



**BlueCross
BlueShield**
Association



THE GOLD STANDARD: SOGI & REL DATA COLLECTION

Self-Reported Data Collection Playbook

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PROPRIETARY AND CONFIDENTIAL — For Blue Plan Use Only

The Blue Cross Blue Shield Association is an association of independent, locally operated Blue Cross and Blue Shield companies.

THE GOLD STANDARD: SOGI & REL DATA COLLECTION

Self-Reported Data Collection Playbook



EXECUTIVE SUMMARY

In recent years, Blue Cross Blue Shield Association (BCBSA) and BCBS Plans have identified significant gaps in Race, Ethnicity, and Language (REL), Sexual Orientation (SO), and Gender Identity (GI) data. While BCBS Plans have identified an approach to collecting or imputing REL data for some or all lines of business, most Plans have indicated that they have not collected SOGI data elements beyond standard Gender definitions.

To help address these data gaps, BCBSA has conducted consumer research to:

- 1) Identify the optimal way of asking SOGI/REL questions and answer options that would maximize responses
- 2) Assess barriers to providing personal information
- 3) Identify messages or content to improve opt-in rates

When compared to financial institutions such as mortgage lenders, findings showed that health-related organizations (e.g., health insurance companies) are largely trusted. However, when answering these sensitive questions, people are seeking to understand why their data is being requested, especially marginalized groups such as LGBT and Non-White individuals. As such, providing upfront context, inclusive language, and an understanding of personal benefit is key.

Further, wording preferences in SOGI/REL questions can vary across several subpopulations. Some domains (i.e., SOGI) are more polarizing than others. Differences are largely driven by generational cohorts, political affiliations, sexual orientation, and gender identity. Younger generations prefer more inclusive ways of asking questions and more robust response options.

This Playbook summarizes research from the quantitative survey and insights gleaned from in-depth BCBS Plan interviews. The resource presents findings on preferred SOGI/REL question and answer options across the study population, as well as key subgroups. The Playbook will also highlight the lessons learned shared by Plans at varying stages of the SOGI/REL data collection journey.

INTRODUCTION

Significant disparities plague the US healthcare system, mostly impacting the underserved, underrepresented, and socio-economically disadvantaged populations. To improve health care across the nation for all populations, BCBSA seeks to understand the source of disparities and take steps to address them. While many BCBS Plans capture member Race, Ethnicity, and Language (REL) data for some or all lines of business, it is primarily imputed data. Additionally, most Plans have indicated that they have not historically collected, nor are currently collecting Sexual Orientation and Gender Identification (SOGI) data elements beyond standard Gender definitions.

In Phase One of this work, BCBSA conducted qualitative consumer research to better understand consumer perceptions and concerns on SOGI/REL data collection by a health insurer. Phase One also explored ways to address consumer concerns and build trust with consumers when collecting SOGI/REL data. As part of this effort, BCBSA leveraged research methods such as the Virtual Diary Study, In-depth Interviews, and Concept Stimuli Testing.

In Phase Two, BCBSA expanded on insights from Phase One and conducted quantitative consumer research to deepen its understanding of consumer perceptions and preferences regarding SOGI/REL data collection. This playbook provides design recommendations and question-response options for gathering sensitive information from consumers.

HOW TO USE THIS PLAYBOOK

1 DEVELOPING Your SOGI/REL Data Collection Strategy

This Playbook will provide BCBS Plans with key considerations that can be applied as they develop their SOGI/REL data collection strategy. Considerations include recommended rationale for asking SOGI/REL questions (**Consideration: Why We Are Asking**) and options for questions and answer choices (**Recommendation: Question and Response Options**).

2 VALIDATING Your SOGI/REL Data Collection Strategy

For Plans that have already developed their SOGI/REL data collection strategy, this Playbook will provide **Key Insights** that can be leveraged to validate their existing strategy. The Playbook can confirm alignment between the Plans' existing strategies, key insights from the quantitative study, and lessons learned shared by other Blue Plans (**Plan Case Studies** and **Journey Map**).

3 REFINING Your SOGI/REL Data Collection Strategy

Plans seeking to refine their existing SOGI/REL data collection strategies can leverage the **Personalizing Context** section to identify opportunities to enhance their current SOGI/REL question and answer options to align with potential member preferences. Further, Plans can take the lessons learned shared by other BCBS Plans in the **Plan Case Studies** as they determine ways to further refine their own strategies.



METHODOLOGY

Primary results from this Playbook are based on a large-scale online survey conducted in June 2023, which was completed by 15,000 U.S. adults. The surveyed respondents included members of key subgroups such as race, gender, region, sexual orientation, etc. The survey was conducted in English only.

Survey participants were informed that the survey was for research purposes only and that researchers were seeking to obtain opinions from consumers like themselves. The information would remain confidential and would never be used to sell them anything. As part of the survey, they may be asked to provide personal information such as behavior and attitudes which may be used to plan new products or services, gauge customer satisfaction, measure awareness of products or services, or to gauge reaction to products, services or communications. Demographic information was collected to ensure the survey participants are a representative sample of the population. Participation in the research was voluntary and survey participants were able to opt-out of the survey at any time.

BCBSA leveraged an experimental design to understand individuals' preferences regarding how, when, and why SOGI/REL questions should be posed. The experimental design took into consideration the nuanced variations in these preferences, which may be driven by the diverse backgrounds of the respondents. BCBSA also gathered augmented learnings via surveys administered to the followers of an LGBT social influencer via Instagram.

The survey provided respondents with two different options across the five domains (SOGI/REL). In one option, respondents were presented with a baseline question based on current standards. In the second option, respondents were given the opportunity to construct the question themselves and select their preferred answer options.

Respondents indicated their likelihood of answering sensitive demographic questions, their likelihood of answering the newly devised optimal questions, and their suggestions for enhancing the questions further.

Lastly, respondents were prompted to share their individual demographic information. With this information, BCBSA conducted analyses to further explore differences in preferences across the key subgroups.

THE ‘WHY’

Effective data collection strategies should stem from a clear understanding of the purpose or rationale (“the why”). For SOGI/REL data collection, considering member experiences and potential health journey challenges should inform the approach. This involves studying disparities and inequities faced by marginalized populations, as highlighted below.

Race/Ethnicity/Language

- Nearly 34% of Hispanic adults, 24% American Indian and Alaska Native (AIAN) adults, 21% Native Hawaiian or Other Pacific Islander (NHOPI), 19% Asian, and 18% Black adults reported that they did not have a personal health care provider.^[2]
- AIAN, Hispanic, and Black people experienced larger declines in life expectancy than White people between 2019 and 2021.^[2]
- Black, Hispanic, AIAN populations experienced higher rates of COVID-related hospitalizations and deaths compared to White populations.^[2]
- Around six in ten Hispanic adults did not receive a flu vaccine between 2021 to 2022.^[2]
- A study examining self-reported health status among Hispanic adults in the United States found that Mexican, Puerto Rican, Cuban, Dominican, and other Hispanic people who responded to a survey in Spanish were more likely to report a poor/fair health status than Hispanic adults who responded to the survey in English.^[3]

Sexual Orientation/Gender Identity

- Lesbian and bisexual women are at greater risk of developing breast cancer compared to heterosexual women.^[4]
- Transgender youth have higher levels of mental health problems, such as depression and self-harm, than their non-transgender counterparts.^[5]
- While electronic health record (EHR) data analyses show that transgender women on estrogen therapy have a higher incidence of ischemic stroke, further research is hindered due to limited clinical data available on LGBT adults.^{[6],[7]}

“

Data is more than numbers—it represents people. Our data must be as diverse and inclusive as our nation’s population. Standardized, precise data provide opportunities for insurers, health care providers, and patient advocates to design and implement targeted health solutions to better meet the needs of disproportionately impacted communities. Through the adoption of comprehensive data collection standards, we can address health inequities head on and create a better system of health for all Americans.”

