The CAHPS Home and Community-Based Services Survey (HCBS CAHPS) Database

Data Use Agreement

Instructions

- 1. All organizations that want to participate in the CAHPS® Home and Community-Based Services Survey (HCBS CAHPS) Database must submit a signed Data Use Agreement (DUA) and provide the organization name (hereinafter termed "Participating Organization"), and the Participating Organization's point of contact.
 - Data collection vendors <u>may not</u> sign this DUA on behalf of a State Agency or participating organization (even if they have been given permission by the State Agency or participating organization to handle the actual submission of data). Only a duly appointed representative from the State Agency or participating organization may sign this DUA.
- 2. AHRQ's Contractor, Westat, has pre-signed this Data Use Agreement (DUA) in its current form. Any changes or modifications to the DUA other than those required to complete the DUA, such as contact information, will require review and execution, by both parties, of a new DUA or addendum.
- 3. This DUA includes important addenda requesting authorization from Participating Organizations to use measures from the HCBS CAHPS Survey data they provide to the CAHPS Database for purposes of reporting state-level HCBS CAHPS Survey results in specific private and public reporting products.
 - MANAGED CARE PLANS: If you are a Managed Care Plan (MCP) submitting data, and you are not a State Agency, please complete the reporting authorization requests in *Addendum A* on page 5.
 - **STATE AGENCIES:** If you are a State Agency submitting data, please complete the reporting authorization requests in *Addendum B* on page 6.
- **4.** Please sign and upload a scanned copy of the signed DUA by logging into the data submission system at https://www.cahpsdatabase.ahrq.gov and selecting the DUA tab.
- 5. Please retain a copy of the fully signed and executed DUA for your records.

If you have any questions or require any additional information please contact the CAHPS Database at 855-580-4657 or by email at HCBSCAHPSDatabase@westat.com.

The CAHPS Home and Community-Based Services Survey Database

Data Use Agreement

1.	This Data Use Agreement (DUA) is made by and between the Agency for Healthcare Research and Quality (AHRQ), AHRQ's
	contractor, Westat, and the organization named below (hereinafter termed "Participating Organization") which includes any
	State Agency or Managed Care Plan listed under item 13 on page 3 of this DUA.

ame of Participating Organization		
eet Address of Participating Organization		
		_
City	State	Zip Code



<u>VERY IMPORTANT</u>: Type or write in the name of the Participating Organization above. If more than one Program is represented, list the name of the overall or parent organization (e.g. State Agency) above, and under item 13, page 3 of this DUA, **IDENTIFY EACH INDIVIDUAL PROGRAM** for which data will be submitted.

- 2. AHRQ's Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Database is a central repository of data on State Agency, program, provider, health plan, medical group and State performance as measured by a selected set of CAHPS surveys. This DUA specifies the terms and conditions of Participating Organization's submission of its HCBS CAHPS Survey data to AHRQ's contractor, Westat (hereinafter termed the "Contractor") for participation in the CAHPS HCBS CAHPS Survey Database (hereinafter termed the "Database").
- 3. The Database is populated with HCBS CAHPS Survey data through the voluntary participation of organizations that have administered the HCBS CAHPS Survey and are willing to submit their HCBS CAHPS Survey data to AHRQ for inclusion in the Database. Because Participating Organizations voluntarily submit data to the CAHPS Database, the CAHPS Database data do not constitute a nationally representative sample.

The Database is funded by the Centers for Medicare and Medicaid Services (CMS) and managed and administered by AHRQ's Contractor. AHRQ's Contractor will operate the Database in compliance with the provisions in this DUA.

- 4. Participating Organizations will provide their HCBS CAHPS Survey data to the Database for AHRQ's research, analysis and reporting programs according to the terms specified in this DUA. By agreeing to participate in the Database, each Participating Organization agrees to make every good faith effort to provide data for inclusion in the Database, as specified by the data specifications outlined below. The data provided for inclusion in the Database are collectively referred to as the "Data." Participating Organization's Data include:
 - a) A copy of the final HCBS CAHPS Survey instrument(s) administered, including copies of paper and/or web- based versions as applicable, for each surveyed population for which data will be submitted to the Database showing all survey instructions and items administered. If more than one version of the HCBS CAHPS Survey was administered, a copy of each HCBS CAHPS Survey instrument administered must be provided with the corresponding results for each version of the survey instrument for which data are submitted;

Public reporting burden for this collection of information is estimated to average 3 minutes per response, the estimated time required to complete the form. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: AHRQ Reports Clearance Officer Attention: PRA, Paperwork Reduction Project (0935-0245) AHRQ, 5600 Fishers Lane, Rockville, MD 20857.

