Aligning Forces to Reduce Racial and Ethnic Disparities:

Executive Summary

Racial and ethnic disparities in health and health care are well documented.[i] While performance on certain nationally recognized quality measures has improved in recent years, disparities in health care persist.[ii] A recent Institute of Medicine (IOM) report[iii] identified a framework found in successful initiatives addressing disparities that includes the following steps:

(1) Collection of standardized patient race, ethnicity and language (R/E/L) data;
(2) Analysis of performance measures by R/E/L; and
(3) Identification and evaluation of quality improvement interventions targeted to specific patient populations.

Though a growing body of evidence supports the effectiveness of this framework in addressing disparities in care, little is known about implementing such an approach among providers and health plans at a regional level. Within the Aligning Forces for Quality program, Alliances are charged with using this framework in order to improve and sustain equitable care throughout their communities. In developing an action plan to achieve this goal, Alliances conducted a series of interviews with select providers and health plans to investigate current R/E/L data collection and use practices. This report summarizes aggregate findings across the AF4Q Alliances and offers several recommendations for implementing the framework outlined above.

Alliances found that some elements of race, ethnicity or language data are being collected by most of the providers and health plans interviewed, though less frequently by plans, and generally not in a standardized manner. Legislative and regulatory mandates appear to be the strongest lever to encourage data collection, but do not necessarily result in the successful acquisition or meaningful use of that data. Several challenges exist in collecting and using standardized R/E/L data, though Alliances identified clear examples of early adopters among providers and health plans that were able to overcome these challenges and may serve as champions for this work within the AF4Q communities.

Alliances learned that while most of providers and health plans interviewed collect some R/E/L data, few use the data to identify disparities in quality of care or in health outcomes. As new federal reform efforts affecting the health care system unfold, it will become increasingly important for providers and plans to demonstrate not only that R/E/L data are collected, but that the data are being used in a meaningful way. This presents an important leverage point for Alliances in working with providers and health plans to contribute to the adoption of a regional approach to eliminating disparities.

Based on these findings, we recommend that the AF4Q Alliances consider a staged approach to moving the equity agenda forward. Alliances can leverage short term activities that are likely to yield early successes to improve stakeholder buy-in and demonstrate the value of R/E/L data collection using local examples. Building on this foundation, Alliances can also implement long-term strategies that will lead to more robust R/E/L data collection and that can be used to develop patient-level interventions. The combination of short-term and long-term strategies provides Alliances with an opportunity to affect measurable change in the quality of care provided to racial and ethnic minorities.

Aligning Forces to Reduce Racial and Ethnic Disparities:

Overview and Findings from the Provider and Health Plan Assessments

Across the U.S., racial and ethnic minorities often receive lower-quality health care than whites and these gaps remain even after adjusting for differences in access to care and disease severity.[iv] While performance on certain nationally recognized quality measures has improved in recent years, disparities in health care persist.[v] To provide equitable care and reduce disparities, health systems must implement a quality improvement framework that includes four separate but related steps: (1) the collection of standardized patient race, ethnicity and language (R/E/L) data; (2) the analysis of performance measures by R/E/L; (3) the identification of quality improvement interventions targeted to address disparities for specific patient populations within an institution or throughout the community; and (4) continued analysis of stratified performance measures to evaluate the impact of the interventions. The collection and use of direct data are essential components in moving toward more equitable health care.[vi]

For the 15 Alliances within Aligning Forces for Quality (AF4Q), a major goal is to improve and sustain high-quality, patient-centered, **equitable** care in their communities by 2015. The AF4Q Alliances are expected to implement a region-wide approach to standardized R/E/L data collection, as well as to develop the capacity to stratify performance measures by R/E/L. As a first step toward these goals, Alliances conducted interviews with select providers (hospitals and medical groups) and health plans in order to: (a) understand current practices around the collection and use of patient R/E/L data; (b) consider associated challenges at both the organizational and regional level; and (c) identify potential strategies to address challenges. The assessments afforded the Alliances an opportunity to learn about issues related to R/E/L data collection and use from the perspective of providers and health plans.

Methodology

Alliances selected the providers and health plans to assess and determined a point of contact at each organization. Providers and health plans were selected based on high patient volume or known experience with R/E/L collection and are not mean to be representative of the entire community. Interviews with providers were led by staff from the George Washington University (GW) in collaboration with an Alliance representative or, alternatively, were led by the Alliance with participation by GW. Interviews with health plans were conducted by the Center for Health Care Strategies (CHCS) in collaboration with the Alliances. Interview participants received a copy of the interview guide (customized for either providers or health plans) in advance. (See attached interview guides.) Interviews were conducted by phone and lasted approximately one hour. After completing the interviews, each Alliance summarized the findings from providers and from health plans and used these findings to develop an action plan of strategies for the next 12-18 months.[vii]

A total of 37 provider assessments were conducted in 11 of 15 AF4Q Alliances, including 20 medical groups, eight Federally Qualified Health Centers (FQHC) and nine hospitals.[viii] Sixteen health plan assessments were conducted with plans operating in six AF4QAlliances. Participants included 14 commercial plans (10 regional and four national), as well as two Medicaid plans.[ix]

The next two sections discuss the findings across all Alliances for providers and health plans including current R/E/L data collection practices and perceived challenges in standardizing data collection from the perspective of both providers and health plans.

