

Summary of Changes to Questionnaire
 Medical Monitoring Project
 OMB # 0920-0740
Attachment 5d

Beginning in early 2021, CDC began an evaluation of the MMP questionnaire. The evaluation focused on examination of the relevance, coherence, and scientific contribution of interview questions. The result is a modified interview questionnaire (see Attachment 5c for the previously approved version of the questionnaire and Attachment 5a for the new version of the questionnaire. A redlined version was not feasible because of extensive reformatting of the questionnaire, which was necessary to reduce programming errors and automate the collection of meta-data).

Sections of the questionnaire were modified to improve the efficiency of administration and the quality of the data collected. All new sections of the questionnaire were tested for comprehension through mock interviews. CDC staff conducted test interviews of the revised questionnaire using scenarios involving hypothetical respondents with different characteristics and determined the average time to complete the interview was 40 minutes. In addition, cognitive testing was performed to improve questions on gender identity, sexual orientation, patient-provider communication, unmet need for ancillary services, and discrimination. The changes to the questionnaire are described in the following table.

Table 1. Proposed Modifications (Deletions)

Location in Documents	Modifications (with brief justification)	Question #(s)	Burden (Increase, Decrease, No change)	Total Number of Questions
Attachment 2021: p. 26	We removed one question about whether respondents have medical bills they are paying. This question has questionnaire design issues. For instance, the wording is cumbersome and vague, and the responses do not align with the question.	2021: Removed BILLS_N5 (FH.4.0.)	Decrease	1
Attachment 2021: p. 34 - 36	We removed 13 questions belonging to the Health Care Trust Scale - Revised (HCR-R). The HCR-R scale we use received a negative evaluation on several psychometric properties according to a literature review.	2021: Removed TRUS1N8 - TRUST13N8 (KB.2.0. - KB.14.0)	Decrease	13

	For example, items in the scale might be measuring the same concept, it is unclear how to interpret the meaning of the score, and the scale had high ceiling effects. The scale was also burdensome to respondents.			
Attachment 2021: p. 33	We removed one question on satisfaction with the HIV care respondents have received in the past 12 months. This question (and any patient satisfaction question) gives highly favorable results that are unreliable. This construct is better measured using qualitative methods. Several researchers and survey methodologists have also highlighted the problem with measuring patient satisfaction.	2021: Removed GESAT_8 (KS.1.0)	Decrease	1
Attachment 2021: p. 37	We removed one question about whether respondents had an HIV clinic that was easy to get to. We noted that this question does not measure a facilitator of HIV care engagement.	2021: Removed FACCI1N8 (KP.7.0.)	Decrease	1
Attachment 2021: p. 43	We removed a single question on how often respondents are supposed to take their HIV medication. This question was rarely used in data analyses. Further, HIV treatment regimens are changing, making this question irrelevant to some respondents.	2021: Removed OFT_N5 (TA.3.0.)	Decrease	1
Attachment 2021: p. 94-97	We removed 13 questions on discrimination in HIV health care settings. These questions were	2021: Removed DISC1N8 - DISSEX_8 (RD.1.0. - RD.13.0.)	Decrease	13

	burdensome to respondents and had questionnaire design issues.			
Attachment 2021: p. 105 - 106	We removed questions on barriers to receiving needed ancillary services. These questions had questionnaire design issues (for example, they were double barreled) and were burdensome to respondents.	2021: Removed CSMNC_5 - CSMNF_5 (ND.1.2. - ND.1.5.)	Decrease	4
Attachment 2021: p. 106-107	We removed questions on barriers to receiving needed ancillary services. These questions had questionnaire design issues (for example, they were double barreled) and were burdensome to respondents.	2021: Removed TKMDC_N5 - TKMDF_N5 (ND.2.2. - ND.2.5.)	Decrease	4
Attachment 2021: p. 107	We removed questions on barriers to receiving needed ancillary services. These questions had questionnaire design issues (for example, they were double barreled) and were burdensome to respondents.	2021: Removed ADAPB_N5 - ADAPD_N5 (ND.3.2. - ND.3.4.)	Decrease	3
Attachment 2021: p. 108	We removed questions on barriers to receiving needed ancillary services. These questions had questionnaire design issues (for example, they were double barreled) and were burdensome to respondents.	2021: Removed PATNACN5 - PATNAFN5 (ND.4.2. - ND.4.5.)	Decrease	4
Attachment 2021: p. 109	We removed questions on barriers to receiving needed ancillary services. These questions had questionnaire design issues (for example, they were double barreled) and were burdensome to respondents.	2021: Removed RSGRPBN5 - RSGRPDN5 (ND.5.2. - ND.5.4)	Decrease	3
Attachment 2021: p. 110	We removed questions on barriers to receiving needed ancillary services. These questions had questionnaire design issues (for example, they were	2021: Removed DENSA_N5 - DENSD_N5 (ND.6.2. - ND.6.5.)	Decrease	4