– Kim Keck, President and CEO of BCBSA ^[1]

Intersectionality

When developing a strategy around data collection and application, it is crucial to take an intersectional approach. Intersectionality aims to understand the unique experiences, risks, and resiliencies of people impacted by multiple systems of power.^[8]

For instance, queer women of color have reported that they delay access to care, in part due to anticipation of stigma and distrust of health systems^{[9],[10]} As such, understanding that an individual’s many marginalized identities are interconnected and collectively play a role in their experiences can help to develop a thoughtful strategy that seeks to close the many gaps faced by said individuals.

CONSIDERATIONS | WHY WE ARE ASKING

Despite significant industry-wide efforts, health disparities and inequities persist as an ongoing challenge. Addressing health gaps remains difficult due to members' reluctance to sharing sensitive information.

Clearly explaining the purpose of asking these sensitive questions and how the information will be utilized can foster members' comfort in sharing such data.

Participants were asked to select up to three messages that would make them feel most comfortable sharing their personal information. The messages provided spanned from **personal benefits** to **community-minded benefits**.

Nearly 54% of respondents indicated that they would feel most comfortable if the messaging indicated

that the data would be used to deliver the "best whole person care," "higher quality healthcare," and "improve healthcare experiences and outcomes" for them personally.

Only 11% of respondents indicated that they would feel most comfortable if messaging captured benefits to the overall community, e.g., identifying where healthcare resources are more needed, gaps in healthcare quality, and less inclusive parts of the healthcare system.

While articulating personal benefits will likely drive higher response rates across subgroups, it is important to note that Millennials, Transgender/ Genderqueer, Non-Heterosexual, Non-White, and Democrats slightly lean towards community minded messages.

RESPONSE RATES

HIGH

24%

To ensure healthcare providers, insurance companies and others can **deliver the best whole person care** regardless of who you are, where you live, or your life experiences

18%

To **deliver better and higher quality healthcare** — no matter who you are, where you live, or the language you speak

12%

To **improve healthcare experiences and outcomes** for you — meeting you where you are regardless of who you are, where you live, or your life experiences

MEDIUM

9%

To **connect you with information and support** related to your health experiences and needs

7%

To **increase access to preventative health care services** and resources to keep you healthy and lower how much you pay for care

7%

To confirm if healthcare programs and **services are available to and supporting everyone**

LOW

4%

To **identify communities where healthcare resources are most needed** to improve overall health

4%

To **identify gaps in health care quality that exist** and understand the causes of those gaps

3%

To locate parts of the health care system that **might fall short of being inclusive**

KEY INSIGHTS

In collecting sensitive data, trust is crucial, and context matters. Health-related organizations, like health insurance companies, are widely trusted compared to financial institutions. Across the six scenarios tested (e.g., doctor's office, case manager, benefits enrollment), question and response preferences remained consistent across the four domains (SOGI/REL). This is likely due to each of the six context scenarios involving health-related professionals, which are amongst the top entities when it comes to the likelihood of sharing personal information.

When answering the SOGI/REL questions, people consider the credibility of the industry and institution, and are seeking authentic reasons as to why their data is being requested. This is especially true for marginalized groups such as LGBT, particularly Transgender/Genderqueer and Non-Heterosexual, and Non-White individuals, as they are less comfortable providing personal information. These populations are less likely to answer SOGI/REL questions without upfront context, inclusive language, and an understanding of personal benefit.

The choice of wording in SOGI/REL questions also holds substantial weight for certain populations and can diverge noticeably across subpopulations; preferences can differ by generational cohort, political affiliation, sexual orientation, and gender identity. For example, younger generations prefer more inclusive ways of asking questions and more response options.



It's ok for us to be **ahead** of standards.

– **BCBSA Plan**

GENDER IDENTITY

Provide The Reason As Some Respondents Will Only Provide Under The Right Circumstances

"I feel most comfortable when I know that my gender has a prevalent reason to be asked for." - Social Influencer Survey

SEXUAL ORIENTATION

The Most Sensitive – Be Prepared for "Why Are You Asking?"

"Ask only in a place where it's actually relevant, and not in places where it isn't. Why would an auto loan need to know that? But for some medical things it makes sense." - Social Influencer Survey

RACE & ETHNICITY

Context Is Helpful As Discrimination Is Cited As A Reason Not To Answer

"It would give a good reason why this information is needed. We live in a country where racism is common, and people are often discriminated against."

LANGUAGE

Less Controversial But Context Will Be Appreciated

"How is this information pertinent to the setting in which it is asked? Why is the information being requested?"

SEXUAL ORIENTATION | SUMMARY

QUESTION & RESPONSE OPTIONS – RECOMMENDATION

OPTION 1

What is your sexual orientation?

- Straight or heterosexual
- Lesbian, gay or homosexual
- Bisexual
- I don't know
- Prefer not to answer
- None of these
- Other: _____

OPTION 2

Which of the following best describes you?

- Straight or heterosexual
- Lesbian, gay or homosexual
- Bisexual
- I don't know
- Prefer not to answer
- None of these
- Other: _____

“

Consider being **responsive to the community**, rather than shaping for the masses.

– **BCBS Plan**

KEY CONSIDERATIONS

1

Sexual Orientation is a sensitive topic due to its ongoing evolution, which will likely lead to dynamic shifts in perspectives and understanding over time.

2

Marginalized groups prefer inclusive options. However, inclusivity of options is polarizing due to preferences influenced by generational, political, and SOGI groups.

3

Review preferences from this research against those provided by NCOA Health Equity Accreditation Requirements and key industry standards.

SEXUAL ORIENTATION | SUMMARY (CONT.)

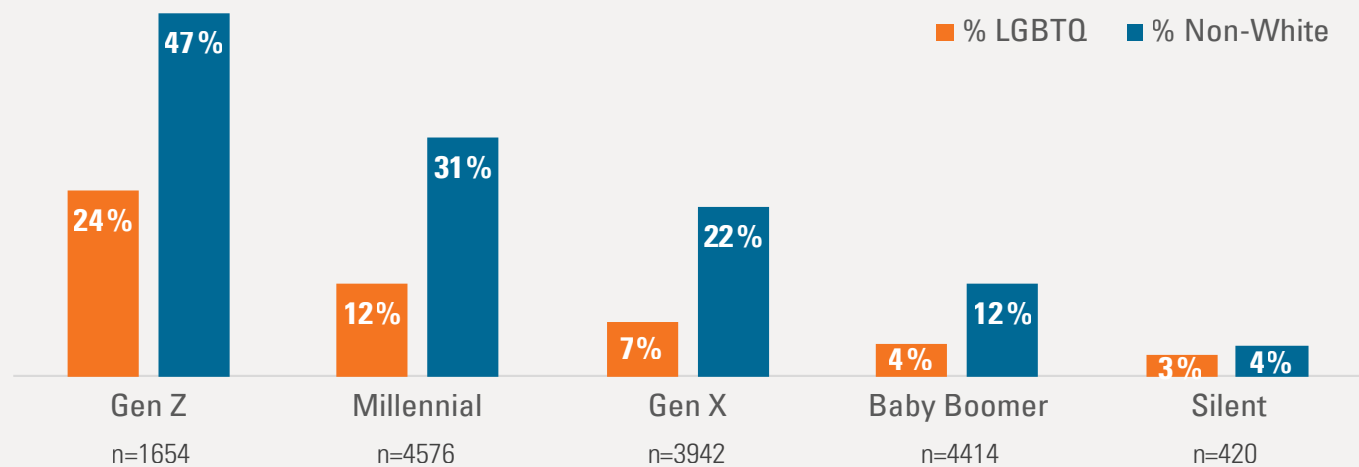
PERSONALIZING CONTEXT

How to Ask

Although Option 1 and Option 2 are similar in popularity, Republicans are more likely to prefer “What is your sexual orientation?” Further, Millennials, Gen Z, LGBTQ, and Democrats also preferred “How do you identify,” which was the third most popular option.

Sexual Orientation questions should either be optional or include answer options such as “Don’t know” or “Prefer not to answer”, so that members have the option to opt-out of answering the question. Lastly, a free-text answer option should only be included if the member responses will be utilized.