Hospital and Medical Group Assessment Findings

Provider Type	Number Interviewed	Size (Range)	Collect R, E and/ or L	Standardized Collection	Use data for Quality Improvement	Federal, State, grant requirement
Medical Group	20	5-336 clinicians	80%	50%	20%	81%
FQHC	8	11-97 clinicians	100%	88%	25%	100%
Hospital	9	76-600 beds	100%	67%	11%	75%

1. *The majority of providers interviewed collect some data on patient race, ethnicity and/or language (R/E/L), and almost half collect all three data elements.* Of the 20 medical groups interviewed, 16 collect some portion of R/E/L information, while all eight FQHCs and all nine hospitals collect R/E/L information. As FQHCs are required to collect and report R/E/L data as a condition of their federal funding, all FQHCs reported collecting all three data elements. However, only 7 of 16 medical groups and 5 of 9 hospitals collected all three data elements.

   Findings from hospital interviews do not differ greatly from similar national level studies that found that a majority of hospitals collect elements of R/E/L data. For example, one study by the National Public Health and Hospital Institute found that more than three-quarters (78.4%) of non-federal acute care hospitals in the U.S. collect information on the race of their patients, and half collect information on patient ethnicity (50.4%) and language (50.2%). [x]

   Findings from provider interviews reveal a higher percentage (80%) of medical groups (excluding FQHCs) collecting R/E/L information than reported in previous research. [xi] This difference may be the result of several factors (e.g., an increasing awareness of the value of R/E/L information; technological improvements and increasing adoption of electronic medical records). The difference may also be due to selection bias, in which the sample of medical groups selected by the Alliances tended to be those organizations that were already engaged in R/E/L data collection.

   When asked about completeness of R/E/L data (e.g., what percent of your hospital's patient records include an entry for race), about half of providers reported having race, ethnicity and/or language data on virtually all their patients. The remaining providers were unable to answer the question, either because the data were not immediately available, or because their system does not allow for such a query (e.g., use paper records).

2. *The majority of providers collect R/E/L data in a standardized manner, though standardized data collection is more common among hospitals and FQHCs than medical groups.* For the purpose of this report, standardized data collection is defined as (a) asking all patients to self-report their race, ethnicity and language and (b) using the same categories at all points of entry to the system. One-half of medical groups interviewed collect self-reported patient R/E/L data using standardized categories, while two thirds of hospitals and nearly all FQHCs used a standardized framework to collect the information.

Using a standardized framework to collect race, ethnicity, and primary language information from patients can result in more accurate and complete data.[xii, xiii] When no such framework is in place, information is often collected by "eye-balling" the patient and basing race and ethnicity on the way a person looks. Alternatively, patients are categorized as "unknown" or "other" without being asked. These practices result in data that are unreliable, and not trusted by those who might use the information for quality improvement purposes.

3. *The R/E/L categories used vary across providers*. Most providers determined which R/E/L categories to use in one of two ways: (a) following the Office of Management and Budget (OMB) guidelines for race and ethnicity[xiv] or (b) by using the pre-populated categories included with their practice management system or electronic medical record (EMR). Three providers reported using historical data related to requests for language services to determine language categories.
    - Approximately half of the medical groups that collect patient race and ethnicity data use OMB categories and the remainder use differing methods (e.g., free-form field, pre-populated categories, and limited categories representing the patient population).
    - FQHCs are required to use OMB categories for race and ethnicity. Language is reported as the percentage of patients best served in a language other than English.[xv]
    - Almost all of the hospitals that collect race and ethnicity information use OMB categories to capture patient race and ethnicity with two hospitals collecting more granular categories based on the demographics of their patient population.

4. *Providers use R/E/L data for a variety of purposes, including language services, resource allocation, marketing, and strategic planning.* Hospitals and FQHCs are most likely to use R/E/L data, while the majority of medical groups report not using the data. The most common use of R/E/L data is for language services, cited by two-thirds (17 of 26) of providers that collect patient language information. This includes assuring the availability of interpreter services, translating patient education materials and facility signage into the most commonly used languages, and informing decisions on what equipment to purchase (e.g., TTY telephones, remote video).

    More than 40 percent (14 of 33) of providers use R/E/L data to inform decisions about resource allocation (e.g., deciding where to build new clinics; identifying areas for needed services and patient education; and recruiting and hiring staff). One-third of providers use the data to understand their patient population better (e.g., analyzing service lines by race and ethnicity, trending changes in patient demographics for marketing and strategic planning).