	double barreled) and were burdensome to respondents.			
Attachment 2021: p. 111	We removed questions on barriers to receiving needed ancillary services. These questions had questionnaire design issues (for example, they were double barreled) and were burdensome to respondents.	2021: Removed SUBUA_N5 – SUBUD_N5 (ND.7.2. – ND.7.5.)	Decrease	4
Attachment 2021: p. 113	We removed questions on barriers to receiving needed ancillary services. These questions had questionnaire design issues (for example, they were double barreled) and were burdensome to respondents.	2021: Removed TRANB_N5 – TRAND_N5 (ND.9.2. – ND.9.4)	Decrease	3
Attachment 2021: p. 112	We removed questions on barriers to receiving needed ancillary services. These questions had questionnaire design issues (for example, they were double barreled) and were burdensome to respondents.	2021: Removed MENTC_5 – MENTF_5 (ND.8.2. – ND.8.5)	Decrease	4
Attachment 2021: p. 114	We removed questions on barriers to receiving needed ancillary services. These questions had questionnaire design issues (for example, they were double barreled) and were burdensome to respondents.	2021: Removed SHLTC_N5 – SHLTE_N5 (ND.10.2. – ND.10.4.)	Decrease	3
Attachment 2021: p. 114 – 115	We removed questions on barriers to receiving needed ancillary services. These questions had questionnaire design issues (for example, they were double barreled) and were burdensome to respondents.	2021: Removed FOODD_N5 – FOODF_N5 (ND.11.2. – ND.11.4)	Decrease	3
Attachment 2021: p. 115 – 116	We removed questions on barriers to receiving needed ancillary services. These questions had questionnaire design issues (for example, they were	2021: Removed MEALA_N5 – MEALD_N5 (ND.12.2. – ND.12.5.)	Decrease	4

	double barreled) and were burdensome to respondents.			
Attachment 2021: p. 116 - 117	We removed questions on barriers to receiving needed ancillary services. These questions had questionnaire design issues (for example, they were double barreled) and were burdensome to respondents.	2021: Removed DOMSA_N5 – DOMSD_N5 ND.13.2 – ND.13.5.	Decrease	4
Attachment 2021: p. 119	We removed one introduction that let respondents know they were transitioning to a portion of the questionnaire that asked about where respondents get information about HIV. We removed all those questions, which meant removing the introduction statement.	2021: Removed Intro_INFT3N8A	Decrease	1
Attachment 2021: p. 119 - 120	We removed 8 questions on where respondents get information about HIV and how much they trust that information. We have 6 years of data on this topic and decided to remove it to decrease the length of the overall interview.	2021: Removed INFT3N8A – INFTX2N8 (PM.1.0. – PM.2.6.)	Decrease	8

Table 2. Proposed Modifications (Additions)

Location in Documents	Modifications (with brief justification)	Question #(s)	Burden (Increase, Decrease, No change)	Total Number of Questions
Attachment 2024: Basic Demographics	We added two questions about whether respondents identify with a gender identity other than male, female, or transgender. If they do, we ask them to specify the gender identity they identify with. Adding these two questions allows us to	2024: GENDEREXP24, GENDEXPOS24 (DG.2.1.-DG.2.2.)	Increase	2

