**Attachment 12
0920-0740**

**Medical Monitoring Project (MMP) Summary of Changes to Data Collection Instruments**

Changes to Standard Interview questionnaire:

| **Type of change** | **Module** | **Question #** | **Description** | **Burden** |  |
| --- | --- | --- | --- | --- | --- |
| Addition | Access to care | A17a | Added a question about the number of days spent in the hospital. During the past 12 months, how many days total did you spend in a hospital because of an HIV-related illness? | Increase | add 1 |
| Addition | Health conditions and prevention therapy | C11 | Based on recommendations from the STD Division, added a questions that asks about specific locations where a participant may have received STI testing, diagnosis, or treatment.  | Increase | add 1 |
| Deletion | Health conditions and prevention therapy | C11 | Based on recommendations from the STD Division, deleted question about whether the participant went to a clinic for STD treatment. | Reduce | remove 1 |
| Deletion | All | D12a, A37, T5a , T10, T15, P1a | Based on findings from previous cycles, removed other specify 3 and other specify 4 options for all check all that apply questions. The questionnaire will now have 2 other specify responses instead of 4.  | Reduce | remove 2 additional response solicitations from 6 questions (12 total) |
| Addition | Health conditions and prevention therapy | C10 series | Based on recommendations from the STD Division, we modified C10 to ask about 5 additional STI diagnoses.  | Increase | Added 5 questions |
| Addition | Health conditions and prevention therapy | C9 series | Based on recommendations from the STD Division, we modified C9 to ask about STI screening/testing of 7 specific STIs  | Increase | Added 7 questions |
| Deletion | Health conditions and prevention therapy | C9 series | Removed question about whether the participant had an exam or test for an STD | Increase | Removed 1 question |
| Addition | Met and unmet needs | A36 | Based on review of the other specify responses from previous cycles in the met and unmet section, we added a question about nutritional services in the met and unmet need question series.  | Increase | Add 1 question |
| Addition | Serosorting | S26, S27, S28, S29 | Four additional questions have been included to measure serosorting. MMP Principle Investigator, Project Coordinator, Community Advisory Board, and Provide Advisory Board members recommended adding serosorting questions to the questionnaire.  | Increase | Added 4 questions |
| Addition | Gynecological and reproductive history | G2 | Based on recommendations from the STD Division, we added G1a. Were the results of this Pap smear normal or not normal? [PAP1A\_12] | Increase (however questions are only asked to a small subset of sample | Added 1 question |
| Deletion | Gynecological and reproductive history | G1 | Based on feedback from the STD Division, we deleted the question about whether the participant had a pelvic exam. | Reduce | Deleted 1 question |
| Modification | Gynecological and reproductive history | G2a | Based on recommendations from the STD Division, we added G1b. Did you receive follow-up exam or tests for this abnormal result? [PAP1B\_12] | Increase (however questions are only asked to a small subset of sample | Added 1 question |
| Deletion | HIV adherence and treatment | T4a-T4g | Based on feedback from stakeholders, concerns about recall, and desire to limit questions so that they refer to the surveillance period, we removed all questions that ask about specific medications that were **ever** taken.  | Reduce | Removed 7 questions |
| Modification | Health conditions and prevention therapy | C14b-C14d | Removed questions about whether the participant had received any other flu vaccinations.  | Reduce | Removed 3 questions |

Summary of changes to Minimum Dataset:

The following 56 variables were added to the Minimum Dataset, the majority of which were added to enhance understanding of specific conditions that affect the clinical prognosis of HIV-infected persons. For example, patient’s most recent CD4 test result (an indication of disease progression) was included in the previously approved instrument, but the addition of the value of the patient’s first CD4 test date and result after HIV diagnosis provides information on whether the patient delayed HIV testing and/or medical care entry. Another example is that added information about current gender and current sex will complement the collection of sex at birth (previously approved) to allow for ascertainment of transgender status. There is limited information on HIV-infected transgender persons, but this subpopulation has been found to engage in high levels of HIV transmission risk behaviors and have poor access to healthcare. Other variables added are composite variables constructed by the HARS system that aggregate information already approved for collection. For example, transmission category is a calculated variable representing HIV exposure, which is based on a group of risk behavior variables already approved for collection. This variable calculates the most likely route of HIV transmission based on a presumed hierarchical order of transmission.

Because Minimum Dataset data are extracted from an existing database using a computer program run by MMP staff, these additions do not change the burden of the project.

