

# Community-Level Interventions to Collect Race/Ethnicity and Language Data to Reduce Disparities

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## Background

The systematic collection and use of race/ethnicity and language (REL) data by healthcare organizations has long been recognized as a critical step in identifying and reducing healthcare disparities locally and nationally.<sup>1-3</sup> The American Recovery and Reinvestment Act of 2009 urges the “use of electronic systems to ensure the comprehensive collection of patient demographic data, including, at a minimum, REL and gender information.”<sup>4</sup> The 2010 Affordable Care Act has explicit expectations regarding the standardized collection and reporting of self-reported REL data. Private accreditation organizations such as the Joint Commission and the National Committee for Quality Assurance have developed standards regarding the collection of REL data by hospitals and health plans.<sup>5</sup> Despite widespread consensus that these data are necessary for identifying, monitoring, and reducing disparities in care,<sup>6</sup> few healthcare organizations systematically collect this information.

Kilbourne et al recommended a framework for addressing disparities in the healthcare system, which included 3 broad phases: “The first requires detection; the second, understanding; and the third involves the development, implementation, and evaluation of interventions that reduce or eliminate disparities.”<sup>7</sup> Collecting REL data is largely about detection. In this regard, evidence of pervasive healthcare disparities is readily available through national surveys, reports, and peer-reviewed literature.<sup>1,3,8</sup> However, among healthcare providers and leaders, including even those familiar with the national data pointing to disparities in care, there is a tendency to believe that disparities exist “somewhere out there” but not within their own organizations.<sup>9,10</sup> One reason such views can persist is the frequent lack of data to demonstrate or disprove the existence of disparities at the local, organizational level. Organizations need to collect data to detect potential disparities within their communities and be accountable for addressing this pervasive problem.

A substantial body of work has examined the barriers and facilitators to collecting REL data in individual healthcare organizations such as hospitals, physician practices, and health plans.<sup>2,3,11-13</sup> This paper examines a set of community-level interventions for

## Abstract

**Objective:** The systematic collection and use of race/ethnicity and language (REL) data by healthcare organizations has long been recognized as a critical step to reducing healthcare disparities locally and nationally. We seek to identify the challenges and opportunities in implementing community-level interventions to collect REL data for detecting and reducing disparities in care in the 14 multi-stakeholder communities participating in the Aligning Forces for Quality initiative.

**Study Design:** This was a cross-sectional descriptive qualitative study.

**Methods:** We conducted 1-hour, face-to-face, semi-structured interviews with identified key informants during 2-day visits to each of the 14 communities in 2010, and supplemented this information with 2 rounds of semi-structured telephone interviews. Data were analyzed using a qualitative analysis software program, which assists with organizing and analyzing large quantities of interview data through creation of analytic units. We used deductive and inductive qualitative methods to analyze the data.

**Results:** Communities found it challenging to implement a community-level intervention to collect standardized REL data because addressing disparities is complex, the utility of having individual healthcare organizations collect these data is difficult to communicate, and perceptions of disparities in the community vary across stakeholders. Opportunities include working with credible “early adopters” in the community and leveraging federal or state mandates to encourage providers to collect this information.

**Conclusions:** Community-level efforts to collect REL data require securing buy-in from organizational leadership, developing a dialogue across the community, and generating awareness across key players about disparities-reduction efforts, especially REL data collection, without alienating patients, communities, and providers.

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collecting REL data. The Aligning Forces for Quality (AF4Q) initiative, a national program of the Robert Wood Johnson Foundation (RWJF), is designed to help targeted communities improve the overall quality of healthcare including reductions in racial and ethnic health disparities.<sup>14</sup> It provides an unprecedented opportunity to examine a range of community-level strategies to institute standardized REL data collection to detect disparities in local health system performance. The multi-stakeholder AF4Q alliances (the generic term used for the multi-stakeholder partnership in each community) are focused on propelling communitywide efforts to build the local infrastructure to collect patient demographic data for disparities detection and reduction activities. As federal and state mandates and accreditation standards begin to require the collection of REL data, the experiences of these AF4Q alliances might provide important lessons.