LGBTQ and Non-White by Generation (%)



Response Options

“Straight or heterosexual” was selected over 40% of the time by each demographic sub-group analyzed, indicating that it should be strongly considered as an option. Both LGBTQ and non-LGBTQ groups preferred the inclusion of “Lesbian, gay or homosexual.”

Among the additional options included in the survey, (e.g., bisexual, pansexual, asexual), bisexual was the top choice for inclusion. When asked about additional sexual orientation options, nearly 50% of respondents indicated that they do not want these options to be included. These differences were largely driven by generational cohorts, SOGI, and political affiliation. The Silent Generation and Baby Boomer respondents are less likely to include additional sexual orientation options while most Millennial/Gen Z respondents want to add at least one.

As shown in the chart above, younger generations are more likely to identify as LGBTQ. As noted by a BCBS Plan, “the needs of the community we are seeking to serve should drive data collection decisions.” Given that many respondents shared that they do not feel there is ever a need to provide this information, targeting the needs of the community of interest by providing inclusive options may drive greater opt-in rates on sexual orientation-related questions.

In terms of open-ended options, most respondents preferred “Other” (strongest preference), “I use a different term” and “Another sexual orientation.”

GENDER IDENTITY | SUMMARY

QUESTION & RESPONSE OPTIONS – RECOMMENDATION

OPTION 1

What is your gender?

- Male
- Female
- Transgender
- Non-binary
- None of these
- I don't know
- Prefer not to answer
- Other OR Prefer to self-describe, describe here:

OPTION 2

Which of the following best describes you?

- Male
- Female
- Transgender
- Non-binary
- None of these
- I don't know
- Prefer not to answer
- Other OR Prefer to self-describe, describe here:

“

Members **expect** to have transgender categories.

Include this and if 2025 comes in different, we **change it.**

– **BCBS Plan**

KEY CONSIDERATIONS

1 Gender identity is notably the most polarizing of the four topics, with the stronger opinions influenced by generational, political and SOGI groups; Millennials and Gen Z generations exhibited a greater inclination towards openness and inclusivity.

2 Across all key subgroups, there was a clear preference for the “Male/Female” answer option.

3 Transgender options were more divided. Non-heterosexual and other marginalized groups preferred that a Transgender option be included, and nearly 26% of respondents preferred that Non-Binary be included as an option.

4 Gender Identity is not a replacement for sex assigned at birth, rather an addition.

GENDER IDENTITY | SUMMARY (CONT.)

PERSONALIZING CONTEXT

How to Ask

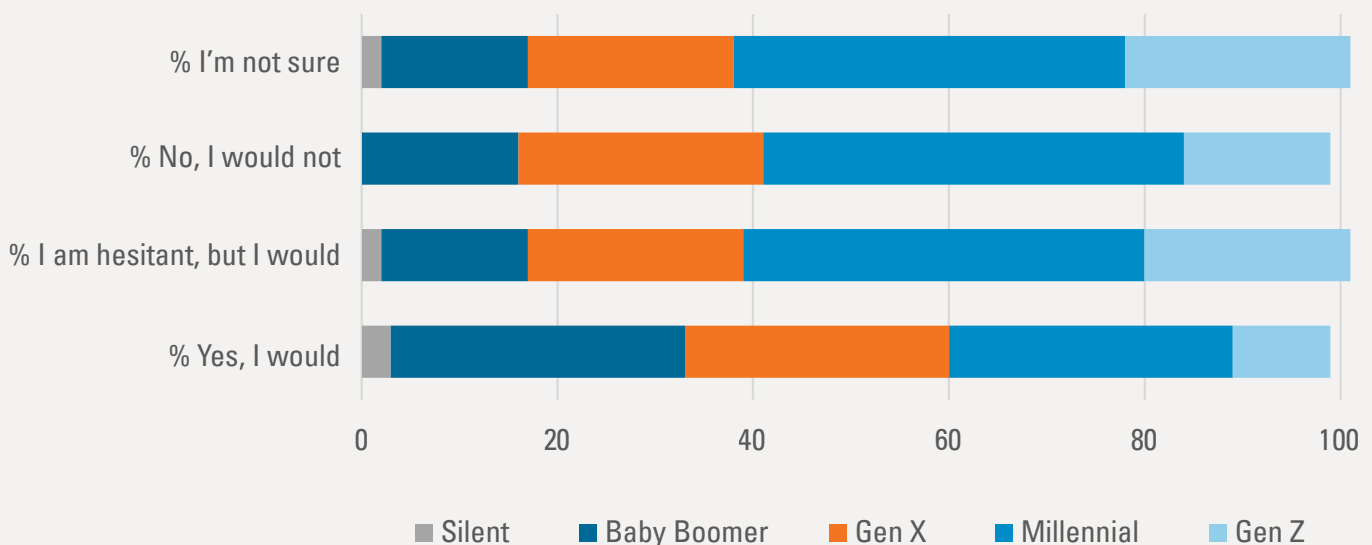
When tailoring Gender Identity questions, there must be a keen understanding of the member population’s demographics. Older generations, non-LGBTQ, Republicans and Independents prefer “What is your gender?” Whereas Millennials, Gen Z, LGBTQ, and Democrats prefer “How do you identify?”. Further, it is important to note that younger, Transgender and Genderqueer, and non-White populations are more hesitant when answering gender identity questions. As such, depending on the makeup of a Plan’s member population’s demographics, Plans may choose to adjust the framing of the question to target these specific subgroups. Further, some states may have regulations pertaining to gender identity questions. Legal/Privacy teams must be consulted to determine any limitations with asking this question.

Gender Identity questions should either be optional or include answer options such as “Don’t know” or “Prefer not to answer”, so that members have the option to opt-out of answering the question. Lastly, a free-text answer option should only be included if the member responses will be utilized.

Response Options

While there was alignment across subgroups for certain response options (e.g., 75% of individuals preferred the inclusion of Male/Female), preferences for other response options were divided. The inclusion of Transgender is preferred by over 50% of Millennials, Gen Z, and LGBTQ respondents. Social influencers also overwhelmingly prefer that a Transgender option be included. However, 62% of respondents preferred no additional options to be included - this was largely driven by older generations, Republicans, and Independents. One thing to note is that the Transgender option may not meet data interoperability standards until at least 2025 for organizations outside of BCBS System and their trading partners. It is recommended that the BCBS System is pacing alongside the ongoing work on HL7 Gender Harmony standards. The overall population is divided between “Other” and “Prefer to self-describe, describe here”. While Republicans prefer the former, Democrats prefer the more descriptive option. Older generations (Baby Boomers & Silent) are less supportive of using pronouns and less likely to use pronouns themselves (46%). Millennials, Gen Z, and LGBTQ more receptive to use of pronouns (60%+).

Gender Identity | Answering Profiles (%)



QUESTION & RESPONSE OPTIONS – RECOMMENDATION

Which of the following best describes you?

- White or Caucasian
- Black or African American
- Native American or Alaskan Native
- Native Hawaiian or Other Pacific Islander
- Asian (e.g., Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese) OR Asian Indian Chinese Filipino Japanese Korean Vietnamese Other Asian (as a list)
- Middle Eastern or North African
- Northern Asian or Eastern European
- Indian or Pakistani
- I don't know
- Prefer not to answer
- Other: _____ OR Another race, please describe: _____

“

Write-in data is **not data**, it's information that we can't capture.

– **BCBS Plan**

KEY CONSIDERATIONS

1

More descriptive wording of the Race question is generally preferred, as it allows respondents to share how they would describe themselves.

2

Inclusivity in response options for race categories is highly preferred as it allows individuals to see themselves reflected. This is especially true for younger generations.

3

Review preferences from this research against those provided by NCQA Health Equity Accreditation Requirements, US Census and other standards.

For instance, the Office of Management and Budget (OMB) has recently announced updates to Statistical Policy Directive No. 15: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity (SPD 15). One said update includes the addition of Middle Eastern or North African in the race category.