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **SAS variable Number**  | **eHARS PERSON dataset** | **SAS Variable Name** | **Label** | **Description** | **Values** | **SAS Format** | **HARS Var Name** |
| **405** | Stateno | STATENO  | State patient number (STATENO) |   |   | Stateno | stateno |
|   |   |   |   |   |   |   |   |
| **258** | current\_gender | current\_gender | Current gender | The patient’s current gender | CD- Cross dresser  | $CUR\_GEN | N/A |
|   |   |   |   |   | DQ- Drag queen |   |   |
|   |   |   |   |   | F- Female |   |   |
|   |   |   |   |   | FM- Female to male |   |   |
|   |   |   |   |   | I- Intersexed |   |   |
|   |   |   |   |   | M- Male |   |   |
|   |   |   |   |   | MF- Male to female |   |   |
|   |   |   |   |   | SM- She male |   |   |
| **259** | current\_sex | current\_sex | Current sex | The patient’s current sex | M- Male | $CUR\_SEX | N/A |
|   |   |   |   |   | F- Female |   |   |
|   |   |   |   |   | I- Intersexed |   |   |
| **173** | cd4\_first\_hiv\_value | cd4\_first\_hiv\_value | Value of first CD4 test after HIV diagnosis | The value of the first CD4 test after HIV diagnosis |   |   | N/A |
| **174** | cd4\_low\_cnt\_dt | cd4\_low\_cnt\_dt | Date of lowest CD4 count  | The date of the lowest CD4 count test result value |   | YYYYMMDD | N/A |
| **175** | cd4\_low\_cnt\_value | cd4\_low\_cnt\_value | Value of lowest CD4 count | The lowest CD4 count test result value |   |   | N/A |
| **176** | cd4\_low\_pct\_dt | cd4\_low\_pct\_dt | Date of lowest CD4 percent | The date of the lowest CD4 percent test result value. |   | YYYYMMDD | N/A |
| **177** | cd4\_low\_pct\_value | cd4\_low\_pct\_value | Value of lowest CD4 percent | The lowest CD4 percent test result value. |   |   | N/A |
| **178** | cd4\_recent\_cnt\_dt | cd4\_recent\_cnt\_dt | Date of most recent CD4 count | The date of the most recent CD4 count. |   | YYYYMMDD | N/A |
|  |   |   |   |   |   |   |   |
|  |   |   |   |   |   |   |   |
|  |   |   |   |   |   |   |   |
| **164** | cd4\_first\_14\_dt | cd4\_first\_14\_dt | Date of first CD4 percent < 14  | The date of the first CD4 percent that was less than 14 |   |  YYYYMMDD | N/A |
| **165** | cd4\_first\_14\_value | cd4\_first\_14\_value | Value of first CD4 percent < 14 | The value of the first CD4 percent that was less than 14 |   |   | N/A |
| **166** | cd4\_first\_200\_14\_dt | cd4\_first\_200\_14\_dt | Date of first CD4 count < 200 or percent < 14 | The date of the first CD4 count < 200 or CD4 percent < 14 |   |  YYYYMMDD | N/A |
| **167** | cd4\_first\_200\_dt | cd4\_first\_200\_dt | Date of first CD4 count < 200  | The date of the first CD4 count that was less than 200 |   |  YYYYMMDD | N/A |
| **168** | cd4\_first\_200\_value | cd4\_first\_200\_value | Value of first CD4 count < 200  | The value of the first CD4 count that was less than 200 |   |   | N/A |
| **169** | cd4\_first\_350\_dt | cd4\_first\_350\_dt | Date of first CD4 count < 350  | The date of the first CD4 count that was less than 350 |   |  YYYYMMDD | N/A |
| **170** | cd4\_first\_350\_value | cd4\_first\_350\_value | Value of first CD4 count < 350  | The value of the first CD4 count that was less than 350 |   |   | N/A |
| **171** | cd4\_first\_hiv\_dt | cd4\_first\_hiv\_dt | Date of first CD4 test after HIV diagnosis | The date of the first CD4 test after HIV diagnosis |   |  YYYYMMDD | N/A |
| **172** | cd4\_first\_hiv\_type | cd4\_first\_hiv\_type | Type of first CD4 test after HIV diagnosis (count or percent) | The type of CD4 test after HIV diagnosis (count or percent) |   |   | N/A |
| **173** | cd4\_first\_hiv\_value | cd4\_first\_hiv\_value | Value of first CD4 test after HIV diagnosis | The value of the first CD4 test after HIV diagnosis |   |   | N/A |
| **174** | cd4\_low\_cnt\_dt | cd4\_low\_cnt\_dt | Date of lowest CD4 count  | The date of the lowest CD4 count test result value |   | YYYYMMDD | N/A |