Even under ideal circumstances, meeting the multiple AF4Q programmatic goals would be daunting. Each of the AF4Q alliances comprises volunteer partner organizations and individuals, bringing distinct perspectives and sometimes competing interests to the table,<sup>11</sup> which can present opportunities and challenges in accomplishing goals. Given resource limitations and competing demands within these voluntary alliances, the challenges and opportunities they have faced in collecting REL data might presage experiences soon to arise in other communities nationwide. This article describes why collecting these data has remained difficult despite the fact that many alliance leaders understand that this information forms the foundation for detecting and reducing disparities in care.

## Methods

### Study Subjects

This paper examines the experience of 14 AF4Q alliances (data from additional alliances that joined the AF4Q initiative in 2009-2010 are not included in this analysis). This study's target population included AF4Q alliance leaders, project directors, and disparities/equity staff leads; we selected these individuals based upon their overall roles in their alliance, and because they had broad and specific knowledge about challenges and strategies to reduce disparities in their communities. The study protocol was approved by the Office of Research Protections at Pennsylvania State University.

### Data Collection

Two senior researchers from the AF4Q evaluation team conducted 1-hour, face-to-face, semi-structured interviews with key informants during 2-day visits to each of the 14 AF4Q communities in 2010. Protocol questions covered a

wide range of topics, including questions about disparities-related activities and REL data collection. All informants were asked a set of key questions. The interview protocol was also tailored to ensure that we captured the most relevant information from the best sources.

Alliance visit data were supplemented with data collected from the AF4Q initiative project directors in the summer and winter of 2011 about the alliances' progress on disparities-related activities; senior researchers collected these data through regular, 6-month, 90-minute, semi-structured telephone interviews to provide ongoing perspective on the alliances' activities. All interviews were digitally recorded after consent was obtained.

### Data Analysis

Data were analyzed using the ATLAS.ti (Version 2011; Cologne, Germany) qualitative analysis software program, which assists with organizing and analyzing large quantities of data through creation of analytic units, which contain all the documents, quotations, codes, and associated files for the study. We used deductive and inductive qualitative methods to analyze the key informant interview data.<sup>12,13,15</sup> First, data were transcribed from audio recordings and saved in standard word processing document files. The text files were then read and coded using a codebook that was developed a priori, based on theoretical concepts from the extant literature. This codebook served as a tool for organizing segments of similar or related text and provided a framework for subsequent analysis. The coded texts were entered into ATLAS.ti. Code-based queries were used to retrieve responses regarding disparities-reduction activities and race and ethnicity data collection from target subjects. We then reviewed these transcripts to distill emerging themes. Three members of the research team developed a list of themes that focused on strategies that alliances used to collect race and ethnicity data in the community, barriers and facilitators to collecting data, and other disparities-related activities and discussions. The authors jointly extracted the themes discussed by the interviewees using a deductive and inductive analytical process and resolved discrepancies through discussion to attain group consensus.<sup>13</sup>

We conducted a total of 51 face-to-face interviews across 14 AF4Q alliances with 22 project directors and 29 disparities/equity staff leads. We conducted a total of 28 follow-up telephone interviews with 14 AF4Q project directors (2 rounds of telephone interviews).

### Results: Study Cohort

We identified 6 emergent themes. To begin, we present results that describe alliance leaders' and staffs' perceptions

of alliance members' sentiments about the AF4Q initiative's focus on reducing REL disparities, starting with data collection. The first theme is quite broad, and provides a backdrop to interpret the remaining themes, which highlight several more specific challenges and opportunities.

### **Theme 1: Disparities Are Difficult to Tackle**

Overall, disparities in care were not a top-of-mind issue for the majority of AF4Q alliance leaders, given the range of demands of the AF4Q initiative and other competing priorities. Even when alliance directors and key staff acknowledged that disparities in care were a recognized problem within their community, they were unsure how to start tackling them. Key informants from every AF4Q alliance expressed trepidation about how to engage community leaders and partners on the topic of disparities reduction:

“[In] the AF4Q initiative, the focus on disparities is probably the trickiest for us because we don't have a lot of experience in this area.... Even for our leadership team to have some frank discussions around what type of disparities are occurring [in our community] is challenging because we don't necessarily feel comfortable talking about inequities in terms of the care that's being delivered.”