    Only one-quarter of all providers report using R/E/L data to assess variation in quality measures or in health outcomes, and the majority of medical groups that collect R/E/L data report not using the data for any specific purpose. All but one of the providers that collect but do not use the data cites lack of executive support as a barrier.

5. *Legislative, regulatory and/or funding mandates were identified frequently as a primary driver to collect R/E/L data. Mandates, however, do not necessarily indicate use of that data or an organizational focus on equity.* Most (81%) of the providers that collect R/E/L data cited an external mandate or regulation as the primary driver for doing so. This includes all FQHCs that are required to collect and report R/E/L data as a condition of their federal funding, and medical groups that participate in other federally funded programs (e.g., Title X Family Planning program, Title V Maternal and Child Health program). Additionally, five of the states represented in the assessments have regulations mandating that patient demographic data, including R/E/L, be included in hospital discharge data.

    Providers that collect R/E/L data in the absence of a legislative, regulatory or funding mandate cite a variety of influential factors including: involvement in clinical trials; participation in a Patient Centered Medical Home pilot; belonging to a larger health system; fields built in to their patient registration system; response to a lawsuit regarding access to language services; and executive leadership or other champion within the organization.

Though external mandates were often cited as the impetus to start collecting these data, such mandates do little to guarantee use of the data in a meaningful way (e.g., to improve equity). Rather, executive leadership or other champion was commonly cited as the driving force behind initiatives to use the data to examine racial and ethnic differences in performance measurement data. Conversely, the lack of executive support was identified as a barrier to standardized collection and use of R/E/L data. Several providers noted that R/E/L data collection simply was not a priority for their organization as no disparities exist in their organization (e.g., no demonstrated need for the data) or competing priorities serve as a barrier to collecting the data.

6. *Efforts to use R/E/L data in quality improvement efforts, including assessing variation in quality measures or in health outcomes, appear to be hampered largely by technological barriers.* Over 40 percent of providers identified information technology (IT) challenges in collecting and using R/E/L data to develop quality improvement interventions. Technological barriers include linking registration systems with EMRs (e.g., linking R/E/L data with clinical data), developing standardized R/E categories, and capturing data in a field that cannot be queried. Additional challenges to using R/E/L data in quality improvement efforts include the lack of reliable data or sufficient data to stratify performance measures and limited resources for implementing all the necessary steps to address disparities (e.g., conducting manual chart audits to collect necessary data, analyzing existing data, and developing quality improvement interventions). Limited resources were often cited as a challenge by hospitals and medical groups that also stated R/E/L data collection was not a priority within their organization.

7. *Despite the challenges cited by providers, Alliances were able to identify several "early adopter" organizations that have already made the commitment to implementing standardized collection of patient R/E/L data and to using that data in a meaningful way to identify and reduce disparities.* Though not a specific focus of these assessments, anecdotally the Alliances identified several common characteristics among early adopters. First, these providers tended to have an organizational commitment to equity, including executive support for the collection of standardized R/E/L data and use of these data to address disparities.

   Second, many of these providers saw equity as an integral component of their quality improvement efforts and necessary to be able to respond to their patients' needs and to remain competitive within their markets. These rationales seemed to be common among providers who served a large or growing minority patient population.

   Further research into the characteristics of early adopters is clearly an area warranting additional exploration in order to better understand specifically what drove their efforts, how they overcame barriers, and what role might the Alliances play in facilitating greater use of R/E/L data.

Health Plan Assessment Findings

Table 2: Health Plan Characteristics

Plan Type		Collect R/E/L data*	Medicaid is only or primary R/E/L data source	R/E data volume (range)
Commercial/Medicaid	**Regional/National**			
14 Commercial	10 Regional (including five independent Blue Cross Blue Shield plans, three non- Blues plans, and two integrated systems) 4 National	13/14	6/14	0-32%
2 Medicaid	-	2/2	2/2	~100%

*Denotes direct collection of self-reported R/E/L data or access to self-reported R/E/L data from an external entity

1. *Nearly all (13/14) of the commercial health plans interviewed collect some R/E/L data from their members or access the data from an external source. For almost half of these plans (6/14), Medicaid is either the only or the primary source of R/E/L data.* Although virtually all plans have made some inroads in collecting or accessing R/E/L data, for most, R/E/L data collection activities remain limited. Regional plans were less likely than national plans to collect a substantial volume of R/E/L data through vehicles other than Medicaid. This could be attributed, in part, to the participation of national plans in broader disparities efforts like the National Health Plan Collaborative on Disparities.[xvi]

   Health plans are generally less consistent in the collection of language data than race and ethnicity data. This is due in part to the variety of ways in which health plans may be inquiring about language access needs (e.g., asking about whether translation or interpretation services are needed or whether English is a member's primary language).