| **175** | cd4\_low\_cnt\_value | cd4\_low\_cnt\_value | Value of lowest CD4 count | The lowest CD4 count test result value |   |   | N/A |
| **176** | cd4\_low\_pct\_dt | cd4\_low\_pct\_dt | Date of lowest CD4 percent | The date of the lowest CD4 percent test result value. |   | YYYYMMDD | N/A |
| **177** | cd4\_low\_pct\_value | cd4\_low\_pct\_value | Value of lowest CD4 percent | The lowest CD4 percent test result value. |   |   | N/A |
| **178** | cd4\_recent\_cnt\_dt | cd4\_recent\_cnt\_dt | Date of most recent CD4 count | The date of the most recent CD4 count. |   | YYYYMMDD | N/A |
| **179** | cd4\_recent\_cnt\_pct\_dt | cd4\_recent\_cnt\_pct\_dt | Date of most recent CD4 test (count or percent) | The date of the most recent CD4 test result (count or percent). |   | YYYYMMDD | N/A |
| **180** | cd4\_recent\_cnt\_value | cd4\_recent\_cnt\_value | Value of most recent CD4 count | The value of the most recent CD4 count. |   |   | N/A |
| **181** | cd4\_recent\_pct\_dt | cd4\_recent\_pct\_dt | Date of most recent CD4 percent | The date of the most recent CD4 percent. |   | YYYYMMDD | N/A |
| **182** | cd4\_recent\_pct\_value | cd4\_recent\_pct\_value | Value of most recent CD4 percent  | The value of the most recent CD4 percent. |   |   | N/A |
| **183** | cd4\_vl\_first\_hiv\_dt | cd4\_vl\_first\_hiv\_dt | Date of first CD4 or viral load test after HIV diagnosis | The date of the first CD4 or viral load test after HIV diagnosis |   | YYYYMMDD | N/A |
| **184** | cd4\_vl\_first\_hiv\_type | cd4\_vl\_first\_hiv\_type | Type of first test after HIV diagnosis (CD4 or viral load) | The type of the first test (CD4 or viral load test) on or after HIV diagnosis | 1- CD4  | $CD4\_VL | N/A |
|   |   |   |   |   | 2- Viral Load |   |   |
|   |   |   |   |   | U- Unknown |   |   |
| **235** | trans\_categ | trans\_categ | Transmission category | This calculated variable represents HIV exposure, based on a group of risk behaviors. The risk factors are grouped by adult and pediatric, based on the patient's age at diagnosis of HIV. The selection of the most likely route of transmission is based on a presumed hierarchical order of transmission. | 01- Adult MSM | $TR\_CAT | mode |
|   |   |   |   |   | 02- Adult IDU |   |   |
|   |   |   |   |   | 03- Adult MSM & IDU |   |   |
|   |   |   |   |   | 04- Adult received clotting factor |   |   |
|   |   |   |   |   | 05- Adult heterosexual contact |   |   |
|   |   |   |   |   | 06- Adult received transfusion/transplant |   |   |
|   |   |   |   |   | 07- Perinatal exposure, HIV diagnosed at age 13 years or older |   |   |
|   |   |   |   |   | 08- Adult with other confirmed risk |   |   |
|   |   |   |   |   | 09- Adult with no identified risk (NIR) |   |   |
|   |   |   |   |   | 10- Adult with no reported risk (NRR) |   |   |
|   |   |   |   |   | 11- Child received clotting factor |   |   |
|   |   |   |   |   | 12- Perinatal exposure |   |   |
|   |   |   |   |   | 13- Child received transf/transplant |   |   |
|   |   |   |   |   | 18- Child with other confirmed risk  |   |   |
|   |   |   |   |   | 19- Child with no indentified risk (NIR) |   |   |
|   |   |   |   |   | 20- Child with no reported risk (NRR) |   |   |
|   |   |   |   |   | 99- Risk factors selected with no age at diagnosis |   |   |
| **236** | transx\_categ | transx\_categ | Expanded transmission category | This calculated variable represents an expanded list of HIV exposures, based on risk behaviors, grouped by adult and pediatric dependent on the patient's age at diagnosis of HIV. | See Section 3.10 | [$TRX\_CAT](file:///C%3A%5CDocuments%20and%20Settings%5Cgur0%5CLocal%20Settings%5CTemporary%20Internet%20Files%5CContent.MSO%5C437C96E7.tmp#RANGE!A1550:A1575) | modex |
| **196** | death\_rep\_dt | death\_rep\_dt | Date death reported | The date on which the vital status of the case is changed to dead (vital\_status = 2) in eHARS |   | YYYYMMDD | deathrep |
| **194** | death\_age\_mos | death\_age\_mos | Age at death (months) | The calculated age, in months, of the patient at the time of death  |   |   | N/A |
