Advancing Health Equity by Making Racial, Ethnic and Socio-Demographic Disparities Visible in Minnesota’s Health Care Quality Measurement System

Report to Minnesota Department of Health

By Voices For Racial Justice and its Community Partners

December 2014
# Table of Contents

I. INTRODUCTION ........................................................................................................... 2

II. INTERVIEW OBJECTIVES, METHODOLOGY, AND LIMITATIONS .................................. 5

   A. Objectives .................................................................................................................. 6
   B. Methodology .............................................................................................................. 6
   C. Limitations .................................................................................................................. 11

III. FINDINGS .................................................................................................................... 11

   A. Community Interviewees .............................................................................................. 12
      1. Consumer Experience (Findings) ............................................................................. 12
      2. Interviewees Acceptance of Race Ethnicity Language (REL) categories ............... 12
      3. Willingness to share socio-demographic information .............................................. 13
      4. Communities’ Comfort Level in providing Socio-demographic Information ........... 15
      5. Consumer Perspectives on How, When, and By whom Socio-demographic Information Should be Collected in Health Care Settings .............................................................. 16
      6. Barriers to consumers' provision of socio-demographic information ....................... 19
      7. Community’s use of information ........................................................................... 21
      8. Community perspectives around creation of health and health equity .................... 22
      9. Inequities/barriers impacting the health of the community ....................................... 23
     10. The role of the system in creating health ................................................................. 23
     11. Structural barriers ................................................................................................... 24

   B. Safety Net Clinics (Findings) ...................................................................................... 24
      1. Drivers of Patient Socio-Demographic Information Collection and Factors Collected .......... 24
      2. Experience Collecting Patient Socio-Demographic Information ............................. 26

IV. RECOMMENDATIONS: HEALTH CARE QUALITY MEASUREMENT ........................... 29

V. Appendices .................................................................................................................... 32

   A. Principles of Authentic Community Engagement VRJ .................................................. 32
   B. Script to contact community member ........................................................................ 32
   C. Introductory script for interviewer ............................................................................ 32
   D. Form to ask interviewees for REL ............................................................................ 32
   E. 2014 Federal Income Guidelines Household size ...................................................... 32
   F. Community Questionnaire ......................................................................................... 32
   G. Safety Net Questionnaire .......................................................................................... 32
   H. Definitions Used ........................................................................................................ 32

VI. Project Team (in alphabetical order by organization) .................................................. 32
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I. INTRODUCTION

The 2014 Minnesota Legislature directed the Minnesota Department of Health to provide a report to the 2015 Legislature with an implementation plan for changing Minnesota’s provider health care quality measurement system so that differences in the quality of care experienced by communities of color and racial, ethnic, cultural and other socio-demographic groups can be identified and addressed through improvements in the health care system. The intent of the law is to improve health equity through making existing disparities more visible in existing health care data collection and reporting systems.

It is well documented that not all Minnesotans experience the same level of health, quality of care and outcomes. Even though Minnesota’s health care system, as a whole, scores well on these measures, the results are much poorer for people of color, American Indian/Native American, new immigrants, and certain other identifiable socio-demographic groups who differ from the mainstream, average population in significant ways. Minnesota’s racial, ethnic and socio-demographic (“RESD”) disparities are described in detail in “Advancing Health Equity in Minnesota,” a report of the Minnesota Department of Health published in February 2014.\(^2\)

This report is unique compared to many legislatively mandated reports in that it was developed collaboratively by the Minnesota Department of Health and Voices for Racial Justice, a community nonprofit organization that engaged many community leaders and organizations from RESD groups in the process of developing the report and recommendations. This was done in part to respond to the Legislature’s directive in the 2014 law that the commissioner of health “use culturally appropriate methods of consultation and engagement with consumer and advocacy organizations led by and representing diverse communities by race, ethnicity, language, and sociodemographic factors.”\(^3\) It was also done because the 2014 law was another step in a multi-year campaign of racial and ethnic community leaders and organizations, called “The Visibility Campaign,”\(^4\) to improve health equity by making health disparities more visible and therefore easier to address through changes in how health care data are collected and reported. The 2014 law was passed to continue implementation of the

\(^{1}\) [http://voicesforracialjustice.org/](http://voicesforracialjustice.org/)


\(^{3}\) Minn. Laws, Ch. 312, Article 23, Section 10 Retrieved from [https://www.revisor.mn.gov/laws/?id=312&year=2014&type=0](https://www.revisor.mn.gov/laws/?id=312&year=2014&type=0).

\(^{4}\) [http://mnarche.wordpress.com/2012/08/17/the-visibility-project/](http://mnarche.wordpress.com/2012/08/17/the-visibility-project/)
recommendations of an earlier report published by state agencies in partnership with community leaders and organizations, “Collection of Racial/Ethnic Health Data by the Minnesota Departments of Health and Human Services” (January 2011). It also builds upon the recommendations made in MDH’s “Advancing Health Equity in Minnesota” report to “develop a long-term plan for improving the collection, analysis, reporting, dissemination and use of health equity data.”

The Visibility Campaign of leaders and community organizations representing RESD populations was launched initially because racial, ethnic and immigrant community leaders saw the serious challenges and extreme disparities their communities faced in Minnesota but were unable to get and see specific data on their own community members’ experience because the data was all aggregated into larger totals rather than being reported for each particular racial, ethnic or immigrant group. They knew that getting data that is broken down for their particular racial, ethnic or immigrant community was vital to being able to identify and quantify the particular disparities experienced by their communities and develop culturally tailored plans and programs to reduce the disparities. Armed with data, communities will be in a stronger position to improve health for their members.

This report contains two parts:

1. **Part One: A Framework for a State Health Equity Data Plan.** This part is a summary and synthesis of past recommendations and plans of RESD community organizations and leaders and state commissions, task forces and advisory groups on improving the visibility of – and response to – health disparities through improved data collection methods; and

2. **Part Two: Community Voices.** This part is a summary of the activities, findings, conclusions and recommendations of the recent community engagement project that was undertaken as required by the 2014 legislation to obtain the perspectives of the RESD community organizations and leaders and the community-based, safety net clinics that serve RESD populations.

### Part One: The Framework of a State Health Equity Plan to Make Health Disparities Visible

The 2014 legislation recognizes that the time has come for the state to act on the plans and recommendations that have been made in a number of significant state agency, task force and commission reports dating back to 2011 that addressed the inadequacies of current data collection and reporting methods in identifying and addressing health disparities experienced by RESD populations. The 2014 legislation calls for an implementation plan and budget for moving forward with changes to statewide data collection and reporting methods.

This section provides an overall summary and synthesis of past recommendations and plans that were presented in the following reports:

- Collection of Racial/Ethnic Health Data by the Minnesota Departments of Health and Human Services. (January 2011)
• Race, Ethnicity and Language Work Group Recommendations to the Governor’s Health Care Reform Task Force. (May 2012)\textsuperscript{6}
• Advancing Health Equity in Minnesota.” Minnesota Department of Health (February 2014)\textsuperscript{2}

Framework for State Plan for Health Data System Improvements to Identify and Address Disparities:

1. **Identify and measure health disparities for each RESD population.** Minnesota’s serious health disparities experienced by RESD populations cannot be effectively addressed unless the disparities experienced by each RESD group can be identified and quantified through health care data.

2. **Expand and improve RESD categories.** Existing categories for dividing data by race, ethnicity, language and socio-demographic factors are inadequate. More detailed categories are needed and the categories must be developed in partnership with the RESD communities so that they match the ways in which RESD community members identify themselves. Data collection systems should be designed with flexibility so that categories can be changed in the future as needed to adapt to state demographic changes. Categories should be more expansive and granular than national U.S. Office of Management and Budget (“OMB”)\textsuperscript{7} standards, but should be able to be aggregated into the OMB standards.

3. **Establish a statewide standard construct for RESD data.** A uniform data construct should be developed so that all health data collected uses the same categories for race, ethnicity, language and socio-demographic factors. The uniform construct should be used by the Minnesota Department of Health and the Minnesota Department of Human Services, but also by licensing boards, governmental agencies, health plans, hospitals, clinics, health care homes, nonprofit agencies, quality and performance measurement programs and others who collect, analyze and report health data. All entities that are required to collect maintain or report health data or who participate in health data measurement and reporting programs should be using the expanded RESD categories and following the statewide standard construct.

4. **Improve methods of obtaining RESD information.** Methods of requesting information from patients on their race, ethnicity, language and socio-demographic factors should be improved. Different methods of asking for and collecting RESD information are needed for the different populations to reflect the different ways in which each population interacts with the health care system, health care providers and governmental agencies. Methods of requesting RESD information should include informing patients about why the information is being requested, how it will be used, and how the privacy and security of the information will be protected. Training and tools should be developed for use by those organizations and staff persons who are responsible for obtaining health care information from patients. Methods, training and tools should be developed in authentic partnerships with the RESD communities themselves.

