------|------------------|----------------------|------------------|
|                     | %           | ratio            | %                    | ratio            |
| White               | 16%         | reference        | 37%                  | reference        |
| Black <sup>‡</sup>  | 23%         | 1.5 <sup>†</sup> | 47%                  | 1.3 <sup>†</sup> |
| Latino <sup>‡</sup> | 29%         | 1.8 <sup>†</sup> | 47%                  | 1.3 <sup>†</sup> |
| MSM                 | 18%         | reference        | 41%                  | reference        |
| PWID <sup>‡</sup>   | 32%         | 1.8 <sup>†</sup> | 53%                  | 1.3 <sup>†</sup> |
| 13-19 years old     | 29%         | 1.4              | 46%                  | 1.1              |
| 19-24 years old     | 22%         | 1.0              | 51%                  | 1.2              |
| 25+ years old       | 21%         | reference        | 43%                  | reference        |

<sup>†</sup>Significant disparity compared to reference group:  $p < 0.05$   
<sup>‡</sup>Significant disparity ratio decrease from not in care to not retained in care:  $p < 0.05$

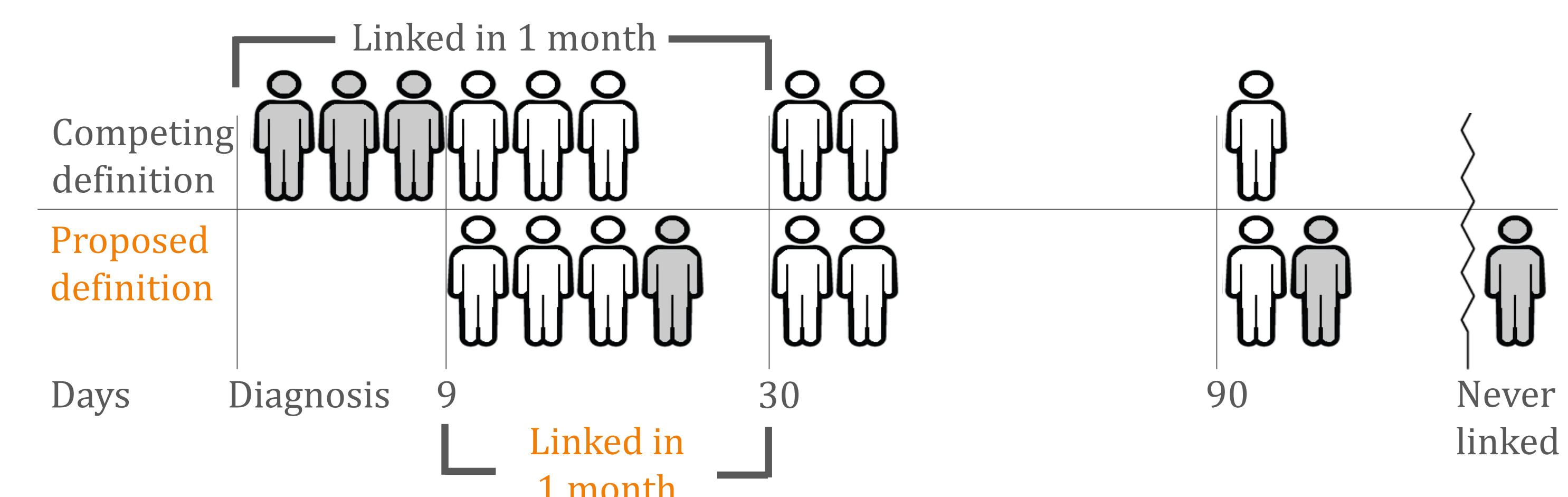
# Linkage to Care

## Proposed Definition

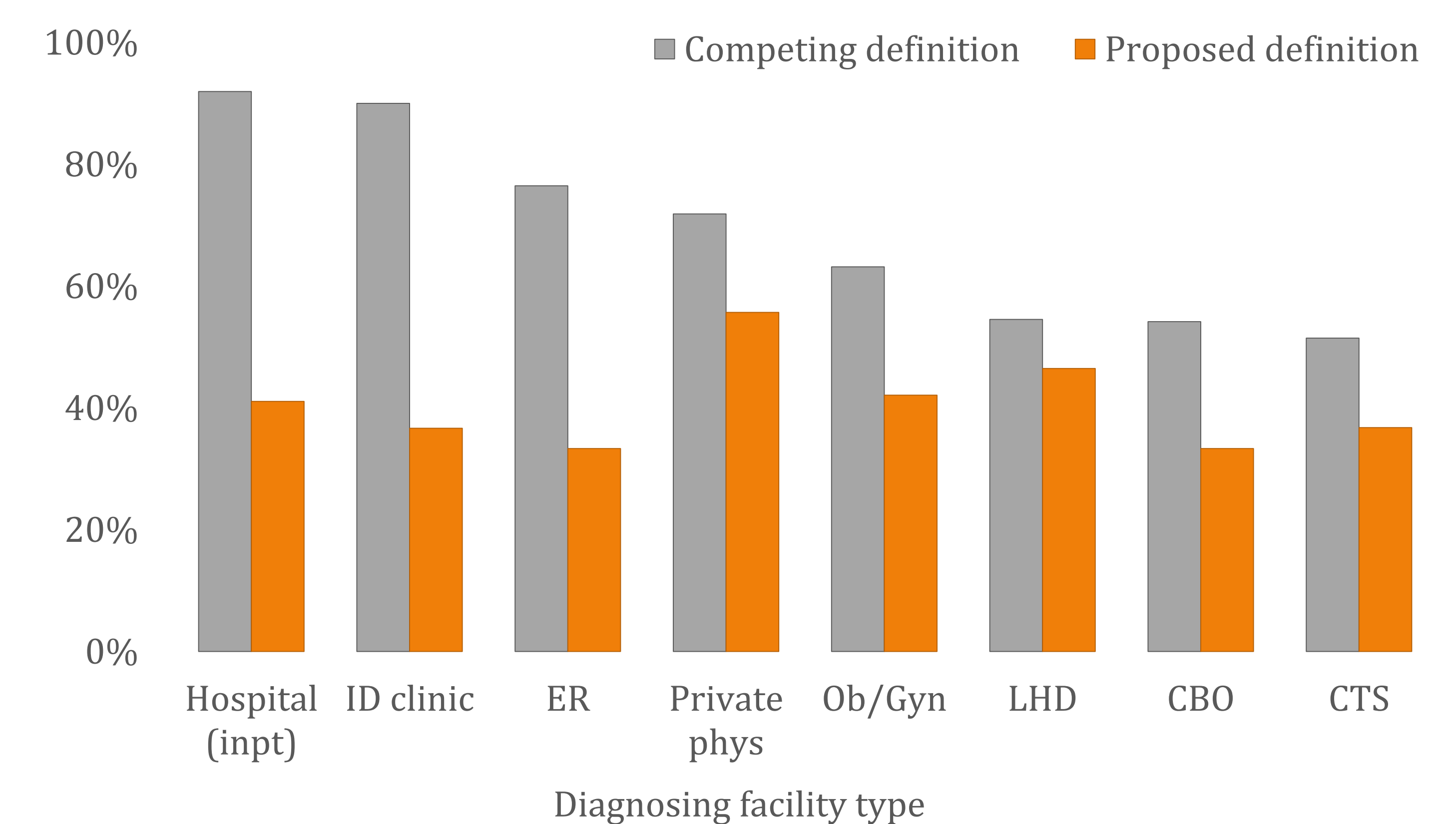
The time between HIV diagnosis and the first CD4, viral load, or genotype excluding labs collected within the first eight days following diagnosis.

**Primary competing definition:** The most commonly used definition includes labs run within eight days of diagnosis. Under this definition, persons who receive a CD4 or viral load as part of the diagnostic process are categorized as "linked to care" even if they are never informed of their infection and never return for treatment.

**A comparison of the proposed and competing definitions:** The figure below shows the linkage rate of nine newly diagnosed persons – in the first row, they are positioned based on the competing definition; in the second row they are positioned based on the proposed definition. Three had a first CD4, viral load, or genotype test within eight days of diagnosis (grey). Under the competing definition, these labs are included and all three (along with three others) are considered linked to care. Under the proposed definition, however, these individuals are re-positioned. One is moved to 9-30 days, one is moved to 90+ days and one was never linked. Under the proposed definition only four of the nine are considered linked in one month.