RACE | SUMMARY (CONT.)

PERSONALIZING CONTEXT

How to Ask

While Republicans are split between “What is your race?” and “Which of the following best describes you?”, most respondents in all other sub-groups preferred the latter option. It is also important to note that there is a nuanced difference between the two options, as one allows the respondent to “describe themselves”. Based on the patterns observed in the SOGI questions, it is evident that inclusive language is key for the marginalized and younger generations. As such, the recommended option will lead to a higher opt-in rate. Race questions should either be optional or include answer options such as “Don’t know” or “Prefer not to answer”, so that members have the option to opt-out of answering the question. Lastly, a free-text answer option should only be included if the member responses will be utilized.

Response Options

While all subgroups preferred White or Caucasian (~50%+), “Caucasian” is widely considered outdated, and problematic, given its historical and anthropological origins. It is recommended that Plans avoid using such terminology. Respondents also preferred a similar option for “Black or African American”. Nearly 50% of the individuals analyzed across sub-groups preferred this option, including the Black or African American subgroup (52%).

When asked whether Native American or Alaskan Native or American Indian or Alaska Native is preferred, at least

seven out of 10 respondents preferred Native American or Alaskan Native, which coincides with the Native American or Alaskan Native subgroup’s preference (65%). Over 50% of respondents preferred the Native Hawaiian or Other Pacific Islander (NHOPI) option. However, it is important to note that 61% of respondents who identify as NHOPI preferred the “Native Hawaiian Guamanian or Chamorro Samoan Other Pacific Islander”. This highlights the need to understand member demographics to ensure that respondents can see themselves in the answer options. If a Plan has a large NHOPI member population, then it would be beneficial to ensure that their preferred option is included.

Younger generations and non-White respondents (including 48% of the Asian population) preferred the more granular Asian race options. In terms of additional options, nearly 63% of individuals chose more than one additional race option, which was led by Middle Eastern or North African (MENA). This directionally aligns with the approach the US Census is seeking to take with the inclusion of MENA as a race option. Further, 39% of the Asian subgroup preferred to include the “Indian or Pakistani” option. Like the patterns observed in the other domains, younger generations, such as Gen Z, prefer the inclusion of additional options.

Lastly, while the overall population is divided between “Other” and “Another race, please describe,” the older generations prefer the former option.

ETHNICITY | SUMMARY

QUESTION & RESPONSE OPTIONS – RECOMMENDATION

What is your ethnicity or ethnic background?

OPTION 1

- Hispanic or Latino
- Not Hispanic or Latino
- I don't know
- Prefer not to answer
- Other: _____

OPTION 2

- 15 Options (See Appendix A)
- I don't know
- Prefer not to answer
- Other: _____

OPTION 3

- 34 Options (See Appendix A)
- I don't know
- Prefer not to answer
- Other: _____



Build the **trust** and show the **transparency.**

– **BCBS Plan**

RACE & ETHNICITY – SINGLE OR SEPARATE QUESTIONS?

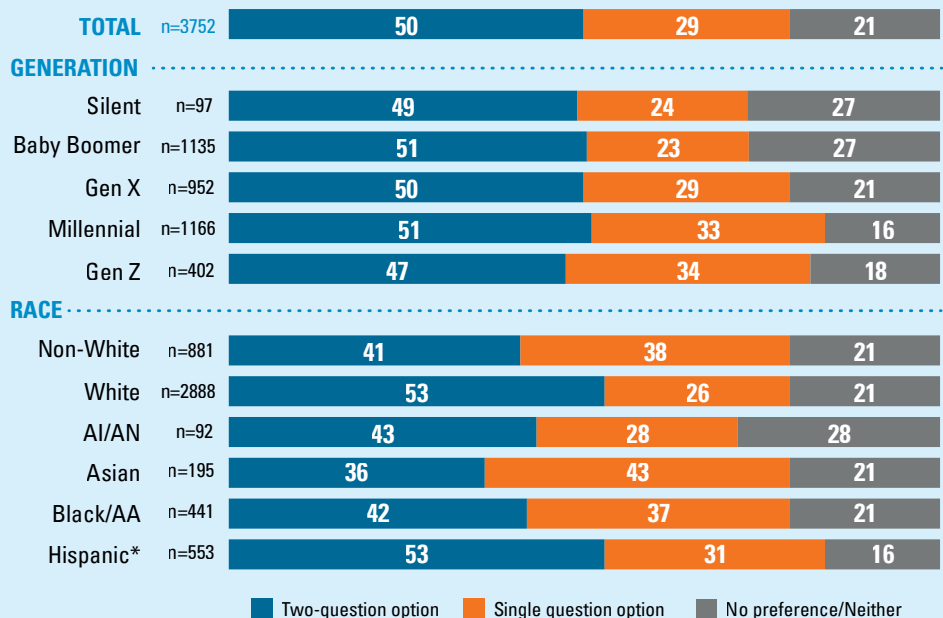
In January 2023, The Office of the Chief Statistician announced its formal process to revising Office of Management and Budget (OMB)'s statistical standards for collecting and reporting race and ethnicity data (Directive No.15). Among several recommended revisions, the Interagency Technical Working Group that led this effort proposed that race and ethnicity should be collected with a single question. When assessed with the respondents of this survey, all generational, White, and non-White groups preferred the separation of race and ethnicity into two questions. However, when compared to White respondents, non-White respondents (e.g., Asian) tend to prefer the single question approach more. This can be attributed to the more expansive list of examples included for certain racial/ethnic groups (e.g., Asian) in the single R/E question (as shown above) compared to the separate R/E response options. In March 2024, OMB issued updates to Directive No. 15, including the adoption of a single combined race and ethnicity question that allows for multiple responses. Notably, these updates also broaden the range of response options for race and ethnicity questions, aligning with the preferences expressed by respondents (Appendix B).

Single Question Example

Please describe your race/ethnicity.
(Select all that apply.)

- African (e.g. Nigerian, Ethiopian, Ugandan, etc.)
- Afro-Caribbean (e.g. Jamaican, Haitian, Trinidadian, etc.)
- Asian American
- Black/African American
- East Asian (e.g. Chinese, Japanese, Korean, etc.)
- Hispanic/Latino/Latina (e.g. Mexican, Puerto Rican, Colombian, etc.)
- Indigenous or Native American (e.g. Navajo, Cherokee, Alaska Native, etc.)
- Middle Eastern or North African (e.g. Egyptian, Lebanese, Syrian, etc.)
- Pacific Islander (e.g. Native Hawaiian, Samoan, Guamanian, etc.)
- South Asian (e.g. Bangladeshi, Indian, Pakistani, etc.)
- Southeast Asian (e.g. Cambodian, Filipino, Vietnamese, etc.)
- White or Caucasian (e.g. German, Italian, Lithuanian, etc.)
- I identify as another race/ethnicity: Specify here: _____
- I prefer not to identify

Single or Separate Question Preference (%)



*Included for reference, but classified independently of race

ETHNICITY | SUMMARY (CONT.)

PERSONALIZING CONTEXT

How to Ask

Around 40% of all respondents preferred “What is your ethnicity or ethnic background,” especially non-White respondents. The Silent Generation also preferred “Which of the following best describes you,” and “Which of the following best describes your heritage or ancestry.” Given the strong preference for the former question option among all other generations, Plans should consider using this option.

Ethnicity questions should either be optional or include answer options such as “Don’t know” or “Prefer not to answer”, so that members have the option to opt-out of answering the question. Lastly, a free-text answer option should only be included if the member responses will be utilized.

Response Options

Currently, OMB’s standards for collecting ethnicity data only includes two options (Option 1). However, when presented with a more robust list of options (15 options and 34 options), non-White respondents preferred a more comprehensive set of ethnicity options. Given that non-White respondents are more likely to be hesitant or refuse to answer race and ethnicity questions, it would be beneficial to strongly consider this population’s preferences.

In terms of open-ended questions, the overall population is split between “Other” and “Another ethnicity, please describe”. Older generations, White, Republicans, and Independents prefer “Other:” while younger generations, non-White, and Democrats are split between the two options. As such, the former option will likely drive greater response rates.