2. *The percentage of existing direct race and ethnicity (R/E) data within commercial health plans ranges from 0 – 32 percent.*[xvii] While some of the estimates provided by national plans were at the national level, these organizations expected that the volume of data in specific markets would be comparable (particularly when collected from members with a common mechanism, such as a web portal). One national plan, however, did describe some variations in R/E volume based on different Alliance markets, which may reflect states (e.g., California) or regions (e.g., Boston) that have legislative or regulatory requirements for R/E data collection.

3. *Medicaid plans benefit from broad and more specific federal mandates that afford them access to R/E/L data across their entire membership.*[xviii] Title VI of the Civil Rights Act of 1964 – which prohibits discrimination based on race or national origin by any federally-funded services – is the basis for the collection and/or reporting of R/E/L data by federal programs.[xix] Historically, the regulations governing various federal programs gave effect to this prohibition by requiring assurances that the program did not discriminate, which would usually require collection of R/E/L data.[xx] Under the new health reform legislation, recipients of federal funding for health care will be specifically required to collect and report R/E/L data to US Department of Health and Human Services.[xxi] Medicaid agencies also must provide their contracted health plans with the race, ethnicity, and primary language of enrollees as part of

implementing the state's overall quality strategy.[xxii] As a result, in many Alliances, Medicaid R/E/L data are more readily accessible via health plans than R/E/L data on commercial health plan populations.

Despite the greater availability of R/E/L data from Medicaid enrollment files, plans described some concerns about data quality and completeness. Two plans also mentioned challenges in electronically integrating the information with their main data files.

4. *The majority of health plans that collect self-reported R/E/L data use multiple collection vehicles, which make data collection, storage, and use much more challenging.* Health plans justifiably pursue different and/or multiple collection strategies in order to maximize their opportunity to collect R/E/L information from members. While collection at enrollment is advantageous primarily because the information is more likely to reside in the main member file or in a location that electronically feeds into that file, some states prohibit health plans from collecting R/E/L information on the application form.[xxiii] Even in states where this is permitted, plans often do not do so to avoid potential member suspicion around the use of this information.

   Prominent vehicles for self-reported R/E/L data collection beyond enrollment include:

   - Member web portal;
   - Health risk assessments (HRAs);
   - Member services interaction;
   - Disease management interaction; and
   - Data received from external entities such as Medicaid, Medicare, etc.

   External factors may limit access to potential R/E/L data. For example, several plans noted employers as a potential source of R/E/L data, via the Health Insurance Portability and Accountability Act (HIPAA) 834 Benefit Enrollment and Maintenance transaction standard. The HIPAA 834 transaction provides initial enrollment or update information from the sponsor (e.g., employer or state) to the insurance organization (e.g. health plans). Despite a seemingly high opportunity to access R/E/L data, several challenges present for acquiring data in this way. These include issues such as: R/E not being a required data element; the HIPAA R/E field code not directly aligning with OMB standards; and R/E information available only on the member, and not other household members.

5. *Some health plans report using indirect strategies as interim steps to self-reported R/E/L data collection.* While obtaining self-reported R/E/L data is often considered the gold standard for enabling population-based improvement efforts, member-level disease management, and marketing strategies, some plans use indirect methods to estimate R/E, including geo-coding, surname analysis, and a method combining surname and geo-coded information.[xxiv] A few plans interviewed described having imputed a significant proportion of their membership, and have found high correlation levels based on validation processes using existing self-reported data.

6. *No specific race and ethnicity categorization stood out as the dominant form; however, there were many variations of a single question format inquiring about race and ethnicity.* The majority of plans utilized a variation on the following response categories: *White, African American or Black, Hispanic or Latino, Asian, Other*. While the OMB standard for classification of federal data on race and ethnicity is widely looked to for minimum R/E designation, in the absence of a mandate, health plans do not necessarily use this standard. The lack of a standard categorization can become an internal problem for an organization, where data obtained from different sources are not aligned, particularly data received from external entities.

7. *Those health plans collecting R/E/L data use the data for a variety of activities, including stratification of performance data, development of culturally-tailored programs, risk-identification for disease management, marketing outreach, and strategic planning.* Consistent with previous findings – despite health plans typically having fewer language data – the most common R/E/L related activities for health plans are around language access services such as interpretation and translation.[xxv] Health plans that are more actively engaged in R/E/L data collection activities are using available R/E information to inform the development of innovative and comprehensive programs targeting specific racial/ethnic groups.

8. *Legislative mandates, such as California's Language Assistance Policy-Senate Bill 853, were identified repeatedly as among the strongest, but not necessarily sufficient, levers for R/E/L data collection.* Notably, while some national health plans have focused on implementing the proper insurer processes and vehicles for collecting R/E/L data as outlined in the mandate, these activities are often isolated to the California line of business. This lack of diffusion may stem in part from plans' ongoing difficulties in capturing a greater volume of R/E/L data from its membership in that state, despite the activities and infrastructure in place to do so.