5. **Protect and preserve health data privacy and security.** All changes to health data collection and reporting systems and methods must be made in ways that protect and preserve the privacy and confidentiality of information about individual patients and in full compliance with laws governing data privacy and security. Public reports on health disparities of RESD

\textsuperscript{7} [http://www.whitehouse.gov/omb/fedreg_1997standards/](http://www.whitehouse.gov/omb/fedreg_1997standards/)
populations should only contain aggregated, summary data that does not identify individual patient information.

6. **Authentically partner with RESD communities.** State and local governmental agencies, health care organizations and policymakers should develop and implement health equity data policies and systems in partnership with RESD communities using authentic community engagement methods that enable RESD communities to participate in policymaking and system change that directly affect them. Aggregate, summary data on health disparities should be made freely available to RESD communities so that they can identify and address the disparities their members’ experience.

7. **Establish a long-term state health equity data plan.** A long-term plan is needed for improving health data systems to better identify, quantify and address health disparities, including the actions and activities that are needed and a timeline and budget for implementation. The elements of the plan are described in more detail in the Minnesota Department of Health’s report on “Advancing Health Equity in Minnesota.”

**Part Two: Community Perspectives**

**Findings, Conclusions and Recommendations**

II. **INTERVIEW OBJECTIVES, METHODOLOGY, AND LIMITATIONS**

This part of this report provides the findings, conclusions and recommendations of community engagement activities undertaken by Voices for Racial Justice under a contract with the Minnesota Department of Health (“MDH”) to obtain updated and expanded perspectives from communities experiencing health disparities related to race, ethnicity, language or other socio-demographic factors (“RESD” communities) regarding health equity data. This recent activity builds upon the past work and activities of RESD communities and leaders on this issue which are summarized in Part One above. So, the perspectives of RESD communities and leaders are presented in both Part One and Part Two.

The 2014 legislation required MDH to develop its report, recommendations and plan for improving health equity data “in consultation with consumer, community and advocacy organizations representing diverse communities; health plan companies; providers; quality measurement organizations; and safety net providers that primarily serve communities and patient populations with health disparities.” In addition, the legislation required MDH to engage with RESD communities using “culturally appropriate methods of consultation and engagement with consumer and advocacy organizations led by and representing diverse communities by race, ethnicity, language, and sociodemographic factors.”

In response to the legislative requirements for consultation and community engagement, MDH pursued two parallel processes:

1. **Consultation of health care industry stakeholders** including health care providers, health plans and quality measurement organizations. The results of this activity are reported by MDH.

2. **Community engagement and consultation with RESD communities, consumers and advocacy organizations** using culturally appropriate methods. This activity was undertaken on behalf of MDH by Voices for Racial Justice and the results are described in this report.

This report pertains to the second process: RESD community engagement to respond to the 2014 law’s requirement that the health care quality measure stratification plan be developed in consultation with
consumer, community, and advocacy organizations representing diverse communities, and safety net providers, and that consultation and engagement occur through culturally appropriate methods.

However, in addition to meeting this legislative requirement, VRJ intends that the information in this report will also be valuable in providing a context for public discussion of health inequities: To present the perspectives of RESD communities in a way that provides the context needed by policymakers, public officials, health care leaders and others to build authentic relationships, partnerships and communication channels for having the important continued conversations of the future and vitality of Minnesota’s communities who are disproportionately impacted by health inequities based on race, ethnicity, language, and socio-demographic factors (including but not limited to gender identity, sexual orientation and disabilities status.) This report’s value and validity is the knowledge drawn from within these communities and the wisdom they provide to Minnesota’s continued work to achieve health equity.

A. Objectives

Voices for Racial Justice had five key objectives for community engagement with RESD community members and leaders to obtain the RESD consumer perspective on collection of RESD data in the health care system:

1. To probe consumers’ willingness to provide information on race, ethnicity, language and other socio-demographic factors to health care provider organizations;
2. To identify barriers to consumers’ provision of RESD information to provider organizations;
3. To identify methods providers could use to increase consumers’ willingness to share RESD information;
4. To identify methods that communities could use to increase consumers’ willingness to share RESD information; and
5. To better understand RESD consumers’ and communities’ perspective of how health is impacted by RESD and structural or institutional racism, the role of the health system in improving health, and the importance of health data in improving the system to achieve greater health equity for RESD populations.

At the request of MDH, Voices for Racial Justice also undertook activities to consult with and engage the community-based, nonprofit safety net health care providers who provide health care services to RESD patients and communities. These health care providers have a long history of experience working with RESD patients and communities and already collect more thorough and robust information on their patients’ RESD. The three key objectives for consultation with safety net providers were:

1. To obtain the safety providers’ experiences in collecting, reporting, and using RESD information;
2. To identify barriers of the collection and use of RESD information; and
3. To identify methods providers’ organizations could use to overcome identified barriers.

B. Methodology

Traditional methods of public input used in the US political process and by government and health care institutions have limited effectiveness in obtaining accurate and meaningful information on the perspectives of many RESD consumers and communities. To participate effectively in traditional public input individuals and organizations must possess high levels of advanced education, expertise, English
language communication skills, deep knowledge of the health care political systems and institutions, contacts and relationships with political and organizational leaders and staff, and extensive human and financial resources that are needed to devote substantial time, attention and expertise to influencing policymakers and decision-makers. Many RESD consumers, leaders and organizations do not have access to these skills and resources and are therefore frequently disenfranchised from the policymaking and decision-making processes. The public input process results in wide disparities in the impact of political, governmental and institutional decision making on RESD consumers and communities compared to mainstream health industry stakeholders whose representatives are better resourced and represented to influence decision-makers in a way that will benefit their particular interests. This is a form of “structural” racism where there is a racist or discriminatory impact of the decision-making process, even if there may not be conscious or intentional racist intent by those who are responsible for conducting public input.

It is not easy to obtain public input from RESD communities. No single process for community engagement and public input will work for all communities. Written and telephone surveys are not as effective for RESD individuals due to language, cultural and literacy barriers and the presence of a higher level of distrust on institutions and government. Public hearings and town hall meetings are also less effective for these same reasons but also due to the added barriers of lack of transportation, child care, difficulty attending daytime meetings due to work obligations, lack of public speaking skills or experience, and fears that speaking out publicly will result in recrimination, something that many RESD groups have experienced in the past both in the U.S. and in many new immigrants’ countries of origin.

Culturally appropriate community engagement methods must be more organic, informal and flexible in order to accommodate the wide differences in the way various RESD communities communicate, organize, identify their leaders, make community decisions, and interact with health care and governmental entities. For these reasons, MDH contracted with Voices for Racial Justice to undertake a unique and more culturally appropriate community engagement process for obtaining the perspectives of RESD communities to guide the development of MDH’s report to the legislature. For these reasons, this report does not purport to be scientific, statistically valid, or a representative sample of the RESD communities. Instead, it is intended to be a culturally appropriate supplement to the type of public input that is provided in legislative committee hearings, town hall meetings and other public input meetings that do not purport to be scientific or fully representative of the people affected by policymaking but gather useful perspectives from various stakeholders – except in this case the voices of those who are often disenfranchised are more likely to be heard.

**Principles for Authentic Community Engagement.** To honor the wisdom within each community, Voices for Racial Justice used Authentic Community Engagement (ACE) principles as the basis for this project (See Appendix A Principles of Authentic Community Engagement VRJ). As defined by Voices for Racial Justice (VRJ), “authentic community engagement is the intentional process of co-creating solutions to inequities in partnership with people who know through their own experiences the barriers to opportunity best. Authentic community engagement is grounded in building relationships based on mutual respect and acknowledge each person’s added value to developing solutions.” ACE principles allow the community to fully participate in voicing their opinion, perspectives and concerns. These principles are rooted in the inherent value and knowledge that community members bring to the table. As such, each and every step taken towards involving community in the process of data collection was done through the lens of authentic community engagement. These principles were endorsed by MDH as the approach to fulfill project requirements.
Community Engagement Methodology. Following the ACE principles, leaders from communities disproportionately impacted by health inequities were recruited by VRJ to conduct interviews and conversations with members of their respective communities, and one leader conducted interviews with service providers in the Safety Net Coalition. These communities include: American Indian/Native American; Black-African American, African Immigrant, Asian Pacific Islander, Latino/Hispanic, Lesbian Gay Bisexual Transgender Queer (LGBTQ) Two-Spirits\(^8\), and People with Disabilities.

The project team (interviewers and project coordinator are listed at the end of this report) met every Monday for 8 weeks to participate in project planning and development by sharing the importance of this project within each community. The team developed and finalized interview questions, discussed the interview protocol, and also debriefed interviews after they were completed. Furthermore, the team proposed some recommendations for this report. The involvement of these community interviewers throughout the process was critical to develop trust and ownership of the project as well as to build relationships with each other. The team’s diversity and wealth of knowledge made incredibly interesting meetings where the information was so rich and vast that at times it was challenging to accomplish some tasks within the allotted timeframe.