Respondent-level HCBS CAHPS Survey data that are de-identified to prevent identification of any individual in the Database. A Participating Organization will submit its final, de-identified respondent-level HCBS CAHPS Survey data, as collected by the Participating Organization itself or by a survey data collection vendor, according to the data specifications outlined for the Database; and

- c) Selected survey administration and organizational characteristics data (e.g., State, program type, mode of survey administration, dates of administration, sample size, response rates, etc.).
- 5. AHRQ's Contractor agrees to establish appropriate and necessary administrative, technical, and physical procedures and safeguards including limiting access to the Data and providing appropriate staff training to protect the confidentiality of the Data and to prevent the unauthorized use of it or access to it. Only AHRQ's Contractor and duly authorized representatives appointed by AHRQ will have access to the identifiable source Data provided by Participating Organization.
- 6. Participating Organization's Data will be accepted into the Database provided that the version of the HCBS CAHPS Survey administered is deemed acceptable by AHRQ's Contractor, (i.e., not modified from the original HCBS CAHPS Survey instructions and items) and the Data submitted by Participating Organization are deemed acceptable. AHRQ's Contractor will promptly notify the Participating Organization of any problem with the survey version(s) administered or with the Data submitted. If the survey version administered is acceptable but the Data submitted are problematic, AHRQ's Contractor will make a good faith effort to work with the Participating Organization to complete or correct the data submission, but reserves the right to not include incompatible or flawed Data in the Database.
- 7. Participating Organization's Data will be used for AHRQ's research, analysis, and reporting programs, and the Data will be aggregated along with other Participating Organizations' Data in the Database. AHRQ will publicly report aggregated statistics overall and at the State level on the HCBS CAHPS Survey composite scores and items, and present statistics by various organizational characteristics (e.g., program type and region), using data from Participating Organizations. Only aggregated data will be publicly reported, and only when there are sufficient data so that such aggregation will not permit the identification of individual respondents or programs by other Participating Organizations or the public, with the exception that in the event that only one program's data are submitted for a given State, and the Participating Organization for that program authorizes the use of its HCBS CAHPS data for State-level reporting, that one program's results will be displayed in State level results in the CAHPS Database in a way that might enable the identification of that program. Results will be made available publicly at no charge.
- 8. AHRQ's Contractor conducts analyses of the Data to examine its distributional properties (variability, missing data, skewness), to assess the factor structure and reliability of the items and composites, and examine relationships of the Data with organizational characteristics. In any data analysis reports that may be produced, such reports will not identify individual Participating Organizations by name and results will only be reported in a manner that will not permit the identification of Participating Organizations.
- **9.** AHRQ and its Contractor agree to use the Data submitted by Participating Organization only for the purposes stated in this DUA.
- 10. Researcher Access to Participating Organization's Data. The AHRQ confidentiality statute, Section 944(c) of the Public Health Service Act (42 U.S.C. 299c-3(c)), requires that data collected by AHRQ or one of its contractors (including Westat) that identify establishments be used only for the purposes for which the data were supplied. AHRQ may grant researchers access to Participating Organizations' de-identified Data according to the following provisions:
 - a) Access to respondent and organization level data files that <u>do not</u> identify or permit re-identification of individual respondents or Participating Organizations may be granted by AHRQ without the specific authorization of Participating Organizations whose Data are included as part of the data files. Individuals requesting de-identified HCBS CAHPS Survey data (hereinafter termed "Data Requesters") must submit a Research Abstract Form detailing the research purpose, hypotheses and methodology for analyzing the Data. AHRQ will review all Research Abstract Forms and approve or deny the requests. Data Requesters must also sign a Data Release Agreement in which they agree with the following requirements. Data Requesters agree that they: 1) will not use, and will prohibit others from using or disclosing, the deidentified Data except for the purposes specified in their Research Abstract Form; 2) will ensure that the de-identified Data are kept in a secured environment and that only authorized users will have access to it; and 3) will limit the use of

the de-identified Data to the individuals who require access in order to perform activities for the purposes specified in the Research Abstract Form.

