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)

Type of change	Module	Question #	Description	Burden	
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

Type of change	Module	Question #	Description	Burden	
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

Type of change	Module	Question #	Description	Burden	
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	The value of			N/A

			CD4 percent < 14	the first CD4 percent that was less than 14			
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		YYYYMMDD	N/A

				CD4 count test result value			
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	modex
196	death_rep_dt	death_rep_dt	Date death reported	The date on which the vital status of the case		YYYYMMDD	deathrep

				is changed to dead (vital_status = 2) in eHARS			
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	A- AIDS (HIV, stage 3) case defined by clinical disease (OI) criteria		

				Reference Guide.			
					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	N – No		

				(i.e., aids_categ = A or 7) and have a person view status of either Active or Warning (status_flag = A or W).			
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		YYYYMMDD	dxx_mo yr

				current AIDS case definition (aids_dx_dt).			
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	death ndi_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		YYYYMMDD	hposdate	

			(pediatric cases only). Legacy HARS cases maintain their HIV report date (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, displays the 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	