9. *Although conceptually all organizations agree with the importance of the equity agenda, the level of commitment and activity around R/E/L data collection vary greatly.* R/E/L data collection is an emerging area of interest across the plans. Significant opportunity remains to expand efforts, even among early adopters. However, major reforms resulting from the health reform legislation (including the Patient Protection and Affordable Care Act of 2010) may aide health plans in establishing R/E/L data collection (or facilitating such collection among its provider network).[xxvi] For most plans, the business imperative for addressing disparities did not appear to be a dominant driver, although a few are exploring or already engaging in the use of R/E/L information to support marketing and outreach to increasingly diverse memberships. In some regions, a less diverse population (and plan membership) has also made it more difficult to elevate the equity agenda and R/E/L data collection activities.

10. *There are limited resources available in health plans to make major systemic changes for R/E/L issues, such as creating a central data repository.* For the majority of health plans, one of the greatest barriers to collecting and using R/E/L data more effectively is the lack of a centralized repository. Multiple data silos exist, requiring that any broader analytic efforts begin with a manual process of linking independent data files. The lower priority given to the equity agenda and R/E/L data collection in relation to other issues translates into fewer available resources. In a few organizations, plans for a major system conversion are underway or likely to occur in the next few years. These health plans could not, thus, justify interim efforts on systems that will be discontinued.

11. *Many plans underscored the broader audience of stakeholders that need to be engaged and supportive of R/E/L collection activities.* Many plans described a need to address members' willingness to provide information, and some even proposed the need for a broader, community-wide effort to raise public awareness on the importance of providing R/E information in delivering more patient-centered care. A few plans also noted the insurance broker community as critical to advancing the agenda, given its involvement in member enrollment processes.

12. *While the presence of formal policies around the collection of R/E/L data are atypical outside states with specific legislative mandates, more than half of the plans reflected at least one of the following characteristics/activities that signal a commitment toward R/E/L data collection*:
    - A committee dedicated completely or in part to disparities activities, often inclusive of high-level leadership, promoting organizational visibility for the issue;
    - An explicit charge to develop a quality improvement plan that might warrant investing different levels of resources in specific populations, and an acknowledgment that the delivery of high-quality care requires accurate risk assessments of patients including their R/E/L information;
    - An organizational bent toward being highly data-driven; and

- A growing interest and investment in member engagement services; some plans have begun establishing a portfolio of member services that better meet cultural and linguistic needs and are coming to view member engagement activities as a means to attract prospective members.

The findings from the health plan assessments are not inconsistent with those for the provider assessments. There are some forces pushing for more collection and use of R/E/L data, but except among early adopters, those forces are not sufficient to drive widespread and proactive investments in this arena.

Discussion

Equity is one of the core tenets of the AF4Q program. As such, Alliances are faced with the two-pronged task of facilitating standardized R/E/L data collection among disparate provider and health plan organizations and developing the capacity to aggregate these data across organizations in order to stratify performance measures and identify disparities.

The Alliance assessments reveal a variable level of R/E/L data collection and use within providers and health plans, ranging from little or no engagement to encouraging pockets of R/E/L data activity. The assessments also identify several potential leverage points that may serve to increase stakeholder commitment to a region-wide approach to improving the availability of R/E/L data necessary for identifying and addressing disparities. Based on the findings from the assessments, we recommend AF4Q Alliances take a staged approach to working with providers and health plans. Both the following short-term recommendations and long-term opportunities (largely resulting from changes in federal or state policy) will help Alliances overcome identified challenges to achieve the ultimate AF4Q goal of high-quality, patient-centered, equitable care by 2015.

Short-term Recommendations

1. *Alliances should consider building relationships with those providers and health plans identified as early adopters, and spread lessons learned from these organizations across the region.* The assessments revealed that R/E/L data collection and use activities are nascent among many providers (particularly medical groups) and commercial health plans. Early adopters have begun collecting R/E/L data, though not necessarily in a standardized manner. Alliances can support these early adopters in improving data collection and use activities, as well as mine these early efforts for valuable best practices to show case to providers and health plans in the community.

   Alliances may consider engaging in the following activities to improve existing data collection and use efforts among early adopters and to provide support to those hospitals and medical groups interested in beginning to collect R/E/L data:

   - Facilitating discussions to reach agreement on a set of locally relevant standardized R/E/L categories following OMB standards, at a minimum, or using the IOM recommendations[xxvii] on more granular ethnicity categories;
   - Engaging executive leadership and staff in "train the trainer" sessions on implementing standardized data collection;
   - Assisting health plans in linking R/E/L data received by Medicaid to its enrollment files;
   - Serving as the analytical hub for data collection (e.g. from Medicaid), and providing actionable reports of stratified performance measures; and
   - Sharing/disseminating best practice interventions from early adopters.

