November 2, 2023

Medicaid Primary Language and Limited English Proficiency Data Collection

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Medicaid and CHIP Payment and Access Commission

www.macpac.gov

Overview

- Definitions
- Health disparities
- Medicaid language data collection
- Considerations for data collection
- Next steps

Definitions

- **Primary language**: identifies an individual's primary spoken or written language
  - Often used as a proxy for determining if someone has language service needs
- **Limited English proficiency (LEP)**: identifies individuals who have difficulties reading, writing, and communicating in English
  - Level of proficiency can provide more granular information about an individual's language service needs

Health Disparities

Research findings indicate that compared to those without LEP, individuals with LEP are more likely to:

- experience barriers during the enrollment and redetermination process,
- report poor health outcomes, higher rates of disability, poor self-reported health, and mental illness, and
- have difficulty scheduling appointments, understanding written health care materials, and communicating with providers

Medicaid Language Data Collection

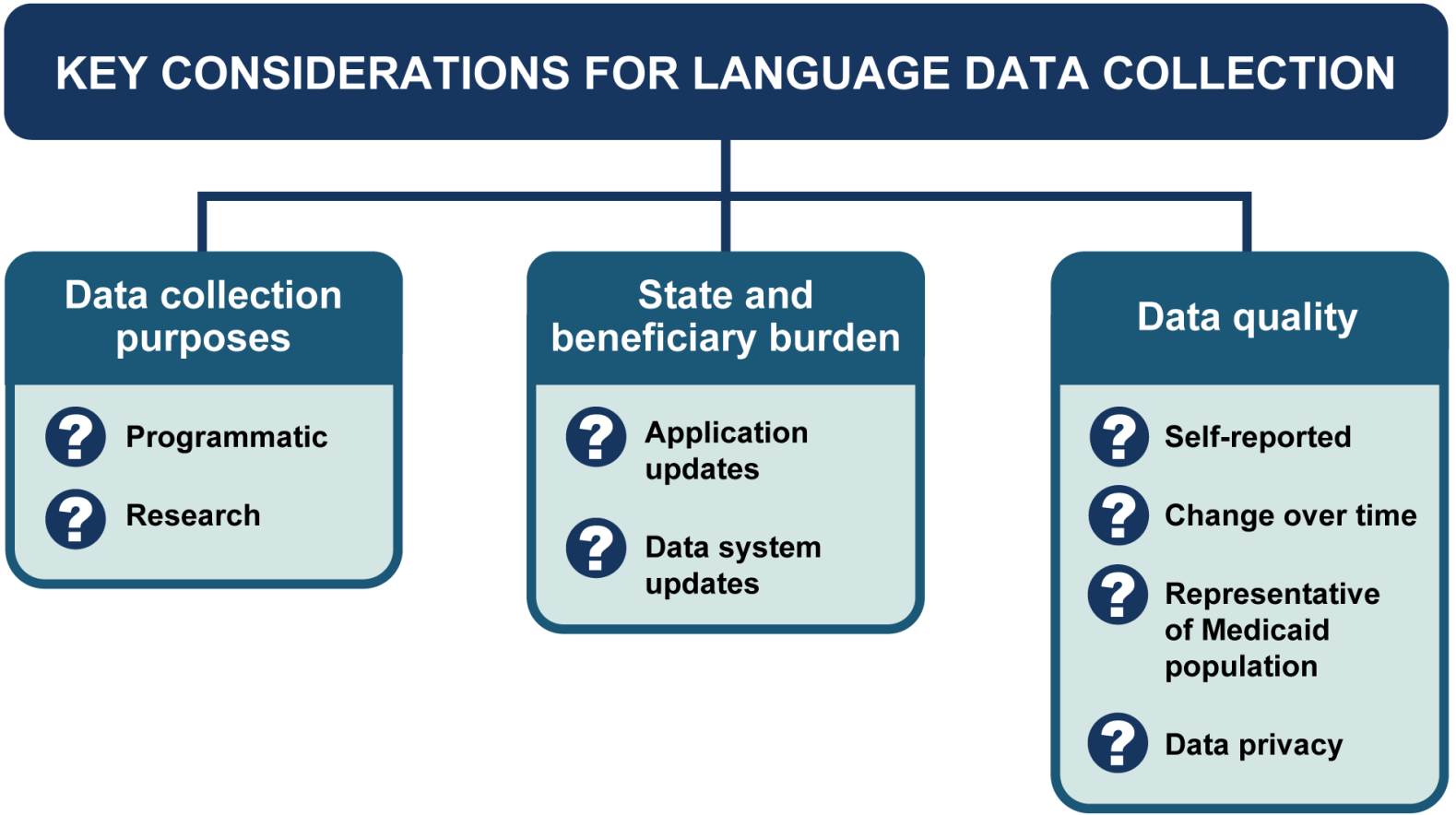
Medicaid application

- Beneficiary-level information about primary language can inform states about language service needs and be disaggregated to measure the differences in use of services
- Almost all Medicaid programs collect primary language and a few collect LEP
  - The Data Quality Atlas assessment indicates that 37 states report primary language data and 4 states report LEP data that are usable for analyses (CMS 2023)

Medicaid Language Data Collection cont.