- b) The de-identified data files may include organizational characteristics (e.g., program type and region), provided the characteristics do not permit re-identification of individual respondents or Participating Organizations. Participating Organizations will not be identified by name in the research data set, but in the event that only one State Agency or Program's data are submitted for a given State, and the Participating Organization for that State Agency or Program authorizes the use of its HCBS CAHPS data for State-level reporting, that one State Agency or Program's results will be included in the research data set in a way that might enable the identification of that State Agency or Program. However, as noted in item 10a, data requesters sign a Data Release Agreement in which they agree they will not use the research data for public reporting and will not report, through any medium, data that could identify, directly or by inference, individual Participating Organizations.
- c) Access to data files specific to an identifiable Participating Organization may be approved only with the express written authorization of the Participating Organization whose data files are requested (except as noted in item 10b, in the event that only one program's data are submitted for a given State, that one program's results will be included in the research data set in a way that might enable the identification of that program). However, results containing any identifying information may not be released, disclosed or made public without the express written authorization of any Participating Organizations that may be identified in the published research analysis.
- d) Valid purposes for the use of HCBS CAHPS Survey de-identifiable or identifiable research data sets do not include the use of Data for public reporting, proprietary, commercial or competitive purposes involving those Participating Organizations, or to determine the rights, benefits, or privileges of Participating Organizations.
- 11. AHRQ's Contractor has signed this DUA in its current form. Any changes or modifications to the DUA other than those required to complete the DUA, such as contact information, will require review and execution, by both parties, of a new DUA or addendum.
- 12. Participating Organization may change or revoke this consent by sending written notification to the CAHPS Database, Westat, 1600 Research Boulevard, Rockville, MD 20850. Requests for changes or revocations must be received within 2 weeks of the current year's data submission deadline to be excluded from the current year's database and all reporting for that year. The request for revocation will not apply to Data already authorized and released prior to receipt of a written request to revoke consent.
- 13. If Participating Organization represents <u>more than one State Agency or Program</u>, use the space below to (1) TYPE OR WRITE THE NAME OF EACH INDIVIDUAL STATE AGENCY, PROGRAM AND (2) TYPE OR WRITE ITS ADDRESS, INCLUDING CITY AND STATE which is represented by the Participating Organization and therefore covered under this Data Use Agreement. Attach additional sheet(s) if necessary.

Name of State Agency or Program	Address, City and State

14. Please complete the information below, sign, and return all pages of this data use agreement to Westat.

The undersigned individual hereby attests that he/she is duly authorized to represent the Participating Organization and all State Agencies or Programs listed under item 13 and in so doing, enters into this Data Use Agreement on behalf of the Participating Organization and the State Agency or Programs listed under item 13 and agrees to all the terms specified herein.

Complete all information	
· ·	
Title:	
Address:	
Phone number:	Fax number:
Email address:	
Sign and Date	
(Signature)	(Date)
15. Name and Address of Participating Organization	n Contact for this DUA (if different from above):
as needed Name of contact: Title: Address:	
Phone number:	Fax number:
Email address:	

DUA Addendum A: For Managed Care Plans Only

To Provide Authorization for Use of HCBS CAHPS Survey Data for State-Level Private and Public Reporting

The U.S. Agency for Healthcare Research and Quality (AHRQ) is requesting authorization from individual Managed Care Plans to use measures from the HCBS CAHPS Survey data they provide to the CAHPS Database for purposes of reporting HCBS CAHPS Survey results in the following private and public reporting products:

- 1) State-level public reporting for the AHRQ CAHPS Database;
- 2) State-level public reporting by the Centers for Medicare & Medicaid Services (CMS) on Medicaid.gov and Data.Medicaid.gov;
- 3) State-level private report to be provided to your State Agency; and
- 4) Release of program-identifiable results to CMS to enable CMS to review states' Medicaid Home and Community-Based Services Programs and to analyze the data for National Quality Forum (NQF) measure endorsement.