| **195** | death\_age\_yrs | death\_age\_yrs | Age at death (years) | The calculated age, in years, of the patient at the time of death |   |   | N/A |
| **151** | aids\_age\_mos | aids\_age\_mos | Age at AIDS diagnosis (months) | The calculated age at AIDS (HIV, stage 3) diagnosis, in months  |   |   | age\_mos |
| **153** | aids\_categ | aids\_categ | AIDS case definition category | The CDC case definition for AIDS (HIV, stage 3) met by the patient; calculated based on lab information and opportunistic diseases entered for a person.  | 7 - AIDS (HIV, stage 3) case defined by immunologic (CD4 count or percent) criteria | $A\_CAT | categ |
|   |   |   |   | For a description of the algorithm used to calculate aids\_categ, refer to section 8 of the eHARS Technical Reference Guide. | A- AIDS (HIV, stage 3) case defined by clinical disease (OI) criteria |   |   |
|   |   |   |   |   | 9- Not an AIDS (HIV, stage 3) case |   |   |
| **156** | aids\_cdc | aids\_cdc | CDC case definition for AIDS | Has this person met the CDC AIDS (HIV, stage 3) case definition? | Y- Yes | $YN | N/A |
|   |   |   |   | To meet the CDC AIDS (HIV, stage 3) case definition, the case must be defined by immunologic criteria or clinical disease criteria (aids\_categ = A or 7). | N – No  |   |   |
| **157** | aids\_cdc\_elig | aids\_cdc\_elig | CDC eligibility for AIDS | If this person is an AIDS (HIV, stage 3) case, does this person/case meet CDC eligibility criteria? | Y- Yes | $YN | N/A |
|   |   |   |   | To meet the CDC eligibility criteria for AIDS (HIV, stage 3), the case must be defined as AIDS by immunologic criteria or clinical disease criteria (i.e., aids\_categ = A or 7) and have a person view status of either Active or Warning (status\_flag = A or W). | N – No |   |   |
| **158** | aids\_dx\_dt | aids\_dx\_dt | Date of first AIDS classifying condition | The date of the first condition classifying as AIDS, based on the 1993 CDC AIDS case definition |   | YYYYMMDD | dxmoyr |
| **159** | aids\_dxx\_dt | aids\_dxx\_dt | Date of first AIDS classifying condition, applicable AIDS case definition  | The date of the first condition classifying as AIDS, based on the applicable case definition. If the date is before 1993, eHARS returns the date of first OI diagnosis based on the pre-1993 expanded AIDS case definition (aids\_oix\_dt); otherwise, eHARS returns the date of the first AIDS classifying condition based on the current AIDS case definition (aids\_dx\_dt).  |   | YYYYMMDD | dxx\_moyr |
| **163** | antigen\_first\_pos\_dt | antigen\_first\_pos\_dt | First positive HIV antigen test result date | The first positive HIV antigen test result date; the earliest of all HIV-1 p24 Antigen tests entered for the patient |   | YYYYMMDD | N/A |
|   |   |   |   |   |   |   |   |
| **185** | Class | class | HIV class | The HIV classification variable, based on the algorithm in HARS | A1- Asymptomatic (HIV, stage 1), CD4 count > 500 or percent > 29% | $CLASS | class |
|   |   |   |   | For a description of the algorithm used to calculate class, refer to sections 8 and 18 of the eHARS Technical Reference Guide.  | A2- Asymptomatic (HIV, stage 2), CD4 count 200-499 or percent 14-28% |   |   |
|   |   |   |   |   | A3- Asymptomatic (HIV, stage 3), CD4 count < 200 or percent < 14% |   |   |
|   |   |   |   |   | A9- Asymptomatic, unknown CD4 |   |   |
|   |   |   |   |   | B1- Symptomatic (HIV, stage 3), CD4 count > 500 or percent > 29% |   |   |
|   |   |   |   |   | B2- Symptomatic (HIV, stage 3), CD4 count 200-499 or percent 14-28% |   |   |
|   |   |   |   |   | B3- Symptomatic (HIV, stage 3), CD4 count < 200 or percent < 14% |   |   |
|   |   |   |   |   | B9- Symptomatic (HIV, stage 3), unknown CD4 |   |   |
|   |   |   |   |   | C1- AIDS (HIV, stage 3), CD4 count > 500 or percent > 29% |   |   |
|   |   |   |   |   | C2- AIDS (HIV, stage 3), CD4 count 200-499 or percent 14-28% |   |   |