	<p>collect granular data on gender identity and evaluate the other gender identity questions we have historically used. This change was also informed by a report from the Subcommittee on Sexual Orientation, Gender Identity, and Variations in Sex Characteristics (SOGI) Data published in January 2023.</p>			
<p>Attachment 2024: p. Basic Demographics</p>	<p>We added one question on sexual orientation, which will only be asked to respondents who identify as “something else” when asked about their sexual orientation. This will allow us to collect more granular data on sexual orientation and evaluate the sexual orientation question we have historically used. This change was also informed by a report from the Subcommittee on Sexual Orientation, Gender Identity, and Variations in Sex Characteristics (SOGI) Data published in January 2023.</p>	<p>2024: SEXOREXP24 (DG.3.1.)</p>	<p>Increase</p>	<p>1</p>
<p>Attachment 2024: Patient Provider Relationship</p>	<p>We added two questions on patient-provider communication. We also added an introduction to transition respondents to these 2 questions. We removed 14 questions about trust in the patient’s health care provider, but we had to continue to measure a similar construct. Thus, two questions were added relating to patient-provider communication.</p>	<p>2024: Intro_COMMU1N24, COMMU1N24, COMMU2N24 (KB.2.0.-KB.3.0.)</p>	<p>Increase</p>	<p>2</p>
<p>Attachment 2024: Emotional Social</p>	<p>We added four questions on emotional social support. We also</p>	<p>2024: Intro_SUPPORT1N24,</p>	<p>Increase</p>	<p>4</p>

Support	added an introduction statement that transitions respondents to these questions. Social support has been associated with positive health outcomes, which is one reason we added these questions.	SUPPORT1N24 - SUPPORT4N24 (VS.1.0. - VS.4.0.)		
Attachment 2024: Adherence	We added four introduction statements that transition respondents to questions about their adherence to different kinds of HIV medications (e.g., IV infusion, pills, implants). Respondents will only receive certain introduction statements depending on the type of treatment regimen they are on.	2024: Intro_ARTTYP1N24, Intro_IMPADH1N24, Intro_INJADH1N24, Intro_IVADH1N24	Increase	4
Attachment 2024: Adherence	We added 13 questions about adherence to ART. We added questions because the HIV treatment landscape is changing, with long-acting ART options becoming available to people with HIV. Thus, we had to change our questionnaire based on the changing science. We will ask respondents if they took ART in the form of pills, IV infusions, shots, or implants. Depending on their answers, they will be asked additional questions about adherence to their medication.	2024: ARTTYP1N24 - IMPADH3N24 (TA.1.0. - TA.1.15)	Increase	13
Attachment 2024: Services and assistance programs	We added two questions that measure possible reasons for not receiving a specific ancillary service despite expressing a need for it. The first question asks the respondent if they knew the service existed and if they did, the second question asks if	2024: CSMNCN24 - CSMNDN24 (ND.1.2. -ND.1.3)	Increase	2

	they knew how to receive the service. These are two common reasons why people with HIV might not receive services they need.			
Attachment 2024: Services and assistance programs	We added two questions that measure possible reasons for not receiving a specific ancillary service despite expressing a need for it. The first question asks the respondent if they knew the service existed and if they did, the second question asks if they knew how to receive the service. These are two common reasons why people with HIV might not receive services they need.	2024: TKMDCN24 – TKMDDN24 (ND.2.2–ND.2.3.)	Increase	2
Attachment 2024: Services and assistance programs	We added two questions that measure possible reasons for not receiving a specific ancillary service despite expressing a need for it. The first question asks the respondent if they knew the service existed and if they did, the second question asks if they knew how to receive the service. These are two common reasons why people with HIV might not receive services they need.	2024: ADAPCN24 – ADAPDN24 (ND.3.2. –ND.3.3.)	Increase	2
Attachment 2024: Services and assistance programs	We added two questions that measure possible reasons for not receiving a specific ancillary service despite expressing a need for it. The first question asks the respondent if they knew the service existed and if they did, the second question asks if they knew how to receive the service. These are two common reasons why people with HIV might	2024: PATNACN24 – PATNADN24 (ND.4.2. –ND.4.3.)	Increase	2