“...There are elements of the AF4Q initiative, like the focus on disparities, that our board (alliance) hasn't addressed. We will need a level of commitment from their organizations [individual providers] if we're really going to collect REL data.”

Some alliance directors and staff were enthusiastic about addressing disparities despite challenges. They saw the logic of beginning with one dimension of disparities in care (REL) before addressing other aspects (socioeconomic status or geography) and viewed systematic data collection as a logical entry point. An informant captured these sentiments:

“We (alliance) had a visioning session and started meeting after that to discuss disparities. It is hard, because it is such a large issue. Where do you start in equity work? We agreed that we would start with REL and get grounded in what is happening in our community, which will then help us in other disparities work.”

### **Theme 2: REL Data Collection Is a Hard Sell**

Many alliance directors and staff found the focus on REL data collection misguided; most of this group came

from communities where there was minimal REL diversity. Representative comments included:

“The biggest challenge that we confront in the (alliance) is the small number of members that we have in vulnerable populations, if you're looking at REL as a defining feature. In terms of socioeconomic status, there's certainly a fairly high level of poverty in the state, but we're 96% Caucasian.”

“People are thinking, racial and ethnic disparities in our community? Really? Urban and rural disparities, yes, but racial disparities? You're kidding me. We have to work really thoughtfully to raise awareness.”

These alliances were concerned about getting buy-in for data collection activities from key community partners. Some racially homogeneous communities related that the only reason they were attempting to collect REL data was that it was a requirement for continued participation in the AF4Q initiative. These alliance directors and staff said that their communities had more pressing issues, such as health differences by socioeconomic status. They suggested that REL data collection was an ineffective use of resources and unintentionally stymied the alliance's ability to achieve its other quality improvement goals by undermining the social capital built with the member organizations of the alliance.

For alliances with racially and ethnically diverse populations, targeting disparities was generally supported by their partners and the broader community, but getting buy-in to specifically get providers to collect REL data as a starting point was still often a hard sell to community organizations representing minorities. In part, these community organizations saw REL data collection as myopic or misguided, since they felt REL disparities in health outcomes stemmed from sources other than differences in physician and hospital care. As an alliance disparities staffer summarized:

“We're tending to focus on the provider end, but there is a whole community component that's going on around disparities and we need to look at that. If we started to collect REL data without the larger community understanding why—the leaders of the black community, the church leaders, the politicians—that could be misunderstood. We have to lay groundwork of ‘disparities exist and there are some things we need to do (ie, REL data collection) to get a handle on them.’”

## Reports

Some AF4Q alliances were able to build constructive partnerships with community organizations on the topic of disparities, and then use this to leverage buy-in on REL data collection activities:

“We [the alliance] are working with a community-based African American organization. They provide an outside lens for the REL work. They were really helpful in dispelling myths about HIPAA [Health Insurance Portability and Accountability Act] violations for collecting data and laying the groundwork preparing the community that this is coming.”

### **Theme 3: Hospitals Can Be an Entry Point for Collecting REL Data**

Alliance staff have struggled with how to address individual providers' perceptions that disparities are not an issue for them. They report that these views pose a barrier in securing commitment from provider organizations to collect REL data. However, among providers, the majority of alliance directors and staff found hospitals to be willing partners in collecting REL data: at the time of the interviews, 10 of the 14 alliances had actively engaged with the hospital community around data collection and the other 4 had started a dialogue.

Alliance directors and staff generally viewed hospitals as an easier sell on this topic compared with physician practices. Some thought that this may be because hospitals have an infrastructure for collecting data and engaging in quality improvement. One alliance leader said:

“Hospitals were much easier to work with than ambulatory sites because of resource issues. Even if the will and desire is there [for practices], the resources are not necessarily sufficient.”