LANGUAGE | SUMMARY

QUESTION & RESPONSE OPTIONS – RECOMMENDATION

What is your preferred language?

OPTION 1

- English
- Spanish
- I don't know
- Prefer not to answer
- Other: _____

OPTION 2

- 20 Options (See Appendix A)
- I don't know
- Prefer not to answer
- Other: _____

“

Who are we disappointing, if we ask and do not provide?

– BCBS Plan

KEY CONSIDERATIONS

- 1** Language is the least polarizing domain, though there is opportunity to be more inclusive.
- 2** Rather than asking for language preference in various scenarios (e.g., speaking, reading, discussing health information), respondents prefer being asked their overall language preference.
- 3** There is a relationship between race, ethnicity, and language preferences, as non-White populations prefer more robust response options.
- 4** When translating US English terms into different languages, it is important to ensure clear and easily understandable translations, as this is not always guaranteed.

PERSONALIZING CONTEXT

How to Ask

Nearly 65% of respondents preferred the question option “What is your preferred language?”
















Language questions should either be optional or include answer options such as “Don't know” or “Prefer not to answer”, so that members have the option to opt-out of answering the question. Lastly, a free-text answer option should only be included if the member responses will be utilized.

Response Options

While older generations and Republicans prefer a shorter list of two options, younger generations and select non-White populations (largely Asians) prefer a longer list of 20 options.

The same percent (55%) of Hispanic and non-Hispanic respondents prefer the shorter list of options (i.e., two options). However, considering that select non-White populations expressed a preference for a more comprehensive list, it is advisable for Plans to expand the list of languages to enhance inclusivity.

CONSIDERATIONS | ACTIVATION PLAN

DESIGN PRINCIPLES	STEP	GUIDANCE	RELATED PRINCIPLES
 <p>Personalize Context Consider the situation and context from an individual's perspective.</p>	Understand Your Member Demographic	Leverage existing SOGI/REL data, publicly available, and purchased data (e.g., American Community Survey, voter registration data, etc.) to understand the potential demographic makeup of your member population. Our survey findings show that polarization was driven by political, generational, non-White vs. White, and LGBT differences. To develop an effective self-reported data collection, it is crucial to know the population from which you are seeking to collect data.	 
 <p>Look Forward Flexibly Be mindful of the evolving societal norms and demographic shifts impacting data collection.</p>	Educate and Prepare Key Stakeholders	To ensure a successful data collection strategy, gain leadership and cross-functional support by developing and socializing key use cases aligned with corporate objectives and health equity goals. Engage cross-functional teams (such as technology, health equity, and legal) during strategy development. Lastly, train key staff members to approach sensitive questions empathetically.	
 <p>Engage Authentically Be genuine and honest to establish rapport and trust.</p>	Define "The Why"	To improve response rates, address the hesitancy of marginalized populations by transparently explaining why sensitive questions are asked and how the information benefits respondents personally. Understand your member population's health experiences, analyze available data, and identify potential disparities. Incorporate these insights into messaging that resonates with members. Finally, conduct focus groups to test the effectiveness of your approach based on demographic estimates from Step 1.	 
 <p>Empathetically Respond Respond inclusively and meaningfully to the data provided.</p>	Thoughtfully Ask the Question	Consider your member population's demographic makeup to determine inclusive question and answer options using insights from this Playbook. Look ahead to align with upcoming demographic shifts. Additionally, construct options that make hesitant populations feel well-represented when sharing sensitive information.	 
 <p>Meet People Where They Are Consider BCBS members' unique perspectives when providing survey choices.</p>	Strategically Enhance Systems to Collect and Securely Store Data	Identify all instances where member SOGI/REL data are collected and store the data in a centralized location. Establish rigorous data governance rules to ensure proper and consistent management of data provenance, data access, and data security. Develop a process for determining the most reliable source of information for SOGI/REL data (such as patient portals, state data, or Electronic Health Record data). Lastly, ensure that systems are adaptable and can accommodate refinements to the data collection strategy (e.g., expansion of answer options).	 
	Promote Transparency by Sharing Data Use Cases	Follow through on "The Why" by sharing key findings from research (e.g., health equity reports). If the key findings lead to the implementation of programs and interventions, incorporate this information into Step 2, such that members are aware that the data they provide are being used for their benefit.	

KEY ACTION ITEMS

1
Thoroughly test back-end data collection systems and survey tools and ensure they are flexible to include more categories in the future.

2
Review preferences from this research against those provided by NCQA Health Equity Accreditation Requirements, US Census, OMB, etc.

3
Identify and coordinate all technological enhancements required to implement data collection strategy (e.g., enrollment channels).

4
Obtain leadership support and collaborate cross-functionally with teams such as Legal, Account Managers, Health Equity, IT, Marketing, to develop data collection strategy.

5
Vet the SOGI/REL data collection strategy with key stakeholder groups (employers, providers, members, community partners, etc.).

CONSIDERATIONS | DATA COLLECTION JOURNEY MAP

PREPPING FOR DATA COLLECTION



- Modifying enrollment channels can be time and resource intensive
- Some employer groups may require that certain data elements should not be collected for their employee populations
- Integrating new question and answer options into internal systems can be time and resource intensive
- Engage key stakeholders (e.g., Employer groups, Brokers/Consultants) to define approach to updating enrollment forms
- Develop customized forms for employer groups that request certain questions not be posed to their employees
- Ensure that systems are flexible such that they can be easily be updated as SOGI/REL standards evolve over time
- Members do not feel represented in the answer options presented in SOGI/REL questions
- Conduct a demographic analysis (using existing SOGI/REL data, publicly available/purchased data), disparity analyses, and literature reviews to understand the potential demographic makeup of your member population as well as the healthcare gaps driven by SOGI/REL related inequities in regions where your member population is densely populated.
- Lack of trust/understanding as to why sensitive questions are being asked and how this information will be used
- Frame the "why", questions, and answer options based on the demographic makeup of your member population.
- Obtaining internal support for the data collection roadmap may be challenging due to competing priorities and resource constraints
- Seek internal and external alignment on SOGI/REL data collection strategy by articulating the use cases for the data,
- Conduct internal / external staff SOGI/REL cultural sensitivity and responsiveness trainings, which promote the consistent application of data collection strategies

DATA COLLECTION



Member signs up for benefits / logs into Plan Patient Portal



Member visits hospital/clinic



Member registers at front desk



Member consults with provider



Member follows up with case manager

- Lack of trust/understanding as to why sensitive questions are being asked and how this information will be used
- For data collected via member portal, member churn may result in constant SOGI/REL data gaps
- Aim to collect SOGI/REL data via enrollment channels
- Incorporate the refined rationale, SOGI/REL questions and answer options
- Ensure that the member's preferences are well documented for downstream member interactions
- Frustrated with the number of times sensitive questions are being asked
- Incorporate the refined rationale, SOGI/REL questions and answer options
- Ensure that the member's preferences are well documented for downstream member interactions
- Confirm that EHRs can accommodate SOGI/REL inputs
- Lack of trust/understanding as to why sensitive questions are being asked and how this information will be used
- Incorporate the refined rationale, SOGI/REL questions and answer options
- External staff SOGI/REL training should incorporate tips on creating a welcoming and culturally sensitive environment for members
- Confirm that EHR / Case Management systems can accommodate SOGI/REL inputs

POST-DATA COLLECTION



- Assess data quality from various sources and develop decision tree to define system logic such that data from the most reliable source is selected
- Evaluate efficacy and effectiveness of data collection approach and conduct follow-up discussions with key stakeholders to align on strategy refinements
- Apply REL/SOGI data to program development efforts and disparity research and share findings from research back with community
- Member Pain Point**
- Plan Opportunity**
- Potential Plan Pain Point**

PLAN CASE STUDY | BLUE CROSS BLUE SHIELD OF NORTH CAROLINA

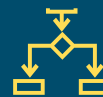
KEY TAKEAWAYS



Collaboration with stakeholders, including technical data architects, is crucial for successful planning and integration of SOGI/REL data in the system where the data will be stored. Collaboration will also allow data owners to determine the method of use, access, security, and analytics



Education on data standards, such as USCDI, is essential to ensure consistency in the standards applied across the organization.