Each community leader conducted 4 to 11 interviews with people in their own communities. In an effort to gather broader voices each interviewer diversified its interviews by gender, age, socio-economic background, geography, race, and ethnicity. Interviewee confidentiality was maintained by carefully coding interview response instruments, rather than recording personally identifiable information.

A total of 94 interviews were conducted: 85 interviews with community members and 9 interviews with Safety Net Coalition members representing 6 clinics (see Table 1 below). Summary demographic information is displayed in Tables 2a and 2b for the community interviewees. Interviewees self-identified demographic information, including multiple racial identities and other socio-demographic factors. This self-identification accounts for the difference in number of interviewees by community category between Table 1 and subsequent data tables.

Table 1 Community and safety net coalition interviews

<table>
<thead>
<tr>
<th>Community Groups and Clinics</th>
<th>Number of interviewees</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Indian/Native American</td>
<td>10</td>
</tr>
<tr>
<td>Black-African American</td>
<td>8</td>
</tr>
<tr>
<td>African Immigrant</td>
<td>5</td>
</tr>
<tr>
<td>Asian Pacific Islander</td>
<td>30</td>
</tr>
<tr>
<td>Latino/Hispanic</td>
<td>18</td>
</tr>
<tr>
<td>LGBTQ Two-Spirits</td>
<td>10</td>
</tr>
<tr>
<td>Disability</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td><strong>85</strong></td>
</tr>
<tr>
<td>Safety Net Coalition</td>
<td>9</td>
</tr>
<tr>
<td><strong>Grand total:</strong></td>
<td><strong>94</strong></td>
</tr>
</tbody>
</table>

\(^8\) The term Two-Spirit is a phrase that can be applied to Native Americans who are Gay, Bisexual, Lesbian, or Transgendered. Two-Spirit is generally felt to be the more culturally sensitive and accurate term when referring to Native LGBT individuals.
<table>
<thead>
<tr>
<th>Demographics</th>
<th>Percent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>53%</td>
</tr>
<tr>
<td>Male</td>
<td>45%</td>
</tr>
<tr>
<td>Transgender</td>
<td>2%</td>
</tr>
<tr>
<td><strong>Sexual orientation</strong></td>
<td></td>
</tr>
<tr>
<td>Other than heterosexual</td>
<td>19%</td>
</tr>
<tr>
<td><strong>Income</strong></td>
<td></td>
</tr>
<tr>
<td>Below 250% federal poverty level</td>
<td>53%</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>High school or less</td>
<td>31%</td>
</tr>
<tr>
<td><strong>Geography</strong></td>
<td></td>
</tr>
<tr>
<td>Living inside the Twin Cities</td>
<td>71%</td>
</tr>
<tr>
<td>Living outside the Twin Cities</td>
<td>29%</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>18 to 35 years</td>
<td>40%</td>
</tr>
<tr>
<td>36 to 88 years</td>
<td>60%</td>
</tr>
<tr>
<td><strong>Health insurance</strong></td>
<td></td>
</tr>
<tr>
<td>No health insurance</td>
<td>9%</td>
</tr>
<tr>
<td>Government insurance*</td>
<td>32%</td>
</tr>
<tr>
<td>Employer based insurance</td>
<td>47%</td>
</tr>
<tr>
<td><strong>Country of origin</strong></td>
<td></td>
</tr>
<tr>
<td>United States</td>
<td>55%</td>
</tr>
<tr>
<td>Other</td>
<td>45%</td>
</tr>
<tr>
<td><strong>Language preference for health care information</strong></td>
<td></td>
</tr>
<tr>
<td>Reading: English</td>
<td>64%</td>
</tr>
<tr>
<td>Listening: English</td>
<td>66%</td>
</tr>
<tr>
<td><strong>Disability</strong></td>
<td></td>
</tr>
<tr>
<td>Persons with disabilities</td>
<td>16%</td>
</tr>
</tbody>
</table>

*Note: Government insurance includes Medicare, Medicaid, and MinnesotaCare.
Table 2b Community Interviewee Demographics (Race and Ethnicity)

<table>
<thead>
<tr>
<th>Race</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Indian/Native American</td>
<td>26%</td>
</tr>
<tr>
<td>Asian</td>
<td>32%</td>
</tr>
<tr>
<td>Black- African American</td>
<td>13%</td>
</tr>
<tr>
<td>African Immigrant</td>
<td>7%</td>
</tr>
<tr>
<td>Native Hawaiian or Other Pacific Islander</td>
<td>2%</td>
</tr>
<tr>
<td>White*</td>
<td>13%</td>
</tr>
<tr>
<td>Some other race</td>
<td>6%</td>
</tr>
<tr>
<td>Decline</td>
<td>1%</td>
</tr>
<tr>
<td></td>
<td>100%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hispanic or Latino</td>
<td>21%</td>
</tr>
<tr>
<td>Not Hispanic or Latino</td>
<td>78%</td>
</tr>
<tr>
<td>Declined</td>
<td>1%</td>
</tr>
<tr>
<td></td>
<td>100%</td>
</tr>
</tbody>
</table>

*Note: Out of the 11 interviewees who chose White as their race, 9 self-identify as Hispanic/Latino, and 1 as Arab born in Egypt.

To ensure all interviews follow a similar format, an introductory script was developed and every interviewer was asked to read it at the beginning of the conversation with each interviewee (see Appendix B Script to Contact Community Member & Appendix C Introductory script for interviewer). After the introduction, interviewers asked questions in the following areas:

1. **Questions about the Interviewees Race, Ethnicity and Language (REL).** These questions were asked to each interviewee using the “Recommended Questions and Variables for Standard REL Data Collection” which were developed in 2011 by the REL Data Work group. The purposes of asking this question were to determine the RESD socio-demographic factors of interviewees and to evaluate the acceptance of the previously developed REL categories. (See Appendix D Form to ask interviewees for REL).

2. **Questions about other socio-demographic factors:** Questions about Income, Gender identity, Sexual orientation, Disability Status, Zip Code and Age, were also asked in order to determine the socio-demographic factors of interviews but also to partially replicate the “real life” conditions that will be experienced in health care settings when this information is requested of patients and consumers for purposes enabling stratification of health care data by RESD categories in order to identify and address health disparities. (See Appendix E 2014 Federal Income Guidelines Household size & Appendix F Community Questionnaire).
3. **Questions on How, Who and When to request socio-demographic information:** These questions were based on the national report “Reducing Health Care Disparities: Collection and Use of Race, Ethnicity and Language Data,” published by American Hospital Association.

4. **Questions on what additional information, if provided, would help consumers provide their socio-demographic information to the health care system.**

Other general questions were also asked about possible challenges in collecting this data, the importance of training of health care workers and staff on how to ask the questions, the importance of RESD community education and engagement to create community acceptance of the value of providing this information in order to improve the health care system and address inequities, and how a healthy community would look like and about structural racism/barriers.

VRJ reviewed, analyzed, and synthesized interview results in collaboration with the interview team.

**C. Limitations**

The community engagement process undertaken by VRJ faced a number of serious limitations related to having limited time and a limited budget for completing the work and the challenges and complexities of authentically engaging the very diverse range of RESD communities that exist within Minnesota. As a result, it is important to view the findings, conclusions and recommendations in this report as supplementing and adding to existing knowledge about the perspectives of RESD communities drawn from previous reports and community engagement activities, including those described in Part One.

This report has had the following limitations:

- A very short timeline for developing, implementing and compiling results of the community engagement process.
- A narrow scope of health equity focus due to the specific legislative charge
- Limitations on the number of people who could be interviewed meant results cannot by fully generalized to entire communities.
- Inability to recruit an interviewer from the West African Community
- Some interviewees, including those from communities of people with disabilities, found the questions to be difficult to understand.

**III. FINDINGS**

As stated previously, this report does not purport to be a scientific, complete or fully representative sample of RESD communities’ perspectives. Even so, the information is a valuable addition to the body

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of information on community perspectives that have been presented in other reports and studies. The purpose of this additional report is to further identify themes, commonalities and differences among the RESD communities relating specifically to collecting information on RESD for purposes of stratifying quality measures in order to identify and address health disparities in the health care system.

**Overarching themes.** The findings from the community engagement process are presented below, but two themes are worth presenting initially:

- **Commonality across RESD communities.** One of the most interesting and unexpected general findings is that we did not see major differences in perspectives on key questions across RESD communities on the collection and reporting. This is good news for purposes of developing a statewide system for stratifying health care quality data by RESD status for purposes of identifying and addressing health disparities.
- **Distrust.** A second general finding is that distrust of the “mainstream” health care system was prevalent across all RESD consumers and communities. This means that the states’ plan must include components to build trust so that RESD patients and consumers are more willing to share information that will be helpful in addressing their health care and treatment needs within the health care system.

### A. Community Interviewees

#### 1. Consumer Experience (Findings)

Key findings from interviews with RESD community members or health care “consumers” were:

- Most interviewees were willing to share some socio-demographic information with health care providers.
- Most interviewees did not know how the information would be used.
- A significant barrier to consumers sharing socio-demographic information was a lack of trust in the health care system and government systems.
- Interviewees think the general information obtained on disparities for particular RESD communities should be shared with those communities.
- Lastly, community members also expressed that data collected needs to be intentionally used to create the conditions which make ALL Minnesotans healthier.