A small number of AF4Q alliances were using some “early adopter” hospitals to propel data collection activities on both the inpatient and ambulatory side:

“The strategy we (the alliance) created was to bring hospitals on board by focusing on early adopters—those hospitals that are interested in health disparities. We had a number of fairly high-level people say that we want to do this as a community. The early adopters were used as advocates. We had the support of the board chair.”

One reason why hospitals may be promising early adopters has been the work of hospital learning collaboratives in

AF4Q communities, such as the Equity Quality Improvement Collaborative (EQIC)<sup>16</sup> and the Hospital Quality Network (HQN).<sup>17</sup> These programs have provided a degree of momentum and opportunities for learning about systematically collecting REL data within hospitals and expanding this knowledge into the community. All alliances with hospitals that participated in collaboratives mentioned leveraging the lessons learned:

“The EQIC grant made use of an effective resource in terms of training hospital registration folks on collecting data and presenting materials to educate folks on the hospital side. We're making headway because we have 11 hospitals in [the] HQN, which requires REL data collection. Most of the hospitals in the HQN are in the area of the state with disparities. So we think we're going to get a lot accomplished through the HQN work.”

“We have our local initiative which builds off an existing model for collecting REL data [that is part of the] Expecting Success [project].<sup>18</sup> We have had significant communitywide training around the standardized collection of REL data. We are starting to look at the readmission data relative to REL. While we're retraining on the inpatient side, we're also beginning to do some training in the ambulatory setting.”

Although generally positive, some alliances have experienced tension working with hospitals in a learning collaborative. Alliance directors reported finding it difficult to engage these hospitals because they were already committed to learning collaborative activities which were not necessarily synchronous with the AF4Q alliance activities. As an alliance director stated:

“It has been a significant challenge in our HQN work. We have had significant barriers trying to get information about what's going on with our hospitals in the HQN. We can't get access to the data. We are responsible for keeping the hospitals engaged, but we are operating in the dark.”

### **Theme 4: Physician Practices Pose Unique Challenges**

Alliance directors and staff expressed that it takes a lot of effort to engage physician practices around issues related to disparities, particularly data collection. This may be because practices have a variety of work cultures and use a wide range of data management systems. Many smaller practices also lack infrastructure (eg, electronic health records) that can

serve as a tool to support data collection. Typical alliance leader comments included:

“Well, we (alliance) did a survey of physician practices and REL data are just not available. There’s more confusion and lack of consistency in collecting REL [data] in medical practices.”

Alliance staff found that physicians believed they knew their patients and treated them the same, and that they would not provide lower-quality care to their minority patients. Alliance staff worried that discussing disparities with physician practices seemed like an attack on their professionalism:

“When we talk to the medical groups, they don’t really understand the value in collecting REL [data]. We’re going to need resources to help them understand why it is important to collect. The conversation with physicians has to be about improving healthcare broadly. Physicians will become extremely defensive if the only conversation is around health disparities and health equity.”

There was also uncertainty about the utility of the data and whether there would be sufficient numbers for analytical purposes. Alliance staff conveyed that physician practices need to see models that use the data to implement measurable improvement and show a return on investment. An alliance director stated:

“I would bet that perhaps many physicians don’t even think that there’s a problem with equity. We need to provide them with whatever it is they need to improve their focus and improve their practice—whether it’s best practices that come from within the area or by connecting them to projects from outside the area.”

However, those alliances working with physicians in Federally Qualified Health Centers (FQHCs) found important opportunities for advancing the AF4Q initiative equity agenda. Alliances that were working with FQHCs found that these practices were successfully collecting REL data and using it to target quality improvement and disparities-reduction activities. One reason for this success could be that alliances working with FQHCs did not struggle with physicians in these settings, and that physicians acknowledged that disparities may exist within their practices.

#### ***Theme 5: Health Plans Are Currently Not a Primary Source of REL Data***

Very few alliances were working with health plans to capture REL data. In general, few health plans were thought to be collecting REL data. Alliance directors and staff found it difficult to obtain this information even if plans reported having it.

“We interviewed health plans and the only time they collected REL [data] was for special projects and for health risk assessment projects. They just don’t have the capacity to collect the information and store it where it is easy to retrieve.”