Identify data use cases and define a plan to effectuate the use cases prior to capturing information from members (e.g., identifying ways in which members' preferred language can be incorporated into future correspondence)

Background

Blue Cross Blue Shield of North Carolina (Blue Cross NC) is in the process of developing its data collection strategy for member self-reported SOGI/REL data. Currently, the Plan receives REL data from the Healthcare.gov Marketplace and state government-sourced data. Following the implementation of the SOGI/REL data collection strategy, the Plan will begin collecting the SOGI/REL data from its member portal. The Plan currently leverages OMB, OMH for REL, and will follow USCDI standard for SOGI data collection.

Educate and Prepare Key Stakeholders

Leverage Existing Member SOGI/REL Data to Develop Self-Reported Data Collection Strategy and Use Cases

Perform inventory on the data that Plans already have on members and leverage existing SOGI/REL data (self-reported and/or imputed) to conduct initial health equity assessments. Blue Cross NC linked data to quality and HEDIS metrics aligned to population health indicators to help prioritize work and shared findings from different lines of business to highlight the disparities that should be prioritized and addressed.

Confirm Key Stakeholder Alignment

Ensure leadership buy-in prior to socializing with remaining stakeholders. Temper the understanding

of where the Plan currently is and what it will take to meet the data collection goal. Manage expectations, as internal alignment can take some time. Continue to be creative and innovate to ensure that all stakeholders understand the importance of collecting self-reported SOGI/REL data.

Socialize approach with the appropriate stakeholders by identifying solid use cases that align with organizational goals and the health equity strategy. When developing use cases, ensure that they are broad and resonate with others within the organization. For instance, Blue Cross NC identified use cases that resonate with stakeholders across health equity, care management, and marketing teams, which drove greater stakeholder buy-in.

Develop elevator pitch messaging that can be shared with Members, Providers, Employer groups and external audiences to ensure their alignment with the SOGI/REL data collection strategy.

Form Core Project Team

Identify the most appropriate owners of the data and data collection strategy to promote data stewardship. Form an internal working group to discuss and plan for SOGI/REL data collection. When forming its internal working group, Blue Cross NC engaged functions such as Healthcare/Health Equity, IT, Data Strategy, Care Management, Digital Strategy and Marketing. Blue Cross NC learned that engaging technology &

digital platform resources as early as possible is key to ensuring the data collection strategy is listed as an organizational priority.

Define “The Why”

Conduct Literature and Resource Review to Inform the Data Collection Strategy

Use existing literature and resources to define “the why”. Blue Cross NC leveraged resources such as the Ethical Guide for Data Collection developed by BCBSA, Collection of Race and Ethnicity Data for Use by Health Plans to Advance Health Equity by Urban Institute. Blue Cross NC also consulted with other Blue Plans (e.g., BCBSMA and BCBSRI) to learn more about their best practices and approaches. Rather than reinventing the wheel, Blue Cross NC used concrete and existing foundational information to inform its strategy.

Engage Internal Resource Groups and Community Partners

Leverage employee resource groups and other community partners, conduct health equity focus groups with members, and engage providers to inform the SOGI/REL data collection strategy.

Offer Employee Trainings and Educational Sessions.

Conduct necessary trainings with key stakeholders (e.g., Clinical teams) on the importance of this data and reasons for collecting.

Thoughtfully Ask the Question

Leverage Best Practices and Lessons Learned Shared by Blue Plans

Rely on the lessons learned by Plans that are further along in the data collection journey. Engage with said Plans and consider incorporating their best practices where applicable and appropriate.

Maintain Objectivity When Developing Data Collection Strategy

When exploring opportunities to refine SOGI/REL question and answer options, remain grounded and objective in the purpose of collecting the SOGI/REL data. Business goals and objectives should be at the forefront of the data collection strategy.

Strategically Enhance Systems to Collect and Securely Store Data

Identify the Most Reliable and Effective Source of SOGI/REL Data and Prioritize Accordingly

If enrollment channels are modifiable, leverage enrollment forms to collect SOGI/REL data.

Establish hierarchical rules such that the data used across the organization are from the most reliable sources. Maintain and assess data from all sources before overriding the prior data. It is also key to account for non-standard data sets that vary from standards (e.g., HL7) and developing a crosswalk if needed.

Establish Necessary Data Management Processes and Procedures within Internal Data Systems

Prior to data collection, establish the data flow, architectural footprint, and the secure location where data will land. Blue Cross NC created a centralized database through which approved downstream applications can pull to populate for different end users. Lastly, given the impending OMB updates, avoid hard coding to specific options.

Identify the end users who need access to the data. Blue Cross NC identified Care Managers as key end-users. As such, development work will need to be completed to integrate SOGI/REL data into the care management platform.

Promote Transparency by Sharing Data Use Cases

Develop health equity reports for providers in value-based care arrangements and create a member-facing dashboard. The Dashboard will include key quality performance measures stratified by REL.

PLAN CASE STUDY | BLUE CROSS & BLUE SHIELD OF RHODE ISLAND

KEY TAKEAWAYS



Leadership support is crucial, to overcome barriers, navigate competing priorities and drive organization-wide support



Technology updates may be required to effectively implement the SOGI/REL data collection strategy. Consider where the data will be stored, the ultimate source of truth, who will be able to access the data, and how to manage updates to existing data



Vet the SOGI/REL approach with key stakeholder groups, particularly Account Managers and Employer groups. Prepare to implement a data collection workaround for Employer groups that may request customized forms for their employee populations

Background

Blue Cross & Blue Shield of Rhode Island (BCBSRI) is in the process of validating and refining its SOGI/REL data collection strategy. Currently, BCBSRI collects self-reported SOGI/REL data through its member portal, mobile application and customer service. The Plan leverages OMB for REL data collection.

Understand Your Member Demographics

Consider the potential attitudes and beliefs of membership by assessing member demographics, affiliations, political climate, state regulations and policies and other factors that may influence the perceptions and reactions of members to both the specific questions and the rationale for asking them.

Educate and Prepare Key Stakeholders

Confirm Key Stakeholder Alignment

Consider engaging different groups of stakeholders, internally and externally, to vet SOGI questions before implementation. This will help to ensure that SOGI/REL questions are being framed appropriately and response options are inclusive and effective. Furthermore, it will help validate that the reasoning for asking these questions is clear and understood.

Effectively communicate to internal stakeholders the rationale for asking SOGI/REL questions and how these data will improve the work the Plan does. Leadership

should be the biggest advocate for these efforts, so it is key to obtain their support and alignment for this work.

Form Core Project Team

Engage appropriate internal teams when developing the SOGI/REL data collection strategy. BCBSRI engaged Legal, Enterprise Technology, Member Portal leads, Enrollment leads, Customer Service Leads, Retail Office leads, Community Engagement leads, Health Equity team, and third-party vendors responsible for system updates. Given that Account Managers have direct lines of communication with key Employer groups, engaging them early on will ensure that regular reminders are provided to members to complete their forms.

Offer Employee Trainings and Education Sessions

Recognize that certain SOGI/REL questions can be personal and there is a sensitivity that needs to be considered when asking these questions. Consider offering trainings to employees (including the Executive Leadership team) to educate them on why SOGI/REL data collection is important, and how to best collect such sensitive data. BCBSRI partnered with The National LGBTQIA+ Health Education Center, a program of The Fenway Institute at Fenway Health, to offer a special training for customer-facing associates, *Achieving Health Equity for LGBTQIA+ People*, related to the company's health equity initiatives. Fenway Health provided live virtual trainings to customer-facing associates focusing on how to collect SOGI data,

why it's important, key terminology, and how to ask questions in a non-offensive manner. In addition, these trainings were recorded so that they are now part of the company's onboarding process. Fenway Health also developed modules that associates can refer to on terminology, asking questions, and why collecting this data is important to BCBSRI's work and mission.