	not receive services they need.			
Attachment 2024: Services and assistance programs	We added two questions that measure possible reasons for not receiving a specific ancillary service despite expressing a need for it. The first question asks the respondent if they knew the service existed and if they did, the second question asks if they knew how to receive the service. These are two common reasons why people with HIV might not receive services they need.	2024: GRPSCN24 – GRPSDN24 (ND.5.2. –ND.5.3.)	Increase	2
Attachment 2024: Services and assistance programs	We added two questions that measure possible reasons for not receiving a specific ancillary service despite expressing a need for it. The first question asks the respondent if they knew the service existed and if they did, the second question asks if they knew how to receive the service. These are two common reasons why people with HIV might not receive services they need.	2024: DENSCN24 – DENSDN24 (ND.6.2. –ND.6.3)	Increase	2
Attachment 2024: Services and assistance programs	We added two questions that measure possible reasons for not receiving a specific ancillary service despite expressing a need for it. The first question asks the respondent if they knew the service existed and if they did, the second question asks if they knew how to receive the service. These are two common reasons why people with HIV might not receive services they need.	2024: SUBUCN24 – SUBUDN24 (ND.7.2. –ND.7.3.)	Increase	2
Attachment 2024: Services and	We added two questions that measure possible reasons for not	2024: MENTCN24 – MENTDN24 (ND.8.2. –ND.8.3.)	Increase	2

<p>assistance programs</p>	<p>receiving a specific ancillary service despite expressing a need for it. The first question asks the respondent if they knew the service existed and if they did, the second question asks if they knew how to receive the service. These are two common reasons why people with HIV might not receive services they need.</p>			
<p>Attachment 2024: Services and assistance programs</p>	<p>We added two questions that measure possible reasons for not receiving a specific ancillary service despite expressing a need for it. The first question asks the respondent if they knew the service existed and if they did, the second question asks if they knew how to receive the service. These are two common reasons why people with HIV might not receive services they need.</p>	<p>2024: TRANCN24 - TRANDN24 (ND.9.2. -ND.9.3.)</p>	<p>Increase</p>	<p>2</p>
<p>Attachment 2024: Services and assistance programs</p>	<p>We added two questions that measure possible reasons for not receiving a specific ancillary service despite expressing a need for it. The first question asks the respondent if they knew the service existed and if they did, the second question asks if they knew how to receive the service. These are two common reasons why people with HIV might not receive services they need.</p>	<p>2024: SHLTCN24 -SHLTDN24 (ND.10.2. -ND.10.3.)</p>	<p>Increase</p>	<p>2</p>
<p>Attachment 2024: Services and assistance programs</p>	<p>We added two questions that measure possible reasons for not receiving a specific ancillary service despite expressing a need for it. The first question asks the respondent if</p>	<p>2024: FOODCN24 - FOODDN24 (ND.11.2. -ND.11.3.)</p>	<p>Increase</p>	<p>2</p>

	they knew the service existed and if they did, the second question asks if they knew how to receive the service. These are two common reasons why people with HIV might not receive services they need.			
Attachment 2024: Services and assistance programs	We added two questions that measure possible reasons for not receiving a specific ancillary service despite expressing a need for it. The first question asks the respondent if they knew the service existed and if they did, the second question asks if they knew how to receive the service. These are two common reasons why people with HIV might not receive services they need.	2024: MEALCN24 – MEALDN24 (ND.12.2. –ND.12.3.)	Increase	2
Attachment 2024: Services and assistance programs	We added two questions asking respondents if they received any other type of food assistance besides SNAP/WIC or free or low-cost food. This question will allow us to measure unmet needs for other types of food assistance and evaluate our questions relating to SNAP/WIC and free or low-cost food.	2024: FATYPAN24 – FATYPBN24 (ND.12.4. –ND.12.5)	Increase	2
Attachment 2024: Services and assistance programs	We added two questions that measure possible reasons for not receiving a specific ancillary service despite expressing a need for it. The first question asks the respondent if they knew the service existed and if they did, the second question asks if they knew how to receive the service. These are two common reasons why people with HIV might	2024: DOMSCN24 – DOMSDN24 (ND.13.2. –ND.13.3.)	Increase	2