#### 2. Interviewees Acceptance of Race Ethnicity Language (REL) categories

Interviewees were asked for their REL status and asked whether the categories used for race, ethnicity and language were appropriate and acceptable. The REL categories used were the “Recommended Questions and Variables for Standard REL Data Collection” developed in 2012 by the REL Data Work group and presented to the Exchange Task Force.

Some interviewees answered these questions by reading them, others by listening to the questions and others by a combination of reading and listening. Some 80% of respondents felt the REL questions were very good, good or acceptable. Table 3 (below) shows community members’ acceptance of these REL categories.
Question asked: How good do you think the categories of Race Ethnicity and Language in the past document define you?

Table 3 REL Categories Acceptance*

<table>
<thead>
<tr>
<th>How Good</th>
<th>All Communities (85)</th>
<th>American Indian/ Native American (22)</th>
<th>Black/ African American (11)</th>
<th>African Immigrant (6)</th>
<th>Asian Pacific Islander (27)</th>
<th>Latinos/ Hispanics (18)</th>
<th>LGBTQ-Two Spirits (12)</th>
<th>People with Disabilities (14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Good, Good and Acceptable</td>
<td>80%</td>
<td>77%</td>
<td>73%</td>
<td>100%</td>
<td>85%</td>
<td>72%</td>
<td>75%</td>
<td>86%</td>
</tr>
<tr>
<td>Poor and Very poor</td>
<td>16%</td>
<td>9%</td>
<td>27%</td>
<td>0%</td>
<td>15%</td>
<td>28%</td>
<td>0%</td>
<td>14%</td>
</tr>
</tbody>
</table>

* Percentages of missing information are not included.

While 80% of interviewees said the current REL categories define them well, 28% of Latinos and 27% of Black-African American interviewees said those categories were poor or very poor in defining their REL category. Latinos poor and very poor acceptance can partly be explained by the confusion around the definitions of Race and Ethnicity. 50% of Latino interviewees chose “White” as their race, and 22% chose “Some Other Race.” Black/African American poor and very poor acceptance of the categories can partly be explained by their feeling that the current recommendations document were not inclusive of them and therefore they would be less likely to answer these questions.

“1. Add the continent of Africa. 2. They did not list black. 3. Also, problems with listing of Latino description (not complete). 4. Race is a term that has been established by White America. 5. Separate African American from African Immigrant. I consider myself as a Black American. 6. If I wanted to select more than one option, the other option was not available. 6. Forms seem to accommodate US immigrants. 7. Tribal affiliations only list Midwestern/Minnesota typical tribe” Black/ African-American interviewee

3. Willingness to share socio-demographic information

On average, 85% of interviewees said they would be willing to share their socio-demographic information with health care providers. Table 4 (below) shows respondents’ willingness to provide information about each socio-demographic factor. We asked: “Would you be willing to provide information about (factor)?”
Table 4 Consumers’ willingness to share socio-demographic factors with health care providers (percent of interviewees who responded, "Yes, I would answer a provider’s question about [factor]")

<table>
<thead>
<tr>
<th>Factor</th>
<th>All Communities (85)</th>
<th>American Indian/ Native American (22)</th>
<th>Black/ African American (11)</th>
<th>African Immigrant (6)</th>
<th>Asian Pacific Islander (27)</th>
<th>Latinos/ Hispanics (18)</th>
<th>LGBTQ- Two Spirits (12)</th>
<th>People with Disabilities (14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race</td>
<td>92%</td>
<td>96%</td>
<td>100%</td>
<td>100%</td>
<td>96%</td>
<td>72%</td>
<td>100%</td>
<td>93%</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>88%</td>
<td>86%</td>
<td>82%</td>
<td>100%</td>
<td>100%</td>
<td>78%</td>
<td>83%</td>
<td>64%</td>
</tr>
<tr>
<td>Language</td>
<td>94%</td>
<td>96%</td>
<td>100%</td>
<td>100%</td>
<td>78%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Country of origin</td>
<td>85%</td>
<td>91%</td>
<td>91%</td>
<td>83%</td>
<td>93%</td>
<td>67%</td>
<td>92%</td>
<td>79%</td>
</tr>
<tr>
<td>Income</td>
<td>57%</td>
<td>59%</td>
<td>73%</td>
<td>50%</td>
<td>48%</td>
<td>56%</td>
<td>67%</td>
<td>79%</td>
</tr>
<tr>
<td>Gender identity</td>
<td>89%</td>
<td>100%</td>
<td>82%</td>
<td>100%</td>
<td>96%</td>
<td>72%</td>
<td>92%</td>
<td>86%</td>
</tr>
<tr>
<td>Sexual orientation</td>
<td>68%</td>
<td>73%</td>
<td>73%</td>
<td>33%</td>
<td>82%</td>
<td>56%</td>
<td>67%</td>
<td>36%</td>
</tr>
<tr>
<td>Disability</td>
<td>89%</td>
<td>86%</td>
<td>100%</td>
<td>100%</td>
<td>89%</td>
<td>83%</td>
<td>92%</td>
<td>93%</td>
</tr>
<tr>
<td>Zip code</td>
<td>91%</td>
<td>96%</td>
<td>91%</td>
<td>100%</td>
<td>93%</td>
<td>83%</td>
<td>100%</td>
<td>79%</td>
</tr>
<tr>
<td>Age</td>
<td>93%</td>
<td>96%</td>
<td>100%</td>
<td>83%</td>
<td>96%</td>
<td>89%</td>
<td>100%</td>
<td>79%</td>
</tr>
</tbody>
</table>

Even though most communities’ responses are above 85% willingness to share information, there are some factors and communities that differ:

- **Income.** Many interviewees were reluctant to share information about their income. Only 57% of respondents said they will share their income. Many stated they did not understand the connection between health care services and their income level and questioned why the information was needed. Furthermore, some believed providing their income would affect the type of health care they receive. The Asian Pacific Islander community was least willing to share information about income (only 48% were willing to share this information).

- **Sexual orientation.** Many interviewees expressed less willingness to share information on their sexual orientation. Only 68% of respondents said they would provide their sexual orientation. Many considered it a very personal matter and LGBTQ-TS interviewees expressed fear of being mistreated by the health care system if their sexual orientation was disclosed. Only 33% of the African Immigrant community was willing to share this information.

- **Race and ethnicity.** Willingness to share information on race and ethnicity was in part related to interviewees’ views about whether the RESD categories given were appropriate and acceptable for how they view themselves. As mentioned in Table 3, the Black/African American community felt there were not represented in this category and their roots were not included. The American Indian/ Native American community also expressed the current recommendations document was confusing and didn’t fully identify them. Latinos are consistently less willing to share their socio-demographic information. One reason expressed by some Latino interviewers was related to immigration status and the fear of being identified and deported.
4. Communities’ Comfort Level in providing Socio-demographic Information

In addition to asking about their willingness to provide socio-demographic information (describe above), interviewees were asked for their level of comfort in providing the information. Overall, 81% of respondents felt comfortable (very comfortable, comfortable or somewhat comfortable) providing socio-demographic information to the health care system. Based on information in the interview summaries, we concluded that the level of willingness to provide the information had a relationship to each interviewee’s understanding of the health system’s use of health care data and the value of data in identifying and addressing health disparities. A number of the interviewers and interviewees were more knowledgeable than the average patient or consumer about the overall health system, the efforts to RESD communities to improve data on health disparities, and the need for and importance of stratifying health care quality data based on RESD status in order to identify and address disparities. A lesson learned from this is that it will be helpful to give consumers and patients some brief information on why the information is being requested and how it will be used to improve both their treatment and the treatment of others from their RESD community.

Table 5 below shows the percentage of respondents answering about their comfort with RESD questions: “Generally speaking, how comfortable have you felt, or would you feel, sharing information about race, ethnicity, language, socio economic status, disabilities, sexual and gender orientation with the health care system?”