Offer opportunities for best practice sharing across teams. For example, the BCBSRI Medicare Advantage Customer Service team identified ways to effectively collect SOGI/REL information when speaking with members. As such, the Medicare Advantage Customer Service team shared best practices with other teams to improve response rates.

Define "The Why"

Vet the Proposed Member-Facing Messages with Experts

Engage key internal and external subject matter experts to inform the data collection strategy. BCBSRI met with the State Department of Health SOGI equity workgroup, the Plan's Blue pRIde employee business resource group, as well as other LGBTQIA+ and aging related community-based organizations and stakeholder groups to help inform its strategy.

Develop and Evaluate Member-Facing Messages to Identify the Approach that Resonates

The following messaging has been provided to BCBSRI members regarding SOGI/REL data collection:

- BCBSRI wants all Rhode Islanders to have quality, affordable, and equitable care when they need it. The first step is to gain a better understanding of the healthcare needs of our members and their communities. Sharing information like race, ethnicity, and gender identity supports the effort.
- This information will give the company a more complete picture of its membership and will help to identify unmet needs.
- The information you share will be protected as BCBSRI protects all health information (link to privacy policies).
- Your responses will not affect your health coverage or premiums. BCBSRI does not discriminate on the basis of race, color, national origin, age, disability, or sex, including sexual orientation, gender identity, or gender expression.

- You do not have to answer these questions. Not answering the questions will not affect your health coverage or premiums. But your answers can help BCBSRI to improve access to care for all of its members.

When asking members SOGI/REL questions, the following messaging may be effective: "So that I can confirm the information in our records are accurate, what is your [insert data element]?" It is best to choose wording that resonates with your member population. For example, "how do you identify?" can be confusing to some members, particularly those in older populations.

Thoughtfully Ask the Question

Manage Member Expectations

Members may anticipate that immediate action will be taken based on the responses they provide in the form. To help manage expectations, BCBSRI includes a message on its member portal indicating that the company is in the gathering phase and that members may not immediately receive communication in the language spoken at home. However, BCBSRI is seeking to expand options.

To align with new NCOA Health Equity Accreditation requirements and emphasize to members that proper data privacy protocol will be followed, consider updating privacy statement to include SOGI.

Develop and Evaluate SOGI/REL Questions to Identify the Approach that Resonates with Members

Consider keeping SOGI simple, vetting options with key stakeholder groups, and making the connection to existing LGBTQIA+ services. BCBSRI has vetted SOGI questions with key stakeholder groups. For gender identity, BCBSRI selected the question-and-answer options that members wanted to see. For sexual orientation, BCBSRI developed two questions:

- **Question 1:** Yes, no or prefer not to say on whether the member is part of the LGBTQIA+ community.
- **Question 2:** Yes or no on whether the member would be interested in receiving more information about certain services and programs designed to help LGBTQIA+ members access affirming and inclusive care, such as BCBSRI's Safe Zones program. Note: If a member selects Yes, they receive an automated email with additional information on the services.

Identify the SOGI/REL answer options that will likely resonate the most with members. For example, BCBSRI developed two language-related questions. The first question asks members how they would like to receive their correspondence and includes the top three languages in Rhode Island (per Census data) as options. The second question asks members the most common language spoken in the home, listing the top 10 languages in Rhode Island (per Census data) as options.

Identify innovative ways to collect SOGI/REL information. BCBSRI includes QR codes leading to the Member Portal on posters during community events.

Strategically Enhance Systems to Collect and Securely Store Data

Establish Necessary Data Management Processes and Procedures within Internal Data Systems

Consider utilizing an Agile project approach to tackling deployments. Testing in sprints will drive agility in the process and offer flexibility in the workflow.

Some systems may be limited when it comes to SOGI fields. For instance, BCBSRI had to create an attachment to store the data in Facets. Further, updating commercial enrollment forms may prove to be challenging as certain member information is shared with employers, which would violate privacy policies. If some enrollment forms are being submitted via paper, adding SOGI/REL questions may make the forms longer. Lastly, certain systems may not have the same categories for R/E as listed on the Plan's member portal.

Thoroughly test systems before go-live and ensure systems are working as expected before promoting the REL/SOGI data collection.

Ensure Data Systems are Flexible

Develop a system that is easy to update. Questions and categories can change over time, so it's important to have systems that can be easily updated.

Keep in mind that certain employer groups may prefer their employees not be asked SOGI questions. If so, prepare to edit member portal and mobile applications to only ask REL questions for such employer groups.

Implement Data Collection Progress Tracking Mechanisms

Develop dashboards accessible to key internal staff members to ensure that staff and leadership leads are kept up to date on progress being made. Dashboard stats can include collection progress by REL/SOGI domain, lines of business, and employer groups. The dashboards also make it easier to identify large changes in the data collection, which can be shared out to various internal stakeholders as needed.

Promote Transparency by Sharing Data Use Cases

Develop health equity reports that are accessible to members, providers, and other key stakeholders. BCBSRI offers a [health equity report](#) that aligns its race and ethnicity member data with HEDIS measures. The report is located on its website and publicly accessible. The report is also used when meeting with certain stakeholder groups to demonstrate where there are gaps in care and how BCBSRI plans on addressing them.

KEY TAKEAWAYS



Barriers that may impede members from reporting REL information

include: “lack of understanding as to why they should report their REL data, data protection concerns, high friction surrounding the reporting process, and discrimination and concerns regarding lack of representation in answer options”



Conducting pilot studies can help test and validate

efficacy of various data collection approaches and better understand the approach and wording that resonates with the member population



Collecting SOGI/REL data during enrollment or benefit changes

can solve for gaps caused by member churn, dependent minors, and member consent

Background

Blue Cross Blue Shield of Massachusetts (BCBSMA) has tested, implemented, and validated its SOGI/REL data collection strategy. The Plan receives SOGI/REL data from its MyBlue Portal, paper surveys, Account reported race/ethnicity data – (834 electronic enrollment files), government registry data (Massachusetts Immunization Information System), provider data, and imputed data. The Plan leverages FHIR standards to collect race and ethnicity data, has developed custom language standards, and is working towards collecting SOGI self-reported data.

Understand Your Member Demographics

Conduct pilot studies to understand the Plan’s member demographics and the data collection approach that is most effective within and across demographic groups. For instance, BCBSMA’s REL Pilot study showed that race and ethnicity disclosure was highest among certain demographic groups (i.e., Black (93%) and Other Race (92%)). The Pilot study also tested response rate differences across age groups and the performance of REL request messages across various demographic groups.

Educate and Prepare Key Stakeholders

When developing the data collection strategy, BCBSMA worked cross-functionally and ran lean. Stakeholders included analysts (Performance Measurement & Improvement team), the Nudge unit, Enterprise Technology, User Experience/Customer Experience teams, Legal, etc.

Define “The Why”

Vet the Proposed Member-Facing Messages with Experts

Engage provider groups to understand the work they are doing to promote health equity. BCBSMA manages the Equity Action Community, which includes Value-Based Program-affiliated providers. This forum enables providers to share their perspectives on the infrastructure and tools that they need to perform well under Value-Based Care arrangements.

Engage community partners to inform SOGI/REL data collection strategy. BCBSMA manages the Health Equity Council, which include local and national experts that bring the community voice and have helped BCBSMA craft the strategy for data collection.

Develop and Evaluate Member-Facing Messages to Identify the Approach that Resonates with Members

Consider making the race and ethnicity questions and rationale behaviorally informed. For instance, BCBSMA’s REL Pilot study showed that a “Collective Action Explanation significantly increased disclosure of race and ethnicity over the Business-as-Usual message (BCBSMA Health Equity Technical Methods Retreat, 2023):

- **Collective Action Explanation:** “Be part of our efforts to reduce inequities in healthcare by sharing this information. It helps us to identify inequities in care and then address any gaps in services that vulnerable communities are experiencing.”