	not receive services they need.			
Attachment 2024: Services and assistance programs	We added an introduction and two questions on job assistance programs. Employment is an important social determinant of health. We want to measure how many people with HIV have an unmet need for help from a job assistance program.	2024: Intro_EMPLAN24, EMPLAN24 - EMPLDN24 (ND.14.0. -ND.14.3.)	Increase	2
Attachment 2024: Services and assistance programs	We added 10 questions about discrimination in everyday settings. These 10 questions come from the HIV stigma subscale from the Multiple Discrimination Scale. Experiencing discrimination has been associated with suboptimal and poor health outcomes.	2024: DISC1N24 - DISC10N24 (RD.1.1. -RD.1.10.)	Increase	10

Table 3. Proposed Modifications (Revisions, no change in burden)

Location in Documents	Modifications (with brief justification)	Question #(s)	Burden (Increase, Decrease, No change)	Total Number of Questions
Attachment 2021: p. 15 - 16 Attachment 2024: Language ability	We modified the language ability questions to match what is in the American Community Survey. Only people who speak another language other than English are asked how well they speak English. This should reduce respondent burden.	2021: LANWL1N3 - LANN3_OS (DL.1.0. - DL.2.1.) 2024: LANWL3N8_24 - LANN3_OS_24	No change	4
Attachment 2021: p. 33 Attachment 2024: Patient provider relationship	We modified one question based on findings from our cognitive interview project. Respondents had a difficult time understanding the term "health care provider." Thus, we will now be	2021: Modified HCPROVN8 (KB.1.0.) 2024: HCPROVN8_24 (KB.1.0.)	No change	1

	asking about a “doctor, nurse, or other health care worker,” which also aligns with other MMP questions.			
Attachment 2021: p. 42 Attachment 2024: Adherence	We modified one introduction statement and split it in two to improve respondent comprehension. Specifically, we reduced the length of one introduction and made the other introduction specific to adherence to HIV medicine in the form of pills as.	2021: Modified Intro_8_ADH1_N5 2024: Intro1_N24_ADH1_24, Intro2_8_ADH1_24	No change	1
Attachment 2021: p. 42 Attachment 2024: Adherence	We modified three adherence questions to ask specifically about adherence to HIV medicine taken in the form of pills. This change was warranted based on the changing HIV treatment landscape in which people with HIV are now taking HIV medicines in different forms other than pills such as implants, injections, or IV infusions.	2021: ADH1_N5 – ADH3_N5 (TA.1.0. – TA.1.2) 2024: ADH1N5_24 – ADH3N5_24 (TA.1.4. –TA.1.6)	No change	3
Attachment 2021: p. 84 Attachment 2024: Smoking and vaping	We modified one introduction statement to add the term “other tobacco products.” The subsequent questions ask about cigarette use and other tobacco use. Thus, this modified introduction is more accurate than the prior introduction, which only referenced cigarettes.	2021: Modified Intro_CIGEVN5 2024: Intro_CIGEVN5_24	No change	1
Attachment 2021: p. 114 Attachment 2024: Services and assistance programs	We modified two questions about SNAP and WIC. These two modified questions more closely match survey questions asked by the U.S. Census, the USDA, and NHANES, which are large scale surveys. We tested these	2021: FOODA_N5 – FOODB_N5 (ND.11.0. – ND.11.1) 2024: FOODAN5_24 – FOODBN5_24 (ND.11.0. – ND.11.1.)	No change	2

	two modified questions during cognitive interviews and all participants easily understood the modified questions.			
Attachment 2021: p. 115 Attachment 2024: Services and assistance programs	We modified an introduction to questions about free or low-cost food to improve comprehension. This introduction was cognitively tested and performed well.	2021: Intro_N5_MLSF12_9 2024: Intro_MLSF12_24	No change	1
Attachment 2021: p. 115 Attachment 2024: Services and assistance programs	We modified two questions about getting free or low-cost food. We did so to improve respondent comprehension. We also cognitively tested these two modified questions, which performed well.	2021: Modified MLSF12_9, MLSFOD_9 (ND.12.0. - ND.12.1.) 2024: MLSF12_24-MLSFOD_24 (ND.12.0-ND.12.1.)	No change	2