<table>
<thead>
<tr>
<th>Factor</th>
<th>All Communities (85)</th>
<th>American Indian/ Native American (22)</th>
<th>Black/ African American (11)</th>
<th>African Immigrant (6)</th>
<th>Asian Pacific Islander (27)</th>
<th>Latinos/ Hispanics (18)</th>
<th>LGBTQ- Two Spirits (12)</th>
<th>People with Disabilities (14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Some level of comfort</td>
<td>81%</td>
<td>73%</td>
<td>91%</td>
<td>100%</td>
<td>85%</td>
<td>78%</td>
<td>75%</td>
<td>93%</td>
</tr>
<tr>
<td>Neutral</td>
<td>8%</td>
<td>9%</td>
<td>9%</td>
<td>0%</td>
<td>7%</td>
<td>5%</td>
<td>8%</td>
<td>0%</td>
</tr>
<tr>
<td>Somewhat Uncomfortable</td>
<td>11%</td>
<td>18%</td>
<td>0%</td>
<td>0%</td>
<td>7%</td>
<td>17%</td>
<td>17%</td>
<td>7%</td>
</tr>
</tbody>
</table>

Among the different communities, American Indians/ Native Americans, Latinos, and people from the LGBTQ-TS community have felt, or would feel, somewhat uncomfortable sharing their socio-demographic information. In our analysis, the level of comfort and willingness to provide this information is greatly influenced by distrust on the health care system, and communities’ lack of knowledge of the use of data collection – respondents’ knowledge of use of data was limited. People didn’t know why the information was collected and who would have access to it. Moreover, respondents didn’t understand the relationship between their socio-demographic information and their health, nor the potential impact and/or benefit of the collection, use and sharing of this data.
“Depending on what is done with the information; if doctor/nurse/receptionist uses information for health care, personal health it is okay; if not relevant question, why need to ask it, for example income, language, unless not speak English.” Asian Pacific Islander interviewee

“We are asked these questions and then do not know where the information goes.” White interviewee

Not knowing this made respondents uncomfortable and hesitant to share their information and skeptical and fearful their information could jeopardize their health care or treatment. Many interviewees mentioned how historical context, generational trauma, past communal and individual experiences with the health care system, and other government agencies and systems, have made them apprehensive to share their information out of fear of the information being used against them.

“Historically information provided has been used to the person’s detriment.” Black/African American interviewee

“It needs to be clear on how will they be using the information, who share the information or they would be penalized. It’s important to say that because all of these questions are categories we put people in, and depending on where your personal values or thoughts are, a physician may or may not treat somebody different because of their REL, income or sexual orientation.” Latino interviewee

Communities’ knowledge of the use, collection and sharing of data collection varies which indicates that more intentional work needs to be done to improve communication and understanding between the health care system and communities.

“Also, community understanding of the data would help, as this enables community to self-validate and provide accurate information.” Black / African American- Interviewee

5. Consumer Perspectives on How, When, and By Whom Socio-demographic Information Should be Collected in Health Care Settings

Because some socio-demographic information will be collected by health care clinics and hospitals, consumers were asked how should this information be collected, who should collect this information and when should the information be collected. For the purpose of this report we used the questions suggested in the national report “Reducing Health Care Disparities: Collection and Use of Race, Ethnicity and Language Data”.9
a) HOW - Respondents answers on HOW socio-demographic information should be requested. (See Table 6 below)

- Respondents were split on whether RESD information should be requested verbally or provided in written or electronic form:
  - The option preferred by the largest number of respondents (35%), is for the information to be requested verbally. Latinos and LGBTQ-TS individuals prefer the information to be collected verbally at 67% and American Indian/Native American at 46%
  - The second most preferred option is for the information to be collected in written form (26%).
  - The next option, preferred by only 14% of respondents, is for the information to be collected electronically. However, respondents 35 years old or younger were more likely to prefer providing the information electronically (21%), while only 10% of respondents ages 36 and older preferred providing the information electronically.

Based on these findings, the question of HOW to collect socio-demographic information is an individual preference and so all options should be available to patients and consumers.

Table 6 compares percentages between all communities’ and each community answers to HOW socio-demographic information should be collected.

<table>
<thead>
<tr>
<th>HOW</th>
<th>All Communities (85)</th>
<th>American Indian/ Native American (22)</th>
<th>Black/ African American (11)</th>
<th>African Immigrant (6)</th>
<th>Asian Pacific Islander (27)</th>
<th>Latinos/ Hispanics (18)</th>
<th>LGBTQ- Two Spirits (12)</th>
<th>People with Disabilities (14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paper Based form</td>
<td>26%</td>
<td>36%</td>
<td>27%</td>
<td>17%</td>
<td>22%</td>
<td>28%</td>
<td>17%</td>
<td>29%</td>
</tr>
<tr>
<td>Electronically</td>
<td>14%</td>
<td>9%</td>
<td>9%</td>
<td>17%</td>
<td>22%</td>
<td>6%</td>
<td>8%</td>
<td>7%</td>
</tr>
<tr>
<td>Verbally</td>
<td>35%</td>
<td>46%</td>
<td>36%</td>
<td>17%</td>
<td>11%</td>
<td>67%</td>
<td>67%</td>
<td>36%</td>
</tr>
<tr>
<td>No preference</td>
<td>12%</td>
<td>0%</td>
<td>18%</td>
<td>33%</td>
<td>22%</td>
<td>0%</td>
<td>0%</td>
<td>14%</td>
</tr>
<tr>
<td>Combination</td>
<td>13%</td>
<td>9%</td>
<td>9%</td>
<td>17%</td>
<td>22%</td>
<td>0%</td>
<td>8%</td>
<td>14%</td>
</tr>
</tbody>
</table>

b) WHO - Respondents were asked WHO should collect socio-demographic information. (See Table 7 below)

- Overall, respondents were fairly evenly split on WHO should request the information – the front desk staff, the medical assistant or nurse, or the health care doctor or other provider:
  - The option preferred by 28% of respondents is for the information to be collected by the Provider/Doctor. This was higher for Latinos and Asian Pacific Islanders -- 44% of Latinos prefer the information to be collected by the Provider/ Doctor and 33% of Asian Pacific Islanders.
  - 21% overall preferred the information to be collected by the Medical Assistant or Nurse.
  - 22% overall preferred the information to be collected by the Front Desk.
• Overall, of those who expressed a preference, the largest percentage (69%) preferred to have the information collected by a health care worker (Medical Assistant, Nurse or Provider) rather than the Front Desk staff.

These results suggest the socio-demographic information should be collected by the Medical Assistant, Registered Nurse or Provider/Doctor to collect accurate information from respondents.

Table 7 compares percentages between all communities’ and each community answers to WHO should collect socio-demographic information.

<table>
<thead>
<tr>
<th>WHO</th>
<th>All Communities (85)</th>
<th>American Indian / Native American (22)</th>
<th>Black/African American (11)</th>
<th>African Immigrant (6)</th>
<th>Asian Pacific Islander (27)</th>
<th>Latinos/Hispanics (18)</th>
<th>LGBTQ -Two Spirits (12)</th>
<th>People with Disabilities (14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Front Desk</td>
<td>22%</td>
<td>23%</td>
<td>27%</td>
<td>0%</td>
<td>22%</td>
<td>28%</td>
<td>17%</td>
<td>29%</td>
</tr>
<tr>
<td>Medical Assistant/Nurse</td>
<td>21%</td>
<td>41%</td>
<td>9%</td>
<td>34%</td>
<td>11%</td>
<td>22%</td>
<td>33%</td>
<td>21%</td>
</tr>
<tr>
<td>Provider</td>
<td>28%</td>
<td>9%</td>
<td>18%</td>
<td>17%</td>
<td>33%</td>
<td>44%</td>
<td>17%</td>
<td>21%</td>
</tr>
<tr>
<td>Combination or No Preference *</td>
<td>28%</td>
<td>27%</td>
<td>46%</td>
<td>50%</td>
<td>33%</td>
<td>6%</td>
<td>34%</td>
<td>28%</td>
</tr>
</tbody>
</table>

*Interviewees chose multiple options or indicated not having any particular preference

“There has to be someone that I trust, someone that builds on that relationship.”
But, he mentioned he doesn’t trust the doctor.” Latino interviewee

c) WHEN - Respondents were asked WHEN should socio-demographic information be collected. (See Table 8 below)
  o Respondents were fairly evenly split on the question of whether the information should be collected in the Exam Room (40%) or at the time of Check-in (39%). Latinos prefer the information to be collected at the Exam Room at 72% and LGBTQ TS community at 67%.
  o Only a small percentage responded that the information should be collected by phone (4%).

Based on these findings, the question of WHEN to collect socio-demographic information both options (at exam room or time of check-in) should be available to patients and consumers. Given the low rate of respondents preferring data being collected when making the appointment over the phone, this option should not be seriously considered.
Table 8 compares percentages between all communities’ and each community answers to WHEN socio-demographic information should be collected.

<table>
<thead>
<tr>
<th>WHEN</th>
<th>All Communities (85)</th>
<th>American Indian/ Native American (22)</th>
<th>Black/ African American (11)</th>
<th>African Immigrant (6)</th>
<th>Asian Pacific Islander (27)</th>
<th>Latinos/ Hispanics (18)</th>
<th>LGBTQ- Two Spirits (12)</th>
<th>People with Disabilities (14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Check in</td>
<td>39%</td>
<td>50%</td>
<td>36%</td>
<td>33%</td>
<td>41%</td>
<td>28%</td>
<td>33%</td>
<td>57%</td>
</tr>
<tr>
<td>Phone</td>
<td>4%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>11.00%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Exam Room</td>
<td>40%</td>
<td>41%</td>
<td>36%</td>
<td>33%</td>
<td>19%</td>
<td>72%</td>
<td>67%</td>
<td>36%</td>
</tr>
<tr>
<td>Other</td>
<td>18%</td>
<td>9%</td>
<td>27%</td>
<td>34%</td>
<td>29%</td>
<td>0%</td>
<td>0%</td>
<td>7%</td>
</tr>
</tbody>
</table>

“At the examination room with the nurse. Some of these questions can be confidential, and nurse can help answer questions to do with collection of data.”