Some alliances primarily focused on Medicaid plans to obtain REL data because these plans were more likely to have this information. However, some alliance directors acknowledged that state budgetary constraints were making extraction of this information difficult.

#### ***Theme 6: Federal Initiatives Can Be Facilitators and Distracters***

We asked alliance directors and staff about the impact of the federal meaningful use criteria and incentives for collecting REL data in electronic health record systems. Their perceptions varied in regard to the benefits of such drivers; many found them to be a positive force, but a few viewed them as negative. Comments included:

“We might have had to push harder to get hospitals and doctors to come along without the federal initiatives. We’re working through meaningful use with the doctors in the field so we are there where we can help and train them.”

“The AF4Q initiative is a good example that reform is local. We continue to look for ways that we can work collaboratively with the Regional Extension Center on the data collection side, and we’re (alliance) taking advantage of the situation to say we all know that REL collection is something that we’re going to have to do.”

A few alliance directors found the federal drivers to be distracters. A director captured this sentiment:

“Meaningful use has created a distraction and a lot of noise. It’s heightened some of the competitive tension for the hospital systems.”

## Discussion

Our qualitative results suggest that working with many stakeholders to address local disparities is a challenging task. Getting them to rally around collecting REL data as a first step in reducing disparities in care, as described by Kilbourne et al, is even more challenging.<sup>7</sup> Fortunately, the alliances' experiences provide several helpful, early insights on how one might improve the strategy of building local systems to collect data to detect disparities.

First, an initial focus on collecting REL data can work if some early adopters are on board and can provide useful models with local credibility. The AF4Q alliances that have made substantial progress have facilitated communitywide dialogues, led by organizations with local experience, about the importance of having these data to detect, monitor, and reduce disparities in care.<sup>19</sup> However, even in these communities, providers are often unsure about the utility of collecting REL data, and many do not believe that the most important disparities in their communities are race-based, reinforcing findings from other studies.<sup>20</sup> These concerns cannot be dismissed, as evidence shows that disparities are multifaceted and driven by many factors.<sup>21</sup> However, racial and ethnic disparities remain pervasive, even when accounting for factors such as socioeconomic status, necessitating systematic REL data collection.<sup>1</sup>

Second, alliances have faced barriers similar to those encountered by individual organizations. Ultimately, collection of REL data needs to occur in discrete facilities, even when the push may be to collect these data at the community level. It remains difficult for any one hospital or physician practice to see the value of these REL data for their particular organization. Most AF4Q alliances have been focused on facilitating the collection of REL data by individual providers at the facility level, with the implied goal of later aggregating these data at the community level. However, this strategy may not be optimal. A more promising strategy might be to focus on building community cohesion by explicitly stating at the outset that the goal is to aggregate data across provider entities in the community, with the added benefit of individual organizations being able to use their data to implement organization-specific initiatives.

Finally, leveraging federal initiatives holds promise. The Health Information Technology for Economic and Clinical Health Act of 2009 was identified as a facilitator by a number of the AF4Q interviewees. Under the Act, hospitals and physician practices receive incentive payments if they adopt electronic health record systems that are used to collect REL data. Many of the key informants hoped that this would lend more credibility and momentum to the AF4Q alliance work in data collection. Of course, collecting these data in elec-

tronic health records is only one step toward using the data to reduce disparities in care.<sup>22</sup>

National experts and others have identified that there is a critical need for a multifaceted plan of action to reduce disparities in care. This plan needs to incorporate obtaining the support of organizational leadership, developing incentives to address disparities, and generating awareness across key players. As King et al suggest, "Ultimately, the challenge lies not only in developing the strategies that would eliminate disparities, but also in the difficult and often time-consuming process of persuading healthcare organizations across the country to adopt these strategies."<sup>23</sup> The AF4Q alliances have certainly begun an important local dialogue about what is needed to reduce disparities in care and, despite challenges, many AF4Q communities are on the path of being able to detect disparities in care as a first step. However, the ultimate goal is to reduce disparities at the local level, which will be the long-term measure of success.

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