Addendum A1. State-level public reporting for the AHRQ CAHPS Database that will not display the name of your Managed Care Plan(s)

Please i	initial one:
	YES: Authorization is hereby granted to AHRQ to use the HCBS CAHPS Survey data we provide to the AHRQ CAHPS Database to present State-level HCBS CAHPS Survey results in the public reporting products of the AHRQ CAHPS Database (including the annual HCBS CAHPS Survey Chartbook and the AHRQ Data Tools website).
	NO: Authorization is not granted for the requested use of our HCBS CAHPS Survey data.
Addendum A	A2. State-level public reporting on Medicaid.gov and Data.Medicaid.gov that will not display the name of your Managed Care Plan(s)
Please i	initial one:
	YES: Authorization is hereby granted to AHRQ to release to CMS the HCBS CAHPS Survey data we provide to AHRQ's CAHPS Database to allow CMS to publicly report State-level HCBS CAHPS Survey results on CMS's Medicaid.gov and Data.Medicaid.gov.
	NO: Authorization is not granted for the requested use of our HCBS CAHPS Survey data.
	A3. Release of program-identifiable results to your State Agency for state-level private reporting initial one:
,	YES: Authorization is hereby granted to include results for my managed care plan(s) in a private report to
	be provided to my State Agency. This private report will display results for each program within my state that authorizes the release of their results to the State Agency. Program-identifiable results will be displayed in the private report using the name of each program.
	NO: Authorization is not granted for the requested use of our HCBS CAHPS Survey data.

Form Approved: OMB No.: 0935-0245
Exp. Date: 10/31/2022

Addendum A4. Release of program-identifiable results to CMS to enable CMS to review states' Medicaid
Home and Community-Based Services Programs.

Please	initial one:
	YES: Authorization is hereby granted to release my managed care plan(s) program-identifiable results to CMS. Program-identifiable results will be provided to CMS using the name of each program. CMS will use these results to review states' Medicaid Home and Community-Based Services Programs. In addition, the data will be analyzed for National Quality Forum (NQF) measure endorsement.
	NO: Authorization is not granted for the requested use of our HCBS CAHPS Survey data.

DUA Addendum B: For State Agencies Only

To Provide Authorization for Use of HCBS CAHPS Survey Data for State-Level Public Reporting

The U.S. Agency for Healthcare Research and Quality (AHRQ) is requesting authorization from State Agencies to use measures from the HCBS CAHPS Survey data they provide to the CAHPS Database for purposes of reporting HCBS CAHPS Survey results in the following public reporting products:

- 1) State-level public reporting for the AHRQ CAHPS Database;
- 2) State-level public reporting by the Centers for Medicare & Medicaid Services (CMS) on Medicaid.gov and Data.Medicaid.gov; and
- 3) Release of program-identifiable results to CMS to enable CMS to review states' Medicaid Home and Community-Based Services Programs and analyze data for National Quality Forum (NQF) measure endorsement.

Addendum B1. State-level public reporting for the AHRQ CAHPS Database that will not display the name of your program(s)

	of your program(s)
Please	initial one:
	YES: Authorization is hereby granted to AHRQ to use the HCBS CAHPS Survey data we provide to the AHRQ CAHPS Database to present State-level HCBS CAHPS Survey results in the public reporting products of the AHRQ CAHPS Database (including the annual HCBS CAHPS Survey Chartbook and the AHRQ Data Tools website).
	NO: Authorization is not granted for the requested use of our HCBS CAHPS Survey data.
Addendun	B2. State-level public reporting on Medicaid.gov and Data.Medicaid.gov that <u>will not</u> displa the name of your program(s)
Please	initial one:
	YES: Authorization is hereby granted to AHRQ to release to CMS the HCBS CAHPS Survey data we
	provide to AHRQ's CAHPS Database to allow CMS to publicly report State-level HCBS CAHPS Survey results on CMS's Medicaid.gov and Data.Medicaid.gov.

Addendum B3. Release of State Agency program-identifiable results to CMS to enable CMS to review

	states' Medicaid Home and Community-Based Services Programs.
ase	initial one:
	YES: Authorization is hereby granted to release my State Agency program-identifiable results to CM State Agency program-identifiable results will be provided to CMS using the name of each State Age program. CMS will use these results to review states' Medicaid Home and Community-Based Service Programs. In addition, the data will be analyzed for National Quality Forum (NQF) measure endorse
	NO: Authorization is not granted for the requested use of our HCBS CAHPS Survey data.