African Immigrant interviewee

6. Barriers to consumers’ provision of socio-demographic information

Based on our analysis, we concluded that, even though most of the respondents were willing to provide the information, they identified three important barriers to collecting this information from patients and consumers in the health care system:

(1) Distrust of the “mainstream” health care system; and
(2) Lack of understanding of the purpose of collecting RESD data and how it will be used.

These two barriers were common across different communities.

Distrust of the mainstream health care system was founded in the history and personal experiences of people of color and other RESD groups of being discriminated against or mistreated by mainstream systems.

Closely connected to the trust issue is the lack of understanding of the purpose for collecting RESD information. Interviewees expressed lack of trust that data collected will be used to benefit themselves and the community. This is due in part to historical and personal experiences that create distrust, but also to a lack of understanding of how the health care system works. For instance, many consumers did not know that their information is protected from being publicly disclosed. It was clear consumers are not fully aware about privacy, security and confidentiality laws and regulations imposed under the Health Insurance Portability and Accountability Act (HIPAA) and other federal and state laws. They will be more likely to be comfortable providing RESD information if they are informed that their individual information will not be disclosed to people other than those involved in providing their treatment.

In addition to the two major barriers of mistrust and lack of understanding, some particular communities face special barriers. Language is perceived as a barrier especially among consumers with English as a second language. However, there is also a concern among native English speakers about the technicalities of the language or words used within the health care system to identify particular RESD groups. In addition, there are some members of the community who face unique and specific
circumstances which it make difficult for them to know their socio-demographic information – such as adoptees and interviewees who identify themselves as multi-racial.

“I feel I don’t know how to answer some of those questions. Especially the race question, I get confused on what that means. It [race question] always comes up in all types of forms and I don’t know what box to check”. Multi-racial interviewee

a) Information that Will Increase Patients’ Willingness to Provide RESD Information

Interviewees were asked –“What information would be helpful for you to know in order to decide whether to provide this kind of information to your provider, clinic, or hospital?”

The overwhelming majority of interviewees agreed that knowing how the data will be used and who will have access to it would increase their willingness to provide the information (see table 9 below). Another factor that would increase willingness to provide the information is knowing that the aggregate, non-patient-identifiable data will be shared with the community and will be valuable in identifying and addressing health needs in the community.

Table 9 shows percentages of all interviewees’ answers to “What information would be helpful for you to know in order to decide whether to provide this kind of information to your provider, clinic, or hospital?”

<table>
<thead>
<tr>
<th>All Communities</th>
<th>Yes, very helpful or helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowing how is it going to be used</td>
<td>93%</td>
</tr>
<tr>
<td>Knowing who is going to use it</td>
<td>97%</td>
</tr>
<tr>
<td>Knowing who will have access to it</td>
<td>95%</td>
</tr>
<tr>
<td>Knowing it will be shared with the community but without the possibility of being identified</td>
<td>87%</td>
</tr>
</tbody>
</table>

b) Addressing challenges to collect socio-demographic data

(1) Training for the health care system

Most interviewees agreed that it will be very helpful if staff persons asking the questions about a patient or consumer’s RESD information are trained on how to ask the questions in a culturally appropriate way. Furthermore, most interviewees consider training to be critical to succeed in efforts to collect the data needed to achieve health equity.
“Cultural sensitivity trainings are not enough. It is a lifetime of learning. One-time trainings are not good enough. You need to constantly challenge your assumptions. How can you assess someone’s well-being (emotional, psychological, etc.) without getting to know a more complex set of information about them?” African Immigrant interviewee

(2) Education of the Community

Interviewees were asked how helpful it would be if RESD communities received education on how collecting this kind of information can improve the health of the community. Most interviewees agreed this will be very helpful because RESD communities will become more actively involved in planning, supporting and implementing the new data collection methods and will rebuild trust in the health care system within their communities.

“It will be helpful because the community will be comfortable providing this kind of information knowing why and for what reasons they are being collected especially if the collected information is going to improve their lives.” African Immigrant interviewee

(3) Community Engagement

Interviewees were asked how important it is that people in their community are engaged in conversations with health care and governmental leaders in the health care system to plan and implement the next steps in the effort to collect this data. Most interviewees answered that this is a critical factor because: (a) it will create community ownership of the process increasing willingness of patients to provide the information, making efforts more accurate, effective and sustainable in the long term. (b) It will support the development of authentic relationships between people who work in the health care system and RESD communities, and (c) It will help to improve RESD community credibility and trust of the health care system.

“There’s a lot of mistrust because after the information is collected the researchers or scientist or leadership makes the decisions thinking they understand us and they are making the right decisions for us in belief that our voices are fully heard. But we were not included in making these decisions. We need to be participants of the decision making too. They need to show us how is done and we will do the same, sharing and co-creating knowledge.” Latino interviewee

7. Community’s use of information

Interviewees agreed that RESD data collected should be intentionally used to improve the health of the community and increase health equity by promoting a more equitable allocation of resources to inform development of policies and build capacity.

a. Data collected should be used to improve the health of the community
RESD data collected should be used to improve services to RESD patients and communities. The data will enable the health care system to better understand the complexity and diversity of the populations
they are serving and identify and address the health disparities and inequities experienced by RESD patients and communities. Data collected should be used to create opportunities for better health for RESD communities by transforming the understanding, narrative and framework of the health care system. The system needs to be less medically oriented and become more holistic considering how social conditions that consumers are immersed in impact their health. The collection of this socio-demographic data should support the creation of healthier communities by improving the understanding we all have around the root causes of unhealthy individuals and communities.

“Stop treating the symptoms and treat the cause (s)”. Black-African American interviewee

b. Data collected needs to support the allocation of resources, policy development and building capacity

Interviewees emphasized the importance of authentic engagement of RESD communities in planning and implementing data system changes and partnering to use the data to improve the health of RESD communities, but identified lack of funding and capacity as a major barrier to engagement and partnership to improve health equity. In addition to other uses of RESD data, data should be used to identify funding needs and opportunities for community-based organizations led by, and working with, the groups most impacted by health inequities. Resources should be provided to build capacity to address health inequities both within the health system but also within the communities experiencing the inequities. In addition, data collected should be used to inform policy and funding decisions made by legislators, governmental officials and health care leaders in order to improve health equity.

c. To be used, data collected needs to be shared with the community

Interviewees expressed the view that RESD data collected within the health care system should be accessible not only to health care providers and organizations to enable them to improve their services and address inequities, but also to RESD communities so they can use the information to improve the health of their communities as well as individual consumers and patients. In addition, interviewees expressed great interest in seeing health care leaders authentically engaging communities to be partners in efforts to identify and address health inequities.

8. Community perspectives around creation of health and health equity

Interviewees were asked for their perspectives about how to create health and health equity for their communities. A common view expressed by many interviewees was the importance of fully honoring and trusting RESD communities’ knowledge and ability to be active participants and co-creators of solutions to improve health and health equity. Many interviewees also sought to expand the narrative around health to go beyond the notion that health is mainly created by individuals interacting with the health care system, and by individuals making healthy choices to the broader view of the impact of social determinants of health. Community members were asked what a healthy community looks like to them. Various interviewers expressed the importance of spirituality, connectedness, sense of belonging, self-determination, collaboration and a community free of racial and economic discrimination.

- A healthy community has access to information collected about them.
A healthy community is one where ALL people are able to be part of the decisions impacting their lives.

“[a healthy community has] equitable access to healthy community based activities. My community members walk and run for health and not just for necessity. People would be using Nice Ride. Community would have healthy restaurants and markets. Community Supported Agriculture is available to everyone. Spiritual and mental health activities and resources are available.”

American Indian/Native American interviewee

9. Inequities/barriers impacting the health of the community

Interviewees were asked “What inequities/barriers are impacting the health of their community?” Respondents mentioned many facts negatively impacting the health of their communities but most common were: (a) Lack of access to basic needs such as healthy food, jobs, stable housing, quality education and transportation b) Lack of funding to develop and implement solutions and build capacity within communities to impact inequities and c) Lack of access to healthcare.

“There are so many but I would say racism, discrimination, lack of economic possibilities and education priorities. Often we are shamed and stress is put upon our communities.” “It’s very depressing when communities are not treated like humans due to being judged.” LGBTQ – TS interviewee

10. The role of the system in creating health

Interviewees were asked about the role of the health care system (e.g. health care providers, health insurance companies, governmental health care agencies) can play in creating health. Respondents said that health care systems should play a more active role in creating overall health for patients and communities – which is more than just delivering health care services – and that these broader efforts should be done in partnership with communities most impacted by inequities. Programs and policies to create healthier communities must consider and address the broader socio-economic conditions in which members of the community are immersed, including structural racism and discrimination experienced by RESD individuals and communities.

