Best Practices Identified by CORE Participants for the Collection and Exchange of Socio-demographic Information.

CORE has developed new and updated operating rules to facilitate the standardized collection and exchange of patient socio-demographic information. Throughout the development of these rules, CORE Participants emphasized that collection of this information necessitates requirements that ensure privacy and security, informed member consent, and "gold-standard" self-reporting of sensitive personal information. Where possible, and appropriate, the rules include mandatory and discretionary requirements that fulfill these considerations.

In recognition of federal privacy regulations, existing industry variability in how information is captured and shared, and understanding that operating rules do not prescribe health plan policy and procedures - the CORE Operating Rules provide a basis for implementing the collection and exchange of socio-demographic information in ways that are considerate of member privacy and consent, but do not prescribe the specific mechanisms that must be put in place to carry out these practices.

For example, CORE Participants acknowledged self-reported socio-demographic information as a "gold standard" to avoid bias in reporting and remain fully representative of the member experience. Despite the clear advantages of self-reported information, not all reporting and exchange is carried out using this method. For example, CORE Participants acknowledged that employers often send human resources records to fulfill race and ethnicity reporting. Accordingly, to support standardized data exchange, rule requirements accommodate other methods of collection in-use by industry stakeholders. Exchange using best practice self-reporting is encouraged.

Though the CORE Operating Rules cannot be applied at the level of specificity necessary to guide the implementation of Federal Policy or to dictate health plan procedures, they can be used as a venue to transmit best practices that help guide implementation. As such, listed below are several <u>best practices</u> shared by CORE Participants during the development of the rules that guide implementation in a way that is sensitive to privacy, consent, and self-reporting.

- **Opt-in Consent:** Rule requirements compel health plans and their agents to accommodate a consent process consistent with provisions in the HIPAA Privacy Law at 45 CFR 164.506 and as advised by their internal legal counsel. Implementers maintain the option to use opt-in or opt-out consent process.

  CORE Participants recognize "opt-in" consent as a **best practice implementation method** because it requires members to consciously agree to collection and exchange through a "box check" or some similar mechanism. Compared to "opt-out" methods, this strengthens privacy and increases engagement.

- **Self-reporting of Race and Ethnicity:** Where appropriate, rules require socio-demographic information to be self-reported by a member to a health plan or its agent. Self-reporting is required for the collection and exchange of member language and gender identity but is not specified for race and ethnicity. As introduced, race and ethnicity are not always collected or exchanged based on what was self-reported by the member and can be fulfilled administratively.

  By indicating how this information is collected, its quality and utility in the design and administration of value-based payment programs can be evaluated. CORE Participants acknowledge that collection of this information varies, but state that collection via self-reporting is a best practice and, as such, should be considered by health plans and their agents as they implement CORE Operating Rule requirements.

- **Recognition of the Fluidity of Collected Concepts:** A benefit of collecting sensitive socio-demographic information is more accurate and timely recognition of a member's personal experience. Rule requirements support this by accommodating a maintenance process that allows reporting of new concepts over time. Though concepts such as race, ethnicity, and

language may remain relatively stable, those encompassing self-reported gender identity can change more frequently.

Changes to socio-demographic concepts are supported through maintenance of member records and through member renewal to a health plan. Though current rule requirements do not indicate how to chronicle changes to socio-demographic information over time, the X12 transactions that the rules facilitate can be leveraged to provide a longitudinal view of changes. CORE Participants encouraged implementers to utilize flexibilities in the X12 transactions to show changes to socio-demographic reporting over time.

- **Display and Availability of Disclosure Language:** Rule requirements state that health plans and their agents must generate disclosure language detailing the collection, exchange, and potential uses of member socio-demographic information. Consistently, the rules establish a minimum requirement for this language to be included in transaction-specific companion guides and to be displayed, unaltered, to members at the point of enrollment, renewal, or maintenance requests.

    CORE Participants, in support of the requirement, encourage health plans and their agents to include the disclosure language in additional areas – such as member facing websites or collateral – to enhance the reach of the disclosure language. In turn, this increases the opportunity that members will engage with the language as they consider providing their consent for the collection, exchange, and use of sensitive personal information.

Note that, though the above information details best practices that aid in the security of personal information, they are not presented as rule requirements. The purpose of this resource is to provide best practice implementation guidance for the requirements outlined in the CORE Operating Rules. Additional information, where appropriate, will be included in rule specific frequently asked question (FAQ) documents.