- **Business as Usual:** “This helps us to improve the quality and equity of care for everyone we serve”

Thoughtfully Ask the Question

When asking about member race/ethnicity, consider separating race and ethnicity questions and allow for multiple endorsements of race and ethnicity categories (“Select all that apply”).

If Plans are leveraging HL7 FHIR standards for race and ethnicity categories, consider expanding to include FHIR level 2, and some FHIR level 3, categories, which provide greater level of granularity in response options. For instance, BCBSMA members have indicated certain FHIR level 1, and 2 options lack representation. As such, it can be beneficial to include FHIR levels 1, 2, and 3 to ensure users are able to select an option that represents them (BCBSMA Health Equity Technical Methods Retreat, 2023).

Strategically Enhance Systems to Collect and Securely Store Data

Identify the Most Reliable Source of SOGI/REL Data and Prioritize Accordingly

Plans generally do not control enrollment forms. There are several key stakeholders that are involved in the enrollment process (i.e., “Account Decision Makers,” Brokers/Consultants, Third-Party Vendors, and Member Enrollment leads). Further, prioritizing the data collection effort may be challenging during open enrollment due to competing priorities, time, and the required investment.

All data is good data. Although inequities typically measure lower with imputed data, it is still instructive and directionally aligned when additional self-reported data is available. Additionally, even as question and response options evolve over time or as imputation methods change, do not throw away old data. Ensure you have appropriate data provenance standards in place.

Develop and Evaluate SOGI/REL Questions to Identify the Approach that Resonates with Members

Consider incorporating a Randomized Control Trial or a similar approach to determine which mode of data collection is most effective for the Plan’s member population. Findings from BCBSMA’s Randomized 24- Arm Trial of Paper Survey showed that the mailed survey paper responses were higher than the digital responses. (BCBSMA Health Equity Technical Methods Retreat, 2023).

Leverage a customer-centric approach to digital surveys. For instance, BCBSMA ensures that all pop-ups for new users can be snoozed for 14 days. While BCBSMA does not give members option to decline to answer, REL questions are always voluntary, and members are able to skip the question.

Assess Data Accuracy and Formatting

If Plans are leveraging multiple sources for SOGI/REL data collection, it is key to check the data for accuracy. BCBSMA conducts accuracy checks by (BCBSMA Health Equity Technical Methods Retreat, 2023):

- Examining the format type, output format, and specific categories for race and ethnicity in the incoming data sources – noting any differences between the incoming data and the self-reported data
- Identifying individuals for which both data sources have non-missing values
- Calculating accuracy metrics of interest and conduct secondary accuracy checks
- Completing accuracy calculations (i.e., sensitivity, specificity, Positive Predictive Value, Negative Predictive Value, Estimation of Racial/Ethnic Prevalence) using the format needed for analysis
- Recording key findings for future uses of the data

Collect data using the Endorsement format (i.e., a set of indicator variables (binary yes/no) for each potential race and ethnicity category). (BCBSMA Health Equity Technical Methods Retreat, 2023).

Establish Necessary Data Management Processes and Procedures

Establish data governance and controls for access and use for each type of SOGI/REL data. BCBSMA has identified two allowable use cases for race and ethnicity data: “1) to measure inequities in care and 2) to reduce inequities in care.” BCBSMA has also established that race and ethnicity data can only be used for population-level analyses. Lastly, BCBSMA has established “multiple layers of data oversight, controls, and management for the use and disclosure of REL & SOGI data” (BCBSMA Health Equity Technical Methods Retreat, 2023)

Establish data provenance codes that record the exact sources and data collection methods for each race & ethnicity value in databases (where it came from, how

it was collected, when it was collected, what data standard it's on) (BCBSMA Health Equity Technical Methods Retreat, 2023). While BCBSMA originally had some race and ethnicity data, the data had minimal provenance codes. To ensure data provenance is prioritized, BCBSMA made the strategic decision to start fresh with a standalone data table – this decision enabled the Plan to determine true data provenance and standards for all race and ethnicity data. These gold-standard data have made it possible to evaluate the accuracy of every other data source (e.g., from providers, government databases, vendors, and imputation methods).

Promote Transparency by Sharing Data Use Cases

Publish an annual health equity report that can be accessed by all stakeholders. For instance, BCBSMA publishes an annual [Health Equity Report](#) on its website and shares information on programs and provider collaborations in the news media.

APPENDIX A

What is your ethnicity or ethnic background?

(15 options)

- European
- American
- Hispanic/Latino
- Mexican
- Latin American
- Black
- African/American
- Vietnamese
- Asian Indian
- Iranian
- Filipino
- Arab
- Laotian
- Chinese
- Russian

What is your ethnicity or ethnic background?

(34 options)

- German
- Black or African American
- Irish
- Mexican
- English
- American
- Italian
- Polish
- French
- Scottish
- Scotch-Irish
- American Indian or Alaska Native
- Dutch
- Puerto Rican
- Norwegian
- Swedish
- Chinese
- Russian
- Asian Indian
- West Indian
- Filipino
- French Canadian
- Welsh
- Cuban
- Salvadoran
- Arab
- Vietnamese
- Czech
- Hungarian
- Portuguese
- Korean
- Danish
- Dominican
- Greek

What is your preferred language?

(20 options)

- English
- Spanish
- Arabic
- Cantonese
- Farsi
- French
- French Creole
- German
- Hindi
- Hokkien
- Italian
- Korean
- Mandarin
- Polish
- Portuguese
- Russian
- Somali
- Swahili
- Tagalog
- Vietnamese

APPENDIX B

OMB SPD 15 Updates

On March 29th, 2024, the Office of Management and Budget (OMB) announced revisions to Statistical Policy Directive No. 15: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity (SPD 15).⁽¹¹⁾

The revisions in SPD 15 include:

- Collecting data using a single combined race and ethnicity question, allowing multiple responses.
- Adding Middle Eastern or North African (MENA) as a minimum reporting category, separate and distinct from the White category.
- Updating terminology in SPD 15, such as definitions for race and ethnicity categories and removing the use of “majority” and “minority.”
- Requiring the collection of the detailed race and ethnicity reporting categories unless an agency requests and receives an exemption from OMB’s Office of Information and Regulatory Affairs. The deadline for compliance with the revised SPD 15 is five years from the publication of the update (March 28th, 2029)
- Requiring agency Action Plans on Race and Ethnicity Data and timely compliance with this revision to SPD 15 within 18 months.
- Establishing an Interagency Committee on Race and Ethnicity Statistical Standards, to be convened by the Chief Statistician of the United States, that will undertake regular reviews of SPD 15. These reviews will take place on a 10-year cycle and will include opportunity for public input.

What is your race and/or ethnicity?
Select all that apply and enter additional details in the spaces below.

American Indian or Alaska Native – Enter, for example, Navajo Nation, Blackfeet Tribe of the Blackfeet Indian Reservation of Montana, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community, Aztec, Maya, etc.

Asian – Provide details below.
 Chinese Asian Indian Filipino
 Vietnamese Korean Japanese
Enter, for example, Pakistani, Hmong, Afghan, etc.

Black or African American – Provide details below.
 African American Jamaican Haitian
 Nigerian Ethiopian Somali
Enter, for example, Trinidadian and Tobagonian, Ghanaian, Congolese, etc.

Hispanic or Latino – Provide details below.
 Mexican Puerto Rican Salvadoran
 Cuban Dominican Guatemalan
Enter, for example, Colombian, Honduran, Spaniard, etc.

Middle Eastern or North African – Provide details below.
 Lebanese Iranian Egyptian
 Syrian Iraqi Israeli
Enter, for example, Moroccan, Yemeni, Kurdish, etc.

Native Hawaiian or Pacific Islander – Provide details below.
 Native Hawaiian Samoan Chamorro
 Tongan Fijian Marshallese
Enter, for example, Chuukese, Palauan, Tahitian, etc.

White – Provide details below.
 English German Irish
 Italian Polish Scottish
Enter, for example, French, Swedish, Norwegian, etc.

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