Federal surveys

- Population-level information that can be disaggregated to assess the experiences of Medicaid-covered individuals with language service needs with accessing and using health services, satisfaction with providers, and quality of care
- In a review of 13 federal population health surveys, fewer than half of the surveys include questions about primary language and LEP
  - Analyses can be limited by comparability of questions and a small sample size of individuals who may need language services


KEY CONSIDERATIONS FOR LANGUAGE DATA COLLECTION
Data collection purposes
Programmatic
Research
State and beneficiary burden
Application updates
Data system updates
Data quality
Self-reported
Change over time
Representative of Medicaid population
Data privacy

Data Collection Purposes

- State Medicaid agencies are required to provide applicants and beneficiaries program information in both paper and electronic formats that are accessible to individuals with LEP and via oral interpretation (42 CFR 435.905)
  - MACPAC analyses indicate that language data are often sufficient for identifying beneficiary language service needs
- Language data can be disaggregated to compare experiences of individuals with and without language service needs
  - Most states reported not currently using language data for analytical purposes, but some are considering how to use data to monitor and address disparities

State and Beneficiary Burden

Application updates

- Resource and time intensive to update applications and translate into multiple language
- In states with integrated Medicaid eligibility systems, updates must align with multiple program requirements
- Applications are often long, and additional questions may increase individual burden

Data system updates

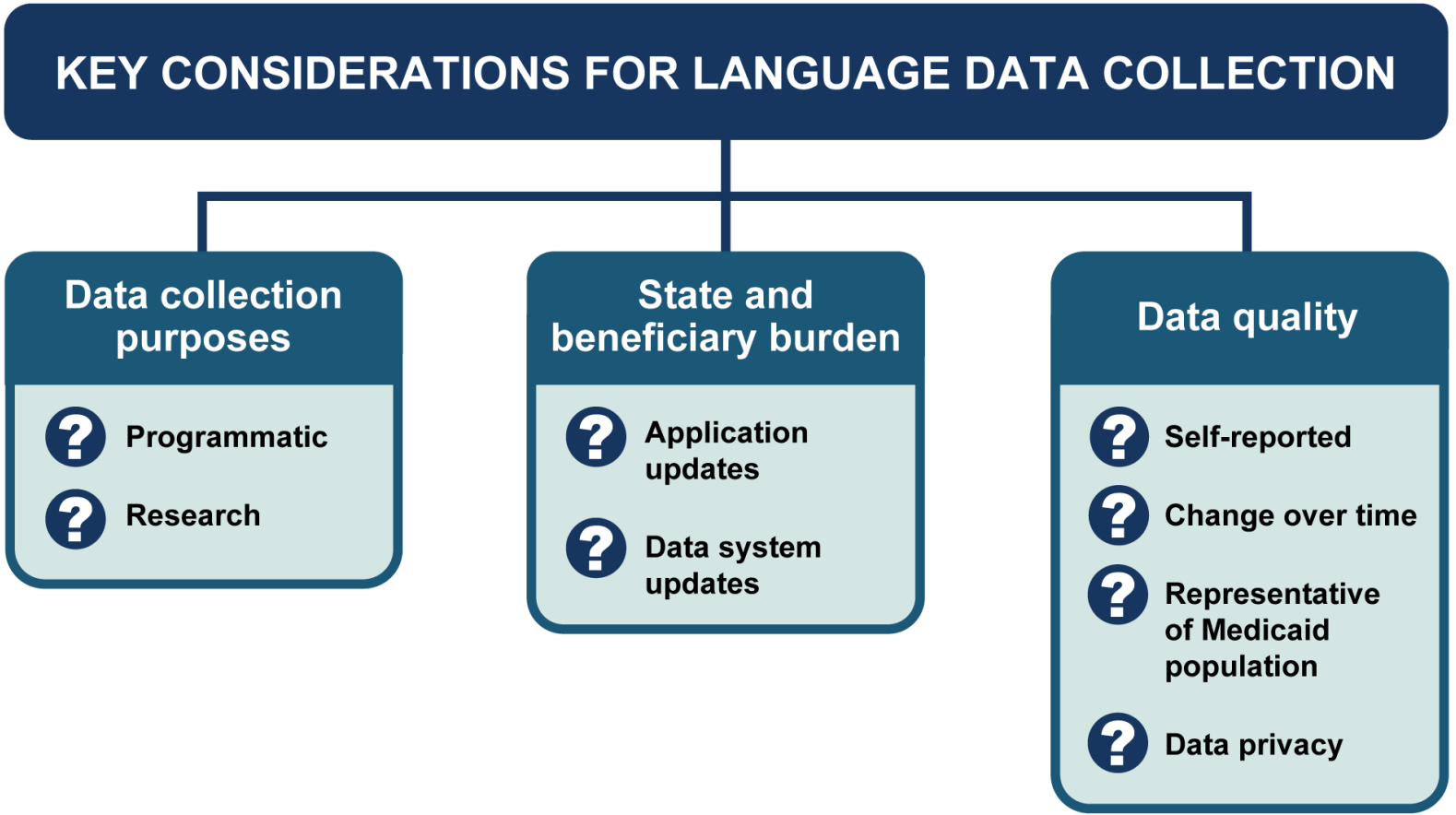
- Resource and time intensive to update and test changes to the data systems used to store and report Medicaid eligibility and enrollment data to the Transformed Medicaid Statistical Information System (T-MSIS)

Data Quality Considerations

- **Self-reported:** considered the best method for collecting information that reflects an individual's identity
- **Change over time:** language characteristics can change over time, so updating language information can improve data accuracy
- **Representative of Medicaid population:** data collection methods should allow for generalizability to the Medicaid population, inclusive of those who do not speak English or have LEP
- **Data privacy:** providing individuals with assurance that their data are secure and will not be used inappropriately or to harm them can improve their willingness to respond accurately

Next Steps

- Upcoming demographic data collection topics:
  - December: sexual orientation and gender identity (SOGI)
  - January: self-reported disability
- It would be most informative to receive Commissioner feedback on the considerations presented:
  - Are there any considerations that should be prioritized when developing policy options?
  - Are there any other factors that we should take into consideration?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