   The assessments also identified several incremental steps that Alliances can encourage health plans in their community to consider in developing the internal capacity to collect standardized R/E/L data, including:

- Facilitating discussions to reach agreement on a set of locally relevant standardized R/E/L categories following OMB standards, at a minimum, or using the IOM recommendation[xxviii] on more granular ethnicity categories;
- Identifying and implementing the most accepted standards for the process of collecting R/E/L data (e.g. the message that is communicated to members);
- Emphasizing the collection of R/E data at enrollment, especially among those plans that are already collecting language data at enrollment;
- Using targeted collection vehicles that may be implemented at a marginal cost increase (e.g., existing member web portal, piggybacking on member service interactions or interactive voice recognition encounters);
- Pursuing other creative strategies that are emerging among health plans, but are still in pilot forms (e.g., a physician portal through which providers can upload R/E/L data or member kiosks located at worksites which provide members access to claims and health risk assessments);
- Working with their state Medicaid agencies to mine and fine tune R/E data on plan members and linking such data with health plan enrollment files; and
- Engaging plans both at the corporate *and* regional levels, as analytics involving R/E/L data occur at the corporate, not the regional level.

2. *Alliances will need to develop a multi-faceted messaging strategy establishing the value proposition for R/E/L data collection and use for a variety of stakeholders including consumers, employers, brokers, health plans, physicians, and hospitals.* The assessments revealed that, for many organizations, R/E/L data collection is not an organizational priority, and this serves as a fundamental barrier to expanding community-wide efforts to measure and reduce disparities in care. A critical strategy for engaging providers and health plans around the equity agenda must begin with the foundational step of establishing the value proposition for committing to R/E/L data collection and use at both the level of the organization and across the entire region.

   To do this, Alliances will need to (a) promote awareness of any possible problems with unequal care in their region, particularly in communities with limited diversity or changing demographics or among organizations that do not believe there are disparities; (b) show how region-wide collection of standardized R/E/L data can lead to quality improvement efforts that can close the gap between whites and minorities; and (c) communicate the benefit of such efforts to disparate stakeholder groups. Staff from GW, CHCS, and others providing technical expertise to the AF4Q Alliances will work with the Alliances to develop relevant messages for the various stakeholders that need to engage in R/E/L data collection and use.

3. *In order to meet AF4Q expectations around performance measure stratification, Alliances should consider initial efforts that build upon existing data sources.* Building capacity to collect and use self-reported R/E/L data may take some time and involves multiple steps that include:

   - Identifying the catalyst for focusing on equity (e.g., mandate or stakeholder priority);
   - Building awareness among stakeholders and obtaining commitment;
   - Setting short-term and long-term goals;
   - Developing standardized R/E/L categories; and
   - Using R/E/L data to improve equity by identifying and addressing disparities.

   Based on interviews with hospitals, medical groups and health plans, the most robust sources of R/E/L data with the greatest immediate opportunity appear to be: (1) hospitals; (2) Federally Qualified Health Centers; and (3) Medicaid. Hospitals and FQHCs are more likely to be collecting R/E/L data compared with medical groups or health plans and are far less burdened with the complexities of multiple points of R/E/L data collection than are health plans. Hospitals in particular may be easier to engage than medical groups and health plans, as most have experience in data collection and reporting of performance measures, as well as an existing quality improvement infrastructure. Alliances can explore working with providers who currently collect R/E/L data (often in response to a state and/or federal mandate) to determine the feasibility of stratifying that data, as well as to build additional political will for performance measure stratification. For example, while hospitals may collect R/E/L data, additional steps are needed to stratify performance measures that are reported publicly, e.g., performance measures on Hospital Compare.

Many Alliances have access to R/E/L information on Medicaid patients via health plans. This includes not only Medicaid-only plans but commercial plans that have a Medicaid product line. As an interim step toward acquiring and stratifying R/E/L data for their entire population, Alliances can examine the feasibility of stratifying Medicaid data, especially as Medicaid constitutes a significant proportion of the racially and ethnically diverse populations in many Alliance communities.

Given the limited amount of direct race and ethnicity data within commercial health plans, some Alliances may also wish to support health plans in developing and refining indirect methods for collecting R/E/L data as a short-term goal. While indirect R/E/L data cannot be used for patient-level interventions, health plans can use indirect data to develop population-level interventions, e.g., identifying potential "hot spots" that represent a high volume of Hispanic patients with diabetes who have not had their low density lipoprotein checked in the prior year.[xxix] This information can then be helpful in developing more targeted interventions.

4. *Alliances should create synergies between other core AF4Q activities, for example ambulatory quality improvement (QI), and R/E/L data collection efforts.* Given the increasing probability of R/E/L data collection at the point of care, Alliances should think strategically about how to link the acquisition of those data with future ambulatory QI efforts. Such initiatives could give Alliances a platform for accessing and improving provider capacity to collect R/E/L data.