|   |   |   |   |   | C3- AIDS (HIV, stage 3), CD4 count < 200 or percent < 14% |   |   |
|   |   |   |   |   | C9- AIDS (HIV, stage 3), unknown CD4 |   |   |
|   |   |   |   |   | X1- Unknown clinical category, CD4 count > 500 or percent > 29% |   |   |
|   |   |   |   |   | X2- Unknown clinical category, CD4 count 200-499 or percent 14-28% |   |   |
|   |   |   |   |   | X3- Unknown clinical category, CD4 count < 200 or percent < 14% |   |   |
|   |   |   |   |   | X9- Unknown clinical category, unknown CD4 |   |   |
|   |   |   |   |   |   |   |   |
|   |   |   |   |   |   |   |   |
| **205** | hiv\_age\_mos | hiv\_age\_mos | Age at HIV diagnosis (months) | The calculated age at HIV diagnosis, in months |   |   | hage\_mos |
| **251** | Dod | Date of death | The date the patient died |   | YYYYMMDD | deathndi\_date |   |
| **204** | expo\_categ | Exposure category | The exposure category of the patient | 01- MSM Only | $EX\_CAT | N/A |   |
|   |   |   |   | 02- IDU Only |   |   |   |
|   |   |   |   | 03- Heterosexual contact only |   |   |   |
|   |   |   |   | 04- MSM and IDU |   |   |   |
|   |   |   |   | 05- IDU & Hetero. Contact |   |   |   |
|   |   |   |   | 06- MSM & Hetero. Contact |   |   |   |
|   |   |   |   | 07- MSM & IDU & Hetero. Contact |   |   |   |
|   |   |   |   | 08- Perinatal Exposure |   |   |   |
|   |   |   |   | 09- Other |   |   |   |
|   |   |   |   | 10- No identified risk (NIR) |   |   |   |
|   |   |   |   | 11- No reported risk (NRR) |   |   |   |
| **216** | hiv\_dx\_dt | Date of first positive HIV test result or doctor diagnosis of HIV | The date of the diagnosis (first positive HIV test result or doctor diagnosis) of HIV infection |   | YYYYMMDD | hivpmoyr |   |
| **220** | hiv\_rep\_dt | Date reported as HIV positive | The date the case was reported to the health department as HIV positive; based on the eHARS system date when the HIV case definition category for the person/case (in Person View) changed to HIV Definitive (adult and pediatric cases) or Presumptive (pediatric cases only). Legacy HARS cases maintain their HIV report date (hposdate). |   | YYYYMMDD  | hposdate |   |
| **225** | receive\_dt | Earliest date the first document was received at the health department | Earliest date the first document was received at the health department; among all documents entered for a person, the earliest of either the date the document was entered in eHARS (document.entered\_dt; assigned by the system) OR the date the document was received at the health department (document.receive\_dt; entered by a user) |   |   | N/A |   |
| **232** | test\_recent\_dt | Date of most recent test result  | The date of the most recent test result (CD4 or viral load) |   | YYYYMMDD  | N/A |   |
| **233** | test\_recent\_type | Most recent test type | Most recent test type | 1- CD4 | $CD4\_VL | N/A |   |
|   |   |   |   | 2- Viral load |   |   |   |
| **234** | test\_recent\_value | Most recent test result value | Most recent test result value; for viral load tests, displays copies/ml value; if there are CD4 count and percent results from the same day, displaysthe CD4 count value | POS- Positive | $PNI  | N/A |   |
|   |   |   |   | NEG- Negative |   |   |   |
|   |   |   |   | IND- Indeterminate  |   |   |   |
| **274** | vital\_status | Vital status | The vital status of the patient | 1- Alive | $VIT\_STS | stat |   |
|  |   |   |   | 2- Dead |   |   |   |
|  |   |   |   | 9- Unknown |   |   |   |
| **239** | vl\_last\_non\_det\_dt | Date of last non-detectable viral load test result | The date of the last non-detectable viral load test |   | YYYYMMDD | N/A |   |
| **240** | vl\_recent\_dt | Date of most recent viral load test result  | The date of the most recent viral load test |   | YYYYMMDD | N/A |   |
| **241** | vl\_recent\_value | Most recent viral load test result value (copies/ml) | The most recent viral load test result (copies/ml) |   |   | N/A |   |