“Instead of government agencies or healthcare system saying we are going to do X, Y and Z, implementing it and placing it upon communities, it will be switching the way they work in saying: we are going to build relationships with the community to figure out this problem around health and the communities would lead and inform the work and what we would do as a system is support that vision.” Latino interviewee
11. **Structural barriers**

Interviewees were asked about structural barriers and its role in preventing ALL communities from being healthy. Although some interviewees stated not understanding the question, or not knowing how to answer, many interviewees expressed that structural barriers are perceived as a very important reason for not trusting systems like health care or government.

B. **Safety Net Clinics (Findings)**

In addition to interviewing patients, consumers and community leaders from RESD groups experiencing health disparities, VRJ interviewed people from six safety net health care clinics that serve primarily patients from RESD groups (see Appendix G Safety Net Questionnaire). These interviews were undertaken in cooperation with the Minnesota Association of Community Health Centers (MNACHC), an association of Minnesota’s federally qualified health centers (FQHCs).

1. **Drivers of Patient Socio-Demographic Information Collection and Factors Collected**

   a) **Factors collected**

   Table 10 shows socio-demographic factors collected by Safety Net Clinics interviewed

<table>
<thead>
<tr>
<th>Factor</th>
<th>Yes</th>
<th>No</th>
<th>Sometimes / Not Standard</th>
<th>Other Factors Collected</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race</td>
<td>6</td>
<td></td>
<td></td>
<td>Address</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>6</td>
<td></td>
<td></td>
<td>Insurance status</td>
</tr>
<tr>
<td>Language</td>
<td>6</td>
<td></td>
<td></td>
<td>Homelessness/housing status</td>
</tr>
<tr>
<td>Country of origin</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>Lifestyle overview</td>
</tr>
<tr>
<td>Income</td>
<td>3</td>
<td></td>
<td></td>
<td>Military status</td>
</tr>
<tr>
<td>Gender identity</td>
<td>2</td>
<td></td>
<td>3</td>
<td>Employment</td>
</tr>
<tr>
<td>Sexual orientation</td>
<td>2</td>
<td></td>
<td>4</td>
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</tr>
<tr>
<td>Disability</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Zip code</td>
<td>5</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>5</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
b) Current Public Reporting Areas

Five of the six safety net organizations interviewed said they already report RESD data to Minnesota Community Measurement (MNCM), the organization that collects health care quality information from Minnesota health care providers under the State of Minnesota’s Statewide Quality Reporting and Measurement System. Interestingly, multiple interviewees stated they were not sure why MNCM was collecting the RESD data or how it was used, if at all.

All six organizations said they report REL and income and homelessness data to federal agencies, including to CMS (Centers for Medicare & Medicaid Services) as part of “meaningful use” of electronic health records (EHR) to improve patient care (for the Medicare and Medicaid EHR Incentive Programs) and to the Health Resources and Services Administration (HRSA) as part of the Uniform Data System (UDS) data used to review the operation and performance of health center grantees under Section 330 of the Public Health Service Act.

Overall, providers stated that the main driver for reporting was the data being tied to state/ federal requirements, grant funding and other financial incentives.

c) Internal use

The safety net organizations interviewed reported using RESD data for a number of internal purposes:

- To look at risk factors (causal or correlated) for readmission and “no-show” rates
- To identify racial disparities in provider quality measures and develop interventions
- To see outcomes by geography (zip code) and compare against neighboring areas
- Income data is used for financial counseling and for determining eligibility for sliding scale fee discounts
- To identify RESD factors of homeless patients
- To identify and meet language/interpreter needs of the patient population

d) Desired uses

Safety net organizations interviewed expressed a strong interest in using RESD data to develop methods of risk adjusting provider quality measures so that the quality measures take into consideration the RESD risk factors and complexity that have an impact on health and treatment outcomes. Without risk adjustment, providers who serve large numbers of patients with RESD barriers and inequities will be negatively impacted under provider payment methods and quality reports.

Additional uses that were mentioned included:

- Identifying RESD patients and communities that require greater effort or resources in order to achieve the desired health and treatment outcomes (e.g. homeless patients, low income patients)
- To identify and address health disparities
- To identify best practices in serving RESD patients and communities where providers are doing well and where is improvement needed to identify correlated or causal factors of
disparities, (e.g. how racial disparities in homelessness are connected to disparities in diabetes and hypertension)

○ Community asset mapping: to identify needs and connect patients to services and resources that exist in the community and build those cross-organization/cross-sector relationships, e.g. legal services for low-income individuals

○ To support requests for health disparities grants and funding

○ To guide marketing and public relations activities to reach the desired populations

○ To tailor care delivery and/or develop interventions for specific patient populations or topics, (e.g. Hmong women diabetes management)

○ To document how many homeless patients are seen and build a case for supporting community health centers or other providers disproportionately seeing homeless patients

○ For MDH/MNCM to take action based on the data toward development of different guidelines and guidance for providers to specific populations

○ Payment reform to create tiered payment categories for socio-demographically complex patients who currently do not fit into easily classifiable categories for medical complexity

2. **Experience Collecting Patient Socio-Demographic Information**

Safety net organizations were asked for information on their experience collecting RESD data from their patients.

**a) Processes used to collect information**

Table 11 shows processes to collect socio-demographic factors used by Safety Net Clinics interviewed

<table>
<thead>
<tr>
<th>How is data collected?</th>
<th>When?</th>
<th>By whom?</th>
<th>How is data stored?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Verbally asked (3)</td>
<td>1 Registration/ check-in (5)</td>
<td>1 Registration/ front desk staff (5)</td>
<td>1 Manually entered into EHR (6)</td>
</tr>
<tr>
<td>2 Paper form (1)</td>
<td>2 Combination of front desk &amp; patient room (1)</td>
<td>2 Combination of front desk staff &amp; nurse (1)</td>
<td></td>
</tr>
<tr>
<td>3 Combination of verbally asked &amp; paper form (2)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(1) Costs factors associated with collecting this information

Organizations interviewed stated that there were costs incurred in collecting RESD information. Substantial staff time is needed to request, collect and record the information.

(2) Successes

Organizations interviewed identified some successful practices that could be used to guide development of the new methods for collecting RESD data:
Collecting the data during new patient registration (separate from check-in) seems to work well.

- Having multi-lingual staff requesting the information is important for those patients for whom English is not their primary language.
- When collecting information on a patient’s income, it is helpful to have the patient select from income ranges rather than generating their own estimate.
- For some patients and communities, country of origin may be a more accurate way to identify ethnicity rather than, or in addition to, race or language.

(3) Challenges in Collecting RESD Data

Safety net organizations identified a number of barriers and challenges to collecting RESD data from patients:

- Substantial staff time is needed to do data collection and reporting (both registration staff and providers).
- There is a need for standardization in both processes and definitions, so providers aren’t duplicating efforts reporting the same data to different organizations in different formats.
  - For example, one interviewee mentioned that because UDS data is at the organization level and meaningful use is at the individual provider level, they couldn’t streamline it into one report, even though it is the same information.
  - For example, providers mentioned disability and homelessness need definitions.
- The need for more granularity, e.g. country of origin would help disaggregate.
- “More than one race” is not an option in EHR/EMR.
- Language barriers (need translation/interpretation).
- Barriers related to strict patient privacy laws.
- Lack of staff with the necessary level of expertise to pull information from EHR.

(4) Ways to overcome challenges

Safety net organizations interviewed offered suggestions for how to overcome barriers and challenges in collecting RESD data:

- Develop standards for terminology, e.g. defining things like disability, homelessness, how HA1c is reported. Some providers suggested ICD-10 codes. Develop toolkit/training resources for dealing with disability and homelessness.
- Add new requirements incrementally to minimize disruption to staff and patients.
- Funding staff capacity and support for time spent on data collection.
- Staff trainings on how to use the technology.
- Develop interoperability so patient data can be exchanged across all providers they see.
- Create standardized scripts that staff can use (perhaps produced by the EMR vendor and included right in the EMR).
b) Patient willingness to share this information

Safety net organizations offered some information related to willingness of patients to share RESD information.