Long-term Opportunities

1. *Implementation of recent federal health care reform legislation will accelerate regional adoption of health information technology and build provider capacity for the collection and use of R/E/L data.* The Patient Protection and Affordable Care Act of 2010 will require all federally supported hospitals and providers to collect self-reported R/E/L data following U.S Office of Management and Budget (OMB) standards, at a minimum, by 2012. Additionally, the American Recovery and Reinvestment Act of 2009 (ARRA) established incentive payments for eligible physician and hospital providers to adopt, implement and upgrade electronic health records (EHRs) that can facilitate the collection and use of R/E/L data to reduce disparities in care. Other provisions of ARRA establish financial incentives for physician and hospital providers who can demonstrate meaningful use of the EHR technology, including a requirement that providers collect R/E/L data consistent with OMB categories to be eligible for incentive payments. Beginning in 2015, payment reductions will be imposed on eligible providers who are not meaningful EHR users.[xxx]

Increased availability of standardized R/E/L data resulting from these two pieces of legislation—among other efforts—will improve providers' ability to provide more patient-centered care and to identify disparities within their organization. Alliances could play an important role in ensuring R/E/L categories are standardized regionally so the data are meaningful to the local population and can be aggregated across providers in order to identify and address disparities in the health care delivery system between organizations.

Given barriers to collecting R/E/L data at the health plan level, plans will likely increasingly rely on providers for access to the rich clinical and demographic data documented electronically. Plan support of hospital and medical group efforts to implement and use EHRs to drive improvements in patient care will be critical. Alliances could be well positioned as neutral conveners within their communities to facilitate relationships between health plans and providers to accelerate regional adoption of health information technology. Increased adoption of EHR offers a great opportunity to strengthen the linkage between data collection and quality improvement.

2. *Regional policies requiring R/E/L data collection can be a significant driver among providers and health plans.* The assessments showed that local mandates drive data collection efforts. In several states or other jurisdictions, legislative and regulatory mandates requiring hospital, medical group, and/or health plan collection of R/E/L data currently exist. The impact of activities resulting from California Senate Bill (SB) 853 (which mandates that health plans provide Limited English-Proficient members with language assistance services) and Massachusetts's regulations for Uniform Reporting System For Health Care Claims Data Sets (which requires health plans to collect and report R/E data for an all-payer claims database) are still unfolding. While such policies may not ensure that the data are collected in a standardized manner across organizations or are used in a meaningful way (e.g., to improve equity), this type of policy drives change among providers and health plans. While not all stakeholders are supportive of locally mandated data collection (e.g., national plans could be concerned that disparate legislative mandates that would further fragment and complicate the already challenging agenda of centralizing and standardizing R/E/L data collection[xxxi]), the implementation of mandatory collection of R/E/L data provides an opportunity for the Alliances to encourage and facilitate standardized data collection. Ongoing activities in states like California and Massachusetts may provide lessons learned around the realities of implementation such as cost inputs, compliance, quality issues, etc. In places where legislative activity is already occurring, it also lays the foundation for the Alliances to focus their efforts on stratifying performance measures by R/E/L to identify any disparities and to inform quality improvement interventions.

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[i] Smedley, B, Stith, A.Y., and Nelson, A.R., eds., *Unequal Treatment* (Institute of Medicine, 2002), http://www.iom.edu/?id=16740; Jha, A. et al., "Racial trends in the Use of Major Procedures among the Elderly," *The New England Journal of Medicine* 353;7 (2005): 683-91; Mead, K.H. et al, *Racial and Ethnic Disparities in U.S. Health Care: A Chartbook* (Commonwealth Fund Chartbook, 2008), http://www.commonwealthfund.org/Content/Publications/Chartbooks/2008/Mar/Racial-and-Ethnic-Disparities-in-U-S--Health-Care--A-Chartbook.aspx.

[ii] Ulmer, C., McFadden, B., and Nerenz, D.R., eds., *Subcommittee on Standardized Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement Collection of Race/Ethnicity Data for Healthcare Quality Improvement* (Institute of Medicine, 2009).

[iii] Ulmer et al.

[iv] Smedley, B, Stith, A.Y., and Nelson, A.R., eds., *Unequal Treatment* (Institute of Medicine, 2002), http://www.iom.edu/?id=16740; Jha, A. et al., "Racial trends in the Use of Major Procedures among the Elderly," *The New England Journal of Medicine* 353;7 (2005): 683-91; Mead, K.H. et al, *Racial and Ethnic Disparities in U.S. Health Care: A Chartbook* (Commonwealth Fund Chartbook, 2008), http://www.commonwealthfund.org/Content/Publications/Chartbooks/2008/Mar/Racial-and-Ethnic-Disparities-in-U-S--Health-Care--A-Chartbook.aspx.

[v] Ulmer et al.

[vi] Ulmer et al.

[vii] Not all the AF4Q Alliances conducted interviews with providers and health plans. Some of the Alliances had previously collected information regarding current practices for R/E/L data collection and use through other means (e.g., surveys). Those Alliances also submitted summaries of their findings, but those findings are not included in these results.

[viii] Four AF4QAlliances conducted provider assessments independently. Findings reported by these Alliances did not differ from the findings in this report.

[ix] CHCS conducted independent interviews with various regional arms of the national plans participating in multiple Alliances.