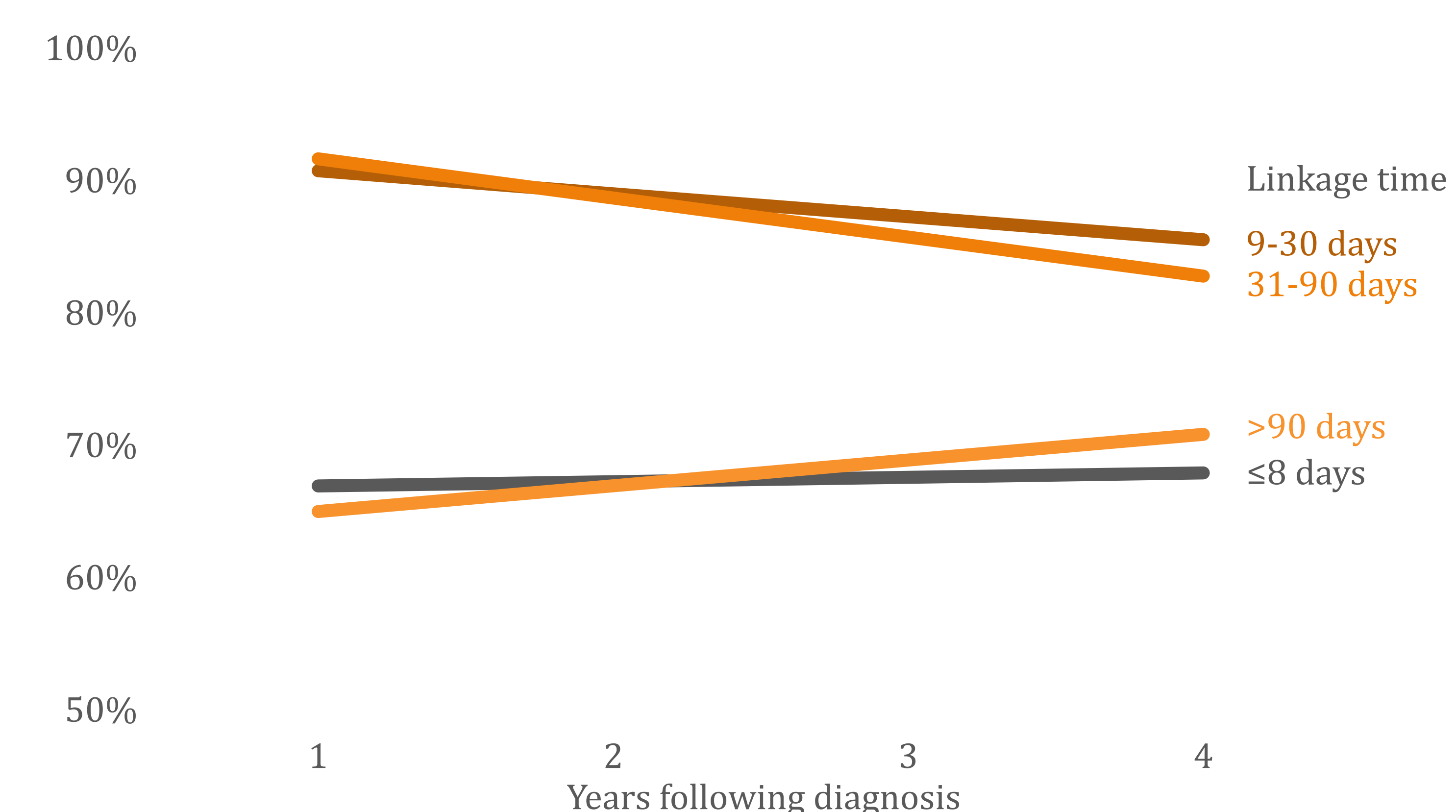


One month linkage rates among Michiganders by facility type, diagnosed 2015



Persons "linked to care" within eight days of diagnosis and not seen again for at least 90 days have significantly lower care rates ( $p < 0.05$ ) during the years following diagnosis (below). Improved care rates are an essential step to improving viral suppression.

Best fit lines for proportion in care 1-4 years following diagnosis by linkage to care rates, Michigan 2010-2014



Slopes of best fit lines are not significant