(1) Challenges

- Patients and consumers are reluctant to provide information on their income
- Some patients find questions about their mental health (abuse, trauma, child abuse) to be invasive
- Some patients do not identify with any of the RESD options on the list of categories, especially the race and ethnicity categories
- Some expressed concern that the time and/or invasiveness of asking these questions could hurt the patient-provider relationship

(2) Strategies to overcome challenges

- Develop scripted explanations of why income information is being requested (e.g. for sliding fee scale)
- Let patients know that the data is requested to better know, understand, and serve them
- Tell patients data is also used to improve care for all patients and the community and to reduce health disparities for particular groups (not just more data collection for no reason)
- Always give patients the option to refuse to provide the information
- Add mental health information collected to the patient’s care plan, rather than it being used only to identify disparities
- Create a standard notice of privacy practice so patients know how their identifiable information will be protected from disclosure and kept secure
- Willingness to provide the information will improve if the larger community understands the value of the information. For example, an active outreach program could be established to share aggregate reports on health outcomes, disparities and improvements by RESD characteristics.

c) Community Data Dissemination

- Data could be included in annual reports of providers and nonprofit agencies (publicly available)
- Data could be posted on providers’ websites
- Data could be used in grant proposals and grant reports
- Data could be shared with funders, government agencies, university partners, etc.
- Sharing aggregate data on RESD outcomes and disparities with community-based groups would both increase understanding and acceptance of the need for data and willingness to provide the information, but it will also increase the effectiveness of programs to reduce disparities. Communities would have better information for them to use to identify and address disparities in their own communities and providers, governments and health care organizations would build trust and collaboration that will enable them to better address disparities for their patients.
IV. RECOMMENDATIONS: HEALTH CARE QUALITY MEASUREMENT

The following recommendations are based on the community engagement activity undertaken by Voices for Racial Justice on behalf of MDH in response to the 2014 legislation. These recommendations are intended to supplement and expand the recommendations in Part One that were provided in previous reports.

1. **Improve Categories of Race, Ethnicity and Language (REL).** The “Recommended Questions and Variables for Standard Race, Ethnicity, and Language Data Collection” are an acceptable set of categories to use as a starting point to collect REL data. However, the categories should continue to be evaluated, modified and continuously improved. In particular, more work is needed to improve questions and categories for Black/African American and American Indian/Native American Communities.

2. **Develop Other Socio-demographic Data Categories.** Income, gender identity, sexual orientation and disabilities are sensitive and personal questions. Additional work is needed to develop categories for these characteristics and methods of asking patients and consumers for this information, including ways to explain why this data is important and how it will be used and shared.

3. **Explain Data Privacy and Security Protections.** When RESD information is requested, consumers and patients should be informed about how current health data privacy and security laws protect their health care information from misuse or disclosure. Explaining these protections is likely to improve their willingness to provide the information requested.

4. **Communicate the Purpose and Use of RESD Data.** Consumers, patients and RESD communities would benefit from understanding why RESD information is needed and how it will be beneficial to patients and communities. The benefit and potential impact of collecting socio-demographic data needs to be clearly defined and communicated with patients, consumers and communities. Consumers, patients and communities should be reassured that their treatment will not be negatively impacted by their RESD factor(s), income or ability to pay for the services needed. Public awareness and education about this should be undertaken both within the healthcare system at the individual patient or consumer level and in the larger community.

5. **Build Community Trust of the Health Care System.** There is a general issue of lack of trust which needs to be acknowledged by those who work in and lead health care organizations. Many interviewees expressed fear that their socio-demographic data would be used against them. To improve trust, there is a critical need for health care organizations to hire people who look more like the people they are working with and share their RESD factors.

6. **Provide Training on community engagement methods.** Health care organizations would be better able to improve care and reduce inequities by learning best practices for authentically engaging RESD communities disproportionately impacted by inequities. Training is critical in order to build
the trust that is needed to better serve RESD patients and reduce inequities. Training should include learning how to understand and address institutional racism and discrimination.

7. **Make Aggregate Health Equity Data Available to Communities.** A plan to make data collected available to the community should be developed by every health care organization and by research, public health and quality measurement organizations that collect health data. In addition, MDH should become more intentional in making RESD data accessible not only to mainstream organizations but to RESD communities and the broader community in general. Socio-demographic data collected by the health care system should be used to create public reports easily accessible online. This transparency of the process will motivate actions and collaborations between systems and communities, which in the end will make everybody accountable to create a healthier community. The dissemination of this information is part of MDH’s role in collecting information “*used to inform policy makers, consumers, and other stakeholders in Minnesota’s health care system*”¹⁰ Community access to this information on inequities is an essential element to succeed in efforts to create a healthy community by expanding the possibilities for government and health care system leaders to co-create solutions with the affected communities. It will make it easier to identify needs and set priorities for the allocation of resources that are more equitable. It will also enhance the opportunity to improve quality of health care services and patient experience while decreasing costs. Information should be widely disseminated in multiple forms, not only digitally but also in various written forms. The language used should be understandable not only by the experts, but by community-based organizations and regular citizens.

8. **Develop Inclusive, Culturally Appropriate Methods of Collecting RESD Data.** The collection of RESD data should be undertaken in ways that are culturally appropriate for the particular patient or RESD community. The best way to achieve this goal is by intentionally involving the communities in developing and implementing the plan for how to collect, use and share this data. Further, different methods are appropriate for different patients and communities. Because most respondents expressed a preference for data to be collected using either paper forms or being asked verbally, rather than requesting the information electronically. It may be preferable to use a combination of both written and verbal requests, such as general questions about Race Ethnicity and Language (REL) and Socio-Economic Status (SES) can be collected by paper at registration at the clinic, and more sensitive information such as gender identity, sexual orientation and disability requested in the exam room by the health care provider, nurse or medical assistant. Language used for the questions should be at 6th grade level or lower in order to be understandable to as many patients and consumers as possible. The plan for collecting the information should be designed to avoid people being asked multiple times for the same information.

9. **Develop a uniform construct for collecting RESD data across all systems.** Socio-demographic data needs to be collected using consistent standards across the entire health care system in the state to be able to make comparisons around quality improvement. This is an important recommendation of earlier reports. This will make the efforts more effective by allowing data from multiple sources to be used and to allow comparisons of outcomes in different parts of the system. Further, other governmental and systems beyond health care -- such as education, housing, transportation, social services, etc. -- should also use the same uniform standards for collecting RESD data. This will create better opportunities to collaborate across different parts of government and society and allow development of a more comprehensive strategy for achieving healthier communities.

¹⁰ [http://www.health.state.mn.us/healtheconomics](http://www.health.state.mn.us/healtheconomics)
10. **Understand Providers’ Perspectives on Collecting RESD Data.** Safety Net Providers serving high concentrations of RESD patients and communities should also be consulted in developing the plan for implementing RESD data changes. Those interviewed for this report recommended the following changes to improve data on disparities:

- Additional RESD data categories that should be explored are:
  - Mental health
  - Housing stability
  - Employment status
  - Education level
  - Social support
  - Health literacy

- Statewide provider quality measures should be risk-adjusted to reflect RESD status of patients and populations served. Adjustments must go beyond race, ethnicity and language to also include additional social determinants of health and socio-demographic risk factors that have an impact on health, access to services, quality of care, patient satisfaction and other health system quality indicators.

- Comparison of rural and urban populations.

- The state has a vital role in advancing RESD data stratification and risk adjustment methods. The science and existing practices are still emerging. The state should commit resources and expertise to improving data collection and risk adjustment methods in order to better identify and address health disparities.

11. **Understand Social Determinants of Health.** Interviewees felt that there is also a need for greater awareness and understanding by people who work in the health care system of how social determinants like economic status and challenges around jobs affect the health and patients and communities.

12. **Develop Awareness of Structural Racism and Discrimination.** Health care providers, health care professionals, and health care and government leaders within Minnesota’s health care system would benefit from understanding how structural racism and structural discrimination based on socio-demographic factors has adversely impacted RESD communities and patients as well as the entire community at large by increasing health disparities. With increased awareness they will be better prepared to be intentional in changing the system.

13. **Recognize Challenges New Immigrants Face.** The systems need to recognize that immigrants face unique challenges which are impacting their health and treatment. This situation is even more challenging for immigrants who are undocumented and even less likely to provide RESD data or to trust that the information provided will not be used in a way that will negatively impact them.

14. **Work with Communities to Improve Health Equity Data.** The health care system needs to work with communities to define and then communicate how socio-demographic data collected will be used and shared. Assessing the challenges and strengths of communities disproportionately impacted by health inequities should be an ongoing effort.
V. Appendices

A. Principles of Authentic Community Engagement VRJ
B. Script to contact community member
C. Introductory script for interviewer
D. Form to ask interviewees for REL
E. 2014 Federal Income Guidelines Household size
F. Community Questionnaire
G. Safety Net Questionnaire
H. Definitions Used

VI. Project Team (in alphabetical order by organization)

<table>
<thead>
<tr>
<th>Organization</th>
<th>Name</th>
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<tr>
<td>African American Leadership Forum- Health and Wellness Group</td>
<td>Gene Nichols</td>
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<td>Akress Associates Inc.</td>
<td>Ricardo Cardenas</td>
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<td>American Indian Cancer Foundation</td>
<td>Amanda Dionne</td>
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<td>Melanie Plucinski</td>
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<td>Sarah Dar</td>
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<td>Centro Campesino</td>
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<td>Association of Kenyans in America (MN)</td>
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<td>Minnesota Association of Community Health Care Centers</td>
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<td>National Asian Pacific American Women’s Forum</td>
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<tr>
<td>Sewa-AIFW Asian Indian Family Wellness</td>
<td>Raj Chaudhary</td>
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<td>Tate Topa Consulting</td>
<td>Lenny Hayes</td>
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<tr>
<td>Voices For Racial Justice (Consultant)</td>
<td>Ana Isabel Gabilondo</td>
</tr>
<tr>
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