[x] Regenstein, R. and Sickler, D., *Race, Ethnicity, and Language of Patients: Hospital practices Regarding Collection of Information to Address Disparities in Health Care* (National Public Health and Hospital Institute, 2006); Hasnain-Wynia, R.,

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Pierce, D., and Pittman, M.A., *Who, When and How: The Current State of Race, Ethnicity, and Primary Language Data Collection in Hospitals* (The Commonwealth Fund, 2004).

[xi] Nerenz, D.R.., Currier, C., and Paez, K. "Collection of Data on Race/Ethnicity by Private Sector Organizations: Results of a Medical Group Survey." *Eliminating Disparities: Measurement and Data Needs, National Research Council Report.* Ed. M. Ver Ploeg and E. Perrin. Washington, DC: National Academies Press, 2004. 249–71.

[xii] Beal, A.C. et al., "The Changing Face of Race: Risk Factors for Neonatal Hyperbilirubinemia", *Pediatrics* 117:5 (May 2006): 1618-1625.

[xiii] Ulmer et al.

[xiv] United States Federal Register. *Recommendations from the Interagency Committee for the Review of the Racial and Ethnic Standards to the Office of Management and Budget Concerning Changes to the Standards for the Classification of Federal Data on Race and Ethnicity* Washington: Office of Management and Budget, July 9, 1997: 36873-36946.

[xv] Uniform Data System Reporting Manual, Bureau of Primary Health Care, 2009, accessed 12/28/09 at http://bphc.hrsa.gov/uds/2009manual/table3b.htm.

[xvi] Gold, M., and Taylor, E.F., *The National Health Plan Collaborative: Overview of Its Origins, Accomplishments, and Lessons Learned*. Final report prepared for the Agency for Healthcare Research and Quality. Washington, DC: Mathematica Policy Research, Inc., 2009.

[xvii] One plan's R/E rate of above 49% was less comparable to other figures provided by plans because of the prominence of Medicare data, which not all plans may have included. Medicare also presents greater concerns around data reliability compared to other data sources.

[xviii] 42 C.F.R. § 438.204(b).

[xix] 42 U.S.C. 2000d, et seq. (Title VI); Perot, R.t. and Youdelman, M, *Racial, Ethnic, and Primary Language Data Collection in the Health Care System: An Assessment of Federal Policies and Practices* (The Commonwealth Fund, September 2001)

[xx] E.g., 45 C.F.R. §80.6 (2009) ("For example, recipients should have available for the Department racial and ethnic data showing the extent to which members of minority groups are beneficiaries of and participants in federally-assisted programs.")

[xxi] The health reform law requires the Secretary of Health and Human Services to ensure that any "ongoing or federally conducted or supported health care or public health program, activity, or survey" collects and reports 1) data on race, ethnicity, sex, primary language, and disability status for applicants, recipients, or participants; 2) data at the smallest geographic level if such data can be aggregated; 3) sufficient data to generate statistically reliable estimates according to targeted categories; and 4) any other demographic data as deemed appropriate by the Secretary regarding health disparities. The Patient Protection and Affordable Care Act, Pub. L. 111-148 (2009), as amended by the Health Care and Education Affordability Reconciliation Act, Pub. L. 111-152 (2010), at §§ 10334, 4302(b)(2).

[xxii] 42 C.F.R. § 438.204(b).

[xxiii] Rosenbaum, S. et al.; America's Health Insurance Plans. *A Legal Perspective for Health Insurance Plans: Data Collection on Race, Ethnicity, and Primary Language.* Washington, D.C.: AHIP, March 2009. http://www.ahip.org/content/fileviewer.aspx?docid=10760&linkid=224048

[xxiv] Fiscella, K. and Fremont, A.M. "Use of Geocoding and Surname Analysis to Estimate Race and Ethnicity."

Health Services Research 41.4 pt 1 (August 2006): 1482–1500.

[xxv] America's Health Insurance Plans. *Collection and Use of Race and Ethnicity Data for Quality Improvement*: *2006 AHIP–RWJF Survey of Health Insurance Plans.* Washington, D.C.: AHIP, November 2006. http://www.rwjf.org/files/publications/other/2006AHIP-RWJFSurvey.pdf

[xxvi] Patient Protection and Affordability Care Act of 2010. Pub. L. 111-148. March 23, 2010. 124 Stat. 119.

[xxvii] Ulmer et al.

[xxviii] Ulmer et al.

[xxix] Lurie, N. et al., *The National Health Plan Collaborative to Reduce Disparities and Improve Quality* (Joint Commission on Accreditation of Healthcare Organizations, 2008).

[xxx] American Recovery and Reinvestment Act of 2009. Pub.L. 111-5. February 17, 2009. 123 Stat. 467

[xxxi] Higgins, P.C. and Taylor, E.F. *Measuring Racial and Ethnic Disparities in Health Care: Efforts to Improve Data Collection* (Mathematica Policy Research, Inc., May 2009).